



Cox, Paula (2011) *An examination of the psychiatric experiences of patients diagnosed with functional somatic syndrome within the National Health Service: A qualitative study*. D Clin Psy thesis.

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An Examination of the Psychiatric Experiences of
Patients Diagnosed with Functional Somatic
Syndrome within the National Health Service: A
Qualitative Study

AND CLINICAL RESEARCH PORTFOLIO

Part 1

(Part 2 bound separately)

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July 2011

Mental Health and Wellbeing

University of Glasgow

Submitted in part fulfillment of the requirements for the degree of Doctorate in
Clinical Psychology (D.Clin.Psy)

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Acknowledgments

I would like to thank Dr Sarah Wilson for providing much needed support and encouragement over the past two years. It was extremely comforting knowing that your door was always open. I would also like to thank Dr John Sharp for introducing me to Health Psychology and Functional Somatic Syndromes. Thank you for letting my ideas flourish and I appreciate your keen eye for detail.

I would like to thank Dr Tom Brown, Consultant Liaison Psychiatrist, Dr Judith Halford, Consultant Liaison Psychiatrist, Dr Mary Cawley, Clinical Psychologist and Scott Stewart, administrative support. Thank you for supporting this project and for welcoming research in your respective departments.

I would like to give an especially big thank you to the participants who took part in the study. It was a privilege to meet you and I am very grateful to you all for being so frank and open.

A big thank you to my family, friends, and classmates for providing much needed advice, guidance and support. Finally, I would like to thank my partner, Matt. Thank you for supporting me through the hard times and reminding me that the quality of my work will significantly improve if I get out and have some fun. I appreciate the sacrifices you made to support me through the course and for that I am truly grateful.

Lay Summary

Functional Somatic Syndromes (FSS) are a sub-set of conditions that cannot be explained by medical science. Patients with this condition experience physical and mental health symptoms. Therefore, these patients are commonly treated by mental and physical health services. Previous research has focused on FSS patients views of physical health services and found that patients experience stigmatisation from professionals. Stigmatisation may impact on the recovery process and may make patients reluctant to seek treatment in the future. The aim of the current study was to investigate whether stigmatisation occurs in a mental health service. Three participants were interviewed and asked about their experiences of treatment in a mental health service. The results of the interview showed that the participants felt that they were stigmatised by the public for accessing mental health services. The results also showed that the patients viewed their treatment by mental health services positively. This study provided new insights into the benefits of mental health treatment and the treatment factors that professionals can use to improve their service (e.g. educating patients about their condition, providing coping strategies and thinking about the mind/body relationship).

CHAPTER ONE: SYSTEMATIC REVIEW

The Perception and Experience of Stigma among People Diagnosed with Functional Somatic Syndrome: A Qualitative Systematic Review

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Preparation in accordance with guidelines for submission to *Health Psychology Review* (see appendix 1.1)

Submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy)

Abstract

This article presents a systematic review of qualitative studies investigating the stigma experiences of patients diagnosed with functional somatic syndrome. Meta-ethnography was used to select, critically appraise and synthesise the studies. The search strategy involved a search for articles in web of science, OVID and CINAHL databases between January 1950 and December 2010. A hand search of relevant journals and reference lists was also undertaken. The search yielded 243 citations, of which, 9 were applicable for this study. The following four themes were identified from these studies: stigmatised diagnosis, legitimacy of the illness, stigmatised identity and stigmatised relationships. This article discusses the relevance of these themes with regard to the treatment and care of these patients.

Keywords: Qualitative Systematic Review, Functional Somatic Syndrome, Medically Unexplained Symptoms, Medically Unexplained Illness, stigma, patient experience

Introduction

Stigma related to mental illness has been well documented in the research literature (c.f. Thornicroft, Rose & Kassam, 2007). Corrigan and Penn (1999) note that people experiencing mental illness suffer a dual burden of impairment (i.e. suffering the psychological consequences of a mental disorder in addition to the social cost of stigma). Furthermore, Link and Phelan (2001; 2006) state that stigma generates difficulties in every area of an individual's life, as it exposes a vulnerable person to additional stress, leads to social isolation, reduces the impact of any existing coping resources, which can lead to a delay in help seeking behaviour; thus impacting on recovery. Indeed, Mann and Himelein (2004) found a relationship between the concern over mental health stigma and the discontinuation of medication. Although stigmatising attitudes are not limited to mental illness, the public appears to disapprove of psychiatric disorders significantly more than physical illnesses (Corrigan & Watson, 2002). Unlike physical disabilities, individuals with mental illness are perceived to be in control of their disabilities and responsible for causing them. Corrigan and Watson (2002) found these attitudes can also be held by mental health professionals, leading to the stigmatisation and poor treatment of the mentally ill.

The issue of stigma in relation to mental health has been raised by the Scottish Executive and The National Health Service (NHS) in Scotland. The Millan Committee report was commissioned by the Scottish Executive and recommended that there should be a campaign of public education designed to improve public understanding of mental health and to reduce the stigma of mental disorder (Scottish Office, 2001, 2008). This report led to a pledge made by NHS Education for Scotland to eliminate stigma and discrimination within mental health. As part of this commitment, NHS Scotland has signed the 'see me' (NHS Scotland, 2006; 2007) pledge and has agreed to raise public awareness through advertisement campaigns and increase staff awareness of stigma through training and education.

Research has indicated that patients diagnosed with Functional Somatic Syndromes (FSS) may view themselves as being stigmatised by this diagnosis (Looper & Kirmayer, 2004). The term FSS is an umbrella term referring to a number of related disorders characterised by an array of medically unexplained physical symptoms (Page & Wessely, 2007). The research literature also refers to FSS as medically unexplained symptoms (Smith, McGorm, Weller, Burton & Sharpe, 2009) or somatisation disorder (Kroenke, 2006). The most common FSS are chronic fatigue syndrome, fibromyalgia and irritable bowel syndrome (Kuey, 2008),

although it is important to emphasise that this list is not exhaustive. Henningsen, Zipfel and Herzog (2007) categorised constellations of FSS symptoms into three groups: pain, functional disturbance in different organ systems and fatigue. It has been proposed that there is significant overlap in the symptomatology of different FSS (Barsky & Borus, 1999) as fifty percent of clinical populations fulfil criteria for more than one FSS (Henningsen et al., 2007).

Approaches to the diagnosis of FSS and subsequent interventions vary in medical, psychiatric and psychological services (Barsky & Borus, 1999). Currently, the classifications for each FSS are set out separately in the International Classification of Diseases: tenth edition (ICD-10) (WHO, 1992) and Diagnostic and Statistical Manual of Mental Disorders: fourth edition (DSM-IV) (APA, 2000) diagnostic criteria (Kroenke, 2006). The difficulty with this is that it encourages a splitting of symptomatology into either a physical illness or psychopathology, which has implications for treatment (e.g. pathway through physical health services or mental health services). This led to the decision to review the diagnostic classification (Kroenke et al., 2006; Schroder, 2010).

Sharpe, Mayou and Walker (2006) outline the typical diagnostic course of a patient with medically unexplained symptoms. Patients typically present to their GP and report various physical symptoms. The GP is tasked with diagnosing the symptoms and providing advice and treatment. If the GP is unable to explain the symptoms medically, the patient is then referred to a general hospital for further testing. This means that FSS patients have frequently undergone a prolonged period of physical investigations in the form of scans, medical tests and referrals to specialist medical services (Moss-Morris & Chalder, 2003). Consequently, FSS patients often hold the view that there is purely a medical explanation underlying their symptoms. If a medical explanation cannot be found after testing at the general hospital, then patients diagnosed with FSS are referred to mental health services to explore whether there is a psychiatric explanation for their difficulties. It therefore appears that some medical professionals hold a dichotomous view that explained symptoms are medical and unexplained symptoms are psychiatric (Sharpe et al., 2006).

Symptoms of FSS frequently lead to significant reductions in quality of life and often have implications for the individual's self-esteem and identity (Manu, 2004). Symptoms of FSS can have similar negative consequences on an individual's career, social life and leisure pursuits as comparable conditions, which have a clear medical aetiology (Looper &

Kirmayer, 2004). In addition to the social, emotional, physical and employment implications for FSS patients, a survey by Deale and Wessely (2001) indicated that two-thirds of participants were unhappy with their experiences of medical services and were disappointed with the quality of care they received.

This synthesis comes at an interesting time in the field of FSS research as the diagnostic categories are under revision and there is much debate within the literature with regard to best practice and care of these patients. It is hoped that this review will offer an opportunity for reflection on the quality of care of patients diagnosed with FSS receive and whether any lessons can be learned from the perceptions and experiences of patients diagnosed with FSS.

Aim

The aim of this systematic review is to determine the perceptions and experiences of stigma among people diagnosed with Functional Somatic Syndrome.

Review Question

What is the experience of stigma among people with Functional Somatic Syndrome?

Method

Meta-ethnography (Noblit & Hare, 1988) was used to conduct a systematic review of stigma experiences of people diagnosed with FSS. There are a number of different methodological ways of conducting a synthesis of qualitative research (cf. Ring, Ritchie, Mandara & Jepson, 2001), meta-ethnography was chosen as it allows for the synthesis of research studies that draw from a variety of qualitative research methods (Ring et al., 2001). Noblit and Hare (1988) and Atkins et al. (2008) outline seven stages for meta-ethnography (table 1). This synthesis shall follow these key steps in order to select, critically appraise and synthesise qualitative research studies.

Table 1. *Seven stages of meta-ethnography*

Step	Stage	Description of each stage
Step 1	Getting started	<ul style="list-style-type: none"> • Develop a research question
Step 2	Deciding what is relevant for initial interest	<ul style="list-style-type: none"> • Define focus of synthesis • Locate relevant studies • Make decisions on inclusion criteria • Carry out a quality assessment
Step 3	Read the studies	<ul style="list-style-type: none"> • Become familiar with the detail and content of the studies • Extract metaphors and emerging themes
Step 4	Determine how the studies are related	<ul style="list-style-type: none"> • Create a list of themes and metaphors • Juxtaposition of themes • Determine how the themes are related • Reduce themes into categories

Step 5	Translate studies into one another	<ul style="list-style-type: none"> • Arrange each study into chronological order • Compare themes from paper 1 with paper 2 and the synthesis of these two papers with paper 3 and so on
Step 6	Synthesising translations	<ul style="list-style-type: none"> • Higher order interpretation to provide a line of argument synthesis
Step 7	Expressing the synthesis	<ul style="list-style-type: none"> • Discussion and write-up of the results • Publication

Search strategy

Searches were carried out using the following databases: Web of Science, Ovid MEDLINE (In-process & Other Non-Indexed Citations and Ovid MEDLINE (R) 1950 to Present, EBM Reviews – Cochrane Database of Systematic Reviews 2005 to November 2010, EBM Reviews – ACO Journal Club, 1991 to November 2010, EBM Reviews – Database of Abstracts of Reviews of Effects 4th Quarter 2010, EBM Reviews – Cochrane Central Register of Controlled Trials 4th Quarter 2010, EBM Reviews – Cochrane Methodology Register 4th Quarter 2010, EBM Reviews – Health Technology Assessment 4th Quarter, EBM Reviews – NHS Economic Evaluation Database 4th Quarter 2010, British Nursing Index and Archives 1985 to November 2010, Embase 1988 to 2010 Week 48, PsychINFO 1987 to December Week 1 2010, Social Policy and Practice 2010, EBSCO database selection (CINAHL, SocINDEX with Full-Text, Psychology and Behavioural Sciences Collection,

PsycARTICLES, Health Source: Nursing/Academic Edition, Business Source Premier, Professional Development Collection).

A search was also conducted using reference lists from relevant journal articles and a hand search of *The Journal of Psychosomatic Research* and *Psychology and Health*.

Search terms

The text word search strategy involved searching for the following terms: ((somat* syndrome* or medically unexplained symptom* or medically unexplained illness* or medically unexplained condition* or gulf war syndrome* or fibromyalgia* or somat* disorder* or chronic fatigue syndrome* or CFS or persian gulf syndrome* or irritable bowel syndrome* or myalgic encephalopath*)) and ((prejudic* or stigma* or stereotyp* or label))

Inclusion criteria

This review included:

- Studies that used participants diagnosed with functional somatic syndrome, medically unexplained symptoms/illness/condition or somatisation disorder, somatoform disorder, somatic syndrome, gulf war syndrome, fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, persian gulf syndrome.
- Studies investigating the experience or perception of stigma or prejudice in functional somatic syndrome
- Studies that collected data from community samples and inpatient settings
- The review considered evidence from qualitative studies

Exclusion criteria

The review will exclude:

- The systematic review excluded studies that were not published in English
- Case studies were excluded from the review
- The synthesis excluded quantitative studies

- Studies which included chronic pain were also excluded from the systematic review

Results of search strategy

The database search yielded 243 citations, of which, 200 articles were discarded as they were duplicates or the title indicated that the article was not relevant to the topic. The abstracts of the remaining articles were examined using the inclusion criteria, resulting in the exclusion of a further 33 articles. This left 10 potentially appropriate articles, of which, 1 was excluded after reviewing the full-text (Kool, Middendorp, Boeije & Geenen, 2009). The 9 remaining articles were deemed suitable to be included in the review and are discussed below (Asbring & Narvanen, 2002; Dickson, Knussen, & Flowers, 2007; McCue, 2004; Mengshoel & Heggen, 2004; Salmon, Paters & Stanley, 1999; Taylor 2005; Ware, 1992; Whitehead, 2005; Whitehead, 2006). The methodological details of each study are provided in table 2 and a list of the themes for each study is provided in table 3.

Quality appraisal

The quality of the 9 articles in this synthesis was appraised according to the criteria in Appendix 1.2 (Walsh & Downe, 2006). The quality criteria was based on 46 items, and studies were awarded a score of 1 if the criterion was met and 0 if the criterion was not met or it was not possible to determine from information given. Therefore, each paper was given a rating out of 46, with a score of good (>75%), acceptable (>50%) or poor (<50%). All studies were independently rated by an independent researcher using the same quality rating scale (Appendix 1.2). The overall level of agreement was high (77%). The disagreements were resolved through discussion with the independent researcher.

Table 2: *Methodological outline of reviewed papers*

Authors	Country	Data collection	Recruitment	Participant	Quality
					Rating
Asbring & Narvanen (2002)	Sweden	Grounded theory	Hospital	25 women	74%
				13 FSS	Acceptable quality
				12 CFS	
				(aged 32 –	

				65 years old)	
				Length of illness 1-23 years.	
Dickson, Knussen & Flowers (2007)	Scotland	Interpretative Phenomenological Analysis	Alternative Therapy Clinic + Personal Contacts	N = 14 (CFS) 8 females, 6 males Aged 21-68 years	83% Good quality
McCue (2004)	England	Grounded Theory	CFS/ME support groups and ME North East	14 Aged 21-70 years (mean age 42) Illness duration – 2 – 17 years Recovery 6 months – 10 years)	76% Good quality
Mengshoel & Heggen (2004)	Norway	Qualitative Thematic Content Analysis		5 females Aged 37-49 Illness duration 1-15 years	74% Acceptable quality
Salmon, Peters & Stanley (1999)	England	Inductive	General Practice Surgeries	188 Participants , 52% female, mean age 44.5	63% Acceptable quality

Taylor (2005)	Chicago	Grounded Theory	Self help organisations Physicians specialising in CFS, advert in CFS newsletters, local newspaper, CFS websites and local TV	47 (CFS)	70% Acceptable quality
Whitehead (2005)	Scotland	Guided by principles of hermeneutic phenomenology	CFS/ME clinic Support group Snowballing approach	Sample = 17 Age: 13-63 years 6 men & 11 women Onset = 2-40 years	76% Good quality
Whitehead (2006)	Scotland	Guided by principles of hermeneutic phenomenology	CFS/ME clinic Support group Snowballing approach	Sample = 17 Age:13-63 years 6 men & 11 women	80% Good Quality
Ware (1992)	USA	Application of the construct of illness reality (depicting words, experiences and feelings)	Hospital	Sample =50 Age: 22-66 years Duration of illness: 1 ½ years – 25 years	75% Good Quality

Results

In order to determine how the studies are related, Noblit and Hare (1988) recommend listing the themes in order so that a comparison of themes can be made. Table 3 outlines a list of themes.

The results indicated that the following dominating factors impact on the lives of FSS patients: diagnosis, legitimacy of the illness, identity and relationships. This section of the report will explore the patients experiences based on the strongest themes emerging from the synthesis.

Table 3: *Themes*

Name of author	Themes
Asbring (2002)	<ul style="list-style-type: none">- Moral character being called into question in interaction with others- Distress from being psychologised by others- Strategies to handle stigma- Keeping a distance from others- Concealing- Spreading and/or withholding information- Withdrawing from and/or approaching co-patients
Dickson et al (2007)	<ul style="list-style-type: none">- Negotiating a diagnosis of CFS- Negotiating CFS with loved ones
McCue (2004)	<ul style="list-style-type: none">- Diagnosis: physical/organic vs psychological- Acceptance and belief: doctors and health care professionals.
Mengshoel & Heggen (2004)	<ul style="list-style-type: none">- Diagnosis and treatment- Uncertainty of treatment- New interpretations and efficient strategies- Social roles- Resisting the sick role- Unwillingness to celebrate illness- Redefining obligations and goals
Salmon et	Patients accounts of explanations

al (1999)	<ul style="list-style-type: none"> - Rejection - Collusion - Empowerment
Taylor (2005)	<ul style="list-style-type: none"> - Minimisation and distrust of the disability by others - Negative experiences of impairments - Lack of identification with disability community - The focus of advocacy as quest to gain legitimacy from others
Whitehead (2005)	<ul style="list-style-type: none"> - Disruption and identity in the acute phase of the illness experience - Identity reconstruction in the medium term - Identity construction in longer term
Whitehead (2006)	<ul style="list-style-type: none"> - Restitution narrative - Onset - Gaining a diagnosis - Seeking treatment
Ware (1992)	<ul style="list-style-type: none"> - Deligitimation experience and - Insignificance/trivialisation of symptoms - Contesting the definition

Stigmatised diagnosis

The first theme identified was related to diagnosis (Dickson et al., 2007; McCue, 2004; Mengshoel & Heggen, 2004; Salmon et al., 1999; Taylor, 2005; Ware, 1992; Whitehead, 2005; Whitehead, 2006). The general consensus across studies was that during the early stages of the illness, participants typically believed that they had an acute illness such as flu and as a consequence, acted accordingly (e.g. taking time off work). Participants did not report stigma experiences during the acute stage of the illness, instead, stigmatisation experiences typically occurred during the medium to late stages of the condition.

