

HEALTH, PAIN AND THE SOCIAL ENVIRONMENT

By

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Abstract

Since the 1970s the number of people suffering from functional somatic syndromes such as fibromyalgia has increased dramatically. These syndromes are characterised by higher levels of incapacity and disability than can be accounted for by objective medical testing. Here the possibility that socially derived labels and health information are contributing to the incapacity experienced by these patients was investigated. Investigations conducted with healthy people found that the way people perceive themselves as behaving, and whether that behaviour is labelled as healthy, influences how satisfied people are with their own health, and their health in comparison to others. It was also found that people who are labelled as unhealthy are evaluated as having less moral worth than those who are not. Further investigations found that the labels used to understand a painful sensation alter the way people respond to that sensation. Investigations with fibromyalgia patients found that the diagnostic label of fibromyalgia changes the information patients have access to, and therefore the information available to interpret their experiences. It was concluded that incapacity in functional syndromes may be partly driven by people being encouraged by to interpret their experiences in a particularly anxiety-provoking way through information in the environment.

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Chapter One

Introduction

The number of people suffering from chronic pain and other somatic symptoms has increased dramatically in recent decades (Waddell, Aylward & Sawney, 2002). These rises appear to be driven by both the appearance of new “functional somatic syndromes” (FSS), such as fibromyalgia and chronic fatigue syndrome, and increases in the number of people suffering from old problems, such as chronic low back pain. FSS patients experience greater disability and incapacity than would be expected from their known levels of tissue abnormality (Barsky & Borus, 1999). They are more likely to face work difficulties, including unemployment (Reisine, Fifield, Walsh & Dauser, 2004), and personal difficulties, such as divorce (Wolfe, Ross, Anderson, Russell & Hubert, 1995). Investigating FSS is therefore clearly important. The purpose of this thesis is to investigate one potential maintaining factor in the high levels of incapacity and disability seen in people with FSS: the effect of information in the environment and socially derived labels on the way people interpret their experiences. The thesis has two aims. The first is to examine the effect of socially derived labels on the way healthy people understand and interpret their health experience. The second is to examine the way people who have an FSS label, in addition to environmentally derived ideas about health, understand and interpret their health experience.

1.1 Functional somatic syndromes

Functional somatic syndromes are seen in every area of medicine, and are characterised by the patient exhibiting higher than expected levels of incapacity (Barsky & Borus, 1999). Though different symptoms form the primary focus in each FSS, it has been shown that there are high levels of overlap in the “peripheral” symptoms of each. When

examining the published definitions of twelve FSS, Wessely, Nimnuan and Sharpe (1999) found that both abdominal distension and headache were symptoms of eight of the syndromes, and both abdominal pain and fatigue symptoms of six. It has been suggested that these underlying similarities are evidence that the syndromes are different manifestations of the same underlying problem (Wessely, 2004).

Partly because of this overlap, and also because there are no known causes or cures for any of the syndromes, a number of researchers and clinicians have raised questions about the ethical implications of diagnosing patients with an FSS (Wolfe, 2009; Hadler, 1996; Hadler, 2005; Cohen, 1999; Undeland & Malterud, 2007; Woodward, Broom & Legge, 1995; Huibers & Wessely, 2006). These questions are important, as labels and diagnoses have been demonstrated to have significant long-term effects. The use of different labels for chronic fatigue syndrome (CFS), for example, influences the patient's long-term outcome, in that diagnosing CFS leads to a better patient outcome than diagnosing myalgic encephalomyelitis (ME), another name for CFS (Hamilton, Gallagher, Thomas & White, 2005). The effects of diagnosing fibromyalgia are a bit more complex. In general, patients diagnosed with fibromyalgia experience fewer long-term symptoms than patients who receive no diagnosis (White et al, 2002). Despite this, interviews with people suffering from fibromyalgia demonstrate that being diagnosed provides no perceived long term benefit (Undeland & Malterud, 2007). Furthermore, the use of both pain and non-pain related medications increases after a fibromyalgia diagnosis, with the use of non-pain medications steadily increasing for at least three years (Sanchez et al, 2011). These conflicting findings illustrate why diagnosing people with an FSS is controversial and complex.

1.2 Labels

Diagnoses are a form of label. In a more general sense, labels are shortcuts used to make sense of the world (Berry, 1970). It has been shown that the labels ascribed to an object, sensation, illness or emotion have the power to change the way it is perceived, with different labels changing how good things taste (Allison & Uhl, 1964), how pleasant things smell (Herz & von Clef, 2001) and more controversially, how things look (Kay & Kempton, 1984). When labels are not explicitly presented it has been shown that people use information gathered from various sources, including their past first-hand experience, their knowledge of other people's experiences and the things they have been taught, to make judgements about the correct label (Tajfel, Sheikh & Gardner, 1964). Therefore, when labelling their own or others' health, there are a variety of sources of information people can use. As well as their own personal experiences of illness and injury, there are numerous sources of health information in the social environment, including health campaigns, television adverts and programmes, and other forms of media (Kwan, Arbour-Nicitopoulos, Lowe, Taman & Faulker, 2010).

1.3 Personal experiences of illness or injury

A major influence on the way people understand their health is their personal experience, i.e., their physical health status. Not surprisingly, having a chronic illness is associated with negative self-rated health (Reyes-Gibby, Aday & Cleeland, 2002; Molarius & Janson, 2002; Mantyselka, Turunen, Ahonen & Kumpusalo, 2003; Jylha, Leskinen, Alanen, Leskinen & Heikkinen, 1986; Wannamethee & Shaper, 1991). This is also true of functional

disorders; people with fibromyalgia tend to have a negative self-rated health (Kaplan, Schmidt & Cronan, 2000), as do people with CFS (Moss-Morris & Petrie, 2001). The number of somatic symptoms experienced by the general population has also been shown to be linked to self-rated health (Manderbacka, Lahelma & Martikainen, 1998), with people who report more symptoms also reporting worse self-rated health.

1.4 Social influences on health beliefs and behaviour

The way other people respond to pain and illness also alters the way people understand their own experiences. In the laboratory it has been shown that people's responses to painful stimuli vary according to the reactions of a confederate participant (for example, Craig & Patrick, 1985; Craig & Weiss, 1971). Laboratory studies have also shown that there are associations between family members on painful tasks, with the families of students who show very low or very high pain tolerance on laboratory tests achieving similar results (Birklein et al, 2008). Comparable findings have been shown outside the laboratory; for example, in an examination of reported post-operative pain it was found that people who described their family as having poor pain tolerance experienced earlier and more severe post-operative pain than people who did not describe their family as having poor pain tolerance (Bachiocco, Scesi, Morselli & Carli, 1993).

Studies investigating the influence of other people on the tolerance and behaviour of people with chronic illnesses have suggested that certain behaviours lead to increased pain perception and illness behaviour. In one study investigating the reactions of chronic low back pain patients to painful stimuli it was found that higher levels of solicitousness (anxious care

and attention) in the spouse was associated with heightened pain perception in the patient (Flor, Breitenstein, Birbaumer & Furst, 1995). A number of studies have found similar associations between spouse behaviour and patient illness behaviour and experience. In people with CFS higher levels of partner solicitousness are associated with increased fatigue, body pain (Schmaling, Smith & Buchwald, 2000) and illness behaviour (Romano, Jensen, Schmaling, Hops & Buchwald, 2009).

The reactions of parents to their children's symptoms have also been shown to have long term consequences. It has been shown that adults' illness behaviour varies depending on the way they were treated when they were ill as children (Whitehead, Winget, Fedoravicius, Wooley & Blackwell, 1982). In addition, in children with chronic pain, it has been shown that the parents' tendency to catastrophise is associated with the level of their children's disability, with higher levels of catastrophising associated with higher levels of disability (Goubert, Eccleston, Vervoort, Jordan & Crombez, 2006; Langer, Romano, Levy, Walker & Whitehead, 2009).

1.5 Health campaigns

As well as personal experience and the beliefs of others, information in the social environment also influences the way people understand their health (Kwan, Arbour-Nicitopoulos, Lowe, Taman & Faulker, 2010). One of the most trusted sources of health information are government-sponsored health campaigns (Dutta-Bergman, 2003). Though individual health campaigns have been used as a way to educate people about dangers to their health for many years, organised national campaigns are typically thought as coming of

age in the 1980s, with 1988 sometimes called “year zero” for health campaigns (Siegel, 1998). Innovative campaigns were launched in 1988 in both the US and Australia. In California voters adopted Proposition 99, which increased cigarette tax and dedicated 20% of the revenue to anti-smoking education programmes and campaigns. In Australia the Victoria Cancer Council started two famous cancer education campaigns: “Quit”, focusing on smoking and cancer, and “Sunsmart” which generated the famous, and still remembered, “Slip Slap Slop” slogan.

Famous campaigns were also conducted in England in the mid 1980s, the most well-known of which were a series of large scale campaigns designed to warn people about the dangers of AIDS/HIV (Nicoll et al, 2001). These campaigns, with their unprecedented size and reach, aimed to alter the way people thought about their health in a way that had not been attempted before. As the role of lifestyle in the most common illnesses has become clearer, health campaigns have grown more and more common. In May 2010 the government’s Department of Health website listed 12 current campaigns, targeting a range of risks from teen partner violence to swine flu (Department of Health, 2010).

1.6 Types of health campaign

Generally there are two types of health campaign: those that target a particular illness by attempting to educate people about a particular symptom or set of symptoms, and those that target a particular behaviour by attempting to educate people about the healthy or unhealthy nature of that behaviour. Examples of the first type of campaign, focusing on symptoms, include the 2006 Doubt Kills campaign, which described the symptoms of a heart

attack (British Heart Foundation, 2006), and the 2010 Act FAST campaign, describing the symptoms of stroke (Stroke Association, 2010). Examples of the second type of campaign, focusing on behaviour, include the 2010 Catch It, Bin It, Kill It campaign, describing the best way to avoid passing on swine flu (Department of Health, 2011) and the 2010 Change4Life campaign, describing healthy lifestyle choices (NHS, 2010).

Although campaigns are generally targeted at a specific population, for example, smokers, many campaigns are placed on billboards or on television where a large proportion of the population will be exposed to them (Bhargava & Donthu, 1999). Therefore if campaigns are an effective way of altering people's beliefs and behaviours, they are likely to influence what a large number of people label as healthy or unhealthy.

1.7 The effectiveness of public health campaigns

The use of health campaigns is controversial, particularly in the case of the more shocking and distressing fear appeals (Hastings, Stead and Webb, 2004). Because of these concerns, in recent years there has been an effort to determine the effectiveness of mass media campaigns to alter health behaviours. Though some reviewers have found that "targeted, well-executed health mass media campaigns can have small-to-moderate effects not only on health knowledge, beliefs and attitudes, but on behaviours as well" (Noar, 2006), determining the scale of effects is quite difficult, because in many areas not enough work has been done. For example, reviews have shown there is a lack of evidence to determine whether or not mass media campaigns are effective in the case of campaigns to increase sport participation (Priest et al, 2008).

Jepson, Harris, Platt and Tannahill (2010) conducted a review of campaigns designed to alter six health behaviours: healthy eating, physical exercise, smoking, alcohol misuse, sexual risk taking in young people and illicit drug use. They could only find evidence relating specifically to media campaigns in the case of smoking, physical exercise and alcohol misuse. In the case of smoking and physical exercise weak evidence was found to suggest that media campaigns have a positive impact on healthy behaviours. In the case of increasing the number of designated drivers, the evidence was insufficient to draw conclusions (Jepson, Harris, Platt and Tannahill, 2010).

One campaign target that has been investigated to a greater extent is smoking, primarily because smoking has now been the focus of various health campaigns for a considerable number of years. One review, looking at the effect of anti-smoking campaigns on smoking cessation in adults, found that the available evidence suggests campaigns can be effective in improving adult smoking behaviour. However, there was no apparent pattern in what made the campaigns effective or not (Bala, Strzeszynski & Cahill 2008). Another review, this time looking at the effects of mass media campaigns in preventing young people from smoking found that, of the seven studies that met the author's inclusion criteria for high quality investigations, three found reductions in young people's smoking behaviour. It was found that the more effective campaigns also included extra components, for example posters placed in schools, or lessons on the curriculum about the dangers of smoking (Brinn, 2010).

Statistical models have also been created in an attempt to calculate the positive effects of mass media campaigns. Though it is important to remember these can only ever be approximate calculations, they may offer some guidance as to the campaigns' effects. An early paper, attempting to calculate the effect of American anti-smoking campaigns and policies, suggested that more than 200,000 premature deaths had been avoided (Warner & Murt, 1983). Other statistical models have been used to investigate the number of lives that might be saved by further large scale health campaigns. One paper estimated that a combination of large multimedia campaigns and a one-dollar increase to the cost of cigarettes could result in 108,466 lives being saved annually (Rivara et al, 2004).

1.8 Public health campaign controversy

These findings, particularly in the area of smoking cessation, demonstrate that public health campaigns have had positive effects on people's health. However, their use remains controversial and the moral questions raised by health campaigns, and particularly fear appeals, have been discussed at length (for example, Hastings, Stead & Webb, 2004; Guttman, 1997; Guttman & Harris Ressler, 2001; Faden, 1987). There are a number of areas of controversy, the first of which regards autonomy. It has been suggested that health campaigns, particularly the more manipulative fear appeals, compromise people's ability to make free choices (Hastings, Stead & Webb, 2004). However, other commentators have raised a number of objections to this. First Guttman (1997) suggested that it is not possible to make an autonomous choice without being informed. This raises more ethical questions about whether, when information is known that could effectively improve the long-term

health of the majority, it is wrong to not make it as widely known as possible. A second objection is that, compared to other methods of changing people's lifestyles such as banning products or limiting their use in certain buildings, health campaigns are considerably less coercive (Faden, 1987). In addition, Faden (1987) pointed out that there are a number of different ways to persuade people, ranging from engaging them in honest and reasoned debate, to deliberately lying or twisting information. She stated that health campaigns rarely engage in deliberate deception, though emotional manipulation is common.

This emotional manipulation, in the form of distressing images and threatening language has also been a source of controversy. Hastings, Stead and Webb (2004) pointed out that public health campaigns expose all people, including those who are not the target of the campaign, to graphic and potentially distressing images without their consent. This also includes young children and the elderly, along with a number of other groups who may find the images particularly upsetting (Hastings, Stead and Webb, 2004). The argument for using particularly graphic and distressing images is that these are more effective in changing people's beliefs and behaviour than less striking images. In the past this point was controversial, with some studies indicating that moderately anxiety-provoking campaigns are more effective than less or more anxiety-provoking campaigns (for example Janis, 1967). However, a recent meta-analysis of 98 studies of fear campaigns found that the biggest changes come from campaigns highest in both fear and efficacy to change (Witte & Allen, 2000). Though this does not address the controversy over consent, it does suggest that some campaigns will need to use upsetting images if they are to be effective.

Another argument against the use of fear campaigns is that they increase anxiety and paranoia about health, and are therefore likely to result in people misreading the threat level of harmless symptoms. A study of the effects of heart attack campaigns suggests this is a genuine risk. Blohm et al (1997) found that the campaigns did not reduce time taken to go to hospital, as was intended, but in some cases did increase the number of people attending hospital with non-cardiac chest pain. The extent to which this is a problem is debatable. Though it seems likely that the people experienced distress if they believed they were having a heart attack, the study cannot say what people were thinking when they decided to go to hospital. It may simply have been that the campaign encouraged them to do something that they wanted to do anyway, and therefore may not have increased anxiety or paranoia. As it has been shown that one of the contributing factors to delays in hospital attendance with actual heart attack is embarrassment (Dracup, McKinley & Moser, 1997) this appears more likely. The case can also be made that if people are experiencing symptoms which they believe to be serious, anything that encourages them to be checked, even if in the majority of cases it is overcautious, is positive, as it is likely to help at least some people.

A final concern is that campaigns risk stigmatising already vulnerable groups. For example, Wang (1998) described the way some campaigns depict disability as a potential consequence of dangerous behaviour, and include the implicit message “don’t let this happen to you”. Wang (1998) pointed out that this is a highly negative and stigmatising way of portraying people who are physically disabled. There is also the risk that portraying certain behaviours as good or bad stigmatises those who are unable to perform the good behaviours, people who are already likely to be disadvantaged (Guttman, 1997). For

example, people coping with mental health issues may find it harder to control their drinking or eating habits. Guttman (1997) found that people who did not meet certain healthy behavioural standards did not consider socioeconomic reasons for their behaviour, but instead blamed it on their “weak character”. This judging of health behaviour in terms of morality and character has the potential to turn into highly negative victim-blaming (Guttman & Harris Ressler, 2001). Guttman and Harris Ressler (2001) suggested that campaigns which encourage this form of moralising about health reinforce the idea of the just world, and make it easier to denigrate those who do not behave “well” (Guttman & Harris Ressler, 2001).

In addition to these specific arguments against the use of health campaigns, arguments have also been made against the more general prevalence of health information. Furedi (2004) argued that we now live in what he termed a “therapy culture”, where people are constantly surrounded by information that leads to a heightened sense of vulnerability. He argued that the prevalence of health information changes the way we see ourselves, and instead of recognising ourselves as autonomous, independent human beings, we instead see ourselves as weak and susceptible to a world of events outside our control. A similar argument was made by Diprose (2008) who suggested that we are now encouraged to have a “pre-emptive” attitude towards health, where we assume that health threats are highly likely and always imminent. She stated that this turns banal risks into potential catastrophes and therefore negatively alters our perception of our vulnerability.

Guttman (1997) put forward a further argument against the prevalence of health information. She suggested that the promotion of health is sometimes pursued to the extent that other values, particularly those of community and caring for others, are ignored. She wrote that if health is the ideal, those who are unable to achieve it may feel like they are being punished, or that they are inadequate. Guttman (1997) quoted Becker (1986), who suggested that the pursuit of health as an end in itself is selfish: “a dehumanising self-concern that substitutes personal health goals for more important, humane societal goals”.

These arguments over the morality of health campaigns and “therapy culture” depend on the individual’s views on the ethics of reducing autonomy, using emotional manipulation, using stigmatising images and encouraging a potentially damaging attitude towards risk and personal responsibility, in the face of evidence finding that, at least in some cases, campaigns prolong lives. Importantly however, discussions about the ethics of health campaigns have highlighted a number of ways harm in which can be minimised. In some cases this may involve thinking more sensitively about the consequences of the campaign on different groups, or tailoring the message to a particular group (Guttman & Salmon, 2004). It may also mean using different levels of fear in each campaign, as high levels of fear may not be necessary in every case. An interesting example of all of these comes from a study looking at the effects of different breast cancer screening posters on the attitudes of younger and older women. Women who were both in the target age group for screening (over fifty in Australia where the study was conducted), and below the target age group were shown high and low threat posters. It was found that there was no difference between the posters in terms of their effect on the older women’s intentions to be screened. However, in the

younger women, who are not the target group for screening in Australia, the high threat posters reduced their intentions to be screened when they reached the correct age, caused stronger negative emotional reactions and lead to higher perceived susceptibility for breast cancer (Jones & Owen, 2006). This clearly suggests that in this situation, using low threat posters is the most responsible, as they are likely to be equally effective in persuading eligible women to be screened, while significantly reducing the distress felt by women at a much lower risk of breast cancer.

Despite this considerable controversy, advocates both for and against the use of health campaigns generally agree that health campaigns and health information have the power to change the way people think about their health, a claim that is supported by research evidence (for example, van Wechem et al, 1997). If this is the case, public health campaigns are likely to play a large part determining the way people understand and label their health experience, as outlined above.

1.9 Summary

The aim of this thesis is to examine the effect of information in the social environment on the ways in which both healthy and ill people make sense of and experience their health. This is done in the hope of gaining some insight into possible mechanisms maintaining the high levels of disability seen in people with functional somatic syndromes. First the impact of healthy and unhealthy behaviour on the way young people label their own and others' health will be investigated. Second the way new information about threatening stimuli can alter people's responses to that stimuli will be investigated. Finally,

the way people with an FSS, fibromyalgia, label and understand their experiences will be investigated.

1.10 Participants

As the studies in this thesis examine the ways in which both healthy people and people with a functional somatic syndrome understand their health, participants will generally be drawn from two different populations. The majority of investigations into the way healthy people understand their health will involve university and college students. Young people are the group least likely to be diagnosed with a long term health condition (Alder, Mayhew, Moody, Morris & Shah, 2005), including the functional somatic syndromes (Wolfe, Ross, Anderson & Russell, 1995). This means that they are the group who are least likely to have their perception of their health altered by being diagnosed with any particular disease. They are therefore the group most likely to use general health information to understand their health experience.

In the case of the two studies investigating how people with an FSS understand their health, the participants will be fibromyalgia patients. Fibromyalgia is a chronic pain syndrome characterised by widespread pain (Wolfe et al, 1990), fatigue (Goldenberg, Simms, Geiger & Komaroff, 2005) and cognitive difficulties (Park, Glass, Minear & Crofford, 2001). People with fibromyalgia also commonly report other symptoms including low back pain, headaches, arthritis, muscle spasm, tingling and balance problems (Bennett, Jones, Turk, Russell & Matallana, 2007). Fibromyalgia symptoms affect multiple areas of the body and are of a type that cannot be confirmed by objective testing (Ehrlich, 2003). In a random sample

of 2006 people it was found that the prevalence of fibromyalgia was 2% of the sample- 3.4% of the women and 0.5% of the men. It was also found that the number of people suffering from fibromyalgia went up with age, with over 7% of the 60-75 year old women in the sample meeting the diagnostic criteria (Wolfe, Ross, Anderson & Russell, 1995). The cause of fibromyalgia is unknown, though a number of possibilities have been suggested, including viruses (for example Simms et al, 1992; Buskila, et al, 1997), genetics (Buskila & Sarzi-Puttini, 2006) and physiological (Buskila, Neumann, Vaisberg, Alkalay & Wolfe, 1997) or psychological trauma (Amital et al, 2006).

As reflected in diagnostic criteria, fibromyalgia is distinct from other forms of chronic pain, mainly because of its widespread nature and the presence of other symptoms such as fatigue. Fibromyalgia was previously diagnosed using tender point tests: as well as experiencing pain in all four quadrants of the body, patients also had to experience pain in eleven of eighteen “tender points” spread around the body upon the application of pressure. They also had to experience a number of additional symptoms including fatigue and sleep problems (Wolfe et al, 1990). However, because the tender point test was never designed to diagnose individual patients (Wolfe, 1997), in recent years a new diagnostic criteria, not involving tender points, has been proposed (Wolfe et al, 2010). This involves pain in seven or more areas of the body, with the body divided into nineteen areas, and a score of five or more out of twelve for measures of other somatic symptoms. Patients can also have pain in three or more areas of the body and a score of nine or more for measures of other somatic symptoms. For the patient to be diagnosed with fibromyalgia they have to have been

experiencing the symptoms for more than three months, and not have any other disorder that might explain their experiences (Wolfe et al, 2010).

1.11 Overview of studies

The first four studies in this thesis were conducted with university and college participants. Chapter two will give an overview of the general health experience of this group to provide background information about their symptom experience and self-rated health. The aim of this study was simply to determine how many symptoms young British university and college students experienced in a one month period, and what proportion of young people thought they were in excellent, good or poor health.

Chapter three will go on to discuss the self-rated health of this population in greater depth. The aim of the study was to investigate whether students who behave in a way that is labelled healthy, in this case exercising and eating healthily, have improved self-rated health. If young people who behave in a way labelled as healthy then label themselves as healthy, in the absence of any objective improvements in symptom experience, this will provide evidence that labels generated from information in the environment have the power to change the way people think about their health experience.

Having looked at the way young people understand their own health, chapter four will go on to examine the way young people think about others who are labelled in unambiguously unhealthy ways, such as “smoker” or “obese”. Specifically the aim of the study was to investigate whether young people attach less moral worth to these unhealthy groups. This was done to investigate whether one of the common criticisms levelled at

health campaigns, that they lead to the stigmatisation of, and moral judgements against, particular groups, is true.

Having investigated the effect of labels on the way people think about themselves and others, chapter five will go on to discuss whether by changing a label it is possible to change peoples' responses to stimuli. This study involved a series of investigations using laboratory induced pain. If it is the case that it is possible to alter the label people apply to a painful stimulus and in doing so change the rating they give to that pain, this suggests that labels not only have the power to alter the way people think about themselves, but also their behavioural responses.

Chapter six will discuss similar mechanisms to those found to be successful in altering people's responses in chapter five in the real world. The aim of the study was to investigate the effects of a real world health campaign on the way people responded to pain. If the campaign changed people's behaviour, this suggests that the mechanisms investigated in the previous chapter do not just take place in the artificial laboratory situation, but may have real world counterparts.

Having investigated the influence labelling has on the way healthy people make sense of their health, chapters seven, eight and nine will go on to discuss the way people with fibromyalgia make sense of their health. Chapter seven will introduce the methods used in the following two chapters, and provide demographic information about the participants. Chapter eight will discuss the embodied experience of fibromyalgia. The aim of this study was to investigate the impact fibromyalgia has on the lives of those who are diagnosed with

it, and the way they interpret their experiences, acknowledging the impact of the fibromyalgia label.

Finally chapter nine will discuss in more detail the social relationships of people with fibromyalgia, and the impact the label of fibromyalgia has on their wider social experience. Participants in this study were asked about their relationships with family and friends, doctors and work colleagues, to try to understand the interactions they have people in various settings. Participants were also questioned about their interactions with support networks, in order to understand their relationships with other people with the syndrome.

Chapter Two

The symptom experience of university and college students in Britain

2.1 Introduction

In the previous chapter, it was explained that university and college students will be the participants in the majority of studies in this thesis investigating how healthy people understand and interpret their health. In the current study the primary aim was to provide basic information about the health status of that group, in order to contextualise the subsequent studies. Specifically the objectives of the present study were to: a) investigate how many symptoms students in Britain experience in a one month period, and b) investigate what proportion of students rate their own health positively and negatively.

The prevalence of somatic symptoms in healthy adult samples has been examined in multiple studies. For example, in one early investigation 414 university students and staff were questioned about their experience of 25 symptoms during a three day period. Eighty per cent of the sample reported experiencing at least one, with a median report of two symptoms (Reidenberg & Lowenthal, 1968). In another survey it was found that 29% of adult men and 37% of adult women reported experiencing between six and ten symptoms in a thirty day period (Eriksen, Ihlebaek and Ursin 1999).

The prevalence of individual symptoms has also been examined. A study investigating fatigue in the working US population reported that 38% of the sample experienced significant fatigue in the two weeks before the study (Ricci, Chee, Lorandean and Berger, 2007). In a survey of 62,651 adults in Norway, 12.5% of people reported feeling nausea in the previous year (Haug, Mykleton & Dahl, 2002).

The number of symptoms experienced specifically by young adults and adolescents has also been investigated, leading to a range of different findings. For example, in one study conducted with young people in Switzerland, participants were asked about their experience of nine different symptoms at three time points; when the group's average age was 13.5, then 16.3 and finally 19.8. At each time-point they were asked whether they had experienced dizziness, being overtired, aches and pains, headaches, nausea, eye problems, skin problems, stomach ache and vomiting at any point over the last six months. It was found that at the first two time-points the most common symptoms were skin problems and headache, and at the third the most common symptoms were skin problems and being overtired (Steinhausen & Winkler Metzke, 2007).

A very similar study was conducted with young people in the Netherlands at two time-points, when the group was aged between 12 and 16, and then between 18 and 24. At both time-points the most common symptoms were headaches and being overtired (Dhossche, 2001), similar to the skin problems, headache and being overtired found by Steinhausen and Winkler Metzke (2007). Though generally the patterns of symptoms experienced by participants in the two studies were similar, methodological differences led to what initially appear to be very different findings. At the final time-points, when the Swiss participants were aged between 17 and 24 and the Dutch participants were aged between 18 and 24, the prevalence of the nine symptoms in the six months before the study were: dizziness 0.7% for the Swiss participants and 15% for the Dutch, being overtired 6.4% and 40%, aches and pains 2.4% and 12%, headaches 5.65% and 37%, nausea 1.2% and 14%, eye problems 1% and 5%, skin problems 5.7% and 18%, stomach ache 3% and 21% and vomiting

0.8% and 6%. These differences in findings are primarily because of the use of different inclusion criteria across the two studies. However some differences in the symptom patterns across the two studies, such as the comparatively greater number of people reporting skin problems in the Swiss sample, suggest there may also have been genuine variations across the two groups. Unfortunately, the different inclusion criteria means it is impossible to be sure.

These studies provide useful information about the prevalence of some of the most common somatic symptoms experienced by young people, and suggest that the type of symptoms experienced can vary across two countries. However, the inclusion of only nine symptoms makes it difficult to understand just how many symptoms are experienced by young people on a regular basis in either country. To do this it is important to look at a longer list of symptoms.

One study that provided a much broader insight into young people's symptom experience investigated the number of somatic symptoms experienced by 11 to 16 year olds in England. Here a total of 31 symptoms were investigated, with participants being asked about their lifetime experience of each. The most common symptoms were found to be joint pains (40%), having a pounding heart (40%), dizziness (41.5%) and experiencing a lump in the throat (52%) (Eminson, Benjamin, Shortall, Woods & Faragher, 1996). However, though this study provides an interesting insight into how many symptoms British children and young teenagers experience, the use of the lifetime prevalence means there is no indication as to how regularly each symptom was experienced. This therefore means that the study is unable

to provide insight into the true symptom experience of young people, as experiencing, for example, nausea on a monthly basis is considerably more disruptive than experiencing it once a year or lifetime. In addition, though previous time-point studies such as those described above suggest symptom experience stays reasonably steady across teenage years, interesting changes, particularly in symptoms such as fatigue and headache, were found. It is therefore not possible to extrapolate the experience of 16 to 24 year olds from that of 11 to 16 year olds and be sure there will be no difference.

In addition to simply investigating the number of symptoms experienced by young people, the way this group categorise their health in relation to those symptoms is also of interest. The question of how many symptoms young people experience while still believing they have good health is unclear from the current literature, as is the number of young people who believe they have good health. In a sample of Canadian young people aged 12 to 19 the majority rated their health very positively, with only 27.5% rating their health as less than very good (Vingilis, Wade & Seeley, 2002). Similar results were found in a study of American students aged between 11 and 18. Here students were asked about their health at two time-points, one year apart. Very similar results were found, with fewer than 33% of students rating their health as less than very good at either time-point (Boardman, 2006).

In contrast, less positive results were found in a recent survey of Swedish young people who were questioned when they were both between the ages of 12 and 14 and between the ages of 14 and 16. In this study participants were asked to rate their health as high, medium or low. The first time they were questioned 47.4% of participants rated their

health as high, 45.1% rated their health as medium and 7.5% rated their health as low.

Negative changes were found at the second time-point, with only 29.8% of the 14 to 16 year olds rating their health as high, 56.1% rating their health as medium and 14% rating their health as low (Jerden, Burell, Stenlund, Weinehall & Bergstrom, 2011). As before, the wide variation found across these three studies highlights the difficulty in extrapolating across countries and age groups.

In the current study the number of symptoms experienced by young British students was investigated, with participants questioned about their experience of a larger and more comprehensive list of symptoms than in previous studies, and over a much smaller timescale. Participants were asked about their experience of 36 common symptoms over the previous month. Both physical symptoms, such as chest pain, and psychological symptoms, such as depression, were included. Participants were also asked to rate their own health as excellent, good or poor. Data collection took place at four different time points, and with two different age groups: college students, aged 16- 18, and university students, aged 18-35. Data collection took place either face-to-face or anonymously online, to determine whether the data collection method affected the results for potentially embarrassing symptoms. The results of the four groups will be presented separately, in order to highlight the differences between them.

The objectives of the study were to: a) investigate how many symptoms students in Britain experience in a one month period, and b) investigate what proportion of students in Britain rate their own health positively and negatively. It was hypothesised that participants

would report experiencing multiple symptoms in the one month period. It was also hypothesised that the majority of participants would rate their own health positively.

2.2 Methods

2.2.1 Participants

558 participants (mean age 19 years, range 16-35; 451 female) were surveyed. This data was gathered in four separate collections, detailed below.

2.2.1.1 College students 2008

26 students (mean age 16.9 years, range 16-18; 19 female) were surveyed using a face-to-face questionnaire. 15% were taking prescribed medication at the time of the study.

2.2.1.2 College Students 2009

105 students (mean age: 16.9 years, range 16-18, 71 female) were surveyed using a face-to-face questionnaire. 20% were taking prescribed medication.

2.2.1.3 University Students: Face-to-Face Sampling

39 University of Birmingham students (mean age: 22.8, range: 18-35, 21 female) were surveyed using a face-to-face questionnaire. 13% were taking prescribed medication.

2.2.1.4 University Students: Online Sampling

388 members of the University of Birmingham online participation scheme (mean age: 19.9, range: 16-35, 340 female) were surveyed using an online questionnaire. 21% were taking prescribed medication.

2.2.2 Procedure

Participants completed a questionnaire asking about the frequency and duration of their experience of 36 common somatic symptoms in the past month (see appendix one). All participants provided informed consent and the study conformed to University of Birmingham School of Psychology ethical guidelines.

2.3 Results

2.3.1 College Students 2008

The average number of somatic symptoms reported in the one month period was 15.3 (15.7 including menstrual pain) out of a possible 36. The majority (69%) of the students reported their overall health as being good, with 19% reporting their health as excellent and the remaining 12% reporting their health as poor. Amongst those students indicating excellent health, the average number of reported somatic symptoms was 14.4. Amongst those indicating poor health the average increased to 20. The most common symptoms were headache (reported by 100% of the sample) and dizziness (85%; please see table 2.1).

Menstrual pain was also common in the female sample (63% of the females surveyed).

Table 2.1

The percentage of each group who experienced each symptom

Symptom	College 08	College 09	Uni: Face-to-face	Uni: Online	Average
Vomiting	38.46	37.74	15.79	30.57	30.64
Nausea	76.92	66.98	50	75.71	67.4
Diarrhoea	46.15	34.91	39.47	55.81	44.09
Arm/Leg Pain	50	53.77	31.58	43.67	44.76
Joint Pain	48	51.89	21.05	44.96	41.48
Other Pain	42.31	49.06	28.95	56.85	44.29
Heart Racing	53.85	46.23	31.58	49.35	45.25
Dizziness	84.62	58.49	42.11	61.50	61.68
Fatigue	46.15	46.23	47.37	70.54	52.57
Headache	100	73.59	71.05	82.95	81.9
Concentration Problems	73.08	83.02	84.21	83.46	80.94
Depression	69.23	65.71	60.53	77	68.12
Sensitivity to noise/light	23.08	30.19	13.16	26.1	23.13
Abdominal Pain	52	52.83	42.11	48.06	48.75
Gas	42.31	48.11	57.9	56.99	51.33
Food Sensitivity	38.46	42.45	15.79	23.51	30.05
Back Pain	46.15	61.32	47.37	61.5	54.09
Urinary Pain	0	10.48	10.53	15.25	9.07
Shortness of Breath	34.62	31.43	15.79	26.36	27.05
Chest Pain	34.62	30.19	10.53	29.97	26.33
Period Pain	63.16*	61.64*	40.9*	60.88*	56.65*
Stiff Joints	23.08	28.3	10.53	32.82	23.68
Constipation	15.38	22.64	26.32	37.56	25.48
Fainting	3.85	11.43	10.53	11.89	9.43
Anxiety	57.69	60.38	65.79	82.43	66.57
Irritability	52	64.15	68.92	80.62	66.42
Insomnia	42.31	43.81	44.74	46.51	44.34
Circulation Problems	26.92	21.7	28.95	38.76	29.08
Palpitations	15.39	16.35	5.41	14.77	12.98
Memory Problems	50	36.79	21.05	32.04	34.97
Skin Irritation	42.31	39.05	31.58	40.83	38.44
Jaw problems	19.23	17.93	7.9	18.86	15.98
Restless Legs	46.15	30.19	26.32	34.63	34.44
Mood Swings	69.23	72.64	52.63	72.09	66.65
Smell Sensitivity	20	27.36	13.16	19.9	20.11
Body Temperature Fluctuations	50	44.34	21.05	47.55	40.74

*percentage of the female sample

2.3.2 College Students 2009

The average number of symptoms reported in the one month period was 15.1 (15.5 including menstrual pain) out of a possible 36. The majority (72%) of the students reported their overall health as being good, with 16% reporting their health as excellent and the remaining 12% reporting their health as poor. Amongst those students indicating excellent health the average number of reported somatic symptoms was 9. Amongst those indicating poor health the average increased to 17.7. The most common symptoms were concentration problems (reported by 83% of the sample), headache (74%) and mood swings (73%; please see table 2.1). Menstrual pain was also common in the female sample (63% of the females surveyed).

2.3.3 University Students: Face-to-Face Sampling

The average number of somatic symptoms reported in the one month period was 11.7 (11.9 including menstrual pain) out of a possible 36. The majority (74%) of the students reported their overall health as being good, with 18% reporting their health as excellent and the remaining 8% reporting their health as poor. Amongst those students indicating excellent health the average number of reported somatic symptoms was 10.5. Amongst those indicating poor health the average increased to 14.5. The most common symptoms were concentration problems (reported by 84.21% of the sample) and headache (71.05%; please see table 2.1). Menstrual pain was also common in the female sample (40.9% of the females surveyed).

2.3.4 University Students: Online Sampling

The average number of somatic symptoms reported in the one month period was 16.3 (16.9 including menstrual pain) out of a possible 36. The majority (76%) reported their overall health as being good, with 10% reporting their health as excellent and the remaining 14% reporting their health as poor. Amongst those students indicating excellent health the average number of reported somatic symptoms was 13.8. Amongst those indicating poor health the average was 19. The most common symptoms were concentration problems (reported by 83.46% of the sample) and headache (82.95%; please see table 2.1). Menstrual pain was also common in the female sample (60.88% of the females surveyed).

2.3.5 Across groups comparison

As can be seen from figure 2.1, the most commonly experienced pain symptom in all four groups was headache. Arm/leg pain, joint pain, other pain and abdominal pain were all experienced by approximately 50% of each sample on at least one occasion during the month, apart from the University Students: Face-to-face sample who reported experiencing these types of pain in much smaller numbers than the other groups. Menstrual pain was experienced by approximately 60% of the female participants in all groups except the University Students: Face-to-face sample. Chest pain and urinary pain were the least common forms of pain but chest pain in particular still affected a significant minority of each group.

Figure 2.1

The percentage of participants experiencing pain symptoms in each group

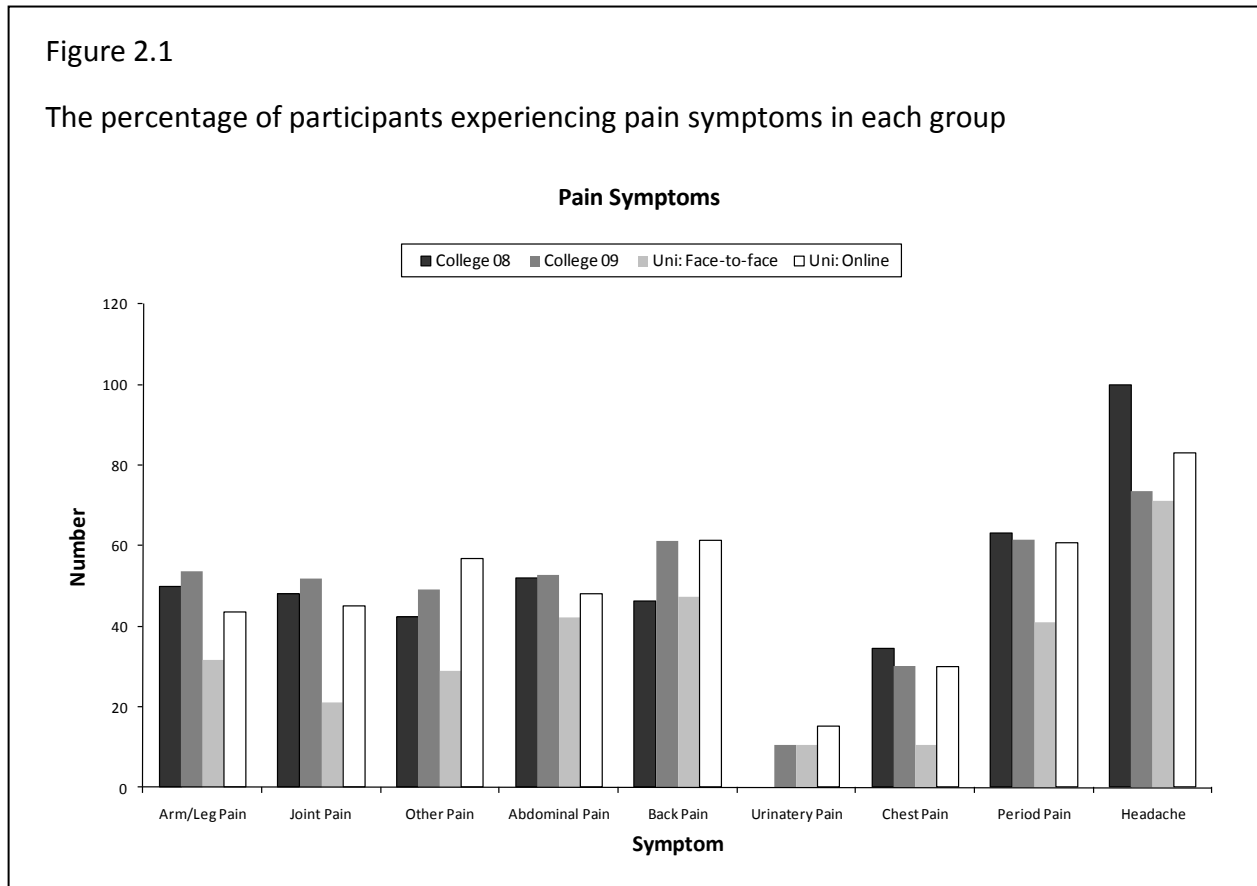


Figure 2.2 shows the percentage of each group suffering from the more well-known somatic symptoms. Nausea was consistently highly reported and the only symptom apart from headache and the psychological symptoms to be reported by over 50% of every group. Dizziness was also common, particularly in the College 08 group.

