Functional Problems: Prevalence In Secondary Care And Perceptions Of Doctors

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Prevalence In Secondary Care And Perceptions Of Doctors

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“In sooth, I know not why I am so sad:
It wearies me; you say it wearies you;
But how I caught it, found it, or came by it,
What stuff 'tis made of, whereof it is born,
I am to learn;
And such a want-wit sadness makes of me,
That I have much ado to know myself.”

Antonio
The Merchant of Venice
Act 1 Scene 1

1 Abstract

1.1 Title

Functional problems: prevalence in secondary care and perceptions of doctors

1.2 Aims

(a) To evaluate the prevalence of functional problems in general medicine, gastroenterology, gynaecology and psychiatry outpatient specialist clinics in a hospital setting in Sri Lanka and

(b) To assess the perceptions of doctors in these specialties around functional problems in the UK and in Sri Lanka.

1.3 Methodology

(a) Prevalence study: Functional problems were defined as those for which a cause could not be ascertained after clinical evaluation and investigations. The prevalence of functional problems was assessed over a three month period in each specialty clinic. The patients' records were reviewed at three and six months to confirm the diagnosis of a functional problem.

(b) Perceptions of clinicians: Qualitative methodology was used to ascertain the perceptions of doctors in the two settings covering the three specialties. A grounded theory approach was used and sixty interviews were carried out. Emphasis was placed on identifying socio-cultural implications around perceived causations and the management of these functional problems.

1.4 Results

(a) Prevalence study: The prevalence study ascertained that functional problems were the commonest diagnoses in the general medicine/gastroenterology and gynaecology clinics accounting for almost a fifth of patients. In psychiatry, functional problems were the fourth common diagnosis and accounted for nearly ten percent. Patients of all consultations with functional symptoms tended to be younger; there were long delays in

making the diagnosis and a substantial proportion of patients were subjected to iatrogenic harm from invasive investigations and inappropriate therapeutic measures.

(b) Perceptions study: The perceptions study revealed divergent views by doctors about what functional problems were, how they could be categorized and how best to manage them. Socio cultural factors were thought to be intricately linked to causation and outcomes. Nonetheless, most doctors tended to isolate the clinical presentation and management from the cultural context in the way they dealt with their patients.

1.5 Conclusions

Functional problems were commonly seen and diagnosed in hospital outpatient clinics. The Sri Lankan prevalence was similar to that reported from the UK. In both cultural settings the doctors who were sensitive to socio-cultural factors used tools beyond pharmacotherapy and those who held improved quality of life as the goal of treatment as opposed to cure, reported greater success in managing people with these problems.

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Declaration

The research contained in this thesis was carried out by the author whilst a postgraduate student in the School of Medicine and Health at Durham University. None of the work contained in this thesis has been submitted in candidature for any other degree.

Statement of Copyright

For Arosha

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2 A review of the literature

2.1 The historical evolution of functional symptoms from Euro Mediterranean medical thinking to today

Functional symptoms are those that are not explained with identifiable pathology at anatomical or physiological levels. “Identifiable pathology” has been inextricably linked to the prevailing level of medical knowledge throughout the age of medical reasoning. Thus a study of the evolution of the concept of functional symptoms needs a review of the evolution of the theory and practice of western medicine.

The roots of present day western medical practice can be traced to the Euro-Mediterranean traditions which dominated medical thinking in Western Europe until the 16th century (1) (2). The Greeks excelled in mathematics, astronomy and medicine. Their excellence in observation and recording of illness contributed much to the development of the science of medicine (3). The writings of Hippocrates and Galen provide an excellent insight into medical thought of the day (4) (5). The Greek/Hellenistic epistemology of medicine postulates that normal physiology constituted an approximate balance in the four humours and pneuma (6). Black bile, yellow bile, phlegm and blood constituted the humours. An imbalance in these caused ill health.

Greek medical thinking took quintessentially a ‘functional view’ of illness. Illness was not merely an adversity arising from humours and pneuma. The humours had a personalised pattern, the pathology that arose in their disturbance was unique to the individual, and their expression was modified by personal, psychological, social, life habits and environmental factors. Thus the cornerstone of a functional view, the concept of a unique ill person as opposed to a unique illness, took prominence in deciding upon treatment. In fact Greek physicians held the view that ‘only sick persons truly mattered’ and not just illnesses (7). Treatment was aimed at the person and addressed psycho-social issues. Physicians of the day treated all illnesses including those with predominant behavioural symptoms such as insanity. All diseases arose from disturbances in the humours and there was no difference in causation or treatment of physical and mental disorders (8).

Modern western European medical thought developed from the 17th century. Symptoms were recognised as the manifestations of illness. The development of semiology gave rise to the study of “signs” as external manifestation of illness. The body was akin to a machine. Normal functioning was described in anatomical and physiological terms. Any untoward change was determined as “disease”. These diseases were detected through eliciting signs and arranging special examinations. People with such “diseases” were thought to undergo a defined and an expected experience. This would be studied via verbal response of the person and his changes in behaviour. The observations were described as “illnesses”. The development of this “disease” versus “illness” axis laid root to the rise of the mind-body dualism noted so prominently in modern western medical practice. Rene Descartes (1596-1650) in his writings had already introduced the concept of mind-body dualism (9). He suggested that the body was like a machine, having material properties like extension and motion and thereby obeying laws of physics. The mind (or soul) he had suggested was a non material entity with no motion and extension. Also he proposed that the mind and body were connected via the pineal gland. There is no doubt that this dominant philosophical thinking had a great influence on the medical scientific thinking of the time (10).

As opposed to the ‘functional view’ of disease, in the Greek/Hellenic/ Mediterranean traditions, the modern European view gradually adopted an ‘ontological view’ of health and illness (11). Observations of patients permitted doctors to define a pattern of behaviour which was typical of a particular disease. Diseases were treated as being unique entities with clearly defined natural histories of progression. The universal nature of a disease was expected to transcend cultural, time and space barriers. Each disease was expected to cause the sufferer a predetermined array of distressing symptoms. Distress experienced either more or less than the “culturally normal” for the population was considered abnormal (12). Thus the supersedence of the “functional view” of disease by the “ontological view” contributed to the mind-body dualism becoming further strengthened in the bio-medical postulations of disease models in modern western medicine.

In the 17th and early 18th century “generalists” continued to care for the set of patients who experienced disproportionate distress to disease. William Cullen (1717 – 1790) is regarded as the first to coin the term “neuroses” to describe this set of patients (13). In the absence of knowledge of detailed neuroanatomy and neurophysiology, Cullen proposed that ‘nervous force’ and ‘nervous energy’ problems lay at the root of “neurosis” (14). With the development of the neuro anatomic location of disease, scientists found localised pathology to explain certain neural conditions but could not identify localised pathology to explain insanity/madness. Greisinger in his writings introduced the concept of “generalised” dysfunction of the nerves in those with insanity. The term “psychosis” was coined to describe this (15).

By the 19th century large numbers of insane people were institutionalised and a group of physicians (proto psychiatrists) evolved to care for them. In parallel, the discipline of psychopathology, i.e. eliciting of not physical but psychological signs developed (16). Psychosis became the property of the newly emerging speciality of psychiatry. The compartmentalisation of illness into mind versus body became further established. Mind-body dualism took root and became firmly entrenched. Interestingly “neurosis” which comprised of many entities which fall under the umbrella of current day functional illness, was still a part of general medicine in the early 18th century. In the latter part of the 18th century, perhaps by accident, perhaps by design, neurosis came to be grouped together with psychoses and it became incumbent on the psychiatrists to care for these patients.

Development in psychopathology brought forth identifiable pathological features for psychoses. But such pathology was not identifiable in most of the neuroses. Thus developed the concept of “somatisation” in psychiatry. This encompassed the patients who had somatic symptoms disproportionate to any physical illness they had. In a background of a strong mind-body dualism, the thought was, “if it is not in the body, by default, it must be in the mind”. Thus we have the current situation of functional symptoms - patients have somatic symptoms, generalists are unable to diagnose a disease to explain them, patients are referred to the psychiatrists and the patients themselves

are resistant to the suggestion that their problems are not authentically medical but psychiatric (17).

Therefore it appears that functional symptoms, as we encounter them, are a by product of two processes. Firstly, the mind body dualism of the modern western biomedical model of illness, which arose with the rise of pathological anatomy, physiology, biochemistry, and microbiology and the resultant compartmentalisation. Secondly, the shift from a "functional view" where the individual was unique. Interestingly, those who exhibit behavioural distress less than they should, have also been labelled as having psychiatric illnesses, e.g. alexithymia, anosognosia. Therefore it becomes clear that some of the developments in modern medicine have come at the price of creating a set of "medical orphans" i.e. those who fall in between the mind/body, functional/ontological, generalist/psychiatrist boundaries (18).

Functional symptoms have held a deep fascination for practitioners. Hysteria was a popular term, with the presumed origin being in the uterus. As treatment for unexplained illnesses the application of ointments to the labia and direct manipulation of the organ was attempted (19). With advancement in the knowledge of anatomy, the view that these illnesses arose from disorders of the nervous system was promulgated. In 1667, the father of neurology, Thomas Willis had written that *"as we have shown before, the passions vulgarly called hysterical could not always proceed from the womb, but often from the heads being affected"*. This fresh insight brought about fresh treatment forms – hitting the patient's head with a stick (20).

The importance of psychological factors in the aetiology was appreciated for the first time towards the end of the 17th century. Thomas Sydenham declared that "*in hysteria, mind sickens more than the body"*. He recommended regular exercise and an interest in the personal welfare of the patient as useful treatments (21). Towards the 18th century, functional symptoms became to be regarded more and more as diseases of the mind. The 19th century saw a return to physical explanations for these. But physicians were baffled by the absence of demonstrable anatomical or pathological abnormality. This led to the development of the concept of

functional disturbance with minimal anatomical or pathological abnormality. Charcot wrote about hysteria in 1889 – *"Without doubt there is a lesion of the nervous centres but where is it situated and what is its nature? Certainly it is not a circumscribed organic lesion of a destructive nature…..one of those lesions which escape our present means of anatomical investigation, and which for want of a better term, we designate a dynamic or functional lesion"* (22). Charcot followed up this physical model with physical interventions – pressure on the ovaries as treatment for hysteria.

With the advent of psychoanalysis at the beginning of the 20th century, Charcot's pupils Babinski, Janet and Freud proposed the importance of psychological factors and over a period, the idea of a functional disturbance of the brain was largely displaced by the idea of psychogenesis. The first attempt at building a psychological model to explain functional illness was made by pioneering French Psychologist Pierre Janet (1859-1948). The "Dissociation Theory" of Janet proposes that in persons faced with traumatic experiences, two phenomena termed 'attentional narrowing' and 'memory activation' occur. Firstly, there is limiting of the number of sensory channels that can be attended simultaneously. Thus the individual pays attention to some sensory channels at the expense of some others. But the unattended channels too continue to produce sensations which escape conscious awareness. This results in negative symptoms like loss of function, loss of memory and loss of sensation. This is the phenomenon of 'attentional narrowing'. Secondly, the memories of the traumatic event become dissociated from the autobiographical memory of the person. Since these are not integrated, the person has little control over the activation of traumatic memories. Trauma reminders within the person or in the environment become triggers for memory activation. This results in positive symptoms like pain and sensory distortions. This is the 'Dissociation' model of explanation for functional symptoms as proposed by Janet (23).

Around the same period of time, Austrian Neurologist and Psychiatrist, Sigmund Freud (1856-1939) proposed the theory of 'Conversion'. Freud suggests that human beings who face traumatic experiences try to suppress the conscious recall of these painful memories. The 'neural energy'

generated by the traumatic memories cannot be discharged due to the suppression of conscious acknowledgement of the negative emotion. The energy thus dissipates by converting to physical symptoms that were experienced at the time of the trauma or which symbolically represents it. This subconscious process results in the patient obtaining both primary and secondary gains. Primary gain is by a reduction in anxiety and secondarily the patient gains in indirect ways like work avoidance and more attention from family. Thus, the generation of physical symptoms due to emotional conflict represents Freud's energy based 'Conversion' model of functional symptoms (24). Subsequently, somatisation was proposed to explain unexplained somatic symptoms. Psychiatrists and psychologists became the source of treatment. The patients remained largely unconvinced about this 'psychologisation' of their symptoms and not surprisingly, the lack of faith resulted in poor acceptance of treatment and poor outcomes where psychological treatment was attempted (25).

During the 20th century, further refinement in investigation procedures resulted in the demonstration of physiological abnormalities in-patients with functional symptoms. There exists evidence to support neuro, endocrine, immunological modulations in these patients. Functional imaging of the brain has demonstrated functional differences in the pre frontal cortical area (26). In parallel a body of evidence has emerged to demonstrate the success of cognitive and behaviour therapeutic interventions in the treatment of functional symptoms (27) (28) (29) (30) (31). Therefore there have been a number of researchers who developed cognitive behavioural models which incorporated physiological aspects and other psychosocial aspects (32) (33) (34) (35) (36) (37). The cognitive behavioural theoretical model incorporates the evidence which emerged to support each of the aetiological aspects investigated (38).

The current thinking on the aetiology has returned to the concept of reversible, minor functional abnormalities similar to that proposed by Charcot and others a hundred years ago. There is evidence to support this for functional gastrointestinal disorders, chronic pain and fatigue, repetitive strain injury and hysterical paralysis (39) (40) (41) (42).

2.2 Which term to use – Functional symptoms? Functional disorders? Medically unexplained symptoms? Somatoform disorders?

Patients seek help from doctors for symptoms. Doctors diagnose diseases to explain them. Whilst symptoms remain the subjective experiences of the patients, diseases are the objective abnormalities detected in the body. Developments in modern medicine in areas such as imaging technologies, human genome mapping and biotechnology have made diagnosis and treatment more refined than at any stage in the development of medicine. Yet, a significant proportion of illness, pain, discomfort and distress remain medically unexplained and poorly understood. Frequently, even after appropriate medical assessment and laboratory investigations, the symptoms or their combination remains unexplained in terms of a conventionally defined disease.

An extensive range of terms have been used in the literature to describe this category of clinical problems. Somatisation, somatoform disorder, somatic distress, abnormal illness behaviour, functional illness, functional problems, functional disorders, functional symptoms, functional somatic symptoms and syndromes, chronic multiple functional symptoms (CMFS), and medically unexplained symptoms and syndromes (MUS) are some of the more commonly used terms. A close inspection of the literature appearing under each of the diagnostic labels give rise to the view that they are describing to a large extent the same group of patients. The confusion in the terminology used is best illustrated in the ABC of psychological medicine published by the British Medical Journal (43) and (44). In the two articles, one describing the aetiology and epidemiology of the problem and the other describing the management, the problem is referred to in different ways, one as ‘functional somatic symptoms and syndromes’ and the other as ‘chronic multiple functional symptoms’.

Whilst removing the category “neurosis”, somatoform disorders was introduced into the Diagnostic and Statistical Manual III (American Psychiatric Association) in 1980. The International Classification of Diseases 10 (WHO) followed in 1992. Somatoform disorders accommodated those patients who

had somatic symptoms unexplained by a medical condition but with too few psychological symptoms to merit an alternative psychiatric diagnosis. The broad group of somatoform disorders included a number of distinct entities, namely, somatisation disorder, conversion disorder, pain disorder, hypochondriasis and body dismorphic disorder.

The ICD 10 required the fulfilling of five diagnostic criteria to make a diagnosis of somatisation disorder (45).

At least a two year history of multiple and variable physical symptoms that cannot be explained by any detectable physical disorder.

Preoccupation with the symptoms causes the patient persistent distress and leads to at least three consultation episodes

Persistent refusal to accept medical reassurance that there is no physical cause for the physical symptoms

Presence of at least six of 14 listed symptoms representing at least two of the organ symptoms

There is no identifiable mood disorder, panic disorder or schizophrenic or related disorder.

Soon it was noted that very few of the original patients with unexplained somatic symptoms met the diagnostic criteria for somatisation disorder. Therefore, in the DSM IV (American Psychiatric Association, 1994) an additional diagnostic category was introduced – undifferentiated somatoform disorder. In making this diagnosis, criteria A, C and E has to be met (except that the duration of the disorder is at least six months) and criteria B and D need be only partially met (45). This definition was noted to include a significant proportion of the patient population targeted. Thus somatoform disorder group went from being an uncommon condition which included a specific set of symptoms to a wide group which included patients complaining of a variety of symptoms with no readily apparent physical or psychological cause.

Despite its value in drawing attention to previously neglected patients, the classification is considered unsatisfactory. The main disadvantage is its presumed psychogenic origin due to categorization among the psychiatric disorders. *Sharpe et al* (2004) states that although intended to be aetiologically neutral, the somatoform disorder concept implied that the cause of these symptoms was understood and was a mental disorder (46). Though the aetiology is not entirely understood, evidence points to a multi factorial origin with functional abnormalities, psychological factors and social factors all playing a role. The main problems arising out of a psychogenic implication is its poor acceptability to the patients and the physicians distancing themselves from the problem as it is deemed out of their specialty. The '*all in the mind*' concept has contributed to furthering the gap between patients and physicians. Equally importantly, due to the long duration of time frames (even undifferentiated somatoform disorder requires the symptoms to be present for a minimum of six months), a significant number of patients will remain unclassified, and therefore untreated. For these reasons, terms with somatisation and somatoform disorder remain unsatisfactory terms to identify patients with unexplained problems. *Mayou et al* (2005) argued that in the DSM V the category of somatoform disorders be abolished completely and an axis based descriptive diagnostic term be introduced in its place (47). *Kroenke et al* (2007), as part of the Conceptual Issues in Somatoform and Similar Disorders (CISSD) project wrote in support of revision of the somatisation disorder category and elimination of undifferentiated somatoform disorder and pain disorder and potential shifting of certain disorders to different DSM categories or axes in formulating the DSM-V (48).

Trimble (1982) introduced the term 'functional symptom' to imply a mere disturbance of bodily functioning rather than structure and did not presume a psychogenesis (22). Several terms woven around the term 'functional' appears in the literature. *Bass et al* (2002) noted that these patients typically have a longstanding pattern of presenting with various functional symptoms, have had multiple referrals for investigation of these, are regarded by their doctors as difficult to help and evoke despair, anger, frustration in doctors. They note that the patients are at times referred to as 'heartsink patients',

‘difficult patients’, ‘fat folder patients’ and ‘chronic complainers’. All of these are considered insensitive and inappropriate and they suggest the term ‘chronic, multiple functional symptoms’ (CMFS)(43). Within this term, chronicity and multiplicity – the long drawn out nature and the coexistence of more than one symptom is given prominence. What of the patient who would present for the first time to the primary care doctor with non cardiac chest pain? How would this be explained medically? Would the doctor have to wait until the patient disclosed another symptom and both lasted for several months to prescribe appropriate treatment? Obvious shortcomings exist in this term.

Mayou et al (2002) use the term “functional somatic symptoms and syndromes” (44). They state that most symptoms are transient and avoid a reference to their chronic nature. They are of the belief that most are multiple but do admit that there could be solitary symptoms. They urge a simple description of the symptom, qualified with simple descriptors single, multiple and acute or chronic.

Likewise, *Wessely et al* (1999) use the term “functional somatic syndromes” in their landmark study conducted across seven specialties (49). They define a functional somatic symptom as ‘*one, that after appropriate medical assessment, cannot be explained in terms of a conventionally defined disease*’. The reason for the use of the term ‘functional’ in the disease description has been an attempt to draw away from psychogenesis as the aetiology. Lack of a demonstrable anatomical pathology or a psychopathology to explain the symptom has propounded the theory that these symptoms arise from a transient or a trivial functional abnormality of an organ or organ system. There is evidence to support a functional aetiology in some of the functional syndromes. *Marshall et al* (1997) demonstrated disordered brain activation in a patient with hysterical paralysis (42). Functional MRI studies of brain was used by *Mertz et al* (1998) to demonstrate disordered activation of the thalamus and the pre frontal cortex in-patients with irritable bowel syndrome (50). But the problem with the incorporation of the term functional to the description is the presumption that all of it is functional in aetiology. That is, all of these patients have a

transient/trivial functional abnormality in the organs which give rise to the symptom. Such a conclusion is not reasonable and could only be reached by stretching the supporting evidence to the maximum. The resultant danger of adopting the functional model is that it may on the rare occasion promote the eager physician to order more and more complex investigations – functional MRI scans, functional endocrine tests etc with a resultant massive increase in investigation costs and no tangible benefits.

The description of a functioning abnormality implies the existence of a normal functioning status. The term functional syndrome sits in well with irritable bowel syndrome. The large bowel has a 'normal' functioning status and this functioning has become disordered and thus the patient has constipation or frequent passage of stool or abdominal pain etc. But if the symptom is backache or tiredness or dizziness where is the functional abnormality? To identify a disorder in functioning, the normal functioning status must be identified first. Which organ/organ system dysfunction gives rise to tiredness? What is its normal function? Whilst these questions remain unanswered it remains difficult to identify disordered function and proceed from there to restore "normalcy". The other major disadvantage of the term functional is the impression it conveys to the patient that they are normal physically but are 'malfunctioning'. For the reasons discussed above, terms such as "functional illness", "functional problem", "functional symptom" and "functional disorder" remain not entirely satisfactory.

There is a current trend in the scientific literature to describe these symptoms as 'medically unexplained symptoms/syndromes'. This is well illustrated in the scientific papers written by some researchers over the past few years. The same authors have changed their terminology from functional symptoms to medically unexplained symptoms (49) (51). The advantage in the use of the term 'medically unexplained symptoms' lies in it bringing honest ignorance to the fore (52). It simply states that there are a number of symptoms and syndromes that present as phenomena for which health professionals at present can find no cause on the basis of physical examination and investigation. Aetiology is left open with room for functional, psychological and social contributions to form a multi origin explanation. But the critics point

out that in view of the traditional mind body dualism in Western medicine and its inherent weakness in accepting the integration of the mind and the body, psychological and psycho physiological explanations may not be considered 'medical' (51).

'Medically unexplained' is a good representation of scientific knowledge to date and often is a preferred term for research purposes. But in a clinical setting, it may make the patients think that their symptom is not being taken seriously, is unlikely to inspire confidence and may jeopardize engagement with future therapeutic endeavours. Therefore, in a clinical setting many clinicians prefer to use the term "functional disorder" as it permits an explanation which admittedly may not be one hundred percent accurate. This is an important aspect of successful treatment of functional disorders. *Carton et al* (2003) and *Ettinger et al* (1999) demonstrated that those who received a positive explanation for non epileptic seizures had a better prognosis. (53) (54). Further, research in clinical settings have shown that 'functional' is more acceptable to the patients than 'psychosomatic', 'medically unexplained' and 'stress related' (55). Therefore in a clinical setting, functional illness remains the preferred term.

Patients often have an unexplained solitary symptom. Pain (including back, chest and abdominal pain and headache), fatigue, dizziness, funny turns and feeling of weakness are common unexplained symptoms presenting to primary care, in the UK (56). In a Sri Lankan cohort, chest pain, back pain, abdominal pain, abdominal cramps, pain in the limbs, pain in the joints, numbness over various parts of the body, headaches, lifelessness, feeling faint, shortness of breath, burning sensation over various parts of the body, loss of appetite, sleep disturbance, puffiness of the abdomen and fatigue were the common symptoms unexplained by disease (57).

Many of the patients seeking treatment for functional symptoms have a number of symptoms which may or may not be related to a particular system. They seek medical help from across a range of specialties. Often the collections of symptoms meet the diagnostic criteria for a symptoms based disease definition. Each medical specialty has its own functional syndrome/s.

In gastroenterology it is irritable bowel syndrome and non ulcer dyspepsia. In gynaecology it is premenstrual syndrome and chronic pelvic pain. In rheumatology it is fibromyalgia. In cardiology it is non cardiac chest pain. In infectious diseases it is chronic fatigue syndrome. In neurology it is tension headache and non epileptic attacks. In dentistry it is temporo mandibular joint dysfunction and atypical chest pain. In ear nose and throat it is globus syndrome and in allergy it is multiple chemical sensitivity.

Nimnuan et al, in the study across seven specialties demonstrated three striking features about this cluster of symptoms (49) (58). Firstly, the diagnostic criteria from specific syndromes overlap with others. Secondly, patients identified as having one medically unexplained syndrome frequently meet diagnostic criteria for others. Thirdly, there exists similarity in non symptom related patient characteristics such as sex, coexisting emotional disorder, proposed cause, prognosis and the response to treatment. Therefore the functional syndrome diagnosis the patient carries is most likely to be a representation of which specialist clinic the patient attended. Ironically if the patient was seen in the gastroenterology clinic, then they would be carrying a label of irritable bowel syndrome, but if it was the psychiatry clinic the label might be anxiety disorder.

In trying to determine the most appropriate term to be used in this PhD research, three aspects were looked at. In terms of scientific accuracy, “medically unexplained symptoms” appeared the best as it reflects the absence of scientific accuracy in identifying the aetiology of diseases. Since a major part of the research would be carried whilst interviewing doctors and patients, this was regarded as an equally important consideration. Patients are more at home with the concept of “functional symptoms” and it provides a term that some of them are already familiar with. The use of it has more acceptance than all other terms. The term “functional symptoms” has appeared in the medical literature for a period of about 25 years and most physicians are familiar with the term. Considering all the aspects of the commonly used terms, “functional symptoms / syndromes” has been adopted for use as the most appropriate for purposes of this research. This is not

perfect but there is no consensus and a perfect term does not exist as of now.

2.3 The prevalence of functional symptoms and syndromes and their healthcare resource utilisation

Since the recognition of functional symptoms as an important health problem in both primary and secondary care, there have been a number of attempts at researching into the magnitude of the problem. Some researchers have focussed attention on functional symptoms in general whilst others have looked at specific functional syndromes. Irritable bowel syndrome (IBS) and chronic fatigue syndrome (CFS) remain the most widely studied of the functional syndromes. Attention has been focussed on obtaining the prevalence/frequency at community, primary care and secondary care levels. Attempts have been made to assess the problem in countries from the West to the Orient, from 'developed' to 'developing' countries. Since such a wide variety of symptoms in a wide range of healthcare settings have been studied; as expected, there is little uniformity in the study methodology that has been used. Different disease definitions and diagnostic criteria have been used in the studies. A wide range of terms have been used to refer to functional symptoms, and these terms have themselves been used in different contexts in the different studies. Despite the lack of uniformity in many respects the studies done in the multitude of health care settings give fairly similar magnitude estimates across countries and cultures. They all conclude that functional symptoms remain an important health concern that needs further research.

A number of investigators have attempted to ascertain the prevalence of functional symptoms at community level. *Kroenke et al* (1993) in a community based study from the USA, analysed data on 13,538 individuals interviewed on the Epidemiologic Catchment Area Program using the Diagnostic Interview Schedule, to determine the prevalence of psychiatric disorders (59). The schedule inquires for the presence of 26 common symptoms. It was noted that 10% of the population at one time or another had been afflicted by the symptoms and that a cause had been identified in only one third of the

cases. Therefore the prevalence of functional symptoms in this community was deemed to be approximately 3%. *Karvonen et al* (2007) in a community based study assessed a sample drawn from the 31 year old Finnish population numbering 1598 (60). Those with four or more somatisation symptoms according to the DSM-III-R criteria were defined as somatizers. The prevalence of functional symptoms was noted to be 6.1%. *Hiller W et al* (2006) studied a representative sample of 2,552 persons in a German population with an instrument for medically unexplained physical symptoms (61). All 53 symptoms from ICD-10/DSM-IV sections of somatoform disorders were enquired about. 81.6% reported the presence of at least one such symptom causing at least mild impairment in the preceding seven days. 22.1% had at least one symptom causing severe impairment. The authors concluded that medically unclear complaints are an everyday phenomenon but about three out of four of them are below clinical relevance.

Functional symptoms are seen in significant numbers at primary care level and some investigators have studied the prevalence rates. *Peveler et al* (1997) in their study of recognition of medically unexplained symptoms by general practitioners noted that GPs identified such symptoms to be the main clinical problem in 19 % of attending physicians (62). Screening of the same patient population with the use of validated self-report questionnaires identified 35% of patients as having symptoms which were poorly medically explained. *Gureje et al* (1997) studied the phenomenon of somatisation across cultures, in 14 countries in a WHO collaborated study (63). The study samples were from primary care settings and the total number of subjects assesses was 25,916. Somatoform disorder as defined by the ICD-10 criteria was noted to prevail at rates ranging from 0.1% in Nagasaki, Japan to 17.7% in Santiago, Chile. The overall prevalence was 2.8%. A less restrictive definition looking at functional symptoms termed Somatic Symptom Index (SSI) revealed prevalence rates ranging from 7.6% in Ibadan, Nigeria to 36.8% in Santiago, Chile. The overall prevalence of SSI was 19.7%. *de Waal et al* (2006) studied the prevalence of somatoform disorders among attendees at general practices in a Dutch study (64). Among the 1,046 consecutive attendees studied, the prevalence of somatoform disorders with

functional impairment was determined to be 16.1% (95% CI 12.8-19.4%). When disorders with only mild impairment were included, the prevalence increased to 21.9%. *Verhaak et al* (2006) made a one year nationwide, representative survey of morbidity in general practice, covering 104 general practices with 400,000 enlisted patients (65). They determined that 25-50% of all reasons for visit to a GP concerned symptoms that were not medically explained. They also concluded that frequent and repeated consultation with such symptoms was much rarer.

Functional symptoms are encountered in hospital practice both in the outpatient specialist clinic setting and also in the in-patient setting. This has been the subject of further research. *Hamilton et a*l (1996) studied 343 patients seeking treatment from cardiology, gastroenterology and neurology outpatient clinics at a large teaching hospital found that 120 (35%) had a final diagnosis of functional 'disorder' (66). *Maiden et al* (2003) studied 203 patients who were newly referred to a specialist rheumatology clinic (67). Rheumatologist ratings of the symptoms found that in 20% of the instances, the symptoms were only 'somewhat explained' and in 8%, 'not at all explained'. Therefore in about 28%, of all new referrals, 'organicity' of symptoms was determined to be 'low'. *Carson et al* (2000) studied 300 patients newly referred to a neurology outpatient clinic. Symptoms remained 'somewhat explained' and 'not at all explained' in 11% (95% CI 7-14%) and 19% (15-23%) respectively among the patients. Therefore in 30%, the 'organicity' was low (68). *Reid et al* (2001) studied medical records of 361 patients utilising outpatient medical and surgical secondary care services of South Thames (West) NHS region (69). 27% of the patients had at least one medically unexplained consultation episode. Of the 971 total consultation episodes of this patient sample, 21% remained medically unexplained. *Nimnuan et al* (2001) in their study of accuracy of physicians' provincial diagnosis of medically unexplained symptoms studied records of 526 patients attending specialist outpatient clinics in Gastroenterology, Gynaecology, Neurology, Rheumatology, Chest, Cardiology and Dentistry were assessed (58). 52% of the total number of patients was noted to have medically unexplained symptoms. Dental clinics had the lowest percentage of such

symptoms, accounting for 37% (95% CI 25-48%) and Gynaecology, the highest with 66% (56-76%). *Mangwana et al* (2009) studied the prevalence of medically unexplained symptoms in an outpatient secondary care medical clinic among the white Europeans and people of South Asian origin attending a UK clinic. The prevalence was noted to be similar among two cohorts and was 52% and 49% for the people of South Asian origin and the white Europeans (70)

The frequency of functional symptoms in the in hospital setting remains a much less studied area. Fink (1992) used the Danish National Patient Register to identify patients between the ages of 17-49 who had at least ten hospital admissions within an eight year period (71). 282 such patients were identified. Of these 19% were identified as being 'persistent somatisers' with no identifiable medical explanation for the symptoms. In addition, *Fink et al* (2004) studied 294 consecutive patients admitted to an internal medicine unit in a Dutch hospital (72). 18.1% (95% CI: 12.8-24.9%) of the patients fulfilled diagnostic criteria for somatoform disorder on ICD-10 criteria and 20.2% (95% CI: 14.7-27.2%) on DSM-IV criteria.

The functional syndrome which remains most widely studied in terms of prevalence rates in the medical literature is Irritable Bowel Syndrome. In a community survey of 41,984 subjects in Europe, *Hungin et al* (2003) noted the overall prevalence of irritable bowel syndrome (IBS) to be 11.5% (6.2-12%). Of these 4.8% had been formally diagnosed. A further 2.9, 4.2 and 6.5% met Rome II, Rome I and Manning criteria for diagnosis of Irritable Bowel Syndrome (73). In a similar US community survey of 5,009 subjects *Hungin et al* (2005) found the prevalence to be 14.1%. 3.3% had been medically diagnosed but a further 10.8% met diagnostic criteria (74). In a community survey of 1,006 subjects in Korea, *Han et al* (2006) investigated the prevalence of IBS using Rome II criteria. The prevalence was found to be 6.6% and equal among males and females (75).

The other prototype functional syndrome, widely studied is Chronic Fatigue Syndrome (CFS). In a primary care study of 3,466 patients attending GP practices in the UK, *Wessely et al* (1997) demonstrated an overall prevalence

of 2.6, 2.2, 1.4 and 1.2% of CFS, when CDC-1994, Oxford, Australian and CDC-1988 criteria were used (76). In a community based primary care study of 1,648 patients attending eight primary care centres in Korea, *Kim et al* (2005) reported that chronic fatigue prevailed at 8.4% (95% CI 7.1-9.7) with CFS being 0.6% (0.2-1.2%) (77). In a community study of 4000 randomly selected subjects in the USA, *Buchwald et al* (1995) investigated the prevalence of CFS using CDC criteria for diagnosis (78). They reported a point prevalence of 75-267 cases per 100,000 persons. The point prevalence of chronic fatigue alone was strikingly higher, ranging from 1,775 to 6,321 cases per 100,000 persons.

The frequency of occurrence of some of the specific functional symptoms has also received much attention in the research literature. *Mahadeva et al* (2006); in their review of the studies dealing with global epidemiology of functional dyspepsia report prevalence of 11%-29.2% depending on the definition used and geographical location (79). They concluded that functional dyspepsia is a particularly common condition, found globally and affecting most populations regardless of location. *Eslick et al* (2003) in a community based study in Australia, assessed 672 subjects via a symptom questionnaire (80). The prevalence of non cardiac chest pain was found to be 33%. They concluded that non cardiac chest pain is remarkably common in general population and that it negatively impacts the quality of life. *Russel et al* (2006) investigated the one year prevalence of tension type headache in a large population based sample in Norway (81). The study population included 33,764 twins aged 12-41 years old from the Danish Twin Registry. The self-reported one year period prevalence of tension type headache was 86.0%. The period prevalence for infrequent episodic, frequent episodic and chronic tension type headache was 63.5%, 21.6% and 0.9% respectively. *Latthe et al* (2006) conducted the WHO systematic review of the prevalence of chronic pelvic pain (82). Globally there were 178 studies reviewed. Dysmenorrhoea was noted to occur at rates between 16.8 - 81%. Rates for dyspareunia were 8-21.8% and for noncyclical pain was 2.1 - 24%. They concluded on the available evidence that there is a high burden of all types of pelvic pain. Thus investigation of functional symptoms in general, specific functional symptoms

and syndromes at population, primary care, secondary care outpatient specialist clinics and secondary care in the in-patient setting reveal a significantly large disease burden.

The burden is not limited to large numbers. A few studies have attempted to consider the impact on health care resource utilisation by patients with functional symptoms. *Barsky et al* (2001) in a primary and secondary care based study in the USA assessed 876 randomly selected patients attending a primary care clinic in a large teaching hospital (83). The patients with the highest somatisation were compared with other patients with regard to health resource utilisation. The adjusted outpatient cost of the somatizing patients was estimated at $1,312(95% CI $1154-1481) compared to the $954 (868-1057) of other patients. Total number of physician visits were 9.21 (95% CI 7.94 - 10.4) and 6.33 (5.87 – 6.90) respectively. Somatising patients had a 24% (95% CI 19 – 30%) chance of hospitalisation as opposed to 17% (14 - 20%) in other patients. They conclude that somatizing patients have high levels of health anxiety and a considerably higher medical care utilisation compared to other patients. Fink (1992) in a study of persistent somatisers based on the Danish national medical registry assessed the utilisation of surgical operations, frequency and outcome of medical and surgical treatment (84). He concluded that physicians used medical and surgical treatment as frequently for somatisers as for those with organic illness. The outcome of surgical treatment of somatisers was unsatisfactory in three quarters of the cases and medical treatment in two thirds. He concluded that costs of somatic diagnostic procedures and fruitless surgical and medical treatments are enormous and only exceeded by the risk of iatrogenic harm.

Therefore, functional symptoms are prevalent in significant numbers and utilise a disproportionately high amount of health care resources. Can improved management reduce the resource utilisation? *Martin et al* (1998) studied the impact of using video/EEG monitoring to confirm the diagnosis of non-epileptogenic seizures (NEPS) (85). Subsequent to diagnosis, there was a 76% average reduction in diagnostic testing charges, 69% decrease in average medication charges, 80% decline in outpatient clinic visits and a 97% decline in emergency room visits. The estimated total reduction in health

resource utilisation was 84%. The authors concluded that with better awareness of the problem, earlier recognition and appropriate treatment can cause a significant saving of scarce health care resources.