It was common for patients to seek a diagnosis to inform the treatment of their condition. The search for a diagnosis could take many years and many patients sought advice from a number of physicians. Patients reported that they were stigmatised if they did not have a diagnosis as they felt they were not justified to continue with the sick role as, in their view, a

label for the illness is a prerequisite to being justifiably ill. Not having a diagnosis and prognosis for their illness left patients feeling uncertain, concerned about the prognosis and without a means of coping. This is evident from the following quotation:

“It would be easier in many ways if someone was to say to me, Ok. We’ve found out what’s wrong with you. You’ve got a tumour the size of a grapefruit and you’ve got two years to live. Ok. Now I know. That’s what it is. We pay off the car. We take a trip to Bermuda. I don’t have to wonder what it is that I’m going to do with the rest of my life” (Unknown, Ware, 1992, p. 353).

Participants generally felt that there was a lack of recognition of their condition by the medical profession and did not feel supported. This is evidenced by the following quotation:

“Although he [GP] gave the impression to me that he was supportive and understood ME, apparently when he got a form from DSS, he just filled it in with all the negative replies, saying... there was nothing wrong with me, and if I couldn’t walk, it was psychological, so he said I had no difficulty walking, I had no difficulty doing any of the things that he’d said... y’know, that were on this form” (Maria, Whitehead, 2005, p. 2236).

The results of the synthesis indicate that the lack of recognition was displayed in the following ways. Firstly, some patients felt that they were denied a diagnosis or explanation for their difficulties. An example of this was given by Salmon et al. (1999) as patients would frequently undergo a number of medical tests. If the test results came back clear, then some patients were told that there was nothing wrong with them, invalidating self-reports, rather than being told that the doctor was unsure. Ware (1992) proposed that this was deemed as a shameful experience by the patients because the reality of their experience was devalued by the medical profession.

Some participants felt that their physician did not believe in the credibility of the diagnosis. The participants were given a diagnosis that they sought, but were also labelled with a contested diagnosis (Whitehead, 2006).

Finally, some patients felt that their physical difficulties were ignored and they were diagnosed with depression or anxiety. This is evidenced by the following quotation:

“That’s been my experience [with doctors] over and over again. They really try. They really listen. And then they try a whole bunch of things that they think might turn something up, and when everything fails, they just think you’re nuts. And then they get sort of angry”. (Unknown, Ware, 1992, p. 351).

The participants who were given a diagnosis generally felt relieved as the prognosis for their condition was not fatal. Some of the studies indicated that participants were relieved by the diagnosis, but felt more comfortable with a biological explanation for their difficulties (Mengshoel & Heggen, 2004; Whitehead, 2006). Not all patients were uncomfortable with a psychological explanation, but they were under the impression that medical professionals feel uncomfortable giving a psychiatric label to the difficulties. The patients reported that despite the professional’s discomfort, they would actually feel relief at being given an explanation for their difficulties (McCue, 2004).

Legitimacy of illness

The second theme to emerge from the synthesis was the legitimacy of the illness by professionals, friends, relations and the self (Asbring & Narvanen, 2002; McCue, 2004; Mengshoel & Heggen, 2004; Taylor 2005; Ware, 1992, Whitehead, 2006). As stated, many of the patients were in search of a diagnosis for their difficulties for a number of years. Upon gaining a diagnosis, many found that they were still unhappy about the relationship with professionals and the services offered. For example, Ware (1992) reported that patients were told that there was either “no observable evidence of disease in the form of clinical signs or laboratory findings can be found” or “the illness has yet to be accepted as a diagnostic entity in the standard professional nosology”. The view of the condition as a real illness was often called into question and patients felt that physicians were sceptical when patients reported physical symptoms of the illness (McCue, 2004).

Taylor (2005) summarised the experiences of patients with health providers as:

1. Outright disbelief in the legitimacy of CFS as a medical entity
2. Lack of validation of participants described impairments and symptoms
3. Lack of knowledge about CFS
4. Absence of treatment planning and recommendations

5. Tendency to overemphasise psychological and social variables as possible causes of the symptoms
6. Tendency to overprescribe psychotropic medications
7. Tendency to view exercise and psychotherapy as the only non-pharmalogical treatments for CFS.

“I think it is a good thing when a doctor makes inappropriate comments, like, that CFS does not exist. It then becomes obvious that you need a new doctor. It’s much more dangerous when a doctor keeps his beliefs silent. In this case you are probably not going to get the level of care you need but you won’t know why.... I think it’s important to find out what your doctor believes” (Unknown, Taylor, 2005, p. 501).

One study found that patients felt that their moral character was being called into question through delegitimisation experiences (Mengshoel & Heggen, 2004) and reported that they were disbelieved. The participants felt they were viewed as malingering to escape responsibilities of life. Many saw themselves as honest people and this challenged the concept of who they were. Some respondents experienced constant disbelief and doubt, which they found hurtful. These repeated delegitimisation experiences led many patients to question the reality of their symptoms, which was documented as frustrating. This was important because they required support due to the debilitating nature of their condition. Instead, the participants were met with doubt and disbelief about the reality of their experience. This was evident from the following quote:

“I remember standing in front of the mirror, and I looked wretched. People told me I looked like I was going to die! And yet the doctor said it was just a viral illness and that it should go away. And I’d looked in the mirror and think are you crazy? Maybe there’s nothing wrong with you. Maybe it’s all in your head.” (Unknown, Ware, 1992, p. 352).

Taylor (2005) emphasised the consequences of professional delegitimisation of the condition and found that people were reluctant to seek treatment as they felt stigmatised by professionals. The study also indicated that participants felt that there was insufficient support from them after receiving a diagnosis as they were not referred to rehabilitation services. Furthermore, many patients faced challenges in receiving state benefits and community support due to the delegitimisation of the condition by professionals as they have to sign the forms to allow access to many of these services. Patients also found that

professionals were unaware of any services that could benefit the sufferers or had a lack of knowledge about what they could benefit from.

Stigmatised identity

The third theme to emerge from the synthesis was that the participants experienced a disruption to their identity due to the stigmatising nature of their condition (Dickson et al, 2007; Taylor 2005; Whitehead, 2006). Changes to identity typically occurred during the early stages of the illness. Many patients assumed that their illness was acute during the early stages and patients were initially happy to take a break from social roles and adopt the sick role (Parsons, 1951). This was generally accepted by family, friends and colleagues as a socially acceptable way to behave when experiencing a socially acceptable illness such as flu (Whitehead, 2006).

The results indicate that as the course of the illness progressed, the disruption of the person's identity worsens and people experience a loss of role (Dickson et al., 2006; Whitehead, 2006). Whitehead (2006) reported that participants went from living busy, active lives, to a complete loss of role where they were house bound. This meant that they went from having the identity of an active person to an all encompassing disabled identity.

As the illness developed it became clearer that the illness was more complex than many of the patients first anticipated. A commonality to emerge across studies was that many of the patients rejected the idea of being known as disabled. This could be classified as a double stigmatisation as disability is also a stigmatised identity (Whitehead, 2006). This is evidenced in the quotation below:

“CFS as a disability” “I hate hearing these labels! The more you label yourself as disabled, the sicker and more dependent you will be”(Unknown, Taylor, 2005, p. 503).

Some people did accept they were disabled, but felt this was a temporary condition. The results also found that patients diagnosed with chronic fatigue syndrome were rejected by the disability community because the legitimacy of this diagnosis was called into question. The participants found the reactions of persons with disabilities to their disabling condition similar to that of those who were not members of the disability community. Taylor (2005) provides an example of one participant who asked for assistance when calling a taxi cab from

a disabled receptionist. The receptionist indicated to the participant that she looked “perfectly able to run down to the corner and get a cab herself” (Unknown, Taylor, 2005, p. 504).

Stigma and relationships

The final theme evident in the research papers was the perception that friends, family and colleagues stigmatised the patient for the illness (Dickson et al, 2007; Taylor 2005). Many participants felt that this occurred because of the changing nature of their condition. The participants experienced fluctuations in the severity of symptoms, which may have made it difficult for others to understand and instead more likely to question whether the symptoms were real (Dickson et al., 2007). This was evident from the quotation below.

“The thing I hear from everybody is, Gee, you look much too good to be sick! I hear that all the time because I’m not emaciated and I’m not staggering , and of course when people see me, they see me on the good days, when I can get out of the apartment. They don’t see me on the bad days when I can’t get out of bed”. (Unknown, Ware, 1992, p. 351).

Taylor (2005) adds that the delegitimisation of the condition by the medical profession may compound the idea that the condition is not real. Feeling ill and assuming the sick role but not having a diagnostic label, could be seen in Goffman’s (1963) terms as being ‘discrediting stigma’ as the behaviour is visible to others. Furthermore, this could be viewed a ‘felt stigma’, which can arise from the fear of discrimination.

The studies indicated that some patients were in a bind between wanting to meet the expectations of others in order to prevent stigmatisation and the questioning of the illness, but it was also difficult to meet other’s expectations because of the nature of the illness.

“Something is wrong with our bodies, but it doesn’t stop there. The illness extends into the world and the way it is...” (Unknown, Taylor, 2005, p. 502).

Due to the inconsistent nature of their symptoms, participants reported that they had to make last minute cancellations with friends. Participants felt that this put a strain on the friendships as this was likely to upset their friends, so participants typically found that they would stop being invited to social events with the passage of time. Some participants reported that they desired support from their friends and would discuss their symptoms, but often found their

difficulties were minimised by friends. Therefore, it appears that due to the loss of common ground, the inability of participants to reciprocate and the minimisation of symptoms led to the termination of friendships. Participants explained that they often felt angry and frustrated after social interactions. Furthermore, many participants described similar interactions with family members and reported feeling distressed by negative interactions. These experiences frustrated both the patient and the family member, leading to conflict at home, which put stress on the relationship.

Moreover, the negative experiences with others with regard to the reality of their illness left some patients feeling reluctant to seek support and help. In addition, many were also hesitant about asking people to make allowances for them. Some respondents were more likely to push themselves to the limit rather than experiencing disbelief with regard to their illness. This was evident in participant's social life, relationships with family members, partners and colleagues.

"I am constantly in a Catch-22 between always overextending myself to please others and facing people's disbelief and judgement when I can't go and ask for help" (Unknown, Taylor, 2005, p. 502).

Discussion

This synthesis reviewed qualitative literature which investigated the perceptions and experiences of stigma in a FSS population. The following four themes emerged from the literature indicating that some patients experience stigma through: diagnosis, the legitimacy of the illness, identity and relationships. It is important to emphasise that this synthesis is qualitative in nature, therefore, the results cannot be generalised. Instead, the results provide insight into the way in which some patients perceive their experiences.

When undertaking the search process, a bias was evident in the literature with regard to stigma experiences of patients diagnosed with CFS as opposed to the other forms of FSS. This may be because CFS is viewed as the most stigmatising of the FSS. This view is supported by quantitative research, as Looper and Kirmayer (2004) found that patients with CFS, fibromyalgia and irritable bowel syndrome report a higher level of perceived stigma in comparison to patients diagnosed with comparable medical conditions. When the perceived levels of stigma were compared between each of the FSS, the results indicated that patients

diagnosed with CFS reported the highest levels of perceived stigma. Looper and Kimayer (2004) suggest this may be because of the uncertainty with regard to the origin of the condition. Stahl (2001) also put forward this argument and stated that in recent years, fibromyalgia has become accepted as a legitimate condition, partly because there is now a better understanding of the illness.

Stigmatised diagnosis

Corrigan (2000) proposes that stigma is the use of stereotypes and labels to describe a person and prejudice occurs when these stereotypes are endorsed by society. The stereotypes generate emotional reactions in others, which, in-turn leads to discrimination in the form of negative behaviours towards the stigmatised person. It would therefore seem that labelling is a key factor when considering stigma. Despite this, the results of the review indicate that many patients were keen to have a diagnosis or label for their difficulties and participants may be in search of this diagnosis for many years. This is in line with Parsons (1951) who proposes that patients require a label for their condition to legitimise it. Unfortunately, the diagnostic labels the participants seek may be stigmatised by the medical profession as FSS has been a contested and is a controversial diagnosis (Barsky & Borus, 1999; Mayou, Kirmayer, Simpson, Kroenke & Sharpe, 2005).

It is of interest as to why some patients felt that they were denied a diagnosis. Previous literature has indicated that some professionals have reported that they do not view CFS as a legitimate disorder (Raine, Carter, Sensky & Black, 2004). Given the recent emergence within the literature with regard to a debate about the diagnostic label for FSS and whether or not this disorder exists as a distinct illness (Sharpe, Mayou & Walker, 2006), it is interesting to consider whether this reflects an old fashioned view. It could be that clinicians are aware that the label is stigmatising and do not wish to diagnose someone with a disorder that is self-stigmatising. Furthermore, given the difficulties diagnosing patients with FSS, it may be more useful to conceptualise a patient's difficulties using a psychological formulation when FSS is suspected. This will inform the treatment plan, but also provide the patient with a possible explanation for their difficulties. This may bridge the gap between the patient's need for an explanation for their difficulties, without gaining a stigmatised diagnosis.

The literature investigating the stigma of mental illness proposes that being given a psychological/psychiatric explanation for physical symptoms or being labelled as a

‘psychiatric patient’ for the first time could feel threatening as these labels are generally stigmatised by society (Mann & Himelein, 2004). The results of the synthesis indicated that some FSS patients prefer a diagnosis that is rooted in biology, whereas, others felt relief at a psychological explanation. It appears that there is not a one size fits all approach to diagnosis, which perhaps supports the utility of a formulation-based approach to treatment.

Legitimacy of diagnosis

The research literature suggests that non-adherence to medical regimens is associated with a poor relationship with the medical team and disagreement with the need for treatment (Kirmayer & Looper, 2006). Therefore, the relationship the patient has with the medical team is vital for recovery. It is also likely that the way FSS patients are treated by staff is important for the formation of beliefs about the efficacy of treatment. A common theme in the synthesis was that the legitimacy of the patient’s illness experience was called into question by medical practitioners. The results of the review suggest that patients are in search of a diagnosis to legitimise their difficulties; however, this legitimisation turns to stigmatisation as patients feel dismissed and devalued by medical practitioners. Indeed, many patients felt that their character was called into question and patients reported feeling judged to be malingering, which resulted in them being faced by disbelief or doubt about the reality of their symptoms.

The results of the review were in line with the research literature investigating perceived stigma of mental illness (Kuey, 2008) as the experiences the FSS patients had with professionals was important for the formation of opinions and beliefs about medical and psychiatric services. Many patients were reluctant to seek help for their difficulties because of the delegitimisation of their illness. In addition to these experiences, patients found that after care and rehabilitation services were not available to help them manage their symptoms.

It is still possible that the legitimacy of the illness may be improved by the recent debates within the literature with regard to epidemiology, epistemology and aetiology of FSS (De Gucht & Maes, 2006; Kroenk et al., 2007; Mayou et al., 2005; Sharpe et al., 2006). It is therefore of interest to see whether clinicians will gain clarity from the changes within the diagnostic criteria.

Stigmatised identity

The diagnosis of FSS can be seen as a mixed blessing as the label helps the patient to understand the condition, but this comes at the price of accepting and adopting a stigmatised identity. As the illness progresses, it becomes difficult for the individual to maintain their identity and social roles due to the debilitating nature of the difficulties. With a newly adopted illness identity comes the possibility of being labelled as someone with a disability. FSS patients appear to be reluctant to accept this label, but it is necessary for society to understand their difficulties in order to accept them. Many patients do not want the disability label as it summons the concept of chronicity and loss of hope for recovery, whereas many FSS patients may see themselves as momentarily disabled. As well as having to accept a new identity, it may be that FSS patients are rejected from the disability community as they are perceived to be functioning at a high level, but rejected from their own social group as they are not functioning at a high enough level.

Whitehead (2006) proposed that the identity of a patient diagnosed with FSS is on a trajectory and many patients in this study reconstructed a new positive identity and value system by finding ways to accept and manage their symptoms. Although some FSS patients are able to form a positive identity to overcome illness, others may not, and this may lead to the maintenance of difficulties. Patients may therefore require further support to help overcome this. It is likely that these patients would benefit from a psychological approach to intervention to help manage the chronic nature of their difficulties and explore their new identity. Henningsen, Zipfel and Herzog (2007) reviewed the evidence for effective treatments of FSS and proposed that the treatment of FSS should integrate psychological and biomedical treatments. As part of this review, they indicated that if an integrative biopsychosocial approach is adopted, then this will require a change in the approach to the training that Medical students receive with regard to the treatment of FSS.

Relationships

As stated, a diagnosis of a mental illness can lead to stigmatisation, social exclusion, discrimination and stigmatisation (Baumann, 2007). The results of the synthesis indicate that many friends and relatives lack understanding of the condition and may view FSS as purely psychological. Furthermore, it appears that FSS patients are in a difficult position as stigma

by others prevents them from having a normal relationship with people. Unfortunately their condition also impacts on relationships because of the disabling nature of the difficulties. There is emerging evidence for the effectiveness of family focused interventions in relation to the adjustment to chronic physical illness in adults (Carr, 2009). Therefore, there may be value in considering the use of a systemic approach integrated into a wider multi-modal intervention for people diagnosed with FSS.