Figure 2.2

The percentage of participants experiencing common non-pain symptoms in each group

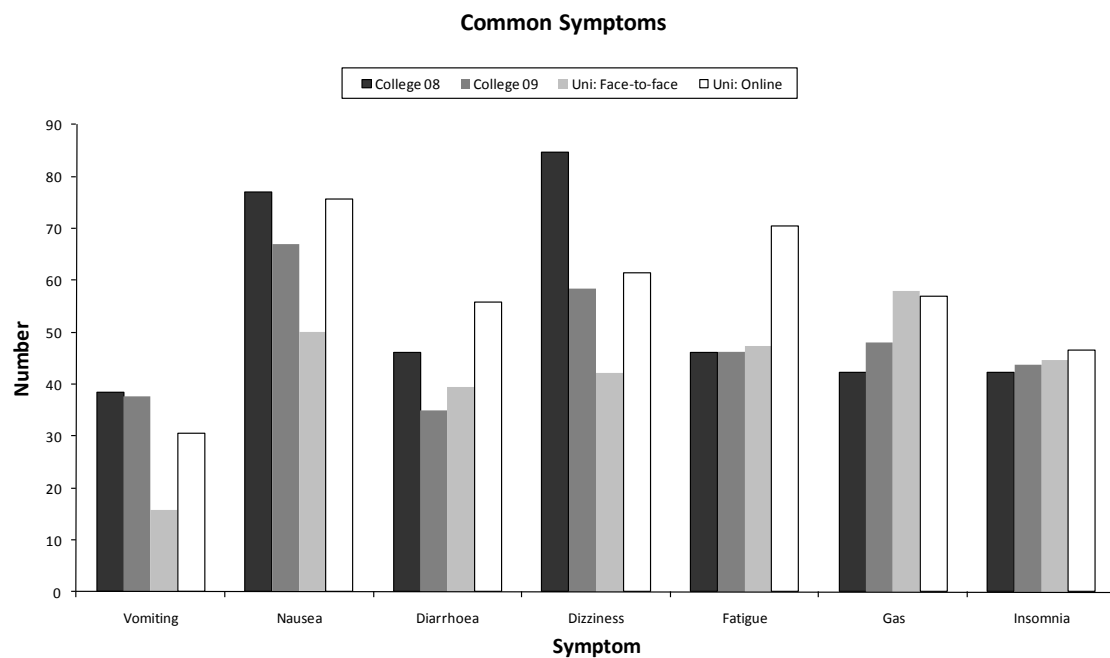
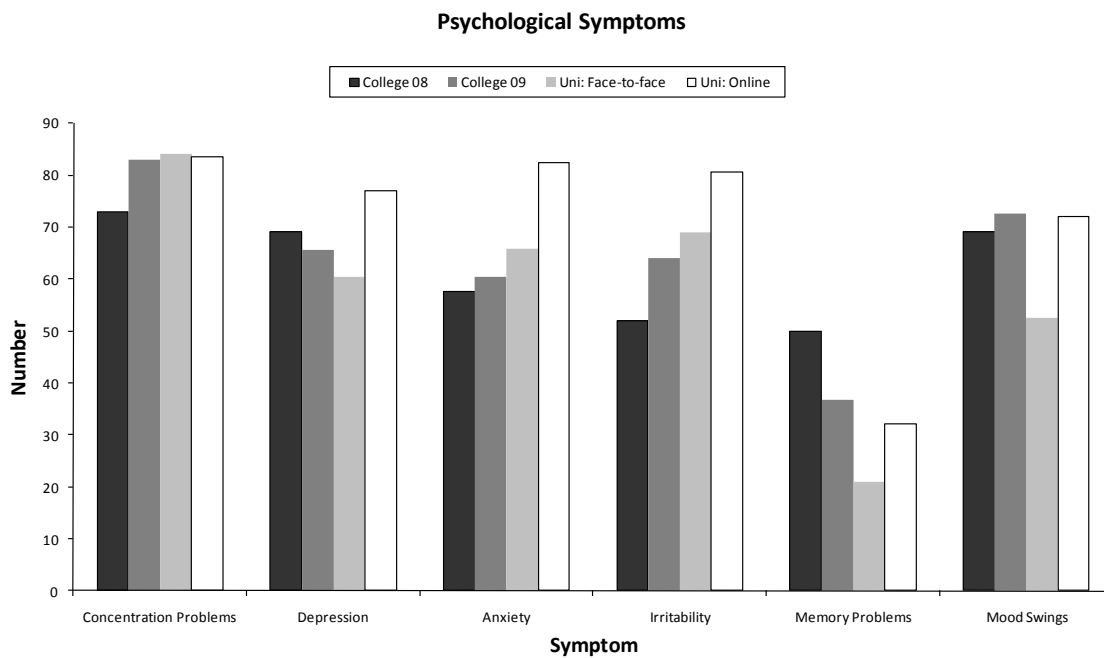


Figure 2.3 shows the percentage of each group who reported suffering from the listed psychological symptoms. Psychological symptoms were very common across all groups. Concentration problems in particular appeared to be extremely common, with over 70% of each group reporting them. Depression, anxiety and irritability were also common, particularly in the University Students: Online group.

Figure 2.3

The percentage of participants experiencing psychological symptoms in each group



2.4 Discussion

This study had two objectives, to: a) investigate how many symptoms students in Britain experience in a one month period, and b) investigate what proportion of students in Britain rate their own health positively and negatively. The average number of somatic symptoms reported in any one month period across the four samples was 14.6 (15 including menstrual pain) out of a possible 36. The most common symptoms reported were headache (reported by an average of 82% of the sample) and concentration problems (80.9%). The average percentage of students who rated their health as good across the four samples was 73%. 16% rated their health as excellent and 12% as poor.

The participants in this study reported all of the symptoms in greater numbers than adolescent participants of previous investigations, and over a much shorter time period. For example, in Dhossche et al's (2001) study, more comparable in terms of inclusion criteria than the Swiss study that followed it (Steinhausen & Winkler Metzke, 2007), 37% of participants reported experiencing headache in the six month study. In the present study an average of 81.9% of participants reported experiencing headache in the past month. In a study conducted with British 11-16 year olds, only 31.5% of students reported experiencing headache in their lifetime (Eminson, Benjamin, Shortall, Woods & Faragher, 1996).

It is unclear what could cause the results of this study to be so much higher than in previous investigations. The general consistency across the four groups suggests that this was not due to one unusual sample. It is therefore possible that the results reflect a genuine difference between British students and young people from other countries, and between

under and over 16s. However, as there were some methodological differences between this and other studies it is important to explore the effects these may have had. One difference between this and other studies was that participants were asked about their symptom experience over a much smaller time period than in other studies. It may be possible that asking participants about the previous month triggered a form of recency effect (Murdock, 1962) making it more likely they would remember a greater number of symptoms. Studies asking about symptom experience over a short period of time suggest that people do experience multiple symptoms regularly. For example, in Reidenberg & Lowenthal's (1968) study participants reported experiencing a median of two symptoms in three days.

Another difference between this and previous studies was in the way the questions were asked. In Dhossche et al's (2001) study participants were asked to rate their experience of the nine symptoms on a 0 to 2 scale, with 0 indicating "not true", 1 indicating "somewhat or sometimes true" and 2 indicating "very true or often true". A score of 1 or 2 was taken to mean that the symptom had been experienced, unlike in the later Steinhausen and Winkler Metzke (2007) where only scores of 2 were included. Dhossche et al's (2001) criteria appears to be very similar to the scale used in this study, where participants were asked to rate their experiences on a scale from 0 to 3, and scores of 1, 2 and 3 were included as "experienced". This therefore seems unlikely to explain the large differences found between this and the current study.

Another potential cause of the high results was that the data for this study was collected in the late spring, when both the college and university students were likely to be

studying for exams. It is possible that some students may have found this stressful, and experienced more symptoms as a result (Hendrix, Steel & Schultz, 1987).

Despite reporting high numbers of symptoms, participants appeared to have a largely positive view of their own health, comparable to the higher rates found in previous work (Vingilis, Wade & Seeley, 2002; Boardman, 2006). This suggests that the symptoms participants were experiencing did not make any great negative impact on their day-to-day lives, and for the most part they did not view themselves as unhealthy or unwell. There was some level of variation in average number of symptoms experienced by participants who categorised themselves as having poor, good or excellent health. Participants who reported excellent health experienced 11.9 symptoms, a reduction from the average of 14.6, while those who reported poor health experienced 17.8 symptoms. This suggests that symptom experience does impact somewhat upon self-rated health. However, the study showed that participants believed experiencing multiple symptoms was compatible with excellent health.

It is also important to note that the four groups did not all answer in exactly the same way. These differences were particularly pronounced in the answers given by the university students surveyed face-to-face and those surveyed online. The online group reported more fatigue, vomiting, diarrhoea, heart racing, food sickness, joint stiffness, other pain, chest pain and urinating pain. One potential cause of these differences could be variations in the type of student choosing to participate in the study face-to-face and the type of student choosing to participate online. Most psychology students at the University of Birmingham choose to participate in experiments for course credits and are free to select their preferred studies

from a large number of ongoing research projects. It is possible that students who preferred to meet the experimenter directly differed from students who preferred to complete the research online. Those completing online may have suffered increased social anxiety or may simply have been less healthy than those able to meet the experimenter directly, and this may have led to the differences between the two groups. An alternative explanation is that people answering online may have felt more comfortable answering personal health-related questions than those answering face-to-face. It has previously been shown that different methods of questioning can produce different answers when the questions deal with sensitive information (Tourangeau & Smith, 1996). It is possible that participants completing the questionnaires with the experimenter present were too embarrassed to say that they suffered from symptoms such as “diarrhoea” or “urinating pain”. It is also possible that, while the face-to-face sample had to complete the questionnaire in appointments scheduled between 9am and 6pm on weekdays, the online sample were able to answer the questionnaire whenever they liked and may have completed the questionnaire very early in the morning or late at night. This may have especially influenced ratings of fatigue. Further research is needed to discover the true reason for the differences.

There were some limitations to this study. First, the group sizes varied across the four samples, with the first college sample and the face-to-face university sample being particularly small. This may have led to less accurate results in these groups than would have been found if more participants were questioned. Second, it is unclear whether the exam period data collection contributed to the high number of symptoms reported by the groups. Collecting the data at different points in the year would have made it less likely that

students were completing the questionnaire during a potentially stressful time, when they may have been more likely to report somatic symptoms.

2.5 Conclusion

It was found that students studying at a British college and university reported experiencing an average of 14.6 symptoms out of 36 in a one month period, with headache and concentration problems being the most common. The majority of participants categorised their own health as “good”.

2.6 Thesis objectives and future directions

The present chapter found evidence to suggest that, though the participants reported experiencing a wide range of symptoms, they generally rated their own health positively. It was also found that though symptom experience appeared to alter self-rated health, participants who experienced multiple symptoms still rated their health positively. The next chapter will go on to investigate one of the main questions of this thesis, that of whether labels, and specifically whether behaviour is labelled as healthy or unhealthy, makes an impact on the way young people rate their own health.

Chapter Three

The influence of behaviour labelling on health beliefs

3.1 Introduction

The previous chapter investigated the health of university and college students in Britain. In this chapter the way in which this group interpret and label their own health will be examined. Young people are the group who are least likely to be diagnosed with a functional somatic syndrome, such as fibromyalgia (Wolfe, Ross, Anderson & Russell, 1995) and therefore are the group least likely to have a syndrome diagnosis influencing the way they understand their own health. Because of this other factors, such as lifestyle and symptom experience, may be more influential. In the previous chapter it was found that young people who rated their health as excellent reported fewer symptoms than those who rated their health as poor. In this chapter the effects of another factor were investigated. Specifically, the aim of this study was to investigate whether perceived behaviour, and whether that behaviour was thought of as healthy or unhealthy, influenced participants' beliefs about their health. The objectives of this study were to a) investigate the relationship between making healthy lifestyle changes and self rated health in a young British sample, and b) investigate the way in which young people who do or do not attempt to live healthily judge their own health in relation to other people.

Previous investigations have suggested that performing behaviours understood to be healthy leads to better self-rated health. For example, studies conducted with adult populations have shown that the more leisure time activity people do, the better they rate their own health (Galan, Meseguer, Herruzo & Rodriguez-Artalejo, 2010; Abu-Omar, Rutten

& Robine, 2004; Kaleta, Makowiec-Dabrowska, Dziankowska-Zaborszczyk & Jegier, 2006; Molarius et al, 2006; Sodergren, Sundquist, Johansson & Sundquist, 2008).

When the association between healthy behaviour and self rated health is investigated more thoroughly, as in a study by Kaleta, Makowiec-Dabrowska, Dziankowska-Zaborszczyk and Jegier (2006) the perceived health value of the behaviour, rather than performing the behaviour itself, is found to be most important. In the study, participants were not only asked about leisure time physical activity, but also at-work physical activity and housework-related physical activity. It was found that only higher levels of leisure time physical activity, and not higher levels of work or housework related physical activity, lead to greater self rated health (Kaleta, Makowiec-Dabrowska, Dziankowska-Zaborszczyk & Jegier, 2006). This suggests that merely living an active lifestyle is not the important factor, but voluntarily taking time to exercise during leisure time is.

Previous research has suggested that young people are aware of the importance of healthy behaviour and the negative consequences of, for example, obesity (Booth, Wilkenfeld, Pagnini, Booth & King, 2008). It has also been shown that young people are aware of the importance of healthy eating (Lattimore & Halford, 2003) exercise (MORI, 2001) and using sun protection (Broadstock, Borland & Hill, 1996), even if this knowledge does not always translate to healthy behaviour. This suggests that young people will have the same positive associations between these behaviours and health as adults, and will therefore show more positive self rated health if they engage in these activities.

Previous investigations have shown this to be the case. The same associations have been found between the health behaviours and health ratings of adolescents and young people as adults, with factors such as smoking, being overweight, taking low levels of exercise and/or having a poor diet linked to worse self rated health in young samples in Sweden (Breidablik, Meland & Lydersen, 2008), Norway (Breidablik, Meland & Lydersen, 2009), Iceland (Thorlindsson, Vilhjalmsson & Valgeirsson, 1990), Canada (Vingilis, Wade & Adlaf, 1998; Vingilis, Wade & Seeley, 2002; Tremblay, Dahinten & Kohen, 2003), Ireland (Kelleher, Tay & Gabhain, 2007) and the US (Swallen, Reither, Haas & Meier, 2005). The associations between these factors have not been investigated in young people from the UK, but the volume and strength of previous findings suggests that a similar pattern is likely.

However, in looking at these associations, existing studies do not provide an insight into other ways that performing or not performing healthy behaviours influences the way young people think about health, particularly how they think about their own health in relation to that of other people. This is important because it may potentially lead to different health outcomes if someone thinks of themselves as unhealthy but average, compared to someone thinking of themselves as much more unhealthy than their peers. The way people label themselves and the consequences that label has is entirely dependent on context. For example, if young people who do not perform healthy behaviours think of themselves as less healthy than their peers this may lead to negative consequences such as denial (Lazarus & Folkman, 1984) or increased negative self beliefs and reduced efficacy for change (Strecher, DeVellis, Becker & Rosenstock, 1986). It could also lead to positive consequences such as increased motivation to change (Van-Dijk & Kluger, 2004). In contrast, if this group

think of themselves as unhealthy, but the same as all other typical students, it is less likely that they will believe their lifestyle worthy of attention.

It is currently unclear as to whether people who perceive themselves to have made lifestyle changes they believe to be healthy think of themselves as healthier than their peers, or if they assume that everyone lives the same healthy lifestyle as themselves. Equally, it is unknown whether young people who have not made lifestyle changes they believe to be healthy believe that they are living less healthy lives than their peers. The objectives of this study were to a) investigate the relationship between making healthy lifestyle changes and self-rated health in a young British sample, and b) investigate the way in which young people who do or do not attempt to live healthily judge their own health in relation to other people. It was hypothesised that young people who did perceive themselves to have made healthy lifestyle changes would rate their own health more positively. Conversely it was hypothesised that young people who did not perceive themselves to have made healthy lifestyle changes would rate their health more negatively. It was also hypothesised that young people who did perceive themselves to have made healthy lifestyle changes would rate themselves as healthier than average and than their peers. Conversely it was hypothesised that young people who did not perceive themselves to have made healthy lifestyle changes would rate themselves as less healthy than average and than their peers.

3.2 Method

3.2.1 Participants

Data was gathered using an opportunity sample questionnaire, both face-to-face and via the university's online participant recruitment system. The participants were those questioned in chapter two; for demographic information see sections 2.2.1.1 to 2.2.1.4.

3.2.2 Procedure

All participants completed a multiple choice questionnaire, an extension of the symptom questionnaire described in chapter two. Participants were first asked about the original 36 symptoms. After completing this section they were asked a number of questions to investigate their attitude towards their own health and their own health compared to their perceived average for their peer group. Questions included "Over the last few years, have you made lifestyle changes in order to make yourself healthier?" and "How would you rate your health compared to others in your age group?" (see appendix one). Though the questionnaire and the multiple choices were the same for all participants, the way participants were surveyed varied across groups (please see chapter two, sections 2.2.1.1 to 2.2.1.4).

3.3 Results

3.3.1 Collapsing the four groups into one large group

The four groups were collapsed into a single large group for analysis. The decision to collapse the groups rather than present the results separately was taken after investigating

the differences in responses across the four groups. It was found that there were very few significant differences between them, and the decision was then taken to collapse the four groups into a single group to allow greater ease of interpretation. Specifically, there were no significant differences between the groups in terms of whether participants rated their health as excellent, good or poor ($\chi^2(6, N = 501) = 6.485, p = 0.371$), whether participants thought they were healthier than their age group ($\chi^2(12, N = 502) = 13.111, p = 0.361$), whether participants believed they should feel well more than they did ($\chi^2(3, N = 501) = 1.727, p = 0.631$), whether participants believed they should feel ill more than they did ($\chi^2(3, N = 500) = 3.146, p = 0.370$), how healthy participants would rate their lifestyle as being ($\chi^2(12, N = 500) = 9.872, p = 0.627$), how healthy participants would rate their lifestyle as being compared to average ($\chi^2(12, N = 501) = 14.139, p = 0.292$), and how healthy participants would rate their diet as being compared to average ($\chi^2(12, N = 499) = 15.502, p = 0.215$). There were also no significant differences between the groups in terms of whether participants thought that a healthy diet ($\chi^2(3, N = 500) = 4.925, p = 0.177$) or lifestyle ($\chi^2(3, N = 501) = 4.609, p = 0.203$) improves health. There were trends towards significance in participants' responses to the question of whether they believed they were healthier than the average person ($\chi^2(3, N = 501) = 7.091, p = 0.069$) and whether they believed that their diet was healthy ($\chi^2(12, N = 500) = 20.426, p = 0.059$).

The two significant differences were found between the four groups. The first was found for the question of whether participants felt that they experienced more or less symptoms than others ($\chi^2(12, N = 499) = 21.749, p = 0.04$). However, an examination of the four individual conditions found that the differences between the relevant responses of all

four groups were insignificant, something that was also found for the overall group ($\chi^2(4, N=497) = 1.648, p = .8$). A similar finding was also found for the question of how many symptoms participants in each group experienced ($F(3, 553) = 6.406, p < .001$). Again, the differences between the relevant responses of all four groups was insignificant, as was the response for the overall group ($t(500) = -1.499, p = .135$). Therefore, in view of these results and the overall similarity between participants' responses to the other questions, it was decided that collapsing the four groups would allow the results to be interpreted more clearly, without losing any important information that could have been gleaned from the individual groups.

3.3.2 Perceived lifestyle change and non-change group comparisons

Before analysis three people who completed the questionnaire online were excluded for selecting the "I would prefer not to say" option in answer to every question.

Participants were then divided into separate groups depending on their answer to the questions "Over the last few years, have you made lifestyle changes in order to make yourself healthier?" and "If yes, do you believe that these worked?". Participants either answered "No, not applicable" "Yes, yes" "Yes, no" or "Yes, not sure". For the purpose of analysis only the "no, not applicable" and "yes, yes" groups were used. Two people were excluded from the "no" group on the basis of answering "no" to the first question and "yes" to the second. This left the "no, no" group (or "no changes" group) with 251 participants (average age: 19.21, 199 female, 48 male and 4 who declined to respond) and the "yes, yes" group (or "changes" group) also with 251 participants (average age: 19.6, 207 female, 44 male). A chi-squared test showed no significant difference in the number of people taking

medication in the two groups ($\chi^2(1, N = 500) = 1.127, p = 0.288$). See table 3.1 for full results and significances.

The first set of questions explored whether people who had made lifestyle changes experienced more or less symptoms than those who had not. For a wider exploration of the number of symptoms experienced by young healthy college and university students please see chapter two; in this study only wider trends were examined. Participants were asked about 36 common symptoms, specifically vomiting, nausea, diarrhoea, arm/leg pain, other pain, heart racing, pounding or skipping, dizziness, fatigue, headaches, concentration, depression, sensitivity to light or colour, abdominal pain, gas, food sensitivity, urinary pain, shortness of breath, chest pain, menstrual pain, joint stiffness, fainting, anxiety, irritability, insomnia, poor circulation, palpitations, memory problems, sore/irritated skin, jaw problems, restless legs, mood swings, smell sensitivity and difficulty regulating body temperature. As can be seen in figure 3.1, there were no significant differences in the number of symptoms experienced across the two groups, ($t(500) = -1.499, p = .135$). To ensure this effect was not due to the immediate effects of taking part in more sport or exercise, any symptoms that could have been caused by an increased level of sport participation were removed. Specifically participants' responses to arm and leg pain, joint pain, heart racing, fatigue, shortness of breath, chest pain, joint stiffness, palpitations and unregulated temperature were removed. Symptoms were selected liberally, with the aim of removing anything that could be related to exercise. Removing these did not change the significance of the result ($t(500) = -1.910, p = .057$), though a trend towards participants who had not made lifestyle changes experiencing fewer symptoms emerged (see figure 3.1).

Table 3.1

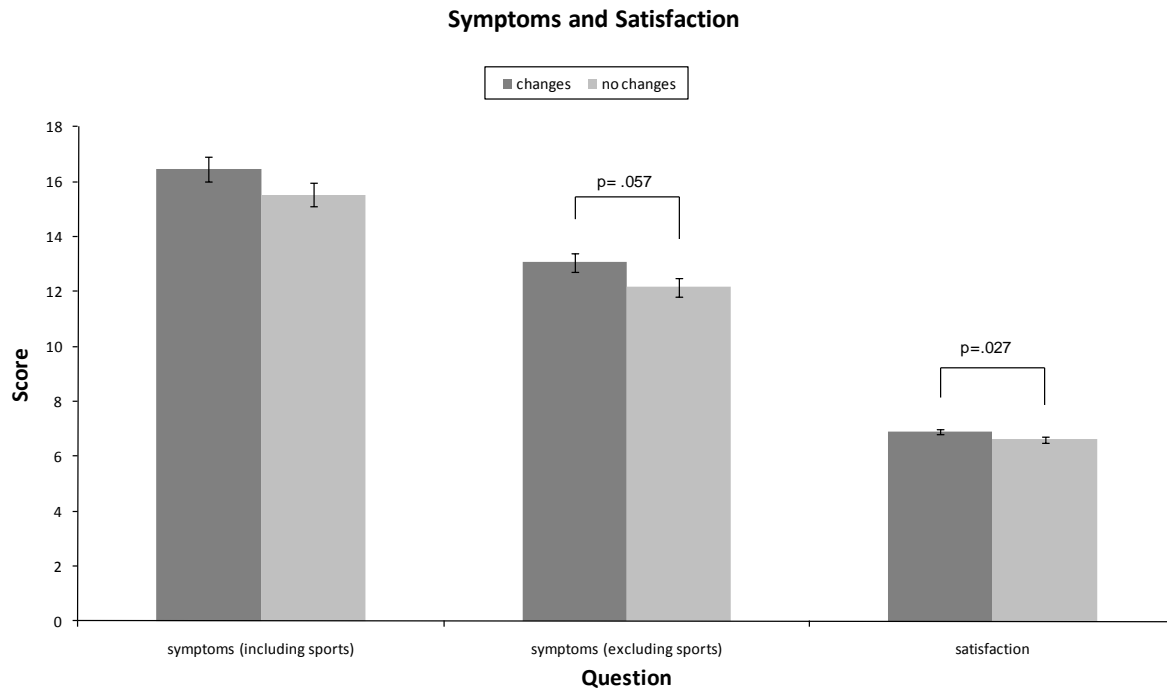
Summary table of results

Question	Significance	Direction
Number of symptoms experienced	t(500)= -1.499, p= .135	N/A
Number of symptoms experienced removing symptoms potentially related to sport and physical exercise	t(500)= -1.910, p= .057	N/A
Self-rating of health as "excellent", "good" or "poor"	χ^2 (2, N= 501)= 8.795, p= .012	No changes group more likely to rate health as poor. Changes group more likely to rate health as good.
Satisfaction with health	t(470.6)= -2.213, p= .027	Changes group significantly more satisfied with their health.
Health compared to peers	χ^2 (4, N= 502)= 8.471, p= .076	N/A
Health compared to average	χ^2 (1, N= 501)= 11.809, p= .001	Changes group more likely to say they are healthier than average.
Healthiness of lifestyle	χ^2 (4, N= 500)= 67.868, p< .001	No changes group more likely to rate their lifestyle as unhealthy or very unhealthy. Changes group more likely to rate their lifestyle as healthy or very healthy.
Healthiness of lifestyle compared to peers	χ^2 (4, N= 500)= 48.468, p<.001	No changes group more likely to rate their lifestyle as unhealthier or much unhealthier. Changes group more likely to rate the lifestyle as healthier or much healthier.
Healthiness of diet	χ^2 (4, N= 4)= 42.185, p<.001)	No changes group more likely to rate their diet as unhealthy or very unhealthy. Changes group more likely to rate their diet as healthy or very healthy.
Healthiness of diet compared to peers	χ^2 (4, N= 4)= 24.752, p<.001	No changes group more likely to rate their diet as unhealthier or much unhealthier. Changes group more likely to rate the diet as healthier or much healthier.
Number of symptoms compared to peers	χ^2 (4, N= 497)= 1.648, p= .8	N/A
Well more often	χ^2 (1, N= 501)= .017, p= .897	N/A
Ill more often	χ^2 (1, N= 500)= 9.918, p= .002	No changes group more likely to say that they should feel ill more often than they do, considering their lifestyle.

Significance- whether there was a significant difference in score between the group who had made lifestyle changes and believed they had worked and the group who had not made lifestyle changes. Direction- An indication of the direction of the result found, if applicable.

Figure 3.1

The number of symptoms experienced (including and excluding sport related symptoms), and satisfaction with health



We then examined how many participants in the change and no changes groups rated themselves as having poor, good and excellent health. It was found that though both groups contained a similar minority of people who rated their health as “excellent” (31 in the change group and 35 in the no change group) there were significant differences in the number of people in the two groups who rated their health as “good” or “poor”. Members of the change group were more likely to rate their health as good, whereas members of the no change group were more likely to rate their health as poor ($\chi^2 (2, N= 501)= 8.795, p= .012$). Participants were also asked to explicitly rate their satisfaction with their health out of ten. As can be seen in figure 3.1 participants in the changes group were significantly more

satisfied with their health than the no changes group ($t(470.6) = -2.213, p = .027$), though the difference in reality was quite small (6.9 vs 6.6).

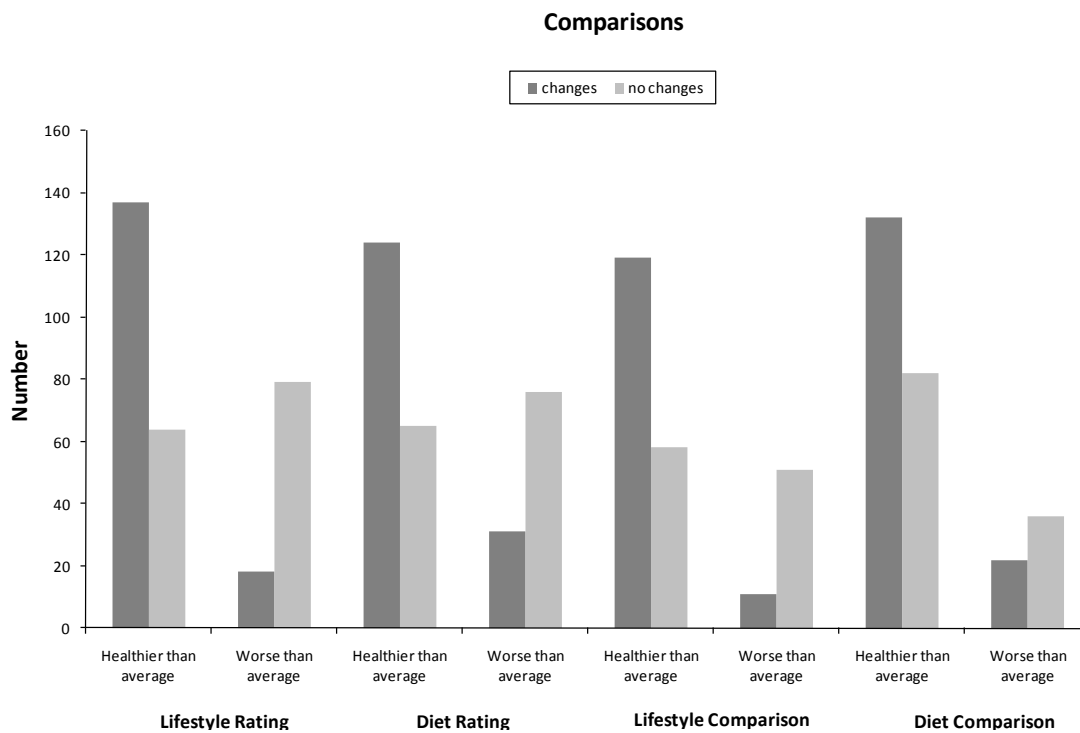
The next set of questions asked participants to rate their lifestyle and diet, both objectively and in comparison to others in their age group. In answer to both the lifestyle and diet questions the change group were significantly more likely to say they were objectively healthier than average ($\chi^2(4, N = 500) = 67.868, p < .001$; $\chi^2(4, N = 4) = 42.185, p < .001$) and also healthier than their peers ($\chi^2(4, N = 500) = 48.468, p < .001$; $\chi^2(4, N = 4) = 24.752, p < .001$) (see figure 3.2). Conversely the no change group were more likely to say they were less healthy than average and less healthy than their peers. This can be seen in figure 3.2 where the “lifestyle rating” and “diet rating” columns display participants’ answers to the questions about whether they were healthier than average. The “lifestyle comparison” and “diet comparison” columns display participants’ answers to the questions of whether they were healthier than their peers.

High numbers of participants in both the change and no change groups answered “yes” to the questions “do you believe that a “healthy” lifestyle leads to better health?” and “do you believe that a “healthy” diet leads to better health?”. 99% of the change group believed that a healthy lifestyle leads to better health and 97% believed a healthy diet leads to better health. 96% of the no change group believed a healthy lifestyle leads to better health and 92% believed a healthy diet leads to better health. These results show both the widespread belief in the importance of a healthy lifestyle and diet, but also that this belief is

as prevalent among people who have not attempted to improve their lifestyle and diet as among those who have.

Figure 3.2

Comparisons to typical age group member and comparison to peers



Finally, participants were also asked about feeling well and ill, a measure more specifically related to illness rather than good health. There was no significant difference between participants' responses to the question of whether, based on their lifestyle and diet, they believed they should feel well more often than they do ($\chi^2(1, N = 501) = .017, p = .897$). However, there was a significant difference in responses to the question "do you believe that, considering your lifestyle, behaviour, diet, etc, you should feel ill more often

than you do?”, with the no change group significantly more likely to say yes ($\chi^2 (1, N= 500)= 9.918, p= .002$). Participants were also asked whether they believed that others in their age group suffered from more or less of the symptoms. There was no significant difference in the responses to this question ($\chi^2 (4, N= 497)= 1.648, p= .8$).

3.4 Discussion

This study had two objectives, to a) investigate the relationship between making healthy lifestyle changes and self-rated health in a young British sample, and b) investigate the way in which young people who do or do not attempt to live healthily judge their own health in relation to other people.

It was found that participants who reported making healthy lifestyle changes were more likely to rate their own health as good rather than poor. Conversely it was found that participants who did not report making healthy lifestyle changes were more likely to rate their own health as poor than good, though a small number of participants in each group rated their health as excellent. Participants who did report making healthy lifestyle changes also reported being significantly more satisfied with their own health than participants who did not. This finding conforms to the same pattern seen in studies conducted with young people in various countries (Bleidablik, Meland & Lyderson, 2008; Bleidablik, Meland & Lyderson, 2009; Thorlindsson, Vilhjalmsson & Valgeirsson, 1990; Vingilis, Wade & Adlaf, 1998; Vingilis, Wade & Seeley, 2002; Tremblay, Dahinten & Kohen, 2003; Kelleher, Tay & Gabhain, 2007; Swallen, Reither, Haas & Meier, 2005). As the number of symptoms reported by participants did not vary between the two groups, this suggests that when participants

perceived themselves to be making healthy lifestyle changes, the way in which they interpreted their health changed, rather than their physical health status.

In this study the way young people who perceived themselves to have made healthy lifestyle changes thought about their health in relation to the people around them was also examined. It was found that participants who had made healthy lifestyle changes were more likely to say that they lived more healthily than their peers. It was also found that participants who had not made changes were more likely to say they lived more unhealthily than their peers. This suggests that the hypothesis, that people who did not report making healthy lifestyle changes would believe they lived a less healthy lifestyle than their peers, rather than thinking their behaviour was the norm, was correct.

The results found in this study are an example of the good and bad outcomes of positive and negative health labelling. The participants who perceived themselves as behaving in a healthy way, and therefore their adoption of the label of someone who behaves healthily, appeared to have multiple positive consequences. This group were not only more satisfied with their own health, they also thought of themselves as healthier than their peers. This suggests that living healthily is not only likely to improve long term physical health but also self image and self esteem, something that has previously been shown in the research literature (see Penedo & Dahn, 2005 for a review). However, the reverse was true of those who were unable to label themselves as healthy. This group were less satisfied with their health and also thought of themselves as being less healthy than their peers. This finding suggests that future interventions to improve rates of exercise and healthy eating

should take into account these negative attitudes, and should ensure that people who are not currently living healthily feel encouraged, rather than inferior to their healthier peers.

Another significant difference between the two groups was in the proportion of people who agreed that they expected to experience more symptoms than they actually did. People in the no changes group were significantly more likely to say that they expected to experience more symptoms than they did, compared to the other group. This suggests that young people who had not made lifestyle changes had unmet pessimistic expectations of their health. It is possible that this may act as a barrier to lifestyle change: if young people do not feel as ill as they expect to feel, this may reduce the motivation they have to change. Accurate understanding of healthy behaviours is important, as it has been shown that there are associations between recognising the importance of a healthy behaviour and performing that behaviour. This has been shown to be true in the case of using sun protection (Peacey, Steptoe, Sanderman & Wardle, 2006), exercising (Dishman et al, 2006; Motl et al, 2002; Hasse, Steptoe, Sallis & Wardle, 2004), eating fruit (Pearson, Ball & Crawford, 2011) and breast self-examination (Umeh & Jones, 2010). However, any negative consequences of not performing these behaviours are likely to happen quite far into the future for this group. This highlights the importance of managing expectations, and ensuring that any health information designed to educate young people about their health is accurate, and does not leave them with false expectations about immediate negative consequences. Therefore health promotion should ensure that young people do not expect to feel immediate ill effects, but that they instead think about the future, to ensure that motivations remain high for performing these behaviours.

There were some limitations to this study. First, participants were not asked objectively about their diet and exercise habits. Though the primary focus of the study was whether participants perceived themselves to have made healthy lifestyle changes, rather than whether they actually had, it would have been interesting to see how closely those perceptions matched reality. It also would have allowed an investigation of whether the members of the group who did the most and least exercise differed from each other in similar ways to the groups examined above. Second, participants were not asked more specific questions about when they made lifestyle changes, and what their lifestyle was like before they made them. This again may have provided clearer information about the objective changes to participants' lives and habits.

3.5 Conclusion

Participants who perceived themselves to have made healthy lifestyle changes were more satisfied with their health than participants who had not made changes, even though they experienced the same number of somatic symptoms. This group also believed they lived healthier lives than their peers. In contrast, participants who had not make healthy lifestyle changes were less satisfied with their own health. They also thought of themselves as both unhealthy and less healthy than their peers. This implies that though living a healthier lifestyle may not make any short-term physical difference to health, it improves health satisfaction and self image, and positively changes the way young people label their own health.

3.6 Thesis objectives and future directions

The present chapter found evidence to suggest that the way young people behave, and how they label that behaviour, has the power to change the way they understand and interpret their health experience. Evidence was also found to suggest that the same labels have the power to change the way people think about their own health in relation to the health of others. The next chapter will go on to investigate the way participants think about the health of others to greater depth, particularly the way in which they think about people who are labelled as unhealthy.

Chapter Four

Beliefs about other people labelled as unhealthy

4.1 Introduction

The previous chapter investigated the effects of labels on the way people understand and interpret their own health experience. It was shown that people who reported behaving in a way they labelled as healthy were more satisfied with their own health and also believed they were healthier than their peers. The opposite was found to be true of people who did not report behaving healthily. This finding, that people's understanding of their health varies according to the way they behave, and the way that behaviour is labelled, raises questions about the impact of labels on the way people think about others. One common criticism of health campaigns is that they encourage stigmatisation and negative moral judgements towards groups deemed to be acting in an unhealthy or irresponsible way (Guttman, 1997). The aim of this study was to investigate whether people make negative moral judgements about people labelled as unhealthy. To examine this, the objective of the study was to compare participants' responses to three groups of people (smokers and the obese, and controls) in a series of moral dilemmas.

Various commentators have discussed the role of health campaigns in increasing stigma and moral judgements, particularly against already disadvantaged groups (Guttman, 1997; Guttman & Salmon, 2004; Guttman & Harris Ressler, 2001; Herek & Capitanio, 1993; Wang, 1992; Garcia, 2007; Warner, 2009). Evidence has been presented to show many groups have been portrayed in a negative light by campaigns, including people with HIV/AIDS (Herek & Capitanio, 1993), disabled people (Wang, 1992), the obese (Garcia, 2007) and smokers (Warner, 2009). One major reason why portrayals in health campaigns are

sometimes negative is that many campaigns appeal to personal responsibility, and therefore unavoidably promote the idea that behaviours and outcomes are connected (Guttman and Harris Ressler, 2001). Leading on from this is the idea that if people's behaviours lead to predictable negative outcomes, they can be held to have some degree of moral responsibility for what happens to them (Sachs, 1996). Guttman (1997) criticised health campaigns for prompting unfair moral judgements against certain groups, and for promoting the idea of personal responsibility while ignoring the contribution of other factors, particularly socioeconomic factors, to people's health outcomes.

Smokers and the obese are two groups who have been presented negatively in health campaigns in the past (Garcia, 2007; Warner, 2009). It is well demonstrated that obesity reduces life expectancy (Fontaine, Redden, Wang, Westfall & Allison, 2003) and increases the chance of suffering from various diseases such as type-two diabetes (Rosenbloom, Young, Joe and Winter, 1999) and heart disease (Eckel & Krauss, 1998). It is also well demonstrated that there is a stigma attached to obesity (Puhl & Brownell, 2001). In a review of obesity stigma literature Puhl and Heuer (2009) found evidence that obese people face discrimination in employment, health-care, educational and relationship settings, as well as from the media. They also found that obese people are more likely to suffer from depression, low-self esteem and poor body image. It has been suggested that this kind of prejudice has been increasing in recent years (Latner and Stunkard, 2003). Medical professionals also show some prejudicial attitudes: in one study medical professionals who completed the Implicit Association Test (IAT) showed a strong bias against the obese,

although their bias remained lower than the general population (Teachman & Brownell, 2001).

Smoking has been linked to lung cancer since 1950 (Wynder and Graham, 1950; Doll and Hill, 1950) and has since been shown to increase the risk of urinary bladder cancer, cancers of the upper digestive system and cancers of the respiratory tract (Engeland, Anderson, Haldorsen and Tretli, 1996) as well as increasing the risk of stroke (Wolf, D'Agostino, Kannel, Bonita, Belanger, 1988) and myocardial infarction (Doyle, Dawber, Kannel, Kinch and Kahn, 1964). Smokers perceive there to be a stigma attached to smoking (Bell, McCullough, Salmon & Bell, 2010; Farrimond, & Joffe, 2006; Ritchie, Amos, & Martin, 2010). Interviews with smokers revealed that they had reduced the amount they went out socially in order to try to reduce the stigmatization they felt (Ritchie, Amos, & Martin, 2010). Studies have also shown that some smokers are treated differently at work. They are evaluated more negatively by employers, suggesting they are thought of as less professional and dependable (Gilbert, Hannan, and Lowe, 1998) and in 1998 at least 6000 American companies had a policy of not employing smokers (American Civil Liberties Union, 1998). It has also been shown that people are more likely to say smokers' successes are due to external factors than non-smokers' successes (Gibson, 1998).

In order to investigate whether these groups are actually assigned less moral worth than people who do not have an unhealthy label we asked people to make moral judgements in response to a series of moral dilemmas. Specifically it was hypothesised that negative, stigmatising beliefs directed at individuals labelled as unhealthy would influence

moral decision making such that when the person who might be killed was depicted as belonging to an unhealthy group they would be more likely to be killed than when they were not depicted as belonging to an unhealthy group.

There are two forms of moral dilemma, the “personal” moral dilemma and the “impersonal” moral dilemma. An example of a “personal” moral dilemma is the famous footbridge dilemma (Thomson, 1986) where participants can save five workmen from a runaway trolley only by pushing a man off a bridge into the path of the trolley in order to stop the trolley. The “impersonal” version of this dilemma involves participants choosing whether to flick a switch to change the course of the trolley from the five workmen to one workman on another track. Emotional and social factors are thought to have more influence over people’s responses to “personal” moral dilemmas (Greene et al, 2001, 2004) and so personal moral dilemmas were chosen for the current study. The aim was to provoke an emotional “kneejerk” reaction, something that was felt to be more likely to reflect people’s prejudices.

Participants are usually significantly less willing to choose the option that saves the most lives (the utilitarian option) in the personal dilemmas (Greene et al, 2001). It has been suggested that this is due to an increased engagement of emotions in these types of dilemmas. Physically throwing somebody in front of a trolley creates a negative emotional reaction whereas flicking a switch to change the course of the trolley does not. Consequently, rational decision making dominates decision making in the impersonal dilemmas and the utilitarian option is chosen (Greene et al, 2001). In contrast, when people

are asked to make choices in personal dilemmas, emotional and social factors dominate decision making and the utilitarian option is less likely to be chosen (Greene et al, 2001; 2004).

In this study three different personal dilemmas were used, all previously used and published (Greene et al, 2001). The first, the Architect Dilemma, asked participants whether they would deliberately push their boss off a building when they could definitely make it look accidental. The boss was variously portrayed as rude, obese or a chain-smoker. This dilemma was included as a baseline, to investigate how many participants were willing to kill when there was minimal ethical justification for doing so. It was expected that this dilemma would result in very low numbers of participants choosing to push their boss off the building regardless of whether he was portrayed as obese, rude or a smoker.

The next dilemma, the Ecologist Dilemma, asked the participants to kill someone else to save themselves. Participants were asked to imagine that they were part of a team of ecologists working in the jungle who were kidnapped by terrorists. One terrorist tells the protagonist that they are planning to kill the group the next morning, but that he will let the protagonist go, as long as he has a tape of the protagonist killing a colleague to stop him from going to the police. Participants were asked to decide whether or not they would kill the colleague. The final dilemma was the footbridge dilemma. In this participants were asked whether they would kill the man on the footbridge in order to save others. In both of these dilemmas it was hypothesised that more people would be willing to kill the smoker and the obese person, rather than the rude control.

4.2 Method

4.2.1 Participants

134 students (124 female; mean age 19.23 years) from the University of Birmingham completed the experiment for course credits.

4.2.2 Design

Dilemmas were presented using a 3 (Dilemmas: Footbridge, Ecologist, Architect) x 3 (Subject: control, obese, smoker) within-subjects design. Each participant completed the three dilemmas, with a random combination of subjects (see appendix two). After each dilemma was presented it was followed by two “fast” questions, asking first whether the participant would kill the subject and how sure they were of their decision. Participants were then asked five questions about the trivial details of the dilemmas, to encourage them to pay attention to the details and descriptions of the people involved, and to distract attention from the moral dilemma questions.

4.2.3 Procedure

Participants volunteered to complete a study testing their memory. Upon arriving at the laboratory participants were greeted by the experimenter and given an information sheet and consent form to read and sign. Verbal instructions were then administered with participants being told that they would see three short stories followed by a number of memory and comprehension questions. All moral dilemmas and questions were presented on personal computers using MediaLab experimental software (Empirisoft, 2004).

Participants were first asked to read the moral dilemma as slowly and as carefully as they needed to absorb all of the relevant information. They were then told to click “next” and answer as quickly as they could, within five seconds if possible, the question “is it appropriate for you to push your boss off the building in order to get him out of your life/kill your colleague in order to escape from the terrorists and save your own life/push the stranger onto the tracks in order to save the five workmen?” by clicking on the yes and no answer buttons on the screen. They were then asked to indicate how sure they were of their previous answer on a ten point scale, anchored by 1 (not at all sure) and 10 (completely sure). They then answered five open questions about minor details of the dilemma by typing their answers into a text box on the screen. Participants were told that they had as much time as they felt necessary to do this.