2.4 Explanatory models for functional symptoms

The classical Cognitive Behaviour Therapy model to explain emotional distress was proposed by Beck in 1970 (86). The three P's in Beck's model, i.e., Predisposing, Precipitating and Perpetuating factors are retained in the Cognitive Behavioural Therapy (CBT) explanatory model for functional symptoms. The model proposes a cognitive, behavioural, physiological factor interaction to cause symptoms without pathology and their persistence over time causing distress and disability.

Three factors have been identified as those predisposing towards functional symptom development. Firstly, as with many other physical and psychological ailments, genetic influences could reasonably be expected to contribute. Though genetics remains one of the least researched parts of the model, several studies do highlight its importance. *Hickie et al* (1999) in a study of 1004 adult twin pairs demonstrated that familial aggregation of Chronic Fatigue syndrome appeared largely to be due to additive genetic factors (87). *Farmer et al* (1999), in a twin study of children with chronic disabling fatigue reached similar conclusions (88). *Kendler et al* (1995) in a twin study from the "Virginia 30000" twin family sample concluded that 25-49% of total variance was accounted for by genetic effect and that this effect was seen in both males and females (89). Buffington (2009) proposed that epigenetic modulation of gene expression (EMGEX) played a role in functional symptoms (90). Maternal perception of a threatening environment was transmitted to the foetus when hormones crossed the placenta. The affected foetal physiology, effectively 'programming' the foetal stress response system and associated behaviours toward enhanced vigilance. After birth, intense stress responses in the individual resulted in similar vulnerability which was unmasked by subsequent stresses.

Buffington proposed that EMGEX played a central role in creating this 'survival phenotype'.

The second predisposing factor is the influence of adverse early childhood environment. Hotopf (2003) identified early childhood paternal illness as a risk factor (91). *Fisher et al* (2003) observed that Chronic Fatigue Syndrome sufferers reported their parents being overprotective (92). *Janssens et al* (2009) noted parental overprotection to be a predictive factor for development of not merely fatigue but a wide range of other functional somatic symptoms in young adolescents of both sexes (93). There exists a number of research papers to support the view that early childhood adversity in the form of physical or sexual abuse is a risk factor for future development of functional symptoms (94) (95) (96) (97) (98).

A personality trait consistent with neuroticism is the third recognised predisposing factor. This refers to a stable, life long tendency to experience negative effects (99). The individuals demonstrate an increased response to stressors and experience a high level of psychosomatic distress. Neuroticism has been shown to be associated with occurrence and the poorer prognosis of many physical illnesses (100). Not surprisingly neuroticism as a personality trait has been associated with functional symptoms in general as well as with specific syndromes like functional dysphonia (101), IBS (94) and CFS (102).

Therefore, in summary, genetic influence, early childhood experience and neuroticism as a personality trait are recognised in the illness model as predisposing factors and help us in identifying individuals susceptible to future development of functional symptoms.

What causes such vulnerable people develop functional illness? Stressful life events remain the one strong factor for illness precipitation. Many events in the lives of people ranging from death of a close relative, through physical illness, to a child leaving home have been indentified by researchers as being stressful (103). There exists evidence to support the precipitating role for stressful life events for CFS (104), IBS (105), and chronic pain (106). Stresses in the form of infections with Shigella, Salmonella and Campylobacter have all been identified as precipitants for IBS (107). In addition, IBS has been noted to occur after non gastrointestinal infections as well (108).

How do stressful life events set off the occurrence of chronic symptoms without pathology, which are both distressing psychologically, and disabling physically? The interaction of the predisposing factors and stressful life events set in motion a “stress reaction” in the person (109). There exists evidence to prove that there are physiological, cognitive and behavioural changes which result from the ‘stress reaction’. These are considered below:

In terms of physiological changes, the hypothalamo-pituitary axis (HPA) remains the entity which has been studied in detail. The HPA operates via a positive and a negative loop system. The acute stress reaction to injurious stimuli forms the basis of immunological response to acute illness. But the HPA response to the stress reaction in functional illness is a vastly different entity. A “chronic activation” process lies at the centre of the process. Chronic stress reaction leads to a prolonged activation of the HPA axis resulting in an increased sensitivity to the negative feedback effect of the HPA axis. The result is a reduced ACTH response and ‘hyporcortisolism’ (110). But investigations into cortisol levels have yielded equivocal results. Some researchers have demonstrated normal or even increased levels of serum cortisol (111). Some researchers believe that the explanation for this is that the HPA axis activity changes with the timeline of the functional symptoms as it courses through acute stress to chronic disabling long term stress (112). *Tak et al* (2009) assessed 24 hour free cortisol excretion (24-h UFC) in a population based cohort of 741 people who also completed the somatisation section of the Composite International Diagnostic Interview (CIDI) in which the presence of 43 functional somatic symptoms is surveyed (113). They did not find any associate between altered HPA-axis function, as indexed by 24-h UFC and functional somatic symptoms in the general population. Thus the available evidence is equivocal.

The functioning of the immune system is closely linked with that of the cortisol axis. The immune system is responsible for both analgesia and hyperalgesia cycles mediated via inflammatory cytokines. *Reif et al* (2001) have demonstrated a decrease in the concentration of soluble CD8 T lymphocytes and interleukin-6 levels in those with somatoform disorders (114). In addition to mediating analgesia/hyperalgesia, the cytokines are associated with the

subjective feeling of being ill - with fatigue, lassitude and reduced physical activity. *Tak et al* (2009) attempted to assess whether low grade immune system activation is associated with functional somatic symptoms (115). They measured highly sensitive CRP (hs-CRP) levels over the course of the illness in a cohort of 881 adults with functional somatic symptoms. The association for the gastro intestinal cluster did not reach levels of statistical significance but a significant association was noted for the functional somatic symptoms related to the musculoskeletal system. *Lewith et al* (2007) hypothesised that an immunological reaction to Candida yeasts present in the gastrointestinal system played an aetiological role in functional somatic symptoms. No significant relationship was found for IgA and IgM levels for Candida but there was a significant association noted with IgG levels and functional symptoms. They go on to state that whether the link is causal or whether the two observations are parallel manifestations of a common underlying disorder needs further investigation (116)

Other physiological hyper activations have also been noted. *Reif et al* (2001) demonstrated that those with functional symptoms had a delayed 'heart rate activity recovery response' compared to healthy controls when mental stress was induced with the span of apprehension test. This is consistent with a higher autonomic cardiovascular physiological arousal state (117). Functional brain studies for functional symptoms are still at inception. With the use of EEG evoked potentials, PET scanning, functional MRI scanning have demonstrated functional alterations in caudate nuclei, thalamus, basal ganglia, pre frontal cortex and right parietal region, by researchers (118). The specificity of these findings needs to be investigated further. In summary, physiological changes are recognised to be present in the HPA axis, immune response, autonomic cardio vascular arousal, and functional brain activation in those with functional symptoms.

Dreary et al (2007) propose that the chronic stress reaction brings the symptoms into the autopoietic cycle which works to perpetuate the functional illness (38). Autopoietic cycle is a term borrowed from systems theory and describes a process where the organisation produces itself. The components through their interaction produce the same process which produced them.

Therefore it is autonomous and self maintaining. It is different to a cloning process where the organisation grows in numbers, exponentially. Here the cycle works to sustain a procedure itself. In any CBT model a cycle lies at the heart of it. In functional symptoms this autopoietic cycle forms the crux of the illness.

As *Deary et al* have discussed the first stage in the cycle is 'sensitisation'. The chronic stress reaction and prolonged activation of the physiological response set off the sensitisation process. In sensitisation, because of prior experience, a heightened response to stimuli occurs. Such heightened response over a long period of time runs the risk of a 'burnout', as is thought to happen with HPA axis. Therefore the net result of sensitisation is the symptom which arose without pathology in the first place, occurring with increasing frequency and sensitivity over a period of time.

The second stage of the autopoietic cycle is then reached. This is termed 'attention'. At any moment, a plethora of messages relating to organ status and function reached the brain. But only a fraction of this information reaches the cognitive process. There is a hypothetical filter which selects symptoms for conscious attention. This cognitive unconsciousness itself is an area of study which is receiving much research attention. In functional symptoms, it is believed that there is a faulty filtering mechanism in operation. On the other hand, due to increased sensitivity, a much higher number of symptoms (without pathology) are being generated and due to the faulty filtering in 'attention', many of these symptoms which would otherwise pass under the 'radar' reach the conscious attention of the ill person.

The third phase of the autopoietic cycle is termed 'attribution'. What does the person attribute these symptoms to? Do they feel it as a 'physical illness' or a 'psychological illness'? Do they feel it could mean something sinister or something temporary, transient, which will pass without any further problem? Essentially, how do patients explain the symptoms to themselves? *Kirmayer et al* (2004) in their qualitative study of illness narratives of those with functional symptoms demonstrated that those who choose to attribute the symptoms to a malfunctioning of the body with anticipated sinister outcomes

were greatly distressed by the functional symptoms (35). Neuroticism personality trait further aggravates the problem.

The fourth and the final phase of the CBT model deals with 'illness beliefs and behaviours'. It is not just the illness, but one's response to the illness that also determines prognosis and outcome. Lackner (2005) demonstrated that catastrophic illness beliefs resulted in poor outcome for patients with IBS (96). Symptom avoidance behaviour learned via medical, social and cultural influences worsen prognosis. *Hotopf et al* (1996) demonstrated that in CFS later fatigue was positively associated with length of convalescence (119). Symptom coping behaviour is also important. *Spence et al* (2005) examined the coping behaviour of 768 patients with Campylobacter infection and demonstrated that IBS at six months was related to all or nothing coping behaviour (120).

In the autopoietic cycle, we return from 'illness beliefs and behaviours' to 'sensitisation'. Inappropriate and illness perpetuating behaviours and beliefs give rise to further sensitisation to the chronic stress reaction precipitated by stressful life events, bacterial and viral infection etc. The autopoietic cycle sets off again, with increased vigour.

Successful CBT measures have targeted various domains of this illness model, which incorporates physiological, behavioural and cognitive domains. Various trials have brought into focus the importance of isolated factors in the cycle. As yet there exists little evidence which tests the interaction between various factors and the relative importance of each domain. The nature of the model makes it difficult to design a trial to check the full model in operation with all its factor linkages.

2.5 Treatment of Functional Symptoms

There has been an interest in the treatment of functional disorders from the latter part of the 20th century. As of now, there is a growing body of evidence on the usefulness or the lack of it on the various functional disorders. Most of the research has been done on the three well recognised functional somatic syndromes, irritable bowel syndrome, chronic fatigue syndrome and

fibromyalgia syndrome. This is believed to be due to the availability of clearly laid down criteria for diagnosis. Other conditions such as non ulcer dyspepsia, tension headache, non specific chest pain, chronic pelvic pain, premenstrual syndrome, temperomandibular joint disorder, environmental illness (multiple chemical hypersensitivity), electromagnetic hypersensitivity, chronic low back pain and somatoform disorders have all been explored to varying degrees on the usefulness of various treatment forms. A multitude of therapeutic approaches exist. Broadly these can be divided in to five different categories. One or more of these approaches has been tested for success by researchers on the various functional somatic syndromes (121).

Pharmacotherapy is either peripheral or central. Peripheral pharmacological therapies are aimed at peripheral physiological processes. Changes of bowel habit in IBS, muscle tension in FMS, pain in tension headache or non cardiac chest pain are some of the peripheral physiological processes. Central pharmacological therapies are aimed at changes in sensation, cognition and affect. Non pharmacological therapies are either active or passive. Active therapies occur with the patient's active participation. Active behavioural intervention is aimed at change of individual and interpersonal behaviour patterns. Graded exercise, psychotherapies and multi disciplinary therapies are examples. Passive physical interventions are non pharmacological measures aimed at peripheral physiological processes. Surgery, trigger point injections, nerve ablations are examples. In addition to the above four, a range of alternative or complementary medical methods have been attempted. Outlined below is a summary of the strength of the available evidence emerging from meta analysis, systematic reviews and randomized trials from the year 2001 to date on the treatment of the various functional somatic syndromes.

2.5.1 Irritable bowel syndrome (IBS)

Among peripheral pharmacotherapies, for the sub group of females, there is strong evidence of benefit with the use of $5HT_4$ agonist tegaserod for those with predominant constipation and $5HT_3$ antagonist alosetron for those with predominant diarrhoea. Tegaserod acts as a motility stimulant by acting on

the serotonin receptors in the enteric nervous system. Though effective, it was withdrawn by the FDA in March 2007 due to concerns about adverse cardiovascular events. Alosetron was also withdrawn from use in by the FDA in year 2000 due to occurrence of serious life threatening GI side effects. It was reintroduced in 2002 but its use is restricted. The decision to reintroduce the medicine was criticized widely with a Lancet editorial arguing that '*the treatment of a non fatal condition did not justify the use of a drug with potentially life threatening side effects*' (122).

There is moderate evidence for the benefit of spasmolytic agents. Bulking agents, prokinetic agents and Loperamide are of no benefit. Among the central pharmacotherapies, for tricyclic antidepressants there is moderate evidence effectiveness. Active behavioural interventions like cognitive behavioural, interpersonal, hypnotherapy and psychodynamic psychotherapy have demonstrated moderate evidence of efficacy. Whether one is superior to the other is not clear. No trials support the use of passive physical interventions. There was weak evidence for benefit with a Chinese herbal medication (123,124,125,126,127).

2.5.2 Fibromyalgia syndrome (FMS)

Among the peripheral pharmacotherapies, the two commonest classes of medications used, NSAIDs and corticosteroids offer no benefit. Strong evidence supports the use of central pharmacotherapeutic agents like tricyclic antidepressants and cyclobenzaprine. There is moderate evidence for efficacy of selective norepinephrine reuptake inhibitors (SNRI) and opioids analgesic tramadol. Selective serotonin reuptake inhibitors (SSRI) are the other group of medications tried and there is weak evidence for their benefit. A range of active behavioural interventions have been attempted with quite good outcomes. Strongest evidence exists for aerobic exercise, patient education and multi disciplinary treatment. Moderate evidence exists for hypnotherapy, bio feedback, strength training and CBT. Among the passive physical interventions there is weak evidence for benefit with chiropractic therapy, massage therapy. Trigger point or tender point injection is of no

benefit. Among the alternative therapies, there is moderate evidence of benefit for acupuncture (128,129,130,131).

2.5.3 Chronic fatigue syndrome (CFS)

Among the peripheral pharmacotherapies, there is weak evidence to support the use of immunoglobulin therapy. There is no evidence for the usefulness of corticosteroids and interferon. Among the central pharmacotherapies there is weak evidence for benefit with antidepressants. Active behavioural interventions like graded exercise and CBT carry strong evidence of benefit to patients. There are no trials supporting the use of passive physical interventions or alternative therapies for CFS (29,132,133.134).

2.5.4 Non ulcer dyspepsia

Among the peripheral pharmacotherapies, trials have shown moderate evidence for benefit with the use of proton pump inhibitors, H2R antagonists and Helicobacter pylori eradication strategies in infected patients. There is weak evidence of benefit with prokinetic agents and no evidence of benefit with antacids. No rigorous trials have been carried out to assess the benefit of centrally acting pharmacological therapies like antidepressants. Active behavioural intervention with different psychotherapies offers moderate evidence of benefit. There are no trials supporting the use of any passive physical interventions or alternative therapies (135,136,137).

2.5.5 Tension headache

There exists weak evidence to support the use of botulinum toxin as a peripheral pharmacological therapy. There is no evidence of benefit with niacin. Among the centrally acting medications there is strong evidence for tricyclic antidepressants and moderate evidence for benefit with SSRIs. Among the active behavioural interventions, there exists strong evidence of benefit with behavioural therapy. As for passive physical interventions, there is no benefit with spinal manipulations and physiotherapy. There is weak evidence for benefit with acupuncture (138,139,140,141.142).

2.5.6 Non specific chest pain

This refers to chest pain with no evidence of underlying coronary, gastroenterological or other organic pathology (143). This is somewhat similar to but more exclusive than non-cardiac chest pain. Some patients with non-cardiac chest pain benefit from treatment with prokinetic agents. The only form of treatment with evidence to support is psychotherapy. There are no trials to support the use of peripheral or physical pharmacotherapies, passive physical interventions or alternative/complementary therapies.

2.5.7 Chronic pelvic pain

This includes subcategories of interstitial cystitis and chronic prostatitis. There is weak evidence for benefit with hormones like progestogens and goserelin. There is no benefit with centrally acting pharmacological agent sertaline. Among the active behavioural interventions, evidence for a moderate beneficial effect exists for psychotherapy. Weak evidence of benefit is shown with ultrasound scanning and counselling and multi disciplinary treatment. A variety of surgical treatments have been attempted. None of these passive physical interventions like adhesiolysis, uterine nerve ablation or manual techniques are of benefit. No trials support the use of alternative/complementary medicine (144,145).

2.5.8 Premenstrual tension

Of the peripheral pharmacotherapies, gonadotropin releasing hormone (GnRH) antagonists offer strong evidence of benefit. Progesterone or progestogen is of no benefit. Among the central pharmacotherapies, strong evidence exists for benefit of SSRIs. No trials show benefit of active behavioural or passive physical interventions. Alternative/complementary methods are of no benefit (146,147 148,149).

2.5.9 Temperomandibular joint disorder

Peripheral pharmacological agents like analgesics are of no benefit. There is weak evidence of benefit from the use of centrally acting pharmacological agents, tricyclic antidepressants. No trials support the use of active

behavioural interventions or alternative/complementary medicine. Use of passive physical interventions like splint therapy is of no benefit (150,151).

2.5.10 Electromagnetic hypersensitivity / environmental illness (multiple chemical sensitivity)

No trials support the use of peripheral or central pharmacotherapies. There is moderate evidence for benefit with CBT. Passive physical interventions like screen filters or shields is of no benefit. Complementary medical strategy of use of selenium for environmental illness is also of no benefit (152,153).

2.5.11 Chronic low back pain

Strong evidence exists for peripheral pharmacotherapy with NSAIDs. Muscle relaxants offer moderate evidence of benefit. There is strong evidence of benefit from the use of centrally acting pharmacological agents like tricyclic and tetracyclic antidepressants. There is evidence of moderate benefit from opioids analgesics. SSRIs are of no benefit. Of the active behavioural interventions strong evidence of benefit exists for CBT and multidisciplinary therapy. Moderate benefit is offered by exercise therapy and back schools. Of the passive physical interventions, weak evidence for benefit exists for radiofrequency denervation and spinal manipulation. Prolotherapy and transcutaneous electrical nerve stimulation is of no benefit. Of the alternative / complementary therapies, there is weak evidence for benefit with acupuncture (154,155,156,157,158,159,160,161).

2.6 Diagnostic analogues used in psychological medicine

These constitute somatoform disorder, conversion disorder and multiple unexplained symptoms. There is no evidence from trials to support the use of pharmacological agents unless there are coexistent mood or anxiety disorders. There is moderate evidence for the usefulness of CBT. Weak evidence exists for the use of hypnotherapy and paradoxical intention for conversion disorder (162).

2.7 Problems in the treatment of functional disorders

Considering the treatment strategies and the evidence of the usefulness of them as a whole, a number of critical issues which need further exploration emerge. The most outstanding feature is, despite the recognition of this important diagnostic category for two decades, our knowledge on how to treat them is still in infancy. Fibromyalgia syndrome causes more disability than a comparable organic disease like rheumatoid arthritis (56). Evidence based successful treatment strategies are well established for rheumatoid arthritis. Comparatively we have progressed very little in our ability to manage fibromyalgia syndrome. A similar analogy is a comparison between irritable bowel syndrome and inflammatory bowel disease. The organic disease has well established treatment strategies and doctors are still struggling to find means to successfully deal with irritable bowel syndrome. The paucity of evidence based treatment strategies arise due to a number of reasons.

Firstly, the aetiology and pathophysiology of functional disorders is still not clear. Organic disorders have biological explanations for pathophysiology. Genetic and cellular level biological abnormalities have been recognised. These act as targets for both prevention of the disease and as treatment foci when the disease occurs. Functional disorders are best described on a bio psycho social model. Factors which precipitate, perpetuate and aggravate are identified from biological, psychological and sociological domains. The precise factors are not known, only suspected. Whether there are factors in addition to what is suspected is not known. The relative importance and individual contributions of biological psychological and social factors are not known. Due to the above reasons, therapeutic targets have remained vague and thus the treatment strategies and the evidence for them remain sketchy.

Secondly, the functional somatic syndromes remain a vastly heterogenous group of disorders. They involve a number of systems and even though there is often overlap, the only common factor remains a lack of recognised organic pathology. Even with individual syndromes, there is little agreement within the medical community about exact diagnostic criteria. Very often patients' complaints do not fit in to one particular syndrome. They merely remain a

single (or a couple) of disabling symptoms. Therefore there is a distinct category of functional somatic symptoms as opposed to functional somatic syndromes. All of the trials look at syndromes and not at individual symptoms. Again the heterogeneity of individual functional symptoms is enormous. In the background of such heterogeneity it is not surprising that such a wide variety of treatments have been attempted and a paucity of evidence for them exists. To have common therapeutic targets and therapeutic agents will not be possible. Though research shows that many patients with one functional problem have clinical features to fulfil diagnostic criteria for more than one functional somatic syndrome, all trials to date have looked at the outcomes related to one somatic syndrome only (49).

Thirdly, there exists disagreement about how success of different treatments should be evaluated. Patients are affected in three ways by functional disorders. They can have severe symptoms. Their normal functioning can be affected. Their quality of life is often impaired. Individual patients are affected to varying degrees in these three aspects. There is disagreement about which aspects are more important and whether one or all should be adopted as therapeutic targets. Most of the trials on pharmacological therapies have adopted symptom relief as the primary therapeutic target while the psychotherapies have considered disability, functioning and quality of life as the therapeutic targets. Even when symptoms are considered there is no uniformity and pain, manual tender points and fatigue have been used as primary therapeutic targets in different trials in fibromyalgia syndrome. It is reported that in 44 trials on the treatment of FMS, 130 different therapeutic targets had been used (128). Thus there is difficulty in generalizing the value of the various treatment strategies even when they have been shown to be of use.

That there is a paucity of evidence for successful treatment strategies for functional disorders is clear. The next stage of the problem is the difficulties encountered in translating the available evidence into clinical practice. Both patient factors and physician factors act as barriers to successful treatment. In the normal course of things, the treatment is focused on the patient. Within the patient setting the focus is on alleviation of the symptom causing the

physiological dysfunction in the patient. In the treatment of functional disorders, focus has to be maintained on the patient, on the doctor and on the contextual factors as well. An organ oriented approach is needed to alleviate the symptom. A cognitive interpersonal approach is necessary to minimize disability, optimize functioning and improve quality of life. The other barrier to treatment comes from the patients themselves. Though active behavioural interventions seem to offer the best bet for beneficial outcome, getting the patients into these treatment modes would require them to accept the bio psycho social role or disease causation. They are often looking for an organic explanation as much as the treating doctors, and the mind body dualism is entrenched in their thinking just as in the medical community for them to think otherwise. Thus failure to accept the psychological and social aspects of the treatment makes them shy away from psychological and psychotherapeutic therapies. Their 'organic' specialists are not familiar with the administration of these therapies. This invariably means that they will need to be seen by psychiatrists and psychotherapists. Most patients would resist referral to psychological services and view it as a dismissal of their symptoms as 'just in the mind'.

Unlike in treatment of most other disorders, there is focus on the doctor too. The doctors are expected to recognize the disorder early, communicate the information to the patient, treat and avoid iatrogenic harm. Doctors find it difficult to explain to patients about the pathophysiology of the illness and explain the treatment rationale and strategies. This is due to inadequate knowledge and doubts they themselves harbour about the illnesses. They have received little training in communicating these concepts to the patients. Even when they are aware of evidence based treatments such as psychotherapy, behaviour therapy, cognitive therapy, they do not possess competence to administer these treatments. If they were going to successfully adopt the evidence, they would need extensive training in the psychological techniques. The time and economic consequences of such an action are enormous. Furthermore, many doctors may not be willing to undergo training to tackle a problem which they consider a low priority issue. Many doctors consider those with functional disorders to represent the

'worried well' segment of the patient population. Therefore, contrary to expectations, very often, successive doctors can keep missing the diagnosis for years, failing to communicate the nature of illness on the rare occasion they diagnose it, failing to treat it and cause iatrogenic harm via repeated unnecessary investigations and invasive treatment procedures, such as surgery. Thus there is a major barrier to translate evidence into practice from the two most important stakeholders in the process, the patients and the doctors themselves.

There is also focus on the context. It is recognised that patient's family, social and cultural environments play a role in the causation and the propagation of functional disorders. Treating patients with a focus on the social contexts is a concept which is alien to many doctors. Functional disorders bring the doctors out of their comfort zones. Only a few are able to successfully blend their treatment strategies with the wider social and psychological issues confronting the patient.

Thus it can be seen that there is both a paucity of evidence for good treatment strategies and also major barriers to translating the little evidence available into practice. The other major and often invisible barrier which extends across medicine is the fact that psychiatrists and the rest of the medical community have failed to meet on common ground when it comes to understanding functional disorders. For the likes of physicians, surgeons, gynaecologists and the GPs there are functional somatic symptoms and syndromes and they are all trying their best to find ways of treating them. For psychiatrists there are somatoform disorders, which is the umbrella term for somatisation disorder, conversion disorders, hypochondriasis, body dismorphic disorder and undifferentiated somatoform disorder. They are on a different quest to find solutions to these 'problems'. Not only is research conducted on either side of the divide, the dissemination even occurs along the divide. The same clinical problem, such as unexplained bowel symptoms would be IBS for one group and somatisation disorder for another. The diagnosis and the treatment that the patient receives to some extent depends on the specialist they sought treatment from. This great divide has been well illustrated in the recent paper by Kroenke titled *'Efficacy of treatment for*

somatoform disorders: a review of randomized controlled trials'. In searching for relevant articles on the MEDLINE he states '*Also excluded from the retrieved articles were studies that focused on specific symptoms (e.g. back pain, headache) and those on functional somatic syndromes (e.g. irritable bowel syndrome, fibromyalgia)'* (163). For the psychiatric community, reviews of RCTs on somatoform disorders exclude RCTs on functional problems well recognised among other specialists. Many of the pharmacological treatments advocated by the other specialists are not part of the armamentarium of the psychiatrists for their management of somatoform disorders.

Unless and until 'mind' and 'body' doctors start speaking the same language, much of the knowledge is not going to be of benefit to the patients. In this study, an attempt is made to understand the perceptions of psychiatrists, physicians and gynaecologists working in two different cultural contexts on functional disorders. It is hoped that the knowledge generated will help bridge part of the gap between the various groups of medical practitioners.

2.8 Outcomes of functional disorders and rate of missed organic illnesses

One of the major reasons for reluctance on the part of doctors to diagnose functional problems is the perceived fear of missing an organic diagnosis. This has led to doctors adopting an approach of 'diagnosis by exclusion of organic disorders'. Thus patients are subjected to numerous and often invasive investigations. Referrals are made to many other specialties. Very often these steps are carried out whilst appreciating that the chance of the symptom having an organic basis is minimal. A missed organic diagnosis has many adverse implications for a doctor. Personally they will have failed their patient, the esteem with which their peers hold them is likely to recede and there are fears of litigation.

Does the available evidence from the medical literature support this perception? The "scientific" basis for such fears was laid by Eliot Slater in 1965 in a paper (Shorvon Memorial Lecture transcript) published in the BMJ titled 'Diagnosis of Hysteria' (164). The research he quoted from was published in the same year in the Journal of Psychosomatic Research. *Slater*

et al followed up 85 patients diagnosed as having 'hysteria' at the National Hospital for Nervous Diseases for an average period of 9 years (165). The authors concluded that one third of the patients were subsequently diagnosed as having clear cut neurological illnesses. A further proportion developed clear cut psychiatric illnesses on follow up. Slater went on to deny the very existence of hysteria. He concluded …"*Looking back over the long history of 'hysteria' we see that the null hypothesis has never been disproved. The malady of the wandering womb began as a myth, and the myth still survives. But, like all unwarranted beliefs which still attract credence, it is dangerous. The diagnosis of 'hysteria' is a disguise for ignorance and a fertile source of clinical error. It is in fact not only a delusion but also a snare"* (164). This influential paper had a profound effect on neurologists and psychiatrists who became reluctant to diagnose hysteria for fear of missing a neurological diagnosis. Despite major flaws in designing and reporting for decades this 'classic' paper kept on appearing as solid evidence that a diagnosis of a functional problem was merely a misdiagnosed case of disease which will eventually emerge. Some claim that this classic status came about due to psychiatrists having a wonderful excuse to send patients with a diagnosis of hysteria back to the neurologists. Others believe that it was due to the memorable eloquence of the conclusion to the original lecture and not the scientific quality. The net result of the Slater study and the subsequent denial of the existence of functional problem was the unwitting stunting of research and clinical care of these patients (166).

Thirty years later, in 1998, *Crimlisk et al* revisited Slater's work at the National Institute for Neurology and Neurosurgery following up 73 consecutive patients diagnosed as having medically unexplained neurological motor symptoms for a period of six years (167). Of the 64 patients with follow up data, the authors concluded that there were only three patients who were subsequently diagnosed as having a neurological disorder. This was a rate of 4% missing an organic diagnosis. Even the three patients presented mitigating circumstances for missing the organic disease. One was subsequently diagnosed to have paroxysmal hemidystonia, a disease which had not been fully characterized at the time of initial presentation in 1989. The second was

a lady with learning difficulties who was subsequently diagnosed as having dystrophia myotonica. The third was a man whose first language was not English, who was subsequently diagnosed as having spinocerebellar degeneration. It was felt that poor communication during initial assessment contributed to missing the diagnosis in the second and third instances. The authors went on to conclude that patients who presented with unexplained neurological motor symptoms who were properly evaluated clinically and investigated were unlikely to be subsequently diagnosed as having an organic neurological illness.

Both the Slater study in 1960s and the Crimlisk study in 1990s were conducted in the same setting. The reasons for the remarkable reduction in the subsequent diagnosis of organic disease merit an in-depth assessment. The eventual diagnoses made in the hysteria group of patients by Slater include trigeminal neuralgia, thoracic outlet syndrome, Takayasu's disease, cord compression and dementia. Insufficient details were given in the paper as to whether these 'new' diagnoses explained the initial unexplained presentation. At least some of these conditions would have been diagnosed at the first assessment in the present day neurological context.

The high diagnostic accuracy of the Crimlisk study probably reflects improved diagnostic skills and better non-invasive investigations. It can be reasonably stated that Slater vastly overestimated the proportion of missed organic diagnoses in the context of medicine today. At the same time caution has to be exercised in generalizing findings of Crimlisk. Patients with neurological problems being evaluated at the National Institute for Neurology and Neurosurgery would have been evaluated by experts with the most sophisticated investigations. A general practitioner or a doctor in an outpatient clinic in a district general hospital would not have the same access to clinical and investigation expertise. Thus it is possible that the rate of missing an organic disease would be higher. At the same time, as these patients are from a highly specialized centre, their prognosis would be poorer than those attending a general practice. Thus the chance of missing an organic illness could also be lower than the figures. A general practice-based follow up study would provide an insight into the real situation. The other

limitation of the study is that the authors considered only patients having motor neurological symptoms. Whether these figures apply in the same way for the vast array of functional problems in the same percentages is a matter of conjecture (168).

In 2005 *Stone et al* in a systematic review of misdiagnosis of conversion symptoms and 'hysteria' considered studies from 1965 to 2003 (169). The overall pooled proportion of misdiagnosis of conversion symptoms and hysteria was 8.4%. They concluded that this overall figure disguised a change over time from 29% in the 1950s to 17% in the 1960s to 4% for every decade since then. Two reasons were postulated for this possible change. The first was the improvement in diagnostic techniques. Against this reasoning is the fact that the 4% figure has been consistently seen from the 1970s, a time before complex imaging techniques became available. The second reason quoted, which the authors considered more likely, was the poor quality in terms of methodology of the studies from the 1950s and 1960s. Studies with poor case definitions tended to have higher misdiagnosis rates. In the higher quality studies, true misdiagnosis was rare. Following the meta analysis, *Stone et al* (2009) published the results of their 19 month follow up of 1,144 patients with functional neurological problems (170). Only four patients were diagnosed to have an organic disease to explain the previously unexplained symptoms. The rate for this study is exceptionally low, at less than 0.4%. Even in these four patients, it was noted that either the ultimate diagnosis had been explicitly considered or the diagnosis was the result of investigations arranged at the time of initial consultation.

Some clinicians may believe that a misdiagnosis rate of 4% is still too high. To evaluate these figures in correct perspective, it must be compared with misdiagnosis in organic diseases. *Smith et al* (1999) stated that epilepsy is a misdiagnosis in up to 25% of instances and is due to a different organic cause such as syncope (171). *Hankey et al* (1987) found that 8% of those diagnosed as having multiple sclerosis had a conversion disorder (172). Thus it is clear that the instances in which organic disorders are misdiagnosed as other organic disorders, organic disorders are misdiagnosed as functional

problems and functional problems are misdiagnosed as organic disorders occur all the time and in similar percentages.

The prognosis of these patients should not be merely limited to discovering whether a subsequent organic disease was diagnosed. In the Slater study four patients committed suicide during the nine year follow up. Even in the Crimlisk study it was noted that there had been preventable deaths from suicide and immobility. 77% of patients were in paid employment prior to the onset of symptoms but only 11% were still employed at the end of the six year follow up period. 40% were on sick leave and 30 % had already retired on grounds of ill health. Thus in the group of patients who continued with no organic explanation, the prognosis in terms of quality of life and functional status was poor (173).

Concern about misdiagnosis is good practice and should prompt the clinician to be thorough and diligent in the clinical evaluation and investigation. But this concern should not be the reason for over investigation and delay in treatment of functional problems. Reaching the balance between concerns of missing the diagnosis and achieving a positive diagnosis for a potentially treatable illness is the challenge every clinician must attempt to surmount.

3 Cultural influences on functional symptoms

3.1 The influence of cultural and sociological beliefs, values and practices on functional illnesses

Cultural and social factors are considered to have an impact on the health and wellbeing of people. Cultural beliefs, values and practices are part of a person as a social being and also affect both illness behaviours and illness coping skills. Emotional and social factors affecting a patient have a role in causation, precipitation and propagation of functional disorders. Any successful management strategies for functional disorders need to take cognizance of these cultural influences. Only a few researchers have considered the influence of these aspects on functional disorders.

The UK has a long documented history of its people. Western allopathic medical traditions have flourished in Britain over the centuries. With an ever increasing migrant population its cultural diversity has also increased over the years. Sri Lanka has a similarly rich cultural tapestry amongst its people. Though the people and the society of Sri Lanka is very different in constitution to that of the UK, the diversities in the various groups of people offer a great opportunity for researchers to delve into this hitherto little touched area. Thus, for purposes of cross cultural study, medical practitioners treating these two social settings in the UK and Sri Lanka were selected for interviews, as in other sections of this thesis. A brief introduction to the cultural and social diversity of Sri Lanka in terms of the different groups of persons living there, their belief systems and the healthcare delivery systems is presented below:

The peoples of Sri Lanka belong to a number of different ethnic communities. Immigration from neighbouring India, visitors from the Arabian regions for trade purposes and colonial invasions have resulted in the formation of these different ethnic communities. Archaeologists believe that there were inhabitants in the island by 10th century B.C. It is recorded that people of the Yaksha and Naga tribes lived during the time of the visit of the Buddha to Sri Lanka in the 6th century B.C. The present day semi tribal Vedda community is

believed to descend from these early inhabitants. These early inhabitants held the belief that everyday natural events were the work of gods. The sun was worshipped as a god (Eru deviyan), earth as a goddess (Mihikatha deviyan), rain as a god (Indra deviyan) and trees, mountains too as gods. Thunder and lightning were viewed as the effect of shaking of the Vajrayudaya (diamond embedded weapon) by the rain god, Indra.

Around the 5th century B.C. the Sinhalese migrated from North India and brought with them the Indo Aryan language that is Sinhalese today as well as the religious traditions of Brahmanism. Prince Vijaya and his entourage of 500 are considered the forefathers of the Sinhalese ethnic group. The Tamils migrated from South India and brought with them the Dravidian language and Hindu religious beliefs. They were well established by the 3rd century B.C. Buddhism was introduced in the 3rd century B.C. and became the predominant religious belief of the Sinhalese community. Sri Lanka was situated in the trade route between the East and the West and many traders passed through the island's ports. Some of the Arabian traders settled down in Sri Lanka establishing the Muslim community and their religion, Islam. Three European powers: the Portuguese, Dutch and the British invaded Sri Lanka successively in the 16th, 17th and 18th centuries. The Portuguese introduced Christianity to the people of the country and these traditions became firmly established during the subsequent Dutch and British periods of rule.