Limitations

There are a number of limitations to this systematic review which restrict the generalisability of the findings. Firstly, it is important to consider that recruiting for a study of this nature may mean that the sample is self-selecting. For instance, FSS patients may volunteer for these studies if they were unhappy with the service that they have been provided with. Whereas, FSS patients who were satisfied with their treatment may be less likely to take part in research as their needs have been met. Therefore, it is important to emphasise that the results are suggestive and not conclusive.

The second limitation of this synthesis is that the qualitative studies selected for this synthesis used different qualitative methodological and theoretical approaches. The feasibility of this is a topic of debate within the qualitative literature (c.f. Atkins et al., 2007). Researchers from one side of the debate argue that it is not meaningful to combine studies from different theoretical standpoints (Dixon-Woods, Fitzpatrick & Roberts, 2001). On the other hand, other authors argue that combining qualitative research from different epistemological basis is valid and enriches the analysis (Doyle, 2003). Although this debate is still present in the literature, it is important to consider that the value of qualitative research is now recognised in the development of health policy, as the opinions of service users are now seen as an important source of information.

Future directions

The studies in this systematic review focus on patients who have been treated by medical services. Given that patients with FSS present with a complicated picture of medical and psychiatric difficulties (Wessely & White, 2004), it may be of interest to undertake a

qualitative research study investigating the experiences of patients who have been referred to Liaison Psychiatry departments within general hospitals. The views of these patients may be of interest as Liaison Psychiatry bridges the gap between medical and psychiatric difficulties (Lloyd & Guthrie, 2007). Furthermore, the clinicians within these departments are more likely to have specialist understanding of FSS. Therefore, it may be worthwhile considering the experiences of FSS patients who have been treated within these services to understand whether patients perceive these experiences to be less stigmatising. If this is the case, then it is possible to learn lessons from this treatment, which could be generalised across medical and psychiatric settings, to improve the quality of the service provided to FSS patients.

Conclusion

This synthesis indicates that there is a bias within the literature with regard to focusing on the experiences of patients diagnosed with CFS. It is unclear whether this is because this is a markedly stigmatised group or whether the research to date views CFS as distinct from other FSS. What is clearer is that stigmatisation experiences for people with FSS can occur in encounters with medical professionals with regard to the diagnosis and legitimacy of the condition. Furthermore, stigma experiences can also impact on the identity and relationships of people suffering with this condition. It may be that the debate within the literature with regard to the diagnostic terms and criteria for FSS may provide clarity for professionals, patients, caregivers and have a positive effect on the patients experiences of health services. Finally, the synthesis indicates that there is a gap in the research with regard to the psychiatric and psychological experiences of these patients.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., test revision). Washington: DC.
- Asbring, P., & Narvanen, A. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, **12**, (2), 148-160.
- Atkins, A., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *British Medical Council Medical Research Methodology*, **8**, article 21.

Barsky, A. J., & Borus, J. F. (1999). Functional Somatic Syndromes. *Annual International Medicine*, **130**, 910-921.

Baumann, A. E. (2007). Stigmatization, social distance and exclusion because of mental illness: The individual with mental illness as a 'stranger'. *International Review of Psychiatry*, **19** (2): 131-135.

Carr, A. (2009). The effectiveness of family therapy and systemic interventions for adult-focused problems. *Journal of Family Therapy*, **31** (1), 46-74.

Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, **54**, 765-776.

Corrigan, P. W. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology Scientific Practice*, **7**, 48-67.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, **1**, (1), pp16-20.

Deale, A., & Wessley, S. (2001). Patients' perceptions of medical care in chronic fatigue syndrome. *Social Science Medicine*, **52**, 1859-1864.

De Gucht, V., & Maes, S. (2006). Explaining medically unexplained symptoms: toward a multidimensional, theory-based approach to somatisation. *Journal of Psychosomatic Research*, **60**, 349-352.

Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the deligitimation experience: an interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology and Health*, **22** (7), 851-867.

Dixon-Woods, M., Fitzpartick, R., & Roberts, K. (2001). Inducing qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice*, **7**, 125-133.

Doyle, L. H. (2001). Synthesis through meta-ethnography: paradoxes, enhancements and possibilities. *Qualitative Research*, **3**, 321-344.

Goffman., E. (1963). *Stigma: notes on the management of a spoiled identity*. Prentice-Hall Inc, Englewood Cliffs.

Henningson, P., Zipfel, S., & Herzog, N. (2007). Management of functional somatic syndromes, *Lancet*, **369**, 946-955.

Kirmayer, L. J., & Looper, K. J. (2006). Abnormal illness behaviour: physiological, psychological and social dimensions of coping with distress. *Current Opinion in Psychiatry*, **19**, 54-60.

Kool, M. B., Middendorp, H., Boeije., H. R., & Geenen, R. (2009). Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis & Rheumatism (Arthritis Care & Research)*, **61**, (12), 1650-1656.

Kroenke, K. (2006). Physical symptoms disorder: A simpler diagnostic category for somatisation-spectrum conditions. *Journal of Psychosomatic Research*, **60**, 335-339.

Kroenke, K., Sharpe, M., Sykes, R. (2007). Revising the classification of somatisation disorders: key questions and preliminary recommendations. *Psychosomatics*, **48**, 277-285.

Kuey, L. (2008). The impact of stigma on somatic treatment and care for people with comorbid mental and somatic disorders. *Current Opinion in Psychiatry*, **21**, 403-411.

Link, B. G., & Phelan, J. C. (2001). Conceptualising Stigma. *Annual Review of Sociology*, **27**, 363-385.

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, **367**, pp 528 – 529.

Lloyd, G., & Guthrie, E. (2007). *The handbook of Liaison Psychiatry*. Cambridge University Press.

Looper, K. J., & Kirmayer, L. J. (2004). Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of Psychosomatic Research*, **57**, 373-378.

Mann, C. E., & Himelein, M. J. (2004). Factors associated with stigmatization of persons with mental illnesses. *Psychiatric Services*, **55**, 185-187.

Manu, P. (2004). *The psychopathology of functional somatic syndrome: neurobiology and illness behaviour in chronic fatigue syndrome, fibromyalgia, gulf war illness, irritable bowel syndrome, and premenstrual dysphoria*. The Haworth Medical Press: New York.

Mayou, R., Kirmayer L. J., Simpson, G., Kroenke, K., & Sharpe M. (2005). Somatoform disorders: time for a new approach in DSM-V. *American Journal of Psychiatry*, **162** (5); 847-855.

McCue, P. (2004). CFS/ME and mental health diagnosis: A qualitative approach to assessing the experiences of women who have recovered. *Clinical Effectiveness in Nursing*, **8**, 194-201.

Mengshoel, A. M., & Heggen, K. (2004). Recovery from fibromyalgia: previous patients' own experiences. *Disability and Rehabilitation*, **26**, (1), 46-53.

Moss-Morris, R., & Chalder, T. (2003). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, **55**, 305-308.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesising Qualitative Studies*. Sage Publications: London.

Page, L., & Wessely, S. (2007). *Functional Somatic Syndromes*. G.G., Lloyd & Guthrie, E (Eds.). Cambridge University Press: Cambridge.

Parsons, T. (1951). *The social system*. Glencoe, IL: Free press.

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

Ring, N., Ritchie, K., Mandara, L., & Jepson, R. (2001). *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews*. NHS: Quality Improvement Scotland.

Salmon, P., Peters, S., & Stanley, I. (1999). Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *British Medical Journal*, **318**, 372-376.

Schroder, A. (2010). The proposed diagnosis of somatic symptom disorders in DSM-IV: two steps forward and one step back? *Journal of Psychosomatic Research*, **68**, 95-100.

Scottish Office (2001). New Directions: report on the review of The Mental Health (Scotland) Act 1984, Edinburgh: Scottish Executive.

Scottish Office (2008). Equally well: Report on the ministerial task force on health inequalities, Edinburgh: Scottish Government.

NHS Scotland. (2006). See me so far: a review of the first four years of the Scottish anti-stigma campaign, Edinburgh, 'see me'.

NHS Scotland (2007). Fairer futures: building understanding, moving forward together, Edinburgh, 'see me'.

Sharpe, M., Mayou, R., & Walker, J. (2006). Bodily symptoms: New approaches to classification. *Journal of Psychosomatic Research*, **60**, 353-356.

Smith, B. J., McGorm, K. J., Weller, D., Burton, C., & Sharpe, M. (2009). The identification in primary care of patients who have been repeatedly referred to hospital for medically unexplained symptoms: A pilot study. *Journal of Psychosomatic Research*, **67**, 207-211.

Stahl, S. M. (2001). Fibromyalgia: the enigma and the stigma. *Journal of Clinical Psychiatry*, **62** (7), 501-502.

Taylor, R. R. (2005). Can the social model explain all of disability experience? Perspectives of persons with chronic fatigue syndrome. *American Journal of Occupational Therapy*, **59**, 497-506.

Thornicroft, G., Rose, D., & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, **19** (2), 113-122.

Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, 22, 108-119

Ware, N. C. (1992). Suffering and the social construction of illness: the deligitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, 6, (4), 347-361.

Wessely, S., & White, P. D. (2004). There is only one Functional Somatic Syndrome. *The British Journal of Psychiatry*, 185, 95-96.

Whitehead, L. C. (2005). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, 62, 2236-2245.

Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: a longitudinal qualitative study. *International Journal of Nursing Studies*, 42 (8), 1023-1031.

World Health Organisation. (1992). ICD-10 classifications of mental and behavioural disorder: Clinical descriptions and diagnostic guidelines. Geneva. World Health Organisation.

CHAPTER 2: MAJOR RESEARCH PROJECT

An Examination of the Psychiatric Experiences of Patients Diagnosed with Functional Somatic Syndrome within the National Health Service: A Qualitative Study

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Preparation in accordance with guidelines for submission to *Psychology and Health* (see appendix 2.1)

Submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy)

Abstract

Introduction: Research has indicated that patients diagnosed with Functional Somatic Syndromes (FSS) perceive that they are stigmatised by this diagnosis. To date, much of the research literature has shown that patients diagnosed with this condition report public experiences of stigma and experiences of stigma in primary care. Therefore it is of interest to investigate the experiences of FSS patients who access mental health services.

Objectives: To determine how patients with a diagnosis of FSS perceive their experiences of Liaison Psychiatry

Design: Three female FSS patients were recruited from Community Liaison Psychiatry Departments. A series of semi-structured, open-ended interviews were used. Transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Five super-ordinate themes emerged: Pathways to Liaison Psychiatry, referral to Liaison Psychiatry, stigma, the importance of knowledge and the benefits of Liaison Psychiatry.

Discussion: The participants stated that they had benefited from a referral to Liaison Psychiatry; however, stigma experiences were evident in the participant's narratives in the form of public and professional stigma.

Conclusion: This study discusses the implications for the treatment and care of FSS patients and provides directions for future research.

Keywords: Qualitative research, patient experience, Functional Somatic Syndrome, Medically Unexplained Symptoms, Medically Unexplained Illness, stigma, psychological, Liaison Psychiatry

Introduction

Functional Somatic Syndromes (FSS) are defined as a cluster of symptoms that cannot be explained by medical science (Manu, 2004). Henningsen, Zipfel and Herzog (2007) categorised constellations of FSS symptoms into three groups: pain, functional disturbance in different organ systems and fatigue. FSS are also known as medically unexplained physical illness, somatisation disorder, symptom based conditions or persistent symptom syndromes (Hymans, 1998). Historically FSS were thought to be specific disorders such as chronic fatigue syndrome (CFS), fibromyalgia, Gulf War Syndrome, Irritable Bowel Syndrome or premenstrual dysphoria (Sharpe, Mayou & Walker, 2006). Recent research challenges this and has shown that these conditions frequently overlap indicating that they are clinical variants of a single disorder (Barsky & Borus, 1999). A recent systematic review (Cox, 2011) indicated that this is reflected in the research literature as there is a higher concentration of research conducted with CFS than any other functional somatic syndrome.

It appears that patients diagnosed with CFS may reject the diagnosis as they feel their symptoms are not viewed as a legitimate medical illness by General Practitioners (GPs, Ware, 1992). Ware (1992) found that ninety percent of a sample of patients with CFS reported delegitimizing experiences when accessing GP services (Ware, 1992). Firstly, they felt that their symptoms were trivialised as common ailments that the majority of the population suffer, thus implying that the patient did not have a major medical condition. The participants also felt that the diagnosis of psychosomatic disorder shows that the medical profession do not believe their symptoms to be genuine. They also felt that this label was unfair as it implies that their symptoms were purely psychological in nature. Those who did not report delegitimising experiences were confident that their CFS was a physical illness or their GP could not dispute their physical symptoms as they were evident during the physical examination.

Salmon, Peters and Stanley (1999) explored patients' perceptions of medical explanations for somatic disorders. The findings indicated that a high proportion of patients did not agree with their doctors' explanations of their symptoms and felt they were rejecting their pain, anguish and distress. Many patients who thought their doctors did not believe them felt stigmatised by their treatment. A small proportion of patients felt empowered by the

explanation; however, this was more likely to occur when they felt that there was a physical explanation or when they did not feel blamed for the occurrence of their symptoms.

Dickson, Knussen & Flowers (2007) also investigated the delegitimising experiences of patients with CFS. The patients in this study reported feeling that their morality was attacked by their GP, as if they were fraudulently trying to avoid personal responsibilities by claiming to have a medical illness. They also perceived a diagnosis of CFS as stigmatising. The interviews also indicated that delegitimation and stigmatisation were not limited to GP surgeries and medical services, but were also encountered in interactions with their friends and partners. Due to the unobservable nature of the symptoms and the fact that the severity of the illness was not constant, patients felt that their friends and partners thought they were malingering.

To date, the research evidence indicates that patients with FSS can perceive their experiences of GP services and social contact with friends/family as stigmatising (Dickson et al., 2007). Furthermore, FSS patients can be left with the feeling that they do not have a legitimate medical problem (Kool, Middendorp, Boeije & Geenen, 2009; Kuey, 2008; Looper and Kirmayer, 2004; Moss-Morris & Chalder, 2009). Much of the research literature focuses on the experience of care provided by GPs and medical services (Arrol & Senior, 2008; Deale & Wessely, 2001; Raine, Carter, Sensky & Black, 2004; Smith, McGorm, Weller, Burton & Sharpe, 2009). FSS patients, however, frequently experience mental health difficulties in addition to physical health problems (Barsky & Borus, 1999; Henningsen et al., 2007; Manu, 2004; Mayou & Farmer, 2002). Therefore there appears to be a gap within the literature investigating experiences of psychiatric services. Due to the combination of physical and mental health symptoms, FSS patients are commonly referred to Liaison Psychiatry. Liaison Psychiatry acts as a bridge within general hospitals to aid planning in the care pathway of patients who require treatment in physical and mental health services (Carson, Dawson, Marshall & Slatford, 1998). Liggins and Hatcher (2005) examined the experiences and perceptions of patients with physical health difficulties who had been referred to Liaison Psychiatry. Although this study did not focus solely on the experiences of FSS patients, it indicated that patients felt stigmatised by this referral and highlighted the difficulties that patients have when they are referred from physical health services into Liaison Psychiatry.

The current study aims to explore the experiences, beliefs and perceptions of FSS patients who have been referred to Liaison Psychiatry and have been working with a Psychiatrist or Clinical Psychologist within this team for at least six months. This is of interest as it is possible that being given a psychological/psychiatric explanation for physical symptoms or being labelled as a 'psychiatric patient' could feel threatening as these labels are generally stigmatised by society (Mann & Himelein, 2004). A diagnosis of a mental illness can lead to stigmatisation, social exclusion, discrimination and stigmatisation (Baumann, 2007). Therefore, individuals who have been referred to Liaison Psychiatry may fear stigmatisation by their family, friends and the general public. It is also likely that the way FSS patients are treated by NHS staff is important for the formation of beliefs about the efficacy of treatment. The literature suggests that non-adherence to medical regimens is associated with a poor relationship with the medical team and disagreement with the need for treatment (Kirmayer & Looper, 2006).

Interpretative Phenomenological Analysis (IPA, Smith & Eatough, 2007) will be used as a tool to explore how these experiences have affected the patients. It is thought that this approach will allow for themes that are important to the participant to emerge, without the views and assumptions of the researcher (Smith, Flowers & Osborn, 1997).

Objectives

To inform the treatment and management of NHS staff who work with FSS patients.

Design

Participants

In accordance with IPA methodology (Smith & Osborn, 2003), purposeful sampling was used to select a homogenous sample of participants for whom the research question was relevant. The sample comprised of three female participants aged 42 years old, 47 years old and 50 years old. All of the participants were recruited from Liaison Psychiatry outpatient services and had been diagnosed with Functional Somatic Syndrome or with Medically Unexplained Symptoms. This diagnosis had been made by a Liaison Psychiatrist. Participants became eligible for the study after they had undergone assessment and at least six months of treatment. Further participant information can be found in table 1.

Table 1: *Participant information*

Pseudo Name	Age	Gender	Age at diagnosis	Length of illness	Diagnosis
Michelle	42 years old	Female	20 years old	27 years	Functional Somatic Syndrome with a primary diagnosis of somatisation disorder
Catherine	50 years old	Female	18 years old	32 years	Functional Somatic Syndrome with a primary diagnosis of Irritable Bowel Syndrome
Laura	47 years old	Female	42 years old	5 years	Medically Unexplained Illness

Inclusion Criteria

- Participants were eligible for the study if they had received a diagnosis of functional somatic syndrome, been referred to Liaison Psychiatry and been assessed and treated for at least 6 months.
- The study focused on adult services and patients were eligible for the study if they were 18 years old or over.