Upon completing the three moral dilemmas and the demographic questions participants were debriefed, with the experimenter explaining that it was not their memory that was being tested, but their answers to the moral dilemmas. Any questions participants had were answered and the full purpose of the study explained.

4.3 Results

The study used a 3 (dilemma: architect, ecologist, trolley) x 3 (victim: rude, smoker, obese) within-subjects design.

Two participants, whose answers to the memory questions clearly demonstrated that they had misunderstood the point of a dilemma (specifically, they both believed killing the

colleague in the ecologist dilemma would save all of the rest of their party rather than just themselves) were excluded from analysis.

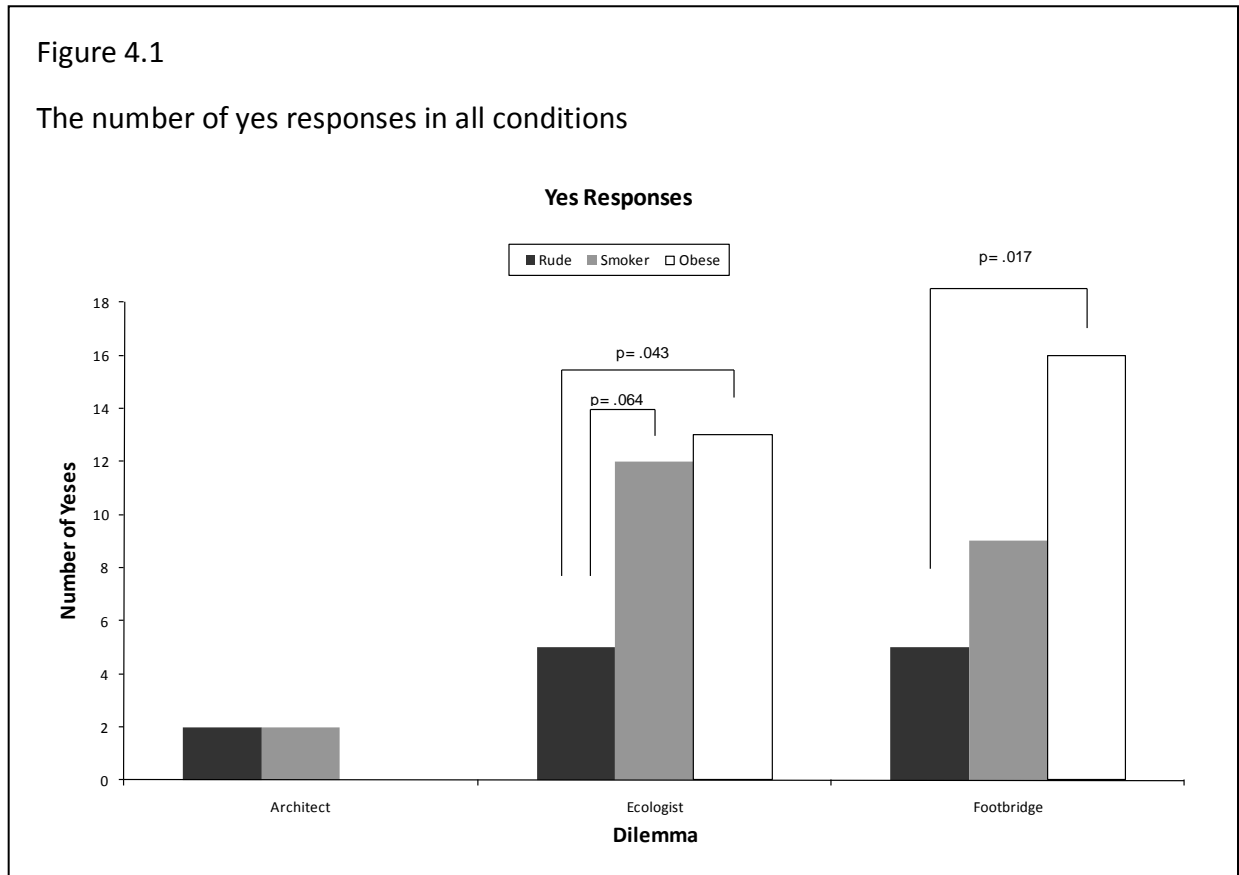


Figure 4.1 shows that participants displayed different patterns of responses for the three dilemmas: they were more willing to kill the smoker and obese person during the ecological dilemma but were more willing to kill only the obese person in the trolley dilemma. Overall there were no significant differences between any of the responses to the architect dilemma ($\chi^2(2, N = 165) = 2.019, p = .364$). In the ecologist dilemma 13 participants were willing to kill the obese character, which was higher than both the smoker character (12) and the rude character (5). This effect of group did not achieve significance ($\chi^2(2, N =$

163) = 4.534, $p = .104$). However, there was a significant difference in participants' responses when comparing the rude and obese characters ($\chi^2(1, N = 109) = 4.085, p = .043$), and a trend towards significance when comparing the rude and smoker characters ($\chi^2(1, N = 108) = 3.421, p = .064$).

In the trolley dilemma 16 participants were willing to kill the obese character, which was higher than both the smoker character (9) and the rude character (5). This effect of group was significant ($\chi^2(2, N = 165) = 6.653, p = .036$) and further testing revealed a significant difference in responses when comparing the rude and obese characters ($\chi^2(1, N = 106) = 5.735, p = .017$), no significant difference when comparing the rude and smoker characters ($\chi^2(1, N = 109) = .667, p = .414$) and a trend towards significance when comparing the obese and smoker characters ($\chi^2(1, N = 115) = 2.995, p = .084$).

4.4 Discussion

The objective of the study was to compare participants' responses to three groups of people (smokers and the obese, and controls) in a series of moral dilemmas. It was found that the participants in this study more readily killed the character in the moral dilemmas when he was depicted as obese rather than rude. However, differences were found in the way participants responded to the smoker character. In the ecologist dilemma there was a trend towards significantly more people being willing to kill the smoker character than the rude character. This trend was absent in participants' responses to the footbridge dilemma. The main differences between these dilemmas are in the nature of the decision participants are asked to make. In the ecologist dilemma, only the participant is saved by their actions,

making a yes answer one of self-preservation. In the footbridge dilemma, participants are asked whether they would save other people, and are not asked to make any decisions that affect their own survival. This result suggests that, when participants are asked to make a selfish decision, they are more willing to kill the smoker and the obese person. When they are not asked to make a selfish decision, they are only more willing to kill the obese person. One explanation for this is that people do not normally devalue smokers, but may do in circumstances where it benefits them. However, when there is no personal benefit, and people are simply asked to make a decision based on what they feel is right, they do not perceive people who smoke as having less moral worth.

Health campaigns have, in recent years, attempted to moralise smoking. As information about the dangers of passive smoking and the dangers of smoking during pregnancy has become available, smoking has changed from being framed as a personal decision to being a moral one (Rozin & Singh, 1999), a change that has informed law making. Despite the widespread support for laws restricting smoking behaviour, a large reduction of the number of smokers (Peto, Darby, Deo, Silcocks, Whitley and Doll, 2000), and the stigma perceived by smokers (Bell, McCullough, Salmon & Bell, 2010; Farrimond, & Joffe, 2006; Ritchie, Amos, & Martin, 2010), the present results suggest members of the public do not yet widely think about smoking as a moral issue. In Northern Ireland, where a work-place smoking ban was implemented in 2004, making it the first country in the world to have such a law, the number of people supporting the ban increased from 43% to 67% in workplaces, 45% to 77% in restaurants and 13% to 46% in bars and pubs (Fong et al, 2006). The increase from below 50% before the ban to between 46% and 77% after the ban suggests that these

increases were based on practical concerns rather than a widespread moral condemnation of smoking. A study investigating the prevalence of numerous health beliefs among university students in thirteen countries (including England, Ireland and the U.S) found that between 1990 and 2000 awareness of the importance of not smoking decreased, while smoking prevalence among university students increased in some countries. (Steptoe, Wardle, Cui, Bellisle, Zotti, Baranyai and Sanderman, 2002). These statistics suggest the idea of smoking as an immoral activity has not really taken hold, despite health campaigns warning about the dangers of passive smoking.

Though the present results suggest smoking does not reduce a person's moral worth in situations where it does not benefit the person doing the judging, obesity does appear to reduce a person's perceived moral worth. In both the ecologist and footbridge dilemmas, significantly more people killed the obese person than the rude control, suggesting that when participants made both selfish and unselfish decisions they felt the sacrifice of an obese person was more justifiable than the sacrifice of a smoker or rude person. The most likely explanation for this is that participants perceived the obese person to have less value than the smoker or the rude person. This matches previous findings suggesting that the obese are stigmatised (Puhl & Brownell, 2001, Puhl and Heuer, 2009).

Saguy and Riley (2005) found that the health construct of obesity frames it as being due to risky behaviour and poor lifestyle choices, while the environmental and socio-economic causes of obesity are often ignored. As it has been shown that obesity is strongly associated with socioeconomic status in western countries, particularly in women (see Sobal

& Stunkard, 1989; McLaren, 2007 for reviews) this is unfortunate. Puhl and Heuer (2010) found that instead of increasing people's motivations to lose weight, obesity stigma creates further health inequalities. These findings therefore highlight the need for healthy lifestyle health campaigns to look at their potential for increasing stigma, as this may be counterproductive to the campaigns' aims.

There were some limitations to this study. First, though we attempted to hide the purpose of the study from participants, by inviting them to attend a "memory test" study, and including a number of memory test questions, it is possible that participants may have been aware of the purpose of the study. As the footbridge problem is quite well-known as a moral dilemma, its presence may have made this particularly likely. It may therefore have been better to include another, less well known, dilemma. Another limitation was the inclusion of only three dilemmas, focusing on the two experimental groups and the control. This may have made our focus on the smoker and the obese person more obvious than it would have been if we had included a larger number of dilemmas, with a range of different protagonists. It may therefore have been better to have asked participants to respond to between five and ten dilemmas, each with a different person as the protagonist.

4.5 Conclusion

Participants showed different patterns of discrimination across the three moral dilemmas. In the dilemma where participants were asked to make a selfish decision, obese people were sacrificed more than the rude character, and smokers showed a trend towards being sacrificed more than the rude character. In the dilemma where participants were

asked to make an unselfish decision, only obese people were sacrificed more than the rude character. It was therefore concluded that, while people appeared to unambiguously devalue the obese character, they may also devalue smokers in certain scenarios.

4.6 Thesis objectives and future directions

The previous chapters found evidence to suggest that the way people behave, and how they label that behaviour, influences the way they understand and interpret their health experience. In this chapter evidence was also found to suggest that health labels influence the way we see others, and in some circumstances lead to negative moral judgements. The next chapter will also investigate the effects of labels, this time by investigating whether it is possible to alter the way people respond to stimuli by changing the label they use to understand them.

Chapter Five

The effect of altered labels on cold pressor pain responses

5.1 Introduction

Previous chapters investigated the way young people labelled and interpreted their own health and the health of others. It was found that the way in which participants labelled their behaviour, as either healthy or unhealthy, influenced how satisfied they were with their health, and the way they thought about their health in relation to other people. It was also found that the way others were labelled, as either healthy or unhealthy, affected the moral judgements made about them by others. In this chapter the aim was to investigate the effect of providing participants with different labels, to examine whether it is possible to alter their behavioural responses in different situations.

The behaviours that influence self-rated health are partly determined by information in the environment, as are people's broader attitudes towards their health (Johnson, Cooke, Croker & Wardle, 2008; Jalleh, Donovan, Lin & Slevin, 2008). In chapter one the role of health campaigns as a source of health information was described. Though there is not enough evidence to prove the success or otherwise of several campaign targets (for example, the designated driver campaigns reviewed by Jepson, Harris, Platt and Tannahill, 2010) others, for example anti-smoking campaigns, have been shown to be somewhat successful (Bala, Strzeszynski & Cahill 2008). Evidence has also suggested that even when campaigns do not change behaviour, they are effective in changing attitudes (van Wechem et al, 1997).

Health campaigns attempt to alter people's behaviour and attitudes by providing them with information about the potential outcome of a certain behaviour or the cause of a set of symptoms. This has also been attempted in the laboratory. Experimental studies have shown

that it is possible to alter people's beliefs about health scenarios by changing the information participants have available to interpret the scenario. In one study participants were asked to use environmental cues to interpret whether symptoms were caused by illness or stress. It was found that when participants were told the symptoms were first experienced at a time of increased stress, for example in an exam situation, participants were more likely to attribute the symptoms to stress than illness. Conversely when symptoms started during periods described as lacking increased environmental stress they were more likely to be attributed to illness than stress (Baumann, Cameron, Zimmerman & Leventhal, 1989).

In this study rather than attempting to change participants' beliefs about an abstract health scenario, we instead aimed to influence how they actually responded to a experienced physical sensation. This was done by providing them with additional information presented in the form of health campaign style posters. The nature of laboratory experiments means it is not possible to change a participant's entire health experience in the lab, or use multiple symptoms as independent variables. It is only possible to approximately recreate a particular experience in a very controlled setting. Laboratory experiments also require the use of stimuli that can be accurately altered and turned on and off in controlled circumstances. This all suggests that instead of focusing on the participants' entire health experience, laboratory experiments should attempt to recreate a particular sensation that has something in common with a well-known somatic symptom.

One symptom that fits this description, and has been shown to be highly subjective and variable, is pain. The level of pain reported in response to a particular stimulus has been shown

to vary both between subjects (Coghill, McHaffie and Yen, 2003) and for the same participant on separate occasions (Rosier, Iadarola and Coghill, 2002). Many potential factors that can make pain more unpleasant for different people at different times have been investigated, ranging from personality traits, including neuroticism and extroversion (Harkins, Price and Braith, 1989) and mental health factors such as depression, anxiety (von Korff & Simon, 1996) and catastrophising (Severeijns, Vlaeyen, van den Hout & Weber, 2001), to more transient internal states like mood (Zelman, Howland, Nichols & Cleeland, 1991), attention (Ahles, Blanchard & Leventhal, 1983) and external factors such as the temperature of the surrounding environment (Hall, 1955). Pain can be easily inflicted over very short periods via the use of equipment such as the cold pressor (a bucket of ice water participants are asked to place their hand in) or heat probes.

Previous studies have investigated whether providing different information to participants in cold pressor experiments alters the way participants respond to experimental pain. In one study men and women's expectations about their gender's average pain tolerance were altered. It was found that when men and women were not given information about average pain tolerance men had significantly greater tolerances than women. However, when information about tolerance was provided, the difference between the genders disappeared (Robinson, Gagnon, Riley & Price, 2003).

Unlike in the above study, many experiments where participants are provided with different information before taking part are designed to alter the level of threat and make the task more or less anxiety provoking. In one study Hirsch and Liebert (1998) simply changed the

labels they gave to their cold pressor study, varying it between “vasoconstriction pain study”, “pain study” and “discomfort study”. They found that students who completed the more painful sounding studies showed lower pain tolerance than those who completed the “discomfort” study (Hirsch & Liebert, 1998). In another experiment, it was found that participants’ pain ratings increased when they were warned about the painful nature of the task before taking part (Cornwall and Donderi, 1988).

The relationship between pain and anxiety has previously been examined. Rhudy and Meagher (2002) investigated the relationship between fear, pain and anxiety. Sixty people were tested using electric shocks and heat pain. It was found that anxiety increased people’s reactivity to pain whereas fear reduced it, a result previously found in animal studies. It has also been found that relevant and irrelevant anxiety produce different effects, with relevant anxiety shown to increase pain intensity reports and irrelevant anxiety to reduce it (Villemure & Bushnell, 2002). Studies using the cold pressor have shown that people who report higher levels of pain in the task are higher in anxiety sensitivity (Keogh, Barlow, Mounce & Bond, 2006).

However, further investigations have suggested that attention, rather than anxiety, is the driving force behind increased pain scores in these studies. The association between anxiety and attention makes sense, as it has been shown that anxiety increases attention to environmental threats (James & Hardardottir, 2002). It has also been shown that participants engage less with distraction tasks when they are in a high threat situation (Van Damme et al,

2008), an effect that is increased in people with a greater tendency to catastrophise (Van Cleef & Peters, 2006).

Arntz, Dreessen and Merckelbach (1991) used electrically generated pain to investigate the relationship between attention and anxiety. They found attention was the factor primarily altering participants' pain experience, with attention to the stimuli increasing the impact of the pain and distraction reducing the impact. Arntz and De Jong (1993) replicated this finding. In a similar study, where forty participants were exposed to electrical stimulation, it was found that their pain ratings were influenced by attentional focus and not anxiety (Arntz, Dreessen & De Jong, 1994).

Warbrick, Sheffield and Nouwen (2006) used Event Related Potentials (ERPs) to investigate the mechanism behind the effects of pain related anxiety on pain experience. They found significant differences in N140 amplitude when participants were encouraged to feel anxious about electrical stimuli compared to when they were encouraged to feel neutral about the stimuli. As this response is generally associated with performance in cognitive tasks (Nakajima & Imamura, 2000), the authors concluded that this result could have been due to either the valence of the anxiety condition stimuli, selective attention, or a combination of both, with the negative emotional value of the anxiety condition stimuli causing participants to increase the attention they paid to them (Warbrick, Sheffield & Nouwen, 2006).

In this chapter participants were presented with information about the cold pressor before taking part, designed to change the way they thought about the task and the way they responded to the pain. The aim was to investigate the effect of providing participants with

different labels, to examine whether it is possible to alter their behavioural responses in different situations. The objective of the first three studies was simply to replicate the results of previous experiments, such as those by Cornwall and Donderi (1988) and Hirsch and Liebert (1998) by providing participants with general information about the cold pressor, designed to make the task sound more threatening, with the intention of increasing their pain ratings. The objective of the final study was to provide participants with a plausible, but anxiety-provoking, label for the specific symptoms they were experiencing, to see whether encouraging participants to interpret their pain in that way increased their pain ratings. It was hypothesised that when participants were given a plausible but anxiety-provoking label with which to interpret their pain, their responses would change, in the form of increased pain ratings.

5.2 Experiment One

5.2.1 Introduction

The objective of this study was to investigate whether providing general anxiety provoking information to cold pressor participants changed their pain ratings, as in previous studies (Cornwall and Donderi, 1988; Hirsch and Liebert, 1998). Participants were shown a poster warning them that taking part in the cold pressor can sometimes be dangerous (the danger itself was unspecified) or a control poster simply saying “relax”. Specifically the aim of this study was to investigate whether encouraging participants to interpret the experimental situation as dangerous could cause them to increase their pain ratings. Participants completed the study three times, first looking at the poster, second doing a distracter task and third

looking at their hand while it was in the cold pressor. This was to examine whether participants were influenced after they stopped looking at the poster.

5.2.2 Method

5.2.2.1 Design

This study was a mixed measures 2 (poster, between-participants: anxiety-provoking, relaxing) x 3 (gaze, within-participants: looking at the poster, distracted, looking at the hand) design.

5.2.2.2 Participants

Participants were 28 University of Birmingham students (26 female, mean age 18.8) who completed the study for course credit.

5.2.2.3 Procedure

Upon arriving at the laboratory participants were asked to complete a consent form and their age and gender were recorded. After doing this they were asked to move to a stool on the other side of the room, and to sit facing a notice board. In the first condition the notice board displayed a poster of a sunset scene over a lake, with the word "Relax" written underneath in pastel purple. In the second condition, the poster showed a skull and cross-bones with the slogan "Warning- Cold Pressor Equipment Can Be Dangerous". Participants sat with the poster in their direct eye line for the 30 seconds it took for the experimenter to set up the cold pressor equipment. The cold pressor comprised of a water bath containing water kept at 4°C. The water was automatically circulated to maintain an even temperature throughout.

The starting hand was counterbalanced across participants. After listening to recited instructions (see appendix three for script) participants placed their hand into the cold pressor while the experimenter timed them. After one minute participants were asked to remove their hand and were shown a ten point pain scale. They chose a number on the scale, and it was noted by the experimenter. They were then told to face the other way on the stool so that their other hand was next to the bath. They were then told that during the next minute they would be asked to do a distraction task, counting down backwards from one hundred in threes. Participants again placed their hand in the bath while the experimenter timed them and again gave a score. Participants were turned around to use their first hand, and were reminded that for the final minute they would be asked to look at their hand in the bath. They again placed their hand in the bath for a minute before giving a score out of ten. After completing all three tasks participants were provided with warm towels to dry off and were thanked for their participation.

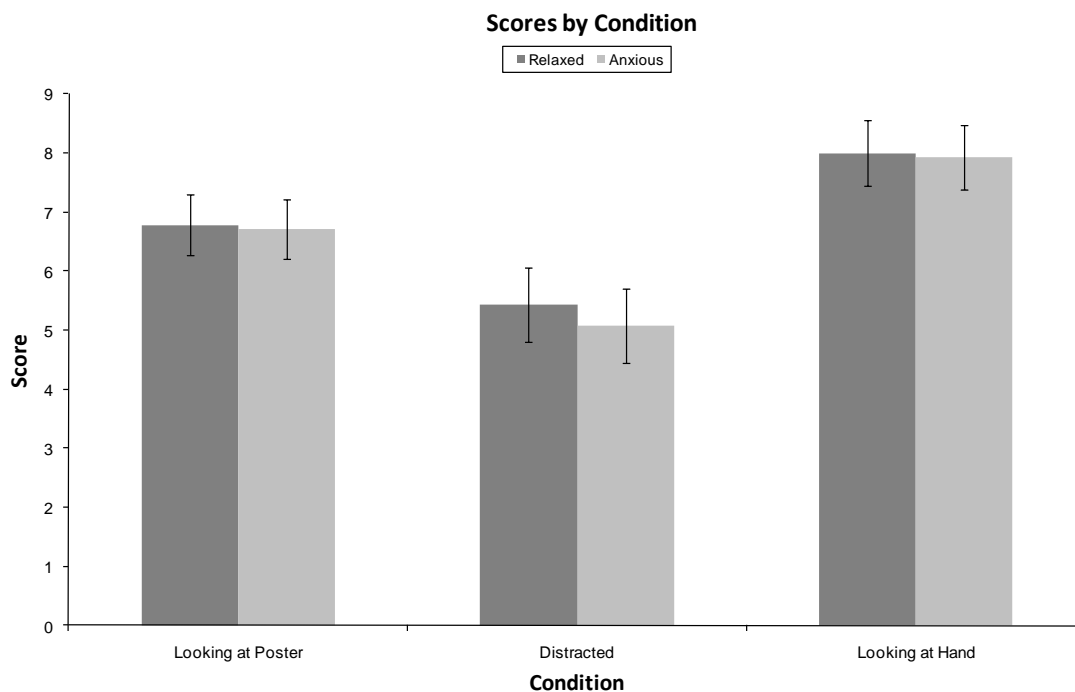
5.2.3 Results

As can be seen in figure 5.1, there were no obvious differences between the relaxed and anxious participants in any of the three conditions. A mixed measures ANOVA confirmed there was no significant difference between the relaxed and anxious conditions ($F(1, 26) = 0.054, p = .817$). Significant differences were found between the three conditions for gaze, looking at the poster, distracted and looking at the hand ($F(2, 52) = 51.76; p < .001$). Post-hoc paired comparisons with a Bonferroni correction were made to investigate which conditions resulted in significantly different scores, with all conditions found to be significantly different from each

other (looking at the poster vs distracted: $p < .001$; looking at the poster vs looking at the hand: $p = .002$; distracted vs looking at the hand: $p < 0.001$). No participants withdrew from the study early.

Figure 5.1

Average pain scores in each of the six conditions (visual cues only)



14 people participated in each of the relaxation conditions and 14 people participated in each of the anxiety conditions.

5.2.4 Discussion

The presence of a warning poster did not increase participants' pain scores in any of the three conditions, suggesting simply being warned once about the dangerous nature of the task was not enough to alter pain scores. No participants dropped out of the experiment in any of

the conditions. These results contradict those of Cornwall and Donderi (1988) who found that providing participants with anxiety provoking information before they completed a painful task increased pain ratings. It is unclear why it was not possible to replicate their result, but one potential explanation could be that they used pressure pain instead of the cold pressor, which may have altered the nature of participants' responses.

One exposure to anxiety-provoking warning information does not reflect the real life reality of exposure to health information. Advertisements are designed to be seen and it therefore seems highly likely that people will see the same advertisement multiple times. As it is not possible for participants to be exposed to the same cue repeatedly during the short time they are in the lab, it was decided to expose participants to different cues, one after the other. This more accurately reflects the real world situation, where campaigns are broadcast across multiple forms of media and each has its own impact (Bhargava & Donthu, 1999).

5.3 Experiment Two

5.3.1 Introduction

In this experiment we aimed to increase the number of cues participants were exposed to. In a real world health campaign the message is transmitted via multiple forms of media, for example posters, television adverts, radio adverts etc. As the posters alone were not enough to alter pain scores, we aimed to investigate whether the poster combined with reinforcing verbal instructions would alter participants' responses.

5.3.2 Method

5.3.2.1 Design

This study was a mixed measures design 2 (poster and script, between-participants: anxiety-provoking, relaxing) x 3 (gaze, within-participants: looking at the poster, distracted, looking at the hand) design.

5.3.2.2 Participants

Participants were 39 University of Birmingham students (29 female, mean age 19.9) who completed the study for course credit.

5.3.2.3 Procedure

Upon arrival at the laboratory participants were asked to read an information sheet and sign a consent form, before being asked to give demographic information. The posters participants were asked to look at remained the same. However, this time the instructions given to the participants differed across the two conditions, with the participants looking at the anxiety-provoking script also hearing anxiety-provoking instructions and the participants looking at the relaxing poster also hearing relaxing instructions (see appendix three for scripts). The procedure then continued as before.

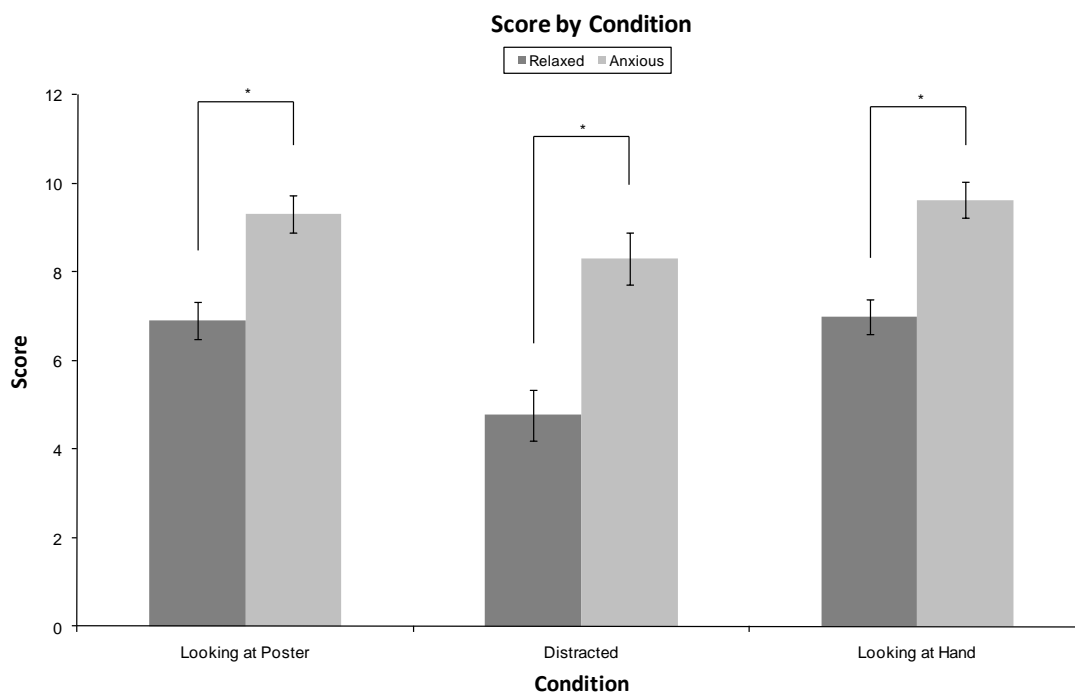
5.3.3 Results

For the purpose of analysis, where participants withdrew their hand early from the bath, they were awarded an automatic score of 11. A total of ten participants in each of the anxiety

conditions removed their hand early. No participants in the relaxation conditions removed their hand early.

Figure 5.2

Average pain scores across each of the six conditions (visual and verbal cues)



20 people participated in each of the relaxation conditions and 19 people participated in completed each of the anxiety conditions.

As can be seen from figure 5.2, the relaxed and anxious participants differed noticeably across all three conditions. A mixed measures ANOVA confirmed a significant group difference ($F(1, 37) = 26.30, p < .001$). Significant differences were also found between the three conditions for gaze, looking at the poster, distracted and looking at the hand ($F(2, 74) = 36.50; p < .001$). Post-hoc paired comparisons with a Bonferroni correction were made to investigate which conditions resulted in significantly different scores. The difference between the looking at the

poster condition and the distraction condition was significantly different ($p < .001$), as was the difference between the distraction condition and the looking at the hand condition ($p < .001$). There was no significant difference between the looking at the poster condition and the looking at the hand condition ($p = 1.0$).

5.3.4 Discussion

Significant differences were found between the relaxed and anxious conditions in all three gaze conditions. This suggests that the visual and verbal warnings led to participants experiencing responding differently than participants in the control condition.

However, an unusual pattern was noted in the data, specifically regarding participant withdrawal. In the first study, no participants withdrew from either condition. In the present study, no participants withdraw from the relaxed condition, but 10 participants withdrew from each anxiety condition. An examination of the script highlighted that in the anxiety condition a reminder of the right to withdraw was used to highlight the dangerous nature of the task. In the previous study, and in the relaxation condition of the present study, the only time participants were told of their right to withdraw was on the information sheet they read before taking part. As any participants who withdrew early were given a high score, causing one group to withdraw more frequently than the other may have had a profound effect on the results.

The reminder of the right to withdraw in the script made it unclear whether it was the anxiety provoking posters and scripts, or the reminder alone, that caused the significant results. It was therefore decided that the best course of action was to repeat the study, this time

removing the reminder of the right to withdraw from the anxiety-provoking script. This was the objective of experiment three.

5.4 Experiment Three

5.4.1 Introduction

In this study we aimed to replicate experiment two, but this time removed the instruction that participants could withdraw from the study early if they felt it was necessary.

5.4.2 Method

5.4.2.1 Design

This study was a mixed measures design 2 (poster and script, between-participants: anxiety-provoking, relaxing) x 3(gaze, within-participants: looking at the poster, distracted, looking at the hand) design.

5.4.2.2 Participants

Participants were 46 University of Birmingham students (37 female, mean age 19.3) who completed the study for course credit.

5.4.2.3 Procedure

As before, upon arrival at the laboratory participants were asked to read an information sheet and sign a consent form agreeing to take part in the study. They were again given thirty seconds to look at the poster before being given their verbal instructions. Participants also again received anxiety-provoking or relaxing instructions, but this time neither included a

reminder of the right to withdraw (please see appendix three for the new anxiety-provoking script).

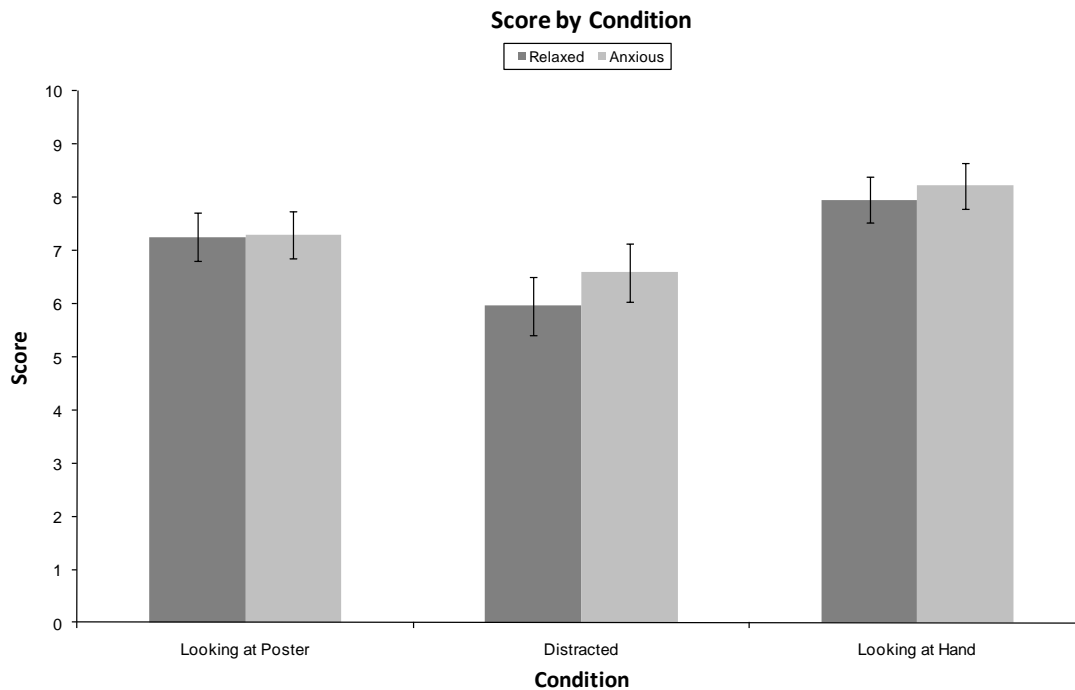
5.4.3 Results

For the purpose of analysis where participants withdrew their hand early from the bath they were awarded an automatic score of 11. A small minority of participants withdrew early in both the relaxed and anxious conditions (3, 2 and 3 in the relaxed conditions and 3, 3 and 4 in the anxious conditions).

As can be seen from figure 5.3, there were no apparent differences between the responses of the relaxed and anxious participants in any of the three conditions. A mixed measures ANOVA confirmed the absence of significant difference between the relaxed and anxious conditions ($F(1, 44) = 0.284, p = .597$). Significant differences were found between the three conditions for gaze, looking at the poster, distracted and looking at the hand ($F(2, 88) = 38.056; p < .001$). Paired comparisons were made to investigate which conditions resulted in significantly different scores, with all conditions found to be significantly different from each other (looking at the poster vs distracted: $p = .003$; looking at the poster vs looking at the hand: $p = .016$; distracted vs looking at the hand: $p < 0.001$).

Figure 5.3

Average pain scores across each of the three conditions (new script)



23 people participated in each of the relaxation conditions and 23 people participated in each of the anxiety conditions.

5.4.4 Discussion

When participants were not reminded of their right to withdraw in one condition, we found no significant differences between the anxious and relaxed conditions in any of the three gaze conditions. This suggests that the right to withdraw reminder led to the significant results found in experiment two.

There are two potential mechanisms explaining why reminding people of their right to withdraw may have led to more participants withdrawing early. First, the reminder, originally included in the script to make the task more anxiety provoking, may actually have caused them to respond differently to the pain, because of the distressing cue it provided. It has previously been shown that subtle changes in the way a cold pressor task is framed can make significant differences to the results. Leventhal, Brown, Shacham and Engquist (1979) found that participant distress at the cold pressor was reduced if they were told about the sensations they should expect to feel before taking part. This effect was then blocked if participants were also warned about the pain. The researchers suggested that the pain warning framed the sensations in an emotional way, leading to increased distress and different responses. It is possible that reminding participants of their right to withdraw had a similar effect.

A second potential mechanism for the increased pain scores is that the instruction to withdraw simply gave participants “permission” to do so. If this caused them to withdraw when they would not otherwise have done so, it means that the way they responded to the pain was unchanged, and that they were instead simply responding to the instruction. It has previously been shown that external factors can alter people’s behaviour in cold pressor studies. In Sullivan, Adams and Sullivan’s (2004) study they asked people to do the cold pressor either alone or in the presence of an observer. They found that people who had previously been shown to be catastrophisers spent longer displaying pain behaviours when they were being observed compared to when they were alone. However, pain catastrophisers did not rate the pain more highly when they were with an observer compared to when they were alone.

The three experiments found that simply providing non-specific anxiety-provoking information to participants did not increase their pain scores. One reason for this may have been the general nature of the anxiety provoking information. Health campaigns generally attempt to warn people about specific and relevant threats, and will therefore be highly salient, especially for certain groups. The anxiety provoking information in this study was highly general. In addition, it is likely that the participants, almost entirely psychology undergraduates, would have been aware that if there were any specific dangers in taking part in the cold pressor, they would have been warned. They may therefore not have genuinely considered themselves in any danger, in which case the posters would not have been anxiety provoking or relevant.

It was therefore hypothesised that information has to be more specific to the participant and the situation, if it is to alter participants' responses to pain. Campaigns in the real world are targeted to their audience, and have been shown to have limited effects outside of those at which the campaign is aimed. For example, an investigation into the effects of an anti-smoking campaign aimed at young people found that the campaign had no effect on the smoking behaviour of adults (Dietz, Delva, Woolley & Russello, 2008). Therefore the next and final study aimed to provide information to participants tailored specifically to the cold pressor situation.

5.4.5 Conclusion

As predicted, when the right to withdraw reminder was controlled for providing participants with unspecific information about a threat did not cause an increase in their

reported pain scores. We were therefore unable to find evidence for the hypothesis that information from the environment has the power to alter people's responses to pain.

5.5 Experiment Four

5.5.1 Introduction

In the previous experiments the information provided to participants was kept very general, and was found to have no effect on participants' pain scores. This does not reflect the real world of health campaigns where campaigns are targeted for specific populations. Studies looking at the effectiveness of advertising campaigns have highlighted the importance of specificity, both in terms of the people depicted in the advert and the content. For example, in a study of the techniques used by two television programmes aimed at promoting healthy eating, interviews with viewers found that adverts containing models the viewers could identify with were thought to be more powerful (Dale & Hanbury, 2010). They also highlighted the need for more specific behavioural guidance in the adverts. In the case of need to identify with the people in the programme, this highlights the need for campaigns to be aimed at a particular target audience, even if the message of the campaign cuts across all groups. For example, the guidelines for eating healthily are broadly the same for the majority of people but if individual groups are not given role models to follow whom they identify with, campaigns will not be as powerful. This effect was seen in a study investigating whether anti-smoking campaigns aimed at young people alter the smoking behaviour of adults. It was found that the campaigns made no difference to the adults' smoking behaviour (Dietz, Delva, Woolley & Russello, 2008). This need to target the campaign towards a specific audience is even greater in the case of health

campaigns where different groups have different levels of risk (for example, in AIDS campaigns- Snyder & Rouse, 1992).

In the final study the aim was to investigate whether providing participants with a relevant anxiety provoking label for the specific pain sensation they experienced during the cold pressor could cause them to respond differently to the pain. Studies where participants have been given threatening information about a health threat specific to the situation have previously been conducted. Jackson et al (2005) found that when participants were given information either about frostbite or about the safety of the cold pressor task participants in the frostbite condition showed reduced pain tolerance, in that fewer participants in that condition completed the task. They did not, however, report more pain. In a later study it was found that when participants completed a similar study in pairs, with one person actually completing the cold pressor and the other providing support with coping, the pairs who read the threatening information showed lower pain tolerance, but not higher levels of reported pain, than the pairs who read reassuring information or mixed information (Jackson, Huang, Chen & Phillips, 2009). In the current study the effect of providing specific information about the type of pain experienced during the cold pressor, as well as the relevant health condition of frostbite, will be investigated to see whether participants report more pain when both of these factors are in place.

In the current study participants were asked to read information about a relevant health condition (a paragraph on the topic of how to treat frostbite) or an irrelevant health condition (a paragraph on the topic of how to treat repetitive strain injury (RSI)). Participants were also

told that an early symptom of frostbite or RSI is a symptom likely to be experienced during the cold pressor (“a sharp, stabbing pain”) or a symptom less likely to be experienced (“numbness or pins and needles”). A control group of participants were asked to read about baking a cake (something that has nothing to do with health, but is still a set of instructions), to investigate the baseline level of pain after reading information.

It was hypothesised that significant differences from the control group would be found only when participants read about relevant symptoms caused by a relevant condition, in this case sharp stabbing pain caused by frostbite. This is because it was hypothesised that in this condition participants would use the information they had read to label the sharp, stabbing pain experienced during cold pressor as an early sign of frostbite, an anxiety-provoking conclusion. It was hypothesised that the other conditions would not lead to increased pain ratings, as the labels provided to participants would not suit the situation. Specifically, in the condition where participants were told that numbness or pins and needles was an early sign of frostbite, participants would not experience pins and needles during the cold pressor, and therefore would not come to the anxiety-provoking conclusion that their fingers were becoming frostbitten. In the two RSI conditions, participants would not see RSI as a relevant threat while taking part in the cold pressor task, and so would disregard that label for the pain experienced.

5.5.2 Method

5.5.2.1 Design

This study was a between-participants 2 (internal cue: relevant, not relevant) x 3 (external cue: frost bite, repetitive strain injury, control) design.

5.5.2.2 Participants

Participants were 107 University of Birmingham students (93 female, mean age 19.5) who completed the study for course credit.

5.5.2.3 Procedure

Upon arriving at the laboratory participants were asked to read and sign a consent form. This time, instead of just doing the cold pressor task, participants were told they would be asked to complete a memory test beforehand. Participants were given a short information sheet, either describing how to treat frostbite, how to treat RSI or how to bake a cake. The frostbite and RSI information sheets followed the same overall pattern, starting with information about what the condition is, who is particularly at risk, the main symptoms and how to treat the condition. Halfway through each information sheet readers were informed that one of the main symptoms of frostbite or RSI is either “a sharp stabbing pain” (symptoms likely to be experienced during the cold pressor) or “numbness and pins and needles” (symptoms not likely to be experienced during the cold pressor). The control “how to bake a cake” instructions were the same for all control participants (see appendix four). Participants were told that they could take as much time as they felt necessary to read through the information, before informing the experimenter that they were ready to take the test. The information sheet was then removed from the table and participants were given a short memory test. The genuine purpose of the memory task was to ensure all participants had

remembered the information about the supposed causes of frostbite and RSI. The tests comprised of five questions including “what is an early warning sign of frostbite/RSI?”. All participants answered these questions correctly.

Participants were then asked to do the cold pressor task. They were first asked for basic demographic information and to state their dominant hand. All participants were asked to do one cold pressor task for two minutes using their dominant hand. Participants were told that every thirty seconds they would be asked to give a verbal pain rating on a scale from 0 (no pain) to 20 (worst pain imaginable). Participants then completed the cold pressor task. Every thirty seconds the participants’ scores were noted. After finishing the task participants were given a towel and thanked for their participation. They were given a debrief sheet to read and any questions were answered.

5.5.3 Results

5.5.3.1 Withdrawals

A number of participants withdrew from each condition (see table 5.1). The time at which they dropped out was also recorded.

Table 5.1

The number of withdrawals and time taken to withdraw in each condition

Condition	Number	Average time	Average time including the rest of group (120 seconds)
Control	4	58	110
Frostbite pain	9	48	91
Frostbite numb	4	58	108
RSI pain	10	52	84
RSI numb	5	37	100

A two-way between-subjects ANOVA was used to investigate whether there were any significant differences in the amount of time taken to withdraw across the four experimental conditions. When only the times of the participants who did withdraw were examined, the condition (frostbite vs RSI) and symptom (pain vs numbness) interaction was insignificant ($F(1, 36) = 1.333, p = .26$). There were also no significant main effects of condition ($F(1, 36) = .662, p = .424$) or symptom ($F(1, 36) = .051, p = .823$). However, when the times of all participants were included, with those who did not withdraw from the study having their time recorded as 120 seconds, it was found that there was a significant main effect of symptom ($F(1, 79) = 4.420, p = .039$), with participants who were warned about pain, rather than numbness withdrawing faster (M_s : 87.5 seconds vs 104 seconds). The condition and symptom interaction remained insignificant ($F(1, 79) = .009, p = .925$), as did the main effect for condition ($F(1, 79) = .817, p = .369$).