Today there are the Sinhalese, the Tamils, the Muslims, the Burgher community and the semi tribal Vedda community living in Sri Lanka. The Sinhalese constitute about 73% of the population. The vast majority of them are Buddhists. The Tamils make up about 20% of the population and the vast majority of them belong to the Hindu religion. The Muslims make up about 6% of the population and are predominantly of Islamic faith. The Burghers are descendants of inter marriages between Europeans and Sri Lankans. Their numbers are few and are predominantly of the Christian faith. There are some Sinhalese and Tamils also professing to Christian faith and Christians make up around 12% of the population. The Vedda community numbers have reduced to a few thousand. They have integrated remarkably little with the

rest of the people of Sri Lanka over the centuries and have customs and beliefs quite particular to their group. As would be expected in such a diverse setting there are many socio cultural differences among the communities. At the same instance, despite the diversity, they do share many socio cultural beliefs values and practices and are closely bound by this common thread.

3.2 Healthcare provision and beliefs

The quality of healthcare enjoyed by people in Sri Lanka is among the highest in the developing world in terms of mortality and morbidity rates and life expectance figures (174). A number of parallel health care systems exist in providing health care provision. There is a well established western allopathic medical system of care delivered through an extensive network of hospitals and preventive care institutions. The invading European forces introduced this medical system to Sri Lanka. The Portuguese and the Dutch established hospitals in Sri Lanka to treat the Europeans. The British expanded these services to reach the local population. The British established the first medical school and started training local doctors in allopathic medicine. Today this network remains the most strongly established and also the most widely accessed healthcare system. In addition some seek treatment from Ayurvedic practitioners. The Indo Aryan traditions of the Sinhalese introduced Ayurveda to the country. This is based on the Vedic traditions and it is believed that illnesses arise due to 'Dosha' in the body humours of Waa (bad air), Pith (bile) and Sem (phlegm). This is believed to result in mental and physical problems. The Ayurveda system has sponsorship from the state and there are formal Ayurveda teaching programmes conducted by the universities. Siddha is a system of treatment originating amongst the Tamil people with roots from South India. Unani is a form of medical care which has its roots in the Arabic region. A small number of patients take treatment from these forms of treatment. In addition to these established traditions with a global flavour, there are two unique groups of healers serving the Sri Lankan community. There are the indigenous herbal specialists and the ritual healers. Herbal specialists use herbal preparations handed over from ancient times which are used to treat all types of ailments ranging from snake bites to fractures. The traditional knowledge is passed

from generation to generation, often from father to son, through apprenticeship.

The second unique group consists of the ritual healers. They are at times astrologers, dancers, exorcists or priests. They perform extensive ritual events to ward off evil influences making a person unwell. These ritual healing practices were widespread in the rural communities over the centuries and remain part of their lives even today, albeit at a much lower level of importance. They are used often for physical complaints arising secondary to adverse psychological influences. They offer fascinating insights into the socio cultural explanations of illness, treatment and restoration of good health. The treatments as a group are named Shanti Karma ('rituals of blessing'). The best known of these ritual healing practices is a ritual of dance performed by traditional practitioners named the Sanni Yakum Yagaya / Daha Ata Sanniya ('Ritual for the 18 devils'). There are many explanations for the origin of this ritual but the most widely quoted story is as follows:

An ancient ruler King Sankapala was at war and his wife queen Aauyupala who was pregnant developed a craving for a mango grown out of season. As she ate it, her maid of honour too wanted a piece of the fruit, but had been refused by the Queen. Angry at this refusal, the maid cursed her and when the King returned after the war, she told him that the Queen had conceived out of wedlock. The story was believed and the Queen was sliced in two with a sword and was thrown into the graveyard. The baby was born at that time of her murder. After birth, he ate off his mother and thus turned into a devil known as Mahakoola sanni Yaka. As the story goes, this devil created 18 other devils and they in turn came to towns and cities and began to spread in the form of diseases.

Therefore it came to be accepted that various forms of disease represented the action of devils. An elaborate dance ritual was designed to ward off the devils and thereby illnesses. This dance ritual came to be know as the 'Daha Ata Sanniya', with 'Daha Ata' being the Sinhalese term for 18 and 'Sanni' for illness.

'Daha Ata Sanniya' is performed in two sections where the first part will consist of seven 'Palis', while the second part is performed as the 18 'Sannis'. The 'Palis' deal with the 'lesser devils' and are a prelude to the 'Sannis'. In the 'Palis' the spirits of the ill person is elevated with humourous acts before bringing on the more evil devils during the 'Sannis'. During the 'Sannis', the dancers perform dances wearing 18 masks in turn which depict 18 diseased faces representing the evil influences of each of the 18 devils. Those 18 masks and the related dances almost read like an index of a therapeutic guide.

1. Buta Sanniya which is associated with derangement, distortion and listlessness of limbs.
2. Jala Sanniya relates with vomiting and dysentery.
3. Gulma Sanniya refers to lack of appetite, swelling of the abdomen.
4. Kana Sanniya relates with secondary / temporary blindness.
5. Kora Sanniya with secondary / temporary lameness.
6. Bihiri Sanniya relates to secondary / temporary deafness; dissociative state.
7. Vata Sanniya is related with flatulence provoked by aerial humour.
8. Slesma Sanniya is associated with phlegmatic diseases.
9. Kola Sanniya represents pneumonia.
10. Maru Sanniya is wallowing and contortions in the eyes.
11. Amukku Sanniya relates with running with the head tilted to the left and trembling of the limbs; fits.
12. Golu Sanniya is temporary / secondary dumbness.
13. Vevulum Sanniya is associated with shivering, chills and rigor.
14. Gini Jala Sanniya is about burning sensation, headache and fatigue.
15. Pissu or Kapala Sanniya is related with madness and delirium possession states.
16. Demala Sanniya is also related with madness with distortion of the body.
17. Naga Sanniya is related with blisters swelling of the faces and peeling of skin.
18. Deva Sanniya is related with epidemics and infectious diseases.

The dancer dons each of the masks in turn and negotiates with the devils in turn and drives them away. The ill person remains close by and when each of the devils is driven away, becomes well at the end of the night long ritual. (175). The intonation is the devils have affected the psychological well being of the ill person and the manifestations of the psychological maladies are in the form of physical symptoms or somatic symptoms. The 'Daha Ata Sanniya' recognises disruption of the smooth functioning of the mind by the devils causes central and peripheral neurological illnesses, gastro intestinal complaints, respiratory symptoms, dermatological complaints and musculo skeletal problems and psychiatric problems. Perhaps one of the most ancient formal recognition of chronic fatigue syndrome comes in 'Gini Jala Sanniya', irritable bowel syndrome via 'Vata Sanniya' and conversion disorder in 'Golu Sanniya' and 'Bihiri Sanniya'. Importantly, these Shanti Karma were never performed for conditions like congenital deafness or blindness. It was only for those who developed symptoms later on in life, quite likely due to the inability to cope with life's stresses.

The whole process of the ritual lasts an evening and the night. The ill person is not given any medicine but merely watches the ritual in the company of relations and well wishers. The treatment process could be described as a form of psychotherapy in the language of allopathic medical treatment that is familiar to us. Daha Ata Sanniya represents one of the oldest recorded attempts at treatment of functional disorders using psychotherapy.

'Riddi Yagaya' is a ritual performed to overcome problems related to subfertility, pregnancy, childbirth. The social stigma related to subfertility is taken away by the projection that it is due to the mal effect of the influence of a devil. In the ritual, the importance of women maintaining good hygiene and health practices and the role of the male in providing the economic and social stability to the relationship is brought into focus. Ultimately the devil is driven away in the hope of restoring success in bearing children. The psychological and social aspects of the medical conditions of subfertility, miscarriages and problems in labour are highlighted in the 'Riddi Yagaya'.

‘Sooniyam Kepeema’ (Destruction of a curse) is another extensive ritual where the belief that a curse from someone meaning harm has caused the physical illness. During the ritual, the practitioner makes strong suggestions to the person that he is taking on the curse onto him and making the ill person free of the malady. At the end of the ritual, the dancer becomes unconscious and at that moment the ill person recovers. Psychotherapies based on hypnosis use similar powerful suggestion techniques for recovery from illnesses. All of the above illustrates the close linking of cultural and sociological beliefs and practices of people of Sri Lanka in the causation and successful management of functional disorders.

When the population is taken on the whole, there are those who remain exclusively with one type of healthcare system but most people take treatment from different traditions for different complaints. At times they also take treatment simultaneously from different practitioners for the same complaint. Even if they are not taking treatment from the practitioners, home remedies from various traditions are tried by many people for minor ailments. Foods are “hot” or “cold” and are not partaken of during particular illnesses. Some perform ‘Kem”. For example for whooping cough, the practice is that before dawn (before birds sing) one of baby’s uncles goes to the jungle and plucks a plant “kehi pittan” (botanical name Cyclea burmanni). He ties it round child’s neck. The uncle avoids speaking to anyone till he finishes the ritual. There are many such ‘Kem’. Another set of rituals are know as ‘Methuruma’. For example it is believed that the effect of an evil eye causes blisters around mouth of a small child. A person needs to take water from a new well to a new pot and the water should be charmed using mango or lime leaves and the child should wash his face with this water. This is believed to cure the illness by driving away the effects of the evil eye.

3.3 Astrology

The other important socio cultural belief aspect which affects people is their belief in astrology. Many believe that they go through good and bad periods of life depending on their individual planetary positioning according to the horoscope. Periods governed by Saturn and Rahu are considered bad

periods where one is vulnerable to ailments affecting head and thought. The beliefs are so strong that people often consult astrologers to find out the bad periods and what needs to be done to overcome them. The astrologers advise on particular rituals. It is not just one community or those of a particular faith who get guidance on the horoscope. Sri Lankans belonging to Sinhala and Tamil communities, most Buddhists and Hindus and a sizeable proportion of those of Christian faith believe in the horoscope. Theoretically according to Buddhism, no other person or external power can help one to overcome difficulties. One has to always find one's salvation. For the Hindus and Christians, assistance can come from God only and not from horoscopes and planets. Despite these religious observations, when difficult times arise, people of all faiths get their horoscopes read and engage in rituals to overcome the difficulties. This is in direct contrast to the 'Western' way of thinking where the patient with functional disorders is assumed to be writing their own scripts for illnesses whereas in this region, the malady is blamed on an external evil influence. Though the position of Buddhism in terms of health and illness is somewhat similar to the Western concepts where it is believed that ultimately the person is responsible for his own wellbeing and happiness. But along with the religious beliefs, man carries many other socio cultural beliefs too. Therefore their pure religious beliefs at times make way for culturally sensitive religious rituals where cultural beliefs are fulfilled. Thus we never see a pure Buddhist response to functional illnesses from patients.

The response to functional disorders remains a mixture of religious beliefs evolving from input from cultural and sociological issues. Many do go to the temples and perform Bodhi Pooja, praying for a quick recovery from illnesses and warding off ill effects of inauspicious planetary influences. A Buddhist practitioner from the UK for example would justifiably feel that these practices are not in keeping with true Buddhist beliefs. These behaviours represent the fusion of Buddhist religious values and cultural practices in Sri Lankans. Many Christians in Sri Lanka have horoscopes and believe in them quite strongly. There are a few prominent horoscope readers belonging to the Christian faith too. The concept of planetary positions influencing people's lives would not be in keeping with the religious beliefs of a Christian in the

UK. But this would be acceptable due to the fusion of Christianity with the local cultural beliefs and practices for a Sri Lankan Christian. The illness explanations as to how one could recover from illnesses are thus intricately linked to the socio cultural beliefs of people. In this cross cultural study where functional disorders are studied in the UK and Sri Lanka, it is evident that whatever similarities they might share in terms of religious values would be further modulated by the local cultural values.

4 Methodology: the prevalence of functional symptoms in specialist general medical, gynaecology and mental health outpatient clinics in Sri Lanka

4.1 Methodology

4.1.1 Title

The prevalence of functional disorders in general hospital psychiatry, gynaecology and general medicine outpatient clinics

4.1.2 Rationale for the study

Although functional symptoms are common and result in extensive morbidity there are considerable gaps in understanding the causes, the factors which maintain the symptoms and the approaches towards successful management of such problems. The disease burden is as yet not evaluated in the Sri Lankan hospital setting and understanding this would constitute the first step in forming strategies to better address their management.

4.1.3 Aim

To understand the disease burden associated with functional problems in outpatient clinics in Sri Lankan hospital setting.

4.1.4 Objective

To ascertain the prevalence of functional symptoms and syndromes in psychiatry, gynaecology and general medical outpatient clinics in a teaching hospital setting in Sri Lanka.

4.2 Setting

The Galle district covers an area of 1652 km^2 and has a population of 1,040,000 as per the 2007 population census. It has both an urban, town based population and a rural population with more than 2,000 scattered villages. Their care is

provided by three base hospitals with specialist services, six district hospitals, eight peripheral units, five rural hospitals, one prison hospital, four maternity homes and 19 central dispensaries. The Teaching Hospital Karapitiya, Galle, acts as the referral centre for all the above and also the primary care point for the large population of Galle city and its environs. This is the third largest hospital in Sri Lanka in terms of bed strength, after the Colombo and Kandy hospitals. It is the largest hospital in the Southern Province of Sri Lanka. All medical and surgical services are located at Karapitiya except for the obstetrics and gynaecology services which are situated at a remote location, in Mahamodera, Galle. The two other districts of the Southern Province, Matara and Hambantota which have populations of 804,000 and 547,000 respectively conduct their own specialist psychiatry, gynaecology and medicine outpatient clinics. Galle, being the premier hospital in the Southern Province of Sri Lanka, draws a considerable number of patients from the two other districts of the Southern Province, Matara and Hambantota as well.

For community based, state sponsored healthcare delivery the district of Galle is divided into 20 DDHS (Divisional Director of Health Services) areas. There are medical officers attached to each DDHS office. They provide preventive services mainly and do not do not provide curative services for patients with gynaecology and medical problems. Psychiatry is the exception. There are medical officers of mental health attached to each DDHS office. They provide cover for the absence of psychiatry services in the smaller hospitals in the Galle districts. They are often first contact doctors for rural populations with psychiatric problems.

In the absence of a state sponsored, community based curative care service, a flourishing, fee levying, privately owned healthcare provision service has come into being. There are a few private hospitals but the private sector is dominated by fee levying services provided by the GPs. They provide community based healthcare for patients in the region with psychiatry, gynaecology and medical problems amongst others. In addition to the financial aspect, even the operation of the GP system in Sri Lanka is very different to that seen in the UK. There is no assigned or registered patient population for a GP. Typically there will be a

number of GPs in a particular locality and the patients choose one to go for their problem/s, depending on their preference. Most of the GP surgeries are open after regular working hours. The GPs work during daytime in the hospitals and conduct their practices after hours. There are a few GPs who work full time in their practices but this group is a minority.

The teaching hospital Karapitiya, Galle, has well established in-patient and outpatient care services including a range of specialties. In-patient services provide care through 50 different units or wards. Total number of beds is 1,491. According to the Hospital Statistics Bulletin published in 2006, on average there were 350 ward admissions per day. A further 1,085 patients sought outpatient department (OPD) treatment everyday for acute illnesses. This department is the equivalent of the accident and emergency department seen in the UK. The main reason for such high numbers coming to the OPD is the lack of a state sponsored GP service. The whole of the GP network operates on a fee levying basis and the vast majority of patients come to the hospital OPD for treatment mostly due to financial constraints. Therefore the burden of morbidity the GPs in the UK tackle is taken over by the hospital sector, in Sri Lanka.

In addition to the OPD, there are specialist outpatient clinics (OPC) which are conducted daily. The specialist clinics see two groups of patients. On the one hand there are those who are already registered who come regularly for long term follow up. A smaller number of patients are on their first visit. Some of the first visit patients are those who have been discharged recently from the wards after an acute admission and require short or long term follow up. The remaining first timers are those who are referred from several other sources. The medical officers at the outpatient department (OPD) of the hospital make referrals to the specialist clinic when they feel an organic disorder is likely and that the patient will require long term treatment and follow up. Referrals also reach specialists from other specialist clinics. Specialist surgeons, ophthalmologists, otolaryngologists, oncologists, dermatologists etc, make referrals from their own specialist clinics and wards to the psychiatrists, gynaecologists and physicians. The other source of referral is from the private sector hospitals where the respective specialists will

see patients as outpatients and arrange for follow up in the hospital clinics. The hospital statistics bulletin states that in 2006 there were on average, 1511 patient treated at the specialist outpatient clinics (OPC) each day.

A closer look at the three specialist clinics in which the research was carried out reveals the following. The specialist psychiatry outpatient clinics are held twice a week. One Professorial Psychiatry Unit clinic is held weekly and has three specialist psychiatrists, several specialist trainee psychiatrists attending the clinic. The hospital psychiatry clinic has one specialist psychiatrist and several specialist trainee psychiatrists attending on the other day. For purposes of ascertaining prevalence of functional problems in psychiatry, both the clinics were selected for further study.

Six specialist outpatient gynaecology clinics are held in the Mahamodera Hospital, Galle, every week. Four of the specialist clinics are held by four of the specialists attached to the Professorial Gynaecology Unit. The other two clinics are held by the two Ministry of Health specialist gynaecologists. There are a number of specialist trainees working at senior registrar (SR) and registrar (R) levels in each clinic. A number of additional senior house officers (SHO) in gynaecology, supplement the doctor team. All the new referrals are seen by the specialist gynaecologist, assisted by the senior registrar assigned for the day. For the purpose of calculation of prevalence of functional problems in gynaecology, one of the six clinics was selected.

There are twelve specialist outpatient general medical clinics held at the Teaching Hospital, Karapitiya, Galle, every week. Four of the specialist clinics are conducted by specialists attached to the Professorial Medicine Unit. The other eight clinics are held by the four Ministry of Health specialist physicians. There are a number of specialist trainees working at senior registrar and registrar levels in each clinic. A number of additional senior house officers and house officers supplement the doctor team. All the new referrals are seen by the specialist physician, assisted by the senior registrar assigned for the day. For the purpose of calculation of prevalence of functional problems in medicine, one of the

Professorial Medical Unit clinics was selected. This particular clinic had two specialist physicians, two senior registrars, four registrar/SHO grade doctors and two house officers in attendance during a session.

4.3 Study Methods

A prospective observational survey of medical consultations and medical records follow up at three and six months.

4.4 Design

The study was based on patients referred to the specialist psychiatry, gynaecology and medical clinics of the hospital. These three clinics were chosen for study after much deliberation, with specific reasons in mind. The objective was to get the most representative cohorts that would be assessed in hospitals in Sri Lanka. The landmark study in assessing prevalence remains the work of *Nimnuan et al* who studied prevalence of functional problems across seven specialties (58). They studied outpatient dental, chest, rheumatology, cardiology, gastroenterology, neurology and gynaecology. In the Sri Lankan setting, specialist rheumatology, cardiology, gastroenterology, neurology services are provided in only a handful of the larger hospitals. From the biggest teaching hospital to the smallest peripheral hospital, the largest numbers of patients with complaints related to these systems are assessed in general medical clinics. The teaching and the base hospitals will have a specialist general physician in attendance but in the smaller hospitals, one of the senior medical officers will attend to these patients. Thus any attempt to calculate the prevalence rate in one of the above specialities would have been restrictive as well as not representative of the health care delivery system of Sri Lanka. By choosing the setting of general medical clinics, cardiology, neurology, rheumatology and gastroenterology studied in the Nimnuan study were all included.

Gynaecology clinics recorded the highest prevalence of functional problems in the Nimnuan study with a rate of 66%. In Sri Lanka there is a well developed gynaecology service taking place in all of the teaching and base hospitals. Thus we decided to include gynaecology clinics as it was considered representative of

the healthcare system of Sri Lanka and the high numbers noted in the Nimnuan study begged for a comparison from Sri Lanka.

Dental clinics represented in the Nimnuan study were not covered in our study. It was felt that the psychiatry clinics should be taken for study instead. The prevalence of functional problems in general psychiatry clinics warranted close scrutiny. For obvious reasons the prevalence of such complaints in a specialist liaison psychiatry clinic would be high due to specific referrals. But in a general psychiatry clinic the problem would merit assessment just as much as a general medical clinic or a gynaecology clinic would. Some of the specialists from 'organic' specialties would feel that the medically unexplained, functional problems they encounter in their clinics are undiagnosed psychiatric disorders. But as pointed out in the literature survey, many patients with functional disorders do not have an ICD-10 definable psychiatric illness. Even when there is detectable depressive or anxiety disorder features these remain mere associations and treatment of depression or anxiety did not alleviate symptoms. Thus it is clear that functional problems pose a challenge to general psychiatrists overseeing the psychiatry clinics.

The other reason why the psychiatry clinics were chosen for study was my training as a specialist in liaison psychiatry. Liaison psychiatry as a speciality is still in its infancy in Sri Lanka. Thus it was felt that it would be of importance to assess the burden of these problems in general psychiatry clinics in order to plan future service provision in liaison psychiatry.

The clinic records of all patients who were referred to these outpatient clinics for a three month period from 1st January 2009 to 30th March 2009 were studied. The investigator sat in the clinic along with the specialist physician / gynaecologist / psychiatrist of the clinic. The specialist would make a clinical assessment of the patients at the initial visit and order relevant investigations. Once each clinical encounter was over, the specialist would discuss with the investigator the presenting problem, the findings of the clinical examination the provisional diagnosis made and the investigations ordered. The investigator noted down the

presenting problem, the clinical observations of the specialist and the investigations ordered. Patients continued to attend the clinic on a monthly basis. The assessments occur monthly but not necessarily because the patients need to be seen monthly. The hospital pharmacies issue medicines only for a maximum of one month, for a patient; therefore patients come monthly to the clinic for assessment and collection of medicine. During the subsequent months the patients were seen by the senior registrar, registrar, and senior house officer grade medical officers. All problems were brought to the attention of the consultant and he/she would then assess the patients during the visit. The investigator made notes in the clinic records to inform her when the patients came for their third month and sixth month assessments. At this point she recorded the subsequent clinical observations of the clinic doctors and the results of investigations. At these two visits, the likely diagnosis was discussed with the clinic specialist. At the six month assessment a decision was made as to whether the patient had an 'organic' illness or a functional problem. Where any ambiguity about the diagnosis existed, the investigator sought advice from the relevant specialist clinician It was felt that the passage of six months since first presentation to the clinic would provide sufficient time for an organic diagnosis, if present, to be diagnosed.

The prevalence of functional problems among all those referred was calculated. *Nimnuan et al* (2000) state that functional symptoms are diagnosed when:

a) the patient presented with physical symptoms;

b) they received investigations for this;

c) the investigations and clinical examinations revealed no abnormality or only abnormalities which were thought to be trivial or incidental.

In the instances the patient defaulted on clinic attendance or was discharged from the clinic prior to the third month or sixth month assessment, the record from the initial visit was considered for diagnosis determination.. This method was used to

assess frequency of functional symptoms in psychiatry, gynaecology and medicine specialist clinics.

In the medical literature, the frequency of functional symptoms has been assessed in some studies with patient self reports and in others by physician ratings but these are considered less rigorous from a methodology point of view. Though it was time consuming, the method adopted in this study i.e. observation followed by evaluating medical records was considered the most reliable method to establish whether particular symptoms functional.

4.4.1 Data collection, handling and analysis

Data was recorded with the investigator sitting in the clinic alongside the relevant specialist. The data recording was limited to the presenting problem; the clinical observations and investigation results at initial visit; three month visit and the six month visit and the diagnosis made at each evaluation. Every case record was assigned a code number (not the hospital number) at the start and data was recorded in relation to this number. This ensured anonymity of the patients whose records were studied. The data were subsequently entered onto an SPSS data sheet. SPSS software was used to calculate descriptive statistics. All the coded records were kept securely locked by the investigator.

5 Results and Analysis: the prevalence of functional symptoms in a specialist general medical outpatient clinic in Sri Lanka

5.1 Results

305 patients were seen during the three month period from 1st Jan 2009 to 30th March 2009. 57 patients (18.7%) were determined to have functional disorders at the initial evaluation. Follow up data at three and six months were available for 53 of them to confirm the diagnosis as per study protocol. Four of them were lost to follow up and the three and six month evaluations were not available.

Of the 53 patients with follow up data available, the clinicians had made a firm diagnosis of 'functional disorder' in 37. Within this group, ten patients were determined to have a functional symptom with no organic pathology but who on investigations were detected to have a significant organic disease in the background. In these instances the clinicians did not feel that the main symptom the patient was complaining of could be explained by the disease diagnosed.

In 16 patients the clinician diagnosis was 'likely functional'. In these instances, functional illness remained the most likely diagnosis but further follow up was planned. It was felt that a further period of observations would be required to arrive at a firm diagnosis of 'functional'. The remaining 248 patients were determined to have well explained organic pathology.

In considering the demographic characteristics, there was a female preponderance compared to organic disorders. The female to male ratio was 1.3 : 1 in the organic disorder group whereas the comparative ratio was 2 : 1 in the functional disorder group. Those with functional disorders were younger. The commonest age group afflicted was the 41-50 year group where as for organic disorders it was the 51-60 age group. More than 50% of patients with functional disorders were in the 31-50 year age group and on the whole those with functional disorders seemed around ten years younger to those with organic disorders. A higher proportion (30%) of those with functional disorders seemed unmarried compared to 20% in the organic disorder age group. Both groups

had similar results for the enquiry whether or not they had children. Overall those with functional disorders had higher academic attainments compared to those with organic disorders. In the functional disorder group, the numbers of those who had had tertiary level education were twice as high when the percentages were considered.

5.2 Demographic characteristics of the subjects studied

Characteristic	Functional 'n' and percentage	Organic 'n' and percentage
Sex		
Male	19 *(33.3)*	118 *(44.4)*
Female	38 *(66.7)*	130 *(55.6)*
Age (Yrs)		
Less than 20	05 *(8.7)*	14 *(5.6)*
21 – 30	08 *(14.0)*	31 *(12.5)*
31 – 40	12 *(21.1)*	41 *(16.5)*
41 – 50	17 *(29.8)*	39 *(15.7)*
51 – 60	11 *(19.2)*	53 *(21.4)*
61 – 70	03 *(5.2)*	50 *(20.2)*
71 – 80	01 *(1.8)*	18 *(7.3)*
81 – 90	Nil	02 *(0.8)*
Marital Status		
Married	37 *(64.9)*	179 *(72.1)*
Unmarried	17 *(29.8)*	47 *(19.0)*
Divorced	02 *(3.5)*	07 *(2.8)*
Widowed	01 *(1.8)*	15 *(6.0)*
Children		
No	20 *(35.1)*	66 *(26.6)*
Yes	37 *(64.9)*	182 *(73.4)*
Education		
Less than O/L	02 *(3.5)*	36 *(14.5)*
O/L	33 *(57.9)*	146 *(58.9)*
A/L	17 *(29.8)*	55 *(22.2)*
Higher than A/L	05 *(8.8)*	11 *(4.4)*
Total	57	248

Functional disorders emerged as the most common diagnosis among the patients having the first consultation at the specialist medical clinic. It was diagnosed with a greater frequency than some of the more significant diagnoses such as Diabetes mellitus, Hypertension, Ischaemic heart disease, Cerebrovascular disease, Obstructive airway disease and Epilepsy. The category 'other' consisted of those conditions which were seen in only one patient attending the clinic.

5.3 Analysis of diagnoses of all patients

Diagnosis	'n' and percentage
Functional disorder	57 *(18.7)*
Diabetes mellitus	48 *(15.7)*
Hypertension	37 *(12.1)*
Ischaemic heart disease	24 *(7.9)*
Obstructive airway disease	16 *(5.2)*
Epilepsy	10 *(3.3)*
Thyroid disorders	10 *(3.3)*
Liver disease	8 *(2.6)*
Valvular heart disease	7 *(2.3)*
Cerebrovascular disease	7 *(2.3)*
Dyslipidaemia	7 *(2.3)*
Lower respiratory tract infection	6 *(2.0)*
Peptic ulcer disease	5 *(1.6)*
Arthritis	5 *(1.6)*
CRF	4 *(1.3)*
Benign positional vertigo	3 *(1.0)*
Parathyroid diseases	3 *(1.0)*
Anaemia	3 *(1.0)*
Osteoporosis	3 *(1.0)*
Cardiac arrhythmias	3 *(1.0)*
Urinary tract infection	3 *(1.0)*
Parkinson disease	3 *(1.0)*
Carpal tunnel syndrome	2 *(0.7)*
Nephrotic syndrome	2 *(0.7)*
Other	31 *(10.2)*

The 57 patients with functional disorders had been referred to the specialist medical clinic by a number of sources. The highest number was from the outpatient department. The patients themselves came to the outpatient department as self referrals. One patient was referred by the specialist physician from another hospital. The remainder constituted of patients who had been

admitted to the medical ward with acute problems but who were referred to the medical clinic for further evaluation as no cause for the symptom could be found.

Patients with functional disorders complained of a multitude of symptoms related to different systems. Many patients had more than one complaint, often relating to different systems. The most troubling symptom of all was noted down in each patient.

5.4 Predominant complaint in those with functional disorders

Functional symptom	**Number**
Backache	11
Joint and muscle pain	8
Chest pain	6
Abdominal pain	6
Headache	6
Dizziness / loss of consciousness	6
Numbness	3
Change of bowel habit	3
Abdominal distension	2
Palpitations	2
Tiredness/sleepiness	2
Burning ear pain	1
Unilateral breast pain	1
Total	**57**

Some researchers have suggested an approach where symptoms are grouped into three broad categories; pain of different locations (back, head, muscles or joints, abdomen, chest etc.), functional disturbance in different organ systems (e.g. palpitations, dizziness, constipation or diarrhoea, movement, sensation) and complaints centering round fatigue and exhaustion. Pain associated functional complaints were the commonest and accounted for more than 70% of complaints. Complaints related to functional disturbances accounted for most of the

remainder. Complaints centering around fatigue and exhaustion was low in number.

Functional symptom category	**'n' and percentage**
Pain	33 *(57.9)*
Functional disturbances	11 *(19.3)*
Fatigue and exhaustion	03 *(5.3)*
Pain and functional disturbances	09 *(15.8)*
Pain and fatigue	01 *(1.8)*
Total	**57**

The symptoms had been present for a long duration of time prior to the diagnosis as a functional disorder. A majority had had symptoms going on for a period in excess of one year. Two patients had been symptomatic for more than five years.

5.5 Analysis of the duration of symptoms in-patients with functional disorders

Symptom duration (Years)	**'n' and percentage**
More than 5	02 *(3.5)*
Between 1 – 5	36 *(63.2)*
Less than 1	19 *(33.3)*
Total	**57**

Of the 57 with functional disorders, 23 (40%) had sought treatment from more than 10 doctors for the problem in the private sector prior to seeking assistance at the hospital specialist clinics. They included specialists, GPs and alternative medical practitioners. The remaining 34 had been attended to by doctors numbering between 1 and 10 previously. Thirty two (56%) were already attending at least one other specialist clinic in the hospital. Out of them 13 (22%) were already attending multiple specialist clinics.

A wide array of investigations had been conducted on these patients which included haematological, radiological and histological assessments. All of these

were normal or revealed abnormalities which were considered unrelated to the presenting complaint. These investigations were expensive and at times invasive and potentially harmful. Four had CT scans, one had a laparoscopy under general anaesthesia, one had a myelogram and another had an endoscopic examination performed. Two other patients had MRI scans. A diagnosis of functional problem was arrived at only after many patients were subjected to extensive investigations.

5.6 Analysis of the investigations done for patients with functional disorders

Investigation	Number of patients
Haematological	57
Basic radiological	57
ECG	21
Endoscopy	7
2D Echocardiography	7
CT scans	4
EEG	4
Hormonal assays	3
MRI	2
Nerve conduction / sleep studies	2
Mammogram	1
Myelogram	1
Laparoscopy	1

Most of the patients with functional disorders were referred to the specialist medical clinic by the medical officers of the outpatient department (OPD) of the hospital. The patients had come to the OPD as self-referrals. In addition, GPs had referred the patients to the OPD on three occasions. In another four instances the patients with functional disorders had been referred to the specialist medical clinic by the surgical, gynaecological, ophthalmology and otolaryngiology clinic.

5.7 Discussion

The results demonstrated that functional disorders constituted around 18.7% of patients in a specialist medical outpatient clinic in a teaching hospital setting in Sri Lanka. Of this the clinicians had come to a firm diagnosis of functional disorder in 12.1%. In 5.3%, it was strongly suspected. This group was named 'likely functional'. As per the study protocol definition, they could be diagnosed as having functional disorders. But relevant clinicians did not arrive at a definitive conclusion within the six month follow up period. They felt further follow up would be required to be certain that there was no organic disorder which was missed. It appeared that the consultants were reluctant to make a firm diagnosis of functional disorder even in the absence of evidence to the contrary. They were keen either to follow them up for a further period or obtain the assistance of the colleagues in psychiatry prior to making a firm commitment on the diagnosis.

The important factor which needs to be appreciated about this prevalence rate is that it is not an accurate reflection of the rate of those with functional disorders who seek treatment at the hospital outpatient department. The medical officers in the department screen and refer to the medical specialist clinic only the patients whom they believe are likely to have organic disorders. There is a weeding out process which occurs at the outpatient department for functional disorders. Therefore if the total numbers of those who seek treatment at the hospital are considered, the frequency of functional disorders is likely to be much higher than the 18%, perhaps twice that much would be a realistic estimate.

The demographic characteristic of the patient population studied makes interesting reading. The group with functional disorders had a female preponderance. Females constituted two thirds of those presenting with functional disorders. This is in keeping with the results from studies in the UK. The male and female numbers were more equitably distributed in the organic diseases group. Functional disorders were predominant in the younger age groups compared to the organic diseases group. The age group 30-50 years contained the majority of those with functional disorders whilst the 50-70 year age group constituted the largest group in those having organic diseases. Marital status and whether or not

they had children showed similar percentages among the functional and organic groups. Most of those with functional disorders were married and had children (64%). Being married did not appear to be a protective factor for functional disorders. Higher educational attainments were noted in the group with functional disorders compared to the organic disease group. The functional disorders group had 38% who had at least up to advanced level education. The percentage of those having tertiary care education among those with functional disorders was twice than those with organic diseases.

These demographic characteristics need to be interpreted with caution. They do not necessarily reflect population trends or patterns. The study was conducted in a hospital clinic and a selection bias in terms of a sampling error occurs. Thus the findings could not be extrapolated to reflect the findings in the community. The demographic features could well reflect the impact of referral patterns. For example, higher educational attainments may be a risk factor for developing functional problems but the alternative explanation is the health care seeking behaviour. The consultation pattern of those with higher education is different and they have a higher chance of getting referred for specialist assessment by the doctor at first contact.

Confidence intervals are used at times to ascertain precision of the mean figures. In the absence of population figures and low sample sizes, it was not feasible to calculate confidence intervals for the demographic characteristics in this study.

Functional disorders emerged as the single commonest diagnosis. It outnumbered common medical conditions like diabetes mellitus, hypertension, dyslipidaemia, ischaemic heart disease, cerebrovascular disease and renal disease which take up much of medical education and research. There were a number of patients in whom a well recognised medical condition like one of the above was diagnosed during the consultation but the predominant problem that they complained of could not be attributed to the disease that was subsequently diagnosed.

Considering the presenting complaint, pain syndromes seemed to dominate the functional disorder spectrum. Unexplained low back pain was the commonest

complaint. Functional disturbance of various organic systems was the other common category. Disturbances related to the nervous system like dizziness and numbness as well as those related to the gastro intestinal tract like diarrhoea, constipation and abdominal bloating were the most frequent complaints. Complaints related to fatigue and exhaustion was notable due to its low frequency. Chronic fatigue syndrome does not seem to occur in high numbers in the Sri Lankan medical setting.

As has been noted in the previous studies, lengthy periods have elapsed prior to diagnosis in many patients. More than two thirds of patients had been symptomatic for a period in excess of one year before the diagnosis was made. Two of the patients in the study had had symptoms for more than five years. These figures go to show that strategies aimed at ensuring early diagnosis are of great importance to reduce the patient morbidity.

There had been much ‘doctor shopping’ in the patients with functional disorders. As much as 40% of patients had consulted more than ten doctors for their complaint. The likely reasons for this are twofold. On the one hand it is well demonstrated that there is a long delay in the diagnosis of the condition. The other possible reason is the lack of success of the various therapeutic attempts these previous doctors have made. Due to the continuing problems, patients keep going for fresh consultations.

The other feature of note was that 56% of those with a functional complaint were attending at least one other specialist clinic with another complaint. What proportion of these were other functional somatic syndromes could not be ascertained by the data available. There is evidence in the medical literature to prove that there is overlap between functional somatic syndromes. It is possible that at least part of the attendance at other clinics were with further functional complaints.

Considering the wide array of investigations with essentially normal results which had been performed on these patients it becomes clear that the diagnosis of functional disorder is mostly a diagnosis of exclusion of other medical conditions.