Exclusion Criteria

The study attempted to isolate stigma related to mental illness. Therefore, participants were excluded from this study if they were members of a social group which may have been a target for stigmatization prior to their referral to Liaison Psychiatry. The study excluded:

- Participants over the age of 65 years as they may have been discriminated against due to age.
- Participants were excluded from the study if they were likely to have experienced discrimination or stigmatization on the grounds of race.
- The study involved an interview which required a good standard of English. Therefore, patients who required an interpreter were not eligible for the study.

Procedure

A favourable opinion was granted by an NHS ethics committee before commencing with recruitment (Appendix 2.2, 2.3 & 2.4). Participants were notified about the study by their Liaison Psychiatrist (Appendix 2.5 & 2.6). After agreeing to participate, participants were informed about the study by the main researcher and invited to the Department of Liaison Psychiatry to take part. Each participant was requested to formally consent to taking part in the study by signing a consent form (appendix 2.7). A series of semi-structured, open-ended interviews were used as it was thought that this would allow the ideas and concepts most important to the participants to emerge. The interviews lasted between 52 and 96 minutes. The topic guide (Table 2) was developed by identifying important issues from relevant research literature (Leventhal, Brissette & Leventhal, 2003; Liggins & Hatcher, 2005). These questions were used to guide the discussion and a non-directive approach was taken to encourage participants to develop and elaborate on their own narratives. Probing questions were used to investigate issues further where necessary (Table 3).

Analysis

The interviews were recorded and transcribed verbatim and anonymised as necessary. The patient's names have been changed to protect confidentiality. The results were analysed with the use of Interpretative Phenomenological Analysis (IPA), taking a bottom-up approach (Smith & Eatough, 2007). In accordance with IPA methodology (Smith & Eatough, 2007) each transcript was repeatedly read and recurrent themes were noted to allow for the

identification of both common and contrasting themes. To check the reliability of the analysis, all three transcripts were analysed by an independent researcher to verify whether the identified themes reflected the views of the participants.

Table 2. Topic Guide

Topic guide
How did your difficulties start?
What are your experiences of seeking medical treatment for these difficulties?
What are your experiences of being referred to Liaison Psychiatry?
How did you feel about being referred to Liaison Psychiatry?
What impact on your life did being referred to Liaison Psychiatry have?
What are your expectations for the future?

Table 3. Probes

Probes
Could you tell me more about that?
Can you give me an example of that?
What did that make you think of?

Results

Five super-ordinate themes emerged from the interviews with regard to how FSS patients viewed their experiences of Liaison Psychiatry (table 4). Each super-ordinate theme was consistent across all three narratives. The first super-ordinate theme to emerge from the data was the pathway that led to a referral to Liaison Psychiatry. The second super-ordinate theme to surface from the data was the referral to Liaison Psychiatry. The third super-ordinate theme was stigma as a consequence of being referred to Liaison Psychiatry. The fourth super-ordinate theme to emerge from the narrative accounts was the importance of knowledge. The final super-ordinate theme evident in each transcript was the benefits of being referred to Liaison Psychiatry. The following five sub-themes emerged from this super-ordinate theme: diagnosis/psychoeducation, normalisation, holistic view, therapeutic factors and coping strategies.

Table 4: *List of super-ordinate and sub-themes*

Theme	Super-ordinate theme	Sub-theme
Theme 1	Pathway to Liaison Psychiatry	• No sub-theme
Theme 2	Referral to Liaison Psychiatry	• No sub-theme
Theme 3	Stigma as a consequence of accessing Liaison Psychiatry	• No sub-theme
Theme 4	The importance of knowledge	• No sub-theme
Theme 5	The benefits of Liaison Psychiatry	1. Diagnosis/psychoeducation 2. Normalisation 3. Holistic view 4. Therapeutic factors

Super-ordinate theme 1: Pathway to Liaison Psychiatry

Each participant discussed the pathway of care which resulted in a referral to Liaison Psychiatry. Michelle's experience of services began when she attended her GP with concerns over her physical symptoms (e.g. fatigue and unexplained pain). Her narrative account was characterised by a sense of rejection from medical and mental health services. The quotation below outlines her first experience of rejection by services:

"I was having difficulty with all sorts of physical symptoms. Went to the doctor 27 years ago, got smacked on the wrist and sent home and told that my husband didn't beat me up and brought the wages home, so what was wrong with me, so. And that's the way they treat somatisers now. So that was it. I was sent on my way." (Michelle, illness duration 27 years)

After a prolonged and chronic illness, Michelle attempted to seek psychological intervention. There was a sense of being passed from pillar to post and the feeling that mental health professionals were unwilling to support her. She was never given an explicit reason why she was rejected from mental health services. In the following extract Michelle describes a sense of rejection and abandonment from services. Michelle listed the number of services she has been referred to since early adulthood. Her words feel disconnected to her emotional experience, perhaps emulating the way she was treated by services:

*"Saw CPN who referred me to psychiatry, who saw me once and referred me to psychology. Saw psychiatrist again, who then referred me to psychology. Saw psychologist 3 times, who referred me to Liaison psychiatry, who saw me once and told me to f*** off basically. So my opinion of the mental health services is absolutely ridiculous and that was the way I was left. What I then had to do was do a letter of complaint."* (Michelle, illness duration 27 years)

Catherine and Laura's experiences by the NHS differed from that of Michelle. Both participants reported positive experiences of services. It appears that Laura's positive view of

services is related to the ease and speed at which her referral was followed up and the holistic approach to treatment:

“I think the way everything sort of progressed it was all kind of followed up really quickly. My GPs been great. Referring me for different things. So he’s been really helpful that way. As I say, when I saw [name of medical consultant] he was great in getting my thyroid and everything diagnosed and recommending the treatment and everything. Getting all that done. Erm, [name of Liaison Psychiatrist], she’s been really helpful as well. Teaching me how to cope with things.” (Laura, illness duration 5 years)

Catherine also viewed her experiences of medical services positively; however, she felt that there was an aspect of her care that was missing from medical treatment alone. Although she was satisfied with the quality of the service she received from medical profession, she felt that this could be improved by taking more of a holistic approach to treatment and considering the emotional aspect of her condition as well as the physical complications. Her view of the emotional aspect of treatment is evidenced below:

“I suppose the main aspect is that going through the medical things, em, is that the emotional if you like, isn’t really addressed and maybe it can’t be or there isn’t time or whatever. But I think em it can. That is quite an important aspect that is overlooked. Em and particularly if it goes on. Chronic illness I think can have quite a profound effect on people’s emotions, psychology and, you know, how they feel about life in general. So I don’t know if that’s acknowledged by medical people. Maybe it needs to be or I think should be, but, but obviously that’s my feeling. And certainly coming here [Liaison Psychiatry] then validated some of these feelings and that you’re not alone. I think that’s one of the main things. That you’re not alone in feeling these things. That it’s quite a normal reaction.” (Catherine, illness duration 32 years)

Super-ordinate theme 2: Referral to Liaison Psychiatry

All three of the participants were open to the idea of being referred to Liaison Psychiatry; however, their experiences of being informed about the referral to Liaison Psychiatry differed. Michelle’s sense of rejection by medical and community mental health services initially continued into her treatment and care by Liaison Psychiatry. She was assessed by

Liaison Psychiatry seven years ago and deemed to be not suitable for the service. She was unclear as to the rationale behind this decision. The experience left her feeling further abandoned by services:

*“The first time I was referred to Liaison Psychiatry would have been, probably been, maybe, 2004 or something. You know I was just desperate to see somebody who was going to actually offer me some help and support. And to be honest with you, with somebody who was so upfront about their symptoms and so upfront about wanting help. Like, please f***** help me. Look, please don’t send me home. I think I said that to the last guy before [Liaison Psychiatrist] I actually got the help and being sent home. What chance does somebody with somatisation disorder have of getting help if I was actually pleading for help and saying that I totally accept if this is what’s wrong with me. Even when I found out, I still had to fight to actually get to see somebody who could actually help me. I think they have no interest in helping people with somatisation disorder.”* (Michelle, illness duration 27 years)

This sense of frustration and abandonment led her to feel like she had no alternative but to make an official complaint about her treatment to the Director of Mental Health Services. Although she is now satisfied with the treatment she is receiving, her current experience was soured by her previous rejection by services and the view that she had to fight the system in order to be accepted:

“I don’t think they really cared who seen me, as long as somebody was seeing me. That’s my only, because it was from writing the letter. No waiting list. Within 8 weeks, I was being seen, from the Director getting this letter. And I just thought ‘Well sometimes you just need to scream.’ You know, and it did take me eh, eleven years, oh getting messed about with them before I thought ‘Oh, enough’s enough. Now I have a diagnosis. I want help’. (Michelle, illness duration 27 years)

Michelle went on to consider the profession who would be best placed to meet her needs:

*“I wanted to see the right person and even in, in this you know, my questions. I didn’t want to see a psychologist. I didn’t want to see a psychiatrist. I wanted to see someone who specialised in my condition because I’m p***** off and I’ve been through enough people.*

And there is no use in sending me to see someone who didn't understand what was wrong with me" (Michelle illness duration 27 years)

Unlike Michelle, Laura's narrative indicated that she moved between medical and mental health services with ease. She felt that the medical specialists took a holistic approach to her well-being and recommended that she seek psychiatric intervention. It appears that her medical specialist was sensitive to her concerns about being referred to a Psychiatrist and openly discussed this with her; however, this could also be viewed that he held a stigmatising view of psychiatric services:

"I mean I was worried about the thought of telling other people more so than myself. I mean [name of specialist] did say at the time. You know it doesn't mean that you are going nuts or whatever. You're not going mad because you are seeing a psychiatrist. He said a lot of people don't like the idea of that. But I said 'I don't care, if they can help me, I will do it. I don't care. Just send me to someone who can help'." (Laura, illness duration 5 years)

Although Laura appreciated and understood his concerns, she recognised that she may benefit from psychiatric intervention. In her view, her self-awareness and willingness to seek help was influenced by the positive experiences her children had with psychological services:

"You know, I think these experiences with my children have made me more willing to look for help myself because I knew what they had been through." (Laura, illness duration 5 years)

Catherine's account of being referred to Liaison Psychiatry shared elements of both Michelle's and Laura's experiences. Michelle's account indicated that she was referred to Liaison Psychiatry as a last resort and Catherine was also left with this feeling. Although Catherine was left with the sense that this was the last resort, she was open to referral; she too had a past experience of the benefits of psychological intervention:

"I was back seeing another, the same, the Gastroenterologist and he'd just done another colonoscopy and he was at his wits end (laughs) I think. And he suddenly said to me. Very out of the blue, in my consultation 'I'm going to refer you to this thing called (laughs) the Psychiatry Liaison Service.' Right. Just. He said 'I've heard good things about them'. And I said 'Oh what are they?' And he couldn't tell me anything about it. I wasn't kinda freaked

out by the term Liaison Psych, Psychiatry. I mean some people I think would have run a mile. Just the word Psychiatry in the title. But I and I did get the distinct impression he was thinking 'I can't find anything wrong with you, so what's your problem? I'm going to send you to this place because I can't think of anything else to do with you'. But I mean I think he did it for that reason although I think it was of benefit to me. I don't know, I don't know that he necessarily knew it was going to be of benefit to me." (Catherine, illness duration 32 years)

Super-ordinate theme 3: Stigma as a consequence of accessing Liaison Psychiatry

Michelle and Catherine both described stigmatising experiences of being viewed negatively because they were accessing mental health services. Catherine described different levels of stigmatisation and delegitimisation of her condition. For Catherine, there were four levels of delegitimisation. Firstly there was the initial reaction of people who believe she was fraudulently making up the severity of her condition, which goes against the family mantra 'get on with it'. Once her family became more aware of her condition; there were those who accepted the reality of her condition completely (e.g. sisters), there were those who did not understand, but pretended to accept her condition (e.g. brother), there were others who did not accept the legitimacy of her condition and were explicit about this (e.g. sister in-law) and there were those who witnessed the reality of her condition, accepted it, but did not understand the psychological consequences of this (e.g. partner):

"I think for quite a long time I felt they were not completely convinced that it was as bad as it seemed to be or it was. I think they kind of. I don't know. I have. Maybe it was me thinking that they thought that but I I don't think they were completely convinced. They thought I was slightly. Not a hypochondriac, but slightly playing it up or overreacting or not getting on with it. Because we are a bit of a family of these kind of get on with it kind of thing. But more recently, since I gave up work and I've seen a lot more of them, they are completely on board and accept that this is what's going on. My brother doesn't have a clue. I mean he will. He'll ask me how I am and that's about it. You know, I'll say 'I'm fine' or 'just the same' or something like that and that's as far as it goes. And his, my sister in-law, his wife thinks I'm completely making it up, so. Cause when I was talking about my tiredness you know her response would be 'well we're all tired' (laughs). So I quickly learnt not to say anything about it or anything. So that's the kind of differences. My partner is em, he has

been amazingly understanding, but I don't think he's completely grasped the really kind of emotional effects of it. I mean of course he's seen. I've had a huge change in my life and I've even given up work but I don't think he really knew the effects of that." (Catherine, illness duration 32 years)

Michelle and Catherine stated that they felt that some of their friends did not understand their condition and, in Catherine's case, this led to the loss of friendships. What is striking from Catherine's account is the acceptance of her stigmatisation experience over the passage of time. In order to maintain friendships, she has learned that she needs to change the way she interacts with the world and others. She has learned that the social rules of life will not adapt to support her and make allowances for her condition:

"The one thing that did used to upset me, but I've got used to it now, is that I've lost one or two friends over this because I had to keep cancelling appointments, especially at first. Em, before I realised I couldn't always plan things, I'd plan things and then I'd have to cancel." (Catherine, illness duration 32 years)

Michelle highlights that she felt that her friends have looked down upon her because of her mental health difficulties and view her as 'less' than them. She also makes an interesting point where people have made excuses on her behalf for the way she acts and behaves. If she engages in behaviour deemed socially unacceptable, then people have excused this by stating that this is related to her mental health, making it a static event that can be changed or excused, rather than part of her personality, which is stable. Michelle's narrative also indicates that she is angry at services for not providing her with a diagnosis. She believes that people must be told if they have a mental illness by professionals. It is therefore of interest to note that if someone upsets her by highlighting her mental health difficulties, she will retaliate by pointing out their mental health problems as she sees them. This is an interesting juxtaposition as it could be seen as a punishment or retaliation for something that she describes as a human right:

"And I've also found that the people that I've told, on some occasions, I would say that they excuse my behaviour or lack of behaviour due to my mental health, when it's got nothing to do with my mental health. It's because that's how I'm feeling. And I think sometimes people will kind of 'oh well, you know, she has mental health problems, you know. But I'm quite up

front and, you know, I'm kind of able enough, you know, to turn round and say to people, you know, 'you've got your own mental health problems', you know. So even when. Because I attend somebody for mine, doesn't mean to say that makes me worse or less than you, you know." (Michelle, illness duration 27 years)

Unlike Michelle and Catherine, Laura did not experience direct stigmatisation because of her mental health difficulties. Laura feared the label of being known as a psychiatric patient and protected herself from this by only telling people she could rely on and trust:

"Um, I think a lot of it is that as soon as you say that you are going to see a psychiatrist. You know (laughs). You know the kind of label. But you know, I think their reactions were ok. My family work in a related area so are tuned into a lot of these things. I didn't tell just general friends. My close friends yes. But, you know, I sort of, but then I've not advertised all my other health problems to casual friends, you know. You are not going to go into detail about everything with them, so. I'm kind of a private person, you know. If I know someone well enough then that's fine. I can sort of open up a wee bit more to them. You know, close family and close friends, but not sort of everybody sort of thing. My children know all about the psychiatry thing. I've been quite open with them about it. They know I've been coming and that [name of Liaison Psychiatrist] has been trying to help me cope with everything. I think a lot of the time I would try and hide things from them and just say. 'Oh, I'm really tired. I need to go to bed.' You know, because you don't want your children to be worrying about their parent. So I would try and not show too much to them. You know, so that they weren't worrying about how I was feeling. But then they would sometimes come home and say, 'how are you feeling today mum? Are you alright?' You know, that's wrong. It's me that should be doing that to them." (Laura, illness duration 5 years)

Catherine has learnt over time who can and cannot be trusted with knowledge of her mental health difficulties. Like Laura, Catherine has come to the conclusion that it is best to keep certain aspects of her life private for fear of stigmatisation. She also emphasises that she sometimes makes a conscious decision not to discuss her condition or treatment she is undergoing because she would like to focus on enjoying the social situation, rather than brooding on her illness experience. This is evidenced by the following quote:

“A couple of friends. Hmmm, I would say not completely . To a certain level. The rest no. I don’t . I just kind of think it’s boring, you know. Who wants to hear all this stuff when I go out with them? I don’t want to talk about it either. If I ever. If I’m feeling well enough to go out the one think I don’t want to be doing is talking about this.” (Catherine, illness duration 32 years)

Catherine was keen to make it clear that her stigma experiences with family and friends pale into insignificance when compared to her recent delegitimisation experience of having her state benefits reviewed. Catherine described the process of exploring her feelings about this assessment in the extract below:

“It wasn’t facing the tribunal as such. It was something about it. And we explored that together [with Clinical Psychologist] and it was a lot to do with being judged and feeling that, you know, I felt a sense of injustice because all this evidence and somebody who’d seen me for half an hour decided against all of this other evidence that their judgement was correct. And I was being put, literally in front of a judge. I was going to write to the newspaper actually funnily enough, but then they did a huge spread on it which covered everything, which was really amazing, so I felt reassured that other people were going through the same thing. They used the same terms as I was using about how they make you feel humiliated and as if you’re lying and all these kind of things. You know and it’s just very stressful.” (Catherine, illness duration 32 years)