5.5.3.2 Pain ratings

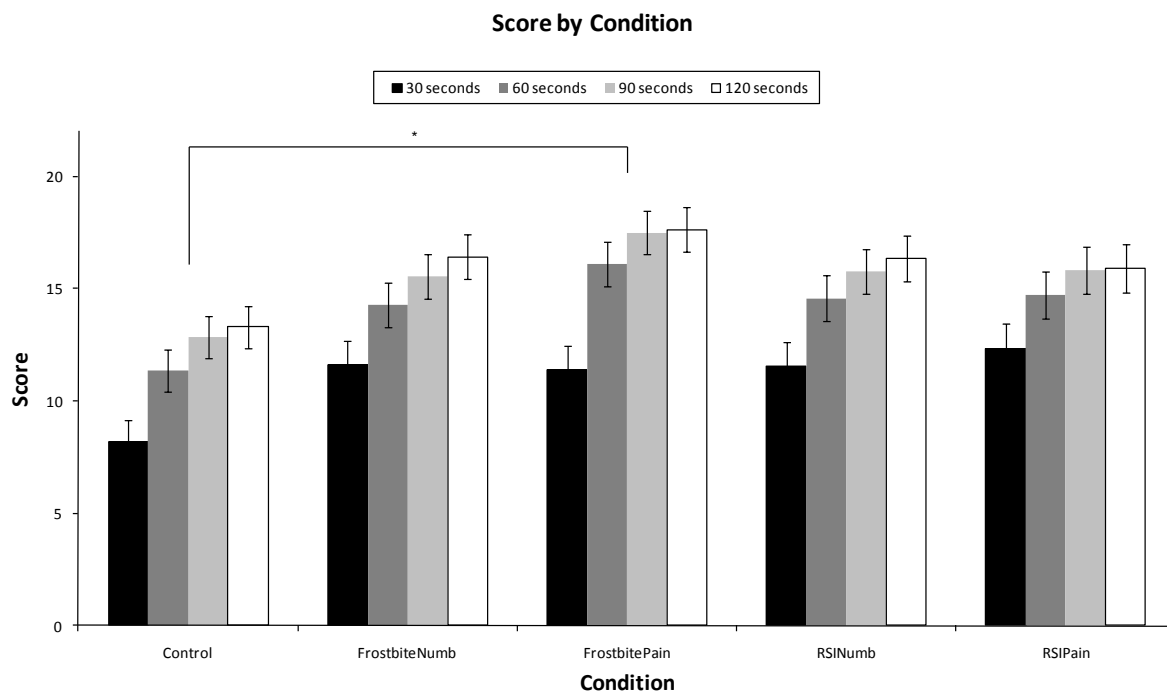
For the purpose of analysis, where participants withdrew their hand early from the bath, they were awarded an automatic score of 21.

As can be seen from figure 5.4, there were clear differences between the frostbite pain, frostbite numb, RSI pain, RSI numb and control conditions, with all of the experimental conditions eliciting higher pain ratings than the control. A mixed measures ANOVA confirmed a significant effect of group ($F(4, 102) = 3.469, p = .011$). Post-hoc paired comparisons with a Bonferroni correction were made to investigate which conditions were significantly different from each other. It was found that the difference between the frostbite pain condition and the

control was the only significantly different condition ($p = .008$). There was also a significant main effect of time ($F(1.731, 176.57) = 904.249$; $p < .001$). Post-hoc paired comparisons with a Bonferroni correction were made to investigate which timepoints resulted in significantly different scores. All timepoints resulted in significantly different pain scores, apart from 90 seconds and 120 seconds ($p = .126$).

Figure 5.4

Average pain scores across the twenty conditions



24 people participated in the control condition, 21 people participated in the frostbite numb condition, 22 people participated in the frostbite pain condition, 21 people participated in the RSI numb condition and 19 people participated in the RSI pain condition.

5.5.4 Discussion

Here it was found that, as predicted, the only condition where participants' pain scores were significantly different from control was the frostbite pain condition, where participants were provided with information about frostbite (a relevant threat to cold pressor participants), that matched their symptom experience (sharp, stabbing pain). This suggests that specific information and an anxiety-provoking label, matched with specific symptoms, can produce a different response. This finding builds on those of Jackson et al (2005; 2009) who found that when participants were provided with information about frostbite before they completed the cold pressor task, their pain tolerance levels reduced, but they did not report more pain. Here it was found that when participants were also told that a symptom of frostbite was the specific type of pain they were experiencing, their pain ratings increased. It should also be noted that though the other experimental conditions failed to achieve significance after the Bonferroni correction, they all resulted in higher pain scores than the control. Therefore in this study, providing participants with health and symptom information of any kind appeared to influence pain scores to some degree. This makes sense in the context of results found by Meerman, Verkuil and Brosschot (2011) who investigated the effect of subliminally priming cold pressor participants with words designed to activate illness related memories. They found that participants who were primed with health complaint words showed reduced tolerance to the cold pressor (Meerman, Verkuil and Brosschot, 2011).

Participant pain tolerances were not investigated in this study as all participants were required to stop at two minutes. This therefore means any investigation of participant

withdrawal times cannot truly comment on the effects the experimental manipulation has on pain tolerances. However, an investigation of the average amount of time participants were involved in each experimental condition found that there were significant differences in conditions across symptom, meaning that when participants were told that a symptom of either condition was pain, average involvement time was reduced compared to when participants were told that a symptom of either condition was pins and needles. This may be due to the word pain causing increased anxiety among participants, as was found in Hirsch and Liebert's (1998) study where participants pain tolerances reduced when they were invited to take part in a "pain" study, rather than a "discomfort" study.

5.5.5 Conclusion

It was found that when participants experienced pain they were told was a sign of frostbite their pain ratings increased. This result suggests that providing participants with a plausible label for their pain has the power to change their pain response.

5.6 General discussion

In this chapter four studies were conducted to investigate the effects of changing the information available to participants to label and interpret their cold pressor experience. The first study measured the effect of unspecific posters designed to create an unspecified threat on participants' scores. There were no significant differences between participants' scores in the threat condition and the scores of a group asked to look at a less threatening poster. The second study measured the effect of both posters and verbal information designed to create an unspecified health threat on participants' scores. There was a significant difference in

participants' scores in the two conditions but a flaw in the methodology was noticed and experiment three was conducted to rectify this. The third study replicated the second but removed the reminder of the right to withdraw from the unspecified threat script. Here no significant differences were found, implying that it was that particular cue that caused the results of the second study. The fourth study investigated the effect of providing participants with a specific anxiety-provoking label for their pain. In this task participants were provided with information about a health problem relevant to the task or a health problem irrelevant to the task, and information suggesting the symptoms did or did not match the sensations caused by the cold pressor. Here the predicted interaction was found, as the only result significantly different from the control was the relevant information and symptom condition.

Other studies have investigated the effect of providing participants with relevant and irrelevant information before they completed cold pressor tasks. Al Absi and Rokke (1990) found that when their participants were provided with information designed to make them anxious about the cold pressor task they were doing, their pain ratings increased. When they were highly worried about a potential future painful task their cold pressor ratings decreased, suggesting that the relevance of the anxiety they were experiencing had a strong influence on their pain ratings. The first three studies reported here did not contain specific information about a well defined specific threat. Only in the final study, the combination of relevant and specific information led to the increase in pain scores.

The results presented here highlight the need for health information to be specific and targeted, both to protect those who are not the main audience and to be effective in the case

of people whom they are trying to influence. In the case of the former group, the results of the second and third studies suggest that though pain response can sometimes be altered in predictable ways, it is difficult to control, and can be influenced by various unforeseen factors. This conclusion provides more evidence that health campaigns, particularly fear campaigns, should be used with caution, as they may have unintended consequences. In the case of the later group, it has been shown that campaigns are generally more effective if they focus on specific groups and symptoms (Dale & Hanbury, 2010).

There were a number of limitations to the studies presented in this chapter. First, the situation created in the laboratory, with participants looking at posters once, or reading information and then being tested on it, is quite different to someone repeatedly viewing a health campaign poster in the real world. This places limits upon what this study can say about the effects of real world health campaigns. There were also a number of methodological issues. One of these was the failure to equalise participants' hand temperatures before they took part in the cold pressor study. Cold pressor equipment varies considerably across different experimental groups and conditions, with some experimenters simply using buckets of iced water kept to a constant temperature (for example, Hylands-White & Derbyshire, 2007; Walsh, Schoenfeld, Ramamurthy & Hoffman, 1989). The cold pressor equipment used in this study comprised of a bath made specifically for the purpose, including a built-in thermometer and automatic water circulator. Because of this it was felt that the circulating water would keep participants' hands at a constant temperature. However, it may have been the case that participants who had particularly warm or cold hands before taking part in the study could have experienced the cold pressor differently to others. Though it is likely that these participants

would have been equally distributed across the experimental groups, it is impossible to tell whether there were any intergroup differences in starting hand temperature. Future experimental work should not overlook this variable, and participants should be asked to first hold their hands in water at 32°C for two minutes before completing the main cold pressor task (von Baeyer, Piira, Chambers, Trapanotto & Zeltzer, 2005).

Another limitation was that the length of the cold pressor tasks (one minute in the first three studies, two minutes in the final study) meant that drop-out rates were low and therefore it was not possible to accurately gauge tolerance times. In addition, in the first three studies the time at which participants dropped out was not recorded. This meant that it was not possible to examine whether the studies replicated those of previous investigations, such as the experiments of Jackson et al (2005; 2009), where differences in tolerance were found across different conditions. This decision was taken because we were primarily interested in the way participants rated the pain they experienced, and therefore wanted a high completion rate so that the majority of participants would provide a complete set of ratings. However, in doing this the opportunity to examine whether pain tolerances had reduced across conditions, particularly in the first three studies where no other significant results were found, was lost.

Another limitation was that no data was collected on why participants chose to drop out of the study. It was always assumed that participants dropped out as they felt that the pain was too intense, and their scores were recorded in a way that reflected this. However, there are a number of reasons why participants may have dropped out of the study, including boredom or a lack of interest. Participants were not asked why they chose to drop out, and therefore it is

unclear whether the assumption that they dropped out because they found the pain too much is accurate. This therefore means that coding all early withdrawals as though they found the pain too intense may have artificially inflated the recorded pain ratings. However, when reflecting upon attrition rates in experimental studies, Hooghe, Stolle, Maheo & Vissers (2010) suggested that drop outs due to factors other than the subject of the study are less of a threat to the internal validity than factors to do with the subject, as they are considerably more likely to be equally distributed across conditions. If this is the case it means that any drop outs due to, for example, boredom, are likely to be equally distributed across conditions, and therefore less of a threat to internal validity. This therefore suggests that if a small minority of the group did withdraw early due to reasons other than pain intensity and so were given an artificially high pain score, these should at least be distributed across all conditions. Though this may unfortunately lead to a small overestimate of scores in each condition, it should not affect the overall differences found between the groups.

5.7 Conclusion

The aim of the study was to investigate whether it was possible to change participants' responses to the cold pressor task when they were provided with information and a label with which to interpret their pain. It was found that, though general anxiety provoking information was not found to alter participants' responses to the task, providing participants with an anxiety-provoking and plausible label for their pain did have the power to do so.

5.8 Thesis objectives and future directions

In this study an investigation into the effect of information and labelling on people's response to their pain was conducted. When participants were provided with a plausible anxiety-provoking label, frostbite, which they were told explained a specific symptom that they were currently experiencing, participants rated the pain as worse than those who did not have a plausible anxiety-provoking label. However, the nature of conducting a laboratory study meant that the situation was an unreal one, and therefore it is unclear whether similar effects would be found in the real world, for example in the case of a genuine health campaign providing an anxiety-provoking label for common symptoms. In the next chapter we therefore attempted to find a real world situation involving similar mechanisms to those investigated here, to see whether a similar effect could be found. The results of this investigation are presented in the next chapter.

Chapter Six

Labelling effects in a real world health campaign

6.1 Introduction

The previous study found that providing participants with an anxiety-provoking but plausible label for the pain they were experiencing led to altered pain responses in the form of worse pain ratings. The aim of the study presented in this chapter was to investigate whether similar mechanisms could be seen to be at work in the real world, in people's responses to real health campaigns.

One recent health campaign was the Doubt Kills campaign, produced by the British Heart Foundation in November 2006. In this campaign large public advertisements were posted around the UK depicting a middle-aged man with an invisible belt around his chest, symbolising the pain caused by heart attack. The message of the poster campaign was that it is important to seek professional care when experiencing heart attack symptoms, and particularly targeted middle-aged men. The campaign both provided a specific label, heart attack, and depicted a specific symptom, a painful "tightening" feeling in the chest. Therefore, it represents a real world counterpart to the final experiment in the previous chapter, with frostbite substituted for heart attack, and sharp, stabbing cold pressor pain substituted for "tightening" chest pain.

Public health campaigns aimed at improving the public's response to heart attack symptoms have had very mixed levels of success. Bett, Tonkin, Thompson and Aroney (2005) investigated whether delays in going to hospital with heart attack symptoms reduced after four Australian media campaigns. They found no significant differences in the length of delays before or after the campaigns. Caldwell and Miaskowski (2002) reviewed eight studies investigating campaigns and found that one reported success and two reported marginal

success. A similar review was conducted by Kainth et al (2004). They found that of eleven studies, five reported a significant positive effect on delay times and six did not. In another review of the effectiveness of heart attack campaigns, Blohm and colleagues (1996) examined studies reporting the effects of health campaigns launched between 1982 and 1994 in Canada, the US, Germany, Sweden, Australia and Switzerland. They concluded that there was little evidence for the effectiveness of these types of campaign in terms of reducing deaths from heart attack, but that the campaigns increased the number of people attending hospital for non-cardiac chest pain.

There are a number of reasons why people decide to seek help for the symptoms they experience, and therefore why the campaign may have had this effect. Men, whom the majority of heart attack campaigns are aimed at, are generally poor at seeking help (Smith, Brunack-Meyer & Wittert, 2006). "Traditional masculine behaviour" has been cited as a main reason for this (Galdas, Cheater & Marshall, 2005), as well as lack of time and ease of access (Courtenay, 2000). However, it has been shown that when help-seeking can preserve a more valued masculine attribute, such as a work role, men will seek help more quickly (O'Brien, Hunt & Hart, 2005). Other factors associated with why people may choose to seek help include the beliefs of other people (Calnan, 1983), whether the symptoms are perceived as worthy of urgent attention (Singh, 1988, Woolcott, 1979) and whether the person has a history of help-seeking behaviour (Whorley & Addis, 2006). People who are aware of the availability of treatment are also more likely to seek help (Mercer, Fenton, Johnson, Wellings et al, 2003). Though all of these reasons may have played some part in people's individual decisions to seek help for their chest pain, the significant increases seen after the start of health campaigns

suggest that the message of the campaigns played a part. This may have increased people's perceptions of the urgency of the problem, and may also have reminded them that treatment is available.

This finding suggests that people's responses to non-cardiac chest pain changed after they viewed the heart attack campaigns. It therefore also suggests that a real world health campaign, which provided an anxiety provoking label, heart attack, for a physical sensation, chest pain, changed the way people responded to that painful sensation. The current study aimed to build upon that result, to investigate whether a similar effect could be found after the launch of the Doubt Kills (2006) campaign.

However, the use of non-cardiac chest pain leaves room for a considerable amount of ambiguity. Non-cardiac chest pain, as a somatic symptom, is not a precise diagnosis. Also, as it has been shown that people sometimes spontaneously experience pain in response to viewing images of people in pain (Osborn & Derbyshire, 2010), it is possible that the increases were caused by people experiencing pain they would not have experienced otherwise. This is different to people responding differently to pain they are already experiencing. Therefore it was decided that it would be better to investigate the effects of the campaign on another illness with chest pain as a common symptom, for which it is possible to obtain a clear diagnosis.

Hypotension is the clinical name for low blood pressure. Though someone can have hypotension for long periods of time without it being noticed, hypotension can also occasionally lead to more serious complications (Chobanian, 1982). Therefore for people to be

admitted to hospital with hypotension they usually have to experience symptoms associated with significant impairment. These symptoms include discomfort or pain in the chest, dizziness, light-headedness or fainting (Chobanian, 1982). Hypotension was selected for use in this experiment as it is possible to have hypotension without knowing it, and to only be diagnosed after experiencing symptoms severe enough to require a hospital visit. However, people who have hypotension are also likely to be experiencing some form of chest pain or discomfort on a regular basis. This suggests that if there is an increase in the number of people admitted to hospital with hypotension during a heart attack campaign, it is more likely that they went to hospital because they responded differently to pain they were already experiencing, rather than misinterpreting spontaneously generated pain.

In Blohm et al's (1996) study heart attack campaigns were found to increase the number of people attending hospital with non-cardiac chest pain. In this study the objective was to investigate the number of people admitted to hospital for hypotension in the months before and after the start of a new campaign, the British Heart Foundation's (2006) Doubt Kills campaign. This was compared with the number of people admitted to hospital in the previous year, in order to control for any seasonal variations in occurrences of hypotension. The aim of this study was to investigate whether providing people with an anxiety provoking label for their pain, heart attack, would cause hypotension sufferers to respond differently to their pain and attend hospital in greater numbers than before the campaign was launched. Because the campaigns appeared to primarily target men, it was hypothesised that the number of men admitted to hospital with hypotension would increase compared to the previous year in the months following the campaign.

As heart attack was the subject of the campaign, the number of people admitted to hospital with heart attack in the months before and after the campaign was also investigated. However, it was hypothesised that the campaign would have no effect on hospital admissions for heart attack. This is because, unlike hypotension, almost everyone suffering a heart attack will be forced to go to hospital within the month, if not a lot sooner, and so monthly hospital admissions rates are unlikely to reflect any meaningful changes. However, this was examined as there is a small possibility that, because hospital admissions statistics do not include anyone who died on the way to hospital, if the campaign was very effective this may have been reflected in a small increase in the number of people admitted to hospital, i.e. a reduction in the number of deaths.

The number of people admitted to hospital for stroke in the same time period was also examined, to serve as a control condition. No significant differences were expected in the number of people admitted to hospital with stroke before or after the campaign.

6.2 Method

Hospital admissions data for all areas of England was requested using the HES website (HES, 2010). Admissions data for hypotension, acute myocardial infarction (MI) and stroke were requested. The data was broken down by month, sex, age and disease. In line with the HES website policy, numbers under five were suppressed to preserve patient confidentiality.

Data was requested for the financial years April 2005-March 2006 and April 2006-March 2007. As the campaign commenced in November 2006 this provided enough data to compare

the months before and after the campaign with the corresponding months in the previous year. This was done to ensure seasonal trends did not influence the results.

As the primary focus was on how many people were admitted to hospital for each condition in any given month, the scores for the four adult age groups were collapsed to give one adult score for each sex, per disease, per month.

We were primarily interested in the first four months after the start of the campaign, as this was felt to be sufficient time for any effects of the campaign to be reflected in the statistics, but immediate enough that any effects would not decline as the initial impact of the campaign receded. The four month period before the campaign was also investigated, to determine whether there were any differences in the patterns of admissions before and after the campaign.

6.3 Results

Paired samples t-tests were used to look for differences in the number of people admitted to hospital for hypotension, acute myocardial infarction and stroke in the four months before and after the start of the health campaign and the same time the previous year. The significant differences are summarised in the tables overleaf:

Table 6.1

Significant differences in the number of people admitted to hospital for each health condition, before and after the health campaign, compared to the previous year

		4 months before the start of the poster campaign		
		Year 1 Mean July 05- Oct 05	Year 2 Mean July 06- Oct 06	Test for significant difference
Hypotension	Male	475	513.5	t(3)=-1.881, p= .156
	Female	525.75	580	t(3)= -2.533, p=.085
MCI	Male	3417.25	3438	t(3)= -.369, p= .737
	Female	2005.5	1956	t(3)= 7.484, p= .005 *
Stroke	Male	3221.5	3169	t(3)= 1.085, p= .357
	Female	3393.5	3288.5	t(3)= 2.458, p= .091

		4 months after the start of the poster campaign		
		Year 1 Mean Nov 05- Feb 06	Year 2 Mean Nov 06- Feb 07	Test for significant difference
Hypotension	Male	415.5	485.75	t(3)= -4.219, p= .024 *
	Female	452	522.5	t(3)= -14.674, p= .001 *
MCI	Male	3667	3634.5	t(3)= .42, p= .703
	Female	2144.5	2092	t(3)= .959, p= .408
Stroke	Male	3070	2992	t(3)= 8.081, p= .004 *
	Female	3407.75	3176.25	t(3)=3.47, p= .04 *

* = significant difference between the number of hospital admissions in year one and year two

As can be seen from table 6.1 and figures 6.1 and 6.2 in the case of hypotension there was no significant increase or decrease compared to the previous year in the number of men (t(3)=-1.881, p= .156) or women (t(3)= -2.533, p=.085) admitted to hospital in the four months before the start of the campaign. As predicted there were significant increases for both men (year one: mean= 415.5, s.d.= 18.57, year two: mean= 485.75, s.d.= 50.8; t(3)= -4.219, p= .024) and women (year one: mean= 452.00, s.d.= 15.12, year two: mean= 522.5, s.d.= 16.13; t(3)= -14.674, p= .001) in the four months after the start of the campaign.

Figure 6.1

The number of males admitted to hospital for hypotension in the four months before and after the campaign and the previous year

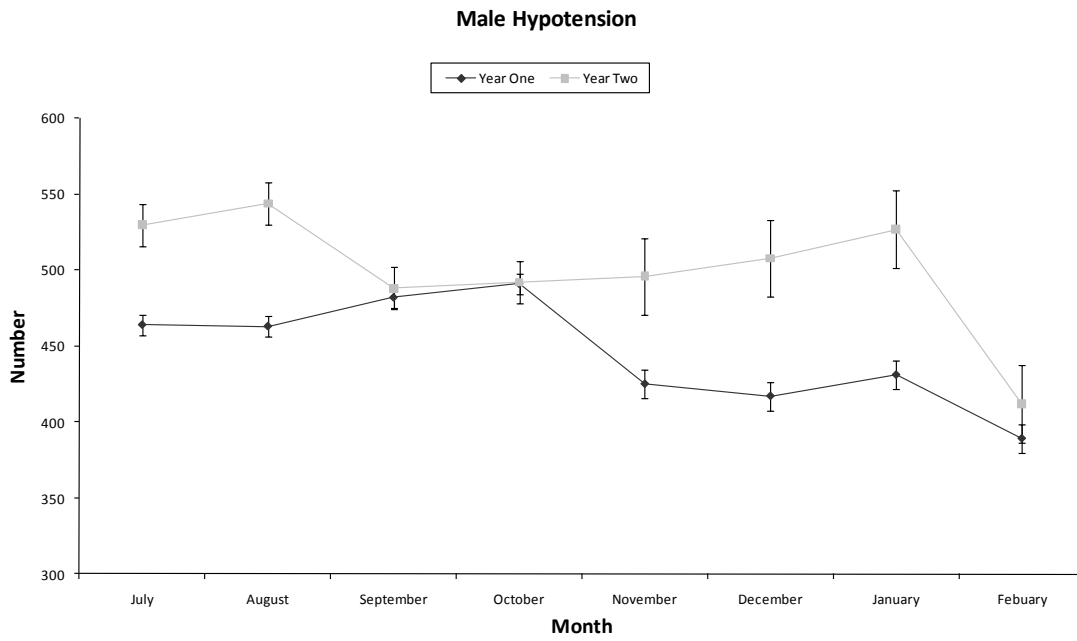
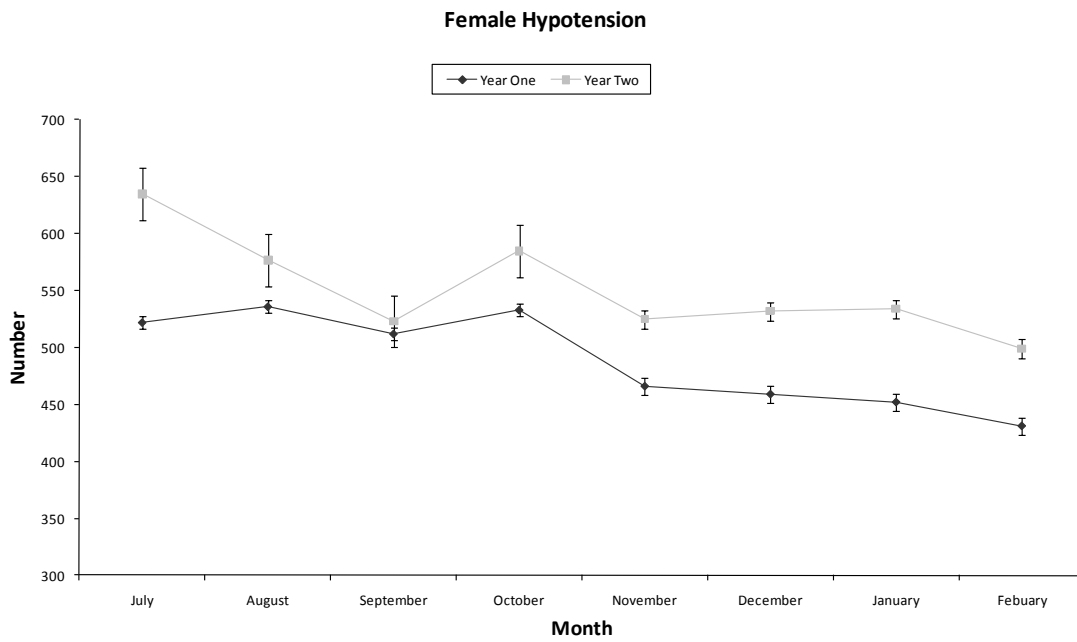


Figure 6.2

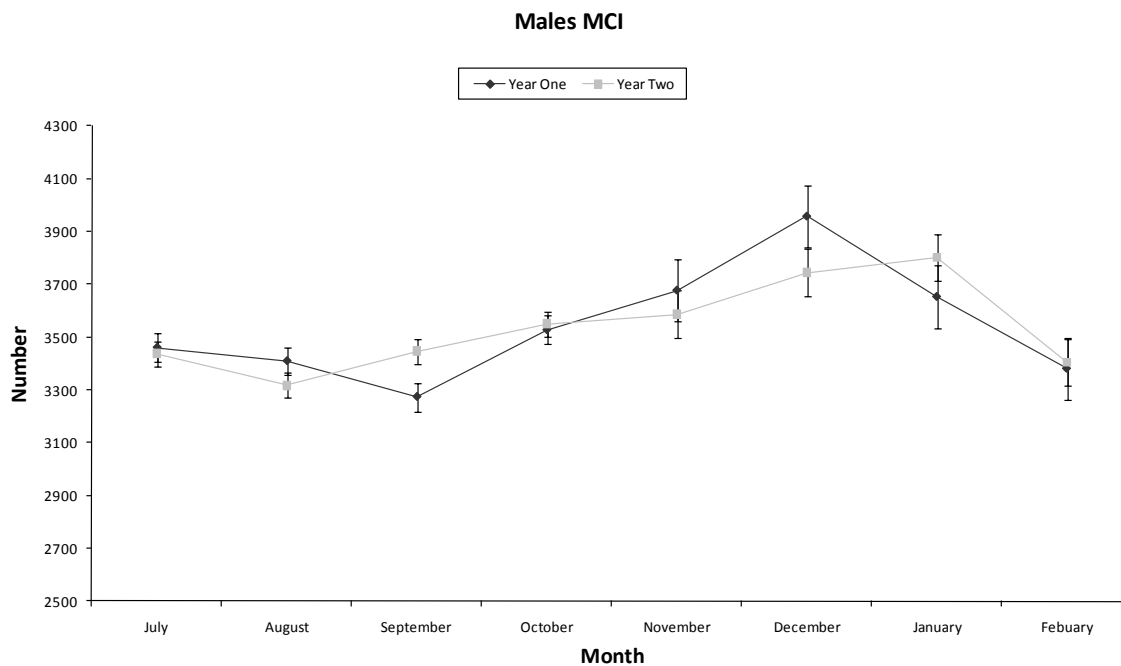
The number of females admitted to hospital for hypotension in the four months before and after the campaign and the previous year



As can be seen from figure 6.3, the campaign appeared to make no difference to the number of men admitted to hospital for acute myocardial infarction, though there appears to have been a small reduction in December 2006, the month after the launch of the campaign. In the four months before the campaign ($t(3) = -.369$, $p = .737$) and the four months after ($t(3) = .42$, $p = .703$) paired-samples t-tests showed no significant rise or drop in the number of people admitted to hospital, compared to the previous year's numbers.

Figure 6.3

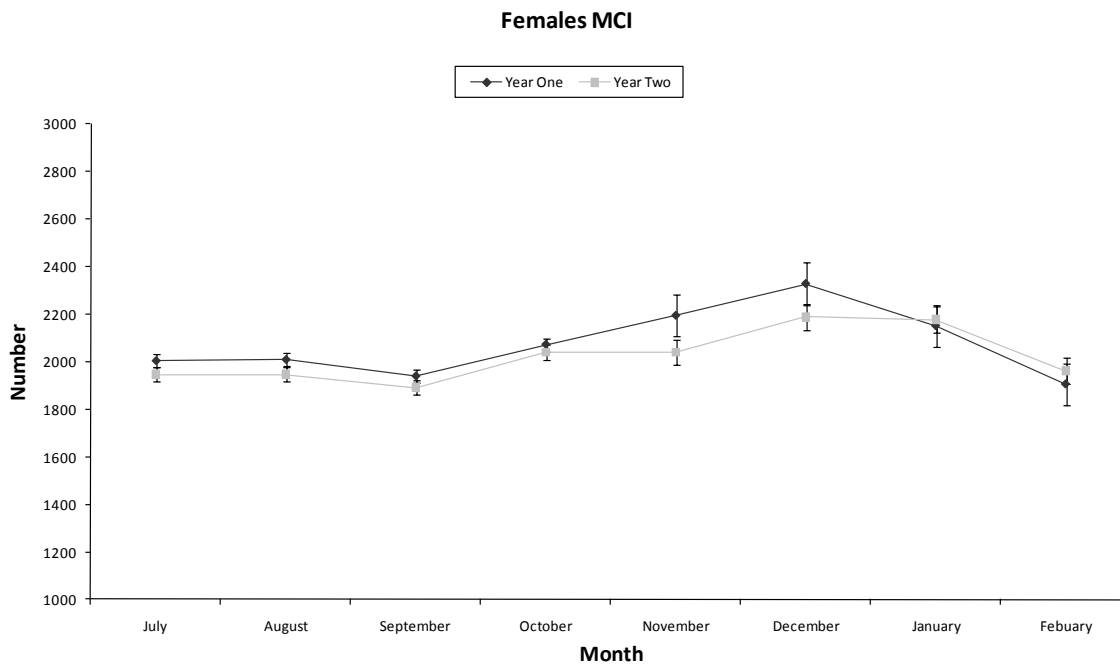
The number of males admitted to hospital for acute myocardial infarction in the four months before and after the campaign and the previous year



As can be seen from figure 6.4 there appears to have been a reduction in the number of women admitted to hospital for acute myocardial infarction in the November and December after the campaign. In the four months before the campaign paired-samples t-tests showed a significant decrease in the number of women admitted to hospital, compared to the previous year (year one: mean= 2005.5, s.d.= 54.34, year two: mean= 1956, s.d.= 61.51; $t(3) = 7.484$, $p = .005$). In the four months after the start of the poster campaign there was no significant increase or decrease in the number of women admitted to hospital for acute myocardial infarction compared to the previous year ($t(3) = .959$, $p = .408$).

Figure 6.4

The number of females admitted to hospital for acute myocardial infarction in the four months before and after the campaign and the previous year



As can be seen from figures 6.5 and 6.6, in the case of the control condition, stroke, there was no significant increase or decrease on the previous year's numbers in the number of men ($t(3)= 1.085$, $p= .357$) or women ($t(3)= 2.458$, $p= .091$) admitted to hospital in the four months before the start of the campaign. There were significant decreases for both men (year one: mean= 3070.00, s.d.= 215.17, year two: mean= 2992.00, s.d.= 207.38; $t(3)= 8.081$, $p= .004$.) and women (year one: mean= 3407.75, s.d.= 316.09, year two: mean= 3176.25, s.d.= 223.36; $t(3)=3.47$, $p= .04$.) in the four months after the start of the campaign.

Figure 6.5

The number of males admitted to hospital for stroke in the four months before and after the campaign and the previous year

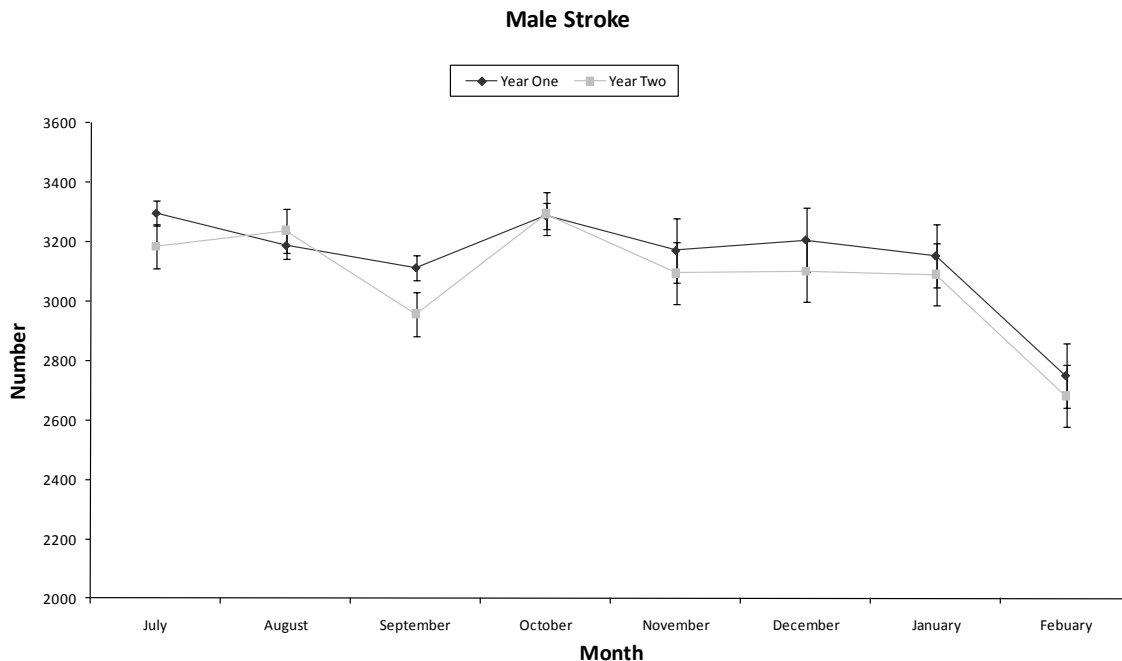
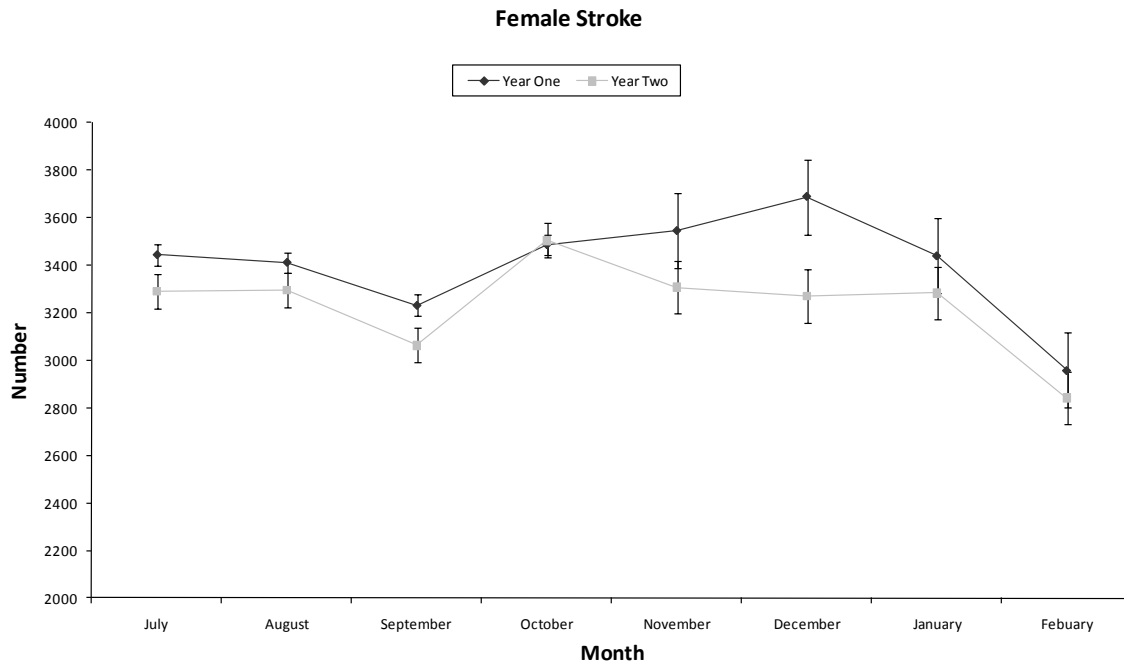


Figure 6.6

The number of females admitted to hospital for stroke in the four months before and after the campaign and the previous year



6.4 Discussion

The aim of this study was to investigate whether the number of people admitted to hospital for hypotension increased in the months following the British Heart Foundation's Doubt Kills campaign. As there were significant increases in the number of men and women admitted to hospital in the months following the campaign, but not in the months before the campaign, this was found to be the case.

The results for heart attack are less clear cut. As predicted there was no significant increase in the number of men admitted to hospital with heart attack either before or after the

start of the campaign. However, there was a significant decrease in the number of women admitted to hospital for heart attack in the four months before the campaign. This decrease then disappeared in the four months after the campaign. An examination of figure 5.4 suggests the differences found in the four months preceding the campaign were small but consistent, whereas the differences after the campaign were larger but more variable. This suggests that the differences found in the four months before the campaign may have been an artefact in the data.

The control condition, stroke, showed an unexpected pattern: though there was no difference from the previous year in the number of men and women admitted for stroke in the four months before the campaign, there was a significant decrease from the year before in the number of both men and women admitted to hospital in the four months after the campaign. An examination of figure 5.5 suggests the differences for men between the two years were small but consistent whereas, as can be seen from figure 5.6, the number of women admitted to hospital with stroke dropped sharply in the four months following the start of the campaign. It is unclear as to why this would be the case. Searches for possible factors affecting the number of people admitted for stroke in November 2006 revealed nothing that could account for the changes. One possible explanation is that it is simply an artefact in the data. This raises some questions about whether it is possible to draw strong conclusions from the other data in this study and any future work should use the opportunities provided by future campaigns to gather further information.

Men and women with hypotension both appeared to be influenced by the campaign. This contradicts research which suggests that, as the campaign featured a male model, it would be less effective for women (Dale & Hanbury, 2010). However, it has previously been shown that women report feeling more threatened by high-threat campaign messages than men (Leventhal, Jones & Trembly, 1966). It is therefore possible that women do not have as greater need to relate to the role model in a campaign in order to respond to a high threat message. This may have important implications in the design of future campaigns, and needs further examination.

There were some limitations to this study, particularly surrounding the use of hospital admissions statistics. The aim of this study was to investigate whether the Doubt Kills poster changed the way at-risk people who viewed the poster responded to their chest pain. To do this the number of people admitted to hospital with hypotension in the months before and after the campaign was examined. Hypotension was selected for two reasons. First, one of the symptoms of hypotension is chest pain, along with the more common symptoms of dizziness and light-headedness. Second, these symptoms are typically mild and so it is usual for people with hypotension to remain undiagnosed, unless something happens to cause the person to come to the attention of medical professionals.

For these reasons, it was thought to be possible that something such as the BHF poster campaign could trigger concern in those experiencing symptoms of hypotension, and that this could lead to an increase in the number of people admitted to hospital with hypotension during the time of the campaign. Once admitted, hypotension can be readily identified, and entered

into the hospital admission statistics. Hypotension is very easily diagnosed via a simple test and is not likely to be miscategorised in the statistics. Therefore, it was felt that hospital admissions statistics were appropriate markers of whether people with hypotension responded differently to their pain in the months after the campaign.

Due to the nature of the campaign, we also decided to investigate whether the poster campaign had an impact on hospital admissions for heart attack. However, there are a range of problems with using hospital admissions statistics to try to determine the effectiveness of the Doubt Kills campaign. Most important is that one of the main causes of preventable deaths from heart attack is that people seek help too late, not because they do not seek help at all (Dracup et al, 1995). Therefore, the most appropriate statistics to use are those that measure the time it takes people to seek help. Survival rates may also provide insight into the effect the campaign had on mortality. In the absence of this information, death rates, though themselves problematic (because increases and decreases in deaths may simply reflect differences in the number of people suffering heart attack, and say nothing about the number surviving them) also provide more useful information than hospital admissions, as if the campaign was effective and encouraged more people to seek help quickly, fewer heart attacks should have been fatal (Simoons et al, 1986).

In light of these issues, to try to gain a slightly more accurate picture of the impact of the Doubt Kills campaign on its intended target, a freedom of information request was made to determine whether the number of people who died from heart attack was reduced compared to the previous year in the four months after the campaign. It was hoped that this comparison

would reduce the effects of any seasonal variations in the number of people suffering heart attacks and therefore mitigate one of the problems associated with using death rates. The findings can be seen in table 6.2 below:

Table 6.2

The number of deaths from heart attack before and after the campaign, compared with the previous year

	Year 1 Mean July 05- Oct 05	Year 2 Mean July 06- Oct 06	Test for significant difference
Four months before the campaign	2666	2519.5	t= (3) 7.169, p= .006
Four months after the campaign	3083	2865	t= (3) 2.354, p= .1

It was found that there were reductions in the number of deaths from heart attack in the four months before and after the campaign. However, despite the larger average reductions seen in the four months after the campaign, only the reductions in the four months before the campaign achieved significance (before: t= (3) 7.169, p= .006; after: t= (3) 2.354, p= .1) as the reductions in the four months after the campaign were considerably more variable. These reductions reflect a wider trend for reductions across the whole year. As it has been shown that the number of people dying from cardiovascular disease has fallen by 44% in the last ten years (BHF, 2010), this continues a more long-term pattern. Though this is extremely positive in that fewer people appear to be dying from heart attacks, as expected it is unclear from these statistics as to whether the Doubt Kills campaign provided any additional benefit.

6.5 Conclusion

In this study, it was found that campaign posters providing people with a distressing label for chest pain led people with hypotension to respond differently to their pain. These findings suggest that information in the environment can change the way people react to pain in the real world, as well as in the laboratory.

6.6 Thesis objectives and future directions

The previous chapters have attempted to investigate factors influencing the way healthy people understand and experience their health. The next three chapters will go on to look at these issues in another population, people with the FSS fibromyalgia.

Chapter Seven

A method to investigate the experience
of fibromyalgia patients

7.1 Introduction

In the previous chapters the way labels affect health experience was investigated, first in young people who were shown to use symptom experience and behaviour to label themselves as healthy or unhealthy, and second in people who were given an anxiety-provoking label for their experiences via information in the environment. Young people were the primary focus of the first four experimental chapters of this thesis. This was because they are the group least likely to have any form of long term health diagnosis (Alder, Mayhew, Moody, Morris & Shah, 2005), and therefore the group most likely to label their health based on other factors, including their behaviour. In this chapter we now turn to a group who have a functional somatic syndrome, to investigate the ways in which having a functional somatic syndrome label alters the way people interpret their experiences. Specifically the way people with fibromyalgia understand their experiences will be examined, particularly focusing on the embodied experience of fibromyalgia and the impact of the syndrome on interpersonal relationships.