All patients with complaints do need a thorough assessment. But the high numbers of investigation which were invasive or carried potential harm does make it clear that an unwarranted number of investigations were carried out prior to a diagnosis of functional disorder was made. Worst off probably, were those who had large doses of radiation with CT scanning and invasive procedures such as myelograms and laparoscopies. In addition, the economic costs of such investigations constitute a significant burden on a health system which is stretched to the limits at the moment. Where to draw the line in investigating functional disorders remains a critical enquiry.

5.8 Conclusions

Functional disorders accounted for nearly one fifth of all patients attending the specialist medicine outpatient clinic. It was the commonest single diagnosis and outnumbered all the well recognised medical conditions. A female preponderance was noted. Marriage and higher educational achievements did not seem to offer any protection from developing the disorder but these demographic patterns may simply reflect the impact of referral patterns. Pain syndromes were the commonest functional complaints. Chronic fatigue was conspicuous by the low numbers. There were unacceptably long delays in making the diagnosis prompting patients to seek medical attention elsewhere. A large number of invasive and expensive investigations were performed on patients prior to a diagnosis of functional disorder was made.

Further research into the methods of making an early diagnosis, best management strategies and minimising of iatrogenic harm are priorities.

6 Results and Analysis: the prevalence of functional symptoms in a specialist gynaecology outpatient clinic in Sri Lanka

6.1 Results

251 patients were seen during the three month period from 1st Jan 2009 to 30th March 2009. 56 patients (22.3 %) were determined to have functional disorders at the initial evaluation. Follow up data at three and six months were available for 52 of them to confirm the diagnosis as per study protocol. Four of them were lost to follow up and the three and six month evaluations were not available.

Of the 52 patients with follow up data available, the clinicians had made a firm diagnosis of 'functional disorder' in 21. Within this group, there were nine patients were determined to have a 'functional symptom due to a physiological variation'. This group constituted those whose complaints had no organic pathology but were thought to have variations in the physiology which could be considered still as normal.

In 31 patients the clinician diagnosis was 'likely functional'. In these instances, functional illness remained the most likely diagnosis but further follow up was planned. It was felt that a further period of observations would be required to arrive at a firm diagnosis of 'functional'. The remaining 195 patients were determined to have well explained organic pathology.

In considering the demographic characteristics of the organic and functional disorder groups, 31-40 year age group had the highest numbers in the functional group whilst a slightly older population, the 41-50 year age group had the dominant numbers in the organic group. More than 60% of patients with functional disorders were less than 40 years of age. There were a higher proportion of unmarried females in the functional disorder group. One third of them were not married whilst in the organic group only 11% were unmarried. As a result, those with functional disorders were much less likely to have children than those with organic disorders. In both groups highest percentages had received school education up to Ordinary Level. But the numbers who went on to receive

education up to Advanced Level in school and tertiary education thereafter were higher in those with functional disorders.

6.2 Demographic characteristics of the subjects studied

Characteristic	Functional 'n' and percentage	Organic 'n' and percentage
Age (Yrs)		
Less than 20	01 *(1.8)*	08 *(4.1)*
21 – 30	13 *(23.2)*	32 *(16.4)*
31 – 40	22 *(39.3)*	42 *(21.5)*
41 – 50	14 *(25.0)*	56 *(28.7)*
51 – 60	05 *(8.9)*	26 *(13.3)*
61 – 70	01 *(1.8)*	18 *(9.2)*
71 – 80	Nil	08 *(4.1)*
81 – 90	Nil	05 *(2.6)*
Marital Status		
Married	33 *(58.9)*	147 *(75.4)*
Unmarried	18 *(32.1)*	23 *(11.8)*
Divorced	02 *(3.6)*	06 *(3.1)*
Widowed	03 *(5.4)*	19 *(9.7)*
Children		
No	23 *(41.1)*	46 *(23.5)*
Yes	33 *(58.9)*	149 *(76.5)*
Education		
Less than O/L	01 *(1.8)*	14 *(7.1)*
O/L	33 *(57.9)*	141 *(72.3)*
A/L	17 *(29.8)*	36 *(18.5)*
Higher than A/L	05 *(8.8)*	04 *(2.1)*
Total	**56**	**195**

Considering the diagnosis, functional disorders emerged as the most common entity among the patients having the first consultation at the specialist gynaecology clinic. It was diagnosed with a greater frequency than some of the important organic gynaecological conditions such as cystocoele / utero vaginal prolapse, miscarriages, dysfunctional uterine bleeding and uterine fibroids.

6.3 Analysis of diagnoses of patients with organic gynaecological problems

Gynaecological Diagnosis	'n' and percentage
Functional disorder	56 *(22.3)*
Cystocoele / Utero vaginal prolapse	33 *(13.1)*
Miscarriages	25 *(10.0)*
Dysfunctional uterine bleeding	24 *(9.7)*
Uterine fibroids	22 *(8.8)*
Subfertility	12 *(4.8)*
Endometriosis	10 *(4.0)*
Vulvo vaginal candidiasis	8 *(3.2)*
Endometrial carcinoma	8 *(3.2)*
IUCD removal and LRT	7 *(2.8)*
Endometrial and endocervical polyps	7 *(2.8)*
Medical / Surgical problems (Peri anal abcess etc)	6 *(2.4)*
Polycystic ovarian syndrome	5 *(2.0)*
Vulvo vaginitis	4 *(1.6)*
Bartholin cyst	3 *(1.2)*
Pelvic inflammatory disease	3 *(1.2)*
Postpartum complications	3 *(1.2)*
Ectopic pregnancy	3 *(1.2)*
Hydatiform mole	3 *(1.2)*
Salpingo oopheritis	2 *(0.8)*
Side effects of Depo Provera	2 *(0.8)*
Keloid formation / skin hypertrophy	2 *(0.8)*
Other (Sexually transmitted disease, Teratoma, Bicornuate uterus)	3 *(1.2)*

Functional symptoms considered physiological variations as a special category of patients unique to gynaecology. The physiologically acceptable variability in the functioning of the female genital system was at times interpreted as a disease. Six of these patients complained of menstrual abnormalities which were ultimately determined as normal physiological variations. Three others complained of

excessive amount or excessive thickness of vaginal secretions. These were also determined as being within normal variations.

The predominant complaint seen among those with functional diagnoses was lower abdominal / pelvic pain. More than half of the patients with functional complaints had pain in this region. Low back pain was the other principal complaint with 43% of patients having this as a symptom. Pain associated with menstruation, menstrual irregularities, dyspareunia and vaginal discharge and weight loss were the other complaints in those with functional disorders.

6.4 Analysis of the nature of functional complaints

Complaint	**'n' and percentage**
Lower abdominal / pelvic pain	29 *(52.8)*
Backache	24 *(42.9)*
Pain associated with menstruation	18 *(32.1)*
Menstrual irregularities	16 *(28.6)*
Dyspareunia	06 *(10.7)*
Vaginal discharge	06 *(10.7)*
Loss of weight	05 *(8.9)*
Subfertility	02 *(3.6)*
Incontinence	02 *(3.6)*

The complaints in the group with functional disorders were grouped into three categories for further analysis. Those who had a pain syndrome, those who had a functional disturbance of an organ system and those with a predominant complaint centering around fatigue and tiredness and then combinations of these were looked at separately. Pain syndromes were the commonest noted. Three quarters had a pain syndrome. In half this was the only symptom category. Functional disturbance of an organ system was the next common being seen in around 25% of the patients.

6.5 Analysis of functional complaints using the three category classification

Functional symptom category	**'n' and percentage**
Pain	28 *(50.0)*
Functional disturbances	10 *(17.9)*
Fatigue and exhaustion	03 *(5.4)*
Combination of pain and functional disturbance	13 *(23.2)*
Combination of functional disturbance and fatigue	01 *(1.8)*
Combination of pain, functional disturbance and fatigue	01 *(1.8)*
Total	**56**

The functional symptoms had been present for extended periods of time. Most frequently the patients had had the symptoms going on for between 1-5 years. The worst affected had symptoms going on for more than 30 years.

6.6 Analysis of the duration of symptoms in-patients with functional disorders

Symptom duration	**'n' and percentage**
More than 30 years	3 *(5.4)*
Between 10 – 30 years	7 *(12.5)*
Between 5 -10 years	11 *(19.6)*
Between 1-5 years	26 *(46.4)*
Less than 1 year	9 *(16.1)*

There had been many consultations with medical personnel for the functional problems. Most of the patients had sought outpatient treatment in the private sector from specialist gynaecologists and GPs. Eight of the patients had sought treatment from more than ten doctors prior to attending this gynaecology clinic. Many of those with functional disorders were already attending other outpatient clinics at the hospital. For 32 patients this was the first clinic. The remaining

twenty four were attending multiple outpatient clinics. The worst affected patient was attending a total of five different specialist clinics for a variety of functional problems.

A wide array of investigations had been conducted on these patients which included haematological, radiological and histological assessments

6.7 Analysis of the investigations done for patients with functional disorders

Investigation	**'n'**
Haematological	56
Basic radiological	56
Ultra sound scanning	56
Histology	8
CT scan	5
Laparoscopy	5
Endoscopy	3
Laparotomy	3
MRI	3
Hormonal studies	2
Colposcopy	2

The patients with functional illnesses had been referred to the gynaecology services by a number of sources. The highest number was from the outpatient department. The patients themselves came to the outpatient department as self referrals. Three were referred for further evaluation by the surgical clinic. They were referred as 'investigated for abdominal pain, no surgical cause identified'. One patient was referred by the specialist orthopaedic clinic as she had gone there with low back pain. She was labelled as 'Low back pain, no surgical cause'.

6.8 Discussion

The results demonstrated that functional disorders constituted around 22% of patients seen in gynaecology specialist outpatient clinics in a teaching hospital setting in Sri Lanka. In around 9% the clinicians had arrived at a firm diagnosis of functional disorder. In the remainder it was strongly suspected. This group was named 'likely functional'. As per the study protocol definition, they could be diagnosed as having functional disorders. But relevant clinicians did not arrive at a definitive conclusion within the six month follow up period. They felt further follow up would be required to be certain that there was no organic disorder which was missed. It appeared that the consultants were hesitant and reluctant. They were keen to either follow them up for a further period or refer them to a surgical or medical colleague stating that there was nothing wrong gynaecological. In the instances where the patients had already seen the surgeon or the physician, the gynaecologist had to make the call. A process of diagnosis by exclusion seemed to exist where functional disorders were diagnosed by excluding organic gynaecological conditions. This reluctance to make a diagnosis of functional and the tendency to fit the patient into some organic territory is an interesting phenomenon. The most likely reasons are the doctors being comfortable about the management of patients with organic disorders and the fear of missing a serious organic pathology.

Considering the demographic profile of the functional and the organic disorder groups, it was evident that functional disorders were seen in a group of patients who were on average about ten years younger than those with organic problems. The commonest age group affected was those in the 21-40 year age group. A higher proportion of females were unmarried in the functional disorder group. As seen in the general medicine prevalence study, it was noted that those with functional gynaecological problems had higher educational attainments compared to those with organic problems.

As mentioned in chapter 4 regarding patients attending the general medical outpatient clinic, these demographic characteristics need to be interpreted with caution. They do not necessarily reflect population trends or patterns. The study

was conducted in a hospital clinic and a selection bias in terms of a sampling error occurs. Thus the findings could not be extrapolated to reflect the findings in the community. However the boundaries between such hospital clinics and general practice are very narrow as many patients will present to the hospital rather than a community doctor due to the fact that hospitals act as the non-fee levying, first contact care point for patients in Sri Lanka. The demographic features could well reflect the impact of referral patterns. Higher educational attainments may be a risk factor for developing functional problems but the alternative explanation is the health care seeking behaviour; the consultation pattern of those with high education is different and they have a higher chance of getting referred for specialist assessment by the doctor at first contact. In the same way, unmarried females may have different health seeking behaviour patterns from those who are married and having children. Thus the study findings could be artefacts due to referral patterns.

Confidence intervals are at times used to ascertain precision of the mean figures. In the absence of population figures, and low sample sizes, it was not feasible to calculate confidence intervals for the demographic characteristics in this study.

If indeed the age groups emerging from this study were a true reflection of the status in the community, the economic and social consequences of the disease predominantly affecting this 21-40 year age group would be enormous. This is the most productive age group in terms of the country's work force and these are the women whose contributions would be of enormous importance to the family wellbeing. Also if the higher numbers of unmarried females being found to have functional problems were true of the community, one would need to delve into possible contributory causes. It is well recognised that life stresses contribute to precipitating, perpetuating and aggravating functional disorders. In the Sri Lankan social context, a woman is expected to get married and bear children. Being unmarried when the 'marriageable age' (generally considered the twenties) is passing places a lot of social pressures and resultant stress on women. It is possible that this stress could be the contributing factor for the functional problem. An alternative explanation exists. Those with functional disorders in discomfort

due to symptoms have disproportionate disability. This would act as an impediment to marriage prospects. Rather than being alternatives the most likely possibility is being unmarried contributes both in causation and also arises as a result of functional disorders.

The most significant factor to note was that functional disorders emerged as the most common diagnosis in the gynaecology clinic. It easily exceeded numbers of patients with well recognised gynaecological conditions like cystocoele, utero vaginal prolapse, miscarriages, dysfunctional uterine bleeding, uterine fibroids, subfertility and endometriosis. A more recently recognised gynaecological condition, polycystic ovarian syndrome on which there is a worldwide research focus was present in one tenth of the numbers seen with a functional disorder.

Pelvic pain and back pain emerged as the most common symptoms narrated by those with functional disorders. This was more common than problems associated with menstruation or complaints related to vaginal discharge and sexual dysfunction. Adopting the three category classification, pain syndromes either singly or in combination with functional disturbances of organ systems accounted for 75% of complaints. Thus in the Sri Lankan context, functional disturbances and complaints related to fatigue seemed less common and complaints related to pain, more common. The reasons for this distribution of complaints are not clear and merit further inquiry.

Almost all the patients who were referred to gynaecology services were patients with chronic symptoms. Three patients had had symptoms for more than 30 years and the vast majority had had symptoms for 1-5 years. Prior to being seen at the gynaecology clinic and being diagnosed as functional or likely functional, they had been to many doctors. Eight of them admitted to having consulted more than ten doctors each. Some were already attending other specialist clinics in the hospital. Research has shown that there is a great amount of overlap in the various functional somatic syndromes and many of the patients satisfy criteria for more than one disorder. This often makes them go to several different clinics. Amongst the patients in this study, the net result was the same, i.e. the

attendance at multiple clinics but due to a different perspective. One was attending five clinics for the same symptom. Her low backache was being looked at by the gynaecologist, the urologist, the orthopaedic surgeon, the rheumatologist and the general medical specialist. Late recognition and delayed diagnosis seemed a major problem affecting most with functional disorders. It is also possible that there was constant reinforcement from the various medical specialists contributed to worsening of the symptoms.

They had undergone multiple investigations and procedures which were negative repeatedly both at the state hospital and in the private sector. Thus some of the added symptoms had been of iatrogenic origin. All of those with functional disorders had been extensively investigated, often with invasive procedures. Eight had had histological assessment and a further five endoscopic procedures and CT scans. Five patients had had laparoscopic assessments under general anaesthesia and the worst off were three who had had explorative laparotomies with negative findings. The repeated unproductive invasive investigations contributed both to iatrogenic harm and financial difficulties for the patients.

The referral to gynaecology clinics came from three sources. Most were self referrals to the doctor at the outpatient department who in turn referred to the gynaecology clinic. Three patients were referred from the general surgical clinic and one from the orthopaedic clinic all stating that there was nothing wrong detected in their territories and spheres.

Functions of the female reproductive system are known to occur within fairly broad physiological boundaries with much individual to individual variations. At times, some of the variations contradict popularly held beliefs about how things should happen. How frequently should menstruation occur? How long should a menstrual period last? What age should menopause occur? There are widely held beliefs that these questions have definite single answers. The inevitable consequence is the frequent misinterpretation of normal variations as being illnesses. This unique category, seen in gynaecology clinics has been termed ‘functional symptom – physiological variation’. There were nine patients in this

group. Six had interpreted normal variations in the menstrual cycle as an illness and sought treatment for a menstrual disorder. A further three patients interpreted normal vaginal secretions to represent some sinister illness. They are neither organic illnesses nor are they true functional disorders. Functional disorders are often considered the inter-phase between physical and psychological disorders. Perhaps this new category which represents normal physiological variations could be an important inter-phase between organic and psychological disorders on one side and functional disorders on the other side.

6.9 Conclusion

Functional problems had a significant prevalence in the gynaecology outpatient clinic of a secondary care teaching hospital in Sri Lanka affecting 22% of patients. This was the most common single diagnosis among the patients. Patients were noted to have symptoms going on for many years having undergone extensive and repeated investigations and multiple unsuccessful treatments. A younger group of patients with higher educational attainments presented with functional disorders in comparison to those with organic problems. Whether this is a reflection of referral patterns to the clinic is not known for certain, but in Sri Lanka patients do frequently present to hospital outpatient departments rather than to GPs and there may not be much of a difference between clinics and the population. Complaints associated with pain rather than those associated with functional disturbances or fatigue and tiredness seemed the most common functional problem.

As functional disorders constituted a significant problem in outpatient gynaecology clinics in Sri Lanka, further attention towards early diagnosis, avoidance of unnecessary interventions and better management strategies is of importance.

7 Results and Analysis: the prevalence of functional symptoms in a specialist mental health outpatient clinic in Sri Lanka

7.1 Results

261 patients were seen during the three month period from 1st Jan 2009 to 30th March 2009. 22 patients (8.4 %) were determined to have functional disorders at the initial evaluation. Follow up data at three and six months were available for 19 of them to confirm the diagnosis as per study protocol. Three of them were lost to follow up and the three and six month evaluations were not available.

Of the 19 patients with follow up data available, the clinicians had made a firm diagnosis of 'functional disorder' in ten. In nine patients the clinician diagnosis was 'likely functional'. In these instances, functional illness remained the most likely diagnosis but further follow up was planned. It was felt that a further period of observations would be required to arrive at a firm diagnosis of 'functional'. The remaining 239 patients were determined to have well explained organic pathology.

In considering the demographic characteristics it was evident that there was a female preponderance in the functional disorder category. Whereas in the organic disorder group, the numbers were similarly distributed, females outnumbered males by a ratio of 2 : 1 in the functional disorder group. In addition, those in the functional disorder group were younger. More than 60% of them were in the less than 40 year age group. In comparison, in the organic disorder group, high numbers were seen in the 41- 50 and 51-60 year age groups. A higher proportion of those with functional disorders were married and had children, compared to those with organic psychiatric disorders. The numbers of those who were divorced or widowed were also less in the functional group.

7.2 Demographic characteristics of the subjects studied

Characteristic	Functional 'n' and percentage	Organic 'n' and percentage
Sex		
Male	08 *(36.4)*	118 *(49.4)*
Female	14 *(63.6)*	121 *(50.6)*
Age (Yrs)		
Less than 20	03 *(13.6)*	20 *(8.4)*
21 – 30	05 *(22.7)*	40 *(16.8)*
31 – 40	06 *(27.3)*	52 *(21.8)*
41 – 50	05 *(22.7)*	51 *(21.3)*
51 – 60	02 *(9.1)*	43 *(18.0)*
61 – 70	01 *(4.5)*	18 *(20.2)*
71 – 80	Nil	12 *(5.0)*
81 – 90	Nil	03 *(1.3)*
Marital Status		
Married	16 *(72.7)*	137 *(57.3)*
Unmarried	04 *(18.2)*	75 *(31.4)*
Divorced	02 *(9.1)*	17 *(7.1)*
Widowed	Nil	10 *(4.2)*
Children		
No	04 *(18.2)*	91 *(38.1)*
Yes	18 *(81.8)*	148 *(61.9)*
Education		
Less than O/L	Nil	39 *(16.3)*
O/L	15 *(68.1)*	149 *(62.3)*
A/L	07 *(31.2)*	44 *(18.4)*
Higher than A/L	Nil	07 *(2.9)*
Total	**22**	**239**

Functional disorders emerged as the fourth most common diagnostic category among patients having the first consultation at the specialist psychiatry clinic. It was diagnosed with a greater frequency than some of the well recognised psychiatric conditions like neurotic disorders, mental disorders due to psychoactive substance use and post partum psychosis. Functional disorders

were seen in the psychiatry clinic as frequently as organic mental disorders. Post partum psychosis, exhibitionism and mild mental retardation were included in the other category. There was one patient each from each of these diagnoses.

7.3 Analysis of diagnoses of all patients

Diagnosis	**'n' and percentage**
Schizophrenia, Schizotypal and delusional disorders	111 *(42.5)*
Affective and mood disorders	72 *(27.6)*
Organic mental disorders	23 *(8.8)*
Functional disorders	22 *(8.4)*
Neurotic / stress related disorders	15 *(5.7)*
Mental disorders due to psychoactive substance use	15 *(5.7)*
Other	03 *(1.1)*
Total	**261**

Patients with functional disorders complained of symptoms relating to different organ systems. The gastro intestinal system, musculoskeletal system, cardio vascular and nervous system were all involved. Out of the 22 with functional disorders, 12 patients had somatic complaints involving three or more systems. In the remaining ten patients, one predominant physical complaint was noted. Dizziness, seizures, paralysis numbness, episodic chest pain, dysphagia, joint pains, body aches and fatigue were the unexplained symptoms troubling these ten patients. Adopting the three category classification in pain disorders, functional disturbances of organ systems and complaints centering around fatigue and exhaustion, it becomes evident that the numbers were highest for pain. More than 70% reported pain as a primary complaint. Most of the remainder were complaints of disturbance of functioning of organs. Complaints suggestive of chronic fatigue were notably few in number.

Functional symptom category	'n' and percentage
Pain	05 *(22.7)*
Functional disturbances	04 *(18.2)*
Fatigue and exhaustion only	Nil
Pain and functional disturbances	08 *(36.7)*
Pain and fatigue	03 *(13.6)*
Pain, functional disturbance and fatigue	02 *(9.1)*
Total	**22**

The functional symptoms had been present for extended periods of time. Most commonly the patients had had functional symptoms going on for between five and ten years before presenting to the psychiatry clinic. A very high proportion, more than 90% of patients had had their symptoms going on for more than five years prior to referral to the psychiatry clinic for assessment.

7.4 Analysis of the duration of symptoms in-patients with functional disorders

Symptom duration (Years)	'n' and percentage
More than 30	02 *(9.1)*
Between 10 - 30	07 *(31.8)*
Between 5 – 10	11 *(50.0)*
Less than 5	02 *(9.1)*
Total	**22**

All of them had sought treatment from more than ten doctors before seeking help from mental health services. There was one patient who was being followed up in six different outpatient clinics in the hospital and was on 15 different medications.

Thirteen of them had multiple diagnoses given by various specialties. Among the labels were chronic fatigue syndrome, irritable bowel syndrome, migraine,

functional dyspepsia, gastritis, non cardiac chest pain, etc. Nine of them did not have previous diagnostic labels. Their notes stated that they were “investigated for abdominal pain”, “investigated for palpitations” etc.

A wide array of investigations had been conducted on these patients. Invasive and/or potentially harmful investigations like CT scans, endoscopies, histological assessments, laparoscopies, had been carried out. One patient had had a laparotomy. Among the investigations, were some expensive investigations like MRI scans for which patients usually need wait for long periods on a ‘waiting list’.

7.5 Analysis of the investigations done for patients with functional disorders

Investigation	**Number of patients**
Haematological	22
Basic radiological	22
Ultrasound scanning	22
CT scan	15
ECG	13
Histological	12
MRI	11
Endoscopy	10
EEG	09
2D Echo	08
Stress ECG	05
Laparoscopy	04
Laparotomy	01

The patients with functional illnesses had been referred to the psychiatry services as the last resort. Five were referred from specialist outpatient clinics such as general medicine and rheumatology. Eight of them were referred from wards when they got admitted with physical symptoms. Nine of them were referred through outpatient department (OPD).

7.6 Discussion

The results demonstrated that functional illnesses constituted around 8.4% of patients in mental health specialist outpatient clinics in a teaching hospital setting in Sri Lanka. Of this, in approximately half of the patients the clinicians had arrived at a firm diagnosis of functional disorder. In the remainder it was strongly suspected and labeled 'likely functional'. But a definitive conclusion was not arrived at within the six month follow up period. There was almost reluctance by the clinicians to arrive at a functional diagnosis. Even a small possibility that this could be a 'proper' psychiatric disorder made the clinicians leave the final diagnosis undetermined. Physicians and surgeons frequently diagnose 'functional' when they have excluded all possible organic causes and have run out of diagnostic possibilities. Then these patients are referred to the psychiatry services. Even in amongst the psychiatrists, a similar process of diagnosis by exclusion seemed to exist where functional disorders were diagnosed by excluding 'proper' psychiatric conditions.

Functional disorders were present in significant numbers. In the outpatient clinic set up, this matched the number of patients with organic mental disorders and exceeded well recognised psychiatric conditions like neurotic disorders, mental disorders due to psychoactive substances like cannabis, alcohol related problems and post partum psychosis. Whether the prevalence figures obtained from the specialist clinic reflects the true community prevalence rates is open to debate. In fact the community prevalence rates are likely to be much higher. Most patients with functional problems are managed in the community both by allopathic doctors and alternative practitioners. Another large number go on without treatment. But those with major psychiatric disorders like schizophrenia, bipolar disorder and

affective disorders become difficult to manage in the community and are often referred to the hospital clinics. Thus the hospital prevalence rates are likely to show up higher percentages for these diseases than in the community. Thus we conclude that the clinic prevalence rates are very likely to underestimate the community prevalence rates of functional problems. An argument to the contrary can also be forwarded. There is much stigma attached to psychiatric illnesses and also to attending psychiatric clinics in hospitals. Those with major psychiatric illnesses are likely to be taken to alternative practitioners instead of being brought to the hospital clinics. Those with functional problems are 'not obviously mad' and are much more likely to come to psychiatric clinics without hesitation. This argument proposes that the gap between community prevalence and clinic prevalence may not be that wide. The only certain way to put the arguments to rest would be to conduct a community survey for functional problems in Sri Lanka.

The number of females outnumbered males amongst those with functional disorders. There were nearly twice as many females as males in the functional group. The female and male patient numbers were equal in the organic psychiatric disorder group. When prevalence rates in the different age groups were considered, it was noted that patients with functional disorders were younger than those with organic disorders. The highest numbers were seen in the 31-40 year age group and the vast majority of patients were younger than 50 years. Most of those with functional disorders were married and had children. The percentages for marriage and having children exceeded the overall figures for those with organic psychiatric diagnoses. At a cursory glance, one could come to the conclusion that being married and having children (recognised protective factors for depression and suicide), seem to be risk factors for development of functional problems. But these demographic characteristics need to be interpreted with caution. They do not necessarily reflect population trends or patterns. The study was conducted in a hospital clinic and a selection bias in terms of a sampling error can occur. Thus the findings could not be extrapolated to reflect the findings in the community. The demographic features could well reflect the impact of referral patterns. If a presumption was made that the study figures

accurately reflected community status what would be the plausible explanation for these findings? What has been noted here is merely marital status but what probably matters greatly for functional disorders is the status of the marriage rather than mere identification as single or married. A qualitative enquiry into the stresses of their lives would shed more light on the actual contribution of these factors such as relationship status to the functional disorders. There is stigma attached to psychiatric disorders in Sri Lanka. The diagnosis of a psychiatric disorder reduces prospects of getting married. This could be a likely explanation for the proportionately higher numbers of married persons among those with functional disorders which are not true psychiatric diagnoses. An equally plausible explanation is an artifact brought about by referral patterns.

Confidence intervals are at times used to ascertain precision of the mean figures. In the absence of population figures, and with low sample sizes it was not feasible to calculate confidence intervals for the demographic characteristics in this study.

All of those with functional disorders had secondary education and were from middle class families. At the time of the visit to the clinic none of them were employed. Half of them had given up their jobs due to the severity of the symptoms.

Almost all the patients who were referred to mental health services were patients with chronic symptoms. The referral to psychiatry clinics came from two sources. Some specialists referred to psychiatry with a view to exploring any psychiatric or psychological basis for the symptoms. The other referrals were facilitated at the request of the carers of the patients who wanted psychological possibilities explored as they had been with the patient to other specialty clinics without success.

Most patients had multiple somatic complaints involving many systems. Few showed a predominant symptom afflicting one particular system. During the existence of the disorder, what often started as one symptom, gathered more symptoms around it and in some cases snowballed into disorder of multiple

symptoms afflicting multiple systems. Even more so perhaps for the lady attending the six outpatient clinics and taking 15 tablets for the day. Pain felt in various regions of the body emerged as the commonest symptom category in the three category classification. Numbers for complaints centering around fatigue and exhaustion were low. It appears that the numbers of chronic fatigue type of complaints is lower in the Sri Lankan context, but numbers of fibromyalgia type of complaints is high.

Patients with functional disorders had seen many clinicians both in the government and the private sector and had undergone repeated multiple investigations and procedures which were negative. Thus some of the added symptoms had been of iatrogenic origin. All of those with functional disorders had had basic haematological and radiological assessments and an ultrasound scan of the abdomen. More than half of them had had CT scans, MRI scans, endoscopic procedures and histological assessments. Four patients had had laparoscopic assessments under general anaesthesia and the worst off was one who had had an explorative laparotomy. These invasive procedures and investigations added significantly to the cost burden on the health system and the burden of iatrogenic harm for the patients with functional disorder.

7.7 Conclusion

Functional problems had a significant prevalence in the mental health outpatient clinic of a secondary care teaching hospital in Sri Lanka. They accounted for 8.4% of the patients seen in the clinic. The numbers were more than those seen for some of the well recognised psychiatric conditions. Patients were referred after having symptoms for many years having undergone extensive and repeated investigations and multiple unsuccessful treatments. Functional disorders were more prevalent among females and younger age groups. The traditional risk factor for depression with regard to marital status seemed not applicable to functional problems but whether this is a result of an artifact created by referral patterns is open to debate.

As functional disorders constituted a significant problem in outpatient mental health clinics in Sri Lanka, further attention towards early diagnosis, avoidance of unnecessary interventions and better management strategies is of importance.

8 Comparative analysis of the prevalence of functional symptoms in general medical, gynaecological and mental health specialist outpatient clinics in Sri Lanka

8.1 Discussion

The prevalence of functional disorders was assessed in three specialist clinics with the details of 817 patients attending over a period of three months. Approximately equivalent numbers were seen in the clinics, with general medical clinic recording the highest number of 305 attendees; and gynaecology, the lowest at 251 attendees. Functional disorders accounted for around one fifth of patients attending the gynaecology and general medical clinics with percentages of 22.3 and 18.7 respectively. In both these clinics, functional disorders emerged as the most common condition compared to the various organic diagnoses. This was a notable finding. Psychiatry clinics recorded a prevalence of 8.4%, ranking functional disorders as the fourth most common diagnostic category. Though comparatively less than gynaecology and general medical clinics, functional disorders accounted for high number of patients seeking treatment at the specialist psychiatry clinic.

With regard to the demographic details of patients with functional disorders it was noted that there was a female preponderance both in the general medical and psychiatry clinics. Approximately twice the number of females was present in the functional disorders group whereas the numbers were evenly spread among the sexes in the organic disorder group. A relatively younger group of patients had functional disorders in all three clinics. The 31-40 year group had the highest numbers in gynaecology and psychiatry clinics and the 41-50 year group had highest numbers in the general medical clinic. Overall it was noted that those with organic disorders were ten years or so older in all the clinics.

Having younger patients with the disorder has wide ranging social impacts. The most productive age groups having disabling illnesses causes economic and social difficulties not only for the individual and the family but to society as a

whole. A disproportionately high number of those with functional disorders were noted to be single in the general medical clinic setting but the reverse was true in gynaecology and psychiatry clinic settings. Whether being married is a risk factor for developing a functional disorder in these settings needs further investigation. The number of those who were divorced or widowed was too small for a meaningful comparison. Having children or not did not show a consistent pattern for functional disorders in the cohort studied.

Higher educational attainments were noted in those with functional disorders compared to those with organic problems. Higher proportions had progressed to secondary school and tertiary education. This pattern was consistently seen in all three clinics studied. How higher educational attainments were associated with higher prevalence of functional disorders needs further exploration.

In Sri Lanka, there is a blurring between patients presenting to the traditional GPs and outpatient clinics. Thus these demographic characteristics need to be interpreted with caution. As pointed out they do not reflect population trends or patterns. The study was conducted in a hospital clinic and a selection bias in terms of a sampling error occurs. Thus the findings could not be extrapolated to reflect the findings in the community. The demographic features could well reflect the impact of referral patterns. Higher educational attainments may be a risk factor for developing functional problems but the alternative explanation is the health care seeking behaviour; the consultation pattern of those with high education is different and they have a higher chance of getting referred for specialist assessment by the doctor at first contact. Similar explanations could exist for the higher proportion of unmarried persons and a female preponderance in some settings.

Adopting the three category classification of pain disorders, functional disturbances and complaints related to fatigue and exhaustion, it was noted that pain disorders were the predominant problem in both the general medical clinic and the gynaecology clinic. Pain combined with functional disturbances was the commonest problem in the psychiatry clinic.

A notable finding was the low prevalence of complaints revolving around fatigue and exhaustion. Clinical problems suggestive of chronic fatigue syndrome was a rare entity among the more than 800 subjects studied. This is indeed a notable difference to the western countries where complaints related to fatigue and exhaustion are common. Whether indeed there is a cultural explanation for this difference is not clear. It is quite possible that pain and functional disturbances are more culturally acceptable health problems compared to fatigue and exhaustion which carries undertones of ‘laziness’ in a society where hard work is the default expectation.

The delays in recognition, diagnosis and treatment of functional problems were noted. The complaints had been present for years, at times more than ten years even before the diagnosis had been made. This was consistently seen in all three clinics and the longest periods prior to diagnosis were seen in the psychiatry clinics. This is probably explained by the fact that the patients were referred to psychiatry services as a last resort, when all other avenues had been exhausted. If functional disorders were to be considered as possible differential diagnoses earlier in the course of the illness, these long delays could perhaps be shortened. As a consequence of this delay in diagnosis, the patients had been subjected to a large number of extensive and often invasive investigations. Much iatrogenic harm might have been caused by both the invasive investigations like laparoscopies and explorative laparotomies conducted. Those who had the most invasive procedures not surprisingly came from the gynaecology clinic. Functional disorders in the hands of surgically skilled doctors result in many invasive procedures.

9 Methodology: doctors' perceptions of functional symptoms in Sri Lanka and the UK

9.1 Rationale for the study

Although functional symptoms are common and result in extensive morbidity there are considerable gaps in understanding the causes, the factors which maintain the symptoms and the approaches towards successful management of such problems. By understanding the perceptions of doctors we hoped to form strategies to better address their management. This research was expected to benefit patients by contributing to newer ways of understanding such problems and enabling a better dialogue between patients and doctors and thus facilitating better outcomes. Special emphasis was placed on the understanding of functional symptoms within the cultural and social settings of the environment studied.

9.2 Aim

This was a study designed to assess the perceptions of clinicians about functional disorders, with special emphasis on the associated socio cultural aspects and to develop a theoretical framework for the ways in which these problems were dealt with when patients presented with functional problems.

9.3 Objectives

To ascertain from the doctors

- Their understanding of the pathology of functional symptoms
- How they make a diagnosis in functional symptoms
- Their understanding of how functional disorders affect patients
- What they perceive as causes of the illness and what makes it worse
- Whether they believe socio cultural beliefs and lifestyles have a role in the illness? If so, what factors?
- Whether they worry about making a diagnosis – especially about missing a serious diagnosis
- What treatment they feel works

- Their beliefs about the usefulness of self help groups, media and alternative therapies
- Whether they would refer the patients to anyone and if so whom?
- Whether they consider patients with functional illnesses easy or difficult to manage
- Their preferred term / terms to describe these illnesses

9.4 Study Methods

Researchers have suggested that qualitative research methods are better suited to understand the meaning people assign to their experiences (176, 177). Five qualitative approaches to inquiry are described and they were all considered and assessed for suitability for this study.

Ethnography is a qualitative design in which the researcher describes and interprets the shared and learned patterns of values, behaviours, beliefs and language of a culture sharing group (178). This technique is appropriate if the needs are to describe how a cultural group works and to explore the beliefs, language, behaviours and issues such as power. Doctors participating in this research do not fit into an ethnographic model and this approach was not adopted. As opposed to study of culture sharing groups in ethnography.

Case study research involves the study of an issue explored through one or more cases within a setting. A case study is appropriate when there are clearly identifiable cases and the inquirer seeks to provide an in-depth understanding of the cases or a comparison of several cases. The cases may be an individual, several individuals, a programme, an event or an activity (179). The approach may have been useful if patient perceptions were evaluated but was deemed not appropriate for study of perceptions of doctors.