Super-ordinate theme 4: The importance of knowledge

All three participants commented on the importance of knowledge and understanding their condition. In Michelle’s experience she sensed that professionals were reluctant to make a diagnosis of FSS. For her, a diagnosis is essential as this label justifies and legitimises her lived experience. She went on to add that knowledge, understanding and a diagnosis gave her a sense of empowerment:

“When you talk about somatisation disorder they are all in agreement that they don’t tell people and I don’t know what gives them the right to no tell somebody what’s wrang with them because knowing. You know and quite often [name of Liaison Psychiatrist] will ask me ‘why does knowing anything make a difference?’ Why wouldn’t it be important to know

what's going on in your psyche, d'you know. Especially when it's having a huge influence on your body and it obviously makes a difference. Its gave me words." (Michelle, illness duration 27 years)

Michelle went on to explain that the diagnosis has been a crucial weapon in the fight against stigmatisation and delegitimisation:

*"But I have reasons now Paula and it's like. See if my man will say, but you said that you were going to do that. Before I would have just became this babbling, like, f***, I don't even remember being asked and taking the whole responsibility or whatever. You know what had or hadn't happened. Whereas now I will say 'You know my memory is extremely poor. So don't ask me to remind you of things' and therefore I feel empowered to an extent [yeah]. I suppose is the word. And I don't mean empowered to p*** people off, which I do, I have to say. You know because I do. I stand up for myself. Whereas before I couldn't Paula. Before it was just people saying, 'but how many psychiatrists and psychologists have you saw who have told you you're depressed?' And you are looking at your best friends even and you're thinking. I am telling them that that's not (crying) and nobody is believing me. And that was really upsetting because you felt that you were battling on all fronts."* (Michelle, illness duration 27 years)

There was a sense from Laura and Catherine that their existing knowledge and access to knowledge may have aided their access to psychiatric services, which ultimately led to satisfaction with their care. Laura felt that her previous knowledge and experience bridges a gap between the powerful, knowledgeable professional and the helpless patient. It appears that by displaying her knowledge, she can protect herself from being patronised, which may actually allow her to gain the respect of professionals:

"When I went for radioiodine treatment, they were trying to explain to me that. Well this is the radioiodine. I just said its ok, I've got a [title of relevant] degree. I understand. It makes things a lot easier when they don't have to go through all the big explanations of what they are going to do and what this does, so. I think it helps because I think sometimes doctors patronise you, you know. They think you're stupid and won't understand anything. You know they try and kind of not give you information and I think that the fact that sometimes I go in and they try to start explaining basic terms. And when I say to them 'You know, I

understand.’ You know it makes a difference because they kind of speak to you more. More sort of on your level, you know, rather than beneath you sort of thing.” (Laura, illness duration 5 years)

All three participants reflected that knowledge and learning about their condition has been crucial for their quality of care. They all note concerns for others who may not have been as able as them to learn and understand their condition. This is evidenced by the quote below where Catherine reflects on her experience. It appears that although knowledge can empower the patient, Catherine wonders whether this can impact on the professional relationship in a different way as professionals may feel irritated by patient knowledge:

“So I’ve just been kind of erm. I have to keep on top of it myself and I do worry about other people who maybe can’t remember things or don’t have as much knowledge or access to knowledge or whatever. How they cope with going to specialists, I don’t know. But anyway, I’m sure they are not very keen on me because I have a lot of questions and do ask lots of questions as well about treatments. I have opinions about treatments as well.” (Catherine, illness duration 32 years)

Catherine feels that her positive experiences of services may be as a result of her confidence and desire for input into her treatment. She reflects on her experience with services and has noticed the implementation of the patient choice agenda:

“But that’s because I can assert my. I’m not cowed by specialists. I will, I will say, you know. I think it should be a dialogue anyway. Obviously they have the knowledge. But I’ve actually found over the years that I’ve been going to specialists they increasingly actually ask you. They don’t say ‘This is what you are going to do’ They kind of, sort of give you a choice.” (Catherine, illness duration 32 years)

Super-ordinate theme 5: Benefits of Liaison Psychiatry

Although the care pathway that led to Liaison Psychiatry differed for each participant, all three participants agreed that they were satisfied with the quality of the service that they were receiving from Liaison Psychiatry. The following quotation reflects the views of all three participants about the benefits of attending Liaison Psychiatry:

“There’s been huge changes with me in the last two years. The first thing is physically. You know, physically I am able to do anything. I may struggle after it, and have to do a lot more of my relaxations and my de-stressing and especially with physical tasks. It takes me now two and a half minutes to get up and it used to take me two and a half hours to get up in the morning.” (Michelle, illness duration 27 years)

Although each of the participants agreed that they are receiving a good service from their respective clinicians at Liaison Psychiatry their views of the individual benefits of Liaison Psychiatry differ. As indicated in table 4, five sub-themes emerged from this super-ordinate theme.

1. Diagnosis and psychoeducation

In Michelle’s view, she feels the biggest benefit of Liaison Psychiatry has been the diagnosis and psychoeducation about her condition. It is of interest to note when she says ‘and I have no idea, and I’m sure you all will’. This may suggest that she is still finding it difficult to trust professionals and may feel that the professionals she is working with at present are hiding elements of her condition or treatment from her:

“Do you know words have made a huge difference. I have no idea, and I’m sure you all will, but I have no idea why that word made a difference, but it made a huge difference. And I’ve had my wee kind of eureka moments where they have said something and I’ve thought. God, you know” (Michelle, illness duration 27 years)

2. Normalisation

Laura feels that Liaison Psychiatry has been of benefit to her as this as this normalised her illness experience:

“Well just coming and meeting with [Liaison Psychiatrist] and talking to [Liaison Psychiatrist] and [Liaison Psychiatrist] telling me that no, I wasn’t going mad. Um, [Liaison Psychiatrist] could teach me ways that I could cope with anxiety. To know that I wasn’t the only person that felt like that. There were other people who were like me or worse than me.

And that helped a great deal. When it's just you yourself, you kind of feel sort of isolated and you think I'm the only person that is like this. You know, I'm sitting in this wee corner going mad myself." (Laura, illness duration 5 years)

Given that she has benefited from having her experience normalised, she feels that her treatment could have been improved by being involved in group treatment:

"My experiences, as I say, have been good. I do think it would have been nice to maybe speak to other people with similar problems to me. The fact that I would be able to reassure people who are going through the difficult times that I've been through. That yes, there is light at the end of the tunnel. You can come out of it and there will maybe be people further down the line in treatment from me, who would say, 'well I was like you a year ago' or whatever, and, you know, and 'things are a lot better now.' So that kind of side of things. It would be nice to have someone else to speak to" (Laura, illness duration 5 years)

3. Holistic approach

Catherine feels that she has benefited from Liaison Psychiatry in a number of ways. She described the importance of having a holistic approach to intervention and being made to be viewed as a person rather than a specific body part:

"It was having someone, it was someone to talk to whose not looking at the medical things because all the different specialists are focusing on physical medical things. Erm, and they don't really talk about anything else. Erm, and they are all looking at different individual bits and its someone who kind of sees you. I mean homeopaths do that, they see you as a whole person, but more and also just talking to, talking to [name of Clinical Psychologist]. [Name of Clinical Psychologist] saw me a whole person not just the bits of my body that were going wrong." (Catherine, illness duration 32 years)

4. Therapeutic factors

Catherine went on to explore the importance of therapeutic factors when engaging in psychological intervention. She described feeling that the therapeutic relationship as vital and allowed her to utilise coping strategies which she could use in everyday life. She also

identified that her treatment helped her to overcome the loss of her previous life and have more acceptance for her new life, post-diagnosis:

“From the very beginning, what I think, what I felt straight away. I felt very at ease in [name of Clinical Psychologist] company. [Name of Clinical Psychologist] was very relaxed. Em, and I didn’t feel like I was some strange person who had all these illnesses and everybody just didn’t know what to do with me. Em, and I felt kind of a an acknowledgement from him that he would help me, if you like, cope with it rather than trying to diagnose me or it was trying to help. Work with me to find ways of coping with some of the aspects and things that I was doing that looking back were utterly ridiculous. Things like I thought I had to save my energy. He used a really great analogy of erm, a marathon runner doesn’t lie on the couch for a month running up to the marathon. They do little bits every day and it just clicked straight away because I was trying to live my previous life. (Catherine, illness duration 32 years)

5. Coping strategies

Catherine went on to describe some of the therapeutic techniques that she found especially useful:

“So he said, you know, really simple straight forward things that you think you would think of, but in the middle of it you can’t always. Which are, break into manageable pieces, do a little bit, you know, when you can, Pacing. All those kinds of things. Erm not trying to do boom and bust.” (Catherine, illness duration 32 years)

Discussion

This study set out to gain insight into the treatment experiences of three patients who had a diagnosis of FSS and were accessing Liaison Psychiatry. The results of the interviews indicated that each of the participants generally viewed their current treatment by their respective Liaison Psychiatry services positively. The narrative accounts differed with respect to the care pathways that led each participant to a referral to Liaison Psychiatry and

the specific treatment factors that were viewed to be beneficial. A discussion of these factors is presented below.

Pathway to Liaison Psychiatry

Michelle's experiences of rejection and dissatisfaction with services were in line with the experiences of other sufferers of the condition. The research evidence to date indicates that this population can feel that the reality of their symptoms is called into question by professionals (Salmon et al., 1999). Furthermore, FSS patients have reported dissatisfaction with their treatment by primary care services (Dickson et al., 2007) and feel that their needs have not been met in relation to a holistic approach to treatment (McCue, 2004). This is of interest as the participants in this study had a positive view of Liaison Psychiatry. It is possible that Laura and Catherine were satisfied by their treatment as when an unmet need was identified, this was followed up quickly with a referral to a relevant service that was likely to meet the patients' hopes for treatment (e.g. mental health services). Laura and Catherine never felt rejected by services. It would therefore be of interest to understand why Michelle was not deemed suitable for intervention for her mental health difficulties at an earlier stage of her treatment.

Referral to Liaison Psychiatry

As stated, the participants accepted the referral to Liaison Psychiatry. This is in contrast with published literature investigating the beliefs of participants with CFS (Mengshoel & Heggen, 2004; Whitehead, 2006). This research has indicated that many of the participants in these studies held biomedical beliefs in relation to their condition, therefore rejecting the biopsychosocial view (Mengshoel & Heggen, 2004; Whitehead, 2006). The participants' acceptance of Liaison Psychiatry in the current study appears to be fostered by two factors: previous knowledge/experience of psychiatric services or desperation for treatment. In relation to this, McCue (2004) found that not all patients with CFS are uncomfortable with a psychological explanation. Instead the participants in the McCue (2004) study felt that medical professionals feel uncomfortable associating a psychiatric label to this condition. The patients reported that despite the professional's discomfort, they would actually feel relief at being given an explanation for their difficulties (McCue, 2004). This view was

echoed in Laura's narrative account as she stated that her medical consultant took time to explain the stigmatisation associated with a referral to a Psychiatric service, perhaps feeling uncomfortable about attaching psychiatric labels to his patient. In contrast, Catherine's medical consultant did not appear to hold a particularly stigmatising view of psychiatric services. Instead he viewed a referral to psychiatric services as a last resort and neglected to take a holistic, biopsychosocial approach to Catherine's treatment. This experience was also reflected in the narratives of the participants in the Liggins and Hatcher (2005) study who felt that professionals fail to recognise the link between the body and the mind.

Stigma as a consequence of a referral to Liaison Psychiatry

Liggins and Hatcher (2005) found that inpatient Liaison Psychiatry patients within a general hospital felt stigmatised by this referral. The participants in the Liggins and Hatcher (2005) study described the power imbalance between professionals and patients. They also reported that they were treated differently by professionals once psychiatric difficulties became evident. The participants also felt that professionals did not view them as having a genuine illness. The participants in the current study were community patients and therefore the stigma-related themes to emerge from the transcripts were different. As stated, the participants felt that the medical professionals viewed a referral to Liaison Psychiatry as a 'last resort' and pre-warned Laura that psychiatry is viewed as stigmatising. Despite this, the participants recognised that the referral would be beneficial. Indeed, Michelle had to fight to gain access to this service.

What became evident from the narrative accounts was the participants' distress in relation to public stigma (i.e. the attitudes, beliefs and reactions of the general population to mental illness) (Corrigan & Watson, 2002). Michelle and Catherine perceived that they were stigmatised as a result of a referral to Liaison Psychiatry by friends and relatives. As with previous research literature, Michelle and Catherine felt that they had control over their illness (Corrigan & Kleinlein, 2006), but were seen as unreliable (Watson, Corrigan, Larson & Sells, 2007) and lost friendships as a consequence of their condition (Dickson et al., 2007; Taylor, 2005). Michelle's account also indicates that she was dehumanised and made to feel inferior because of her psychological difficulties. This is in line with an IPA study conducted by Dickson et al. (2007) where participants with chronic fatigue syndrome recounted delegitimising experiences from relatives, friends and acquaintances. Although Laura did not

experience direct stigmatisation in relation to her condition, she was warned by the medical consultant that this may occur. She therefore protected herself from this by only telling trusted confidants that she was accessing a Psychiatric service.

The importance of knowledge

The importance of knowledge was reflected upon in two ways: knowledge of diagnosis and patient knowledge. Michelle referred to the importance of a diagnosis for her condition as a way of legitimising her experience. This echoes the views of others who have been diagnosed with FSS (Asbring & Narvanen, 2002; McCue, 2004; Mengshoel & Heggen, 2004; Taylor 2005; Ware, 1992).

The participants in this study felt that patient knowledge (e.g. through personal research and asking questions) allowed them to get access to their desired service, but aired concerns about less knowledgeable patients. It appears that the patient had to display this knowledge in order to get the desired service. Based on the narratives above, there is evidence of changing attitudes within professionals to respect the wishes of the patient through the patient choice agenda (Department of Health, 2005). The initiative also means that patient knowledge is becoming increasingly important in a modern NHS as professionals and patients form a partnership to ensure that the patient receives the best service possible.

Benefits of Liaison Psychiatry

There is emerging recognition for the needs of psychological intervention for patients with FSS (Mayou & Farmer, 2002). A number of randomised controlled trials have provided evidence for the effectiveness of Cognitive Behavioural Therapy (CBT) with this population in alleviating psychological and physical symptoms (Kroenke, 2007; Kroenke & Swindle, 2000). The benefits of psychological intervention using a CBT approach are evident in the experiences of the participants in the current study. In particular, although Catherine was satisfied with the quality of her medical care, she felt that her emotional needs were not being met by medical services. Furthermore, the participants note that psychoeducation, normalisation and behavioural techniques (e.g. pacing) were particularly beneficial. The participants all appeared to find different elements of treatment of particular relevance to them. This advocates a formulation-based approach to treatment, which would allow the

individual needs and experiences of the patient to be considered in the treatment plan (Grant, Townhead, Mill & Cockx, 2008; Tarrier, 2006). When asked about the benefits of psychological intervention, it is of interest to note that the participants in this study did not refer to the benefits of cognitive techniques (e.g. challenging thoughts). This may reflect the fact that they had not come to see this element of cognitive behaviour therapy as part of their treatment, rather than because they did not find this particular element of treatment useful.

Henningsen et al. (2007) have recently reviewed the evidence for the treatment and care of patients diagnosed with FSS. They advocate a stepped-care, biopsychosocial model for intervention. As part of this, they propose that FSS should initially be managed in primary care, with the most severe and enduring cases being seen in specialist services (e.g. Liaison Psychiatry). They advocate that the symptoms of FSS patients should be normalised and they should be provided with education related to their condition (Fink & Rosendal, 2008). In the current study, Laura notes that these needs were met by the professionals with whom she was in contact. In contrast, Michelle was not provided with information and normalisation in her early experiences of services. This may partly explain Michelle's dissatisfaction with her treatment and care.

Limitations

Although this study provided a novel insight into the experiences of patients actively seeking treatment in Liaison Psychiatry, there are a number of limitations to the research. Firstly, at the planning stage of this project it was proposed that the main researcher would interview between six to eight participants. Unfortunately, one of the Liaison Psychiatrists who agreed to support the study in terms of recruitment had to take long-term sick leave, which was unforeseen. After seeking out alternative sites, it was deemed not possible to recruit a larger sample size within the given time frame, which resulted in a smaller than anticipated sample size of three.

Although the sample size of this study is small, the research literature advocates that a sample size of three to six participants as acceptable for an IPA study (Smith et al., 2009). Smith et al. (2009) propose that the aim of IPA is to reflect the viewpoint and personal perspective of an individual, rather than a group. Therefore a sample size of three to six is deemed valid as this allows a detailed case-by-case analysis of each participant, while also allowing for a

comparison of the similarities and differences between each participant (Smith et al., 2009). Based on this, it was felt that a sample size of three was valid as the data collected allowed the researcher to undertake a detailed case-by-case comparison of each participant. Although a small sample size is advocated in IPA research (Smith et al., 2009), one limitation of this is that it is not possible to generalise the finding of the research at a group level.

It is also important to highlight that the results may have been influenced by researcher bias as the researcher who interviewed the participants was a Trainee Clinical Psychologist. It is therefore possible that the participants were positive about their experiences of psychological intervention so that they did not offend the interviewer. Furthermore, the participants who were invited to take part in the study were active cases seen at Liaison Psychiatry. As a consequence, each patient that agreed to take part was engaged with treatment at the service and this may have also influenced the results.

A third limitation of the study was that although it was made clear that taking part in the interview would not impact on the participant's treatment, the participants may still have been aware that it was possible that the Liaison Psychiatrists may see anonymised sections of their transcripts in a published article. This may have had an impact on elements of their experiences that they wished to share.

Finally, the Liaison Psychiatrists handed out the participant information sheets to patients who were on their case load. This meant that it was not possible to access patients who were not engaged in the service, who may have been able to provide a different perspective about their treatment experiences.