For patients with many chronic illnesses, receiving a diagnosis is a vital first step on the road to recovery which ensures that the patient receives the correct care and treatment (King et al, 2003). However, in the case of some illnesses, where less is known about the causes and effective treatments, receiving a diagnosis can dramatically alter the way in which people understand their health without necessarily bringing any particular benefit. One syndrome where the benefits of diagnosis are controversial is fibromyalgia. Though one study indicated that being diagnosed with fibromyalgia leads to reductions in the number of symptoms experienced in the long-term (White et al, 2002), it has also been found that the number of

non-pain medications consumed by newly diagnosed patients steadily increases for at least three years after diagnosis (Sanchez et al, 2011). In addition, qualitative investigations of people's experiences have shown that, while there is some initial benefit to diagnosis, this tends to fade over time, leaving the patient feeling no better than before (Undeland & Malterud, 2007).

It has been shown that having a fibromyalgia diagnosis changes the way people interpret the somatic symptoms they experience. van Ittersum, van Wilgen, Hilberdink, Groothoff and van der Schans (2009) asked people with fibromyalgia about their experience of various symptoms and how many of them they ascribed to fibromyalgia. As was demonstrated in chapter two of this thesis, it is common for people to experience a wide range of somatic symptoms on a regular basis. In the study people with fibromyalgia also reported experiencing a large number of symptoms but nearly all of them blamed this on their fibromyalgia (van Ittersum, van Wilgen, Hilberdink, Groothoff and van der Schans, 2009). Nausea or a headache that a healthy student would ignore or label as a passing irritation is interpreted as something more significant by someone with fibromyalgia.

In this study the way people with fibromyalgia understand and interpret their illness was investigated, in the hope of understanding how people who are experiencing their health through the filter of fibromyalgia make sense of their symptoms. Participants were also asked about their social relationships, working lives, and interaction with support networks. In this way we aimed to investigate how having a label of fibromyalgia shapes the lives of people affected.

In order to investigate the impact of fibromyalgia on patients' lives, twenty fibromyalgia patients were interviewed via email and their responses were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009) and Template Analysis (TA) (King, 2004). The results will be presented over two chapters. The first chapter discusses the embodied experience of fibromyalgia, the second the effect fibromyalgia has on interpersonal relationships.

Other authors have discussed the pros and cons of interviewing through the internet (for reviews see Meho, 2006, Hamilton & Bowers, 2006). In summary, the major disadvantages of interviewing through the internet are a lack of visual cues and a potential difficulty in building rapport. The major advantages are access to a different sample and more time for participants to express themselves and think about their answers. For the current study, the advantages of being able to reduce the time pressure on participants and the ability to allow them to discuss what they felt was important, at a pace chosen by them, were considered to outweigh the disadvantages. People with fibromyalgia sometimes suffer from cognitive dysfunctions and it was felt that giving the participants the time and space to think about what they wanted to say would facilitate more complex and representative answers. Using the internet also provided access to a more varied sample than some studies have been able to achieve, including people who were younger than the typical fibromyalgia research participant.

In both studies data analysis was completed using an Interpretative Phenomenological Analysis (IPA) method and a Template Analysis (TA) method. There were a number of reasons why these methods were chosen for analysis. In both studies the aim was to investigate the

way in which people with fibromyalgia understand their experience. IPA is a method particularly concerned with discovering how participants understand and experience a situation (Smith & Osborn, 2007). The analysis itself pairs lived experience with subjective interpretation of that experience (Reid, Flowers & Larkin, 2005) making it ideal for exploring participants' understanding of their lives with fibromyalgia. Smith and Osborn (2007) describe IPA as "particularly useful when the topic under study is dynamic, contextual and subjective, relatively under-studied and where issues relating to identity, the self and sense-making are important", and in this way the strengths of IPA coincide with the aims of this study. However, the in-depth nature of this form of analysis means that there are some restrictions on its use. Due to the level of engagement required for each individual transcript, it is often recommended that sample sizes are kept small. Ten has been recommended as the highest number (Smith et al, 1999), as larger samples are likely to lead to insufficiently penetrating analysis (Smith & Osborn, 2007).

In this study, the richness and quality of the data provided by the sample meant that, in terms of overlapping aims and potential for insight into the fibromyalgia experience, IPA was the ideal method of analysis. Unfortunately, the interest in this study from potential participants meant that more people were willing to tell their story than was practical for IPA analysis on the entire sample. Therefore, the question of how to proceed with analysis was uncertain. It was eventually decided that instead of sacrificing potential gains from using IPA, and to avoid the pitfalls of a larger sample described by Smith et al (1999) and Smith and Osborn (2007), it was best to split the sample, and to use two different forms of data analysis.

Mixed methods of analysis have been used before in qualitative research (for example Bailey & Jackson, 2003; Reissman, 1990) when the researchers felt the data could not be adequately served by an individual method. In a comparison of two similar research projects, one analysed using IPA and one using TA, Reynolds (2003) highlighted the strengths and weakness of each approach, and suggested that IPA should best be used for “an initial “sensitising” phase of the enquiry only, perhaps with fewer than 10 participants”, whereas TA could “facilitate a theory driven analysis”. It was therefore felt that TA would provide an appropriate second method, and that the results of this second analysis could be used to interrogate and validate the findings of the IPA analysis over a larger group.

Template analysis (TA) is a form of qualitative analysis that is similar to IPA, when used within a phenomenological setting (King, 2004; Waring & Wainwright, 2008). However, unlike IPA, TA starts with a set of codes, or the template, representing themes in the data, and less emphasis is placed on individual transcripts before examining the larger sample (King, 2004). The method allows for considerable flexibility in analysis, as the themes and codes can be changed as analysis proceeds according to the needs of the data (King, 2004).

In the present study, the transcripts of eight participants were analysed using IPA, and the remaining twelve participants were analysed using TA. The subset of eight IPA participants was selected by transcript length: four transcripts of average length (approximately twelve pages) from each group. This was done for various reasons. First, we wanted to ensure that the selection was fair, and that particularly interesting or unusual transcripts were not preferentially selected for IPA analysis. There were also practical considerations. Primarily, as

participants were recruited in two groups it was thought to be ideal to have the same number of transcripts, and transcripts of a similar length, from both sets of participants. In addition, we were mindful that analysing multiple, very extended transcripts would potentially cause the same problems as having too many participants, in terms of depth of analysis. All remaining transcripts were analysed using TA.

7.2 Participants

The same twenty participants provided all of the data presented here. The data provided by eight participants (Anne, Beth, Carol, Diane, Ellen, Fiona, Gail and Helen) was analysed using IPA. The first four participants were recruited through an internet support forum and the last four participants were recruited through a real world support group (see table 7.1 for additional participant information).

Table 7.1

Participant aliases and demographic information (IPA)

Group	Alias	Age	Nationality	Marital status	Work status	Years since started symptoms	Years since diagnosis
1	Ann	18-24	American	Single	Full time student with a part time job	4/5	2
1	Beth	18-24	American	Married	Full time job	7	2
1	Carol	30-34	American	Single	Recently left work	13	10
1	Diane	25-29	American	Relationship	Full time job	13	1
2	Ellen	50+	British	Married	Lost job due to symptoms	Over 15 years	2-3
2	Fiona	50-54	British	Married	Part time job	4 ½ years	3 ½
2	Gail	45-49	British	Married	Unable to work due to health	15 years	Less than one year
2	Helen	45-49	British	Single	Retired due to ill health	All of her life	5

Group- Indicates whether participants were recruited from an online support group (1) or a local “real-world” support group (2).

The data of the other twelve participants (Imogen, Jane, Kate, Luke, Mary, Naomi, Olivia, Paula, Quinn, Rebecca, Sally and Tina) was analysed using TA. The first ten participants were recruited through an internet support forum and the last two participants were recruited through a real world support group (see table 7.2 for additional participant information).

Table 7.2

Participant aliases and demographic information (TA)

Group	Alias	Age	Nationality	Marital status	Work status	Years since started symptoms	Years since diagnosis
1	Imogen	25-29	British	Single	Unemployed	8	5
1	Jane	25-29	British	Single	Medically retired	6	5
1	Kate	50-54	American	Divorced/ remarried	full time with leave of absence	10	8/9
1	Luke	40-44	American	Married	Employed	5	2
1	Mary	25-29	American	Remarried	Unemployed	2	0.5
1	Naomi	30-35	Canadian	Married	Part time job	5	4
1	Olivia	30-34	American	Single	Unemployed	25	15
1	Paula	25-29	American	Domestic Partner	Self-employed	15	7
1	Quinn	20-24	British	Married	Part-time self employed	4	1
1	Rebecca	30-34	American	Domestic partner	Unemployed	21 (became severe 7 years ago)	14
2	Sally	45-49	British	Married	Homemaker	7	5
2	Tina	60-64	British	Widowed	Retired	Childhood	1.5

Group- Indicates whether participants were recruited from an online support group (1) or a local "real-world" support group (2).

7.3 Method

The same method was used in both studies. Participants were recruited through an online support group and a local “real-world” group. The online group was chosen because it was highly active and stated clearly that anyone, including non-sufferers interested in finding out about fibromyalgia, was welcome to post. This was felt to be extremely important, as some support groups are “safe spaces” specifically for sufferers (Dias, 2003). A message was posted on the forum asking for volunteers to take part in a research study involving an email discussion of their experiences. The researcher also attended a local support group and advertised the study to the group via a short verbal presentation. Forty one people replied to these advertisements and were then emailed information sheets and consent forms. Twenty provided informed consent and were sent forty questions about fibromyalgia, divided into five categories: history and symptoms, influences on your pain, the reactions of non-sufferers, community and other. They were also asked to provide basic demographic information. Participants were told they could answer as many of the questions as they felt comfortable with and could give as much detail as they felt necessary. Questions were devised from a reading of the literature and aimed to be as open and as wide as possible (see appendix five). Some questions included: “What are your main symptoms?” and “Do you have any other ways of trying to explain fibromyalgia to non-sufferers?” If these were returned participants were asked if they were willing to continue answering questions. Their responses were read and if anything was unclear or could be explained further, further questions were inserted into the text. These exchanges continued until the interviewer felt that no further questions were necessary or until the participant no longer wanted to answer or stopped responding. An average exchange was

between two and four follow up emails. Participants' transcripts ranged from 5 pages to 77 pages.

7.3.1 Interpretative Phenomenological Analysis

After the exchange was completed transcripts were selected on the basis of length for IPA analysis. The median length of the transcripts was 12-15 pages and the four internet and four support group transcripts closest to the median were chosen for IPA analysis. These selected transcripts ranged from 9 to 16 pages. Before starting analysis each transcript was read through in its entirety to ensure a basic understanding and familiarity with the data. The transcript was then read again and using free coding initial reactions, potential themes and objects of interest were noted. Each transcript was then read twice more, and systematic coding of the data began. The aim of this systematic coding was to identify the experiences which were important to the participant and the meanings associated with them. Each sentence was examined and if necessary broken down into separate units of meaning. Each of these meaning units were then coded according to content. Once the coding had been completed, the themes emerging within the codes were identified. Each theme therefore represented a pattern in the participant's account, and illustrated one aspect of the way that they made sense of their experience. Short summaries of each theme were written, along with key quotes which illustrated their content. This process was completed for all transcripts in turn.

After all the transcripts were analysed in this way, the themes from each transcript were examined and commonalities and differences between them were noted. Then the

superordinate themes, themes which were common to the majority of transcripts, were identified, and brief descriptions of their content were written. The individual transcripts were then read again, and the content of these overarching themes was revised accordingly. After it was ensured that each theme accurately reflected the content of the data, then expanded summaries, containing numerous quotes, were drafted. The transcripts were then checked a final time to ensure the expanded summaries were still an accurate reflection of the content. The data coding procedure was monitored at all stages by a senior researcher, to ensure accuracy and objectivity.

7.3.2 Template Analysis

Twelve transcripts remained and were analysed using TA. The TA analysis was conducted after the IPA analysis and the themes found in the IPA analysis formed the basis of the template. As in the IPA analysis procedure, before starting analysis, each transcript was read through in its entirety to ensure a basic understanding and familiarity with the data. After this familiarity was achieved, the coding of the data began. Again, each sentence was examined and if necessary broken down into separate units of meaning, but this time the units were coded according to the themes already identified in the IPA analysis procedure, wherever these were appropriate. The majority of the coding at this stage involved the application of the categories already developed in the IPA stage. However, any information that did not comfortably fit in to any of the themes was noted, and coded separately. Once each meaning unit had been coded, short summaries of each theme were written, along with key quotes. This

process was completed for each transcript in turn. The information that did not fit into the themes was reread and any new emerging themes were noted.

After all the transcripts were individually coded, the themes from each transcript were compared and summaries of each theme were written. A summary was also written for the one additional theme that emerged. The transcripts were then reread to ensure the summarised themes accurately reflected the content of the data. Extra care was taken to ensure that the content of the new theme was accurately reflected in all the transcripts. After it was ensured that each theme was an accurate reflection expanded summaries, along with numerous quotes, were written. Again these were checked, to ensure they still accurately reflected the data. The data coding procedure was monitored at all stages by a senior researcher, to ensure accuracy and objectivity.

After completing both the IPA and TA analysis, the superordinate themes from each were compared and similarities and differences between the two were noted. Short summaries of the similarities and differences were written, and these were checked against the transcripts from both groups. When it was established that these reflected genuine similarities and differences between the two groups, these were expanded and illustrative quotes were added.

In the interests of readability, only the IPA analysis findings, along with a comparison between the IPA and TA findings, will be presented in the following chapters. Please see appendix six for the template analysis findings in full.

Chapter Eight

The embodied experience of fibromyalgia

8.1 Introduction

The aim of the current study was to investigate the way participants experienced their symptoms, the ways in which they attempted to control them, and their beliefs about the causes of their syndrome. Previous research has examined the nature of fibromyalgia pain. In Schaefer's 1997 study participants described their worst pain as "bad, nagging, unremitting, agony, terrible, annoying burning and extreme" (Schaefer, 1997). Söderberg, Lundman and Norberg (1999) found that, in their participants, "the location of the pain changes, but it was constantly present". Other studies have focused on other symptoms including fatigue (Söderberg, Lundman & Norberg, 2002) and cognitive difficulties (Crooks, 2007). Fatigue was shown to cause the body to be a burden and an obstacle, and to make the women feel absent. Cognitive difficulties also contributed to a feeling of distance and "haziness".

Other qualitative investigations have investigated the way people with fibromyalgia cope with their pain. Hallberg and Carlsson (2000) found that pain became a constant preoccupation for people with fibromyalgia, and that it constantly demanded active coping. The participants in the study primarily used coping behaviours that the authors described as potentially having a negative effect in the long term. These included escape behaviours, passivity and catastrophising. Mannerkorpi, Kroksmark and Ekdahl (1999) identified four different ways of coping with fibromyalgia symptoms. These were "struggling", where participants attempted to fight their symptoms, "adapting", where participants planned their lives around their limitations, "in despise", where participants felt they could no longer cope and "giving up", where participants felt that their lives were dominated by their symptoms.

In a metasynthesis of qualitative fibromyalgia studies, Sim and Madden (2008) described four main themes in the reviewed qualitative accounts: experience of symptoms, (pain, describing pain, fatigue and psychological problems), searching for a diagnosis (pre-diagnosis, receiving the diagnosis and post-diagnosis), legitimacy and coping. Though the metasynthesis draws together a wide range of different themes, almost all of the studies examined used different populations with different histories and experiences. In this study we aimed to look at all of these topics within the same people, to try to identify patterns, and the way different experiences impacted upon each other.

8.2 Results

Several main themes were found in the data. These were:

- pervasive pain,
- “killer” fatigue,
- “confused and kind of dazed” fog,
- hypersensitivity and flu-like flares,
- a “giant mess” of other symptoms,
- gradual course,
- the mixed blessing of diagnosis,
- complex and multiple causes,
- complex and multiple triggers,
- strict routines for coping,

- mixed attitudes to medication.

For each theme, the IPA results will be presented first, followed by a comparison of the IPA and TA findings. Please see appendix six for the TA findings in full.

Pain- Pervasive

IPA

The participants' experience of fibromyalgia was characterised in their accounts by a pervasive degree of pain:

I have a constant all over dull pain or ache – sort of like a background pain all of the time, then on top of this there are many and varied pains and aches in almost every part of my body of differing intensities and intervals” (Helen).

The combination of low level constancy (dullness, or background pain) and variability (see flares, below) described by Helen is typical. Thus, all participants described the pain as being constant and this constant pain did typically tend to be described as “*dull*” (Ann, Diane, Ellen and Helen) and as a general “*ache*” (Ann, Beth, Carol, Ellen, Fiona, Gail, Helen). Specific details of the pain varied across the sample. For example, Carol described her pain as being more localised than is typical in fibromyalgia, although it was still characterised by its consistency: “*The muscles in my neck and shoulders feel tight and sore on a constant basis.*”

The constant nature of the pain made it extremely disruptive, making both daily tasks and fun activities more difficult. Ann, who is a full time student and also has a part time job,

described how *"my back always hurts because I have to sit through classes and work daily"*. Gail told a story about when, as a birthday present, she went to a health spa:

"I participated in a game of tennis and although I tried not to be too energetic I really suffered with pain in my legs & back and was really 'off my feet' for 2 or 3 days" (Gail).

TA and IPA comparison

Both groups of participants described constant pain that varied in intensity and type, for example, Helen in the IPA group and Mary and Kate in the TA group:

I have a constant all over dull pain or ache – sort of like a background pain all of the time, then on top of this there are many and varied pains and aches in almost every part of my body of differing intensities and intervals" (Helen).

"There is always at least a small amount of pain there. It just varies at different degrees of pain" (Mary).

"It rises and falls in severity but does not ever go away. Not ever" (Kate).

In addition, both groups described pain spread all over the body, though some participants reported more severe pain in certain areas. Participants in the TA group felt that their reactions to pain appeared to be disproportionate to the amount of pain they were experiencing, a point that was not raised by participants in the IPA group:

"my pain has been so continuous I often don't notice I'm in pain when I am- it feels like minor irritation until I break into a cold sweat and get nauseous." (Paula)

Fatigue- “Killer”

IPA

A symptom mentioned almost as much as pain by participants was fatigue. Fatigue appeared to have different negative effects on the participants to their pain: while pain took away some of the ability to be active and live a normal life, fatigue built up more barriers between people, as participants reported becoming too tired to fight the pain and continue with the activities they might otherwise have been able to do. The effect of fatigue is illustrated by Diane’s experiences with suggested treatment when she was first diagnosed:

"I went through a series of drugs, and told to do some light exercise. Problem was, I found myself too tired to even start exercise. With acupuncture, I have been able to resume some light activity because they treated me for fatigue and brain fog first. This, as a result, has helped with the pain".

This quote highlights one of the main problems faced by participants in many areas including treatment and diagnosis (see below). Making progress, whether towards better health or a diagnosis, often requires the ill person to take an active role in the process, something a lot of fibromyalgia patients feel unable to do.

Unlike Diane the majority of participants were unable to find anything to treat their fatigue, and so were unable to make the kind of positive steps described above. Carol said:

"I can handle the pain—I use a cane a lot—but the fatigue is a real killer. I usually end up calling in at least once a month due to fatigue or not being able to get out of bed".

This shows the impact that fatigue has on the participants and the way they appeared to give it almost equal status to the pain when describing the unpleasant aspects of the illness.

TA and IPA comparison

Participants' descriptions of the fatigue they experienced were similar, with participants from both groups describing it as being almost, or more, distressing than the pain. The comments of Carol and Naomi were similar when they said:

"I can handle the pain—I use a cane a lot—but the fatigue is a real killer. I usually end up calling in at least once a month due to fatigue or not being able to get out of bed" (Carol).

"there are days where I can be so tired I vomit after doing something simple like going out to the store and picking up a few things. I can literally come home shaking" (Naomi)

Participants in both groups also made the point that fatigue prevents effective use of coping mechanisms, leading to increased pain that is harder to cope with, for example:

"I went through a series of drugs, and told to do some light exercise. Problem was, I found myself too tired to even start exercise. With acupuncture, I have been able to resume some light activity because they treated me for fatigue and brain fog first. This, as a result, has helped with the pain" (Diane).

"I think you notice the pain more when you are not doing other things, and also being tired means I am more likely to be sat in the same position for longer periods of time which can also cause pain" (Quinn).

Participants in the TA group were more likely to link their fatigue to lack of sleep than those in the IPA group. For example, Luke stated:

“It is exhausting to deal with pain on an ongoing basis, and of course, every time you move while you sleep, the pain wakes you up” (Luke).

Fog- “confused and kind of dazed”

IPA

Cognitive dysfunction or "fibro fog" was another common symptom, and added another layer of confusion and separation from the world. It made social interaction more difficult for the participants and in some cases also caused them actual physical danger. Described by Diane as being like *“there is a huge wad of cotton in my brain”*, levels of fog seemed to vary more than levels of pain and fatigue across participants. While Beth simply reported having *“days where it is more difficult for me to focus”* (but she was reluctant to call this fibro fog) Ann reported that *“I get confused and kind of dazed, not really knowing what is going on”*. For Helen the fog seemed to be a source of social embarrassment, making it even more difficult to talk to people: *“Quite often my words come out all jumbled up or I can stutter or I just can’t get the words out”*. Diane described the ways the fog had made her life harder:

“I can be extremely forgetful, lose track of my train of thought, forget conversations, events. I have booked myself on wrong flights, gotten into a minor car accident, slurred my speech because my thought process is so slow at times”.

Though pain, fatigue and fog are the main symptoms of fibromyalgia, they do not tell the whole story of the participants' relationships with the disorder. The participants built up a picture of fibromyalgia as an illness with a familiar, but shifting and thus unsettling, pattern. The many different symptoms, including sleep problems, flares, comorbidities and various others, interacted to produce a constant unavoidable experience.

TA and IPA comparison

The participants in the two groups described fibro fog and its effects in similar ways, with both groups highlighting the problems fog causes in everyday activities such as driving, and the difficulties it leads to in social interaction:

"I can be extremely forgetful, lose track of my train of thought, forget conversations, events. I have booked myself on wrong flights, gotten into a minor car accident, slurred my speech because my thought process is so slow at times" (Diane).

"I don't drive, because I get lost or forget the difference between red and green lights" (Quinn).

Participants in the TA group appeared to experience more distress because of their fibro fog, with one participant stating that she missed her mind more than anything else she had lost because of fibromyalgia. One issue that was only raised by the TA group was the way fog can affect different types of cognition, for example, disrupting writing skills one day and organisational skills the next:

“Mine cycles. For a few weeks, I may be able to organize a closet but not balance a checkbook or read books with chapters. A few weeks later, my organizational skills may be lost completely; but my reading and writing skills will return” (Paula).

Flares- hypersensitive and “flu-like”

IPA

A flare was described by participants as being a sudden increase in symptoms, usually to the point where everyday tasks became impossible. Fiona said *“With my normal pain I can continue with normal life but when I get a bad flare op [up] it is impossible to do so”* and according to Ann:

“The flares usually leave me unable to move because of the intense pain. My normal degree in pain is a lot lesser and I can function with it. The pain does increase; I become hypersensitive to everything touching my body.”

The flare experience was different with regard to the types of symptoms affected. For some participants, flares meant increased or altered pain (*“The flares are more sharp and distinct in location”* – Diane), but for others it involved increased fatigue (*“I have flare-ups with the fatigue and flu-like symptoms”* – Carol). Most said they were unable to predict these pains, leading to uncertainty and increased stress. According to Ellen:

“Flares are uncontrollable in the timing and frequency. No prediction on either parameter.”

This unpredictability was not the case for everyone, and some participants, such as Carol, were able to predict their flares:

“I can usually trace the flares back to over exertion. That’s the main cause of my flares. They rarely appear randomly.”

Though none of the participants directly addressed it, the knowledge that pain will flare multiple times a month *“when everything gets worst [worse] for weeks or months on end”* (Helen) implies flares place a considerable mental strain on participants.

TA and IPA comparison

Descriptions of flares were extremely similar across the two groups, though it has to be noted that all participants described slightly different experiences and symptoms when talking about flares, for example:

“The flares usually leave me unable to move because of the intense pain. My normal degree in pain is a lot lesser and I can function with it. The pain does increase; I become hypersensitive to everything touching my body” (Ann).

“I get tingling and burning when I get the flare ups. My bowel gets worse and bladder. All the body inflames even more in a flare up. I do suffer from Myofacial Pain most of the time on the left side and that makes me a bit deaf. Headaches too” (Sally).

Generally however, flares appeared to take the form of severely disabling pain that could not be reduced or brought under control, along with a wide range of additional symptoms.

Other symptoms- a “giant mess”

IPA

As well as basic fibromyalgia symptoms, participants also had to cope with a range of other medical problems, including those unexplained by the fibromyalgia and those caused by other diagnosed illnesses. There was a huge variation between participants in the number and severity of these symptoms, and the way participants understood their relationships to each other. Beth, who has many comorbid symptoms, said *“To me, all of my health issues lump together into a giant mess. I can't really differentiate between them, so it's hard to say how they interact.”* This view was echoed by Helen, who said that her symptoms *“are a part of my every day existence so are a part of what I have to cope with along with the FM.”*

The participants with much fewer comorbid disorders tended to say that any other symptoms just make them feel worse. For example, Diane, who just suffers from hayfever, said that *“the hay fever can exacerbate the brain fog and tiredness”*, while Ellen said of her asthma and arthritis *“astma [asthma] sparks stress nas [and] arthritis is more pain!”*

Gail, who had very few comorbid disorders other than being overweight, described how this changed the way her fibromyalgia is seen, and possibly made others take it less seriously:

“The weight doesn't really (affect or interact with the Fibromyalgia symptoms) but I feel I am judged as being in-active due to the weight rather than the Fibro pain and lack of energy.”

This highlights the indirect way that health related problems can cause extra inconvenience for the participants. When the participants' perception that they already are seen negatively by people outside of the community is taken into account, extra factors such as being visibly overweight may make something that is already damaging to the participants worse.

TA and IPA comparison

Both groups reported experiencing multiple additional symptoms on top of their pain, fatigue and fog, with some participants in both groups commenting that they experience so many symptoms it is difficult to correctly label them as part or not part of the fibromyalgia:

“To me, all of my health issues lump together into a giant mess. I can't really differentiate between them, so it's hard to say how they interact” (Beth).

“There is so much overlap it's hard to figure out what is what” (Naomi)

Both groups also discussed the interaction between their symptoms, and the way some symptoms make others worse or more difficult to cope with. There were some small differences in the number of symptoms experienced by participants in the two groups, in that there were a minority of participants in the IPA group who only experienced one or two co-morbid conditions, which did not appear to be the case in the TA group, who discussed multiple symptoms and conditions:

“lower back lumbar pain. (Prolapsed disc), Hiatus Hernia, knee weakness (lateral collateral Ligament.), irritable bowel and nerve damage in finger and irritable bladder”
(Sally)

There is a lot of uncertainty surrounding the causes and treatment of fibromyalgia. This was reflected in the way that participants approach medication and diagnosis, and their beliefs about the causes and triggers of the illness. Participants described how they realised they were ill and how this led to a diagnosis, before turning to how they cope with their symptoms and their beliefs about what caused them.

Course- “gradual”

IPA

Participants tended to report symptoms starting slowly, sometimes one at a time. For example, when asked whether her fog started at the same time as her pain, Diane responded: *“It came afterward...about three years ago. Maybe earlier, I don’t know”*. For Ellen, it was her pain that came in stages:

“Some symptoms gradually developed eg shoulder pain. Others such as arm pain and overall leg aches became very much worse with a bout of stress coinciding with issues when I worked”.

Participants also said that their symptoms started at different stages of their lives. Regarding this topic, the split between the internet and real-world groups was most obvious. The mean age difference between the two groups meant that the majority of the real world

participants had been experiencing symptoms for many years, whereas many of the internet participants started more recently. This highlighted that, rather than being an old or middle aged person's disease, fibromyalgia seems to have been affecting these people for a lot of their lives, though many were not diagnosed until much later. Ellen, the oldest participant at over fifty, stated that she had been experiencing symptoms for over fifteen years. Diane said that the way people with fibromyalgia are portrayed on television is:

“kind of embarrassing as they are all of these older women, when I'm not even 30 yet. It's kind of misrepresentative since I am young, look healthy, can work full time and do not have any other conditions”.

TA and IPA comparison

In both groups the majority of participants reported the course of their pain as starting gradually and spreading to different areas of their body.

“Some symptoms gradually developed eg shoulder pain. Others such as arm pain and overall leg aches became very much worse with a bout of stress coinciding with issues when I worked” (Ellen).

“I would get random aches or pains that didn't SEEM related to any physical activity I'd done. Also, every once in a while, I would just get a random sharp, stabbing pain in a random location that would last a few seconds and be gone. Initially, I chalked it up to the aches and pains associated with getting older. There were so few that the randomness of it didn't bother me” (Luke).

The majority of participants also described their pain starting in adulthood, though they generally reported experiencing pain for a number of years. There was a small minority of participants in both groups who described their pain as starting in early childhood and being dismissed as “growing pains”:

“When I was a child my pains were dismissed as ‘growing pains’” (Helen).

“I remember waking up in the middle of the night when I was about 7 with terrible pains in my legs and arms. The doctors always said it was 'growing pains' and dismissed it. I would lose a few hours of sleep at least a few nights a week until I was about 9” (Mary)

Participants in both groups were split as to whether their pain had stabilised or whether it was getting worse.

Diagnosis- a mixed blessing

IPA

Though all participants said that they looked for a diagnosis and that there were at least some benefits to getting one, a lot of the participants also reported having problems coping with the impact of the diagnosis, and its true meaning. Ann, who was diagnosed at sixteen said:

“Once I read about the condition, I realized that I couldn’t really ever be fully better again. Knowing what was wrong made it easier to deal with, since I had a definite answer, however emotionally, it was a lot harder”.

The long term impact of dealing with the diagnosis was also brought up by Fiona who, when asked what could be done to improve the process of diagnosis and the information given to the recently diagnosed, responded:

“I think there should be a more structured system for people who are diagnosed. I also think there needs to be a counselling option as I would not accept I had got Fybros and even now I try to look for other answers.”

Despite these negative consequences, receiving a diagnosis seemed to have a positive impact on other aspects of the participants' mental health. One of the most commonly reported positives of the diagnosis was that it reassured participants that they were not “going mad”. When asked whether the diagnosis was a good thing overall Ellen said:

“Overall absolutely a name to embrace the symptoms and some specialist who knew what I had been suffering I was relieved I was not mad!”

This sentiment was echoed by Gail and Carol:

“This (the diagnosis) was a relief in one way ‘THAT I WASN'T GOING MAD’ but sad because how my life was going to change permanently.” (Gail)

“I wasn't crazy or making things up. I had a real disease.” (Carol)

This suggests that after years of suffering unexplained symptoms people sometimes started to doubt their sanity. In addition participants described how having a label made it easier to find out about the disorder, or to explain it to others. For Helen this meant she was able to gain some understanding from others: *“Once I got a diagnosis and support from*

Occupational Health, the management accepted I had a problem". Fiona was able to more accurately describe her condition: "It was also good to be able to explain to friends and family what was wrong and that it was not all in my head".

Having a label for the condition was not always a positive thing for participants. Helen described another experience that highlighted the problems having a label can cause. She wrote about an interaction with her doctors:

"There are no best (experiences with doctors) apart from reaching the stage of actually getting a diagnosis, but then when I complained to my GPs about the lack of support from them over many years, that they asked me to find another doctor (if I didn't they would take me off their list anyway). So that ended up being another 'worst'."

She also said that she felt her previous irritable bowel syndrome (IBS) diagnosis impacted the way she was treated by doctors:

"I feel that being diagnosed with IBS didn't help as each doctor or specialist I saw after this time seemed to think that I was just suffering from stress. Ironically the only stress I had was being caused by medical professional attitude towards me."

The current status of the research on fibromyalgia, and the controversies over what causes it and how it is best treated meant that none of the participants talked about experiencing an improvement in pain symptoms from the diagnosis. This led to participants trying to work out what was best for them in terms of managing their symptoms.

TA and IPA comparison

Participants in the TA group appeared to be more positive about their diagnoses than some participants in the IPA group. Participants in the TA group very rarely reported any issues with diagnosis, apart from the time and struggle it took to get one, whereas participants in the IPA group reported struggling to come to terms with the label, and the negative consequences of being labelled as a fibromyalgia sufferer in medical notes:

“Once I read about the condition, I realized that I couldn’t really ever be fully better again. Knowing what was wrong made it easier to deal with, since I had a definite answer, however emotionally, it was a lot harder” (Ann).

Despite these differences, the positives reported by participants in both groups were very similar. Many participants were reassured by the label that meant they had a “real disease”, and were relieved to be able to give an official disease label to their friends, family and employers:

“I wasn’t crazy or making things up. I had a real disease” Carol.

“Just *knowing* there was an actual name for this thing, that other people had it, that I could tell people I had an illness instead of being looked at as just lazy, that there were things I could actively do to improve my health, and that I could go to a doctor or other health care provider and say "I have this" and at least most of the time they'd take me seriously and know it was real"- Rebecca

Causes- complex and multiple

IPA

Only two of the sample (Beth and Diane) indicated that they had no idea what caused their fibromyalgia; all of the other participants suggested one or more theories. Ann seemed to have more of a definite idea than the other participants:

“I had a knee problem that I had an arthroscopy on, but I can’t remember the name of it for the life of me. It’s where the kneecap rubs against the femur and creates friction. However, after I had surgery and fully recovered, I was unable to walk again..... I had an aerthoscopy on my left knee 4 years ago. 6 months after the recovery the fibromyalgia came about. Also, I have heard theories of radiation exposure being the cause; my great-grandfather was near an atomic bomb testing site and was exposed to a lot of radiation”.

Fiona could also point to specific life events:

“I feel it could be one or even all of the following. 1) A fall that sheered the end of my spine. 2) I thought I had developed breast cancer and reacted very badly. 3) I had a very bad bout of food poisoning on a foreign holiday..... The fall was around three years before and I had been to the Dr with pain in my Pelvis around twice a year which he was sure was caused by the fall and then when I did certain activities it would cause it to flare up. Then one day the pain came and never went away again. The breast scare and the food poisoning were almost together and they were two months before the pain came to stay.”

The other participants were less specific. A popular answer involved chemical or hormone imbalances:

“From my own personal research, I believe fibro patients compute pain differently from non-sufferers. I think a chemical imbalance in the brain may have more to do with the onset of fibro than my loose joints” – Carol

“I think genetics plays a part in it. I think it is a neuropathic condition, with chemical and/or hormone imbalances” – Helen

Other participants mentioned stress, trauma, genetics and a fibromyalgia personality *“work a holic is common busy female trying to do too much over a long period of time seems to be the case in a number I know so is psrt of the theory”* (Ellen).

TA and IPA comparison

Both groups contained similar proportions of people who either did not know what caused their fibromyalgia, had very definite ideas about what caused their fibromyalgia and, most commonly, had a number of possible theories about causes. Though a minority of participants in each group could point to a specific triggering event, the majority of participants in both groups suggested their fibromyalgia was due to a combination of physical and mental traumas that took place in the months or years before their diagnosis:

“I had a knee problem that I had an arthroscopy on, but I can’t remember the name of it for the life of me... 6 months after the recovery the fibromyalgia came about. Also, I

have heard theories of radiation exposure being the cause; my great-grandfather was near an atomic bomb testing site and was exposed to a lot of radiation” (Ann).

“Over a period of stress over a few years. I had 3 operations and 3 IVF. There was family conflict with this. Then went through the adoption process, had a car crash, a flu virus and Gastro-enteritis. So I can only guess. I think the Flu virus and stomach bug could have been the reason as it was soon after these illnesses” (Sally).

These varied theories reflect the wider uncertainty and controversy regarding the causes of fibromyalgia.

Triggers- complex and multiple

IPA

All of the uncertainty and the constant threat of disabling flares meant that the participants had one or more “triggers” or things to avoid if they did not want to make their symptoms worse. Helen described a lifelong process of cataloguing changing triggers:

“I identified some triggers which I have avoided for years, such as caffeine, alcohol, foods with additive; since I was younger I couldn’t even drink tea or orange squash. The orange squash gave me stomach ache, I think adults just thought I was being fussy, because it always gave me stomach ache I never really told anyone I was one of eight children and individual needs weren’t catered for. You ate or drank what you were given or went without. Even now I develop sensitivities to foods I eat too often so have to vary my diet (as much as I can within limits). Salads and raw foods are my favourite

but I can't eat them too often therefore have to take a break from eating them which is the case at the moment.

"Chemicals are a trigger and people wearing perfumes, people spray air freshener and fly spray in public spaces are a real problem.

"The weather especially the cold, damp and even humid hot weather are triggers.

"Physical exertion is certainly a trigger, and repetitive muscle use is also a trigger, if I use my right arm too much it becomes too painful and weak to use, therefore I lose the use of it for a while."

Others could reduce their triggers to a short sentence: "*Activity definitely with me*"

(Gail). Most participants suggested that stress, either physical or mental made them worse. Ann described an antagonistic relationship with her body:

"My body doesn't let stress out any other way, other than getting sick. I have a tendency to push myself way more than I should, and my body tries to get back at me, I think"

Weather was a particularly common trigger:

"Cold and rainy weather is the worst, or any humid weather" (Ann)

"I hurt worse in cold, damp weather" (Carol)

"I have not figured out the foods, cold weather and humidity will trigger flares as well as stress" (Diane)

"Any strenuous activity or cold weather makes my fibro worse" (Fiona)

“The weather especially the cold, damp and even humid hot weather are triggers”

(Helen)

When asked why she thought this was the case, Carol said:

“I think it’s simple physics. My muscles, like most things, seem to constrict when cold.

But in the heat, my muscles loosen and relax”.

Some participants understood triggers which at first seem to have a major psychological component as working in a physical way. For example, when explaining why mental stress has a negative impact on her pain levels Beth said *“Mental stress makes me ache a little more, but only because I tend to tense up my muscles”*. Interestingly, Beth reported that not only too much activity caused her to flare, but also insufficient activity: *“Too much strenuous activity or too little activity (causes a flare)”* suggesting she had a narrow band of activity she had to achieve each day. This highlights the lack of consistency among the triggers reported by participants. Things that are perceived to be extremely harmful to one person may not be seen that way by another.

TA and IPA comparison

Participants in both groups listed a wide range of triggers that they believed made their pain worse. Weather was an extremely common trigger in both groups, with unpleasant weather thought to cause flares:

“The weather especially the cold, damp and even humid hot weather are triggers”

(Helen)

“Rain is like swimming – I can’t regulate my temperature in water. Wind chill makes me ache, from cold pain and exerting myself against the force” (Imogen)

Participants in the TA group appeared to list over- and under- activity more often than participants in the IPA group, who appeared to be more concerned about stress:

“Over activity is a killer – under activity doesn’t do you favours either. I must stretch and move to some extent every day” (Naomi)

Participants in both groups appeared to be very sensitive to any changes in the triggering factors in the environment, with small alterations enough to cause significant pain:

“Chemicals are a trigger and people wearing perfumes, people spray air freshener and fly spray in public spaces are a real problem” (Helen)

“If I attempt to do the same exercise as normal in water that’s 0.5°C lower, I will flare because my body is more active in keeping me warm” (Imogen).

Strict routines for coping

IPA

To cope with these triggers, participants used a wide range of different coping mechanisms. Some participants primarily focused on their bodies (for example, Beth: “*I swear by regular exercise to keep my overall pain levels under control*”), some on their minds (for example, Ellen: “*Cognitive techniques + prayer*”). The level of time and energy put into the

coping mechanisms also changed between participants. Ann described a daily routine of both physical and mental techniques:

“I meditate for about 15 minutes in the morning, unless I woke up late. I walk everywhere on campus (so probably for a good hour a day) since I go to a small school, and I stretch for probably 20 minutes a day” (Ann)

Beth also had a strict routine:

“I work out at the gym 4-5 days a week now. It took me a while to work up to being able to do that much, but it is most definitely worth it” (Beth)

This is a routine that requires a high level of dedication and commitment, done on top of full time work or study. In contrast, when asked what she did to help her pain (excluding medication) Helen said *“At times I have taken a warm bath to help.”* This shows the totally different lifestyles each participant described, and how what worked for one person did not necessarily help another. What worked for some people could actually make another participant’s pain worse. Diane used massage to reduce her flares: *“Depending on the quality of the massage it (the pain relief) may last from a few hours to a week”* but for Carol *“Massage, for me at least, is a bad thing. I’ve had three, and couldn’t move the day after.”*

TA and IPA comparison

Participants in both groups described strict and sometimes complex coping routines, including mental activity, physical activity or a combination of both:

“I meditate for about 15 minutes in the morning, unless I woke up late. I walk everywhere on campus (so probably for a good hour a day) since I go to a small school, and I stretch for probably 20 minutes a day” (Ann)

“If I do very gentle walking and swimming it does energise me for a while. Stretching helps. Generally things that energise me are more mental than physical. That said if I don’t do at least some activity on a regular basis, my energy decreases” (Naomi)

One difference between the two groups was in the way they discussed their limitations. Participants in the TA group spoke more about the need to carefully plan activities in advance, whereas participants in the IPA spoke more simply about being careful not to overdo things physically:

“I try to conserve my energy appropriately – if I know I have an event to go to, I’ll take it easy on chores etc. I also use painkillers for events that I know will be tiring so that I have the pain control” (Naomi)

Mixed attitudes to medication

IPA

In contrast to these dramatic changes in lifestyle participants were reluctant to treat their symptoms with large amounts of medication. Participants usually seemed to see it as something to be taken when absolutely necessary and not more. When asked about the best medicine for her, Ann said:

“Honestly? There is no best medication. I take pain pills when I need them to function, a muscle relaxant if I need it. I get hit with side effects and it doesn’t take enough of the pain away. As for worst medications, it’s pretty much whatever side effects get me.”

This view was echoed by Beth:

“Best: none. I don't take any medications for my fibro other than an occasional ibuprofen (liquigels – the regular stuff doesn't really help) when I'm having a really bad day. I am doing far better without any prescription medications than I ever did when I was on them.”

Diane took no medication and instead treated her pain with herbal pills:

“I have tried a few (types of medicine) but am EXTREMELY drug sensitive. I am now on herbal (ayurvedic) medications.”

Fiona took some medication, but tried to take as little as possible because of a fear of addiction:

“I take Thyroxine because I would die without it and I take my other drugs when I cannot cope any longer. I have seen people addicted to drugs and that scares me more than my pain.”

Gail stuck to only two types of medication after she tried others and suffered from the side effects:

“Both (medications) were very effective to start with but I developed migraines on a regular basis. Since I have stopped taking them approx 6 weeks ago I have not had a headache so frequently.”

Despite the reservations of the other participants, the final two participants, Carol and Helen did seem happy to take their medication, and seemed to benefit from it. Carol mentioned two, one that *“allows my muscles to relax enough for me to sleep at night”* and one that *“gives me an extra energy boost.”* Helen said that she had tried many different medications over the years, and currently took four different types of medication for her pain and bladder frequency, then *“other medications for different symptoms.”* Generally however a fear of side effects, addiction and a perception that drugs are damaging or that they don’t work seemed to prevent participants from taking medication when they felt they could do without.

TA and IPA comparison

Both groups reported very mixed attitudes towards medication, with a minority of participants in both groups reporting that they only took over-the counter painkillers:

“Best: none. I don't take any medications for my fibro other than an occasional ibuprofen (liquigels – the regular stuff doesn't really help) when I'm having a really bad day. I am doing far better without any prescription medications than I ever did when I was on them” (Beth).

“I only take Ibuprofen or Aleve on those days, but it always only dulls it” (Mary).