Narrative research approach consists of focusing on studying one or two individuals, gathering data through the collection of their stories, reporting individual experiences and understanding the meaning of those experiences (180). This approach is best for capturing the detailed stories or life experiences

of a single life or the lives of a small number of individuals. This approach too was deemed not useful for the study of doctors' perceptions but admittedly may have been suited to the study of the experiences of a patient with functional problems. Whereas a narrative study reports the life of a single individual, a

Phenomenological study describes the meaning for several individuals of their life experiences of a concept or a phenomenon (181). This approach was again deemed unsuitable for the study as not just one phenomenon, but many unknown aspects, many grey areas needed to be covered to fully appreciate the range of perceptions of the doctors. Whilst phenomenology describes the meaning of an experience of a small number of individuals, a

Grounded theory goes further to explain the practice. The theory is grounded in the data and is generated from it (182, 183). Hypotheses could be grounded for further research (184,185). This design is suited when a theory is not available to explain a process. Grounded theory was considered the best qualitative approach for the study of doctor perceptions of functional problems. The full width of issues to be studied could be addressed. The grey areas could be dealt with and comprehensive data collection could be made. The researcher could generate working hypotheses by analysis of narratives of participants' experiences of predisposing, precipitating and perpetuating causes of functional problems, diagnostic strategies and management strategies. Thus grounded theory was adopted as the qualitative approach for this research.

In the grounded theory approach, the conduct of the interviews could be done either as focus groups or in-depth interviews. In-depth interviews were chosen as the method. The primary reason for this was the ease of administration. With the busy schedules and long working hours of doctors' in hospital settings getting them together for focus groups was a logistical impossibility. In-depth interviews offered the flexibility the doctors needed. The researcher could meet them at a time when they were free to speak and at a place convenient to them. There were times when interviews were carried out within hospital premises when the doctors were on call.

The implications of the interviewer being a doctor and a psychiatrist were considered at the outset. How exactly this would affect the interviews was not known. The fact that they were speaking with an 'expert' of sorts in the field of functional problems may have made some of the doctors cautious in their observations for the fear of appearing ignorant. At the same time, speaking to 'one of them' assured confidentiality and may have given them a sense of security to speak their mind, without having to rephrase their words in order not to offend as would have happened with a 'lay' interviewer. The precise nature of the impact of being interviewed by a psychiatrist could not be identified and would have constituted ideal material for a phenomenological study.

The other factor of impact may have been the influence of the beliefs of the interviewer in the conduct of the interview. Unwittingly the interviewer's perceptions may have reached into the interviews. In order to minimise this, the interviewer wrote down her perceptions on all the topics dealt with before the interviews and tried actively to exclude them from influencing the interviews and analysis. To further reduce the risk of bias, a non-doctor researcher independently analysed the interviews and identified emerging themes for discussion. Despite these measures it is possible that some impact from the fact that the interviewer was a psychiatrist may have occurred in spite of all possible steps taken to negate this.

9.5 Setting

Doctors working both in the UK and Sri Lanka were interviewed. The broad areas of specialties chosen for study were psychiatry, gynaecology and general medicine / gastroenterology. Care was taken to exclude doctors whose clinics were used to conduct the prevalence study. A considerable amount of time was spent with doctors in these clinics discussing the existing literature on the nature of functional problems, their diagnosis, prognosis etc. Had they been included in the perceptions study, the prior discussions would have given a biased and a restricted view. Thus for purposes of ascertaining perceptions, a group of doctors 'naive' to the proceedings of the prevalence study were selected.

The UK arm of the study was carried out amongst doctors working in the North East region. The doctors interviewed from general medicine, gastroenterology and gynaecology were from the North Tees and Hartlepool NHS Trust. The University Hospital of North Tees and the University Hospital of Hartlepool are the two hospitals administered by this Trust. The hospitals provide both acute services and intensive care for in-patients. In addition, the hospitals provide a range of outpatient services including specialist gastroenterology, general medical and gynaecology clinics. The doctors providing mental health care were drawn from those attached to the Tees, Esk and Wear Valleys NHS Trust. The main hospitals in this trust are the County Hospital in Durham, Lanchester Road Hospital in Durham, West Park Hospital in Darlington, St Luke's Hospital in Middlesbrough, Sandwell Park Hospital in Hartlepool and Cross Lane Hospital in Scarborough. These hospitals offer in-hospital and outpatient services. The in hospital care includes acute, intensive care and rehabilitation services. The outpatient services include specialist mental health clinics including liaison psychiatry clinics conducted daily.

The doctors interviewed in the Sri Lanka arm of the study were those attached to the Teaching Hospital Karapitiya, Galle. A brief account of the gynaecology, general medicine and psychiatry services offered at this institution was outlined in a previous chapter.

9.6 Participants

It was aimed to interview up to ten doctors in each of gynaecology, general medicine and psychiatry units in the UK and a similar number from similar specialties in Sri Lanka. The total number of participants was set at this considering a study on Irritable Bowel Syndrome adopting similar methodology, conducted at the University of Durham (186). The final number was determined depending on the saturation of themes identified. The doctors were drawn from both consultant and training grades.

9.7 Procedure

9.7.1 Entry into the field

The investigator invited doctors in the gastroenterology, gynaecology and mental health specialties and provided an invitation describing the study in detail. The information leaflet (Appendix 1) requested them to send in a consent sheet via prepaid post if they were willing to participate. The UK participants expressing consent were either invited to the Queen's Campus, Durham University for the interview or had their interviews at their place of work depending on their preference. The clinicians in Sri Lanka were interviewed either at Teaching Hospital Karapitiya or the Faculty of Medicine, University of Ruhuna, depending on their preference. Their consent was confirmed verbally once more and confidentiality assured prior to the interview. The interview was recorded with consent from the participant. The participants were assured of the opportunity to review their quotes prior to publication.

9.7.2 Data sources

Each of the sixty doctors participated in 45-60 minute in-depth semi-structured interviews covering the areas set out in the objectives. The participants were encouraged to talk about aspects that they considered important, in their own words, within the broad areas of interest of the study. To do this, open ended questions were used as far as possible. The areas covered in the interviews included:

- a description of functional illnesses, their understanding of the pathology;
- how they would make a diagnosis;
- their beliefs about what type of patient is more at risk of developing a functional illness;
- how such symptoms affects patients;
- how they would treat, how they would explain the diagnosis to the patient;

- the effect on patients when such a diagnosis is made;
- what they felt about treating these patients compared to others with medically explained illnesses;
- and their worries about missing a serious pathological condition.

Doctors' beliefs about lay / complementary treatments for functional symptoms were also explored.

9.8 Data collection, analysis and writing

All of the audio recordings were transcribed verbatim by the researcher. The data collected consisted of more than 400 pages of transcripts. Standard qualitative methodology was used, with a combination of narrative analysis and grounded theory. Grounded theory was applied to elucidate themes and constructs from the interviews. Open coding was done initially examining minute sections of the text made up of individual words, phrases and sentences. This was followed by axial coding where connections were made between categories and subcategories. The analysis was performed by the principal investigator and another researcher. Where interpretational differences existed, these were resolved by discussion or presented as differing perceptions. The analysis proceeded concurrently to data collection. Data collection was terminated only when analysis did not produce codes or themes any more. This was determined as the point of saturation. Accountability was obtained through participant validation of the transcripts. The final results were presented as a report.

9.9 Ethical considerations

Functional illnesses cause much distress and disability to patients. For the treating clinicians also, this would form a rather sensitive discussion. Many doctors find clinical consultations with patients who have functional illnesses difficult. Their familiarity with possible causative factors and treatment strategies may not be accurate. Therefore, all efforts were made by the principal investigator

to conduct the interviews without hurting the sentiments of the physicians. Anonymity of those interviewed was maintained via the use of code numbers.

10 Results and Analysis: doctors' perceptions of functional symptoms in Sri Lanka

10.1 Participants

The research participants were 30 doctors in the three specialties who were working in either the teaching hospitals or general hospitals. Teaching hospitals occupy the apex of the hierarchy of hospitals in Sri Lanka and are tertiary care centres. General hospitals (the equivalent of District General Hospitals in the UK) are next in line in the hierarchy and offer specialist services to patients. Six of the participants were females. 21 were consultants, four senior registrars and the other five registrars. Senior registrars are in the 4th year of specialist training and have passed the MD examination and the registrars are in their first three years of training. Ten of the consultants had more than twenty years experience as specialists whilst eight had between ten and 20 years. The remainder had worked as specialists for varying periods of less than ten years. Out of the seven consultants interviewed in medicine, five specialised in general medicine and two had a special interest in gastroenterology and one each from rheumatology and neurology. One participant was of Tamil Hindu ethnic and religious background, another a Muslim and all other participants were Sinhalese Buddhists. One consultant declined the invitation to participate in the interviews stating that functional problems were a rare entity and that he did not think it was important to discuss them in detail

10.2 Diversity of understandings of functional disorder

This was a strong emergent theme. It centred around the doctors' perceptions about what functional problems mean to them and their perceptions on how they regard these problems. As was expected the understanding of what constituted the entity of functional symptoms was rather diverse. Though all agreed that functional problems existed many found difficulty in describing what they meant by functional diseases. For doctors in medicine, it represented either the 'legitimated' functional syndrome such as Irritable bowel syndrome (IBS), Chronic

Fatigue Syndrome (CFS) or pseudo seizure disorder or simply those presenting symptoms which could not be medically explained. *"Most of those I see with pains look like what they describe as fibromyalgia. But what I cannot say is whether it is actually a functional disease or whether it is a disease which we do not know. When you take all of them, there is a large number of them with this type of thing, where the investigations are normal and they definitely do not have an inflammatory or degenerative type of arthritis but they have musculo skeletal pain."(*SL/M/D/05/1-2).

Physicians were comfortable to try to fit their patient into one of these syndromes. *"Most of these are well recognised entities now. Even IBS is a well recognised entity. They become more and more clear cut problems. So I am not trying to challenge those things."*(SL/M/D/01/1-10). Unusual functional syndromes were mentioned. *"Abdominal migraine is a terrible thing to have. It is like having a typical migraine in the abdomen. You have all the symptoms, aura and vomiting and everything except a headache"* (SL/M/D/02/3-8).

The other physicians reached beyond 'legitimated' syndromes and spoke of symptoms that could not be explained. *"An important sub category is those who have functional symptoms along with explained symptoms. I think that constitutes the most number of patients. At times they may have well established disease and they may have a particular symptom which can be well explained by that particular disease but then they will have a number of other predominantly worrying symptoms which will be completely unrelated to the diagnosis they have"* (SL/M/D/03/1-2).

Those with functional symptoms belonged to two groups: those with transient symptoms causing anxiety about possible underlying illness or those with chronic disabling functional symptoms. *"One is, which is probably the larger number, are people who get a transient illness, transient functional symptom which worries them for a period of time and then it gets better and they get on with life. They are the group I would term 'walking wounded' type of group. The other people are those who have functional symptoms which are extremely disabling and which go*

on and on and on and which really disrupts their lives."(SL/M/D/03/1-4). Thus the physicians identified three groups of patients as having functional problems - those with 'legitimated' functional syndromes, those with transient mild symptoms and those with chronic disabling symptoms

One physician thought the term "functional" was a relative diagnosis which changed with advances in science. *"Functional illness, I think is what we cannot explain pathophysiologically what the patient is experiencing and it does not fall into common illnesses we see. I think the name functional will be relative depending on what we have discovered up to today in terms of pathophysiology. What you call functional today may not be functional in one or two years time where you explore more and find many new things."* (SL/M/D/07/1-2).

The Sri Lankan gynaecologists did not speak of 'legitimated' syndromes. They were not prone to diagnose chronic pelvic pain syndrome as their UK counterparts did. They too identified three groups as having functional problems. The first were those having symptoms which the gynaecologists felt were 'variations in normal physiology' but which provoked anxiety in the patients as the symptoms were not congruent with their lay beliefs about female reproductive system functioning. The beliefs in the community that menstrual periods should occur on the same day each month or that any discharge from the vagina is a sign of a serious illness made people come to doctors. *"It is a very common problem. Even among the educated people. At least 3-4 for a week. Delayed period, vaginal discharge, that sort of a thing we see them quite frequently."* (SL /O and G/D /03/ 1-5). Similar to the physicians, they identified two further groups of functional problems. There were those that were trivial, short lasting symptoms where at times the patients harboured a fear of a sinister illness. Gynaecological malignancies are common and their anxiety is understandable. At times when a patient wanted to rule out a particular diagnosis (HIV/ STD) which is not acceptable socio-culturally; by direct inquiry to the doctor, they would complain of 'suggestive' symptoms in the hope that the doctor would suspect the above and investigate for them.

The other group consisted of those with chronic disabling symptoms such as lower abdominal pain, urinary problems and numbness of legs. This then resulted in multiple medical consultations and multiple diagnostic and therapeutic procedures with resultant iatrogenic harm. *"There are patients who come to me after having a appendicectomy, cholecystectomy and a hysterectomy and still having the same complaint. Still the pain is there. I tell them that it proves that this is functional. But the patients feel that something is left behind. I tell them that they have had three organs removed, all for nothing."* (SL /O and G/D /02/ 3-3). The complaints were at times noted to occur following an invasive gynaecological intervention in the past.

The Sri Lanka psychiatrists considered functional problems from a causative point of view. The emphasis on symptoms was minimal. Two themes emerged. One set of interviewees held the view of functional symptoms as a combination of medical and psychiatric problems. One participant noted that functional illnesses constituted a spectrum where it ranged from being mostly physical abnormalities with a small component of psychiatric morbidity to those with well defined psychiatric disorders which present with somatic symptoms. *"There are many grey areas here. One extreme is physical illness, mainly endocrine disorders. Other side there is depression and anxiety disorders which can give rise to multiple physical symptoms which at once you cannot put into a single picture. In between margin is not clear whether this is physical or psychological."* (SL/MH/D/09/1-6). At times the precipitating, perpetuating and aggravating factors for some of the organic physical disorders could be psychological stresses. *"If it is actually a physical illness which is caused by a certain psychological factor, or worsened or prolonged, that is called a psychosomatic illness. Usual examples are urticaria, asthma, rhinorrhoea and things like that. There is actually a physical illness but with a psychological aspect which is prominent and important."* (SL/MH/D/04/2-2).

The other psychiatric view was quite in contrast to this medical and psychiatric combined aetiology theory. These psychiatrists perceived that most functional symptoms were the result of a psychiatric disorder like depression, schizophrenia,

panic attacks, anxiety disorders, conversion illness and personality disorders. *"My experience is different. If you ask a general physician they will say that 90% of their patients present with medically unexplained symptoms. What happens when they are referred to me, at my level even, these people who are going through grief and such things also present with somatic symptoms. But to me, I find them explainable. It is not a mystery to me. Even the major straight forward depression and even schizophrenia, most of them do present with somatic complaints. That is definitely observable. If you dig enough, in the next two or three minutes, you know what is happening. It is explained."* (SL/MH/D/07/5-1). The presentation of psychiatric disorders in the Eastern cultures is more with prominent physical symptoms. One participant highlighted that this could be the basis of functional illnesses. *"For example if the patient had depression, especially in Sri Lanka, the commonest way it can present is a burning sensation of abdomen. A lot of antacids are given by various physicians and ultimately they do all the investigations and finally send the patients to the psychiatrist."* (SL/MH/D/04/1-2).

An overview of the discussion highlighted the general confusion prevalent about what constitutes a functional problem. The psychiatrists were often convinced that there were 'psychological explanations' to what were mysteries to physicians. The physicians were not convinced. Unique somatic presentations of psychiatric illnesses were described by the psychiatrists.

10.3 Fear of organic disease

One of the strongest themes or probably the strongest component of the discussion was around the missing of organic disease. This manifested itself explicitly without prompting. A few physicians and gynaecologists were keen to consider functional problems in the initial differential diagnosis. *"I do not think it is a diagnosis of exclusion. For the simple reason, in the broad differential diagnosis there might be so called 'physical illnesses' or 'organic causes'. There is no way that you can exclude an organic cause. In this world there is no investigation which can tell you that there is nothing organic wrong with a patient. One can only look only for evidence to support the presence of an organic illness. The absence*

of such evidence does not exclude an organic illness. So I do not believe in this concept that you can exclude organic illnesses and then diagnose a functional disorder. Functional is just like an organic illness and it is part of a differential diagnosis. There may be evidence present to support a diagnosis. At the end of the day, you will weigh the evidence, the positives and the negatives for the organic illnesses and for the functional also and then come to the most likely diagnosis."(SL/M/D/03/4-3).

Quite in contrast, most of the physicians and gynaecologists were reluctant to make a diagnosis of functional disorder for fear of missing an organic disorder. *"I would consider them as pathological until proven otherwise. I am worried about missing something serious and sinister. I do not want to open my mind to the possibility of functional because of the fear of missing something. But sometime I do get the feeling when I see a patient that this might be functional."* (SL/M/D/07/1-2). This was despite them not seeing many instances of misdiagnosis of organic disorders. *"Q – In your experience how frequently have you seen someone who was diagnosed as having functional and then subsequently diagnosed as having a sinister illness? A – Very small number indeed. A handful may be. "(SL/M/D/09/1-7).* It was not just missing sinister illnesses that doctors worried about. At times they worried about missing atypical presentations of common illnesses. *"Things like sleep disorders, sleep apnoea and daytime somnolence, they express it in different ways like unsteadiness. They might not say they are sleepy but will say they are irritable, unsteady, and giddy"* (SL/M/D/06/1-4).

These fears led to a very defensive approach in management. *"I always ask questions to exclude dangerous symptoms. If it is upper GI, I ask for dangerous symptoms like dysphagia, haematemesis, malaena, weight loss. If necessary, I will do the endoscopy and after seeing it by myself, I always tell them that I cannot do much. If it is for a lower one, I will examine the stools, I do the bio chemistry and then at least, I will do barium or a colonoscopy. Then after excluding that I always tell them that this is something. If it is a chest pain, I do the routine*

investigations, and if it is still doubtful, I send the patient to the cardiologist and get the exercise ECG and 2D Echo. If it is negative I will say straight away, there are certain things that you need not worry, but if there are any symptoms I give them symptom related treatment. "(SL/M/D/10/1-6).

Though the participants were hesitant to consider functional problems in the initial differential diagnosis, they were of the view that consideration of this diagnosis should not happen too late in the day. The need to strike a balance between being too hasty and too late was highlighted. *"It takes some time. Just as a patient comes, we could not give a diagnosis of a functional problem. That will take at least 2-3 months. But we should not allow more than 2-3 months also."(*SL/M/D/02/5-1). Leaving it too late would erode the confidence the patient has in the doctor, one participant thought. *"Not after investigating and then saying this is not this, this is not that, then it should be functional. Should be very early. Otherwise patient may think we are hiding something very big and are explaining something else."*

Why was the fear of missing an organic diagnosis viewed as such a calamity? There is a thriving private sector, health care provision system in Sri Lanka. Most of the hospital doctors sit in private surgeries after hours to see patients. There is at times, competition and doctors are not unknown to criticise a fellow doctor's management with the aim of winning over patients. Some felt that if they were to diagnose a complaint as functional, some other person might criticise the diagnosis and start treating the patient and even perform surgery on them. This theme occurred repeatedly. "*The concern I have is that the patient will go on living with the fact that she has problem. She has no answer. So she will go from pillar to post and somewhere down the line, somebody is going to do something negative to her. Either surgery or give some unnecessary vitamin. Some kind of a problem is going to come. Also it is going to have a negative impact on her constitution and her development from the mental as well as the family point of view. We are helpless there. Those are my concerns."* (SL/O and G/D/05/2-5).

Some participants urged caution in making a functional diagnosis, not to use the label to trivialise complaints and then dismiss patients without a proper clinical assessment. *"I have faced this problem myself when one of my family members was diagnosed as having a functional disorder. The patients have symptom/symptoms which is troubling them and the doctors are telling them that there is nothing wrong. Worse still doctors start cursorily dismissing their complaints. Patients feel quite helpless and unfairly treated. This adds to their distress. So they start doctor shopping or taking treatment from alternative practitioners. The diagnosis of functional disorder has to be made carefully. At times doctors, even experienced ones, jump to conclusions without the basic examinations and investigations. In my family member's illness, ultimately it was diagnosed as an organic problem. The diagnosis was not missed because it was a rare illness or that the typical symptoms were not there. It was simply that the senior consultant was not thorough enough in the clinical examination and arranging the required investigations. I am not saying that all possible investigations need to be done but a relevant, comprehensive assessment is essential."* (SL/O and G/D/10/3-1).

Psychiatrists were confident of making a diagnosis of functional disorder at the outset. *"They go to all possible specialists and then come to us. An unbelievable number of investigations have been done and they are all excluded so that most of the time I do not have to worry about the possibility that something physical is missed. When you start talking to them in a different angle, when you talk about the feeling component, for me I think I can get things out so that I feel comfortable in diagnosing something else other than physical illness."* (SL/MH/D/1-6).

The discussion emerging from this theme highlighted the overcautious approach doctors adopted in diagnosis of functional problems. One of the major reasons for this was the competition from fellow specialists in the fee levying private sector. A loss of reputation and a resultant loss of income was unacceptable. Patients had to pay a heavy price to ensure 'safety' of their doctors.

10.4 Importance of 'legitimated' diagnoses

Another emergent theme was what label should be given for a functional problem which was least uncomfortable for doctors and patients. A participant observed that a 'legitimated' diagnostic label explaining the nature of the functional problem was useful to communicate between doctors. This would go to prevent unnecessary repeated investigations. *"In a way, we are not giving a label but putting forward a coded message. We are leaving it open for the subsequent doctor to decide how much further they should go. Someone might take the cue and do only what is considered essential. But someone else will really go to town, and arrange for all the invasive investigations."* (SL/M/D/03/7-1).

Even among the 'legitimated' functional syndromes, the participants noted differences on the likely organic nature. IBS was reassuring but non-ulcer dyspepsia was not. *"If you take the Irritable Bowel Syndrome, the fact that IBS is helpful in the sense, it reassures us that this is not something which is sinister. When you have put in reasonable diagnostic criteria of IBS and then label, then we know that this patient need not undergo endoscopy. We can reassure fairly authoritatively that there is nothing wrong. Non ulcer dyspepsia is a dangerous thing. I do not agree with it. Non ulcer dyspepsia they say when you have to do everything and everything has to be negative. Gastric manometry cannot be easily done. But OGD can easily be done. I think labelling is a double edged sword. You can use it but the danger is if you miss something else where the patient could have been helped"* (SL/M/D/08/5-4).

The gynaecologists mentioned that syndromal diagnosis is becoming part of gynaecology practice too. The participants wondered whether this was an extension of "medicalisation" of a normal process. *"Post hysterectomy syndrome is well described and the emotional and psychological component secondary to loss of menses in a menstruating woman. But more than that there are certain medical things. For example when the hormonal things are not there, the tone of the muscles go down. They have flatulence and the tone is lost. These are physical problems. Not major things. It is not merely the hysterectomy but related*

things. They keep coming to us because we did the hysterectomy. But actually there is nothing there. I told a patient only last week there is nothing wrong, you just diet. She was very unhappy. She wanted something. As she had flatulence, I gave a prokinetic thing. Other than that there is nothing. I advised on reducing weight and exercising." (SL/O and G/D/02/ 4-5).

Some participants thought that though useful from the point of view of doctors, it was not so for the patients. It was believed that in our medical culture, patients placed little emphasis on the diagnostic label. *"I usually try to give an explanation about why this is happening. I do not know whether they are happy or not. I think that helps them to cope with the problem. I do not give a definite diagnosis of fibromyalgia. In our set up I do not think they are particularly interested in a certain name. But I think if you give an explanation of things I think they usually accept."* (SL/M/D/05/2-3).

Whilst the 'legitimated' functional labels such as IBS and CFS were acceptable for doctors, a label of 'functional disorder' was less acceptable. *"To some extent we are very scared to put functional in our diagnosis cards or the documents. One fine day, some doctor may find an organic cause for it. Then we will feel guilty. That is one reason why we keep it open."* (SL/M/D/06/6-7). Some participants felt that it was not scientific to label something that was not understood. *"I would always write, 'investigated for this symptom'. I think we should not put labels. If we do not know, we do not know. There is no shame in it. We probably do not know about 90% of problems. We know only about 10% of medicine anyway."* (SL/M/D/02/4-1).

The psychiatrists used different labels 'legitimated' through the ICD-10 and the DSM-IV. Conversion and dissociation disorders, psycho somatic illnesses, certain grief reactions, Munchausen syndrome, body dysmorphophobia, somatization, hypochondriasis and some trans cultural syndromes like Koro were all considered to fall under the wide umbrella of functional disorders. The majority of them did not consider it important to specifically hang a psychiatric diagnostic label to a functional disorder. They went further and pointed out that while it was a useful

tool in the communication between doctors, such a label could potentially be harmful to the wellbeing of the patient. *"The moment you put the label somatisation disorder, the doctors switch off. Then it is not fair by the patient. If you write a diagnosis card of somatisation disorder well I would not like to carry that diagnosis. Another human being is denying I am having a significant symptom. For me the symptom is quite significant. What I would do is well when I have to communicate with my colleagues, I say, some of these symptoms are likely to be part of somatisation disorder."* (SL/MH/D/03/3-5).

A few of the psychiatrists agreed that it would be better to keep all functional problems in one category such as 'functional disorder' or 'medically unexplained symptoms' till better information on aetiology, management and prognosis was available. But the functional disorder label itself attracted criticism from one psychiatrist. *"I am not happy with the term. Functional is just like those days we used the term hysteria. It is very similar. There is no advantage to us or to the patient. I feel making a diagnosis of functional is useless. There is no meaning in that."* (SL/MH/D/06/1-2).

In the discussion on this emergent theme it came to light that doctors in Sri Lanka hardly every used the legitimated syndromal diagnosis to communicate with patients. The most likely reason was that only the elite minority who speak fluent English would be able to understand the label. There were no Sinhalese or Tamil language translations of IBS and CFS. The doctors perceived correctly or incorrectly that the patients were not interested in a diagnosis. Whether this is a reflection of their true thinking or whether this is an excuse of convenience is a point to ponder. At present the legitimated labels remain a tool for doctors to speak to each other leaving the patient out of the communication.

10.5 Healthcare system related beliefs

The emergent theme considered how doctors dealt with patients with functional problems and their perceptions on how best they should be cared for by the health system. Though the physicians and gynaecologists agreed that the symptoms patients complained of fell within their territory, they believed that they

were not the best persons to manage these patients. Only one physician believed that any doctor who was willing to spend time could manage functional symptoms. *"The problem can be treated by any medical officer or general practitioner really. But very few people have time to spend 45 minutes with a patient." (SL/M/D/02/5-5)*. The participants stated that they did not have this much time available. They considered counsellors or psychologists as a solution. A key worker to deal with these patients, someone in the calibre of a well trained nurse would be a good option for continued attention, one participant mentioned. *"I used to get someone from the psychiatry unit who has an easy way of talking, to talk to them. A lot of these resistant people tend to settle down. The point I am trying to make is we have to find another group of people who can listen and talk to them either in the same set up or have a link to them. You need to build links with those beyond your specialty, not necessarily with other specialists or other doctors, but people who can support them, educate them and counsel them."* (SL/O and G/D/05/ 4-3). But other participants disagreed with the key worker concept stating that in the Sri Lankan medical culture treatment coming from a nurse or a psychotherapist was less acceptable. *"It is there in any field. There is less acceptance for nurse led treatment here. Sri Lanka is still not in a stage that you can divert them to a nurse practitioner."* (SL/M/D/05/5-2).

The ideal method to deal with these problems was mentioned as multidisciplinary teams. But they did accept that this would be very difficult to put in place. *"It is still developing here. I think this should be dealt with by a team, the concept of a multi disciplinary team coming in. Today all over the world, very few things are managed by a single person. Cancers and various other things are managed by multidisciplinary teams which include not only doctors but nurses and so forth. I think that will definitely improve the outcome. Everybody can come in and contribute. In Sri Lanka we have limited resources. But the ideal is a multi disciplinary team."* (SL/M/D/01/2-5).

A few thought these patients should ideally be managed by a psychiatric team. *"We do not tell them it is a psychiatrist. We just tell another doctor will see them.*

The psychiatrists come and see here, in our unit. So sometimes the patient does not even know that they were seen by the psychiatrist. But once they come and sort out, the patient feels comfortable. Then even attending the psychiatry outpatient clinic the patients do not mind. They are confident and comfortable. The psychiatrists are able to build a very good rapport." (SL/O and G/D/03/ 6-3). One group of psychiatrists shared this view that patients would benefit most by early referral to psychiatric services before the symptoms became chronic. They were disappointed at the inordinate delays that occurred at the moment. *"They come to us fairly late, when all the possible investigations have being done and when the patient is exhausted as well as the other clinicians are exhausted they are referred to us."* (SL/MH/D/01/1-2).

But another group of psychiatrists disagreed. They felt the caring doctor, be it a primary care physician or a specialist, should tackle the functional disorders then and there. They believed that a psychiatric referral was merited only in those with chronic and disabling symptoms. *"What I personally believe is though we tend to say that they come to the psychiatrist in the end, I think they probably should not come to the psychiatrist at all unless it is complicated and there is a severe functional impairment and it is running for many months or years. I think the best person to treat functional symptoms is the primary care physician. Patients' cognitions are shaping at that stage towards making the symptoms the most important aspect of their lives and everything is rotating around it." (SL/MH/D/07/2-7).*

Patient discomfiture with a psychiatric referral was recognised by the participants. One reason for this was the patients' perception that psychiatrists were not competent to comment about a symptom they felt as coming from a somatic organ like the heart or the joints. *"I know that some people refer these patients to psychologists and psychiatrists etc. I do not think that works at all. The patient comes with chest pain and you tell them go and meet a psychiatrist. They think you need the psychiatrist rather than them."* (SL/M/D/03/5-3). The stigma attached to psychiatric illnesses was one other reason for this reluctance. "*The stigma of*

sending to a psychiatrist, if you send something like this, the patient will not go even if we try." (SL/M/D/05/3-3). One psychiatrist holding a dissenting view went beyond a personal opinion and quoted information from patients whom she had interviewed, regarding stigma. *"I have interviewed a few patients about this. What they told is, I came here to see another doctor. I know that I will get a solution to my problem'. That is all their expectation is. They are not worried about coming to the psychiatry unit and seeing all the aggressive patients before seeing the psychiatrist. They are not bothered about that factor, much. All the time in their mind what they think is I have come to the hospital to get some treatment. So they have sent me to another doctor to do me some good."* (SL/MH/D/10/5-1).

Physicians, gynaecologists and psychiatrists all thought liaison or joint clinics with the psychiatrist and the physician working together as a good solution. At the moment such a set up is non-existent in the Sri Lankan health care delivery system. *"It is just that the psychiatry colleagues amongst us have had the greater amount of training in this and they probably, however much I hate to admit this, have more competence than I have in inquiring into this. The ideal set up will be if we could have joint clinics, liaison clinics. If we can have a couple of rooms with the clinical psychologist and the psychiatrist, we could always see the patient more or less together."* (SL/M/D/03/5-3). The participants thought that such an approach would help break the stigma related barriers on seeking help from psychiatry colleagues.

Developing the theme further, the participants spoke of joint ward rounds by the psychiatrist and the physician to assess patients in the wards. *"Psychiatrist coming in to see these patients without labelling them as psychiatric. The patients are not really psychiatric or medical. They are in the middle. When we tell the patients they are not happy to see the psychiatrist. If it becomes more acceptable, if there is a ward round done in a medical ward round that will be good."* (SL/M/D/08/6-3).

One psychiatrist spoke of a unique 'psychological rehabilitation centre'. This was a drop in centre for all those with functional problems from the full range of

specialties. This would take away the burden of psychiatrists and support teams having to be part of virtually every specialist clinic. *"They will also need to go to that kind of set up. For example take the rheumatology rehabilitation centre. Whatever the diagnosis, if there is a joint problem, they get rehabilitation there. They might have a clear rheumatological condition, may have a chest problem and need physiotherapy, and may be a cancer. Whatever the original diagnosis, if they need physical rehabilitation and physiotherapy, it is provided in the physiotherapy department. That sort of thing should be there for psychiatric patients who need rehabilitation and can go there for rehabilitation. It may be occupational, it may be more psychological like assertive training. Even cognitive therapy, behaviour therapy, relaxation therapy everything can be incorporated there. Rather than having teams, all the resources can be located there. There can be a doctor in charge. That may be more practical."* (SL/MH/D/02/6-1).

Deficiencies in the health care delivery structure were pointed out one possible contributory factor for the chaotic situation of functional problems. The role of unrestricted access to various healthcare professionals including various specialists and subsequent poor communication or liaising between different medical fields was one such deficiency. *"It is going to be very difficult in a country like Sri Lanka where the health system permits patients very easily to go from a doctor to another. However much I hate to admit this, the patient is likely to find a doctor who is going to say all your doctors who treated you mismanaged you and I am the doctor who is going to treat you properly. Then arrange all sorts expensive investigations and all sorts of invasive surgeries. Because of the very free access to specialists patient is going to go on and on and on, it is going to be very very difficult to stop this."* (SL/M/D/03/5-3).

Evils of the fee levying private sector health care were highlighted. *"In the government sector it is the best policy. Reassurance. But in the private sector I do not think it is a good thing. In Sri Lanka the private sector is different from the other countries. Patients have the right to choose doctors. If you only give advice, some patients may believe that the doctor does not know what is wrong with me.*

So in the private sector, both consultants and GPs tend to give placebos to reassure the patient." (SL/O and G/D/04/2-7). It was also felt that at times the medical practitioners wanted to hang on to the patient with financial motives in mind. That these patients with frequent complaints and multiple consultation behaviour constituted a good source of financial gain for medical practitioners was appreciated. *"If they are seen in the private sector, doctors are not too unhappy to see them."* (SL/MH/D/02/6-5).

Frankly unethical practices were also noted at times in the private sector. *"I have a good example. At that time I was acting Visiting Obstetrician and Gynaecologist here. There was a patient who came with labour pains. She was a 42 year old teacher and admitted as a casualty to my unit as in labour pains. I examined and found that she is not pregnant. Then I did a VE and it was a normal sized uterus. At that time we did not have a scanner here. I asked where she was followed up. She was followed up in the normal village clinic as well as she is carrying a set of notes from a specialist till 26 weeks. Then after that nothing. I said as far as my view is concerned you are not pregnant. But to confirm, I will send you to Karapitiya Hospital to the scan. We sent her there and then she had disappeared from Karapitiya. To make the story short, I went abroad, came back and started the practice and the patient came to me with a card saying that she has undergone a hysterectomy by somebody….. Hysterectomy by somebody for some reason. She is saying that she still has the pain. I was the one who had caused the pain. The scan I ordered has burned the patient's tummy. The gynaecologist who had operated had said the uterus was badly burnt. When she went back complaining of pain, the gynaecologist had said to meet me and talk. I had to personally hand her over to the patient to the psychiatrist. These things are happening. She had not gone to the school afterwards. If she had come to me without disappearing from there, I would have nicely explained and done the needful. She may have become pregnant too. Some sort of an assisted conception we could have tried. But unfortunately a wrong pair of hands has handled her. A wrong pair of hands which is skilful to do the things. These things happen. It did happen and it still happens."* (SL /O and G/D /06/5-5).

At primary prevention level, the gynaecologists suggested the use of public health midwives to provide health education especially on normal physiological variations in the body. *"Yes at the grass roots level. Ideal person is the midwife. Community education at grass root level. Educate people that periods can get delayed up to 45 days etc. Nothing to worry this is physiological. Discharge is normal. We have to educate at the grass roots level. Obstetric part we have done fairly OK. Our field midwives do very well. They go in the community, and identify everything. They treat the anaemia, the worm infestation, spot the PET (pre eclampsic toxaemia). We are quite good in obstetrics community education. The same is not there for gynaecology problems."* (SL/O and G/D/03/ 6-7).

In the discussion ensuing on this emergent theme it appeared that only a few of the participants were willing to engage in managing patients with functional problems. Referral to psychiatrists was promoted heavily. This happened in the state sector hospitals but in the fee levying private sector, functional problems were not unwelcome. The often quoted excuse in the state sector was a lack of time but this time lack did not seem an impediment for them caring for a patient with a complex organic illness, even with a poor prognosis. There were many excuses in the government sector to dispose of the patient either to another organic specialist or to the psychiatrists. One of the reasons quoted for a psychiatry referral was that psychiatrists spoke better to patients!

10.6 Attitudes / assumptions about outcomes in functional disorders

This emergent theme considered the perceptions of doctors on what they managed to achieve in terms of patient care in their encounters with patients with functional problems Satisfactory outcomes were noted when there was a clear underlying psychiatric illness. The participants used drug treatments with or without modern psychotherapy methods. Admittedly number of functional disorder patients falling into this category was low. The remaining patients posed major challenges in management.