Future Directions

All three participants in this study mentioned that they had a desire to share their experiences with fellow sufferers of FSS. There has been a recent development within IPA and within the NHS for service users to be involved in the research process. An IPA study was published recently (Pitt, Kilbride, Nothard, Welford & Morrison, 2007), which used a service-user to interview fellow service-users. Service-user research may be of interest for this study as it would banish the power dynamic as someone who also has lived through a similar experience would be able to understand their experiences.

Although this study gave a detailed insight from a service-user perspective, it would have been of interest to hear the views and perspectives from the position of the Liaison Psychiatrist. This is of interest as therapeutic factors were highlighted as important for successful intervention and therefore the clinician involved in the case may have been able to provide further information about the factors that led to a positive outcome for these patients. Therefore, future research in this area may wish to interview the patients and their clinician.

Finally, it is common for patients with FSS to access psychiatric and psychological services in the community as opposed to Liaison Psychiatry. Michelle's account of her pathway to Liaison Psychiatry was marked by a sense of rejection by psychiatry and psychology; despite her desire for psychological intervention. It would therefore be of interest to investigate the experiences of FSS patients within a community setting.

Conclusion

The results of this study provide a unique insight into the experiences and perceptions of three patients currently engaged in treatment with Liaison Psychiatry services. Although the participants agree that they were satisfied with their current treatment, both public and professional stigmatisation were evident in their accounts, perhaps emphasising the need for further exploration of stigmatisation in community settings. This study has shown that FSS patients can accept a biopsychosocial view of their condition and felt most satisfied when a holistic approach is taken with regard to their treatment and care.

References

- Arroll, M. A., & Senior, V. (2008). Individuals' experiences of chronic fatigue syndrome/myalgic encephalomyelitis: an interpretative phenomenological analysis. *Psychology and Health*, **23** (4), 443-458.
- Asbring, P., & Narvanen, A. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, **12**, (2), 148-160.
- Barsky, A. J., & Borus, J. F. (1999). Functional Somatic Syndromes. *American International Medicine*, **130**, 910 – 921.

Baumann, A. E. (2007). Stigmatization, social distance and exclusion because of mental illness: The individual with mental illness as a 'stranger'. *International Review of Psychiatry*, **19** (2): 131-135.

Carson, A. J, Dawson, H, Marshall, D, & Slatford, K. (1998). Twenty-eight years of liaison psychiatry at a general hospital. *Psychiatric Bulletin*, **22**, 754-758.

Corrigan, P. W., & Kleinlein, P. (2006). The impact of mental illness stigma. In P.W. Corrigan (Eds.), *On the stigma of mental illness: practical strategies for research and social change*. American Psychological Association: Washington.

Corrigan, P. W., & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, **1**, 16-20.

Cox, P. (2011). The perception and experience of stigma among people diagnosed with functional somatic syndrome: a qualitative systematic review. Unpublished thesis. University of Glasgow.

Deale. A., & Wessely, S. (2001). Patients' perception of medical care in chronic fatigue syndrome. *Social Science and Medicine*, **52**, 1859 – 1864.

Department of Health (2005) *Creating a Patient Led NHS: Delivering the NHS Improvement Plan*. Department of Health.

Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: an interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology and Health*, **22** (7), pp 851-867.

Fink, P., & Rosendal, M. (2008). Recent developments in the understanding and management of functional somatic syndromes in primary care. *Current Opinion in Psychiatry*, **21**: 182-188.

Grant, A., Townhead, M., Mill, J., & Cockx, A. (2008). *Assessment and case formulation in cognitive behaviour therapy*. Sage publications: London.

Henningsen, P, Zipfel, S., & Herzog, W. (2007). Management of functional somatic syndromes. *Lancet*, **369**, 946-955.

Hyams, K. C. (1998). Developing case definitions for symptom based conditions: the problem of specificity. *Epidemiology Review*, **20**, 148-156.

Kirmayer, L. J., & Looper, K. J. (2006). Abnormal illness behaviour: physiological, psychological and social dimensions of coping with distress. *Current Opinion in Psychiatry*, **19**, 54-60.

Kool, M. B., Van Middendorp, H., Boeije, H. R., & Geenen, R. (2009). Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis & Rheumatism (Arthritis Care & Research)*, **61** (12), 1650-1656.

Kroenke, K. (2007). Efficacy of treatment for somatoform disorders: a review of randomized controlled trials. *Psychosomatic Medicine*, **69**, 881-888.

Kroenke, K., & Swindle, R. (2000). Cognitive behavioural therapy for somatisation syndromes: a critical review of controlled clinical trials. *Psychotherapy and Psychosomatics*, **69**, 205-215.

Kuey, L. (2008). The impact of stigma on somatic treatment and care for people with co-morbid mental and somatic disorders. *Current Opinion in Psychiatry*, **21**, 403-411.

Leventhal, H., Brissette, I., Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In: Cameron, L.D & Leventhal (Eds.), *The Self-Regulation of Health and Illness Behaviour*. London: Routledge, pp 42-65.

Liggins, J & Hatcher, S. (2005). Stigma towards the mentally ill in the general hospital: a qualitative study. *General Hospital Psychiatry*, **27**, 359-364.

Looper, K. L., & Kirmayer, L. J. (2004). Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of Psychosomatic Research*, **57**, 373-378.

Mann, C. E & Himelein, M. J. (2004). Factors associated with stigmatization of persons with mental illnesses. *Psychiatric Services*, **55**, 185-187.

Manu, P. (2004). *The Psychopathology of functional somatic syndromes: Neurobiology and illness behaviour in chronic fatigue syndrome, fibromyalgia, gulf war illness, irritable bowel and premenstrual dysphoria*. The Haworth Medical Press: New York.

Mayou, R., & Farmer, A. (2002). ABC of psychological medicine: functional somatic symptoms and syndromes. *British Medical Journal*, **325**, 256-268.

McCue, P. (2004). CFS/ME and mental health diagnosis: a qualitative approach to assessing the experiences of women who have now recovered. *Clinical Effectiveness in Nursing*, **8**, 194-201.

Mengshoel, A. M., & Heggen, K. (2004). Recovery from fibromyalgia: previous patients' own experiences. *Disability and Rehabilitation*, **26**, (1), 46-53.

Moss-Morris, R., & Chalder, T. (2003). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, **55**, 305-308.

Pitt, L., Kilbride, M., Nothard, S., Welford, M., & Morrison, A. P. (2007). Researching recovery from psychosis: a user-led project. *Psychiatric Bulletin*, **31**, 55-60.

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

Salmon, P., Peters, S., & Stanley, I. (1999). Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *British Medical Journal*, **318**, 372-376.

Sharpe, M., Mayou, R., & Walker, J. (2006). Bodily symptoms: New approaches to classification. *Journal of Psychosomatic Research*, **60**, 353-356.

Smith J. A., & Eatough, V. (2007). Interpretative Phenomenological Analysis. In E., Lyons., & A, Coyle. *Analysing qualitative data in psychology*. Sage: London

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and health psychology. In L. Yardley (Ed.), *Material Discourses and Health*. London: Routledge, pp 68-91.

Smith, B. J., McGorm, K.J., Weller, D., Burton, C., & Sharpe, M. (2009). The identification in primary care of patients who have been repeatedly referred to hospital for medically unexplained symptoms: A pilot study. *Journal of Psychosomatic Research*, **67**, 207-211.

Smith, B. J., & Osborn, M. Interpretative phenomenological analysis. (2003). In J, Smith (Ed). *Qualitative Psychology*, pp 51 – 79, London: Sage.

Tarrier, N. (2006). *Case formulations in Cognitive Behaviour Therapy: The treatment of challenging and complex cases*. Routledge: East Sussex.

Taylor, R. R. (2005). Can the social model explain all of disability experience? Perspectives of persons with chronic fatigue syndrome. *American Journal of Occupational Therapy*, **59**, 497-506.

Ware, N. C. (1992). Suffering and the social construction of illness: the deligitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, **6**, 4, pp 347-361.

Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, **33**, 6, 1312-1318.

Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: a longitudinal qualitative study. *International Journal of Nursing Studies*, **42** (8), 1023-1031.

Chapter 3: ADVANCED PRACTICE I: REFLECTIVE CRITICAL ACCOUNT

Abstract

The Clinical Psychologist as a consultant: a reflection on whether the process of consultation is similar to individual therapy

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Submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy)

Abstract

Introduction: Consultation refers to a process where an individual is trying to improve a situation, but has no direct control over the implementation of change. There have been a number of recent drivers within the NHS in Scotland which have led to a move towards the provision of consultation by Clinical Psychologists. The requirement for consultation within the NHS has meant that consultation has become an intended learning outcome on the Doctorate in Clinical Psychology. The process of consultation can be thought of as similar to the process of individual therapy with a client. Therefore, in this reflective account, I will use a cognitive behavioural framework to structure my reflection.

Reflection: I used Beck's ten principles of cognitive behavioural therapy as a way of conceptualising the consultation process. In this reflective account, I considered my first experience of consultation. I reflected on my own experience of consultation and the thoughts and feelings that underpinned the professional decisions I made. I considered the experiences that led to changes in my thinking, improvement in my competence and areas where further training is required.

Reflective Review: I conducted a meta-reflection of the value of consultation within clinical psychology. In the reflective review, I discussed my views of the benefits of consultation. I recognised areas where I developed in terms of my skills in consultation. I have also identified gaps in my knowledge and areas where I may benefit from further training.

CHAPTER 4: ADVANCED PRACTICE II: REFLECTIVE CRITICAL ACCOUNT

Abstract

Out of the frying pan and into the fire: a reflection on the move from clinical training to continued professional development

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Abstract

Introduction: This reflective account focused on unit 6.5 of The National Occupational Standards, which centres on the development of personal resources. Set within this specific occupational standard, a psychologist is required to take-part in professional development activities to improve performance and the management of their time and resources to meet objectives.

Reflection: The Continued Professional Development cycle was used as a model for reflective practice. This account reflects on identifying training needs and attendance at a training course to meet a gap in knowledge. The reflection then goes on to discuss the impact this training had on clinical practice and areas for future development.

Reflective Review: The reflection then moves on to identify areas of unresolved issues and discusses the implications for continued professional development in the current political context.

Appendices

Appendix 1: Systematic Review

Appendix 1.1: Notes to author for Health Psychology Review

Preparation of manuscripts

Currently, *Health Psychology Review* can only accept manuscripts written in English. Manuscripts should be double-spaced and should be prepared in accordance with the format and style specified in the Publication Manual of the American Psychological Association (APA), Sixth Edition. Pages should be numbered consecutively and organized as follows:

The Title Page (p. 1) should contain the article title, authors' names and affiliations. It should also include an author note with authors' full affiliations and the address for manuscript correspondence (including e-mail, address and telephone and fax numbers). In accordance with the APA Publication Manual (6th Ed.). No information that would indicate authors' identity or affiliation should be contained in the manuscript itself, all such information should be included on the title page only.

The Abstract (p. 2) must be a single paragraph that summarizes the main findings of the paper in fewer than 200 words. After the abstract a list of up to six keywords that will be useful for indexing or searching should be included.

Manuscript length

There is no formal word limit for manuscripts. Submissions should, however, be as long as necessary and authors of submissions of excessive length which do not convey ideas and points succinctly and concisely will be asked to truncate their manuscript. We also draw authors' attention to the Health Psychology Review online repository of supplemental materials that provides a permanently accessible resource of materials that are too long for the print version of the journal (e.g., oversized tables, intervention protocols, questionnaires etc.) but to which authors of articles appearing in Health Psychology Review wish readers to have access.

Style guidelines

The manuscript should follow the guidelines of the APA Publication Manual, Sixth Edition.

Figures should be in a finished form suitable for publication and should be numbered consecutively with Arabic numbers in order of appearance in the text.

Tables should be numbered consecutively with Arabic numbers in order of appearance in the text. Type each table double-spaced on a separate page, with a short descriptive title typed directly above and with essential footnotes below.

Competing interests

A competing interest exists when your interpretation or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors should disclose all financial and non-financial competing interests.

Authors are required to complete a declaration of competing interests and submit it together with the manuscript. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'. Please consider the following questions:

Financial competing interests

- In the past five years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? Is such an organization financing this manuscript? If so, please specify.
- Do you hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? If so, please specify.
- Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.
- Do you have any other financial competing interests? If so, please specify.

If you are unsure as to whether you, or one of your co-authors, has a competing interest please discuss it with the editorial office.

Authors' contributions

All authors are expected to have made substantive intellectual contributions to, and to have been involved in drafting or revising the manuscript. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship. With the submission of a manuscript, it is assumed that all authors have read and approved the final manuscript.

Acknowledgements

All contributors who do not meet the above criteria for authorship, should be listed in an acknowledgements section in accordance with the APA guidelines. The acknowledgements should be contained on the title page of the manuscript as making acknowledgements available to reviewers will compromise the masked peer-review process. Examples of those who might be acknowledged include those who provided general, technical, or writing assistance. Acknowledgement of funding/grants are also included in this section.

Proofs

The manuscript will be edited according to the style of the journal, and PDF proofs will be e-mailed to the corresponding author for final review. To avoid delay in publication, only necessary changes should be made, and corrections should be returned promptly.

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substantially from a copyrighted source). The reproduction of short extracts of text, excluding poetry and song lyrics, for the purposes of criticism may be possible without formal permission on the basis that the quotation is reproduced accurately and full attribution is given.

Appendix 1.2: Quality criteria (Walsh & Downe, 2006)

Stages	Essential Criteria	Specific prompts
Scope and purpose	<p>Clear statement of and rationale for research question/aims and purpose</p> <p>Study thoroughly contextualised existing literature</p>	<ul style="list-style-type: none"> - Clarity of focus demonstrated - Explicit purpose given, such as descriptive/ explanatory intent, theory building, hypothesis testing - Link between research and existing knowledge demonstrated - evidence of systematic approach to literature review, location of literature to contextualise the findings, or both.
Design	<p>Method/design apparent, and consistent with research intent</p> <p>Data collection strategy apparent and appropriate</p>	<p>rationale given for the use of a qualitative design</p> <ul style="list-style-type: none"> - discussion of epistemological/ontological grounding - Rationale explored for specific qualitative method(e.g. ethnography, grounded theory, phenomenology) - Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims - Setting appropriate - Were data collection methods appropriate for type of data required and for specific qualitative method? - Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail.
Sampling strategy	Sample and sampling method	Selection criteria detailed and description of

	appropriate	<p>how sampling was undertaken</p> <ul style="list-style-type: none"> - Justification of sampling strategy given - Thickness of description likely to be achieved from sampling
Analysis	Analytic approach appropriate	<ul style="list-style-type: none"> - Approach made explicit (e.g. Thematic distillation, constant comparable method, grounded theory) - Was it appropriate for the qualitative method chosen - Discussion of how coding systems/conceptual frameworks evolved - Evidence that the subjective meanings of participants portrayed - Evidence of more than one researcher involved in stages if appropriate to epistemological/ theoretical stance - Did research participants have any involvement in analysis (e.g. member checking) - Evidence provided that data reached saturation or discussion/rationale if it did not. - Evidence that deviant data was sought, or discussion/rationale if it was not.
Interpretation	<p>Context described and taken account in interpretation</p> <p>Clear audit trail given</p>	<ul style="list-style-type: none"> - Description of social/physical and interpersonal conflicts of data collection - Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena. - Sufficient discussion of research processes such that others can follow a decision trail. - Extensive use of field notes entries/verbatim interviews quotes in discussion of findings - Clear exposition of how interpretation led to

	Data used to support interpretation	conclusions
Reflexivity	Reflexivity of the researcher demonstrated	<ul style="list-style-type: none"> - Discussion of the relationship between researcher and participants during fieldwork - Demonstration of researchers influence on stages of research process - Evidence of self-awareness/insight - Documentation of effects of research on the researcher - Evidence of how the problems/complications met were dealt with
Ethical dimensions	Demonstration of sensitivity to ethical concerns	<ul style="list-style-type: none"> - Ethical committee approval granted - Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants. - Evidence of fair dealings with participants - Recordings of dilemmas met and how resolved in relation to ethical issues - Demonstration of how autonomy, consent, confidentiality, anonymity were managed.
Relevance and transferability	Relevance and transferability evident	<ul style="list-style-type: none"> - Analysis interwoven with existing literature drawn from similar settings or studies

		<ul style="list-style-type: none"> - Discussion of how explanatory propositions/emergent theory may fit other contexts - Limitations/weaknesses of study clearly outlined - Clearly resonates with other knowledge and experience - Results/conclusions clearly supported by evidence - Interpretation possible and makes sense - Provides new insights and increases understanding - Significance for current policy and practice outlined - Assessment of value/empowerment for participants. - Outlines further directions for investigation - Comment on whether aims/purposes of research were achieved.
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Appendix 2: Major Research Project

Appendix 2.1: Guidelines for submission (Psychology and Health)

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

INTRODUCTION



Submission of a paper to *Psychology & Health* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

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All submissions should be made online at *Psychology & Health's* [ScholarOne Manuscripts site](#). New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Authors should attach a cover letter addressed to the editors with each submission stating why their manuscript is relevant to the journal.

Submitted papers will be subject to blind review. Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all information identifying the author should be removed from files to allow them to be sent anonymously to referees. When uploading files authors should define the non-anonymous version as "File not for review".

Each paper will be read by at least two referees. Authors will be invited to suggest preferred and non-preferred reviewers when they submit the manuscript, but the editors reserve the right to make the final decision regarding choice of reviewers. Authors should not suggest reviewers with any conflict of interest (e.g. reviewers with whom they have recently collaborated, or from their own institution).