Participants in both groups also reported similar fears of side effects and addiction, though these negatives were weighed against the potential reductions in pain:

“I have seen people addicted to drugs and that scares me more than my pain” (Fiona)

“I am fearful of addiction. I don’t like the way they make me feel on a day in day out basis (a little sleepy and less ‘with it’ – I don’t take enough to get the ‘high’ feeling)”

(Naomi)

Participants in the TA group appeared to be slightly more pessimistic about their medication’s ability to control their pain, reporting that at best their pain was reduced to “tolerable” levels:

“even on a good day, I take pretty heavy pain medication and still feel significant amounts of pain” (Rebecca)

Only one theme emerged in the TA analysis:

Personality and Lifestyle before Fibromyalgia- TA and IPA comparison

A number of participants in the TA group described having a busy lifestyle before they were affected by fibromyalgia, and blamed this on having a type A personality:

“I have the so-called type- A personality. That is, I tend to push myself to do whatever I need or have to do but then I crash after” (Olivia)

Though this theme did not come through as clearly in the IPA group, multiple participants either described themselves as having a type A personality, or being very busy or driven before they were diagnosed. For example, Ann described her weekly routine:

“This term at school I’m running an average of 60 hour weeks (I’m slowly killing myself because of school, I swear!) and I’m expected to take a second job” (Ann)

Though in the majority of cases these beliefs about personality appeared to come from introspection or observation of personal behaviour, participants in both groups described how they had also seen this trait in other people with fibromyalgia, and through these observations had come to believe it was a trait common to the majority of people with the illness:

“Work a holic is common busy female trying to do too much over a long period of time (Ellen)

“Everyone in the support group is a perfectionist and a workaholic” (Imogen)

8.3 Discussion

The aim of this study was to investigate participants’ embodied experience of fibromyalgia to understand the ways in which participants interpreted their experiences. Several main themes were found: pervasive pain, “killer” fatigue, “confused and kind of dazed” fog, hypersensitivity and flu-like flares, a “giant mess” of other symptoms, gradual course, the mixed blessing of diagnosis, complex and multiple causes, complex and multiple triggers, strict routines for coping, mixed attitudes to medication and lifestyle and personality before fibromyalgia. When looking at all of these topics together and examining them more broadly it

is possible to identify two overarching threads running through the data. The first of these is that there is not one overall symptom, certainly not the pain, which drives the unpleasantness of the experience of fibromyalgia. Both physical and mental symptoms seemed to interact within the participants to make the situation and its impact particularly unpleasant, with physical and mental symptoms affecting the participants in different ways. Second is that participants describe spending considerable time and energy trying to manage symptoms that they cannot control.

The first of these themes, that it is the cumulative effect of multiple symptoms interacting that makes the experience of fibromyalgia so unpleasant, is encapsulated in Diane's description of the effects of acupuncture. She found that acupuncture reduced her fatigue and brain fog enough that she had the energy to start the exercise that eventually reduced her pain. However, if she had not tried acupuncture, and so not realised the positive effects it had, she would not have been able to start exercising, and so her fatigue and fog would have indirectly prolonged her pain. When asked why she did not go to the doctor until a particularly bad flare, Diane replied: "denial, basically. Also, often times I was just too tired or forgetful to go to the doctor." Participants in other studies have described "overwhelming" tiredness, which interferes with their ability to carry out tasks (Humphrey, Arbuckle, Mease, Williams, Danneskiold Samsøe & Gilbert, 2010; Theadom & Cropley, 2010)

These findings suggest that the label of fibromyalgia as a pain syndrome obscures the effects of the equally distressing fog and fatigue symptoms. Though descriptions of fibromyalgia include the other symptoms (Wolfe et al, 1990; Wolfe et al, 2010) it is pain that characterises

fibromyalgia. Researchers have highlighted the need for greater recognition of the negative effects caused by fog in patients, as well as the need for effective treatment (Katz, Heard, Mills & Leavitt, 2004). However, this may not be the full story. A study investigating the true extent of cognitive difficulties in people with fibromyalgia suggested that, though they performed worse than controls on various cognitive measures, their perceived deficits were greater than those objectively shown by the test (Grace, Nielson, Hopkins & Berg, 1999). This suggests that people with fibromyalgia may in fact be overestimating the extent of their difficulties, and the difference between themselves and the normal population. This may reflect a similar tendency to that found in van Ittersum, van Wilgen, Hilberdink, Groothoff and van der Schans's (2009) study of symptom attributions in people with fibromyalgia, which showed patients blaming things on fibromyalgia that they would have experienced anyway.

The other main theme in the data is that the participants seem to be continually struggling to control and understand something that cannot be easily controlled or understood. This is reflected in the need and relief that comes from hunting and receiving a diagnosis, the reporting of multiple and varied triggers and the wide range of causes suggested by the participants. All of these highlight how much participants wanted to understand their experiences. However, the range of responses to each question suggests that there are possibly no real answers, at least no answers the participants can access from introspection and research. Many participants reported researching the causes of fibromyalgia, and some found theories that matched their own experiences. At the same time, many participants said they were only guessing the cause of the syndrome in their own case, or did not know at all. This

uncertainty and lack of consensus seemed to make fibromyalgia even more distressing for the participants.

These findings highlight the impact being diagnosed with a syndrome for which there is no known cause or cure. As was found by Undeland & Malterud (2007), being diagnosed with fibromyalgia did not appear to bring the participants any certainty or piece of mind. Instead participants attempted to create a sense of control over their symptoms by cutting out foods or activities they thought might harm them. It has previously been shown that patients restrict their activities and stick closely to routines in an attempt to control their pain (Schaefer, 1995; Gaston-Johansson et al, 1990), something that was also found here. Things like diet and exercise also took on greater importance as many of the participants expressed a reluctance to take medicine, as fears of side effects or addiction outweighed the benefits they thought they were likely to receive.

In addition to fog, fatigue and pain, participants in this study reported a wide range of other symptoms, as is typical for fibromyalgia patients (Clauw, 1995). The wide range of symptoms reported by participants, and the uncertainty of whether they were connected to fibromyalgia or not also seemed to be a source of distress. In the absence of a known cause of fibromyalgia, participants could never be sure whether each new symptom was related to their illness, and so could never be sure just how bad their fibromyalgia had become. Participants were also split as to whether their symptoms had stabilised or were getting worse. This again highlights the lack of reassurance provided by the diagnosis.

8.4 Conclusion

Several main themes were identified and these were described in terms of two overarching themes. First, the participants, particularly those who were young or active, were keen to point out that the cognitive problems caused by fibromyalgia are just as distressing as the pain, but are less easy to obtain any relief from. Second, the participants appeared to be continually struggling to understand and control their syndrome, though their levels of success were highly variable.

8.5 Thesis objectives and future directions

In this chapter the way people with fibromyalgia interpreted their embodied experiences was investigated. In the next chapter data regarding participants' personal relationships will be presented. The same participants were asked questions about the way fibromyalgia had impacted upon their social interactions with family members, friends, colleagues and doctors. The two halves will then be drawn together, to examine whether overarching themes can be found in both sets of data.

Chapter Nine

Examining the interpersonal relationships of
people with fibromyalgia

9.1 Introduction

Fibromyalgia has been shown to have a dramatic impact on the way people interact with those around them. Here four main sources of social interaction are examined: family and friends, doctors, colleagues and fibromyalgia support groups.

Multiple studies have suggested that family relationships are put under strain when one member has fibromyalgia (e.g. see Cudney, Butler, Weinert & Sullivan, 2002; Henriksson, 1995) and Wolfe, Ross, Anderson & Russell (1995) found preliminary evidence suggesting that people with fibromyalgia have a divorce rate more than four times higher than that of the general population. One reason for this may be conflict caused by the lack of certainty provided by the fibromyalgia label, with one study finding that husbands of fibromyalgia patients report a lack of knowledge about the syndrome (Soderberg, Strand, Haapala & Lundman, 2003). Both patients and carers have also described feelings of isolation, as the experience disrupted their ability to relate to each other (Rodham, Rance & Blake, 2010). However it is important to note that while some relationships are placed under strain by fibromyalgia, Kelley and Clifford's (1997) qualitative study suggested that those patients who are able to maintain their relationships are able to use their families and social circle as an effective means of coping with their disorder; being around family and friends provides an alternative identity and label to that of patient, such as mother, father or partner.

Some studies have looked at the relationships between people with fibromyalgia and the medical profession, suggesting that people with fibromyalgia feel their illness is not taken seriously (Cunningham & Jillings, 2006), or that they are thought of as malingerers (Paulson,

Norberg & Danielson, 2002). Importantly this view appears to apply to doctors as a profession rather than doctors as individuals and a study by Egeli, Crooks, Matheson, Ursa and Marchant (2008) found that 83.3% of their fibromyalgia sample reported at least some positive interactions with their own doctors. Similarly, Kelley and Clifford (1997) suggested that some people felt that their doctors understood them better than their friends and family. This is the same study which found that some patients made very effective use of their friends and family, as a supportive resource – which gives a clear indication of the complexity and variability of fibromyalgia patients' relationships and beliefs.

Previous research has found that people also face problems with unsympathetic colleagues who hold negative beliefs about fibromyalgia and the nature of their illness (for example Barker, 2005; Henriksson, 1995). Other investigations have described the experiences of participants who were forced to give up work after their diagnosis (Henriksson, 1995; Liedberg & Henriksson, 2002). As it has been shown that women who work describe having to cope with pain and fatigue, aging, as well as their family situation, it seems unsurprising that some people have to give up (Sallinen, Kukkurainen, Peltokallio & Mikkelsen, 2010). However, not everyone with fibromyalgia is forced into this position. A study by Lofgren, Ekholm and Ohman (2006) asked working women with fibromyalgia (according to one study, 47.7% of people with fibromyalgia work (Reisine, Fifield, Walsh & Dauser, 2004)) about their experiences coping with work and fibromyalgia. They suggested that the women's approach was "action-orientated with a positive spirit."

The label of fibromyalgia allows sufferers easier access to support groups, and many people with fibromyalgia use these to help in coping (Raymond & Brown, 2000). van Uden-Kraan et al (2008) reported that participants interviewed about their use of support groups found them empowering, because they felt they were: “better informed, more confident in the relationship with their physician, their treatment and their social environment, had a better acceptance of the disease, increased optimism and control, enhanced self esteem and social well-being and they had the benefit of collective action”.

Although previous researchers have looked at some aspects of the impact of the fibromyalgia label on interpersonal relationships, relatively little is known about the interaction between them, or about the similarities and differences between relationships across different domains. Most previous qualitative studies in this area have involved interviews, which through necessity tend to focus on a small number of topics. Again it was hoped that interviewing via email would overcome these problems.

9.2 Results

Participants were asked about four sources of social interaction: doctors, family and friends, colleagues and support groups. In every case the IPA findings are presented first, followed by a comparison of the IPA and TA findings. Full TA findings can be found in appendix six.

Doctors – ‘Its impossible to know who you will get’

IPA

As people who can offer or withhold diagnosis and medication, doctors played a large role in the lives of participants, particularly at the beginning of treatment. The uncertainty over the causes, and about the best way to treat fibromyalgia, was perceived as lack of knowledge on the part of doctors, and led participants to feel disillusioned with the medical system. For example, in response to a question asking how she has been treated by doctors, Beth wrote:

“From my experiences so far, primary doctors don't seem to know too much about the condition. My first primary doctor was the one who sent me to the rheumatologist for treatment. I recently had to switch doctors because mine retired, and my new one seems pretty clueless. He made some copies of some information that a rheumatologist gave him to help him be able to treat fibromyalgia on his own, but that seemed to be the extent of his knowledge.”

“I feel like they all want to push medications on me. Now that I have chosen not to go on medications, my rheumatologist seems to not know what to do with me. He makes me come in every 8 weeks, checks me out, asks me if I need anything and sends me on my way, applauding me for keeping up my physical activity. I feel like it's becoming quite the waste of money, so I'm probably going to cut those appointments back a bit.”

Beth's perception that many doctors – GPs and specialists – were 'clueless' about fibromyalgia was common across the accounts. This did not always mean that the doctors were disliked. Participants gave the impression that information was not everything and that if the doctor was supportive and tried their best to help their lack of knowledge could be forgiven.

Individual doctors were not usually disliked, particularly if they had given the impression that they had listened to the patient, and cared about understanding what was going on. Fiona said:

“Both [my GP and rheumatologist] were very kind and gave me basic information. My GP sees me every three months and although this is for repeat prescriptions I suspect he knows this gives me the chance to keep him updated on the highs and lows I am feeling..... I think my doctors were good and could not offer anything more than advice”.

In general, participants didn't seem to have any expectations about being cured by their doctor. Some participants even felt that it was their responsibility to research the condition on behalf of their doctor, highlighting their low expectations but also showing that they felt able to develop an interactive, two-way relationship with their doctor. Beth said:

“I do think it's important [to keep up with the research], particularly because most doctors don't know too much about the condition. So in a way, I get to educate my doctors.”

This sentiment was repeated by Carol:

“My doctor sees patients with all sorts of medical conditions. It is my responsibility to keep up with the latest research and drugs, and to make him aware of them.”

In general, conflict only seemed to arise between the participants and their doctors if they felt that the doctor seemed disinterested or rude. Helen described a particularly upsetting encounter with a neurologist:

“When I walked in he was reading my notes and looked up without me saying anything and told me he was not interested in finding out the cause of my problem, just to see if he thought I should have another anaesthetic or not in the future. I just spent the whole consultant [consultation] crying and he was not at all sympathetic.”

Generally the relationships between the participants and their doctors seemed unfulfilling. If participants did not actively dislike their doctor, or could name examples of times where the doctor had been actively rude, they were generally unsatisfied, lacking faith in the doctor’s knowledge of the condition or ability to cure it.

TA and IPA comparison

Participants in both groups generally reported getting on well with their own doctor, though they appeared to have no expectations that they could be cured:

“I think my doctors were good and could not offer anything more than advice” (Fiona).

“My current doctor has done a lot of reassurance this way with me, even though I baffle him with my varied issues at times. He’s awesome, supportive and addresses my issues promptly without going overboard” (Naomi).

Doctors were generally well liked if they gave the impression of sincerely trying to help. Conflicts tended to arise between doctors and patients if the participant felt their doctor had been rude, or had not listened to their complaints properly:

“When I walked in he was reading my notes and looked up without me saying anything and told me he was not interested in finding out the cause of my problem, just to see if

he thought I should have another anaesthetic or not in the future. I just spent the whole consultant [consultation] crying and he was not at all sympathetic” (Helen).

“My previous family doctor (GP or PCP) was very dismissive and would tell me to take vitamin B when I complained of memory issues and fatigue. He dismissed my long periods and cramps as ‘normal’ for years, just putting me on the pill for years to shut me up” (Naomi).

Doctors who were disliked or were perceived to be unhelpful were often replaced, with many participants reporting that they had seen multiple doctors:

“I’ve had doctors tell me “you shouldn’t have to live in pain, let’s see what we can do to fix it” and doctors that have told me “you’re always going to be in pain so you have to just suck it up and live with it.” I’ve had doctors believe me 100% and test me thoroughly for everything they could think of and try everything they knew of to help and then sent me to specialists when they exhausted what they knew to do. I’ve also had doctors who caused me to cry by berating me and accusing me of exaggerating my symptoms or making things up. I’ve had doctors promise to stay on my case until they figured out what could help me and then give up on me in under three sessions. I’ve had doctors who were clearly frustrated by their inability to do anything or find anything and so they’ve turned me away despite realizing that I was, in fact, in need of their continuing help. I’ve had doctors who looked at me and my mom (who usually goes with me as an advocate to appointments) as if we were crazy – me a hypochondriac and my mom with munchausen syndrome by proxy or something. I’ve literally had doctors lie to

me and make up a diagnosis that doesn't exist just to get me to go away. I've had doctors tell me it's all "stress" and I should just talk to my therapist about it" (Rebecca)

Though seeing multiple doctors had lead to a great deal of stress and disappointment for some participants, their willingness to regularly change their doctor meant that the majority of participants were seeing someone that they liked at the time of their participation in the study.

Family and Friends- How much do they understand?

IPA

Participants were also split as to whether they could expect anyone who does not have the condition to understand what it is like. While Gail said that her family *"do (understand) because as they have pointed out they witness it first hand, and have seen the deterioration and change in me as a person. They empathise with what my body has to deal with on a daily basis"* some participants seemed to believe that their friends do not really appreciate what it is like, though some of them tried hard.

"They do their best to understand, however, they expect a lot of me, regardless" (Ann)

"It (being a member of a support group) was wonderful talking with other young people who understood what I was going through. We, those with fibro, are the only ones who can truly understand how depressing fibro can be" (Carol).

A lot of participants also tried to tell as few people as possible outside of their immediate family, some because they did not want sympathy and some because they had had

bad reactions in the past. When asked how she explained her condition to other people Carol said:

“I usually just tell people it’s a lot like rheumatoid arthritis. I told my former fiancée I had fibro, and his sister told him it was a “hypochondriac” disease. Since then, I rarely tell people I have fibro” (Carol)

Attitudes toward those who did not understand varied considerably between participants. One participant said that before her diagnosis she thought another colleague (who also had chronic pain) was mentally, rather than physically, ill and said that because of this she had more sympathy for those who did not understand it:

“I had a colleague who had Fybro before I knew anything about it and although I was not told what was wrong with her I always considered she had an emotional problem and never considered she was genuinely ill. I know lots of other people felt the same as I did. Because people have used back problems as an excuse to not work I think a lot of people are suspicious of people who have this strange illness that cannot be proven. I was guilty of not believing someone was really ill and I sometimes meet people who seem to want to have Fybro!!!! I can understand why some medical people do treat people badly” (Fiona).

In contrast, Helen said that her colleagues’ main response when she was able to use the disabled facilities at work showed that they had a:

“lack of understanding because I could park in blue bays and had special equipment bought for me. They saw the changes and adjustments made for me but could not see the reason or extent of how much the condition constantly affects me. To them I did not look like someone with a disability” (Helen).

TA and IPA comparison

Participants in the TA group appeared to be more positive about the support they had received from friends and family and more sympathetic to any negative reactions than participants in the IPA group:

“At first, when I first got a lot sicker/disabled by the illness, it was hard for a lot of them get it. I think it’s a difficult thing to accept that someone you love is that sick, in that much pain, and that their life is changing that much. No one wants to see that”
(Rebecca)

Participants in the IPA group reported more negative experiences and times when they had faced blunt disbelief than participants in the TA group, who, though they had lost some friends, did not appear to have experienced the same degree of conflict:

“I have been blessed with incredibly supportive family and friends. Those who don’t believe in fibro don’t stay my friends for long; it’s not worth it. Some people in my life took a bit longer to come around than others, but anybody who truly cares will at least try to understand and ask questions. I think for those who didn’t believe at first, the

proof came when I had so many losses due to the fibro that they figured out, no one would choose to live this way if given the choice” (Paula).

Work- Easily lost

IPA

Participants reported similar conflicts with regard to their work colleagues. A lot did not want to tell colleagues in case it put their job at risk. Other participants had bad experiences, some actually losing their jobs, because of their condition. In contrast others reported getting a sympathetic reaction and having their positions changed according to their limitations. These problems at work may explain in part why participants look so hard for a diagnosis, as Helen said *“once I got a diagnosis and support from Occupational Health, the management accepted I had a problem”*. Ellen, who didn’t have a diagnosis and was believed to be *“medically inefficient..... and occupational health assessor for employer thought [I] was not trying”* ended up losing her job. Diane, who had a diagnosis but placed an enormous value on being able to work, worked hard to keep her condition a secret and did not even give her boss the name of her condition:

“I waited over a year after diagnosis to even say anything to my boss or HR director. If it were up to me, I never would have let them know but several months ago, my job performance was seriously suffering and I felt it was absolutely necessary to let my boss know. When the question as to why I had not finished my Masters thesis yet came up a month later, my boss asked that I inform the HR director. I do not work as closely with any of my other coworkers than my boss, so I can hide that I have fibro pretty well. I’m

sure they notice that I'm gone at least once a week for dr. appts though...However, no one has asked about it and I don't plan on telling" (Diane).

In contrast Fiona's place of work changed her hours when it became necessary (*"I was very lucky that a part time position was made for me when I explained I could not continue to work full time"* - Fiona). Beth still worked full time but said she was treated sympathetically by her colleagues:

"My managers understand that I have a chronic health condition, and have worked things out with me so that I can make up the time for medical appointments. I don't get any additional time off than anyone else, but I have learned to cope with the condition well enough that I don't need it. I just have to make sure that I only take sick days when I'm severely ill".

There seems to be no one particular experience when it comes to the workplace and people with fibromyalgia.

TA and IPA comparison

A greater proportion of the IPA group were still able to maintain employment compared to the TA group. However, participants in the IPA group appeared to be more secretive, with a minority of participants reporting that they had kept their diagnosis hidden from their employers:

"I waited over a year after diagnosis to even say anything to my boss or HR director. If it were up to me, I never would have let them know but several months ago, my job

performance was seriously suffering and I felt it was absolutely necessary to let my boss know” (Diane).

Participants in the TA group did not report engaging in any secrecy. Apart from those participants who reported keeping their illness secret, the participants in the two groups who were able to stay in employment reported having extremely understanding colleagues who were willing to make allowances for their needs:

“I was very lucky that a part time position was made for me when I explained I could not continue to work full time” (Fiona).

“I work from home and on my own hours. If I want to mark at 2 am, I do. If I want to at 1 pm, I do. I just have to keep up, which I can. My boss bought me a laptop so that I can mark even laying down” (Naomi).

Groups- supportive, but a self esteem threat

IPA

Even though all participants were recruited through fibromyalgia groups, not everyone reported entirely positive experiences. Some found them a comfort and enjoyed the opportunity to talk to other people with the same symptoms or experiences, for example, Carol said:

“I loved belonging to my Fibromyalgia Support Group..... It was wonderful talking with other young people who understood what I was going through. We, those with fibro, are the only ones who can truly understand how depressing fibro can be”.

This sentiment was repeated by Gail:

“I find the support group very good. I gain ‘comfort’ (I wish in the physical sense) knowing everyone identifies with the symptoms and understands yours”.

Others, such as Beth, did not seem to get as much personally from the group, but believed it was a good way to help others:

“I don't tend to need to use it very often, but there are others who do and I like to try to support them as much as I can. Some people are less fortunate and have to live with people that just don't get it, so having other people to talk to can be helpful”.

Despite these positives, the groups did not receive universal praise from the participants. Diane said:

“In some ways yes (it does help to be a part of a group), but in many ways it depresses me when I read about all these other people who have it so much worse or are suffering with fibromyalgia and many other ailments that fibromyalgia is often comorbid with”.

Ann brought up a similar point, but in a slightly different way. For her the group represented a self esteem threat, particularly unfortunate as it seemed to stem partly from the positive of still being able to live an active life:

“A lot of times, it does help me. However, other times it makes me feel as though I'm just making it all up (I'm not – I meet the criteria for it) and don't have it as badly as others, therefore posting less. I think it does help a lot of people cope though”.

As with other topics discussed above, there appears to be no one way in which participants relate to their group. For some the groups were a much needed source of support, others a source of information, but for a few they served as a depressing reminder of what could have been or might be in the future. Again this underlines the differences between fibromyalgia sufferers, and the need to ensure that treatment and support comes in a form suitable for that individual person, particularly in the absence of an agreed treatment.

TA and IPA comparison

Participants in both groups described the importance of being able to talk with other people who have fibromyalgia, with many participants thinking other sufferers were the only ones who could truly understand:

“I loved belonging to my Fibromyalgia Support Group..... It was wonderful talking with other young people who understood what I was going through. We, those with fibro, are the only ones who can truly understand how depressing fibro can be” (Carol).

“If it wasn't for my fibro community [location removed], I wouldn't have anyone to talk to about it. No one in my real life *really* gets it, even though they try hard. It's important to be able to talk to someone who has been there and knows exactly where you're coming from”- Mary

Participants in both groups described some negative aspects of support groups. Participants from both the TA group and the IPA group described how the tendency for group

members to compare themselves with others could sometimes be unfortunate, as it could lead to negative feelings of inferiority or competition:

“A lot of times, it does help me. However, other times it makes me feel as though I’m just making it all up (I’m not – I meet the criteria for it) and don’t have it as badly as others, therefore posting less. I think it does help a lot of people cope though” (Ann).

“I think sometimes they become "bitch sessions" or unconscious competitions to see who has it worse” (Luke).

Participants in the TA group also described the negativity that could sometimes overwhelm the discussions and drag the mood of the group down, something that was not discussed by the IPA group:

“A peer support group is also hugely vital – it is good to have the comfort of others that know what you are feeling, but I think it’s important for them to have some purpose and leading so that they don’t always focus on the negative – like have everyone drag everyone down. Venting is good and healthy – but you need a balance. Taking action rather than staying in the victim role etc” (Naomi).

9.3 Discussion

Participants’ perceptions of their relationships with family and friends, doctors, colleagues and support groups were investigated to determine the effects of the fibromyalgia diagnosis on their interactions. The main theme running through these four areas appeared to be the lack of a single “fibromyalgia experience”, with positive and negative interactions

depending on the individual and the other people's perceptions of both them and fibromyalgia. In all four domains the participants reported both positive and negative experiences, some important and life-changing and some on a smaller scale. Participants who reported one negative experience tended to report them in multiple domains, possibly suggesting individual differences in interpretations and expectations, though some reported experiences appeared to be unambiguously negative.

There was an undercurrent of defensiveness running through all of the four domains for a lot of participants. Some of the participants reported being reluctant to disclose details of their illness to anyone they didn't have to tell, either because of previous actual negative reactions or fear of potential negative consequences. As women with fibromyalgia report experiencing stigma both before and after diagnosis (Asbring & Narvanen, 2002), it is likely that those participants who feared possible negative consequences were aware of other people's negative experiences. This defensiveness was also reflected in participants' interactions with doctors. Though the majority did not report actual hostility towards their own doctors, many of the participants reported hearing bad things from other people. As doctors, and the best way to interact with doctors, are discussed in support groups (van Uden-Kraan et al, 2008), it is likely that this is where participants heard about these negative experiences.

Most surprising of all was the defensiveness some participants displayed towards the support groups themselves, for example Ann who said "*other times it makes me feel as though I'm just making it all up*". This feeling seemed to be particularly true of people who felt like their fibromyalgia was less severe, or those who were still able to maintain work or study.

Participants appeared to feel like their illness was measured against that of others, even when they were in a group of fibromyalgia sufferers. Previous studies have suggested that the contrast between looking healthy and being ill can sometimes be a cause of anxiety for fibromyalgia patients (Hallberg and Carlsson, 1998; Henriksson, 1995), though this is generally with regard to non-sufferers rather than other people with fibromyalgia. In a discussion of intergroup processes in cancer support groups, Fobair (1998) listed competitive people as just one type of “difficult” group member, with others including: those who monopolize the discussion, those who moralize constantly, those who complain while rejecting help and those who are silent. In an online setting, many of these groups, for example those who remain silent, are probably easier to ignore but it appears that even online competitiveness is a problem. However these negative feelings were not common to all the participants, and the majority seemed to find the communities useful and supportive, as in previous investigations (Raymond & Brown, 2000; van Uden-Kraan, Drossaert, Taal, Shaw, Seydel and van de Laar, 2008).

9.4 Conclusion

Though previous studies have suggested fibromyalgia patients’ relationships are damaged by their condition, the participants interviewed seemed to have a more positive outlook, with many maintaining positive relationships with the people around them. However, there did appear to be a streak of defensiveness running through a lot of their interactions, even with groups specifically designed to provide fibromyalgia support.

9.5 General Discussion

The aim of this study was to investigate the ways in which the diagnosis and label of fibromyalgia altered the way participants interpreted and understood their experiences. Across the two halves across the study, three overarching themes were found: that the unpleasantness of fibromyalgia was driven by other symptoms, as well as the pain, that participants appeared to spend considerable time and energy attempting to control the uncontrollable, and that there was no particular positive or negative tone to fibromyalgia patients' interactions with other people.

Drawing together the findings of the two studies, there appeared to be two main consequences to being diagnosed with fibromyalgia, with regard to the effects of the label itself. The first is that participants gained access to the fibromyalgia support groups, and second was that they were labelled as having a controversial syndrome.

Gaining access to fibromyalgia support groups appeared to make a considerable impact upon the lives of participants, with both positive and negative consequences. On one hand fibromyalgia support groups appeared to be an importance source of support for both the majority of participants in this study and in previous works (Raymond & Brown, 2000; van Uden-Kraan, Drossaert, Taal, Shaw, Seydel and van de Laar, 2008). Participants stated that it was only possible for other people with fibromyalgia to truly understand their experiences, and therefore maintaining contact with them was vital. Participants also used the groups as a source of information, to keep up with the latest news and discussions.

However, views of the support groups were not universally positive, and participants also described them as depressing, or as a self-esteem threat. A number of participants tried to control their pain based on techniques they had learnt from discussions with other sufferers, but only achieved limited success with the sometimes quite restrictive routines they put in place. Concerns about the nature of the support groups, and also self-help books, alternative therapies and websites aimed at people with fibromyalgia have been raised before. In one published dialogue between a doctor and a researcher and ex-patient, the researcher highlighted the dangers of what she called “fibromyalgia culture”, and the need to discourage newly diagnosed patients from becoming involved in it. This is because she felt it encouraged obsession and pathologising, without providing genuine hope (Alghalyini & Oldfield, 2008). This pathologising does seem to be a genuine problem for fibromyalgia sufferers, as they have been shown to overestimate the extent to which their cognitive difficulties (Grace, Nielson, Hopkins & Berg, 1999) and somatic symptom experiences (van Ittersum, van Wilgen, Hilberdink, Groothoff & van der Schans, 2009) differ from the general population.

The way people respond to and define their symptoms, internal states and body indications is known as “illness behaviour” (Mechanic). Previous work has shown that people’s responses are highly dependent on social factors, including the health status and behaviour of other people in the social environment. For example, it has been found that the children of parents with higher levels of disability, pain behaviour and emotional distress are more likely to report pain than those with pain-free parents (Jamison & Walker, 1992). It has also been shown that children with recurrent unexplained pain report more models of pain and illness behaviour in their social environment than children with recurrent explained pain (Bennett Osborne,

Hatcher & Richtsmeier, 1988). The siblings of children with functional abdominal pain also show higher levels of behavioural and emotional symptoms than controls (Guite, Lobato, Shalon, Plante & Kao, 2007). Similar patterns have also been found in children with fibromyalgia, whose parents have been shown to be more likely to report multiple pain-related conditions (Schanberg, Keefe, Lefebvre, Kredich & Gil, 1998). Though being a member of a fibromyalgia support group is not directly comparable to the experience of growing up with people who suffer from chronic pain, these findings at least provide evidence that if someone is in a situation where chronic pain is present and highly salient, it can negatively change the way they respond to their own symptoms.

It has also been shown that the way people respond to the pain of others can also alter subsequent illness behaviour. For example, it has been shown that people who reported being treated with gifts or favourite food when they were ill as children were more likely to have irritable bowel syndrome and to exhibit chronic illness behaviour as adults (Whitehead, Winget, Fedoravicius, Wooley & Blackwell, 1982). In the case of people with fibromyalgia, it has been shown that responses to pain by significant others significantly affects pain behaviours. For example, it has been shown that having a spouse who is attentive to nonverbal pain behaviours leads to more physical disability in depressed fibromyalgia patients, and more pain behaviours in those who report higher levels of pain (Romano et al, 1995). It has also been shown that dysfunctional fibromyalgia patients show more pain behaviours when their spouse is present than other fibromyalgia patients (Thieme, Spies, Sinha, Turk & Flor, 2005). The fibromyalgia support groups were described by some participants in a way that suggested they provided a greater understanding and support than their family. In this way it appears likely that the

groups play a similar role to the attentive and solicitous spouses found to increase pain behaviour in the studies described above. For all of these reasons, this study suggested that gaining access to both the positive and negative aspects of support groups and “fibromyalgia culture” is a major consequence of the fibromyalgia diagnosis.

The second major consequence of being diagnosed with fibromyalgia, in terms of the label itself, was that participants were labelled as having a controversial syndrome. It has been shown that some doctors have a negative view of fibromyalgia and fibromyalgia patients (Asbring & Narvanen, 2003), and that, according to one survey of GPs, nearly a quarter of doctors believe that patients are malingerers (Hayes et al, 2010). At least some of the participants appeared to believe there were potential negative consequences to having these sorts of diagnoses attached to them, for example, Imogen who stated:

“There are days I wonder if I’d be better off without a diagnosis of FMS. Say that instead of FMS, I just had a diagnosis of the resulting conditions: Insomnia, Secondary Hyperalgesia (referred and radiated), restless limbs syndrome, migraines (cause and intensity), minor reactive depression, irritable bowel, irritable bladder and hypoglycaemia. So I should be referred to a sleep clinic for insomnia, the pain clinic for the hyperalgesia, neurology for the headaches, counselling or CBT for the reactive depression, visit a diet clinic for the IBS, have botox injections in my bladder, and have a blood sugar monitor for the hypoglycaemia. In a way, saying Fibromyalgia is like saying ‘on my period’ – the medic’s brain shuts down lateral thinking and will only say one thing: For periods it’s The Pill, and for FMS it’s ‘offer no treatment’”

Interestingly a number of participants appeared to go out of their way to contradict the “malingerer” stereotype. This could be seen in the way the participants tried to control how they were seen by other people. In the case of participants who worked, this was particularly true in the way they approached sharing information about the syndrome with colleagues. Diane’s determination to continue as normally as possible at work, where she would not have told her boss or anyone else about her condition if she didn’t have to, suggested not only a strong desire to work, but also a concern about being seen as less than a very hard worker. Beth also said she worked hard to ensure her performance was not affected by fibromyalgia, and learned to cope with the condition so that she did not need any more sick days than anyone else. She stated that she was “trying to live as normal of a life as I possibly can, and I don't need to constantly bug people about my health problems”, suggesting a reluctance to draw attention to any limitations. The participants who no longer worked also appeared to have a strong desire not to be seen as lazy. Carol said that she had started to tell people she had rheumatoid arthritis after an unpleasant incident with her former fiancée, showing a reluctance to be seen as having what was termed a “hypochondriac disease”. Imogen repeatedly spoke of her struggle to gain a degree despite having fibromyalgia, and her pride in graduating. As the participants appeared to be aware of the negative associations with the label, it may be the case that these traits were highlighted in an attempt to create a more positive image. Though it is arguable whether being extremely controlled and perfectionistic, as well as very hardworking, is an attractive characteristic, it is almost entirely opposite to being a malingerer. Whether this is the case, or whether there genuinely are differences between the

fibromyalgia community and non-sufferers in terms of work ethic and perfectionism, is unclear from the current study. Please see appendix seven for a short investigation of this topic.

9.5.1 Methodological reflections

The interview technique used in this study, with its absence of face-to-face contact with participants, separates this work from other studies looking at similar themes. It has previously been argued that face-to-face meetings, and so the bodily interactions of the interview situation “provide a crucial context, an area richly deserving of attention” (Finlay, 2006a) and that “for all its inevitable, inescapable ambiguity, the body reveals, informs and discloses.” (Finlay, 2006b) In this study it was not possible to use these subtle bodily cues to derive meaning and the meaning had to be derived simply from the words participants wrote. The nature of this technique also meant that participants could think about what they wanted to say, and hide their first reactions if they felt it necessary. Despite these methodological differences, the themes found both echoed and built on those found in previous studies, with no obvious differences or inconsistencies from that which had gone before. We hope that this provides evidence that the technique is valid and can be used to obtain accurate information. There also appeared to be certain advantages to the technique; participants seemed to be comfortable with the slow and considered style, and for both participant and interviewer it seemed to allow extra time for thought, and reflection on which themes needed to be followed up. Also it seemed that though the opportunity to examine bodily communication and immediate reactions was lost, rich well-considered transcripts were gained, with participants

taking the time to carefully explore different issues. For example, Imogen, who provided one of the longest transcripts in the TA group wrote:

“As ironic as it may sound, I go numb when I’m in a flare up. I liken it to a state of shock, as it’s similar to when I slipped and needed stitches in the back of my head as a child: The pain was so intense and overwhelming that I went into shock and went numb and cold; my brain was still receiving pain signals but decided not to pass it on to the conscious part of my brain. That’s what flare ups feel like to me: I get more pain and then I go numb. And when I say numb, I mean someone can hug me from behind and I won’t realise until I go to move and am being restricted. Mentally my mind has gone AWOL, and nothing will go in or come out consciously: Rather upsettingly sometimes people ask me things and I can give them answers, like my memory is connected to my mouth but not my conscious. Coming out of the flare, the pain is nauseating and it doesn’t matter how still or restless I am, I can’t escape it. It’s like Influenza (I had Influenza when I was 17/8). All my symptoms are worse during a flare, and it usually both frustrates and upsets me by how debilitating it is.”

It is unlikely that any participant would have been able to produce anything as detailed and descriptive as this in a face-to-face interview situation.

In this study mixed methods of analysis were used. Though this technique has been used before (for example Bailey & Jackson, 2003; Reissman, 1990), it is still quite unusual. Despite this, the use of two techniques offered multiple advantages: all of the demands and recommendations of both techniques were met; it was possible to validate the findings of the

IPA sample against a larger group; and a larger number of participants had the opportunity to express their views and contribute. The findings from the two groups appeared to complement each other, with only one extra theme found in the TA analysis, that of “Personality and Lifestyle before Fibromyalgia”. A number of topics the findings overlapped with Sim and Madden’s (2008) metasynthesis, but here we were able to go into further detail, for example on the topic of fibro fog and its problems. Sim and Madden found that “Cognitive difficulties were also reported, including limitations with problem-solving and abstract thinking, and an inability to make judgment calls or on-the-spot decisions; these problems influenced employment opportunities.” It was possible to extend this to include individual participants’ descriptions of what fog feels like and descriptions of the impact it has on them socially. The present participants differed slightly from those interviewed in the studies included in the metasynthesis by suggesting fog is a common and distinct part of fibromyalgia, but the basic problems caused by fog were described in a similar way across both studies. This ability to compare the findings with both previously published work and another sample of participants from the same pool allowed a greater degree of confidence in the findings.

9.6 Conclusion

Interviewing fibromyalgia patients via email provided the opportunity to discuss a number of different topics with the same people. The data was presented in two halves: the embodied experience of fibromyalgia and the impact fibromyalgia has on interpersonal relationships. It was found that there were two major consequences to being diagnosed with fibromyalgia, in terms of the label itself. First participants gained access to the “fibromyalgia

culture” of support groups and self-help guides. Participants were also labelled as having a controversial illness.

Chapter Ten

General Discussion

The first aim of this thesis was to examine the effect of environmentally derived labels on the way healthy people understand and interpret their health experience. The second aim was to examine the way people who have a functional somatic syndrome label, in addition to socially derived ideas about health, understand and interpret their health experience.

These aims were approached in two ways. The first was via experimental studies with university and college students. These experimental studies investigated the way health is understood, labelled and experienced in young healthy people. The second was via two studies with people suffering from fibromyalgia. The studies with fibromyalgia patients investigated the way health is understood, labelled and experienced in people with a functional somatic syndrome label.

10.1 Findings in context

Chapters two and three of this thesis aimed to provide a broader understanding of the health experience of young people in Britain. Previous work has examined the number of symptoms experienced by children and adults in various countries (Eriksen, Ihlebaek & Ursin, 1999; Reidenberg & Lowenthal, 1968; Ricci, Chee, Lorandean and Berger, 2007; Haug, Mykleton & Dahl, 2002; Steinhausen & Winkler Metzke, 2007; Dhossche, 2001; Eminson, Benjamin, Shortall, Woods & Faragher, 1996). However, the current examination of both physical and mental symptoms over a one month period aimed to provide a considerably more detailed examination of the somatic symptom experience of young adults than previous studies have attempted.

Examining the number of symptoms experienced by young people was necessary for two reasons. First, because interesting differences were found between the current participants and other groups around the globe, with the current participants reporting more somatic symptoms. Second, because it allowed comparisons between the number of symptoms experienced by individual participants and their beliefs about their own health, the aim of chapter three. Though a number of previous studies have investigated the ways in which young people's judgements about their own health status are influenced by whether they behave healthily or unhealthily (Breidablik, Meland & Lydersen, 2008; Breidablik, Meland & Lydersen, 2009; Thorlindsson, Vilhjalmsson & Valgeirsson, 1990; Vingilis, Wade & Adlaf, 1998; Vingilis, Wade & Seeley, 2002; Tremblay, Dahinten & Kohen, 2003; Kelleher, Tay & Gabhain, 2007; Swallen, Reither, Haas & Meier, 2005), in chapter three it was possible to ensure that there were no significant differences between the groups in terms of symptoms experienced. Unexamined differences in the number of symptoms experienced by the two groups would have led to ambiguity as to whether the groups were benefiting from the psychological or physical consequences of healthy lifestyle changes. Chapter three also allowed an examination of whether young people who behave in a way that they perceive as healthy believe that they are healthier than other people. This distinction is important, as someone thinking of themselves as unhealthy but average is likely to have a different psychological outcome to someone thinking of themselves as unhealthier than everyone else.

The participants who reported acting in a healthy way believed themselves to be healthy. Importantly, this self-reported 'healthy' group experienced the same number of symptoms as people who did not report themselves as acting in a healthy way. One

interpretation is that the group who labelled their behaviour as 'healthy' perceived their symptoms as less troublesome because they believed themselves to be healthier than average. This group also believed they were healthier than other people, both in general and compared to their peer group.

Having examined the way participants thought about and labelled themselves compared to others, chapter four attempted to examine the way participants thought about unhealthy others, particularly in terms of their moral worth. A common criticism of health campaigns is that they encourage stigmatisation of certain groups (Guttman, 1997) and the results of the study appeared to reflect that. It was found that participants were more likely to say they would kill an obese person to save others, compared to a control person. This result suggests that people who are labelled as unhealthy are thought of as having less moral worth than those who are not.

If it is the case that the interpretation of own and others' health alters depending on the labels used to make that interpretation, it was hypothesised that it should be possible to change participants' responses to stimuli by changing the labels used to understand them, within an experimental setting. In chapter five a series of cold pressor studies were designed to address this possibility. Providing generalised anxiety provoking information, as in some early studies (for example Cornwall and Donderi, 1988; Hirsch and Liebert, 1998), did not change reported pain. However, when participants were given a plausible and anxiety provoking label for the specific type of pain they were experiencing, reported pain intensity increased. Specifically, when participants were informed that the specific form of pain they were likely to

experience during the cold pressor task was an early symptom of frostbite, participants rated their pain significantly higher than when they were told it was a symptom of RSI or when they were not given any health related information. This result suggests that by changing the label the participants attached to their pain, the participants' responses to the pain changed.

The aim of chapter six was to examine whether labelling might influence people's responses to pain in the real world. In November 2006 the British Heart Foundation (BHF) ran a national poster campaign encouraging people with chest pain to seek treatment. In the previous cold pressor study participants informed that their pain was a potential symptom of frostbite, an anxiety provoking and plausible label, reported more pain from the cold pressor. Consequently, it was hypothesised that the BHF poster might provide an anxiety provoking and plausible label for people experiencing chest pain that would lead to changes in the number of people admitted to hospital with hypotension. British hospital admission statistics were used to examine this. A significant increase in the number of people admitted with hypotension was demonstrated. As, unlike in the previous study, it is not possible to know exactly how the people who went to hospital rated their pain, it is not possible to say that people experienced worse pain from viewing the posters. However, the increased number of admissions for heart attack suggests that the labels people are given for their pain at least changed the threat value assigned to that pain. Taken together the first five studies in the thesis suggest that information from the environment, via its influence on the labels people use to understand their experiences, has the power to change the way people understand their own health and the health of others. It also has the power to alter how certain physical sensations are responded to.