Participants were often not certain about what outcome they were attempting to achieve with functional problems. Some believed that nothing worked, no

improvement could be achieved. *"In my practice, possibly nothing works. The problem is we cannot go beyond what we have. We can sit down and spend a little more time and explain things to them and possibly talk to them. Because of my personal concern and interest in domestic violence and gender based violence I might take it a little further and I might pick up a few cases and I might refer to some people who deal with it. From the average gynaecological point of view I think we utterly fail in these cases. They will possibly be OK for one or two consultations but thereafter go to someone else because her primary problem has not been answered in the consultation."* (SL/O and G/D/05/3-4).

Some aimed for a cure. They were not certain whether they achieved it. One psychiatrist who used uncommon psychotherapy methods mentioned quite dramatic and instant recovery in some of his patients. For example he quoted an instance where there was a male patient who had sudden onset of blindness and had been investigated and treated without success for a number of months by many ophthalmologists. He was ultimately referred to the psychiatric unit as having a functional blindness. Under hypnosis he was regressed to the moment of onset of the blindness and it was revealed that it happened on the day he got a letter from his girlfriend saying that she was going to get married to someone else. *"I said, alright, you have the letter in your hand now, and he said yes. I said now you had the letter, you read it. I am sure you can read it. By now I had regressed him to the point where he had just become blind. So I said now you can read. He said yes. Then I said alright, I will count back from 10 to 1 and when I count from 10 to 1 and when I reach number 1 you will open your eyes and you will see all these medical students here. Actually it was a moment of suspense for me also. When I was counting up to one, he opened his eyes, looked around and said, I can see, I can see, and he jumped at one of the female medical students and said I can see your sari, I can see your blouse, this one's shirt is green and things like that. He actually started dancing and ran out of the room to where the parents were. They were shocked, he was shocked and the person who was shocked most was I. I never expected that drama."*

Some others looking for cures did not see such dramatic results but had to be content with a mere 'impression' of success. *"Most often than not, I can manage such symptoms. I cannot remember a person whom I failed to manage. I do not know whether they went to someone else. That is also a possibility. People who come again and again, I have managed successfully, with psychological input or the drugs we have. I cannot recall any one who is not satisfied with the treatment."* (SL/M/D/01/3-2). Some others who did not see the patients again in their clinics thought they had cured the patients. But they freely admitted that the patient going to another specialist was an equally likely scenario. *"They do not come because they have got better or whether they have not been happy with us and gone to another doctor. That we do not know."* (SL/M/D/06/2-3).

Steering clear of admission of total incompetence and chasing an elusive cure, many doctors stressed the need to change the agenda on how outcome is considered. Instead of focusing on short term or immediate outcome, they shifted emphasis to long term outcomes aiming at reduction of symptoms, improvement in functioning level, reduction of repeated investigations and procedures, reduction in number of consultations, better coping and overall improvement of quality of life. *"These patients are difficult to manage and these measures will not give an instant cure. But they will, over a period of time, make life better for the patient."* (SL/O and G/D/10/4-3). Periodic fluctuations in symptom severity made assessment of outcome even more difficult. *"With my past experience over 16 years including one year in the UK, I have not seen anyone who is completely cured from irritable bowel syndrome. This comes from time to time. Whenever they feel they should come and see whether it is going to the wrong way, that little bit of reassurance does a lot of good to them, rather than looking for a complete cure."* (SL/D/M/10/4-3).

One participant extensively described the success achieved by practicing therapies which are not commonly practiced nowadays. Among them were hypnotherapy, abreaction, analytic therapy and psycho drama. Although he did not practice them, he had observed past life therapy, meditation and yoga being

used successfully in-patients with functional symptoms. The majority agreed with the success they gained by developing a good rapport with the patient. Empathic listening, accepting that they are suffering, developing insight and teaching how to cope with symptoms were mentioned as bringing about a considerable functional improvement in these patients.

Another important theme highlighted was how the time and the effort put in by one doctor might all come undone with another doctor who would take the 'easy way out' by resorting to further investigation and placebo treatment. In these instances, a relatively satisfactory outcome would change to a poor outcome. *"Ultrasound has become a routine procedure for anyone complaining of abdominal pain. Although you realize that one of the common sources of abdominal pain is the bowel and you cannot get it on the ultrasound. In this process you might find a small fibroid or a small cyst, which you yourself, the clinician would feel that it is not the cause. But in the scenario that the patient is having the pain and our not being able to identify a cause, having found a small thing, it is very difficult for you to quantify the significance of it and say this is the cause. Patient will invariably link with this, unless we positively say that it is not so. We are coming to a situation where we are somewhat convinced that it is not so but we are unable to categorically say it is not so. Eventually the patient will or may be before the patient we will possibly say it is not likely to be because of this but because we are helpless in finding a source, the patient will possibly take it further and meet somebody else and eventually get this out. But the chances are that she will continue to have the pain or the symptom."* (SL/O and G/D/05/1-8).

Participants did not believe that placebo treatments provided satisfactory outcomes. *"I have seen a lot of patients who have gone to a lot of other people. Every IBS patient I see has already seen about 10 doctors who have given about 10 drugs. If placebos are effective, they will not come to me."* (SL/M/D/01/5-2).

The usefulness of alternative therapies, native treatments was not certain. Some participants perceived that the outcomes would be better. *"For example if it is back pain, we are always geared to see why there is backache. Whether there is*

a pathology behind it. The patient may not be all that interested in that, though we are. When they go to the alternative practitioner, they will be not be emphasizing pathology but will be focused on the back pain. That is what the patient wants. They might be giving gradual physiotherapy and they can get gradually rehabilitated. In that sense that may be ok, but the question is the expenses and whether they are making the patients' belief more and more. I think substantial proportion are getting into alternative treatment and are getting what they want. We dismiss them saying there is nothing wrong." (SL/MH/D/02/7-1). These views were not universally held by the participants. *"We have seen certain people who have gone to acupuncture. Also some for Ayurvedic medicine. I think even if they go there, the same thing happens. They are being given some medicine and when they feel that things are not going right, they come back to us".* (SL/O and G/D/04/5-8).

An overview of the discussion in this theme revealed that a number of participants changed their agenda, conveyed as much to the patients and thought they had marginal to moderate success. An extremely skilled psychiatrist exercising psychotherapeutic practices spoke of a few instances of spectacular success. Unfortunately these skills seemed to elude the younger generation of doctors who quite naively presumed that patient not coming back to the clinic meant successful outcomes.

10.7 Sensitivity / Insensitivity of doctors to psycho social factors

This was a strong emergent theme which looked at the perceptions of doctors about causation of functional problems. Their ability to move beyond biological explanations and consider psycho social factors of patients was noted. Some participants acknowledged that some psychiatric illnesses could present as functional problems and clearly needed treatment from psychiatrists. *"Functional in the sense these unexplained symptoms mean depression or obsessional disorder or something where I cannot help the patient but can be helped by someone like a psychiatrist."* (SL/M/D/08/2-1).

A view that psychological stresses such as ongoing conflicts, relationship issues and violence at home come out in the form of somatic symptoms was expressed by a number of participants. For some, illness represented the only way to come out with the psychological worries. *"Sometimes females come because they want to get away from home or maybe there is wife battering going on. They are stressed up, but this is happening unconsciously. They want to tell something. Things like sexual problems, poor libido and things like that, they come and say totally unrelated symptoms."* (SL/M/D/07/3-6).

How does stress cause functional problems? Some looked for a biological explanation. *"There are a lot of things which we do not understand. A lot of people believe that there is a connection between the gut and brain and stress and that the gut function goes haywire when there is stress. I do not understand the physiology and how it is connected. What I do understand is there are people with stresses and pressures and they come out with psychosomatic symptoms."* (SL/M/D/01/1-6). Another participant observed that there may be no direct biological link but could be an instance of a normal phenomenon being interpreted by the brain as a problem. *"The fact that they are having big worries and stories running in the background and they being more sensitive to somatic sensations, I do not think that they are separate from each other, I am fairly certain that they are probably linked to each other."* (SL/M/D/03/1-4).

A few mentioned secondary gains as a cause. *"In the stressful situation, one possibility is, when they have difficult situations or difficult circumstances at home, illnesses kind of gives them power. People fear illnesses. People around are scared of illnesses. It kind of gives the ill person some kind of power to handle situations better." (SL/M/D/03/8-3).* Another participant elaborated*. "When the patient has an unexplained illness, the family members and well wishers will try to invoke blessings of the gods on the patients. They will arrange the more formal religious blessings like going to temples and chanting 'pirith' and holding 'bodhi puja' etc or even arrange the more extensive cultural rituals like 'seth kavi', 'piliweth', 'shanthikarma', 'thovil ceremonies' etc. Some of these are held to drive*

away the bad influence of demons. All of these confer great attention on the ill person and some of the background family disputes and family stresses get addressed indirectly in the process. The increased attention helps the psychological wellbeing of the patient. So these beliefs also perhaps play a role in causation, aggravation and ultimately recovery also from functional illnesses. The downside of this is, with those prone to functional disorders, this at times becomes a way of life. Whenever the life's stresses become too much and the family disputes arise, functional disorders become a way of settling matters and getting everyone together against demons, evil eyes and graha apala." (SL/M/D/03/2-3). Another added, "*They are not lying about their complaints or suffering but indeed stand to gain attention from the family and close relatives when they have functional illnesses. I see this kind of patients at Wennappuwa where children are in Italy, all the children have left for Italy, and the mothers are there and are basically domestic servants who are looking after the grand children. They have the worry that children will not come even before their deaths. They get this functional type of illness for which the children have a good enough reason to come to Sri Lanka to see the mother who is sick. They get cured when the children come and see them but then the next year the same time they come."* (SL/MH/D/03/1-4).

The secondary gain was a subconscious effort. In contrast deliberate manipulation was also noted albeit, occasionally.*" There are patients with Munchausen's disease. There were two patients for us. Where you know that after extensive investigations, the patients would comply. They would manipulate symptoms. We had two such patients. We extensively investigated them. We sent to Colombo, their consultants went through the patients, CTs, MRI, Liver biopsies we did. Everything we did and finally realised that the patient was manipulating. That sort of a category also exists. I think they are psychiatrically ill people and we cannot offer anything."* (SL/M/D/04/1-6).

Some normal life changes came out as illnesses as well. *"The other thing is after the Sinhalese new year festival, I see many older ladies. I think during this period,*

all the children come home and celebrate. When they leave, these ladies feel very sad, the mothers. Then they come out with a lot of various lower and upper GI problems." (SL/M/D/10/3-3).

Almost all the participants raised the issue of modern day anxiety provoking culture. They mentioned mass media, health insurances, health advertising, and anxiety provoking relations, friends and neighbours as main roots. *"Somebody had a stroke and they are worried whether they are going to have a stroke. Patient says I have everything, pain and numbness, started from head to the bottom. I know he is worried whether he is going to get paralysed. Some phobias, they are going to get some cancer or whether they are going to get a heart attack."* (SL/M/D/08/1-4). At times the health anxiety was not with the patients but with the carers. *"The patient is 95 years and has been constipated for three days. The relatives were very worried and brought the patient. The patient is not worried but the relations are."* (SL/M/D/04/1-4). Doctors appearing on mass media were also responsible for this excessive health anxiety *"It is a problem, especially the TV programmes, to some extent the internet or the newspapers they read and say so and so, who is a very prominent clinician, has explained this entity. I am having exactly similar symptoms. They have heard of the investigations done for those things. I think to some extent these health education things should be re organized and there should be some guidelines for anybody who goes to the media and talks about these illnesses. What the patients gather generally is the worse of what is discussed."* (SL/M/D/06/7-3). People who gathered their information from sources beyond the television such as internet were as poorly informed but were more amenable to changing their views after explanation. *"Only a few patients have access to the internet and other knowledge and information. They are the ones who want all the big investigations. They are the people whom we can easily convince because they are educated that this is not a necessary investigation."* (SL/M/D/02/3-2).

At times there was no health anxiety but inaccurate personal health beliefs also caused functional problems. *"Even yesterday there was a patient who was being*

investigated for constipation by a colleague of mine. Third year nursing student. My colleague had assessed her and said nothing was wrong. I examined and found nothing other than constipation. She had this false belief that everybody should have a bowel motion every day." (SL/M/D/01/3-3).

One participant thought that some patients simply liked coming and speaking to doctors even without being anxious about something. *"There is another category who always wants to go to a hospital and talk to a doctor. Once I came across a patient. She had a problem, irregular menstrual bleeding. We assessed the endometrium, did hysteroscopy, and performed histology. She is being given norethisterone to regulate the cycle. She is taking it. We have given the prescription. We advised her to take medicine for 6 months to get an improvement. We have already explained everything but still she comes back to the clinic in one month. I might sometimes get annoyed and ask why you came again. She would say that the old prescription is over and want a new prescription of the same drug. They are fond of coming. I will write the prescription again and she would be happy."* (SL/O and G/D/08/2-10).

An overview of the discussion in this theme revealed that doctors considered psychosocial factors to be important in the causation of functional problems. The ability to relate to these differed between doctors. Some left all matters psychological to psychiatrists and looked at individual organs. But there were a few who inspired hope for those with functional problems who managed to identify the issues and explain them to patients even if they admitted they could do precious little to change circumstances.

10.8 Cultural sensitivity

The emergent theme on cultural sensitivity was one of the strongest areas which formed the base of this study, a cross cultural comparison of doctors' perceptions in Sri Lanka and the UK. Participants believed that cultural beliefs had a complex interaction with functional problems. At times they were seen as causing functional problems. Others believed that it was in fact the breakdown of cultural values which caused the functional problems. Some stated that cultural beliefs

helped patients cope with the distress of functional problems better. Some saw its influence in modifying consultation behaviour. The gynaecologists thought functional problems provided a gateway for patients to discuss culturally taboo topics. Some participants thought patients used the cultural beliefs about symptoms to reach out to doctors to get help for their domestic problems. Finally one participant felt that the language used to express emotions caused the emotions to be misidentified as functional problems.

A psychiatrist brought into focus the role of religious beliefs and perceptions in the causation of functional symptoms. *"Then one of the trans cultural syndromes is Koro. People think that Koro is rare. I have seen more than 25 cases in Sri Lanka. I have not seen so many abroad. That is a person, usually a young man, feels that the phallus is getting withdrawn into the body. Sometimes he tells the parents or usually the grand mother and they keep pulling at it. Sometimes they tie a rope and they pull it. They think that the moment it goes inside the patient will be dead. So there is horror. The whole household is sometimes involved. This has a significance, because the thing is, for example, the Buddha has certain characteristic physical features. One of them is that the penis is not visible outside. This just means that the Buddha has control and has completely taken sex out of his mind. Sex does not play a significant role in any of the motivations of the Buddha, i.e. Viragism. There is a poem, in one of the books which describes the Buddha. It is like this. 'Piyumehi kemiyata, weda siti gatha thulata, puris gathi eththeya muniduta. " That is like part of the lotus hiding inside the 'kemiya', the Buddha has that feature. That has gone inside his body. I can see some sort of a cultural thing where Koro is a representation of withdrawal of sexual feeling. It may be given various other interpretations but this may be significant. There are certain factors in our culture, which gives some special prominence to various parts of the body. The other important features for a woman, the sexually significant parts of the body, breasts, they can also recede in the female equivalent of Koro." (SL/MH/D/04/5-5).*

Another participant spelt out how religion seems to play a role in giving understanding to the patients as to the causation of the functional problems. Such an understanding was thought to help them cope better with problems. *"The ones who come to my mind are women who come with symptoms and say this is 'Karume' (Bad effects of bad actions from the past). So this cannot be helped. And they attribute that to something they did in the past. I did this to my mother in law so that is why I am suffering like this."* (SL/MH/D/03/2-3).

Further causal cultural influences were noted when people believed bad astrological periods cause functional problems. *"In the culture, I can think of astrology, for example, there are planets. One of the planets, Rahu, actually Rahu is not a planet but indeed the absence of a planet. It is symbolized by the absence of a head. There is a body without a head."* (L/MH/D/04/5-2). It is believed that during Rahu period people do things bordering on 'madness'. Beliefs in 'charms' and 'evil spirits' were also used to explain the causation of functional problems. *"Some others may believe that it has been done by some other 'spirit' or some one has enacted a 'charm'."* (SL/MH/D/05/5-5).

The gynaecologists identified some common lay beliefs which had roots in native medical systems about the reproductive system, as creating more and more worried well in the society. One such belief was the "body melting syndrome" which the patients associated with a whitish vaginal discharge. *"This is common in this country. In Sinhala, people call this 'enga unu karawa yanawa. They feel that the entire body is melting and is coming out through the vagina. You can see people with massive thyroids do not go for medical attention, but when there is a small vaginal discharge for one or two days, they go to a doctor. When the discharge occurs, they think the whole body is melting down. They will say I am losing weight, I am not eating, and I am tired. They think this is due to the discharge. These are all our beliefs."* (SL/O and G/D/03/1-3). Similar beliefs relate to menstruation. These have been around for so long that they are part of rural culture. *"For example, menstruation. Most of the people in the villages believe that the dirts of the body come out during the menstrual period. So when there is a*

one or two week delay, there is a big problem for them. They think that till the menstrual blood comes out, the entire bodies get dirty. So they come with these symptoms. For example they will say, bloated feeling, I feel dizzy, I feel all that, but this could be in no way attributed to the menses. It simply is a delayed period. As we know the period can vary from 28 to 45 days. Normal periods can vary. There are no particular dates. Having said that, according to the cultural beliefs, they come with all sorts of symptoms bloated feeling heaviness, tiredness with a simple delay in the period." (SL/O and G/D/03/1-2).

Other gynaecologists warned of dismissing these, pointing out that these cultural beliefs had been built on observations about the human body and illnesses over centuries and had some scientific validity even today. *" All these traditional beliefs have a scientific bearing. Although they did not know the exact reason, some of the white discharges are cancers. They become thin. They get emaciated. So it is rational."* (SL/O and G/D/02/2-4).

Rather than cultural beliefs causing functional problems, some participant thought that break down of traditional cultural and religious beliefs resulted in causation of functional problems *"So I think the causative role of religious, cultural and social beliefs is minimal. It is in fact the very lack of such an explanation that make those without these beliefs to keep going to doctors to seek explanations for their symptoms. Spiritual health has only been recently added as an important tenet of health. I feel it is often the lack of spiritual well being which prompts people to develop functional disorders."* (SL/O and G/D/10/3-3)

A participant elaborated on how cultural beliefs helped patients deal with functional problems better. *"Rather than culture causing these symptoms, I think religious and cultural beliefs help. Those determine the extent to which the patients successfully deal with the problem. Some patients might be having some disabling symptoms which might be occurring due to some background stress in their lives. But if they have strong religious beliefs and background in which they firmly believe in, they might be able to cope better with the symptoms*." (SL/M/D/03/2-3).

Cultural beliefs gave explanations to certain symptoms and changed consultation behaviour patterns. *"Some other beliefs about food, bathing etc too may be playing a role. Some people have great belief in this the 'Ushna versus Seethala kema' that is the 'cold food' and 'hot food' battle. This not quite the hot and the cold that we know and experience. I think this stems from Ayurveda traditions and all food has been categorized into either hot or cold or neutral. Consumption of some of these foods are supposed either cause certain illnesses or aggravate the severity of some other illnesses. For example, tuna and cuttlefish are 'hot' foods and they are not good for gastro intestinal disorders like dyspepsia and haemorrhoids whilst curd, yoghurt and fresh milk are 'cold' and are not good for upper respiratory tract infections. Many of those seeking treatment from allopathic practitioners strongly hold to these beliefs. The relationship to functional illnesses comes when in their minds they connect up the origin or the aggravation of the functional disorder due to these. Often these beliefs are unshakeable and doctors find it hard to convince patients otherwise. Normal variations in body functional patterns are identified as illnesses because the variation occurred after they consumed a particular food. The same holds about bathing too. For some illnesses having a bath after noon is not considered good and again, may be held as the culprit for precipitating certain respiratory complaints".* (SL/M/D/03/2-4).

The gynaecologists identified culturally taboo topics. Dyspareunia, premarital sex, extra marital affairs, sexually transmitted diseases, sexual abuse and doubts related to what is normal in a sexual relationship were all mentioned. Discussing these topics, even with a female doctor was distressing. Patients with these concerns at times complained of symptoms that they felt the doctor would somehow relate to the concern they had. *"Some people have sexual problems. They do not say at the very beginning that they have dyspareunia or they do not feel like having sex. They come complaining of lower abdominal pain, pelvic pain, backache."* (SL/O and G/D/10/6-3).

One participant thought that people made use of these cultural beliefs to reach out to doctors as they believed that was the only way to get doctors to pay

attention to their problems. *"I think she has something beyond that which we cannot reach. She makes use of this belief about discharge to reach us. That is my personal belief. Somebody who has no problem, who has an absolutely good family life, will probably ignore this discharge. She will ignore this discharge as it causes no problem for her. Even if she looks at it and is concerned, she will come and tell and when we tell her that there is nothing to worry about, possibly she will get on with life."* (SL/O and G/D/05/3-2).

Cultural influences were evident in the language that is used to express emotions. *"In this country at least till recently people never said, I am depressed and things like that. They usually express it in a physical symptoms, usually chest pain or burning sensation in the chest. That is in the culture and that is reflected in many songs, poetry. My famous example is 'laso ginidal dalvuna, oba magen wen wu dine'. That means the day you separated from me, my heart started burning. Things like that. Which comes first I do not know. Whether the cultural thing comes first and therefore you express it whether because you express it whether that is in the culture, I do not know. It is like the chicken and the egg."* (SL/MH/D/04/4-5).

Even within Sri Lanka particular communities used unique expressions to state their discomfort. *"When I was in Matara people used to come and say, 'kan deken gindara pitawenawa' (fire coming out of the ears). When I meet other consultants in the consultant lounge, I used to say this is a very common symptom which I had never seen anywhere before. I was never able to explain that symptom. But then when I got hypertension, I get this feeling that the ear lobes are getting warm. I cannot retrospectively reclassify those patients. I never could relate hypertension and that symptom. In my personal case as a patient, and I always tell the patients that hypertension is an asymptomatic disease and that they will never know. People think they should get headache or vertigo. They feel if they do not have symptoms their blood pressure is under control. I always tell the patients that this is not the case. I have seen in myself that when my blood pressure is high, I have symptoms like what I described to you. The book does not*

explain or people have not reported. These symptoms may have genuine physical basis for it though we cannot explain that with what we know." (SL/M/D/08/1-4).

With regard to ethnicity, there was an observation that persons from the Muslim community presented less with functional problems. This was noted by more than one participant. *"The Muslims, they may come with some very trivial thing but medically unexplained things are less. They have very often, pain or something which you can deal with. That may be there. I do not know whether the religion has to do with this or whether their biological make up makes this." (*SL/M/D/08/4-1). Participants stated that they saw more functional disorders among the majority Sinhalese community as compared with the Muslim community. Whether this was a truly significant association or whether this was merely the representation of overall percentages of the population of the communities was not clear to the participants.

An overview of the discussion brings forward the fact that there were many doctors who understood the implications of cultural beliefs on the causation of functional problems. The observations they had built up, helped them understand the happenings behind the facade of functional symptoms and assisted in trying to address them. The role played by illness to change family relationships and the fact that patients used cultural beliefs, both at times being used as vehicles to bring out problems, was enlightening.

10.9 Impact of experience and education on doctors perceptions.

This emergent theme brought forth the changes in the perceptions of doctors as a result of them accumulating experience and also as a result of education they had on functional problems There were a few participants from the younger age groups who were less sensitive to socio cultural aspects in-patients. *"Q – Have you come across any cultural or religious beliefs associated with these odd presentations? A – Not really. I may not have enquired a lot. That might be the reason."* (SL/O and G/D/08/2-7). In contrast, senior doctors were happy to spend more time with these patients as soon as they felt this was likely to end up as a functional illness. *"It is how well you listen to them and take the verbal cues to ask*

the follow up questions which help you to get the information. I take lot of time over a patient. I try to understand their lives and background." (SL/O and G/D/10/1-2). Learning from senior colleagues handling patients with functional problems made some doctors adopt similar approaches. *"I learnt it from my consultant, who spends the same amount of time going to the history of the parents and identifying the problem than just writing something. I would not hesitate to spend that time. In fact there is enough time. I never found any problem with time."* (SL/M/D/02/4-3). Experience helped doctors decide on when to stop invasive measures. *"After practicing nearly 20 years, I know what to be operated and what not to be operated. What word to be talked and what word not to be talked to the patient. I believe, everybody will get that with maturity. First two or three years as a consultant you will cut the whole town. By the third year you are settled."* (SL/O and G/D/06/4-2).

An experienced psychiatrist possessing a wide range of psychotherapeutic skills felt comfortable in management and did help patients even when many others had failed. *"One of the rare things, a very interesting case, it is called the Fax illness, facsimile. Fax means that you put a paper in Colombo and in London you get the identical thing out. That is why this is called fax illness. It may not be so rare as people think. It may be undiagnosed. I saw a case about 4-5 years ago. A young woman, about 25 years, who developed a very severe pain in the lower abdominal area. Excruciating pain. She went to surgeons, physicians, gynaecologists. No one could help her, no one could find the cause as all the investigations were negative. She would yell in pain. Because I was sure that it was nothing organic I did not do any investigations and I hypnotized her. I asked her to go back to as far as where her memory went and she actually stayed at a certain point in time. She said I am now in severe pain. I asked what happened and she described it. I said go to that van. I created the hallucination of that. She said yes and she started screaming. What had happened was her father was driving a HiAce van and he fell asleep and this was night time. The van went and hit a lamp post and the lamp post came almost into the van through the windscreen. The glass of the windscreen cut the father's lower abdominal area*

and he started bleeding profusely. She saw this and screamed and screamed. The father died before he was admitted to the hospital. As usual she was crying for days and she of course recovered from that. Suddenly years later, she started this pain. That incident was I cannot say it was forgotten but it was not even considered significant. The main thing was after the ab reaction, the pain disappeared completely and I followed her up and there was no pain at all." (SL/MH/D/04/2-3).

Some of the experienced specialists took the effort to teach specialist trainees about diagnosis and management of functional problems. *"My trainees, whenever they get these functional symptoms, I show them. At the first presentation I say, this looks more functional. At times I do not tell them if I see them in the private sector. I will see them again in the clinic and the trainees list the possible diagnoses. They will say A and I will rule it out, then they will say B and I will rule it out. This is before investigations. Then they scratch their heads and say functional. I say probably, but let us investigate and rule out all what I said. That training I give them. So it is in the differential diagnosis."* (SL/O and G/D/02/3-5).

Some of the changes taking place in teaching in the medical schools seemed to better equip the young doctors in dealing with patients who have functional problems. A participant spoke of using 'role play' as a training tool in understanding and managing these. *"We have had this new curriculum in the Colombo Medical Faculty, which includes behavioural sciences. There we had a lot of discussion, once a week or so discussions and practicing dialogues, giving scenarios and how to handle them. For example, some patient not accepting what you say. Role play etc. Initially when I was a student I did not like it. Now I feel it is very important in counselling patients and breaking bad news, I think it has helped me a lot, this behavioural sciences programme at the faculty."* (SL/M/D/07/4-2).

Despite these positive changes, the overall deficiencies in the medical undergraduate education were pointed out as having an adverse impact on the doctors' perceptions of functional problems. *"What I feel happens there is that medical education and training is entirely based on the western model and*

western culture. We are trained to think in the western way where this all or none, black or white, grouping people, grouping symptoms and things like that. But the eastern culture or the Sri Lankan culture is entirely different to that. That is where the secret lies. Even if you are a student from this area and you are Eastern or Sri Lankan, when you go to a medical school you are changed to a western person and think in these terms. I think that is why most of the doctors find it very difficult to understand these patients and treat them. There are lots of patients who are treated for heart disease or sometimes inappropriate psychiatric disorders or just given medication without a diagnosis. If you can switch to the eastern model and Sri Lanka culture, and then listen to them it is easy to diagnose most of the disorders. I think we need a shift of paradigm here about the medical education. If they are going to go to England or Australia and treat the westerners, that is fine and they would be successful. But in Sri Lanka they are not, sometimes because they cannot switch to their original culture and think in those terms." (SL/MH/D/07/6-1).

An overview of the discussion highlights that education and experience did play a role on perception of functional problems but this was of a highly selective nature. The few who were responsive to the needs and problems of patients felt empowered by experience and education. But they failed to touch the vast majority who had the same experience and the same education. As yet undefined personal characteristics made doctors better or worse in dealing with functional problems and the correlation with experience and education was poor.

11 Results and Analysis: doctors' perceptions of functional symptoms in the UK

11.1 Participants

The research participants were 30 doctors from specialities of general medicine / gastroenterology, gynaecology and mental health. All of them were working in the North East of the UK, and were from North Tees and Hartlepool NHS Trust and doctors in Tees Esk and Wear Valleys, Mental Health Trust. 11 of the participants were female. 11 were consultants. Eight of them were specialist or trust grade registrars who had undergone four years of training. 11 were of the specialist trainee grade in their first and second years of training. 18 of them were British, the remainder from Asian backgrounds. Of the physicians six were from gastroenterology and three from a general / acute medicine background. Though the invitations were given initially to the doctors in GI units, three doctors refused stating that they were not interested in functional problems. Therefore the invitations were extended to the general medicine units as well.

11.2 Diversity of understanding of functional disorder

This was a strong emergent theme. It centred around the doctors' perceptions about what functional problems mean to them and their perceptions on how they regard these problems. For many participants, this constituted of one or more symptoms related to one or more organs for which there was no detectable pathology. "*We get people who are coming with chest pain with a normal angiogram and various other symptoms like palpitations with normal tapes, history of recurrent headaches, things like that mainly."* (UK/M/D/07/1-6). For some, unexplained symptoms along with repeated consultations constituted functional problems. *"I have personal experience of dealing with some patients who are frequent attendees with different symptoms. I particularly remember this person who had attended more than twenty times with different things and he had scans of all descriptions done. He would come again with a new symptom. No one*

would confront him and say there is nothing wrong. One of the consultants finally did that and he stopped coming." (UK/M/D/07/9-10).

The pattern of symptoms associated with functional problems had evolved over time it appeared. *"I think the functional symptoms change over time. In the Victorian times people had a lot of fainting attacks or migraines. It seems to have changed over time."* (UK/MH/D/05/2-7). The common symptoms for gynaecologists were chronic unexplained pelvic pain and sexual disorders *"One of the areas is chronic pelvic pain, which is really something most of the time, even the description of the symptom is very vague. It does not point to any cause. Even if we investigate, it is really to reassure patients that we do diagnostic laparoscopies.*" (UK/O and G/D/06/1-2).

For some participants functional problems meant not just symptoms but the 'legitimated' functional syndromes. *"In terms of functional problems, the commonest ones are irritable bowel syndrome, also functional dyspepsia and reflux disease which can have a functional element. Actually I must tell you that, there are about 60-70 specific syndromes which can be described ranging from rectal pain to biliary and pancreatic type of sphincter related pain." (UK/M/D/03/1-6).*

One participant highlighted differences between the methods of diagnosis of different 'legitimated' syndromes. *"For irritable bowel syndrome the diagnosis is usually made on a positive basis by correlating the diagnosis with a series of symptoms and other findings. In some instances, there are some exclusion tests to be done but those are not done to exclude other problems but to conclude the presence of IBS for example, having a normal full blood count and the ESR is indicative of IBS, in the presence of certain types of symptoms. For most of the other defined symptoms in gastroenterology you need to have quite exhaustive investigations, even for functional dyspepsia or functional reflux disease, endoscopies help make the diagnosis. So it is a diagnosis of exclusion of virtually all the other problems." (UK/M/D/03/1-6.)*

IBS was 'legitimated' sufficiently enough for some participants not to consider it a functional problem anymore. *"Well I am not sure whether irritable bowel syndrome is medically unexplained. There are research led diagnostic criteria. They get better with certain medications like anti spasmodics and changes in diet. There is a problem in the smooth coordination of bowel contractions which cause this illness. It is a bit like a cardiac arrhythmia. Only thing we do not know is what causes it. Sure we do not have a particular diagnostic test. Even in well recognized medical conditions like Parkinson's disease there is no diagnostic test. The diagnosis is clinical. It is the same with IBS." (UK/M/D/09/2-2).*

As was observed in the Sri Lankan interviews, the psychiatrists spoke in a 'different language'. They had a group of patients with psychiatric labels who presented with somatic symptoms. These labels were bound by a common thread with there being no direct method of treatment, no similar and comparable outcomes and no similar prediction of prognosis. Somatisation, hypochondriasis, dissociative or conversion disorders, malingering, Munchausen syndrome, dysfunctional motor symptoms were among the psychiatric diagnoses in this category. *"My impression of people who present to services in this way is they are unable to express what they are actually going through psychologically and they manifest them in a physical way."* (UK/MH/D/07/1-2). Separate to this, they identified a set of functional problems which the other specialists had diagnosed where the duty of the psychiatrists was to look for an underlying psychiatric diagnosis. IBS, unexplained abdominal pain, non epileptic attack disorders, non cardiac chest pain, headaches, tempero-mandibular joint (TMJ) pain, atypical facial pain, globus hystericus, chronic fatigue syndrome, chronic backache, were among the presentations they mentioned as functional.

An overview of the findings under this theme indicated that amongst the participants there was general confusion in what individuals perceived as functional problems. A functional problem for one was clearly not so for the other. Psychiatrists identified a wholly different set of psychiatric diagnoses and had to, often quite unsuccessfully, try and fit patients with 'medical' functional diagnoses

into their diagnostic labels. There quotes bear testimony to the wide gap between psychiatrists and physicians, the strong influence of mind body dualism dragging medical professionals apart in their practice of medicine.

11.3 Fear of organic disease

One of the strongest themes or probably the strongest component of the discussion was around the missing of organic disease. This manifested itself explicitly without prompting and highlights the essential place this research has in doctors' minds. Two of the psychiatrists went on to quote instances where serious diagnoses had been missed. *"I remember a patient with some strange behaviour who was managed by the GP. The patient was referred to the psychiatrist because the patient was not getting better. When the psychiatrist examined the patient, even with their limited medical skills and they found that the patient had abnormal physical signs. They did an MRI and found that the patient had a brain tumour." (UK/M/D/01/1-8)*. They admitted that this was rare. *"Oh yes there are. I can remember someone with a pancreatic carcinoma who had been seen through all of the psychiatric diagnoses and had almost got a Munchausen syndrome. She was depressed but she did have a pancreatic carcinoma. But this is uncommon occurrence."* (UK/MH/D/03/3-5). Thus the psychiatrists insisted on 'exclusion' of organic diagnoses before they assessed functional problems. *"First step is to rule out the organic causes, absolutely. Then concerning functional illnesses, the research in the last few years, there have been suggestions that we were not good at diagnosing organic disorders and some with physical illnesses have been labeled as functional."* (UK/MH/D/07/1-3). The physicians and gynaecologists could not recall instances of missing organic illnesses but they worried about it in their practice. *"You always have that worry particularly if the woman is a bit older. You are worried about a malignancy. Even in a young woman, they still want an explanation as to why they have got whatever symptom, pain or bleeding." (UK/O and G/D/01/2-1).*

The participants appreciated that such a missed organic illness could have serious implications for their career. Concerns about litigation for negligence

played heavily on the minds of the participants. *"The worry is always about missing something. But you need to be pragmatic and make a clinical sort of decision based on your best assessment. Even the best will miss the diagnosis at times. You just need to base your decision on defensible information gathering, collateral history taking etc. I still think there is a niggle that may be you have missed something and it will come back and take you to the GMC."* (UK/MH/D/05/2-11).

This worry resulted in participants not entertaining the possibility of a functional problem in the differential diagnosis. The approach was to exclude organic pathology and ultimately diagnose functional disorder by default. *"The difficulty is most of the time you have to do investigations to exclude pathology. It is when you do that we find that there is nothing else. It is a diagnosis of exclusion. So they end up being investigated by and large."* (UK/O and G/D/01/1-12).

The participants did admit that this approach resulted in extensive investigation of patients often with invasive procedures such as surgeries and laparoscopies. *"We do investigate even though we have suspicion about an underlying functional problem, for e.g. if a patient is coming with pelvic pain, you rule out any risk of infection or even we do laparoscopies to rule out a pathology like endometriosis or PID and only after excluding other possibilities for pain that we will classify the person as having a functional disorder. It is the same for functional sexual disorders. Even dyspareunia we do investigate thoroughly before we say that it could be a psycho sexual problem."* (UK/O and G/D/02/1-10).

The dilemma facing the doctors, choosing between investigating too much and harming the patient and investigating too little, thereby missing a problem and again harming the patient, was highlighted. *"Missing something is my big worry. It is easy to slap on a label of chronic pain or chronic dysfunction. At the same time you worry whether you are investigating too much. There are two sides to this coin. You have to find a balance somewhere in between on what best to do."* (UK/O and G/D/03/1-8).