FORMAT OF MANUSCRIPTS

Manuscripts should be typed according to the guidelines in the Publication Manual of the American Psychological Association (5th edition, 2001). Manuscripts should be double-spaced throughout (including tables and references), and each page should be numbered consecutively. Manuscripts should not exceed 30 pages (including references, tables, and figures), with a font size of 12 in New Times Roman, and all margins should be at least 2.5cm.

Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 200 words and should be presented on a separate page.

Key words: Abstracts should be accompanied by between three and six key words or phrases. These will be used for indexing and data retrieval, and so where appropriate we recommend using standard MeSH terms (the terms used for indexing articles for MEDLINE)..

Reports of statistical tests should include an indication of effect size whenever possible. Reports of randomised controlled trials should state any registration details of the trial and should follow CONSORT guidelines where relevant (see Moher, D., Schulz, K.F. & Altman, D.G. for the CONSORT group, 2001. The CONSORT statement: Revised recommendations for improving the quality of reports of parallel-group randomized trials. *Annals of Internal Medicine*, 134, 657-662).

Style guidelines

The primary headings should be: Objective, Design, Main Outcome Measures, Results, Conclusion.

Description of the Journal's [article style](#)

Description of the Journal's [reference style](#), [Quick guide](#)

Please use British spelling (e.g. colour, organise) and punctuation. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

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FIGURES

All figures should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. Figures should be kept separate from the text but an approximate position for each should be indicated in the text. It is the author's responsibility to obtain permission for any reproduction from other sources.

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Number tables with consecutive arabic numerals and give each a clear descriptive heading. Avoid the use of vertical rules. Table footnotes should be typed below the table, designated by superscript lower-case letters. Tables should be kept separate from the text but an approximate position for each should be indicated in the text. It is the author's responsibility to obtain permission for any reproduction from other sources.

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- [Information about supplementary online material](#)

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ETHICAL POLICY

All manuscripts must include a statement confirming that the research had obtained relevant local ethical approval and was carried out in accordance with universal ethical principles (see Emanuel, E.J., Wendler, D. & Grady, C., 2000. What makes clinical research ethical? *Journal of the American Medical Association*, 283, 2701-2711).

INFORMED CONSENT

Manuscripts must include a statement that informed consent was obtained from human subjects. Authors should protect patient anonymity by avoiding the use of patients' names or initials, hospital number, or other identifying information.

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Appendix 2.2: Ethics Approval Letter

WoSRES

West of Scotland Research Ethics Service

West of Scotland REC 2

Ground Floor – The Tennent Institute

Western Infirmary

38 Church Street

Glasgow G11 6NT

www.nhsggc.org.uk

Dr Sarah Wilson

Date 5th November 2010

Senior Lecturer in Health Psychology

Your Ref

University of Glasgow

Our Ref

Section of Psychological Medicine

Direct line 0141 211 2123

Fax 0141 211 1847

E-mail Liz.Jamieson@ggc.scot.nhs.uk

Academic Centre

Gartnavel Royal

1055 Great Western Road

Glasgow G12 0XH

Dear Dr Wilson

Study Title: An examination of the medical and psychiatric experiences of patients diagnosed with functional somatic syndrome within the NHS: A qualitative study

REC reference number: 10/S0709/44

Thank you for your letter of 15 October 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		
Protocol	1	20 August 2008
Extract From SS1		
REC application		
Interview Schedules/Topic Guides	1	25 August 2010
Letter of invitation to participant	1	20 August 2010
Participant Information Sheet	2	15 October 2010

Response to Request for Further Information		15 October 2010
Participant Consent Form	1	25 August 2010
CV Student		15 October 2010
Referees or other scientific critique report		15 July 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S0709/44	Please quote this number on all correspondence
--------------------	---

Yours sincerely

Liz Jamieson

Committee Co-ordinator

On behalf of Dr S Langridge, Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: “After ethical review – guidance for researchers”
Erica Packard, NHS Greater Glasgow and Clyde

West of Scotland REC 2

Attendance at Sub-Committee of the REC meeting on 05 November 2010

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr A Crighton	Oral Medicine	Yes	
Dr Jesse Dawson		Yes	
Dr S Langridge	General Practitioner	Yes	
Dr David Shaw	Lecturer in Ethics & Law	Yes	

Appendix 2.3: Research and Development Approval: Greater Glasgow & Clyde

Coordinator/Administrator: Dr Erica Packard/Ms Elaine O'Donnell
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d



10 November 2010

Dr Paula Cox
Trainee Clinical Psychologist
Dept of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Dr Cox,

Study Title:	An examination of the medical and psychiatric experiences of patients diagnosed with functional somatic syndrome within the NHS: A qualitative study
Principal Investigator:	Dr Paula Cox
GG&C HB site	Western Infirmary, Southern General & Crosshouse Hospitals: Liaison Psychiatry
Sponsor	NHS GG&C
R&D reference:	GN10CP440
REC reference:	10/S0709/44
Protocol no:	V1 20/08/08
(including version and date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

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R&D Approval_GN10CP400


2. **For all studies** the following information is required during their lifespan.
- a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator

Cc: NRSPCC

Appendix 2.4: Research and Development Approval NHS Ayrshire & Arran

Healthcare Quality, Governance and Standards Unit
Research, Development & Evaluation Office
58 Lister Street
Crosshouse Hospital
Kilmarnock
KA2 0BB



Dr Paula Cox
NHS Greater Glasgow & Clyde
Dept of Psychological Medicine
Gartnavel Royal Hospital
Great Western Road
Glasgow
G12 0XH

Tel: (01563) 825856
Fax: (01563) 825806

Date: 22 February 2011
Your Ref:
Our Ref: CAW/KLB/NM R&D 2010AA078

Enquiries to: Karen Bell
Extension: 25850
Direct Line: 01563 825850
Email: Karen.bell@aaaht.scot.nhs.uk

Dear Dr Cox

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through NHS Ayrshire and Arran for the purpose and on the terms and conditions set out below. This right of access commences on **22 February 2011** and ends on **7 January 2012** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to NHS Ayrshire and Arran premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Ayrshire and Arran you will remain accountable to your employer **NHS Greater Glasgow and Clyde** but you are required to follow the reasonable instructions of your nominated manager within the **Department of Liaison Psychiatry** in this NHS organisation or those given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Ayrshire and Arran policies and procedures, which are available to you upon request, and the Research Governance Framework.

R&D 2010AA078

An examination of the medical and psychiatric experiences of patients diagnosed with functional somatic syndrome within the NHS: A qualitative study

Appendix 2.5: Cover Letter



Name of Liaison Psychiatrist
Hospital.....
Address
Date.....

Dear Sir/Madam

Please find enclosed an invitation to take part in a research study. The research will be conducted by Paula Cox, Trainee Clinical Psychologist, who is a final year student at the University of Glasgow. If you would like to gather more information about the study, please complete the tear off slip and post it in the stamped addressed envelope provided.

Please note, participation in this study is voluntary and your NHS treatment will not be affected by participation in this study.

Yours sincerely

Dr
Consultant Liaison Psychiatrist

.....

Dear Paula

I would like to note my interest in your study. Please contact me to provide me with more information about the research and what this would entail.

Please provide your name and telephone number. Please note, your telephone number will only be used to contact you with regard to participation in the study and will be kept confidential.

Name (PLEASE USE BLOCK CAPITALS):

Telephone number:

Appendix 2.6: Participant Information Sheet



Paula Cox

Department of Psychological Medicine

University of Glasgow

Gartnavel Royal Hospital

Glasgow

G12 0XH

Email: p.cox.1@research.gla.ac.uk

Telephone number: 0141 418 4940

PARTICIPANT INFORMATION SHEET

Title of Project: An examination of the medical and psychiatric experiences of patients diagnosed with functional somatic syndrome within the NHS: A qualitative study

Name of Researcher: Paula Cox

Introduction

My name is Paula Cox and I am a Trainee Clinical Psychologist. I am inviting you to take part in my final year research project. The research will be submitted as part of a Doctorate in Clinical Psychology at the University of Glasgow.

What is the study about?

I am interested in finding out about your experiences of treatment under the care of the NHS. You will have the opportunity to describe your beliefs about your illness, your experiences of being referred to liaison psychiatry and how these experiences have affected you. These insights may add to the knowledge base of staff and may identify areas where staff may benefit from training.

What will happen if I agree to take part?

If you would like to participate then you will be invited to take part in an interview which will last approximately 1 hour. The interview will be recorded on a digital voice recorder. The recordings will be transcribed and any information that could identify you will be

removed. Anonymised quotes from the interviews may be used in the write-up of the study. Your current NHS care will not be affected by participation in this study. The interviews will take place at the Department of Liaison Psychiatry.

Will my taking part in the study be kept private?

Yes, your personal information will be kept private and confidential. Once the recording of the interviews has been transcribed, all identifiable information will be removed from the document and the recording will be destroyed. Both myself and my supervisor, Dr Sarah Wilson, will have access to the print-out of the interview. This will be anonymised and stored in a locked filing cabinet on NHS premises.

Do I have to take part?

No, you do not need to take part. This study is voluntary and your NHS care will not be affected if you decide you do not want to participate in the study. If you initially agree to participate, but decided to withdraw at a later point, then you are free to do so. You do not have to give a reason for this and all of the data collected about you will be destroyed.

Are there risks or benefits to taking part?

The research involves an interview about your experiences; therefore, there are no anticipated risks to taking part in this study. The questions will focus on your beliefs about your illness, your experiences of being referred to liaison psychiatry and how these experiences have affected you. If you become upset by these questions, then you are free to withdraw from the study. You will then have the opportunity to discuss this with your Liaison Psychiatrist. It is hoped that the study will add to staff knowledge about patient satisfaction. This study may provide information for staff training, leading to improved patient experience.

What will happen to the results of the study?

The results of the study will be written-up for submission as a final year project as part of the Doctorate in Clinical Psychology at the University of Glasgow. If the results are of scientific interest, the study will be written-up for publication in a research journal. A copy of the project can be made available upon request.

Who has reviewed the study?

This study has been approved by the Department of Psychological Medicine. The project was submitted for review by an NHS ethics committee and a favourable opinion has been given for this research to take place.

What do I do now?

If you would like to participate in the study, please complete the reply form and post it back in the stamped addressed envelope provided. Alternatively, you can contact Paula Cox, Trainee Clinical Psychologist, by email or telephone.

Email: p.cox.1@research.gla.ac.uk or telephone number: 0141 418 4940.

Who do I contact if I wish to complain

If you are unhappy with any aspect of the study and wish to make a complaint, the normal NHS complaint mechanism is available to you and you should contact the Complaints Officer for Gartnavel Royal Hospital, 0141 211 0370

Can I find out more?

If you have any questions you would like to ask, please do not hesitate to contact me, Paula Cox, or my supervisor Dr Sarah Wilson at:

The Department of Psychological Medicine

University of Glasgow

Gartnavel Royal Hospital

Glasgow

G12 0XH

Email: p.cox.1@research.gla.ac.uk

Telephone number: 0141 418 4940

Thank you for reading this – please ask any questions if you need to

Appendix 2.7: Participant Consent Form

CONSENT FORM

Name of Trainee Clinical Psychologist: Paula Cox

Name of participant:

Department where the person will be interviewed:

	Please Initial:	YES	NO
Have you read the information sheet?		[]	[]
Have you had opportunity to ask questions and to discuss?		[]	[]
Have you received satisfactory answers to the questions?		[]	[]
Have you received enough information?		[]	[]
Have you spoken to anyone about the use of this information?		[]	[]
If YES who.....			
Do you understand that you are free to withdraw your consent at any time?		[]	[]
without having to give a reason?		[]	[]
and without affecting future NHS care?		[]	[]
Do you consent to the information being used for educational purposes?		[]	[]

Participant signature: Date:

Name in Block Letters:

Appendix 2.8: Major Research Project Proposal

Title: An examination of the medical and psychiatric experiences of patients diagnosed with functional somatic syndrome within the NHS: A qualitative study

Name: Paula Cox

Academic Supervisor: Dr Sarah Wilson

Word Count: 3657

Abstract

Background: Research has indicated that patients diagnosed with Functional Somatic Syndromes (FSS) may perceive that they are stigmatised by this diagnosis. To date, much of the research into the experience of stigmatisation by FSS patients have used quantitative methodology. One limitation of this is that the ideas and beliefs of the individual participant may be missed if they do not fit with the format of the quantitative methodology. Therefore a qualitative study is proposed which will allow the participant to express their views and beliefs more freely.

Research Question: Do patients with Functional Somatic Syndrome perceive themselves as being stigmatised by NHS staff.

Participants: The study plans to recruit 6-8 participants diagnosed with FSS.

Design and Procedure: A qualitative study is proposed. A series of semi-structured, open-ended interviews will be used. Transcripts will be analysed using Interpretative Phenomenological Analysis.

Practical Application: By taking this approach it is hoped that this study will add new insights to the existing literature, have implications on the treatment and care of FSS patients and provide directions for future research.

Introduction

Stigma related to mental illness has been well documented in the research literature (Thornicroft, Rose & Kassam, 2007). Corrigan and Watson (2002) note that the impact of stigma is twofold. Firstly, people with a diagnosed mental illness can experience public stigma (i.e. the attitudes, beliefs and reactions of the general population to mental illness). Secondly, people with mental illnesses may experience self-stigma (i.e. the prejudice which people with mental illness use against themselves).

Corrigan (2000) states that the public can infer mental illness from four signals: psychiatric symptoms, social skills deficits, physical appearance and labels. Research has indicated that some symptoms alarm the public (e.g. inappropriate affect, unusual beliefs or odd topics of conversation) (Corrigan, 2000). Common stereotypes include the belief that people with mental illness are dangerous, incompetent and to blame for their illness (Corrigan & Kleinlein, 2006). Negative public attitudes and subsequent stigmatisation can lead to discrimination and segregation of the individual diagnosed with a mental illness (Crisp, Gelder, Rix, Meltzer & Rowland, 2004). Public stigma has important implications for the individual as it can reduce employment opportunities as employers may feel that people with mental illness are unreliable and unpredictable (Watson, et al., 2007). This has direct implications for housing as an individual may have to reside in poor living conditions. Public stigma may also impact on friendships and family relationships due to personal fears and concerns over mental illness or whether they themselves will experience stigmatisation by association (Corrigan & Kleinlein, 2006).

Living in a culture of stigmatisation and discrimination can have a negative impact on individuals who later develop mental illnesses. These individuals may accept and internalise the views of society (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001). As a consequence, they may experience diminished self-esteem and self-efficacy, which may lead to feelings of hopelessness (Watson et al., 2007). Self-stigma is not inevitable but, if it occurs, it can impact on the likelihood of an individual seeking treatment as a consequence of internalised negative attitudes and hopeless beliefs (Corrigan & Watson, 2002).

Research has indicated that medical professionals may stigmatise mentally ill patients (Daumit et al., 2006). A study by Corrigan (2005) found that many patients felt dehumanized by staff. They reported that they were treated like children and were not informed about important decisions relating to their treatment and care. Clarke, Dusome, and Hughes (2007) found that patients with mental illnesses who attended an emergency department reported that they were not treated with respect by the medical staff. The patients believed that they were triaged to the bottom of the waiting list as a result of their psychiatric history. They felt that a diagnosis of a mental illness overshadowed their physical illness. The respondents reported that they wanted to be viewed as legitimate people and desired compassionate, respectful, non-judgemental and attentive care. A review by Kuey (2008) also found that stigma can impact on the care for individual's experiencing co-morbid physical and mental disorder. This review suggested that stigma can lead to low self-esteem, a feeling of disability and chronic mental health difficulties (Kuey, 2008).

Research has indicated that patients diagnosed with Functional Somatic Syndromes (FSS) may view themselves as being stigmatised by this diagnosis (Looper & Kirmayer, 2004). FSS refers to a category of illnesses characterised by somatic symptoms that are related to

disability and cannot be medically explained (Page & Wesley, 2007). The research literature also refers to FSS as medically unexplained symptoms (Smith et al., 2009) and/or somatisation disorder (Kroenke 2006). FSS refers to a number of syndromes, for example, chronic fatigue syndrome, fibromyalgia and irritable bowel syndrome (Page & Wesley, 2007). Barsky & Borus (1999) highlight that there is significant overlap in the symptomatology of these conditions. Due to the nature of FSS, patients have commonly undergone a prolonged period of physical investigations in the form of scans, medical tests and referrals to specialist medical services (Moss-Morris & Chalder, 2003). Consequently, FSS patients often hold the view that there is a medical explanation underlying their symptoms. If a medical explanation cannot be found, then patients diagnosed with FSS, are often referred to mental health services to explore whether there is a psychiatric explanation for their difficulties. A subsequent diagnosis of FSS and a referral to psychiatric services is likely to be a difficult time for a patient as they may continue to harbour beliefs regarding a medical explanation of their difficulties. Furthermore, the experiences FSS patients have during the early stages of a diagnosis may impact on their acceptance of such a diagnosis and also on future treatment.

Salmon, Peters and Stanley (1999) explored patients' perceptions of medical explanations for somatic disorders. The patients were asked to describe their experience of having their symptoms explained by doctors. The findings indicated that a high proportion of patients did not agree with their doctors explanations of their symptoms and felt he was rejecting their pain, anguish and distress. Many patients who thought that their doctor did not believe them felt stigmatised by their treatment at the hospital. A small proportion of patients felt empowered by the explanation. However, this was more likely to occur when they felt that

there was a physical explanation or when they did not feel blamed for the occurrence of their symptoms.

Freidl, et al. (2007) provide evidence that patients with somatic complaints can anticipate that they are going to be stigmatised as a result of their illness. The authors compared the attitudes and anticipation of stigma of patients with epileptic, dissociative and somatoform pain disorder using a modified version of the Link Stigma Questionnaire. The results indicated that the fear of stigmatisation for close personal relationships and trustworthiness is greater in somatoform patients. In contrast, the somatoform patients reported lower rates of “asking for a job”, “working as a school teacher” or “being treated as anyone else”. The authors proposed that this may be because somatoform patients may be able to disguise their difficulties. The authors note that the extent to which people with mental diseases encounter stigma in their daily lives has important implications for their recovery. If a patient anticipates that they will be stigmatised then they are less likely to adhere to treatment.