The final two studies in the thesis examined the experience of people with fibromyalgia. Of particular interest was how the label 'fibromyalgia' influenced their symptom experience and their lives more generally. Previous qualitative investigations conducted with fibromyalgia patients suggested that all aspects of participants lives were affected by their fibromyalgia, including their ability to plan activities, enjoy a normal social life and work (Humphrey, Arbuckle, Mease, Williams, Danneskiold Samsøe & Gilbert, 2010; Theadom & Copley, 2010; Rodham, Rance & Blake, 2010; Sallinen, Kukkurainen, Peltokallio & Mikkelsen, 2010; Arnold et al, 2008; Crooks, 2007). The two studies involved qualitative interviews with a group of fibromyalgia sufferers. The results demonstrated that all of the symptoms associated with fibromyalgia, not just the pain, contributed to the negative experience. It was also found that participants spent considerable time and energy attempting to keep their pain levels under control, but still experienced regular, highly debilitating flares. Finally it was found that there was no one "fibromyalgia experience" when it came to interpersonal relationships. Looking at patterns running through all of the data, across the two studies, it was found that the fibromyalgia label itself appeared to affect participants' experiences in two main ways. First, it provided them with access to the "fibromyalgia culture" and second it linked them with a controversial health condition. Both of these appeared to influence the participants' lives in a number of ways, including the ways they tried to control their symptoms, the way they interpreted their symptoms, the way they interacted with doctors and the way they interacted with friends and family.

10.2 Therapy culture and the different groups

In this thesis the effects of labelling on healthy and ill people's understanding of their illness experience was investigated. In the introduction it was suggested that one of the main influences on the way people construct the labels they use to understand health is information in the external environment, particularly in the form of health campaigns. Though there is evidence that health campaigns have made a positive impact on, for example, the number of people dying prematurely from smoking related illnesses (Warner & Murt, 1983) the campaigns have been criticised from a number of perspectives. One of these criticisms related to the pervasiveness of health information in the environment, and concerns about what impact this stream of negative information might have on the way people think about themselves and their weakness and vulnerability (Furedi, 2004). The studies in this thesis provide some evidence to suggest that this information does have a negative impact on people in some circumstances, but not others.

One group who appeared to benefit from labelling their health in a certain way were the participants in chapter three who did report making healthy life changes. This group reported being healthier and more satisfied than their peers, despite experiencing the same number of symptoms. This result suggests that there is a psychological benefit to health information causing people to think of some behaviours as healthy and some as unhealthy, in that people who perform those behaviours think more positively about their health. As it has been shown that increased self-rated health has been associated with higher self esteem (Misra, Alexy & Panigrahi, 1996; Kristenson, Olsson & Kucinskiene, 2005; Rohrer & Young, 2004) and self-

efficacy (Loeb, Steffensmeier & Kassab, 2011), this in itself may have a number of additional benefits for this group. This therefore suggests that people who have made lifestyle changes will feel better about themselves and their ability to maintain those changes, making it more likely that this group will follow the lifestyle recommendations made by health campaigns.

Unfortunately, while the people who were able to label themselves as healthy appeared to gain a number of benefits from health information, the same was not true for the other participants in that study. Young people who had not made healthy choices were less satisfied with their health and also thought of themselves as less healthy than their peers. As previous work has suggested that these people will have lower self-esteem (Misra, Alexy & Panigrahi, 1996; Kristenson, Olsson & Kucinskiene, 2005; Rohrer & Young, 2004) and self-efficacy (Loeb, Steffensmeier & Kassab, 2011) this implies that they are also the group least equipped to positively change their behaviour.

Previous investigations into the effects of health campaigns, particularly fear appeals, have shown that these appeal most to those who are in least need of their message. In a study looking at the effect of a skin cancer fear appeal, it was shown that people who had already taken preventative measures against skin cancer responded significantly more favourably to a fear appeal on the topic (Cho and Salmon, 2006). Similarly in a study where safe sex booklets were distributed to sexually active female students those who already practised safe sexual behaviour found the higher-level fear appeal version of the booklets more persuasive than the lower-level fear appeal booklets. The opposite pattern was found in students who did not already practise safe sexual behaviour (Keller, 1999). These findings, along with the results of

the current study showing that those who have not made lifestyle changes feel worse about themselves than those who have, highlight the need for the construction of campaigns that specifically meet the needs of the people who need to hear the message most. This is particularly important in light of the findings of the other studies in the thesis that examined the effect of relevant threatening labels. The cold pressor study showed that when participants were provided with a relevant threatening label for their pain, their pain ratings increased, implying that the way they experienced the sensation changed. This therefore suggests that badly constructed campaigns, which do not take into account the effect they are having on different groups of people, run the risk of harming those that they are trying to help. Finding ways to engage people without increasing their feelings of vulnerability, but in a way that still captures their attention, should therefore be a priority.

After examining the effects of environmental information and labelling on the way healthy people interpret their experiences, we then went on to look at the experiences of people with fibromyalgia. Having the label of fibromyalgia was found to alter almost every aspect of sufferers' lives. The interview study highlighted the amount of time and energy participants were spending in the attempt to keep their pain under control. To do this they used a range of coping mechanisms, the majority of which were discovered through support groups or internet forums.

Furedi (2004) suggested that the pervasiveness of health information in the environment would lead people to feel vulnerable and weak. Current studies showed that when information is relevant and threatening, it can change the way something is physically

experienced. People with fibromyalgia, especially people with fibromyalgia who are immersed in so-called “fibromyalgia culture” (Alghalyini & Oldfield, 2008), appear to be surrounded by a great deal more health information than the general population, all of which is both relevant and threatening. Very few participants reported themselves to be getting better, but instead appeared to be getting continually worse and more restricted. As it has previously been shown that people with chronic pain also selectively attend to pain-related information (Pearce & Morley, 1989; Dehghani, Sharpe & Nicholas, 2003) this is highly concerning, and suggests that being enmeshed in this culture may not only be making people feel psychologically more vulnerable, but physically worse as well.

10.3 Chronic and acute pain

There are a number of problems with comparing people’s experiences of chronic and acute pain, and therefore attempting to use the findings of the cold pressor study to comment upon the experience of people with fibromyalgia. Acute pain has been described as pain “elicited by substantial injury of body tissue and activation of nociceptive transducers at the site of local tissue damage”, whereas chronic pain is pain that is “commonly triggered by injury or disease, but may be perpetuated by factors other than the cause of the pain” (Loeser & Melzack, 1999). There are thought to be a number of reasons why some people go on to develop chronic pain after a trauma while others do not. Studies looking at the profiles of people who have experienced chronic pain after operations or other traumas have pointed to a number of factors. In a review of post-operative chronic pain it was found that preoperative pain, psychological variables such as neuroticism, nerve damage during the operation, and

experience of acute post-operative pain were all associated to some degree with chronic pain (Perkins & Kehlet, 2000), making it a highly complex issue.

However, the separation of chronic and acute pain has been questioned. Carr and Goudas (1999) stated that “the traditional dichotomy between acute pain with its recent onset and short duration and chronic pain that persists after an injury has healed is increasingly untenable” as experiences of acute pain can alter pain responses over long periods. It is also true that many of the factors associated with more intense experiences of acute pain are also associated with more intense chronic pain. For example, a tendency to catastrophise is linked to both increased acute postoperative pain intensity (Jacobsen & Butler, 1996) and increased chronic pain intensity (Picavet, Vlaeyen and Schouten, 2002; Turner, Jensen, Warms and Cardenas, 2002). Anxiety has also been linked to acute postoperative pain intensity (Vaughn, Wichowski and Bosworth, 2007) and increased chronic pain intensity (Mccracken, Gross, Aikens and Carnrike Jr, 1996). In terms of attention towards pain, and pain-related biases, it has been shown that there is no difference in attendance to pain in either group, with the experience of pain, not the duration of pain, being the most important factor (Haggman, Sharpe, Nicholas and Refshauge, 2010). This finding suggests that overlaps in the mechanisms affecting chronic and acute pain experience do exist, and therefore investigating one may provide insights into the other. It may therefore be the case that, as in the cold pressor study, the relevant and distressing information provided by “fibromyalgia culture” may be contributing to the high levels of disability seen in fibromyalgia patients by providing them with distressing labels for their experiences.

To conclude, the studies in this thesis suggest that health information in the environment leads to positive outcomes for people who are provided with positive ways of labelling their experiences. However, for the many people do not fit into this category, including people who do not live healthily, people who have restrictive long-term illnesses and people who experience specific short term symptoms, there are a number of negative outcomes. As health information is vital for keeping people educated about the best ways to improve their long term health, care should be taken to ensure that campaigns are designed in a way that minimises harm to all groups, and maximises the positive impact on the people who need the information most.

10.4 Limitations

There are a number of limitations to the approach taken in this thesis. A primary limitation is the examination of multiple topics. In this thesis studies examined the health experience of young healthy people, the health experience of people with fibromyalgia, the way young people's experience of pain can be altered in experimental settings and the way the health experience of the general public can be altered. All of these topics are worthy of detailed and focused examination, and it is likely that a much greater understanding of any one of these topics could have been gained via a more in depth investigation. For example, there are a number of extensions that could have been made to the cold pressor studies in this thesis (see below for specific study suggestions).

A second and related limitation relates to the multiple participant populations involved in this research. University and college students, fibromyalgia patients and the general public

were all the primary focus of different studies. Again, a focused investigation, either into the experience of young students or into the experience of fibromyalgia patients, would have led to a much greater understanding of the experiences of that population. For example, though the fibromyalgia studies provided insight into many aspects of the fibromyalgia experience, a series of other qualitative interviews, each building on the findings of the one before, could have provided a deeper insight into the nature of the influence of external information on the way people with fibromyalgia understand their health.

The use of different methods is a further limitation of the approach taken in this thesis. The methods used varied considerably, with some studies using simple questionnaires, some pain inducing equipment in the form of the cold pressor, two studies using qualitative interview techniques and one the analysis of national statistics. Conducting a series of studies each using the same or very similar methods, would again have potentially led to a much more detailed investigation of a topic. In the case of experimental investigations, such as the cold pressor, it would have been possible to conduct further investigations, looking in more detail at the specific circumstances under which it is possible for labels to change participants' experiences by changing one variable in each iteration. Having established a consistent effect with the cold pressor it would then have been possible to use a different but related method, perhaps attempting to replicate that effect using heat pain. In this way a single method could have been used to replicate and build upon one series of findings.

10.5 Future directions

There are a number of ways in which the findings in this thesis could be extended by future experimental work. In the case of chapter two, examining whether the number of symptoms experienced by students changes over the years would provide insight into whether students' experiences of health evolve over time. We are currently continuing to collect data regarding the number of symptoms experienced by college and university students. In the case of chapter three this data will also provide insight into whether students' attitudes toward health change, and could potentially provide insight into whether fewer or more students decide to make healthy lifestyle choices, and what impact these choices have on their outlook.

Extensions to the cold pressor series of studies could usefully examine how explicitly information about frostbite has to be presented to participants before it has an effect on the way they rate the pain. In chapter five, participants read a paragraph of information about frostbite. It is currently unclear whether looking at a poster about frostbite, or reading a paragraph in which frostbite was briefly mentioned amongst other topics, would be enough to alter their pain response. It would also be possible to conduct a similar study with a different type of pain stimulus. One way to experimentally induce pain is to use a heat probe. Warning participants about the dangers of being burnt before they completed a study with the heat probe would replicate the cold pressor finding using a different stimulus and would strengthen the original finding.

With regard to the final two fibromyalgia studies, there are a number of ways in which these could be extended with experimental work. One interesting application would be to conduct further studies specifically investigating the way people with fibromyalgia interpret and

label pain. For example, it might be possible to conduct the final cold pressor experiment with participants with fibromyalgia, to see if they were more or less susceptible to external information and new labels changing the way they interpret pain. Another study might use a similar questionnaire to that used in chapter two, to examine how many more symptoms people with fibromyalgia experience compared to age matched controls. The questionnaire could also be modified to discover which of those symptoms are threatening to the fibromyalgia participants, compared to pain free controls.

There are also further qualitative studies that could be conducted to extend the present studies. The two studies here provided an overview of a number of aspects of the fibromyalgia experience. It would be possible to conduct further studies looking specifically at the two conclusions drawn from these studies, that the fibromyalgia label provides people with access to “fibromyalgia culture” and a controversial label. It would be possible to ask new participants about the consequences of these to a much greater depth. Questions might include “how do you believe people with fibromyalgia are seen by medical professionals?” and “what impact do you believe this has on the way you are treated?”.

10.6 Conclusions

This thesis aimed to investigate the way labels influence the way both healthy and ill people think about their health and interpret their health experience. It was found that whether people label themselves as healthy or not is influenced by whether they perceive themselves to be acting in a healthy way. It was also found that the way people respond to pain can be altered by the label attached to that pain. Finally it was found that, in the case of people

with fibromyalgia, the label altered the way they understood their experience by providing them with access to “fibromyalgia culture”, and by linking them with a controversial condition. It was suggested that the information people with fibromyalgia are exposed to through support groups and internet forums may encourage them to interpret their experiences in a highly negative way. This in turn may change their reactions to these experiences and increase their perceived incapacity.

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Appendix One

Symptom and Attitude Questionnaire

These questions ask about your health in the recent past. Using the scale below, indicate for each of the following symptoms how often and for how long it has affected you in the PAST MONTH including today.

Frequency

- 0 – Not experienced this problem at all
- 1 – Experienced this problem on one or two separate occasions
- 2 – Experienced this problem between 3 and 5 separate occasions
- 3 – Experienced this problem on more than 5 separate occasions

Duration:

- 0 – Not experienced this problem at all
- 1 – Experienced this problem but never for longer than 60 minutes on any occasion
- 2 – Experienced this problem for 1-3 hours on at least one occasion
- 3 – Experienced this problem for more than 3 hours on at least one occasion

Statement	Freq Rating	Dur Rating	Statement	Freq Rating	Dur Rating
Vomiting (not hangover or pregnancy related).			Abdominal or belly pain (WOMEN: when you weren't menstruating).		
Nausea (feeling sick to your stomach, but not actually vomiting, not hangover related).			Excessive gas or bloating of your stomach or abdomen.		
Loose bowels or diarrhoea.			Foods you cannot eat because they make you sick.		
Pain in your arms or legs (other than the joints, not exercise related).			Back pain.		
Pain in your joints.			Pain when you urinate.		
Other pains (do not count headaches).			Shortness of breath (when not really exerting yourself).		
Heart racing, pounding, or skipping.			Chest pain (not exercise related).		
Dizziness (not hangover related).			WOMEN: Very painful menstrual periods (other than during your first year of menstruation).		

Excessive fatigue.			Stiffness in the joints		
Headaches (not hangover related).			Constipation.		
Poor concentration.			Fainting.		
A feeling of depression/sadness.			Feeling anxious.		
Sensitivity to light or colour (not hangover related).			Irritability		
Insomnia			Problems closing your jaw/ jaw lock/ jaw pain/problems opening your mouth widely		
Poor circulation to hands and/or feet			Restless legs		
Palpitations			Mood swings		
Short term memory problems			Increased sensitivity to smells		
Sore/irritated skin			Difficulty regulating body temperature (do you suddenly become too hot or cold for no obvious reason?)		

How would you judge your current state of health?

EXCELLENT GOOD POOR

Excluding birth control, are you currently receiving treatment for any particular health problem (no need to specify)? YES NO

Would the people who are close to you agree with the above self-assessment of your health? YES NO

How would you rate your health compared to others in your age group?

MUCH BETTER BETTER THE SAME
 WORSE MUCH WORSE

Do you think that others in your age group suffer from more or less of the symptoms listed above, in the same time period?

MANY MORE MORE THE SAME
 FEWER MUCH FEWER

Do you believe that you should feel well more often than you do?

YES NO

Do you believe that, considering your lifestyle, behaviour, diet etc, you should feel ill more often than you do?

YES NO

Do you believe that, at the moment, you are healthier than the average person?

YES NO

Over the last few years, have you made lifestyle changes in order to make yourself healthier?

YES NO

If yes, do you believe that these worked?

YES NO

How healthy would you rate your lifestyle (amount of exercise, etc) as being?

VERY HEALTHY HEALTHY AVERAGE

UNHEALTHY VERY UNHEALTHY

How healthy would you rate your lifestyle in comparison to others in your age group?

MUCH HEALTHIER HEALTHIER AVERAGE

UNHEALTHIER MUCH UNHEALTHIER

How healthy would you rate your diet as being?

VERY HEALTHY HEALTHY AVERAGE

UNHEALTHY VERY UNHEALTHY

How healthy would you rate your diet in comparison to others in your age group?

MUCH HEALTHIER HEALTHIER AVERAGE

UNHEALTHIER MUCH UNHEALTHIER

Do you believe that a “healthy” lifestyle leads to better health?

YES NO

Do you believe that a “healthy” diet leads to better health?

YES NO

How satisfied are you with your health (on a scale of 1-10, 10= completely) _____

Age: _____ Gender: _____ First Language: _____ Nationality: _____

Appendix Two

Moral Dilemmas: Architect
Ecologist and Trolley

Architect Dilemma

You are a young architect visiting one of your construction sites with your boss. Your boss is a despicable, rude individual who makes everyone around him miserable including you.

It occurs to you that if you were to push him off of the building you are inspecting he would fall to his death and everyone would think it was an accident.

Ecologist Dilemma

You and a group of ecologists are studying the wildlife in a remote stretch of jungle when you are captured by a group of paramilitary terrorists. You are held hostage for several days. One of the terrorists takes a liking to you. He informs you that his leader intends to kill you and the rest of the hostages the following morning.

He says that he is willing to help you escape, but that he needs some assurance that you will not go to the police. He devises the following plan. He will videotape you while you kill one of your sleeping colleagues. This particular colleague is someone you don't like, as you felt his weight slowed the group down. The tape will ensure your silence, making it possible for you to escape.

Trolley Dilemma

A runaway trolley is heading down the tracks toward five workmen who will be killed if the trolley proceeds on its present course. You are on a footbridge over the tracks, in between the approaching trolley and the five workmen along with one other man, who is standing on the bridge smoking.

The only way to save the lives of the five workmen is to push this stranger off the bridge and onto the tracks below where his body will stop the trolley. The stranger will die if you do this, but the five workmen will be saved.

Appendix Three
Cold Pressor Scripts

Study one:

“Thank you for agreeing to take part in this pain experiment. It is quite short, you will simply be asked to place your hand in the bucket three times, for one minute each. The first time, as long as you do not look at your hand, it does not matter, you can look at the poster or around the room, whichever you prefer. Then I will ask you to do a distraction task, which I will explain more about when you do it. Finally, I will ask you to actually look at your hand in the bucket. You only need to put your hand in the water up to your wrist, just make sure the back of your hand is covered. Do you have any questions? You can start whenever you are ready.”

Study two:

Condition one (anxiety): “This is a pain experiment, and unfortunately it does sting quite sharply, so please try to prepare yourself before you put your hand in the water. I will ask you to put your hand in the bucket three different times, each of which last for one minute. The first time, as long as you do not look at your hand, it does not matter, you can look at the poster or around the room, whichever you prefer. Then I will ask you to do a distraction task, which I will explain more about when you do it. Finally, I will ask you to actually look at your hand in the bucket. You only need to put your hand in the water up to your wrist, just make sure the back of your hand is covered. If it does hurt too much, please take it out, don’t just leave it there if it really hurts. Do you have any questions? You can start whenever you are ready.”

Condition two (relaxation): “This is a pain experiment but you shouldn’t find it too bad, just try to prepare your hand before you put it in the water and you should be fine. This is a much shorter experiment than some of the others, all I will ask you to do is put your hand in for one minute, three times. The first time, as long as you do not look at your hand, it does not matter, you can look at the poster or around the room, whichever you prefer. Then I will ask you to do a distraction task, which I will explain more about when you do it. Finally, I will ask you to actually look at your hand in the bucket. You only need to put your hand in the water up to your wrist, just make sure the back of your hand is covered. Like I said before, this is a very short experiment and you’ll be fine. Do you have any questions? You can start whenever you are ready.”

Study three

Condition one (anxiety): “This is a pain experiment, and unfortunately it does sting quite sharply, so please try to prepare yourself before you put your hand in the water. I will ask you to put your hand in the bucket three different times, each of which last for one minute. The first time, as long as you do not look at your hand, it does not matter, you can look at the poster or around the room, whichever you prefer. Then I will ask you to do a distraction task, which I will explain more about when you do it. Finally, I will ask you to actually look at your hand in the bucket. You only need to put your hand in the water up to your wrist, just make sure the back of your hand is covered. Do you have any questions? You can start whenever you are ready.”

Appendix Four

Frostbite/RSI/Cake baking Information sheets

Frostbite (numbness/pains and needles)

Frostbite, or congelatio, is a medical condition where the skin and tissue is damaged by exposure to extreme cold. There are a number of people who are particularly at risk of frostbite, for example mountaineers and walkers. If spotted early the first symptoms of frostbite can be acted upon to stop the condition becoming worse. Numbness and pins and needles are an important early warning sign of frostbite and should be taken seriously. Treatment of frostbite involves warming the area affected, either actively or passively. Active warming involves applying heat to the affected area and should not be done without medical supervision as it is difficult to do without causing further damage. Passive warming involves allowing the area to heat up naturally by moving the patient somewhere warm or wrapping them in blankets.

Frostbite (sharp pain)

Frostbite, or congelatio, is a medical condition where the skin and tissue is damaged by exposure to extreme cold. There are a number of people who are particularly at risk of frostbite, for example mountaineers and walkers. If spotted early the first symptoms of frostbite can be acted upon to stop the condition becoming worse. A sharp stabbing pain coming after long term exposure to cold is an important early warning sign of frostbite and should be taken seriously. Treatment of frostbite involves warming the area affected, either actively or passively. Active warming involves applying heat to the affected area and should not be done without medical supervision as it is difficult to do without causing further damage. Passive warming involves allowing the area to heat up naturally by moving the patient somewhere warm or wrapping them in blankets.

RSI (numbness/pains and needles)

Repetitive strain injury, or cumulative trauma disorder, is a medical condition where damage is caused to a wrist or another body part by chronic repetitive use of that part. There are a

number of people who are at risk of RSI, for example typists and office workers. If spotted early the first symptoms of RSI can be acted upon to stop the condition becoming worse. Numbness and pins and needles are an important early warning sign of RSI and should be taken seriously. Treatment of RSI involves changing the working environment so that there is a reduced risk of damaging repetitive behaviour. This can be done by changing equipment, for example mice or keyboards, but more breaks from work can also help. There is also evidence that increasing levels of exercise helps with RSI.

RSI (sharp pain)

Repetitive strain injury, or cumulative trauma disorder, is a medical condition where damage is caused to a wrist or another body part by chronic repetitive use of that part. There are a number of people who are at risk of RSI, for example typists and office workers. If spotted early the first symptoms of RSI can be acted upon to stop the condition becoming worse. A sharp stabbing pain coming after long term repetitive movement is an important early warning sign of RSI and should be taken seriously. Treatment of RSI involves changing the working environment so that there is a reduced risk of damaging repetitive behaviour. This can be done by changing equipment, for example mice or keyboards, but more breaks from work can also help. There is also evidence that increasing levels of exercise helps with RSI.

Cake

Baking a simple sponge cake is one of the simplest things a cook can do and the recipe is thought to originate from the 19th century. Because it can be made so easily, this sort of cake can be served almost anywhere, to great effect. The basic ingredients of sponge cake are flour, sugar, eggs and butter, though flavourings, such as vanilla or cocoa can easily be added. A basic sponge is usually made up of two cakes, stuck together with jam or butter cream. The cake can either be iced or sprinkled with sugar. There are a number of other uses for the basic sponge recipe, as when it is first brought out of the oven it is quite flexible: this allows it to be rolled to

make other cakes, such as the Swiss roll. Although the cake is simple to make, it is easily ruined by the wrong cooking time or temperature. This means that oven manufacturers often use a basic sponge cake to test the accuracy of their ovens.

Appendix Five

Fibromyalgia Interview Questions

How long have you been suffering from fibromyalgia and how long since you have been diagnosed?

What are your main symptoms?

Can you describe what the pain feels like? Is it continuous or at intervals? Is it sharp or achy?

Where on your body?

Do you get flares or is your pain quite constant?

What is the difference between a flare and your normal state? Do you just get an increase in pain or do you get other symptoms that you don't get normally?

Do you have any specific flare triggers?

Do you suffer from fibro fog? What is that like?

Do you feel that the spoon analogy describes your experiences?

Do you have any other way of trying to explain fibromyalgia to non-sufferers?

How many medications have you tried?

What are the best and worst medications?

What else do you use to try to calm the pain?

How have you been treated by doctors? Describe your best and worst experiences.

Do you think that doctors on the whole treat people with fibromyalgia badly?

What is the reaction of your friends and relatives?

Do they understand what you go through?

What about people you don't know very well?

Do you think it would help if people were more educated about fibromyalgia?

How have you got on at work?

How understanding have your boss and colleagues been?

What has been your experience with official bodies e.g. insurance companies?

Do you have any other health problems?

Do you feel that they interact with your fibromyalgia?

Do you have any theories about what caused fibromyalgia?

Do physical health problems have a negative effect?

Do mental health problems have a negative effect?

What do you think of the media coverage regarding fibromyalgia?

Is there anything important that I've missed out?

Appendix Six

Fibromyalgia Template Analysis

The Embodied Experience of Fibromyalgia

Pervasive pain

The main symptom of fibromyalgia is pain spread throughout the body. Participants described experiencing pain that varied in intensity but was always present:

“There is always at least a small amount of pain there. It just varies at different degrees of pain”- Mary

“It rises and falls in severity but does not ever go away. Not ever”- Kate

The pain described varied considerably from participant to participant, both in terms of described intensity and the area on the body it was felt most severely. Words most commonly used to describe the pain sensation were “burning”, “aching”, “sharp” and sore”. Some participants also described feeling different pain sensations in different areas of their body:

“There is pain for the parts I’m using that tends to be acute (fingers writing/typing) and burning (shoulders). It’s shooting in my arms when I’m driving. It’s dull and throbbing in my head. It’s exhausting and heavy if I’ve been sitting or standing. There’s pain in parts where I’ve been inactive, which spasm and tingle, and can be annoying”- Imogen

All participants described experiencing pain all over their body, but some experienced extreme pain in particular areas of their body, for example the “*neck back and shoulders*” (Jane), or the “*hips, thighs and knees*” (Naomi). A number of participants reported their worst pain as being very extreme, to the point where they have to seek emergency treatment: “*I’ve had emergency chiropractor appointments for this pain a few times, and once went to the ER in the middle of the night for treatment*” (Rebecca). Participants also noted that their reactions to pain were sometimes disproportionate, something that they put down to having dealt with extreme pain for such a long time:

“my pain has been so continuous I often don’t notice I’m in pain when I am- it feels like minor irritation until I break into a cold sweat and get nauseous.” (Paula)

“when pain is too much the body goes into semi-shock and numb things (perception/awareness of surroundings) in order to cope with/get through the situation. But my stress never reduces so the sensation is never fully there”. (Imogen)

“Killer” fatigue

Fatigue was described by one participant as *“the most overlooked symptom, and honestly it impacts me the most of all of it”* (Naomi). Participants described the fatigue as a feeling of extreme exhaustion:

“there are days where I can be so tired I vomit after doing something simple like going out to the store and picking up a few things. I can literally come home shaking” (Naomi)

Participants’ fatigue seemed to be caused by a lack of sleep. A number of participants described problems with insomnia, or the inability to get refreshing sleep. This appeared to be a particular problem for participants as even when they were able to sleep for longer periods they could not achieve deep or peaceful sleep:

“It is exhausting to deal with pain on an ongoing basis, and of course, every time you move while you sleep, the pain, wakes you up. In a recent sleep study, they found I never do get to sleep levels 3 or 4 where all the nervous system regeneration takes place. In three hours, I was roused 42 times, even though I only woke all the way up twice” –Luke

As well as issues of fatigue and perceived cellular damage from lack of sleep, being this fatigued had negative repercussions for participants’ abilities to cope with pain and utilise their normal coping mechanisms:

“I think you notice the pain more when you are not doing other things, and also being tired means I am more likely to be sat in the same position for longer periods of time which can also cause pain”- Quinn

“confused and kind of dazed” fog

Cognitive difficulties or “fibro fog” was described as a kind of extreme forgetfulness and *“like a mental block” (Sally)*. Participants described problems with conversation, such as forgetting things they had been told or had said only seconds earlier, or being unable to remember words they wanted to use in a conversation. Other participants reported having to use complex systems in order to remember appointments and birthdays. In the most extreme cases, one participant described how, in her worst bouts of fog *“I don’t drive, because I get lost or forget the difference between red and green lights” (Quinn)*.

For certain participants, fog was the most unpleasant and distressing of all of their symptoms, particularly if they were used to work or leisure activities that require high levels of concentration before they became ill. Participant 1, who was extremely proud of gaining a degree whilst experiencing fibromyalgia stated *“of all the things I’ve lost, I miss my mind the most” (Imogen)*. Another participant described how she could no longer relax doing the same hobbies as before she became ill: *“I have always loved crosswords and word games but many times cant remember words” (Tina)*. Another distressing aspect of fibro fog for the participants was the way it made them feel removed from the social situation around them:

“If my partner or a friend wants to have a discussion with me, I get frustrated easily and become cranky with them. I find myself just nodding and smiling noncommittally when people say things to me, as if there literally is a fog separating us and I can’t see or hear them fully”- Rebecca

As with the pain, levels of fibro fog appeared to cycle over time. It was also described by the participants as affecting different types of cognition at different times. For example:

“Mine cycles. For a few weeks, I may be able to organize a closet but not balance a checkbook or read books with chapters. A few weeks later, my organizational skills may be lost completely; but my reading and writing skills will return”- Paula

Despite the extreme and distressing nature of the fog symptoms, some participants doubted whether fog was a separate issue, or if it was just borne of the extreme fatigue characteristic of fibromyalgia.

Hypersensitivity and flu-like flares

Flares were described by participants as a state of extreme pain that could not be reduced or controlled:

“an increase in pain as of it reaching a level of “white noise” and I am existing outside of it” - Kate

The pain experienced in a flare also appeared to be qualitatively different to the more achy pain experienced on a day to day basis, with participants comparing it to having recieved a physical injury. They also reported experiencing additional symptoms, though these varied considerably across participants. Participants reported experiencing swollen painful glands, headaches, migraines, ear aches, irritable bowel, loss of bladder control, muscle spasms and increased fog and fatigue.

“I get tingling and burning when I get the flare ups. My bowel gets worse and bladder. All the body inflames even more in a flare up. I do suffer from Myofacial Pain most of the time on the left side and that makes me a bit deaf. Headaches too” - Sally

Participants discussed their lack of control their symptoms when they are in a flare state and how their normal coping mechanisms, such as medication, cease to work. They highlighted the need to stop and let the flare pass, without trying to ignore it or carry on:

“on a bad day, a flare day, pain can be up to about nine out of ten and all I can do is sit or lay on the sofa watching tv” - Rebecca

The regular but unpredictable nature of flares meant that participants never really know when they would be reduced to this state.

A “giant mess” of symptoms

All participants listed a number of other symptoms in addition to their pain, fatigue and fog. Some of these they appeared to put down to the fibromyalgia, and did not seem to separate from the classic symptoms. These included insomnia, irritable bowel, extremely low energy levels, dizzy spells, headaches, muscle twitches and spasms and hypersensitivity. The interaction and overlap between symptoms appeared to have a cumulative effect, and made the effects of each worse than any one alone. One participant described the interaction as a “vicious cycle”:

“I see it as a vicious circle: pain interrupts sleep, which promotes pain, which interrupts sleep, etc. The two are interconnected and part of the same process, I think. Saying one was the symptom of the other is somewhat of a chicken-and-egg argument once the pain shows up” - Luke

Defining what symptoms were related to fibromyalgia and which symptoms were caused by something else was made more difficult for the majority of participants by their high number of comorbidities. As described by one participant:

“there is so much overlap it’s hard to figure out what is what” - Naomi

Some participants appeared to experience a number of other symptoms that they could not explain within the normal parameters of fibromyalgia: *“funky symptoms like my legs not working right and strange skin sensations and dizziness that never goes away”* - Rebecca. All these symptoms seemed to add up to create a confused mass of symptoms, that each participant could never really be sure of the cause of.

In addition to their fibromyalgia symptoms some participants had a range of comorbidities that they clearly defined, and which they felt were clearly related to other illnesses:

“lower back lumbar pain. (Prolapsed disc), Hiatus Hernia, knee weakness (lateral collateral Ligament.), irritable bowel and nerve damage in finger and irritable bladder” - Sally

Gradual course

The course of participants' fibromyalgia appeared to vary considerably. Only one participant stated that her symptoms started over a very short, well defined period of time:

“I assume they all came together in the space of a month” - Imogen

All the other participants described a gradual onset of symptoms, some starting in early childhood:

“I remember waking up in the middle of the night when I was about 7 with terrible pains in my legs and arms. The doctors always said it was 'growing pains' and dismissed it. I would lose a few hours of sleep at least a few nights a week until I was about 9” - Mary

“I cannot remember ever being without pain. Consultant who diagnosed thinks I've had it since early childhood” - Tina

Participants generally described pain starting in one area of their body which gradually spread and worsened as time went on:

“I would get random aches or pains that didn't SEEM related to any physical activity I'd done. Also, every once in a while, I would just get a random sharp, stabbing pain in a random location that would last a few seconds and be gone. Initially, I chalked it up to the aches and pains associated with getting older. There were so few that the randomness of it didn't bother me” - Luke

Participants were split as to whether they felt their symptoms had stabilised with some participants believing they were continuing to decline and others thinking they had reached a plateau. One participant described how, though she felt her symptoms were steady at the

present moment, she expected to get worse over time, as her body degenerated as part of the aging process.

Lifestyle before fibromyalgia

When talking about their lives before their pain multiple participants described living busy hectic lifestyles:

“When I was young, I never stopped when I was ill or tired or stressed. I just kept going and eventually the problem would go away. I would never evaluate whether or not I could take on an additional task, I would just do it” - Imogen

Many participants believed the intensity of their previous lifestyles was due to having a “type-A” personality, which they believed was the reason they worked harder than was good for their health:

“I have the so-called type- A personality. That is, I tend to push myself to do whatever I need or have to do but than I crash after” - Olivia

Participants found their inability to maintain this lifestyle and to be active and busy in the present frustrating and painful, particularly after being used to doing so much:

“I used to love working long days with no breaks and having busy schedules packed with work and school and social obligations and other activities. It's been very difficult to give all of that up. I definitely did not want to” - Rebecca

One participant went further than just suggesting that she herself had a type A, workaholic personality, and suggested that these traits are common to the majority of people with fibromyalgia. Imogen stated *“everyone in the support group is a perfectionist and a workaholic” (Imogen)*. Imogen described how she felt these traits had contributed to the onset of fibromyalgia in the people she knew who were affected:

“They are affected because they try to meet unrealistic deadlines and recover from it later, instead of leaving work at 5pm and completing the task the following day. Also, we don’t like asking other people to help complete a task, because they probably don’t share the same unrealistic attainment expectations. This probably feeds into why we suffer in silence with FMS, because we are ashamed and too proud to ask for help, as well as not wanting to be a burden”- Imogen

According to this interpretation of the impact of personality on people with fibromyalgia, the influence of the “Type-A” personality not only makes people with fibromyalgia push themselves too hard, it also alters people’s interactions with other people, making it harder to access support because of their unwillingness to ask for help.

The mixed blessing of diagnosis

Diagnosis was an important milestone for participants and often came at the end of years of searching for an explanation of symptoms. One participant described why she felt it was so important to get a diagnosis:

“People were always questioning why I ‘wanted’ something. In my mind I knew I had something. I just wanted a name so I felt legitimised and could do something about it rather than say ‘I am tired all the time and hurt all the time and feel like crap but don’t know what’s wrong’”- Naomi

The vast majority of participants appeared to be extremely positive about their diagnosis, listing a number of benefits. These included having their pain legitimised in the eyes of themselves and other people, having a label that could be researched which provided an enhanced sense of control, increased support from friends and family and the ability to get special provisions made at work or their place of study. One participant described the way receiving a diagnosis changed the way she interacted with family, friends and doctors:

“Just *knowing* there was an actual name for this thing, that other people had it, that I could tell people I had an illness instead of being looked at as just lazy, that there were things I could actively do to improve my health, and that I could go to a doctor or other health care provider and say "I have this" and at least most of the time they'd take me seriously and know it was real”- Rebecca

Participants also described how having the diagnosis helped them to focus their attention on finding out as much as possible about the illness and the way they could help themselves:

“Huge huge relief. Majorly empowering. Now I had a name. I could research and take action. I could tell people finally what was wrong with me. I could join support groups and find out things. Basically it took me out of a stall and gave me a direction that I could head into”- Naomi

Complex and multiple causes

Participants listed a huge number of potential causes for their fibromyalgia, ranging from injury, to genetics to psychological trauma. Only a minority of participants could point to one event that they felt had been a cause. One participant was an ex-soldier whose leg got badly infected while he was serving and he believed that the nerve damage he received was to blame for his later fibromyalgia:

“One of the nerves in my leg had been irreparably damaged, causing a slight loss of motion, but more importantly causing intense pain .Months of therapy eventually resolved the pain for a while”- Luke

A second participant described going through an abusive relationship and the subsequent PTSD and depression that preceded her fibromyalgia.

In contrast, other participants listed a huge number of different potential causes, usually including both physical and mental trauma. One example of this was a participant who described the events of the years before she was diagnosed:

“Over a period of stress over a few years. I had 3 operations and 3 IVF. There was family conflict with this. Then went through the adoption process, had a car crash, a flu virus and Gastro-enteritis. So I can only guess. I think the Flu virus and stomach bug could have been the reason as it was soon after these illnesses” - Sally

Only a small minority of participants said they had no real idea what had caused their fibromyalgia, though they could also list a number of theories.

“There are theories I’ve read of stress either related to physical injury or emotional as a trigger mechanism perhaps. If so, I have had multiple trigger mechanism. Spine injuries, surgery, trauma (falling). Emotional trauma in an abusive marriage” - Kate

Complex and multiple triggers

Participants listed a wider range of factors that they felt negatively impacted on their pain. One of the most commonly listed triggers was over, and in some cases under, activity:

“Over activity is a killer – under activity doesn’t do you favours either. I must stretch and move to some extent every day. If I must overdo a day (say I want to go with my kids to the lake and play or something) I try and make sure that the next few days I’m prepared for an increase in pain and fatigue” - Naomi

Weather was also a very commonly listed trigger, with cold, cloudy, rainy, stormy weather and changes in atmospheric pressure thought by many participants to be extremely bad for their pain. A number of participants also listed various foods as triggers, though types of food appeared to vary from person to person:

“Avoid: anything that comes in a can that isn’t stewed tomatoes or beans. Those I need to make chilli with. Everything else, I’ve been not eating. I try and avoid fast foods and greasy foods as well, but I am human and do eat them on occasion. Bread products, which includes bread, buns, cakes, etc. I do eat a few cookies as a treat about every other day. Sweets/sugar. Again, have some occasionally. Bananas/peanut

butter/caffine/chocolate trigger my migraines. Eat: Anything that I really love that is vegetative. This has meant sucking up paying high prices for special things out of season, just because I'd go nuts if I ate only apples and oranges. In order to get myself to eat well, I buy stuff that I quite like – say grapes and strawberries and slice them all up into a fruit salad with the apples and stuff I'd get tired of otherwise”- Naomi

Not all participants agreed with this theory however, with one participant in particular displaying scepticism:

“No one has scientifically linked any food with the high levels of neurotransmitter “chemical P” which are found in many fibro patients. No one has linked any food or food component to fibro in a scientific, repeatable way. But since no one definitively knows the cause of fibro, people are free to blame everything from wheat gluten to caffeine. I've tried giving up caffeine, artificial sweeteners, carbs...you name it. No effect. So I figure if I have to suffer, screw it, I'm eating well”- Luke

It appeared to be the case that, with a lot of the listed triggers, very small changes could make a significant difference to pain experience. For example, one participant said *“I get lazy and don't do any stretches for a day or two, my body will react with a flare, as well” (Rebecca)*, while another participant described how important the water temperature is when she is swimming: *“if I attempt to do the same exercise as normal in water that's 0.5oC lower, I will flare because my body is more active in keeping me warm” (Imogen)*. However, despite these already very narrow parameters, many participants said that they still found it difficult to predict how they would feel, because their pain levels remained so unpredictable.

Strict routines for coping

Participants used a wide range of coping techniques to deal with their symptoms, ranging from physical activity to meditation. Generally it appeared that being warm and comfortable was the best thing for many participants as they listed things like heated rice bags, heating pads, hot showers and massage as being particularly helpful.

“Heat, ice, long showers, hot tub soaks, massage (LOVE IT), visual imagery , positioning (pillows and stuff to support my body)”- Olivia

Diet and exercise also played a major role in participants’ routines with most participants attempting to eat well and exercise. The majority of participants described exercise routines that they felt were helpful, with swimming, stretching and light walking particularly popular:

“If I do very gentle walking and swimming it does energise me for a while. Stretching helps. Generally things that energise me are more mental than physical. That said if I don’t do at least some activity on a regular basis, my energy decreases”- Naomi

Participants also used a number of mental techniques such as “guided imagery, progressive relaxation, deep breathing and meditation” –Naomi and distraction through television or music. They also noted the importance of learning about fibromyalgia and self management techniques, stating that having a feeling of control was very useful.

“self education is a powerful and helpful tool in personal coping. I found that it gave me some control over the uncontrollable and helped me make good decisions on what treatment is available and what I can ask for” - Olivia

Participants also spoke of the need to make careful plans for the use or conservation of energy to get the maximum benefit from limited resources:

“I try to conserve my energy appropriately – if I know I have an event to go to, I’ll take it easy on chores etc. I also use painkillers for events that I know will be tiring so that I have the pain control”- Naomi

Participants planned their activity for sometimes days in advance, particularly around the time of more important events.

Mixed attitudes to medication

Participants generally reported taking multiple types of medication, but very few reported having their pain completely under control, with most reporting that it had reduced to “tolerable” (Mary) levels. Typical was Rebecca who stated:

“even on a good day, I take pretty heavy pain medication and still feel significant amounts of pain”- Rebecca

Participants appeared to divide their medications into what one participant called “background’ tablets, in the sense they slow down the cellular damage and keep me ticking over” (Imogen) and stronger narcotic pain relievers that some participants used when the pain got too much:

“narcotic pain relievers are the most frequently prescribed medication, yet one of the least effective for fibro pain. So you have to take quite a strong one (like vicodin) for it to have an effect. I don’t like to do that often, but I must admit two or three times a week it gets bad enough for me to take one. It does dull the edge when the pain gets bad”- Luke

Some participants tried to keep their medication use to a minimum, particularly in the case of narcotic medications, either because of a fear of addiction or the unpleasant side effects. Side effects appeared to affect the majority of participants, leading them to try to work out the worth of taking the medication by balancing the benefits they received from being on the medication against the unpleasant side effects:

“I’m currently on gabapentin for neuropathic pain. It makes me quite drowsy and somewhat dizzy. It helps really well for the pain which is quite bad lately. So it’s worth it for me. If I was only getting a slight amount of relief, it wouldn’t be worth it cause of the sleepyness factor”- Naomi

The Social Relationships of People With Fibromyalgia

Doctors- “its impossible to know who you will get”

Participants described a wide variation in the attitudes of medical professionals to fibromyalgia, from disbelief through to genuine support. Because of this variation the majority of participants had seen multiple doctors in the past and had a range of different experiences:

“I’ve had doctors tell me “you shouldn’t have to live in pain, let’s see what we can do to fix it” and doctors that have told me “you’re always going to be in pain so you have to just suck it up and live with it.” I’ve had doctors believe me 100% and test me thoroughly for everything they could think of and try everything they knew of to help and then sent me to specialists when they exhausted what they knew to do. I’ve also had doctors who caused me to cry by berating me and accusing me of exaggerating my symptoms or making things up. I’ve had doctors promise to stay on my case until they figured out what could help me and then give up on me in under three sessions. I’ve had doctors who were clearly frustrated by their inability to do anything or find anything and so they’ve turned me away despite realizing that I was, in fact, in need of their continuing help. I’ve had doctors who looked at me and my mom (who usually goes with me as an advocate to appointments) as if we were crazy – me a hypochondriac and my mom with munchausen syndrome by proxy or something. I’ve literally had doctors lie to me and make up a diagnosis that doesn’t exist just to get me to go away. I’ve had doctors tell me it’s all “stress” and I should just talk to my therapist about it”- Rebecca

Participants perceived their main conflicts with doctors to be caused by rudeness and disbelief. A number of participants complained about being given the wrong treatment, which, when prescribed by rude doctors, was interpreted as being a sign that the doctor had not listened:

“My previous family doctor (GP or PCP) was very dismissive and would tell me to take vitamin B when I complained of memory issues and fatigue. He dismissed my long periods and cramps as ‘normal’ for years, just putting me on the pill for years to shut me up”- Naomi

When participants got on well with their doctor, they were much more likely to be accepting of ineffective treatment. The majority of participants got on well with their current doctors. Doctors were particularly liked by participants if they displayed empathy and understanding. Even if doctors could not do much to help the pain, if they seemed like they were genuinely trying, participants seemed to respond appreciatively:

“My current doctor has done a lot of reassurance this way with me, even though I baffle him with my varied issues at times. He’s awesome, supportive and addresses my issues promptly without going overboard. I don’t want a pill pusher, I want an advocate. I have that with him. We have an excellent and friendly relationship. He’s very casual and ‘human’ with me, and that’s helped me a lot, cause I know I’m over sensitive to anything resembling critique from doctors now”- Naomi

Family and friends- how much do they understand?