A few of the participants viewed functional problems in an entirely different light. They felt it should not only be included in the differential diagnosis but conveyed to the patient at an early stage of the illness. They felt this was needed to overcome a strong mind body dualism, incumbent in the patient's thinking and prevented a delay in treating a possibly treatable condition. *"Patients see a big divide between what is medical and what is psychological. They do not necessarily see it as one and the same thing. I think a lot of medics also do not see it as one and the same thing. But they certainly can be one and the same thing. I think if at the beginning. If you do not explain it to the patient well enough, and when you have exhausted all the possibilities, there is no point almost of getting liaison psychiatry involved as the patient is not going to be receptive to it. You will probably be alienating patients further."* (UK/M/D/02/2-3). One participant noted that over recent years there has been a shift of thinking, from one of predominant somatic organic explanations to functional explanations for gastrointestinal symptoms. *"I think most doctors would look for symptom patterns. Probably the commonest UGI disorder is GORD and after that it is likely to be IBS. These feature heavily in our minds. I think there has been a change a few years ago when many doctors considered specific somatic disorders like ulcer disease. We know that the rate of ulcer disease is very low and the rate of cancer is very low in younger patients"* (UK/M/D/03/1-11).

It was not merely the fear of missing lesions that made doctors not consider functional problems. Some thought they should look for an as yet unidentified cause to explain the mystery. "*I always wonder if I am missing something. There is always going to be a new discovery like 20 years ago we did not know about HIV or helicobacter pylori. It could be something else which we do not know about which could explain all the symptoms. I do think functional pathologies exist. I do not deny that patients are having symptoms I just always, it is just the medic in me, I feel there might be something in this. But I guess otherwise we would not be doing a good job if we were not investigating."* (UK/O and G/D/09/6-6).

Another participant stated that it was not his duty to diagnose functional problems as he did not have any expertise or training in diagnosing this entity. *"The way I handle these referrals is geared towards making certain that nothing organic is missed. That is why I go for endoscopic evaluations and scans so easily in these patients. My training is in gastroenterology and I do not attempt to look for possible organic causes in the related systems in the abdomen. For instance I do not look for any pathology in the urinary tract or genital tract. That is why I am reluctant to positively make a functional diagnosis. I do not try to nor have the expertise to rule out problems in areas falling outside of my specialty" (UK/M/D/04/3-1).*

An overview of the theme brings forth the insecurity doctors felt with when dealing with functional problems. They were reluctant to trust their clinical judgement. They were not willing to move out of the comfort zone provided by organic diseases.

11.4 Importance of 'legitimated' diagnoses

Another emergent theme was what label should be given for a functional problem which was least uncomfortable for doctors and patients. The participants stated that a 'diagnosis' for the discomfort felt by a patient was essential. *"There is nothing worse than not having a diagnosis I guess."* (UK/MH/D/01/2-7). The diagnostic label would contribute to patients coping better with their symptoms, a participant noted. *"You need to give someone something to hold onto. Otherwise why would they seek help? If they are feeling whatever they feel at the moment, they need to know. You need to tell people what possible things could be wrong with them. I think it is important."* (UK/MH/D/07/2-8).

According to most participants, patients were comfortable receiving a legitimated syndromal diagnosis. "*If you give a name to the diagnosis like irritable bowel syndrome, I think it is something they can talk about to other people, it is fancy, but if we just said pain, then they will not like that. I think it is giving a name is good for patients' psychological benefit."* (UK/M/D/01/3-4). The gynaecologists lamented the absence of a 'legitimated' syndromal diagnosis for them. *"A lot of*

them are quite disappointed because a label is much more helpful. Functional does not sound like anything. We find functional from gynaecology point of view a lot harder as we do not have irritable bowel syndrome or whatever, we cannot give them something to hang on and then they can go and get support from that point of view. A lot of them think you are wrong and that there must be another diagnosis." (UK/O and G/D/03/2-12).

But within the syndromes some were more acceptable than others. *"If people say they have ME, they are just lazy. I think there is a fear about stigma. It depends on which condition you are having. IBS, if you consider to be a functional illness, tends not to be so bad as so many people have it. Someone gets constipated one day and it is 'Oh I have got IBS'. It is OK to have IBS but it is not ok to have chronic pelvic pain. It depends on which set of symptoms one has."* (UK/O and G/D/08/4-7).

Though the legitimated syndromes were acceptable, a label of functional disorder or medically unexplained symptom was less acceptable. *"I would feel cheated in a way as I have got a problem but someone is telling me that it does not exist in your body but that it is all in your mind. I would feel cheated and also embarrassed and also fairly despondent, not knowing how it is going to get better."* (UK/MH/D/05/5-6).

Psychiatric labels such as hypochondriasis and somatization were acceptable even less. *"Personally if I were a patient and had a diagnosis of hypochondriasis or somatization I will see that as a label against me. We would need to have something which is like pyrexia of unknown origin, where you have got the temperature and the cause is unknown. We know it is not feigned so we give a label on the medical side. We give a label of medically unexplained symptoms, that is reasonably acceptable."* (UK/MH/D/02/2-5). Another participant elaborated on the negative connotations in a diagnosis of somatisation. "*Somatisation, I think it implies some sort of a negative attitude, it implies almost a deliberate set up, malingering or cheating. I do not think these people are like that. I have no problem with somatisation as a term but I think the way it is being used, like*

personality disorder, I think it becomes something belittling the patient and not valuing the person enough." (UK/MH/D/06/4-8).

The value of a label for exchange of information within the medical community was discussed at length by the participants. The advantage of such a communication was the prevention of over investigation. *"I think it is very very difficult to ever give a label but then again, when these thoughts are not written down, they are not communicated to other people. Therefore at times having a label helps those others who come into contact with the patients preventing going through unnecessary further investigations. It is just that the balance between the two is difficult."* (UK/MH/D/08/1-10).

In addition to preventing over investigation, other benefits were also noted. Some participants suggested having a label for pelvic pain would generate a lot of discussion in the society and promote research and interest groups and would contribute positively. They believed that IBS was a similar label, which had done much for the patients who had those symptoms. *"Also they feel it is common and understandable when there is a label. There is no support group for chronic pelvic pain or whatever. A label, regardless of what it stands for is actually quite helpful to a lot of people."* (UK/O and G/D/03/3-5).

A number of participants dwelt on the disadvantages as well. The label would be used to cursorily dismiss patients thereafter. *"Because once you have made that decision and you do not follow them up, it is easy for the person who comes after you, to hang onto that label."* (UK/O and G/D/03/1-14). The true nature of the disease would get obscured by such a label *"When you say IBS, patients are stuck to this. I think that also adds to their problems. Because we cannot find anything, we give some label. But they think that is what is causing the problem. They have something. Actually it means nothing. Patient thinks there is a diagnosis, there is some problem."* (UK/O and G/D/06/7-3).

Some of the participants disagreed with the value attached to giving a diagnostic label stating that it meant nothing to the doctors. The purposes of having a label,

would be to provide further information on management, prognosis etc and such details were not available for functional problems. *"You probably need to take time first to listen to the patient as to find out what is the meaning of the symptoms to the patient. The diagnosis is not going to make any difference because there is no direct treatment."* (UK/MH/D/03/1).

An overview of this emergent theme suggested that doctors wanted labels such as IBS which would provide them with a 'tick box' diagnosis and a treatment schedule. This would permit them to essentially deny the very existence of the functional problems and give these illnesses an aura of organic authenticity. This would help the doctors' rank functional problems alongside organic illnesses and bring them within the comfort zones.

11.5 Healthcare system related beliefs

The emergent theme considered how doctors dealt with patients with functional problems and their perceptions on how best they should be cared for by the health system. Only one participant felt that specialist doctors were the best people to manage functional disorders in their settings. *"I wonder whether the patients will accept that more as it is coming from the cardiologists rather than the psychiatrists and they will not be labelled. They might also think 'what do the psychiatrists know about the heart?' But I never have seen it being done because often if they are not having an MI, send them off - non cardiac chest pain, do not really care where it is coming from. I think even if that were the starting block for psychologists and psychiatrists, it might make it easier transaction for the patients to go to a medical specialty."* (UK/O and G/D/09/3-2). Even for the few doctors willing to manage functional problems in the hospital setting, inadequate time per patient in the clinics was an impediment. *"It is very difficult. I do a one man clinic. I need to see about 20 patients a day at times. Some of them are new patients and some are follow ups. I need to arrange all the investigations too. Time is very limited. If I take more time, the waiting lists get longer and then complaints will start."* (UK/O and G/D/11/4-14).

For the majority of participants the duty of a specialist lay in reassurance of the general practitioner rather than the patient. *"I try to give the assurance to the GP that this is not a problem with bowel. Then it is up to him to consider further referrals if thought necessary or make a functional disorder diagnosis."* (UK/M/D/05/3-2).

At times doctors performed investigations expecting them to be normal, to avoid patient complaints. *"This is the medical culture now. Even if I know that there is nothing wrong, I stick to my protocols and I stick to my things. If something goes wrong, I have this explanation, I tried to do this and that. It is all getting more and more defensive. I do not condemn the doctors. Patients have brought this in by complaining about everything. You need to make sure. At times patients will not give you a clue, they will be thankful when they go, but a month later you are informed of a complaint. Everyone is very defensive."* (UK/O and G/D/06/7-5). In other instances the fear of complaints made doctors arrange 'placebo' surgery. *"Some of them, we will succumb to their demands. For example if somebody wants a hysterectomy and demands it to such an extent, we will oblige them knowing that it is not going to solve the problem."* (UK/O and G/D/08/1-10). The ultimate aim of management was to get the patient back to the GP with no complaints to the NHS. *"Some of them, we will have to do a laparoscopy, take some pictures and show them and tell them, look this is what it is. Basically we have a way to put the patient off back to the GP."* (UK/O and G/D/08/1-10).

Thereafter the GP was expected to make the diagnosis of functional disorder after considering input from the specialist. *"We do not give this label. We only say that there is nothing wrong in the gastrointestinal system. It is up to the referring GP to then think of what else can possibly be wrong and refer appropriately."* (UK/M/D/09/1-6). Thereafter the GP was expected to manage functional problems themselves or refer to someone who could. *"Someone with irritable bowel syndrome is obviously difficult to manage. That is why I do not try to manage them but I hand over the GP. My expertise and training is in organic gastro intestinal problems. These are also difficult to manage at times. But I have*

had the training to do so. I do not have the expertise to treat functional disorders. I should be spending my time and effort on those with organic lesions as this is the group I can help." (UK/M/D/04/5-3).

How suited would a patient's GP be to manage this type of problem? *"There used to be a time we had GPs who stayed forever. Now GPs change frequently. Now I am staying in the job longer. I tend to feel that I cannot send back the patient to a GP who is new and I do not know what their views on somatisation are as yet."* (UK/MH/D/01/6-7). The uncertain GP was a contributor to the doctor shopping process *"If you do a laparoscopy and find nothing, and this happens in about 40% of cases of chronic pelvic pain, and if you tell her there is nothing wrong and refer back to the GP, then the GP will refer back to another gynaecologist and she will end up with 5 laparoscopies for no reason. Nobody will find a cause of the pain."* (UK/O and G/D/10/3-1).

The psychiatrists felt that these patients came to them as the last resort and that made the task of psychiatrists more difficult. Stigma towards mental health and lack of insight regarding functional symptoms were mentioned as the main reasons for the delay. *"This is a difficult thing because so many of the patients are not satisfied when they have negative physical procedures and outcomes and then they get passed to the psychiatrist almost as an end thought. And we pick them up, they feel they've been called mad or perhaps malingering and in fact it's quite a difficult piece of work to engage the patient."* (UK/MH/D/01/1-3). Poor communication between psychiatrists and other specialists / GPs contributed to the difficulties the psychiatrists faced treating those with functional problems. *"Traditionally psychiatry notes and medical notes are kept separately. We have to spend a lot of time trying to chase up results. We might not be able to figure out what the thinking behind them why these were done, what has been excluded and what has not been."* (UK/MH/D/08/1-6).

One participant stated that multidisciplinary teams would have helped in management but admitted that such teams did not exist in her setting. These clinics should not be for functional problems as a whole but needed to tackle a

common, single complaint like chronic pelvic pain. *"In many places they have got a special clinic called chronic pelvic pain clinic. A chronic pelvic pain clinic is one where you have the multidisciplinary input. There is a gynaecologist, there is an anaesthetist or the pain management team, there is a clinical psychologist though they may not be sitting there, their help is available, there is a counsellor. There is a way of quick referral to and forth between the specialties, like gynaecology, general surgery, urology, rheumatology or the physicians."* (UK/O and G/D/10/2-7).

Some psychiatrists thought liaison services were the way forward. *"I think that it is a multi agency responsibility. Physicians, psychiatrists, psychologists, all have a role. We should all liaise."* (UK/MH/D/02/5-11). However attractive the idea of liaison services were, the participants were aware of the difficulties in setting up such services on the ground. *"It is a good idea but I do not think this is possible in practical terms. We will need a psychologist in the cardiology clinic, GI clinic, rheumatology clinic etc. This is not practical."* (UK/MH/D/09/2-5).

Another participant felt that community psychologists and counsellors rather than the GPs would be better. *"At the moment it is the counsellors that we are talking about. The problem is many patients do not want to go to them. Even if you mention sometimes whether they need some help whether they need to talk to someone, most people are resistant to the idea."* (UK/O and G/D/04/2-8).

An overview of this emergent theme vividly laid out the trials and tribulations of patients with functional problems, getting passed back and forth between GPs and specialists with no one having the commitment to make a diagnosis and there being even less of an inclination to treat them,

11.6 Attitudes / assumptions about outcomes in functional diseases

This emergent theme considered the perceptions of doctors on what they managed to achieve in terms of patient care in their encounters with patients with functional problems. Some participants had faced disastrous outcomes. "*Very difficult, when you try to tell them they do not accept it. At times they walk out of*

the room screaming at you." (UK/O and G/D/11/2-7). But for the vast majority, as many patients were referred back to the GPs, the outcome was not known. *"We have no feedback from the GP so we do not know whether they continue to be alright."* (UK/O and G/D/11/3-11).

Cure was an elusive goal. "*I do not think I have had a success or what I would call a successful outcome from dealing with them."* (UK/MH/D/05/1-2). Improvement of quality of life for both patients and carers was an attainable goal according to some participants. *"We might never be able to make them stop complaining, but if we can reduce the level of anxiety then quality of life for them and their carers will improve."* (UK/MH/D/04/4-3).

Participants reported several methods with which symptoms improvement and quality of life improvement had been achieved. Empathic communication and explanation was noted to help. "*A lot of the time, they think that when you say there is nothing physical there that we do not believe they are having symptoms. If we acknowledge the fact that you understand the fact that they are having symptoms but there is no biological basis for it, they tend to accept it better."* (UK/O and G/D/09/2-2). Psychiatrists reported success with psychological approaches. *"A good number of patients do well from their treatment from pain clinic and treatment from clinical psychologists and cognitive behavioural therapy. About 30-40% of patients who have been referred, come back and tell that they are doing well. The pain has not gone away, the pain is there, but they feel more empowered to deal with the pain."* (UK/O and G/D/10/2-3). The ones who responded best to psychological forms of treatment were those who had significant anxiety associated with the functional problems. *"The lady who had multiple cardiac and GI investigations for chest pain I think a lot of that was anxiety based. She settled quite well with cognitive behavioural therapy. She did not need that much pharmacological intervention. She did quite well with CBT techniques and anxiety management. When she first came in she was climbing the walls."* (UK/O and G/D/09/2-4).

Placebo treatment was viewed negatively by most of them. *"It's an expression of frustration."* (UK/MH/D/01/5-7). Alternative therapies were viewed positively. *"We did refer them to aromatherapy and acupuncture too. It worked well too. It was free in the NHS Scotland."* (UK/O and G/D/09/7-3). Self help groups were also mentioned. *"Self help groups I have heard of and they are quite useful. I know of people going to Tai Chi and aromatherapy and getting relief through them."* (UK/MH/D/09/3-3)

An overview of the discussion on this theme highlighted the confusion in the minds of the doctors on what outcome to aim at in managing functional problems. A sense of doom seemed to pervade the landscape.

11.7 Sensitivity / insensitivity of doctors to psycho social factors

This was a strong emergent theme which looked at the perceptions of doctors about causation of functional problems. Their ability to move beyond biological explanations and consider psycho social factors of patients emerged. Some participants felt that functional problems were more common in a group of people with certain socio demographic characteristics. *"It is more in females, more in the middle aged group. They are more likely to be from the lower or middle class." (UK/M/D/07/1-10). The 'forty, female' mix was noted by other participants as well. "Usually this group is mainly middle aged and I must say there is more towards the female sex. If I am asked to see a patient around 40 years and if I happen to see a thick set of notes, gives me a clue there is a problem."* (UK/M/D/06/1-2). Urban populations were thought to have more functional problems more. *"I think it is more common in the city than in the rural population."* (UK/O and G/D/08/3-9). Social classes were also listed as possible related aspects. *"Life stressors are more in the lower social classes. Functional problems are also higher in these social groups. I do not know whether there is a causative effect or whether these are mere confounders."* (UK/M/D/08/1-10).

Some participants stated functional problems were the result of personality traits and personality disorders. *"It is incredibly difficult to try and understand some of these people. Personality traits overlie a lot of these problems. It can be incredibly*

hard to elicit." (UK/O and G/D/05/1-6). Linked to the personality were personality traits with associated learned behaviours and personal attitudes which were noted to be causative. *"It must be down somewhat to your personality type, your upbringing, how much of attention you pay to everyday aches and pains. If that leads you to get hung up about what you are feeling then you focus on that it then becomes inevitable eventually it becomes a huge problem when it initially was not and you are going to seek medical help. A lot of these people I have come into contact with have been those who do not want to take any responsibility for their symptoms or for themselves. They are looking to other people to sort it out and solve it and not have insight into the fact that they might have to do something about." (UK/M/D/02/3-3).*

Many others thought psychiatric conditions like depression and anxiety and other psychological problems presented as functional problems to the somatic specialties. *"I think most of the patients I know to be alexithymic. They really do not have the words for subtle mood or feelings state changes so about 50% of them will have frank anxiety or depression."* (UK/MH/D/04/7-4).

Psychological problems such as ongoing conflicts, negative experiences at home like domestic violence, relationship problems and sexual abuse were also identified as causative factors. *"It is an expression of another problem they will be having in their lives. Family problems, financial issues, stress, depression and that gets expressed this way. They need attention. Some of these are like attention seeking behaviour. I think it varies from patient to patient but I feel it is a reflection of psychiatric issues and personal circumstances."* (UK/M/D/01/1-6). Another participant had observed many patients with chronic pelvic pain had past the psychological conflicts due to pregnancy terminations and miscarriages. *"Chronic pelvic pain, we see quite a lot of it following miscarriages or terminations."* (UK/O and G/D/05/1-4).

Deterioration of family links and lack of family support was identified as a contributory factor. *"In certain cultures there is a lot of support from the immediate and extended family. In some others when you are 16, you are pushed out and*

you have to fend for yourself. Associated is alcohol and drug problems, financial problems." (UK/O and G/D/11/5-13).

A considerable number mentioned that some of these patients who come with functional symptoms are there purely for a secondary gain. *"You also see people who get a secondary gain for e.g. following a very minor car accident and then feign a chronic pelvic pain forever, just because they have an insurance claim*." (UK/O and G/D/05/1-4). A number of participants, especially amongst those who had experience working in the Accident and Emergency services, (A and E), mentioned malingering as a rare but an important cause. The objective of malingering was to obtain addictive medicines such as narcotics. "*There are some who come to the acute medicine department to get morphine. They feign pain. All the emergency departments all over the country will have four or five such patients each "* (UK/M/D/01/2-9).

Some participants identified confusing information from the internet and the media and resultant health as having a causative influence. *"You can Google almost anything. But you do not know how credible the sources are. Once you have Googled something you are going to feel the worst if you are not a pretty strong and a well grounded person with a lot of support. I definitely think that does not help."* (UK/M/D/02/5-2).

The way the NHS operates and the way patients view the NHS were also viewed as a factors that continued to facilitate and maintain functional problems. *"If they do not get what they want from the health service they feel let down. The NHS let me down when there is something wrong with me. The NHS does not say, there is nothing wrong and get on with life. The NHS culture also contributes to perpetuation."* (UK/O and G/D/09/7-7)

An overview of this discussion suggested that a deterioration in the quality of supportive relationships both from within the family and from the community left people helpless in the face of stresses. The benevolence of NHS and the social services systems which resulted in responsibility of health and wellbeing was

transferred from the individual to becoming a responsibility of the government, was noted to contribute.

11.8 Cultural sensitivity

The emergent theme on cultural sensitivity was one of the strongest areas which formed the base of this study; a cross cultural comparison of doctors' perceptions in Sri Lanka and the UK. Ethnicity was believed to play an important role in functional problems and the participants drew comparisons between ethnic groups. The presenting symptoms were different. *"Have to say the majority of women are I find with functional problems are Caucasians. Although it's a generalisation and the Asian women let me see them it's often difficult because of the language barrier, not picking up the nuances of what they are saying and how they say it but in general I think they have a lower pain threshold and complain more about pain but accept an explanation much more easily than Caucasian women. But that's a vast generalisation."* (UK/O and G/D/01/2-7). A view to the contrary with regard to presentation with pain was expressed by another participant. *"Different ethnicities fixate different things. Pain does not tend to be something that a lot of the Asian ladies fixate on. They fixate on more on discharge and that kind of symptom. Middle class, middle England type of ladies fixate on the functional abdominal pain side of things."* (UK/O and G/D/03/3-3).

Acceptance of an explanation was also different in different ethnic groups. *"I find that with the Western patient you can have this dialogue and try to sort of open a dialogue about relationship between stress and symptoms and how you can treat specific symptoms. I find that with my Asian patients, particularly Indian patients, that explanation is that much more difficult and they are always looking for some kind of somatic definition of why they have the problem, almost as if they are more reluctant to make the brain body link, or at least that is my perception of it. Remembering a patient recently, she really was not willing to believe that the all her investigations were normal and at the end of the day, no matter how many times I tried she kept going back to the basic question which was, but doctor, why am I getting this pain and what can you give me to take to be over with it. So my*

perception of different cultural situations here is that some people see it as a holistic problem and they are prepared to deal with it on that basis for themselves and some really only see it as a somatic problem and it is the doctors' responsibility to sort it out." (UK/M/D/03/2-7).

The cultural transformation the UK had undergone over the years had given rise to different healthcare seeking patterns for functional problems. *"There seems to be a cultural divide, social divide and an age divide. The older white population tends to be stoical. They will come only when the world is at the end, when they are about to die. The younger whites tend come very quickly. We do not see too many Afro Caribbeans around. The Asian population poses difficulties as well. A lot of them do not speak English and it is difficult to get to the bottom of the problem. The Anglicized Asians fit in with the similar aged local population. The migrants are difficult as we have to get under the skin."* (UK/O and G/D/05/1-8).

Strong religious values, conservative family values too were seen at times contributing to causation. *"Attitudes of strong conservative families, those with strong religious background. To say anything to do with sex is sinful. The children are brought up with an attitude that they should never think of sex, never talk of private parts, never talk of girlfriends or boyfriends. People feel highly inhibited and when they struggle against natural urges and natural development, they do become disturbed."* (UK/MH/D/06/7-1).

Contrary to this view, a protective influence for religion was described by a participant. *"I think religions are a big protective factor which I find is missing in a lot of people nowadays. It is not overly religious and overly believing. It should be realistic religious belief. This is important for children. If you are talking about prevention, you are talking about early age. If the children are inculcated with some beliefs then they have something to hang on to. I find religion a very protective factor from the background I come. I am not saying a religious person does not have somatisation. Even when they have functional symptoms, they cope better. They fall back on religion to explain and reduce the anxiety. They blame external factors rather than internalising it. They still function in their social*

setting. If you do not have a belief system in place and if you have no back up and nothing to cope with and if your relationships are also falling apart those factors also go on. You are left with nothing." (UK/MH/D/04/7-6).

One participant took a 'global' view of functional problems and stated that functional problems were not bound by cultural boundaries. *"I think these symptoms are seen in equal frequency in people of all communities. I think they transcend ethnic and cultural boundaries and affect all and sundry."* UK/M/D/09/1-12). Another stated that it was not an aspect worth spending time to understand. *"What socio cultural influences there are, I do not know. I do not keep the patients long enough with me to get to know about their backgrounds. I do the necessary things to exclude physical organic problems and then they are referred back."* (UK/M/D/04/2-7). Culture was thought by some participants to play no role. *"I don't think culture has anything to do with that. For instance, even in a family where they are exposed to the same culture, common environment, all of them don't get functional type of symptoms. I think it as a more personal thing."* (UK/MH/D/02/1-7). Interestingly, one who had not considered cultural aspects previously was willing to see things in a different light, after the research interview. *"I have not given much thought to whether ethnicity has a relationship with functional disorders. Maybe I will, from now on."* (UK/M/D/08/3-2).

An overview of the discussion showed that doctors had little appreciation of cultural influences on health of people in the UK. Patients formed simple generic groups – Asians or British, Religious or non religious. All Asians were generic and all religions were similar. Either the people of the UK had lost their cultural roots altogether or the doctors had lost their ability to recognise these influences and had started over generalising their patients.

11.9 Impact of experience and education on doctors perceptions

This emergent theme brought forth the changes in the perceptions of doctors' as a result of their having accumulated experience and also as a result of the education they had had on functional problems. A participant observed that the discrepancy between what is taught in medical schools about functional problems

and what students observe in clinical practice made them further confused. *"I think training the medical students is also really really important and to make sure that they are not conveying their attitudes. Even if they are having a couple of lectures but if the rest of their training is given by people who are very negative about this it is going to wipe out whatever they've learnt in medical school. I know from my own psychiatry training, psychiatry teaching itself was very very good but everybody else's attitude about it is very very negative and it is difficult not to take something of that attitude on board."* (UK/MH/D/08/4-2).

Training in psychiatry helped in changing the attitude of doctors towards patients with functional problems. *"The immediate reaction of people is they get frustrated with these people. It is just like in psychiatry, the diagnosis which is a punishment effectively by the doctor is one of emotional and a personality disorder. If you have got that diagnosis, you are like a dog, kicked everywhere, nobody wants to know you. A little bit of education as a pre-empt when you are at medical school would probably would help. Try and understand why they are here. I had nothing of it at all till I did psychiatry. Now I think a little bit differently. Still I am not much different."* (UK/O and G/D/05/4-4). In addition to a positive change in attitude, training in psychiatry even for a few months, was felt to empower doctors to obtain more successful outcomes. *"They hear you saying that it is all in your head and your mind. I did a four month job in psychiatry. It is a bit easier after doing that job to explain to people that there is no biological background to the symptoms does not mean that we do not believe them."* (UK/O and G/D/09/2-2).

Recognition of functional problems improved with experience. *"When I was a student everything was black and white. Since I became a doctor and stepped into the real world, I began to realize there were many shades of grey in between."* (UK/M/D/09/2-6). The changes in approach evolved over years. "*In many ways IBS is a problem for the experienced clinicians. The younger clinicians and the medical students are still chasing after what they regard as real medical problems, ulcers, cancers, things that they can cut out and see or give tablets. I think it is quite difficult to take on board the concept that the majority of patients*

one sees, after a while I am not going to have a specific lesion that can be dealt with. But we plan to try and expose our students to this kind of problems." (UK/M/D/03/4-5).

Experience obtained through dealing with patients with functional problems over years conferred more confidence and skill in treating patients. "*And for me I am less depressed about these problems than I used to be because I know what the patients require are symptom relief rather than theoretical concepts and understanding what their problem is. If you begin to tackle both together you have the basis of dealing with the problem. People may have heard of IBS now and they may begin to be willing to accept the diagnosis rather than assume that you have made a mistake because you have not been able to find anything." (UK/M/D/03/2-3).*

An overview of this emergent theme suggested that though with experience doctors recognised more and more patients with functional problems, their attitude towards the patients did not necessarily improve. Often the more experienced consultants had less compassion and understanding of the difficulties of the patients and made poor role models for junior doctors to emulate. The recent changes in the training of junior doctors where many of them get exposure in psychiatry units during the foundation years seemed to empower them to deal with functional problems better than their senior colleagues and teachers.

12 Discussion and Conclusions

12.1 What I set out to do

From the time I was a medical student, during the clerkships under specialists from diverse areas of medicine, the fact that many patients had complaints which remained undiagnosed after thorough clinical examination and investigation had struck me as being inexplicable. The consultants knew everything. They were giants in the medical community. The registrars had encyclopaedic knowledge about the rarest of illnesses. Endowed with such extraordinary skills and knowledge, how they struggled to diagnose let alone cure, simple complaints like headache was unfathomable. During my house officer period, these thoughts were reinforced. By this time I had taken the first steps towards joining the above mentioned elites in medicine but I remained as helpless more often than not, in coming to a diagnosis. My consultant was never happy to see a discharge summary which stated 'Investigated for chest pain ...etc' rather than give a precise diagnosis in the given column. Often I just did not know what caused the pain. The consultant did not know either, however this was not admitted. Our standard conclusion was that there was 'nothing wrong', a conclusion which would have looked even less impressive than the 'investigated for' title in the discharge summary. Things began to become a little less murky when I entered the specialist training stream in psychiatry. There was mention of somatoform disorders, somatic symptoms of psychological / psychiatric diseases and colleagues were often acknowledging the existence of this rather common entity. There was universal acceptance in the psychiatry community that this was an entity that no one understood well. When the physicians could not find anything wrong with the body, they presumed something was wrong with the mind and many of these patients were sent across to us. Very often the psychiatrists could not identify something wrong with the mind either. That brought us to a dead end, an iron curtain of sorts.

How frequently did such problems arise? Were they as commonly seen in all communities? What caused these symptoms? Did all the unexplained symptoms

have a common aetiology? How could we diagnose these with certainty? How could we manage them? What was the prognosis? Were there socio cultural factors which influenced the causation? So much was unknown and remained hidden. I wanted to learn answers.

I chose to seek answers to some of these aspects in this PhD research. The answers sought were so complex and wide ranging that for the purpose of the PhD that I thought I would limit my efforts to answering two of these questions. Firstly I wanted to find out the frequency or the prevalence of functional disorders. Searching the medical literature revealed that most of the studies on this enigma had come from Europe but precious few studies were available from countries across the Atlantic or the Australian continent, Oriental countries, the African continent or even from Asia. Little or no evidence on the prevalence of these problems in Sri Lanka was available. I decided to evaluate the frequency of functional problems in Sri Lanka as the starting point. I felt that these findings could be generalized to the subcontinent region to some extent at least. This would also permit me to compare the prevalence with available statistics from the UK (where most of the functional problems research had been published) in order to determine similarities and differences. I chose hospital settings for the study. I chose two specialist clinics covering the 'physical' specialties (gynaecology and general medicine / gastroenterology) and 'psychological' specialty, psychiatry. I chose outpatient clinics and calculated the prevalence among the attendees at these clinics.

Secondly I wanted to listen to the doctors working in these three chosen specialties to learn from them. I wanted to appreciate their perceptions of what their functional problems were. How they arrived at the diagnosis; how they managed these problems; how best they thought these problems should be managed; who should be managing them; what prognosis was held for the problems and whether indeed there were socio cultural correlates in the causation and propagation of these illnesses? Also whether there were barriers to successful management stemming from socio cultural beliefs of patients and

doctors? I set out to interview doctors from gynaecology, general medicine / gastroenterology and psychiatry in both the UK and Sri Lanka. I thought this would enable me to perform a comparison between the specialties and also look into intra specialty differences in two diverse socio cultural settings to evaluate the similarities and differences. I wanted to learn and disseminate this knowledge to the profession in order to enable a wider discussion of the issues at hand, and to arrive at methods of better managing functional problems. Thus I started this research for the PhD with the hope that these efforts would in some way be transformed into clinical practices that would provide a better outcome for patients with functional problems.

12.2 The prevalence study – results, comparisons and commentary

The prevalence of functional disorders was assessed in three specialist clinics using details of 817 patients attending the clinics over three months. The general medical clinic recorded the highest number of attendees (305) and gynaecology, the lowest at 251 attendees. Functional disorders accounted for around one fifth of all patients attending the gynaecology and general medical clinics at 22.3% and 18.7% respectively. In both these clinics functional disorders emerged as the most common condition compared with organic diagnoses. This was a remarkable finding. Psychiatry clinics recorded a prevalence of functional problems of 8.4% which ranked as the fourth most common diagnostic category. Though comparatively less than in gynaecology and general medical / gastroenterology clinics, functional disorders still accounted for a high number of patients seeking treatment from the specialist psychiatry clinic. As pointed out in the results chapter, one explanation for this could be the stigma attached to attending a psychiatry clinic. People with functional problems are hesitant to come and sit in a general psychiatry clinic alongside patients with psychotic disorders. In the absence of specialist liaison psychiatry clinics all patients referred were seen in the same clinic. This could have resulted in a lower prevalence rate in the psychiatry clinic. Though there is widespread belief within the medical community that functional problems are psychiatric / psychological disorders, the prevalence was lowest in the psychiatry clinic. Functional problems were two to three times

higher in frequency in the two 'organic' specialties studied, gynaecology and general medicine / gastroenterology. These figures for frequency and prevalence are very similar to the figures that emerged from the research emanating from Europe which were quoted in the literature review section.

During the analysis of the demographic details of patients with functional disorders it was noted that there was a female preponderance both in the general medical and psychiatry clinics. Approximately twice the number of females was present in the functional disorders group whilst the numbers were evenly spread in the organic disorders group. A relatively younger group of patients had functional disorders in all three clinics. The 31-40 year group comprised the highest numbers in gynaecology and psychiatry clinics and the 41-50 year group the highest numbers in the general medical clinic. Overall it was noted that those with organic disorders were ten years or so older in all the clinics. Having younger patients with the functional disorders has wide ranging social impacts. The most productive age groups having disabling illnesses have economic and social consequences not only for the individual and the family but to the society as a whole. A disproportionately high number of those with functional disorders were single in the general medical clinic setting but the reverse was true for gynaecology and psychiatry clinics. Whether being married is a risk factor for developing a functional disorder in these settings raises intriguing questions. The numbers of those who were divorced or widowed was too small for a meaningful comparison. Having children or not did not show any consistent association pattern for functional disorders in the cohorts studied. Higher educational attainments were noted in those with functional disorders compared to those with organic problems with higher proportions having progressed to secondary and tertiary education. This pattern was consistently seen in all three clinics studied. How higher educational attainments were associated with higher prevalence of functional disorders was not clear and had not been a factor reported in previous studies. It is important to note that these characteristics were noted in a hospital specialist outpatient clinic. These rates do not necessarily reflect the demography in the community. Hospital clinic rates are a reflection of referral patterns. Thus

the true picture in the community could be vastly different. Thus for instance, higher educated patients with functional problems could stand a higher chance of getting referred for specialist care by the doctor attending at primary contact level. But it needs to be borne in mind that there is no organised general practice in Sri Lanka and primary care is often provided in the hospital outpatient department. Thus though it is not necessarily so, it may not be surprising if future community based research were to show that hospital rates were a fairly close reflection of the community rates.

Adopting the three category classification of pain disorders, functional disturbances and complaints related to fatigue and exhaustion, it was noted that pain disorders were the predominant problem in both the general medical clinic and the gynaecology clinics. Pain combined with functional disturbances was the commonest problem in the psychiatry clinic. A notable finding was the low prevalence of complaints revolving around fatigue and exhaustion. Clinical problems suggestive of chronic fatigue syndrome were a relatively rare entity among the more than 800 subjects studied. This was a notable difference compared with Western countries where complaints related to fatigue and exhaustion were common. Whether indeed there was a cultural explanation for this difference was not clear. It was possible that pain and functional disturbances were more culturally acceptable health problems compared to fatigue and exhaustion which carried undertones of ‘laziness’ in a society where hard work was the expectation by default.

Delays in recognition, diagnosis and treatment of functional problems were noted. In many instances, complaints had been present for years, at times more than ten years before the diagnosis had been made. This was seen consistently in all three clinics and the longest periods prior to diagnosis were seen in the psychiatry clinics. This is probably explained by the fact that patients are often referred to psychiatry services as a last resort, when all other avenues have been exhausted. If functional disorders were to be considered as possible differential diagnoses earlier in the course of the illness, these long delays could be shortened. As a

consequence of this delay in diagnosis many patients had been subjected to a large number of extensive and often invasive investigations. Much iatrogenic harm would have been caused, particularly by the invasive investigations like laparoscopies and explorative laparotomies. Those who had the most invasive procedures not surprisingly came from the gynaecology clinic. Functional disorders in the hands of surgically skilled doctors resulted in many invasive procedures, the most dangerous and harmful of placebo therapies.

The results from the prevalence studies revealed that functional problems were extremely common and the prevalence was similar to that which had been described in the European studies Such as long delays prior to diagnosis and the patients undergoing numerous and at times harmful, invasive investigations and therapeutic procedures which also affected a relatively younger population with resultant adverse economic and social outcomes for the individual, the country and the society as a whole.