To date, much of the research into the experience of stigmatisation by patients with a diagnosis of FSS has used quantitative methodology (cf. Looper & Kirmayer, 2004). Quantitative methodology is theory led and hypothesis driven (Smith & Dunforth, 2003). This means the methodological design is guided by previous research and the personal assumptions of the researcher (Smith & Osborn, 2003). One limitation of this is that the ideas and beliefs of the individual participant may be missed if they do not fit with the format of the quantitative methodology (Smith, 1996). Qualitative methodology allows the participant to express their views and beliefs more freely (Smith & Eatough, 2007).

Liggins and Hatcher (2005) recognised this limitation and designed a qualitative study which examined the experiences and perceptions of patients with physical health difficulties who had been referred to Liaison Psychiatry. Liaison Psychiatry acts as a bridge within general hospitals to aid planning in the care pathway of patients who require treatment in physical and mental health services (Carson, Dawson, Marshall & Slatford, 1998). Commonly, a patient may be referred if they had attended hospital with medically unexplained symptoms. Therefore, some patients may attend a general hospital with the perception that they have a physical illness and are then referred for a psychiatric assessment. The main findings indicated that the patients felt that they were disbelieved, invalidated, treated differently and stigmatised as a consequence of being labelled as mentally ill. The authors noted that there were methodological limitations to their study. Firstly, the patient group was ethnically heterogeneous and consisted of two Maori and three Caucasian patients. Cultural background may have influenced perceptions and experiences of stigmatisation prior to hospital admission, which may have influenced their attributions after admission. Furthermore, the study included 'old' and 'new' referrals to liaison psychiatry. These two groups are likely to have different experiences of stigma before entering the general hospital setting due to differences in the chronicity of their mental health difficulties.

Given the important implications for stigmatisation on the concept of self and implications for treatment, it is thought that these limitations should be addressed. The current study aims to add to the Liggins and Hatcher (2005) study by focusing on new referrals to Liaison Psychiatry with no prior contact with psychiatric or psychological services. The reason for this is that it is likely that first contact with psychiatry could be a very difficult time an individual. Being given a psychological/psychiatric explanation for physical symptoms or being labelled as a 'psychiatric patient' for the first time could feel threatening as these labels

are generally stigmatised by society (Mann & Himelein, 2004). As mentioned, a diagnosis of a mental illness can lead to stigmatisation, social exclusion, discrimination and stigmatisation (Baumann, 2007). Therefore, individuals who are new referrals to Liaison Psychiatry may fear stigmatisation by their family, friends and the general public.

It is also likely that the way that these patients are treated by NHS staff is important for the formation of beliefs about the efficacy of treatment. The literature suggests that non-adherence to medical regimens is associated with a poor relationship with the medical team and disagreement with the need for treatment (Kirmayer & Looper, 2006). The individual themselves may also hold discriminatory attitudes about mental illness, which may be challenged by a referral to psychiatry. Therefore, the early experiences of medical and psychiatric care may be important for a patients' concept of self and for the formation of opinions and beliefs about medical and psychiatric services.

The study also aims to add to the Liggins and Hatcher (2005) study by focusing on a homogenous sample by controlling for race and focusing specifically on participants diagnosed with Functional Somatic Syndrome. This is a population of interest because these patients are likely to have experienced a challenge to their beliefs about the symptoms (e.g. psychological vs. medical explanations). Any challenge could be explained by the common-sense model of self-regulation of health and illness (Leventhal, Brissette & Leventhal, 2003). This theory proposes that a person holds beliefs about the poor health in the form of illness representation. The illness representation includes the name, course and severity of the ailment. The patient may also hold beliefs about the cause and cure of the illness. Therefore, a referral to liaison psychiatry may challenge an individual's beliefs about their symptoms,

which may make it difficult to understand and cope with the referral. Based on this, an aim of the study will be to explore the patient's views and beliefs about their illness.

If a patient who has been referred to Liaison Psychiatry experiences challenges to their illness representation, challenges to their beliefs about mental illness and concerns about external stigmatisation from family and friends, then it is likely that these individuals may benefit from empathic staff who are attuned and sensitive to their needs. Given that these patients are likely to have had sustained contact with medical services during a prolonged period of medical investigation then this study also aims to explore FSS patients' perceptions, beliefs and experiences of the physical health system and being referred to liaison psychiatry.

The current study proposes to use Interpretative Phenomenological Analysis (IPA, Smith & Eatough, 2007) to investigate the thoughts, beliefs and experiences of FSS patients after they have been referred to liaison psychiatry. It is thought that IPA is a suitable approach when one is trying to find out how individuals perceive a particular situation (Smith, 1996). This approach will allow for themes that are important to the participant to emerge, without the views and assumptions of the researcher (Smith, Flowers & Osborn, 1997). It is thought that this will add to the existing quantitative studies (cf. Looper & Kirmayer, 2004) and expand on the qualitative research undertaken by Liggins and Hatcher (2005).

Research Question

Do patients with Functional Somatic Syndrome perceive themselves as being stigmatised by NHS staff?

Aims

- To explore FSS patients beliefs about their symptoms
- To explore FSS patients experiences of being referred to liaison psychiatry
- To explore how these experiences have affected them

Objective

To inform the treatment and management of NHS staff who work with Functional Somatic Patients

Plan of Investigation

Participants

Purposive sampling will be used to find a closely defined group of participants. This is in accordance with IPA methodology (Smith & Osborn, 2003). Participants will become eligible for the study once they have a diagnosis under the umbrella term Functional Somatic Syndrome and have been referred to Liaison Psychiatry. The diagnosis will be made by a Liaison Psychiatrist based on DSM-IV/ICD-10 criteria. A patient will become eligible for the study once they have undergone assessment and at least six months of treatment. Participants will be recruited from Liaison Psychiatry outpatient services within the Western Infirmary, Southern General Hospital in Glasgow and Cross House Hospital in Ayrshire.

Inclusion Criteria

- Participants will be eligible for the study if they have received a diagnosis of functional somatic syndrome, been referred to Liaison Psychiatry and been assessed and treated for at least 6 months.
- The study will focus on adult services. Therefore patients will be eligible for the study if they are 18 years old or over.

- The study will involve an interview, which will require a good standard of English.

Therefore, patients will be eligible for the study if they do not require an interpreter.

Exclusion Criteria

The study will attempt to isolate stigma related to mental illness. Therefore, participants will be excluded from this study if they are members of a social group which may have been a target for stigmatization prior to their referral to Liaison Psychiatry. The study will exclude:

- Participants over the age of 65 years as they may have been discriminated against due to age.
- Participants will be excluded from the study if they are likely to have experienced discrimination or stigmatization on the grounds of race.

Recruitment Procedures

Participants will be recruited from the Liaison Psychiatry outpatient service at either the Western Infirmary, Southern General Hospital in Glasgow or Cross House Hospital in Ayrshire. Throughout the recruitment process, the main researcher (PC) will be in weekly contact with the Liaison Psychiatrists. Each Liaison Psychiatrist will identify cases from their existing caseload who meet the inclusion criteria and will give the patients a information sheet outlining the study. If they wish to continue with study, they will be asked to contact the main researcher (PC). Prior to taking part in the study, the participant will have the opportunity to ask questions. If they agree to participate, they will be asked to indicate this by signing a consent form.

Design and Procedure

This is a qualitative study which will use IPA (Smith & Eatough, 2007). A series of semi-structured, open-ended interviews will be used. It is thought that this will allow the ideas and concepts most important to the participants to emerge. The topic guide has been developed through identifying important issues from relevant research literature (Leventhal, et al., 2003; Liggins & Hatcher, 2005). It is proposed that these questions will be used to guide the discussion. A non-directive approach will be taken to encourage participants to develop and elaborate on their own narratives. Probing questions will be used to investigate issues further where necessary.

Topic Guide

- How did your difficulties start?
- What are your experiences of seeking medical treatment for these difficulties?
- What are your experiences of being referred to Liaison Psychiatry?
- How did you feel about being referred to Liaison Psychiatry?
- What impact on your life did being referred to Liaison Psychiatry have?
- What are your expectations for the future?
- Is there anything about your experiences that we have not covered that you wish to share?

Section 3: Probes

- Could you tell me more about that?
- Can you give me an example of that?

- What did that make you think of?

The interviews will be recorded and transcribed verbatim and anonymised as necessary. The results will be analysed with the use of thematic analysis from an interpretative phenomenological standpoint (Smith & Eatough, 2007). The analysis will take a bottom-up approach.

Justification of sample size

A thematic approach to analysis will be used, which requires a small sample size. Smith & Eatough al. (2007, p.40) suggest that six to eight is suitable for a postgraduate student project of this nature. It is thought that this will allow for a detailed analysis of the transcripts and will be feasible within the time limitation of the study.

Settings and Equipment

It is proposed that the interviews will be conducted in the Liaison Psychiatry outpatient department in either the Western Infirmary, Southern General Hospital in Glasgow or Cross House Hospital, Ayrshire. The interviews will be recorded on a digital voice recorder and will be transcribed by the primary researcher (PC) onto a word document. All patient data will be saved within Metaframe, which is a password protected system currently used by the NHS.

Data Analysis

In accordance with IPA methodology (Smith & Eatough, 2007) each transcript will be repeatedly read and recurrent themes will be noted. It is thought that this will allow for the

identification of both common and contrasting themes. To check the reliability of the analysis, a subsample of the transcripts will be analysed by an independent researcher to verify whether the identified themes reflect the views of the participants.

Health and Safety Issues

The participants will be interviewed in a private room in a hospital setting. These rooms are routinely used during Liaison Psychiatry outpatient clinic. It is thought that this will protect confidentiality. This will also protect the safety of the main researcher as a member of the outpatient staff will be aware of the researcher's presence, the nature of the research and the approximate interview time.

Ethical Considerations

An application for ethical approval will be submitted to the Greater Glasgow and Clyde Primary Care Trust ethics committee. Prospective participants will be informed of the purpose of the study with the use of an information sheet. This will be given during their initial contact with the Liaison Psychiatrist. If a participant wishes to continue with the study, they will be asked to contact PC. Each participant will be informed about the study and will have the opportunity to ask questions. Participants will be informed that they can withdraw from the study at any time and that this will not affect their future treatment. Due to the sensitive nature of the topic guide, it is possible that participants may become distressed during the interview. If this occurs, they will be reminded that they can discontinue with the interview and will be informed that they can contact their Liaison Psychiatrist to discuss the matter further. It is thought that identifiable information will be collected from participants. Therefore, a coding system will be used to protect confidentiality and identifiable information will not appear in the write-up of the study. Raw data will be

destroyed once transcription has taken place. All transcripts will be held by the University of Glasgow for 10 years before being destroyed. Participants will be asked to agree to participate in the study by signing a consent form.

Financial Issues

It is proposed that the study will cost £39.80. A breakdown of the cost is provided in Figure 1.

Item	Amount Required	Approximate Cost
Paper	<ul style="list-style-type: none"> • 4 reels of plain paper 	<ul style="list-style-type: none"> • £14.80
Photocopying	<ul style="list-style-type: none"> • 500 sheets 	<ul style="list-style-type: none"> • £25
Equipment	<ul style="list-style-type: none"> • Olympus VN 6800 PC Digital Voice Recorder • Olympus AS 2004 Transcription Kit 	<ul style="list-style-type: none"> • Available on loan from the department
Total estimated cost of MRP proposal		<ul style="list-style-type: none"> • £39.80

Figure 1 Costing of the study

Timetable

It is proposed that an application will be made to the ethics committee in August 2010. Data collection will commence in October 2010. Figure 2 provides a timetable of planned research.

Month	Task
August 2010	Submit application to ethics committee
October 2010	Begin data collection. Transcription and analysis will occur as soon as the first interview is completed. This is important as this may help to inform future interviews
December 2010	Write first draft of introduction and method section and submit to supervisor for comments
March 2010	Complete data collection
April 2010	Complete transcription and analysis
April 2010	Write results section and submit to supervisor for comments
May 2010	Write discussion section
May-June 2010	Send a completed first draft of project for comments
July 2011	Deadline for submission

Figure 2 *Timetable of research*

Practical Applications

Research into FSS and patient experiences of NHS physical and mental health service is an important area of investigation as stigmatisation may impact on the recovery process and future interaction with services. Thus far, the research literature has explored the experiences of FSS patients with a chronic disorder. However, it is hoped that this qualitative study will add to the literature by gaining an insight into the experiences of patients who are new referrals to liaison psychiatry. The participants will have the opportunity to describe their beliefs about their illness, their experiences of being referred to liaison psychiatry and how these experiences have affected them. These insights may add to the knowledge base of the staff who care for patients diagnosed with FSS. It is also thought that this study will identify areas where patients feel satisfied and/or dissatisfied with the care they have received and

identify the positive and negative impact of the treatment. This may offer an insight into the possible reasons for adherence or non-adherence to treatment, may identify areas where psychological treatment may benefit FSS patients, or areas where staff may benefit from training.

References

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental health disorders* (4th ed). Washington DC: Author.

Baumann, A. E. (2007). Stigmatization, social distance and exclusion because of mental illness: The individual with mental illness as a 'stranger'. *International Review of Psychiatry*, **19** (2): 131-135.

Barsky, A. J., & Borus, J. F. (1999). Functional Somatic Syndromes. *American International Medicine*, **130**, 910 – 921.

Carson, A. J, Dawson, H, Marshall, D, & Slatford, K. (1998). Twenty-eight years of liaison psychiatry at a general hospital. *Psychiatric Bulletin*, **22**, 754-758.

Clarke, D. E, Dusome, D., & Hughes, L. (2007). Emergency department from the mental health client's perspective. *International Journal of Mental Health Nursing*, **16**, 126-131.

Corrigan, P. W. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology Scientific Practice*, **7**, 48-67.

Corrigan, P. W., & Kleinlein, P. (2006). The impact of mental illness stigma. In P.W. Corrigan (Ed.), *On the stigma of mental illness: practical strategies for research and social change*. American Psychological Association: Washington.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, **1**, 16-20.

Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2004). Stigmatisation of people with mental illness. *British Journal of Psychiatry*, **177**, 4-7.

Daumit, G. L., Pronovost, P. J., Anthony, C. B., Guallar, E., Steinwachs, D. M., & Ford, D. E. (2006). Adverse events during medical and surgical hospitalizations for persons with schizophrenia. *Archives of General Psychiatry*, **63**, 267-272.

Freidl, M., Piralic Spitzl, S., Prause, W., Zimprich F., Lehner-Baumgartner, E., Baumgartner, C., & Aigner, M. (2007). The stigma of mental illness: anticipation and attitudes among patients with epileptic, dissociative or somatoform pain disorder. *International Review of Psychiatry*, **19** (2): 123-129.

Kirmayer, L. J., & Looper, K. J. (2006). Abnormal illness behaviour: physiological, psychological and social dimensions of coping with distress. *Current Opinion in Psychiatry*, **19**, 54-60.

Kroenke, K. (2006). Physical symptoms disorder: A simpler diagnostic category for somatisation-spectrum conditions. *Journal of Psychosomatic Research*, **60**, 335-339.

Kuey, L. (2008). The impact of stigma on somatic treatment and care for people with comorbid mental and somatic disorders. *Current Opinion in Psychiatry*, **21**, 403-411.

Leventhal, H., Brissette, I., Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In: Cameron, L.D & Leventhal (Eds.), *The Self-Regulation of Health and Illness Behaviour* (pp. 42-65). London: Routledge.

Liggins, J & Hatcher, S. (2005). Stigma towards the mentally ill in the general hospital: a qualitative study. *General Hospital Psychiatry*, **27**, 359-364.

Link, B. G., Struening, E.L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001). The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, **52**, 1621-1626.

Looper, K. L., & Kirmayer, L. J. (2004). Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of Psychosomatic Research*, **57**, 373-378.

Mann, C. E & Himelein, M. J. (2004). Factors associated with stigmatization of persons with mental illnesses. *Psychiatric Services*, **55**, 185-187.

Moss-Morris, R., & Chalder, T. (2003). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, **55**, 305-308.

Page, L., & Wessley, S. (2007). *Functional Somatic Syndromes*. Cambridge University Press: Cambridge.

Salmon, P., Peters, S., & Stanley, I. (1999). Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *British Medical Journal*, **318**, 372-376.

Schulze, B. (2007). Stigma and mental health professionals: A review of the evidence on an intricate relationship. *International Review of Psychiatry*, **19**, 137-155.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*, **11**, 261-271

Smith, J. A., & Dunworth, F. (2003). Qualitative methodology. In J. Valsiner and K. Connolly (Eds.), *Handbook of Developmental Psychology*. London: Sage, pp 603-621.

Smith J. A., & Eatough, V. (2007). Interpretative Phenomenological Analysis. In E., Lyons., & A, Coyle (Eds.). *Analysing qualitative data in psychology*. Sage: London

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and health psychology. In L. Yardley (Ed), *Material Discourses and Health*. London: Routledge, pp 68-91.

Smith, B. J., McGorm, K. J., Weller, D., Burton, C., & Sharpe, M. (2009). The identification in primary care of patients who have been repeatedly referred to hospital for medically unexplained symptoms: A pilot study. *Journal of Psychosomatic Research*, **67**, 207-211.

Smith, B. J., & Osborn, M. Interpretative phenomenological analysis. (2003). In J, Smith (Ed). *Qualitative Psychology*, pp 51 – 79, London: Sage

Thornicroft, G, Rose, D, & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, **19**, 113-122.

Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, **33**, 6, 1312-1318.