12.3 The qualitative study on perceptions of doctors – Results, comparisons and commentary

12.3.1 General Medicine/ Gastroenterology

In this doctor perception study, some similarities and notable differences of thinking emerged between the groups studied. In the UK though there was initial enthusiasm at the request to participate in a research, there was a palpable drop in enthusiasm when the topic of discussion was revealed. There were a few physicians who rejected the invitation to participate stating that they had no interest in the subject and did not think it was relevant to them. Interestingly such perceptions were not noted among the UK gynaecologists and psychiatrists. Sri Lankan physicians also did not have such an aversion to discussion of the problem. There was much confusion about what each physician recognised as functional problems and this was seen in both the settings. For some it was an unexplained symptom, for some it was limited to the recognised syndromes. Both groups were reluctant to accept irritable bowel syndrome as a functional problem.

They felt that since there were diagnostic criteria they could make a diagnosis. As there were treatment guidelines, they could follow them. Though why patients got IBS was not clear and whether patients improved with the treatment was not known however, they were comfortable in dealing with IBS. If someone could provide labels, lay out some criteria to diagnose the labels and provide guidelines to prescribe, functional disorders would become less uncomfortable, they seemed to indicate. The Sri Lankan cohort mentioned a disease 'abdominal migraine' which was not mentioned by the UK cohort as one of the functional problems, Some of the UK physicians interviewed mentioned that they had not quite given thought to the problem and it was in fact the information leaflet from the research that showed the true significance of the problem. This highlighted the need to raise awareness within the medical community about the frequency of the problem and the research needed to support this contention. The UK physicians acknowledged that these patients underwent suffering but felt that there was little they could do. This was a problem that some other person needed to solve. The Sri Lankan counterparts empathized with the suffering and did want to try various ways to address the problem. Both groups worried about missing an organic illness when making a functional disorder diagnosis. In the UK it was more about wanting to avoid patient complaints and law suits. In Sri Lanka, the participants thought such a miss may reflect badly on their reputation and pinch where it hurt most – their private practice. Due to the reasons above, very few of the participants from both settings considered the diagnosis of functional problem in the initial differential diagnosis. Discussion of the cultural and social implications on functional problems seemed to puzzle the UK physicians. It was clear that only a few of the participants had given this aspect any thought previously. The Sri Lankan physicians interviewed spoke more about it. They seemed to believe that culture and belief systems had implications on both origin and treatment. They went on to point out both positive and negative influences. On enquiry about perceived causes, the UK physicians were more biologically bent, explaining that it was likely that there were as yet undiagnosed biological factors at play. They lumped social, cultural, psychological, economic reasons together and mentioned

in passing that these may have a role. But there had not been much attempt to look at these factors in-depth. The Sri Lankan physicians went in to detail, discussing role of primary and secondary gains, problems of having a freely accessible health care system, traditional beliefs and the effect of irresponsible media reporting provoking mass health anxiety. One UK physician spoke of the 'physician culture' as opposed to culture in general, referring to arranging all possible sophisticated investigations for functional problems rather than merely doing the essential and stopping at that. He stated that he did not want appear 'odd' by adopting such a stance as opposed to the younger, more sophisticated physician colleagues who were intensively investigation oriented.

The diagnosis and management were seen as problems by both groups of physicians. The UK physicians view was rather simple. Their role was to exclude organic problems in their specialty and make certain that there was no sinister problem. Once that was achieved, it was merely a matter of referring to another person. If organicity remained still possible, it might be a surgeon or a gynaecologist or a cardiologist, but otherwise it would be the general practitioner. Referral to a psychiatrist was not an option considered frequently. They felt that they had served the patient well by excluding an organic problem. They had not attempted to see whether the patient recovered from the problem with treatment received from other general practitioners. Only two of the physicians held a different view, where they felt that since the patient's complaint related to their specialty, they should try to manage the functional problem.

The Sri Lankan physicians did try to manage the problems themselves very often especially when the patients were seen in the fee levying private sector. They tried as many measures as they could think of including symptomatic treatment and the use of antidepressants and anti psychotics as they felt that psychological reasons may be playing a role. Only when reaching the end of their tether did they think of referring the patient to psychiatry services. Perceived reluctance on the part of the patients to go to psychiatry services may also have been a reason. But on the whole they felt that if the complaint was somatic and in their region of

specialty, they should manage the problem. They used the psychiatrist as an escape route when things became unmanageable. The physicians from both settings who had outcome goals set at cure felt frustrated managing the patients. Those who had goals aimed at better quality of life and harm minimization felt satisfied with their efforts. As to who the best person to manage patients with functional problems would be, the UK physicians on the whole thought it should be *'anyone really but not me'*. For the Sri Lankan physicians it was *'anyone who can spend enough time with the patient, but this is difficult for me in the state hospital setting where I am very busy'*; however, they did mention that multidisciplinary joint clinics might be ideal although there were no such clinics in Sri Lanka. The multi disciplinary clinic thought was not entertained by the UK physicians.

Discussion about which label to give brought about contrasting lines of thinking. The UK physicians felt it would be good to have labels for functional problems stating that this would act as a catalyst for the formation of research interest groups, patient interest groups and provision of diagnostic and management guidelines. Sri Lanka physicians felt that the labels would not be useful for the patients as they were more concerned with disability that may arise; such as becoming crippled, having kidney failure or even a stroke. But the Sri Lankan physicians admitted that the labels would be useful for doctors, as such communication within the community would help them to minimize the time, effort and resources wasted on unproductive investigation of functional problems.

In order to improve care, the UK physicians thought they needed better training. The younger physicians pointed out that there would be no trainers as no one knew what to do with functional problems. The senior physicians who are generally looked upon as trainers on the various aspects of medical care themselves seemed ill trained and ill at ease in dealing with the problems. The only method of handling they could impart was, referring back to the GP and stating *'nothing was wrong'*. The Sri Lankan physicians did not speak much of training but felt that awareness should be raised among the medical community

about the existence and frequency of the problem. The senior physicians did worry whether such training would make the junior doctors over-diagnose functional problems as an easy way out rather than taking an in-depth look at the clinical problem thereby missing organic illnesses.

As ways of prevention, the UK physicians felt that improving the people's economic and social status and improving social support structures would help. The doctors were powerless in the current setting. The responsibility on the whole lay with the government. Interestingly Sri Lankan physicians seemed not to link functional problems to economic wellbeing. They were more bent on pointing out the implications of cultural beliefs and the social and family problems in the causation of these. They believed that doctors had a role in educating the public and also helping once problems arise. The Sri Lankan physicians envisaged a role for themselves in bringing about social and cultural reform.

12.3.2 Gynaecology

The gynaecologists in Sri Lanka and the UK provided interesting insights into functional disorders in their interviews. Both groups of gynaecologists saw functional disorders as an important health problem. But the approach they took to these patients was contrasting. The Sri Lankan gynaecologists recognised the problem but were hesitant to give a diagnostic label to that effect. They were reluctant to convey this diagnosis to the patients. It was on one hand not to antagonize the patient and on the other not to lose the patient to a fellow gynaecologist in the fee levying private sector. They operated in the very extreme of *'diagnosis by exclusion'* theory. Prior to making diagnosis and referring the patient to the psychiatry services, antidepressants, anxiolytics, placebo pills, placebo surgeries had all been tried. In the UK it was very different. Patients were sent back to the referring source as soon as possible. The UK gynaecologists were concerned that gynaecological cancers had non-specific presentations and investigated to exclude these. They also appreciated that the uterus and the ovaries were their territory organs and something else could be wrong in the abdomen without the gynaecologists being able to diagnose such problems.

Therefore the principle was to investigate sufficiently to find a gynaecological cause or to cover litigation fears and then send the patient preferably back to the GP or to another specialist.

The GP acted as the cushion to absorb the gynaecologists' lack of enthusiasm and competence in managing functional problems. Unlike their Sri Lankan counterparts, due to the absence of a thriving private sector, there was no motivation to treat the patients for longer. As for arriving at a definite diagnosis, the UK gynaecologists felt that there were pure organic diseases and pure functional problems where the diagnosis was easy but it was extremely difficult in the grey area.

The Sri Lankan gynaecologists felt that the vast majority of functional problems, though unable to be medically explained, could be explained when the social and cultural contexts and circumstances of the patients were taken into considerations. They felt there were only a small number of truly unexplained functional problems in existence. The commonest symptom in UK gynaecology setting was chronic pelvic pain. In Sri Lanka this was a rare complaint. The more common ones were vaginal discharge and menstrual irregularities. As for the appreciation of patient suffering the Sri Lankan doctors empathized with these patients very much.

Still it was noted that when speaking of patients in general, they spoke of 'real' patients and 'functional disorder' patients. Despite appreciating the suffering; functional problem patients were not considered as real patients. The UK the gynaecologists clarified that the suffering came from many sources. The symptoms were unpleasant, the family considered them a pain and the doctors were sceptical of their complaints. The gynaecologists were willing step in and help but felt helpless not knowing what to do. Their training as gynaecologists had not trained them to tackle the problem they would see most commonly in their clinic.

Psychological stresses were identified as possible causative factors by gynaecologists from both settings. Sexually transmitted diseases and sexual dysfunction are taboo topics in the Sri Lankan society. Women with anxieties and fears related to these presented with somatic symptoms. Domestic violence and physical and psychological abuse was quoted by both groups of gynaecologists as causative factors. In the Sri Lankan context, in addition to presentation, the symptoms offered a gain in the form of relief from the abuse. In the cultural context, ill persons are looked after by the family and relatives and offered these patients a path to escape from the abuse.

The UK gynaecologists were not very aware of socio cultural implications. They did state that since the NHS is providing free healthcare, the patients stopped taking responsibility for their good health and transferred the entire responsibility of relief from symptoms to the NHS. The 'NHS culture' was held as a culprit by the UK gynaecologists.

The Sri Lankan gynaecologists went to great lengths to show the relevance of traditional cultural beliefs in the causation and treatment of functional problems. There were both positive and negative impacts noted. In terms of personal attitudes, the senior Sri Lankan gynaecologists felt it was their duty to care for these patients helping them sort out the socio cultural aspects including domestic violence whereas the younger gynaecologists wanted to get out the way as early as possible.

Similar dismissive attitudes were noted among the senior gynaecologists in the UK. But perhaps surprisingly, the younger UK gynaecologists thought otherwise and wanted to make a difference. Some of them had done an appointment in psychiatry as Foundation Level doctors and felt that the skills acquired helped them. At times they tried cognitive behaviour therapies and overall felt more comfortable than their senior colleagues in dealing with these patients. This information may be of use to those who initiated the moves to have Foundation Level training for new doctors include training in psychiatry. Favourable results are already noted.

The UK gynaecologists felt that it would be better to have syndromal diagnostic labels to give their patients. But they admitted that the label they have at the moment of 'chronic pelvic pain syndrome' was not a fashionable one compared to labels such as IBS and felt that the label stigmatized the patient. More fashionable labels were awaited. Sri Lankan gynaecologists were not in favour of labels. They feel that persons with problems become patients through these. The UK gynaecologists wished that the labels be followed by guidelines on diagnosis and treatment. They wanted the guidelines extended beyond ruling out an organic cause to include referring the patient to liaison psychiatry services. They felt that training in management should not only be for the gynaecologists but for liaison psychiatrists and GPs to whom the patients would be referred.

The Sri Lankan gynaecologists felt that though training would be useful; however, due to lack of time and high patient volumes they may not be able to make use of this training. They viewed joint clinics with the psychiatrists as the best way forward. The Sri Lankan gynaecologists also highlighted the importance of making use of the network of public health midwives who are currently engaged in providing community obstetric services to tackle gynaecological problems in the community. They could raise community awareness by disseminating information pertaining to gynaecological health and sexual matters.

As for prevention and early recognition of functional problems in the community, the UK gynaecologists, much in the way that the UK physicians stated spoke of a weak social support structure that needed strengthening. Bonds between people were weak and doctors increasingly had to do what friends and relatives used to do – listen to worries and anxieties of people. The UK society is far more affluent that the Sri Lankan society in terms of material wealth. However, the Sri Lankan gynaecologists did not speak of economic difficulties and worries as a causative influence and they believed existing social and family support structures were satisfactory.

The UK gynaecologists came up with a novel suggestion. They suggested a new specialty – Consultant in Medically Unexplained Disorders. This specialist and his

team could deal with patients with functional problems referred from all specialties and could act as the multi disciplinary team. The patients could get to the team and get their problems sorted out without being stigmatized. A revolutionary thought indeed.

An interesting theme to emerge from the Sri Lanka gynaecologists was the set of functional problems which they considered as 'normal variations in body's physiological processes'. Community beliefs that menstrual periods should occur the same day of each month and that vaginal discharge, however mild, was a sign of serious disease prompted patients to consult doctors. Delayed menses meant dirt accumulating in the body and vaginal discharge meant the body wasting away. Doctors perceived these functional problems to be merely normal physiological variations and thought the patients needed reassurance only. The origin in these beliefs stem from the non allopathic medical systems such as Ayurveda which had been part of Sri Lankan health system for hundreds of years prior to the introduction of allopathic system of medicine. Such a category of functional problems was not identified by the UK gynaecologists. The likely explanation for this might lie in better education about normal functioning of the female reproductive system in the UK population. The absence of exposure to alternative medical systems could be the other important explanation.

12.3.3 Mental Health

The physicians and gynaecologists from the UK and Sri Lanka would be pleased to note that the mental health doctors' perceptions study revealed that even the psychiatrists were not very certain what precisely functional disorders were. The majority in both settings believed that there was a combination of physical and psychological abnormalities. A minority of psychologists felt that these were merely uncommon presentations of psychiatric disorders. Both groups stressed that patients with functional disorders were sent to the psychiatrists only at the very end. Often years had passed since the onset of the symptoms. By the time the patients were seen, the symptom picture had changed and in addition there were many learned behaviours and illness related stresses to deal with.

The reasons for this last resort approach in Sri Lanka were primarily three fold. The stigma attached to psychiatry made the doctor hesitant to refer patients due to fear of antagonizing the patient and relations. Referral to another professional for long term follow up meant a loss of income in the private sector. Egocentric doctors found it difficult to admit to the patients (and themselves) that there were problems they could not solve.

The reasons among UK doctors were different. There were fears of litigation and complaints to the NHS administrators if the patients were unhappy or an organic diagnosis was missed. Secondly doctors were uncomfortable dealing with these patients and the easiest way to get rid of them quickly was to refer back to the GP with a note stating that there was nothing wrong in their specialty. The fee levying private sector dynamics did not come into play in the UK and the GPs formed easily accessible dumping grounds. Referral to a psychiatrist required more positive decision making and subsequently having to explain these choices to difficult patients.

Psychiatrists in both settings appreciated and acknowledged the suffering patients underwent and were quite ready to consider functional problems in the initial differential diagnosis along with psychiatric disorders. The psychiatrists from Sri Lanka who were sensitive to cultural implications provided rich insights into patient matters during the discussions. Amongst others, functional disorders were described as a means of transferring power to the powerless in the Sri Lankan society.

Women and elderly who may not have power in relationships and households obtained power through illnesses and managed to meet their needs. One important factor brought to light was the cultural desensitization that engulfed doctors in Sri Lanka trained in the allopathic medical traditions. For five years in medical school and in the postgraduate training years, these cultural aspects were completely ignored and as a result many young doctors became culturally desensitized and struggled to deal with problems which had roots in socio cultural

aspects. They seemed to regain some of these attributes with the passage of time and with the maturity gained surviving many struggles in their early days.

The UK psychiatrists also appreciated the family and social aspects. Their appreciation of these factors was quite in contrast to the UK gynaecologists and physicians who at times seemed puzzled about being asked about the relevance of social aspects to their patients' problems. Relationships with family and other seemed to form the crux of the relevant social aspects in the UK population. Both causative and preventive influences of these on functional disorders were highlighted. Lack of ability and opportunity to speak about their feelings was a contributory factor, the UK psychiatrists noted.

The psychiatrists felt that half the time it was their duty to manage these patients and felt that they could do it better than their colleagues from other specialties. The other half felt comfortable enough to enjoy managing these problems. They felt they could make a real difference to the patients' lives.

Existing psychiatry settings provided challenges to overcome for the Sri Lankan psychiatrists dealing with patients with functional problems. The state hospital psychiatry units are geared to treating acutely disturbed psychiatry patients. There is no facility to provide behavioural therapy for patients with functional problems. Thus in Sri Lanka, the fee levying private sector offered the best place for treatment for those who could afford the expense.

The UK has liaison psychiatry teams and multi disciplinary teams but their involvement with functional problems remains minimal. There is also much room for improvement in the UK. Psychiatrists from both settings who were culturally and socially sensitive and who aimed for improvements in the day to day functioning of their patients as well as improved coping skills and quality of lives as goals of treatment, reported being comfortable and successful with the treatment they gave. The outcomes were best in the patients with co-morbid depression or anxiety. Of note was the fact that the UK psychiatrists

recommended starting anti-depressant treatment for all even in the absence of depressive symptoms. This view was not held by the Sri Lankan psychiatrists.

Alternative therapies had become incorporated to the NHS in some places but the participants expressed mixed opinions about their benefit. In the Sri Lankan setting, it was the patient's decision to seek alternative care and the psychiatrists were not aware of how successful or otherwise alternative practitioners had been.

What label would suit the patients most? The Sri Lankan psychiatrists felt leaving the diagnosis open with a statement such as 'investigated for chest pain or headache' would be most appropriate. Their UK colleagues preferred a syndromal diagnosis which would communicate information across various specialties to doctors but which would not be stigmatizing or marginalizing the patients. Functional disorder seemed an acceptable label.

The Sri Lankan and UK psychiatrists not surprisingly believed that psychiatrists are the best people to manage those with functional problems. The Sri Lankans thought that the psychiatrist should be involved as early in the course of the illness as possible, before peripheral issues became integrated. They admitted that properly trained physicians could play a role in joint clinics. The UK psychiatrists felt that mild problems could be tackled by trained GPs or trained specialists from other fields but anything which was not quickly responding to management should be sent to the psychiatrist.

Both groups emphasized the value of training. Training doctors to recognise the problem early, training them to institute simple measures, training them to recognise the need to refer to psychiatrists, training psychiatrists and training all doctors in recognizing family and social dynamics would be invaluable. Medical humanities being part of their training curricula would help produce culturally sensitive doctors, the psychiatrists believed. In addition, the UK psychiatrists call for a change in the society at large where members of the community supported each other in times of need more than they did currently. Lack of family and

community help was seen as a causative influence on functional disorders. This view was propagated by all three groups of doctors interviewed from the UK.

Considering all of the emergent themes the simple conclusion was some doctors managed patients with functional problems better than others. It was not quite that Sri Lankan doctors were better than UK doctors or that mental health specialists were better than gynaecologists, but some individuals possessed better skill at managing patients with functional problems.

Such individuals possessed some striking characteristics. They were able to recognise functional problems when they encountered them. For the better managers, functional problems were not merely legitimated syndromes or heartsink patients but those with chronic disabling unexplained physical symptoms. They had confidence in their clinical judgement to recognise functional problems at the outset without being fixed on ruling out all possible organic causes. As one such good manager succinctly pointed out, there was no way that an organic illness could be ruled out with certainty. Everything was relative and there existed no investigation or set of investigations which could ever rule out an illness. A good manager recognised the folly and harms of over investigation. They considered functional problems early in the differential diagnosis, and did not feel insecure in making the call. The good managers took on the management of the patient themselves. They did at times refer the patient to a colleague for an opinion or assistance in management, but they assumed primary responsibility for management of the patient. The manager was always the general who directed the war with others doing his bidding to win battles.

The better manager remained overall in charge, ensuring the patient was on the right path. In terms of outcome, the better manager drew up the agenda with the patient early in the course of consultations. The focus shifted from cure to more attainable goals such as better functioning, less symptomatic discomfort and an increase in quality of life. Quick fixes were ruled out and the manager and patient embarked on a long journey charting unknown territory together, providing comfort and support to the patient. Empathic listening, ability to understand the bio psycho

socio cultural and religious issues of the patient's life empowered the good doctor to help the patient. He possessed a wide range of therapeutic skills and was knowledgeable about evidence proven strategies of management. Even if the individual doctor was not competent in a particular skill, arranging a multi disciplinary care path for patients enabled the doctor to provide optimal care. There were a few doctors from Sri Lanka and a few from the UK who at least part fulfilled these profiles. But they were a small minority. The vast majority of those interviewed did not appear to possess the 'good manager' characteristics for functional problems. These emergent themes bring forth the clinical implications of this research. It pointed the way forward in better management of functional problems.

The other strong emergent theme was the patient safety issue. The iatrogenic harm facing patients with functional problems was enormous. They were subjected to multiple invasive investigations which often resulted in iatrogenic harm. They were often given placebo medication which included those with potentially fatal side effects such as anti psychotics, antidepressants and prokinetic agents. Both the Sri Lankan and UK doctors made the grave admission of performing unnecessary surgery. They admitted that often the patients' complaints worsened and the problems compounded after placebo surgeries. This iatrogenic harm must be minimised. This was another important clinical implication of the research.

12.4 Methodological issues from the quantitative study

The prevalence study evaluated the frequency of functional problems in outpatient specialist clinics in the three chosen specialties. Definitive diagnostic criteria do not exist for functional problems. The general consensus is to diagnose functional problems when the clinical assessment meant to include the clinical history taking and the physical examination and investigations relevant to the complaint do not reveal an organic diagnosis. This was the approach adopted in the study. The drawback of this approach is the concern that some clinical features or investigation abnormalities which are not present in the initial evaluation may

appear subsequently, suggesting an organic diagnosis. Therefore it was decided to follow the patient up for a total of six months following the initial presentation. A firm diagnosis of functional disorder was made only when the symptoms remained unexplained even after a six month follow up period. The researchers felt that this time period would be sufficient for an unrecognized symptom or investigation abnormality to appear. It is appreciated that this method is not foolproof and the very cautious among doctors may wish to follow up the patients for even longer before coming to a firm diagnosis.

Was this the best setting to look for prevalence of functional problems in those seeking medical attention? The study was conducted in three specialist outpatient clinics at a secondary care hospital setting. The figures obtained from the results were likely to be an underestimation of the true number of patients with functional problems who seek treatment from hospital. The patients who come to the clinic are those who are referred by medical officers from the outpatient department and from other wards in the hospital. This resulted in weeding out problems which were recognised as functional and they were treated at the contact point. It was only when the referring doctors believed that the problems were truly organic or likely to be organic that they were referred to the specialist gynaecology and general medicine / gastroenterology clinic. Considering the results of the prevalence study, it becomes clear that nearly 20% of those referred had functional problems. The true number of functional problems which presented to the outpatient department was therefore likely to be higher. As the study protocol was limited to the outpatient clinics this aspect was not investigated. The fee levying private sector where the patients sought consultation with general practitioners or specialists according to their wishes was very often the first port of call for people with illnesses. The numbers here would again be very important in considering the prevalence of functional problems among those seeking medical attention. This aspect also did not form part of the study protocol.

12.5 Methodological issues pertaining to the qualitative study

Qualitative techniques help when venturing into areas which other techniques cannot reach. It helps to study in-depth areas which have previously received little investigations. A qualitative description is a prerequisite for good quantitative research. The process of moving from observations / data towards generalisations, hypothesis or theory is termed ‘induction’, the cornerstone of qualitative research. It is this inducted hypothesis which will be put to test in a randomised controlled trial in quantitative techniques. Successful outcomes in health depend on culture, beliefs, behaviour patterns of healthcare service utilisers and delivery professionals. Qualitative research helps us to develop concepts in order to understand social phenomena in the natural setting. We can thus understand meanings, experiences and views of participants where they are health care providers or utilisers.

Qualitative methods were ideally suited for this extensive enquiry into the perceptions of doctors treating patients with functional problems. There are five major approaches in qualitative methods. Case studies involve developing an in-depth description and analysis of a case or multiple cases and are suitable for providing an in-depth understanding of a case or cases. . Narrative research explores the life of an individual and is suited to telling stories of individual experiences. . Ethnography involves describing and interpreting a culture sharing group and is suited for describing and interpreting the shared patterns of culture of a group. Phenomenology involves understanding the essence of the experience and is suited to describing the essence of a lived phenomenon. The perceptions study drew doctors from diverse cultures and subcultures and none of the above approaches were considered appropriate.

Grounded theory involves developing a theory grounded in data from the field. It is suited for grounding a theory in the views of the participants. This was the most suited method for analysis of the perceptions. I had a choice between using focus groups and using individual interviews for data gathering. In-depth interviews were considered the better and the more practical option and it was adopted. With the

busy clinical commitments of the doctors, there was no hope of arranging focus groups to seek their views. This was the practical problem. Focus groups have their inherent weakness of group interaction which inhibits individuals from discussing issues felt personal to them and also being dominated by those who speak loudest. With the use of individual interviews, each participant was requested to comment on a wide range of issues and express their opinions. These issues included discussing their patient experiences and their experiences about colleagues as well. This type of rich data would have been suppressed in a focus group setting. Individual interviews, though much more time consuming and labour intensive for data collection, provided more comprehensive information. Subsequent analysis was on open coding followed by axial coding and selective coding in order to ground the theory related to doctor perceptions.

12.6 Influences of culture on consultations and explanations

Cultural influences as brought forth by the physicians, gynaecologists and psychiatrists are dealt with in detail in the preceding sections. A summary of the views is presented here. Appreciation of cultural influences increased when moving from physicians to gynaecologists to psychiatrists. This was applicable in equal measure to the UK and Sri Lanka.

The least culturally sensitive were the physicians from the UK. When asked for their impressions, some participants stated that they had never considered such a relationship before. If asked for similarities between and elephant and a biscuit, some participants may have been less bewildered. Did cultural factors actually play no role in the UK? The moment the interviews with the psychiatrists were reviewed the relevance of culture became apparent. Thus cultural insensitivity on the part of physicians and to some extent gynaecologists acted as a barrier to successful treatment. This was less of a problem in the Sri Lankan cohort but remained an issue needing attention. The physicians would think and evaluate efficiently till they exhausted the physical possibilities and then seemed to stop thinking. Next priority was to arrange the referral back. Even patently obvious issues were ignored and swept under the carpet when the doctors were culturally

insensitive. The gynaecologists seemed to recognise traditional values and people's emotions more than the physicians in both settings. The psychiatrists were the doctors who could consistently look beyond the symptom and see the patient as a whole, as a social being. They would ask themselves why the patient came to them with this symptom and seemed to be more adept at getting an answer.

In the Sri Lankan setting cultural and religious values seemed to play a greater role. In the UK, relationship perplexities and stressful lifestyles were the most important factors. Traditional beliefs held by a Sri Lankan were more likely to be causative influences whereas the life stresses of a person in the UK working at Tesco's would be more of a burden than a Sri Lankan working at the local Cargills supermarket. The physicians, gynaecologists and psychiatrists who were culturally and socially sensitive and who used a larger number of tools could understand causation and provide more efficacious therapeutic measures.

All three groups of UK doctors interviewed stated that the society as a whole was no longer supporting the individual members of the community. They believed that economic upliftment and strengthening of support structures may help people overcome their difficulties. The participants admitted that something had gone wrong in their society. Something was amiss in the modern day UK society. This was consistently stated and doctors felt helpless at bringing about a change. They placed the responsibility for it on the government and its agencies.

Sri Lanka is relatively a much less affluent country compared to the UK. Vast numbers live with economic hardships but the participating doctors did not comment on the falling apart of community structures. They felt that despite problems there was family and community support for the patients. They believed that the doctors could make a realistic difference and saw little or no role for the government authorities. Compared to the UK participants, the thought that something was amiss in the modern day society was not encountered from the Sri Lankan participants. The different lines of thinking between the UK and Sri Lankan cohort of doctors provide thought to dwell upon.

12.7 What I learnt

I am a psychiatrist by profession and had started on my training in liaison psychiatry at the time of commencing the PhD research. As a liaison psychiatrist, I encountered patients with functional problems every day. Through personal experience and through speaking with colleagues, I had come to realize that this was a common problem but I was not aware just how frequently colleagues from other specialties encountered these patients. The results from the prevalence study taught me that functional problems are even more common than I had imagined.

As part of my clinical responsibilities, I speak to patients with functional problems daily. Perceptions of colleagues both in psychiatry and other specialties were known to me only through what was related by patients, when speaking of their journey through numerous medical consultations. There appeared to be great heterogeneity among the doctors in the way they diagnosed and managed functional problems. No one seemed certain of how to proceed once an organic problem was ruled out. The perceptions of doctors treating patients with functional problems were not available for study within the published medical literature.

During this extensive journey from the north east of the UK to the south of Sri Lanka, interviewing sixty doctors in different socio cultural settings in the process, I learned much. The perceptions ranged widely on each topic I spoke to them about. Thus the canvas is now drawn in its entirety and full splendour. Future researchers could use this picture to highlight further areas of interest and suggest to us, how best to manage functional problems. What I have leaned will help me set up a liaison psychiatry service in Sri Lanka, to deal with functional problems in order to help colleagues manage their patients better. This will be the first such service in Sri Lanka and I have discovered that it is also novel for the UK.

Further; on a personal note, the training I received from Durham University in both quantitative and qualitative research methodology, was excellent. I was introduced to the concepts of research governance committees within hospitals. I

had to take my proposal through three very demanding ethical review committees, namely the Durham University, the National Research Ethics Council of the NHS and the Ethical review committee of the Faculty of Medicine, University of Ruhuna.

The IT training from the Durham University also enhanced my skills. Being part of a highly motivated research team at the Wolfson Research Institute introduced me to a rich research culture. All of the above remain personal gains at the moment but I have already started disseminating my knowledge and skills to my colleagues at the Ruhuna University in the hope of building research capacity here. Over the three years spent on the PhD I have become a better clinician, a better academic and a better researcher.

12.8 Future research suggestions

The prevalence study results from Sri Lanka show that it is an important enough health problem and accounts for between 10 to 15% of patients attending outpatient specialist clinics. The statistics from the UK and other European countries show similar figures. Therefore functional disorders seem to be a common problem, with a global presence. Hospital settings reveal only a fraction of the burden of the problem. Prevalence in the community, prevalence at primary care level remain poorly investigated in the Sri Lankan setting and in the global setting as well. Research in these areas needs to be conducted as a priority.

Many illnesses revolve around doctor patient consultations only. The patient develops illnesses, takes the medicines prescribed by the doctor and is cured within a short span of time. Functional problems are among the most complex of illnesses to manage. In addition to the physiological and biochemical derangements that may be taking place, it revolves around the worries and anxieties of the patient; relationship between the doctor and the patient; the relationships patient holds with the family; the society; the beliefs and values of the patient and the community.

Thus there are many stakeholders in the process of successful management of functional problems. The patients, the general practitioners, the specialist doctors, the supplementary medical service personnel such as psychotherapists, social workers, physiotherapists, nurses, the patient's family, the community, the society at large, and government agencies are all stakeholders. Doctors are familiar to a certain extent about patient experiences from their personal contacts with the patients. A search of the literature reveals a few papers with narrative analysis of patient experiences. But perceptions of other stakeholders remain poorly studied and little known.

The purpose of this research was to make an in-depth enquiry into a multitude of aspects regarding functional problems from doctors in diverse cultural settings working in three specialties, in secondary and tertiary care hospitals. A valid and comprehensive understanding of the problems would require more research covering other stakeholders. The value of future research where general practitioners are interviewed and their views on management and outcomes of functional problems, would be immeasurable. Similarly patient families and local communities need to be reached out to. Even in the hospital doctor community, these interviews may only be the beginning.

Characteristics of better managers of functional problems was an emergent theme. Future research should be directed into findings ways of encouraging and adopting good management practices. Similarly important was the theme covering iatrogenic harm to patients. Future research should also be directed at finding ways to minimise this harm. Lack of engagement or reluctance to be part of management by doctors needs in-depth study. Research needs to address the question whether better training will make doctors more willing to take responsibility in management. How a shift could be made to a patient centred approach is a question that needs addressing. What are the effects of a fee levying private sector health provision on functional problems needs to be studied. Would education of patients about functional problems, with the same emphasis and vigour as for cancer or stroke make a difference? Would a change of

behaviour from better educated patients force doctors to abandon their negative approaches? Future research needs to address these burning issues and look for answers.

12.9 Conclusion

At the conclusion of my research I remain amazed when regarding a problem which accounts for around one fifth of patients seeking medical attention but for which there is an astonishing lack of interest and apathy from the medical community. For comparison; ischaemic heart disease, a rarer disease affecting an older population, causing less disability and costing less to the healthcare system has centres of excellence devoted for research and treatment spread across the world. Functional problems remain ignored.

In the course of the research I discovered the duplicity in the behaviour of doctors when confronted by patients with functional problems. At the drop of a hat, doctors would embark on long discourses about how they cared for humanity and how they entered this most noble of professions to relieve suffering. They were all keen as long as the suffering was within their comfort zone, preferably of an organic nature where there was a guideline to follow. The moment they were confronted with a functional problem, they were all too enthusiastic to disengage themselves from looking for solutions. Very often they did not have sufficient faith in their clinical judgement to make a positive diagnosis. This led to patients being put in harm's way by unnecessary, often invasive investigations and in extreme situations, placebo surgery. They hid behind a facade of *'not wanting to miss a serious illness'* whilst being fully aware that they could not recall any such instances.

They readily confessed that they were concerned about litigation and complaints to the GMC or SLMC. Are these not the very doctors who are most likely face an inquiry by the GMC? Is it not negligence that would make a doctor order potentially harmful investigations and treatment? The moment they were through with the investigations and nothing could be found, the most likely outcome was to tell patients there was 'nothing wrong'. The patient was having a problem and the

doctor was denying its very existence. Is it a wonder that patients have lost faith in the system and gone shopping for that elusive doctor who could help them with their problem? Many doctors did not want to antagonise patients or display their ignorance.

The next action came in the form of dumping the patient at the feet of the general practitioner or another specialist. Most of the doctors in the UK delegated the duty of making a diagnosis of functional disorder and the duty of managing it, entirely to the GP. This is hypocritical because GPs are usually regarded by high flying consultants as belonging at the bottom of the pile. But in this instance they held high expectations of GPs in functional problems. The avoidance behaviour shown by specialists towards functional problems bordered on being a 'phobia'. Doctors held self serving opinions of what their core business was. They refused to address problems beyond those they identified as their business. They would conveniently and quite happily shrug their shoulders and claim *'not really my problem, I am sorry'*. Functional problems were not the business of physicians, gynaecologists or psychiatrists. The 'denial' behaviour left the patients in the lurch and they were made to fend for themselves most of the time. The gulf between a doctor and disease centred approach and a patient or problem centred approach was never more evident as with functional problems.

The Sri Lankan doctors stated how these approaches changed when patients were seen in the private sector. There were many unethical practices. No complaints were lodged as one was willing to blame the doctor. UK doctors were spared this ignominy, very likely not due to their highly ethical conduct but merely for the relative lack of opportunity. A thriving private sector is the last thing the UK patients with functional problems require in the future.

The way forward, in my view, is to conduct more research to a point where there are publications covering important areas appearing regularly in the medical literature. A critical mass of researchers and clinicians is needed to cause a shift in attitudes and behaviour. This will provide the attention functional problems merit. I wish to believe that my work is one small step forward.

13 Appendix 1

Durham University
School of Medicine and Health

Shaped by the past, creating the future

INFORMATION SHEET – Medical professionals

Functional symptoms: their frequency in secondary care and perceptions of patients and healthcare professionals

Dear <Doctor>

I am currently involved in a research project which will explore beliefs regarding Functional symptoms / medically unexplained symptoms. Functional symptoms are a large problem in terms of prevalence, associated morbidity and costs and a common problem for primary and secondary care physicians. Of all patients seen in specialist outpatient clinics, about half have functional symptoms. (Nimnuan C, Hotopf M, Wessely S. Medically unexplained symptoms, an epidemiological study in seven specialties. J Psychosom Res 2001;51:361-7). Although Functional symptoms are a common disorder and results in extensive morbidity, there are considerable gaps in understanding causes of the condition and, given that there is no definite underlying pathology. The aims of the study are to examine lay beliefs about IBS of patients having functional symptoms and also to examine beliefs of the caring doctors.

As well as examining lay beliefs by carrying out interviews with patients with such conditions, we would like to speak to attending doctors. I would like to invite you to be interviewed. The areas covered will include a description of what functional symptoms are, how we make the diagnosis, how they affect patients and other associated factors. Worries about making the diagnosis will be explored, including the effect on patients of making the diagnosis, and worries about missing serious pathology. Doctors' beliefs about lay treatments for functional symptoms will be explored.

You have been invited to take part in this study because you are a medical professional working with patients with functional symptoms. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

The University of Durham Research Ethics Committee has reviewed and approved this study.

If you have any problems or questions about any aspect of the study, or need advice at any stage of the study, please contact Dr Harshini Rajapakse at Durham University on 0191 3340375

With many thanks

Yours sincerely

Dr Harshini Rajapakse

✂……

Please complete in BLOCK CAPITALS and return in the prepaid envelope provided

Please place a √ in the relevant box

☐ I have read the information sheet

☐ Yes, I am interested in taking part in this research study.

☐ No, I do not wish to take part

Name:_____

Address

Telephone number_____(Day)

_____(Night)

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