Participants described a range of different reactions from the people around them, some supportive and some negative reactions that had led to breakdowns in relationships. One participant reported losing all of her non-disabled friends, as they gradually became aware of her limitations:

“Every healthy friend I had when I was healthy doesn’t keep in touch anymore. I fell sick at a bad time, when we were all going to University. When faced with either staying in the house with me or exploring all these new avenues that University offered, I was simply replaced”- Imogen

Other participants appeared to be more fortunate, and though they had lost some friends, the majority had been supportive:

“I have been blessed with incredibly supportive family and friends. Those who don’t believe in fibro don’t stay my friends for long; it’s not worth it. Some people in my life took a bit longer to come around than others, but anybody who truly cares will at least

try to understand and ask questions. I think for those who didn't believe at first, the proof came when I had so many losses due to the fibro that they figured out, no one would choose to live this way if given the choice" - Paula

Some participants understood the problems their family and friends had when it came to accepting their illness with some participants acknowledging how frustrating they felt their caregivers must find it when they could not do as much as they used to. Participants were also aware of the distress that could be caused by their current disabled state:

"At first, when I first got a lot sicker/disabled by the illness, it was hard for a lot of them get it. I think it's a difficult thing to accept that someone you love is that sick, in that much pain, and that their life is changing that much. No one wants to see that"- Rebecca

Participants described the difficulties their friends and family sometimes had in understanding the extent of their pain, and small thoughtless actions, such as a too tight hug or handshake, could cause considerable distress. Participants also described how it was not always clear to other people that someone with fibromyalgia always has pain and that this always has to be taken into account:

"Some are more understanding than others. People don't realise that when things are bad they don't see you, and that even when you seem fine and say you are ok that it's a new and different definition of ok that includes a background pain level"- Quinn

Work- Easily lost

The vast majority of participants were not working and in the case of some of the younger participants, had never been able to hold a full time job. For those who had been able to maintain employment, this appeared to be largely due to their work environment. These participants reported highly understanding colleagues who had been willing to be flexible and make extra provisions, for example buying extra equipment. Working participants reported that

had they have been in different working environments they might not have been able to maintain their employment:

“I work from home and on my own hours. If I want to mark at 2 am, I do. If I want to at 1 pm, I do. I just have to keep up, which I can. My boss bought me a laptop so that I can mark even laying down. I can’t imagine that I would have been able to keep any ‘normal’ job with set hours and more physical demands – the very nature of this is so unpredictable – some days I can be doing fine and then I’m out with a migraine for 2-3 days. It’s very frustrating that way”- Naomi

Participants who were not able to work reported wanting to be able to work and were frustrated at their own limitations. One participant described how painful it was to hear her doctor say she would probably never be able to work:

“Every time I see or hear my doctor say that I'm "permanently" disabled and "will never be able to" work again - it tears my heart out. This is not something I would ever ever choose for myself. If I were at all capable of working, I'd be doing it. No question”- Rebecca

Participants were also concerned about employment legislation and felt that due to the invisible nature of fibromyalgia, they were not afforded the same treatment as people who were visibly disabled.

“Employers that claim to be ‘disabled friendly’ only want people with ‘visible’ disabilities, so they can show off they employ disabled people. Brilliant is you’re missing a limb or are in a wheelchair. Bad if you have an ‘invisible’ illness”- Imogen

Groups- supportive but a self esteem threat

Participants were generally very positive about fibromyalgia peer support groups. The ability to talk to someone who knows what fibromyalgia is really like, something a lot of participants felt could never really be true of non-affected friends and family, was very important to them:

“If it wasn't for my fibro community [location removed], I wouldn't have anyone to talk to about it. No one in my real life *really* gets it, even though they try hard. It's important to be able to talk to someone who has been there and knows exactly where your coming from”- Mary

Talking to other people with fibromyalgia were described as non-judgemental and provided reassurance that the participant wasn't going “crazy” (*Olivia*). However, some participants described the tendency for the groups to become depressing, as everyone used the groups to vent their negative feelings about the illness:

“A peer support group is also hugely vital – it is good to have the comfort of others that know what you are feeling, but I think it's important for them to have some purpose and leading so that they don't always focus on the negative – like have everyone drag everyone down. Venting is good and healthy – but you need a balance. Taking action rather than staying in the victim role etc”- Naomi

Participants also described how, because of the negativity, people in groups could sometimes be drawn into unhelpful competitions with each other:

“I think sometimes they become "bitch sessions" or unconscious competitions to see who has it worse”- Luke

These problems led some participants to highlight the importance of a moderator or overall purpose to the group to reduce these problems and increase the positivity and energy of the group.

Appendix Seven

Fibromyalgia Personality Questionnaire Study

Introduction

In chapter eight it was found that a number of the participants identified themselves as either having a type-A personality or as being a workaholic, a label that is in direct contrast with the most negative depictions of people with fibromyalgia (Asbring & Narvanen, 2003; Hayes et al, 2010). The aim of this chapter was to investigate whether people in the wider fibromyalgia community report these same traits.

Researchers have previously investigated the prevalence of psychological states and personality traits in people with chronic pain. In a review of the relationship between psychological variables and functional disorders Katon, Sullivan and Walker (2001) stated that “patients with comorbid anxiety or depressive disorders have significantly more medical symptoms without identified pathology and significantly more functional impairment than do those with chronic medical illness alone, after adjustment for severity of physical disease”. Keogh, Hamid, Hamid and Ellery (2004) investigated anxiety sensitivity in people referred to a hospital clinic with chest pain and found evidence suggesting anxiety sensitivity is related to chest pain in women but not in men. They also found a mediating effect of a negative interpretative bias: people who are high in anxiety sensitivity are more likely to interpret body sensations in a negative way.

Personality traits have also been shown to influence illness experience. In the same review of psychological variables and functional disorders Katon, Sullivan and Walker (2001) presented evidence for the relationship between neuroticism, harm avoidance and negative affect and physical symptoms. Patients with atypical facial pain have elevated scores on the

hypochondriasis, depression and hysteria scales of the Minnesota Multiphasic Personality Inventory (MMPI; Hathaway & McKinley, 1951). The authors classified these patients as having “emotionally overwhelmed” profiles, characterised by elevation in scores of the neurotic triad (hypochondriasis, depression and hysteria) and at least one other scale.

Similar results indicating an effect of personality have been found in the fibromyalgia population. In a study also using the MMPI, Perez-Pareja et al (2010) found that, compared to other chronic pain and control groups, fibromyalgia patients scored higher on all the subscales (hypochondriasis, depression, hysteria, psychopathic deviate, masculinity/femininity, paranoia, psychasthenia, schizophrenia, hypomania and social introversion) of the MMPI. Lundberg, Anderberg and Gerdle (2009) recruited 191 fibromyalgia patients and 652 controls to complete the Temperament and Character Inventory (TCI; Cloninger, 1994). They found the fibromyalgia group to be significantly different from the controls on a number of characteristics; specifically the fibromyalgia patients were high in harm avoidance, high in persistence, low in self-directedness and high in self transcendence.

Perfectionism in fibromyalgia is something that has only been investigated indirectly. Van Houdenhove and colleagues have spoken about the relationship between perfectionism and Chronic Fatigue Syndrome/Fibromyalgia, stating both that “in our experience, the onset of FM (and CFS) is often associated with the chronic stress of an overactive lifestyle, pathological perfectionism or self-sacrificing care-giving behaviour” (van Houdenhove, 2003) and “many FM patients appear to have created their own lifestyle stress- often since their early youth- by physically or mentally overexerting themselves, being too perfectionistic or overcommitted at

work or engaging in disproportionate self-sacrificing behaviour”(van Houdenhove & Luyten, 2006). However, the work they use to back up these statements investigates action-proneness (van Houdenhove et al, 1995, van Houdenhove et al, 2001) and physical activity levels (Smith et al, 2006), rather than directly measuring perfectionism. In an early study, van Houdenhove, Onghena, Neerinckx and Hellin (1995) recruited thirty-five CFS patients and four control groups to complete the Dutch version of the HAB Action-Proneness Scale (Dirken, 1970). They found that their CFS patients and their functional pain control group were significantly more action prone than their organic illness controls and their neurotic controls. A later study (van Houdenhove, Neerinckx, Onghena, Lysens and Vertommen, 2001) recruited both CFS patients and FM patients as well as their partners to complete the HAB Action-Proneness Scale, with partners answering the questions about their partner. Both the patients and their partners suggested the patients in both groups were high in action proneness. Though these two studies provide consistent evidence for a difference in the levels of action-proneness in people with and without fibromyalgia, it is unclear how this directly links to perfectionism, particularly as van Houdenhove, Neerinckx, Onghena, Lysens and Vertommen (2001) state that “the relationship between the concept of “action-proneness”- as measured by the HAB- and various behavioural or personality features promoting “overactivity” such as high achievement motivation, obsessive-compulsive traits, perfectionism, type-A like behaviour, “workaholism”, self-sacrificing tendencies, alexithymia etc is not clear”. In this study the aim was to directly measure perfectionism in people with fibromyalgia, as well as to investigate a number of other related personality traits, such as work ethic and fear of failure.

Measures

Here perfectionism in fibromyalgia patients was assessed directly using the Dimensions of Perfectionism (Frost, Marten, Lahart & Rosenblate, 1990) scale. The DoP breaks perfectionism down into six subscales, each of which it was believed could be relevant to people with fibromyalgia. The six subscales are titled: Concern over Mistakes, Personal Standards, Parental Expectations, Parental Criticism, Doubts about Actions and Organisation. The Concern over Mistakes subscale contains nine questions including “I should be upset if I make a mistake” and “if I fail partly, it is as bad as being a complete failure”. It attempts to assess responders’ beliefs about failure and the importance of maintaining high standards. The Personal Standards subscale contains seven questions including “if I do not set the highest standards for myself I am likely to end up a second rate person” and “I have extremely high goals”. It attempts to assess responders’ standards and goals. The Parental Expectations subscale contains five questions including “my parents set very high standards for me” and “only outstanding performance is good enough in my family”. It attempts to assess the standards responders were expected to reach as they were growing up, as well as in the present. The Parental Criticism subscale contains four questions including “as a child I was punished for doing things less than perfect” and “I never felt like I could meet my parents’ expectations”. It attempts to assess the amount of criticism responders felt they received from their parents when they could not maintain their parents’ standards. The Doubts about Actions subscale contains four questions including “even when I do something very carefully I often feel that it is not quite right” and “I tend to get behind in my work because I repeat things over and over”. It attempts to assess responders’ compulsive attitudes towards tasks. Finally the Organisation subscale contains six questions including “organisation is very important to me”

and “I am a neat person”. It attempts to assess responders’ beliefs about organisation and neatness.

A number of other traits were suggested by participants as being potentially important in fibromyalgia, such as fear of failure, and these were also investigated. In addition, a scale looking at a trait that had been investigated before (neuroticism) was also included, in order to see how the present sample compared to previous ones. This meant that the questionnaire sent to participants was comprised of a number of scales. These were the Fear of Failure scale (Conroy et al, 2002), the Social Interaction Anxiety Scale (Mattick and Clarke, 1998), the Protestant Work Ethic (Mirels and Garrett, 1971), the Just World Scale (Lipkus, 1991), the Martin-Larsen Approval Motivation scale (Larsen, Martin, Ettinger & Nelson, 1976), the Rosenberg Self-Esteem Scale (Rosenberg, 1965) and the Neuroticism and Extroversion scale (Eysenck, 1958). In order to minimise participant confusion, and to make the questionnaire as easy as possible to fill in, all questions were answered using the same scale, a seven-point likert scale, anchored by “strongly agree” and “strongly disagree”. This was true of all the questions apart from the Neuroticism and Extroversion scale (Eysenck, 1958) which is comprised of yes/no questions and remained the same. Participants were also asked to describe their current and average pain, using the pain descriptor scale of the short-form McGill pain questionnaire (Melzack, 1987).

The Fear of Failure scale (Conroy et al, 2002) contains twenty-five questions, including “when I am failing I worry that others may think I am not trying” and “when I am failing my value decreases for some people”. It was included as it was thought that participants may be

high in perfectionism because of a higher than average fear of failure and this questionnaire was thought to be most appropriate for testing this.

The Social Interaction Anxiety Scale (Mattick & Clarke, 1998) contains nineteen questions, including “I get nervous if I have to speak with someone in authority (teacher, boss etc)” and “when mixing socially I am uncomfortable”. It attempts to assess general social anxiety, both in a work and social setting. This was included to assess participants’ attitudes towards social interaction, and the ease with which they interact with other people. It was included to compliment the questions asked in the previous chapter’s relationship interview.

The Protestant Work Ethic (Mirels and Garrett, 1971) contains nineteen questions including “most people spend too much time in unprofitable amusements” and “people who fail at a job have usually not tried hard enough”. It was included to provide further information about participants’ attitudes to work and other people’s work ethic.

The Just World Scale (Lipkus, 1991) contains thirty questions including “I have found that the people who work the hardest at their jobs are not always the ones who get promoted” and “people who offer help in times of crisis rarely find their help is reciprocated when they are the one in need”. This scale was included to provide further information about participants’ attitudes towards hard work, and also to assess their attitudes towards the fairness of society and the world around them.

The Martin-Larsen Approval Motivation scale (Larsen, Martin, Ettinger & Nelson, 1976) contains twenty questions including “depending upon the people involved, I react to the same situation in different ways” and “I change my opinion (or the way that I do things) in order to

please someone else". This was included as some participants mentioned that a part of their perfectionism involves sacrificing their own time and wellbeing to make other people happy and to maintain perfect relationships. It was thought that this scale would test this suggestion.

The Rosenberg Self-Esteem Scale (Rosenberg, 1965) contains ten questions including "on the whole I am satisfied with myself" and "I feel that I'm a person of worth, at least on an equal plane with others". This scale was included to assess self-esteem, as it was thought that one possible reason for participants' need for perfection could be a lack of self esteem.

The Neuroticism and Extroversion scale (Eysenck, 1958) includes eighteen questions, nine to measure extroversion, including "do you like having a lot of things going on around you?", and nine to measure neuroticism, including "are you often uneasy, feeling that there is something you want without knowing it?". It was included to assess whether the results of this sample match those of previous samples, as it has previously been shown that people with fibromyalgia score more highly on neuroticism questionnaires than controls.

A measure of pain was also included, specifically the pain descriptor scale of the short-form McGill pain questionnaire (Melzack, 1987). The short-form McGill pain questionnaire is ordinarily comprised of three parts: the primary pain descriptor measure, containing 15 pain descriptor words, and two other measures, a present pain intensity index and a visual analogue scale. These scales were excluded from the current study as it was felt that the descriptor scale would provide sufficient information about the nature of participants' pain.

Method

The questionnaires comprised of the various scales were posted to people with fibromyalgia, other pain controls, and pain free controls. Participants were asked to complete them and post them back using a stamped addressed envelope.

Recruitment

Fibromyalgia patients were recruited through messages sent out to the fibromyalgia support group network and messages placed on websites and in newsletters. As all the fibromyalgia participants were recruited through a support network, the control participants were also recruited through various groups. Participants were recruited in this way as it was felt that all of the participants should be “group-joiners”, as it was felt that there was the potential for personality differences between people with fibromyalgia who join support groups and those who do not. The pain free controls and people with other pain conditions were recruited from Women’s Institutes. The experimenter attended meetings and gave a ten minute presentation to explain the study and recruit volunteers. Information sheets, consent forms and SAEs were available for attendees to take away. Rheumatoid arthritis patients were recruited in a similar way via RA support groups. An invitation to take part was also placed on a large Rheumatoid Arthritis forum.

Participants

Before filling in the questionnaire participants were asked to complete a demographics sheet, listing their age, sex and whether they had been diagnosed with fibromyalgia, rheumatoid arthritis, or any other condition with pain as a primary symptom. They were also asked to indicate whether they suspected they might have these illnesses, if they had not been

formally diagnosed. In total 129 females returned completed questionnaires. Of these 46 were fibromyalgia patients (mean age 49.5, range 27-71), 20 were rheumatoid arthritis patients and 12 had other pain conditions. These latter patients were collapsed into a single pain patient control group (mean age 59.9, range 42-75). 32 participants were healthy pain free controls (mean age 62.2, range 39-77). Participants who reported fibromyalgia and other pain conditions (16) were excluded, as were participants who reported rheumatoid arthritis and other pain conditions (2). One person did not say whether she suffered from rheumatoid arthritis, fibromyalgia or other pain conditions and so was excluded.

Procedure

The questionnaires were posted to participants when consent forms were received. The questionnaire booklet comprised 23 pages, including instructions and demographics. Except for the demographics, pain ratings and 19 yes/no questions all questions included a 7 point Likert scale anchored with “strongly disagree” and “strongly agree” (see appendix eight). 193 booklets were posted and 151 were returned (response rate =78%). Out of the 151 returned booklets, 19 were excluded due to the high number of unanswered questions, two were excluded because the participants answered every question with 1 and two were excluded as they were returned by men. 128 remained.

The questionnaire booklet included the dimensions of perfectionism scale (Frost et al, 1990). This scale breaks perfectionism down into six subscales: Concern over Mistakes, Personal Standards, Parental Expectations, Parental Criticism, Doubts about Actions and Organisation.

The questionnaire booklet also included the Social Interaction Anxiety Scale (Mattick & Clarke, 1998), the Protestant work ethic (Mirels & Garrett, 1971), the Fear of Failure scale (Conroy et al, 2002), the Just World scale (Lipkus, 1991), the Martin-Larsen Approval Motivation Scale (Larsen, Martin, Ettinger & Nelson, 1976), the Rosenberg Self-Esteem Scale (Rosenberg, 1965), the Neuroticism and Extroversion scale (Eysenck, 1958) and the pain descriptor scale of the short-form McGill pain questionnaire (Melzack, 1975).

Results

One-way between subjects ANOVAs were used to compare the mean scores of the three groups (fibromyalgia group, other-pain controls and pain-free controls). For each significant finding, post-hoc paired comparisons with a Bonferroni correction were used to investigate which conditions resulted in significantly different scores. A summary of all findings is presented in table 7.1. The effect of age was investigated as a covariate but was found to have an insignificant effect ($F = 1.158$, $p = .335$) and so was removed from the analysis.

A one-way ANOVA revealed that there were significant differences between the three groups in the level of pain experienced while filling in the questionnaire and the level of pain experienced in general ($F(2, 105) = 41.709$, $p < .001$; $F(2, 105) = 83.787$, $p < .001$ respectively). Post-hoc paired comparisons with a Bonferroni correction were made to investigate which conditions resulted in significantly different scores. When asked about pain experienced while filling in the questionnaire, it was found that the fibromyalgia group experienced more pain than either control groups (fibro vs other-pain $p < .001$; fibro vs pain-free $p < .001$). There was no significant difference in the amount of pain experienced by the two control groups ($p = .147$)

When asked about pain in general, it was again found that the fibromyalgia group experienced significantly more pain than either control group (fibro vs other-pain $p < .001$; fibro vs pain-free $p < .001$). However, it was also found that the other-pain group reported experiencing more pain than the pain-free group ($p = .015$). Entering pain experienced in general, measured by the pain descriptor scale of the short-form McGill pain questionnaire, eliminated all of the significant differences reported below. For a discussion of the meaning of this, please see section the discussion.

Table 1- Summary of results

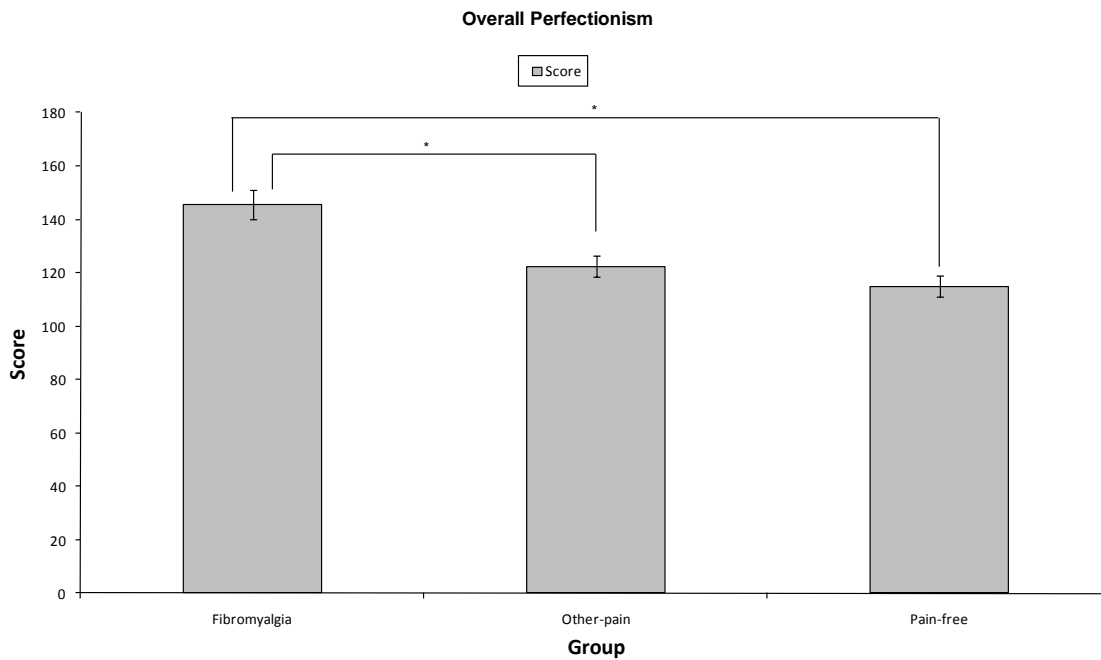
Scale	F raw score	OP raw score	PF raw score	Significance	Direction
Dimensions of perfectionism	145.59	122.48	114.85	F(2, 91) = 11.70, p< .001	Fibromyalgia participants were higher in perfectionism than the two control groups
DOP- Concern over mistakes	31.26	26.11	21.67	F(2, 101) = 9.99, p< .001	Fibromyalgia participants were significantly more concerned over mistakes than the pain-free group
DOP- Personal standards	32.44	26.59	26.53	F(2, 102) = 7.228, p= .001	Fibromyalgia participants had higher personal standards than the two control groups
DOP- Parental expectations	16.56	16.20	15.38	F(2, 99) = .262, p= .77	N/A
DOP- Parental criticism	13.80	9.20	8.48	F(2, 106) = 8.184, p< .001	Fibromyalgia participants experienced more parental criticism than the two control groups
DOP- Doubts about actions	15.93	12.84	10.42	F(2, 103) = 11.546, p< .001	Fibromyalgia participants experience more doubts about their actions than the two control groups
DOP- Organisation	33.01	28.75	32.89	F(2, 105) = 3.58, p= .031	Fibromyalgia participants were more organised than the other-pain group
Fear of Failure	104.83	91.77	78.97	F(2, 98) = 8.4, p< .001	Fibromyalgia participants were more scared of failure than the pain-free controls
Social Interaction Anxiety	67.18	51.86	47.10	F(2, 94) = 8.339, p< .001	Fibromyalgia participants experienced more social interaction anxiety than either of the controls
Protestant Work Ethic	73.28	71.45	76.13	F(2, 97) = 1.036, p= .359	N/A
Just World	125.49	128.77	139.69	F(2, 89) = 11.274, p< .001	Fibromyalgia participants reported less belief in a just world than the pain-free controls
Approval Motivation	74.78	72.90	70.66	F(2, 99) = .952 p= .523	N/A
Self Esteem	43.12	52.17	56.58	F(2, 105) = 14.382, p< .001	Fibromyalgia participants had less self esteem than either of the control groups
Extraversion	4.12	4.80	5.62	F(2, 97) = 3.346, p= .039	Fibromyalgia participants were less extroverted than the pain-free controls
Neuroticism	6.88	5.10	4.17	F(2, 101) = 14.593, p< .001	Fibromyalgia participants were more neurotic than the pain-free controls

Perfectionism

As can be seen from table 1 and figure 1, there were significant differences across the three groups on their average Dimensions of Perfectionism score ($F(2, 91) = 11.70, p < .001$), with the fibromyalgia group significantly higher in perfectionism than either of the control groups (fibro vs other-pain $p = .002$; fibro vs pain-free $p < .001$). There were no significant differences between the two control groups ($p = .88$).

Figure 1

Overall scores on the Dimensions of Perfectionism scale (Frost, Marten, Lahart & Rosenblate, 1990)



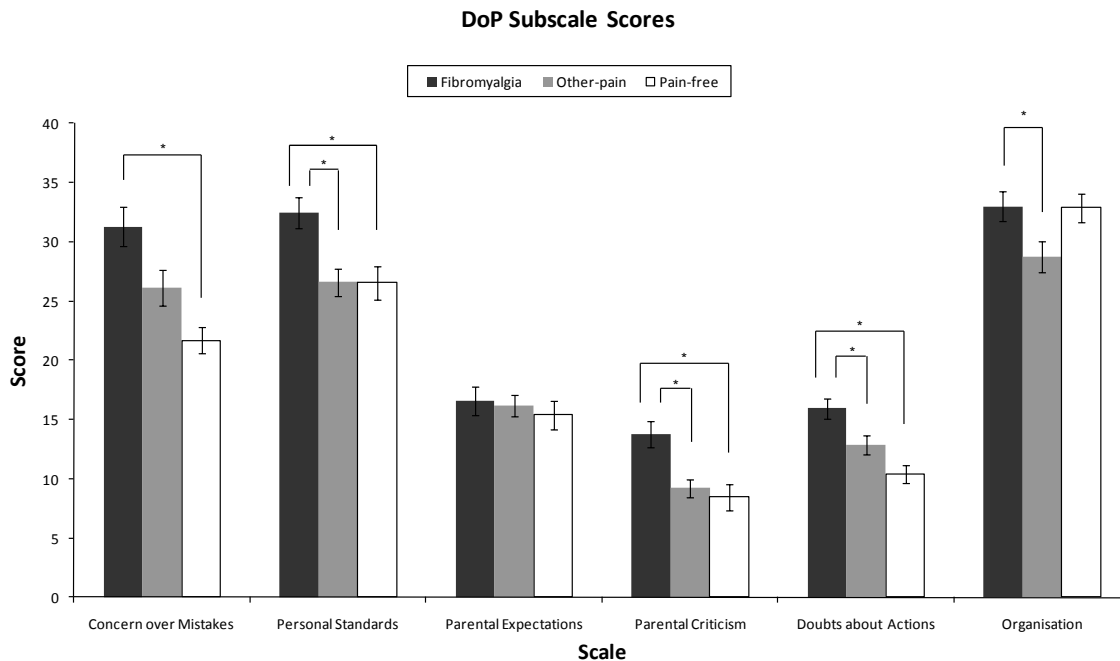
Figure

indicates the average scores of each of the three groups on overall Dimensions of Perfectionism. * = significant at the .05 level.

As can be seen from table 1 and figure 2, there were a number of differences between each groups' scores and overall significant differences were found on five of the six subscales. The five subscales in which there were significant differences between the groups were the Concern Over Mistakes subscale ($F(2, 101) = 9.99, p < .001$), the Personal Standards subscale ($F(2, 102) = 7.228, p = .001$), the Parental Criticism subscale ($F(2, 106) = 8.184, p < .001$), the Doubts about Actions subscale ($F(2, 103) = 11.546, p < .001$) and the Organisation subscale ($F(2, 105) = 3.58, p = .031$). There were no significant differences on the Parental Standards subscale ($F(2, 99) = .262, p = .77$).

Figure 2

Average scores on the six subscales of the Dimensions of Perfectionism scale



Figure

indicates the average scores of each of the three groups on each of the six Dimensions of Perfectionism subscales. * = significant at the .05 level.

On the five subscales where significant differences were found between the groups, post-hoc paired comparisons with a Bonferroni correction suggested that in the majority of cases, it was the fibromyalgia group that was significantly different from the two control groups, which were not significantly different from each other. This was the case for the Personal Standards subscale (fibro vs other-pain $p = .005$; fibro vs pain-free $p = .006$), the Parental Criticism subscale (fibro vs other-pain $p = .006$; fibro vs pain-free $p = .001$) and the Doubts about Actions subscale (fibro vs other-pain $p = .027$; fibro vs pain-free $p < .001$). In the case of the Concern Over Mistakes subscale the only significant difference between the groups was between the fibromyalgia group and the pain-free control group ($p < .001$), whereas in the case of the Organisation subscale, the only significant difference was between the fibromyalgia group and the other-pain control group ($p = .046$).

Other Scales

Figure 3

Average scores of each group on the Fear of Failure, Social Anxiety and Protestant Work Ethic Scales

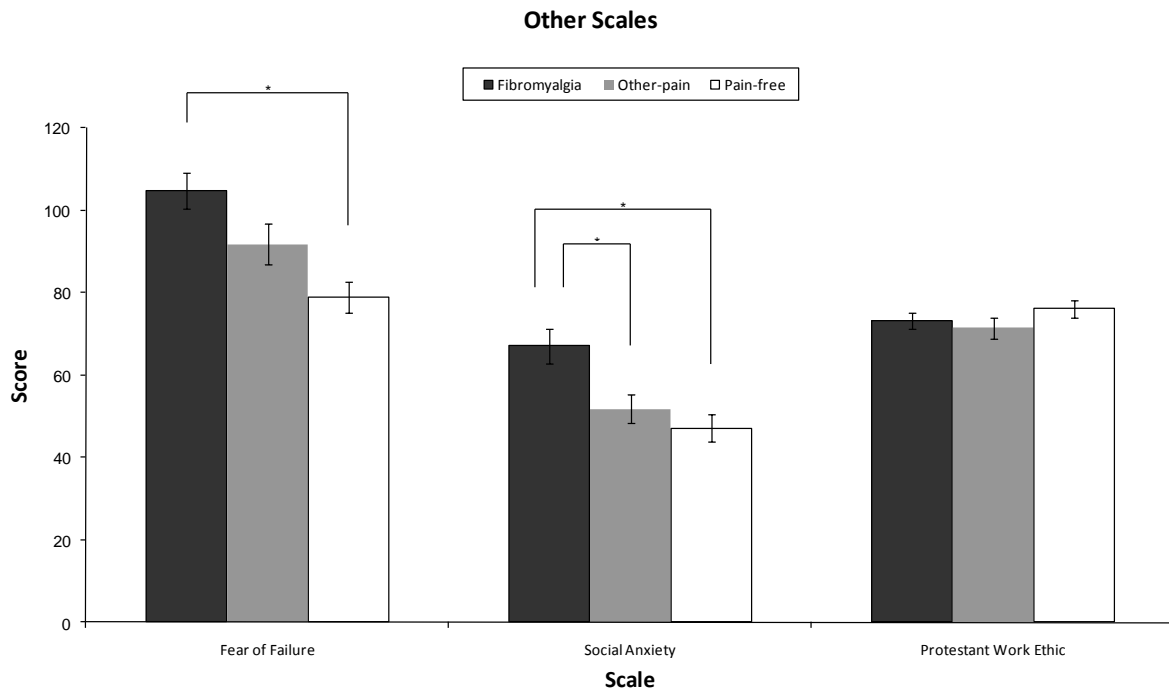


Figure indicates the averages scores of the three groups on the three scales. * = significant at the .05 level.

A number of significant differences were found across the three groups on the eight other scales (see figures 3 and 4). Overall the Fear of Failure ($F(2, 98) = 8.4, p < .001$), Social Interaction Anxiety ($F(2, 94) = 8.339, p < .001$), Just World ($F(2, 89) = 11.274, p < .001$), Self-Esteem ($F(2, 105) = 14.382, p < .001$), Extraversion ($F(2, 97) = 3.346, p = .039$) and Neuroticism ($F(2, 101) = 14.593, p < .001$) scales showed significant differences across the three groups.

There were no significant differences across the three groups on the Protestant Work Ethic ($F(2, 97) = 1.036, p = .359$) or Approval Motivation scales ($F(2, 99) = .952, p = .523$).

Figure 4

Average Scores of each group on the remaining scales

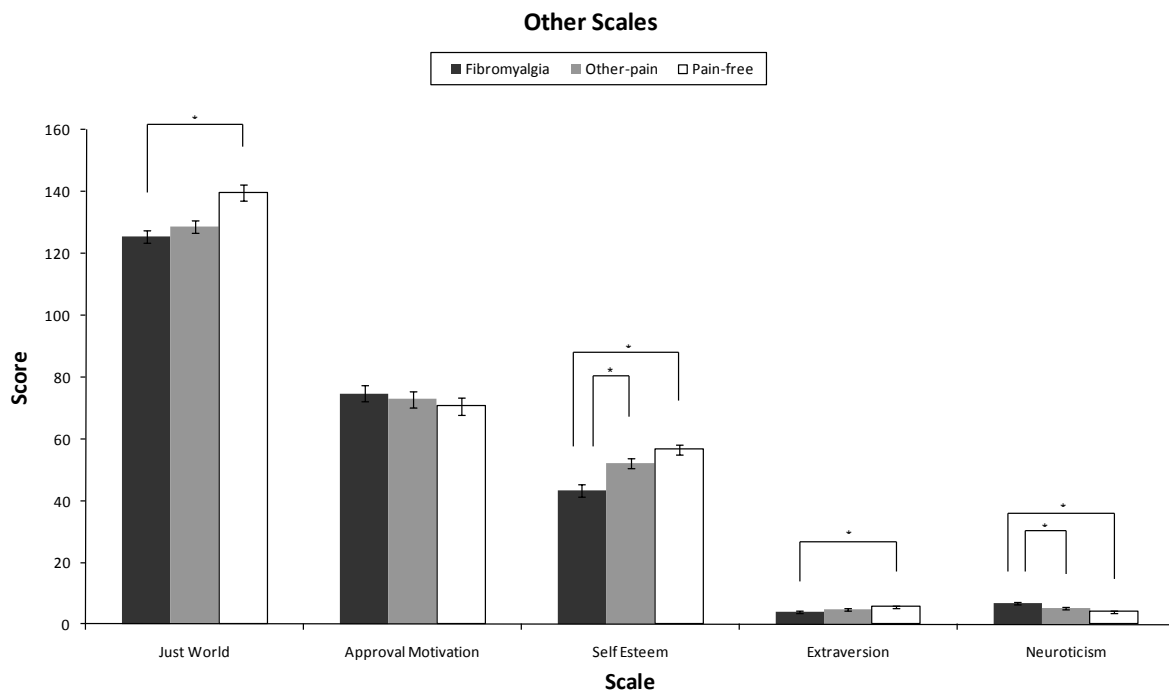


Figure 4 indicates the average scores across the three groups on the Belief in a Just World Scale, the Approval Motivation Scale, the Self Esteem scale, the Extraversion scale and the Neuroticism scale. * = significant at the .05 level.

On three of the scales there were significant differences between the fibromyalgia group and the two control groups only. These were the Social Interaction Anxiety scale (fibro vs other-pain $p = .014$; fibro vs pain-free $p = .001$), the Self Esteem scale (fibro vs other-pain $p =$

.002; fibro vs pain-free $p < .001$) and the Neuroticism scale (fibro vs other-pain $p = .002$; fibro vs pain-free $p < .001$).

On three of the scales there were only significant differences between the fibromyalgia group and the pain-free group. These were the Fear of Failure scale ($p < .001$), the Just World scale ($p < .001$) and the Extraversion scale ($p = .034$).

Discussion

This study supports the view, proposed by the fibromyalgia interview participants in the previous chapter, that fibromyalgia patients are high in perfectionism. Fibromyalgia patients were also shown to be high in social anxiety, high in neuroticism and low in self esteem.

Perfectionism

Here perfectionism was the primarily investigated trait. The results showed that people with fibromyalgia were higher in overall perfectionism than the pain-free and other-pain controls. People with fibromyalgia were also scored more highly than one or both of the controls on five out of the six subscales of perfectionism. The fibromyalgia group scored significantly higher than both control groups on three subscales: personal standards, parental criticism and doubts about actions. The fibromyalgia group scored significantly higher than the pain-free controls on the concern over mistakes subscale, though the other-pain controls were not significantly different from the fibromyalgia group. The fibromyalgia group scored significantly higher than the other-pain controls on the organisation subscale, though the pain-

free controls were not significantly different from the fibromyalgia group. There were no significant differences between any of the three groups on the parental expectations subscale.

Perfectionism is a trait that has been implicated in a number of other syndromes and problems. Chronic fatigue syndrome (CFS), a close relation of fibromyalgia and a common co-morbidity in fibromyalgia patients, has a controversial relationship with perfectionism. A study of 44 CFS participants and 44 controls found that people with CFS scored higher on measures of overall perfectionism and on the Dimensions of Perfectionism subscales Doubts about Actions and Concern over Mistakes (White and Schweitzer, 2000). However both Blenkiron, Edwards and Lynch (1999), who investigated 40 CFS participants and 31 controls, and Wood and Wessely (1999) who investigated 101 CFS participants and 45 rheumatoid arthritis patients found no significant differences in levels of perfectionism across their groups. These differences may have been due to differences in participant recruitment practises across the studies. Blenkiron, Edwards and Lynch (1999) and Wood and Wessely (1999) both recruited participants from specialised clinics, a specialist tertiary care clinic and a specialist CFS clinic respectively. White and Schweitzer (2000) recruited participants from an infectious disease specialist physician. It may be that CFS patients who are already part of a CFS specialist clinic approach studies of personality differently to those who are not involved in specialist clinics. The participants in the present study were recruited from support groups. Though support groups are different to specialist clinics, participation in both of these puts participants in a specialised and focused environment. This may mean that the participants in this sample were likely to be closer in their attitude to their illness to the participants in the Blenkiron, Edwards and Lynch (1999) and Wood and Wessely (1999) studies than the participants in White and Schweitzer's (2000) study.

As significant differences in perfectionism were found in the present fibromyalgia sample, this suggests perfectionism is potentially higher in people with fibromyalgia than CFS. As these are two syndromes that often occur co-morbidly, and are sometimes even suggested to be the same syndrome, any potential differences between the two are worthy of further investigation.

Another common co-morbidity in people with fibromyalgia is sleep problems. Previous work has shown that people with insomnia are higher in perfectionism. In a 1994 study Lundh, Broman, Hetta and Saboonchi found that people with insomnia scored higher than controls in the Concern over Mistakes and Personal Standards subscales. People who were depressed with insomnia scored more highly than non-depressed insomniacs on the Doubts about Actions subscale. Similarly, in a 2001 study Vincent and Walker found that people with chronic insomnia scored more highly in the Doubts about Actions, Parental Criticism and Concern over Mistakes subscales of the Dimensions of Perfectionism scale.

Perfectionism has also been investigated in people suffering from other forms of functional pain. For example, people with non-specific work-related upper limb disorders have been shown to be significantly higher in neurotic perfectionist traits than other, non-functional, chronic pain patients (van Eijsden-Besseling, Peeters, Reijnen and de Bie, 2004). This result, and the result found in this study in the comparison between the fibromyalgia group and the other pain group, suggests that it is not suffering from pain that is associated with higher levels of perfectionism, but suffering from functional pain. As yet there is no indication as to whether perfectionism comes before chronic pain or if chronic pain comes before perfectionism. This is something that needs to be investigated, both in fibromyalgia and other functional pain groups.

Taken together, this evidence suggests that a number of the symptoms of fibromyalgia are linked to perfectionism: chronic pain, sleeping difficulties and potentially, chronic fatigue. It therefore makes sense that fibromyalgia itself would be linked to perfectionism.

Other scales

A number of other scales thought to be relevant to people with fibromyalgia demonstrated a number of significant results, specifically the Fear of Failure scale (Conroy et al, 2002), the Social Interaction Anxiety Scale (Mattick & Clarke, 1998), the Protestant work ethic (Mirels & Garrett, 1971), the Just World scale (Lipkus, 1991), the Rosenberg Self-Esteem Scale (Rosenberg, 1965), the Martin-Larsen Approval Motivation Scale (Larsen, Martin, Ettinger & Nelson, 1976) and the Neuroticism and Extroversion scale (Eysenck, 1958). People with fibromyalgia were significantly different from pain-free and other-pain controls on the social anxiety, self esteem and neuroticism scales.

The neuroticism scale was included to ensure that with the present sample we were able to replicate a common finding, that of higher levels of neuroticism in fibromyalgia groups. In a 2002 study, also using the Eysenck personality inventory, Malt, Olafsson, Lund and Ursin found significantly higher scores on the neuroticism scale in 42 female fibromyalgia patients compared to 48 female controls. Neuroticism has been shown to be common to people with other forms of functional pain. People with facial pain disorder as somatoform disorder scored higher than control groups on the neurotic triad of the MMPI: hypochondriasis, depression and hysteria (Butcher, Dahlstrom, Graham, Tellegen, & Kaemmer, 1989).

The other scales were included as it was believed that they might have relevance to the description of the fibromyalgia personality described by the interview participants. In the case of social anxiety and self esteem, the significant results suggest these scales and others like them are worthy of further investigation in the fibromyalgia population. We also looked at a number of other scales. There were significant differences between the fibromyalgia group and the pain-free control group (but not the other-pain control group) in the fear of failure scale , the belief in a just world scale and the extroversion scale. In the case of these scales it may be that people with all forms of chronic pain, not just fibromyalgia or functional pain, show elevated scores on these scales. This again is worthy of further investigation. There were no significant differences between the fibromyalgia group and both control groups on the protestant work ethic scale and the approval motivation scale.

The effect of pain

When the level of pain experienced by participants, as measured by the pain descriptor scale of the short-form McGill pain questionnaire was added as a covariate, all of these significant differences were eliminated. This makes it difficult to say definitively that there is something unique about fibromyalgia pain, compared with other forms of intense pain. People with fibromyalgia scored significantly higher on general pain than the other-pain controls. It may be possible that people who report displaying higher levels of certain personality traits experience more pain generally, or that higher levels of pain cause extremes of personality, rather than there being something unique about people with fibromyalgia or even functional pain syndromes. Further examination of the data revealed that fibromyalgia patients in the

upper quartile of reported pain were significantly higher in numerous traits than the participants in the lowest quartile. Specifically people in the upper quartile showed higher levels of social anxiety ($F(1,15)= 6.191, p= .025$), protestant work ethic ($F(1,16)= 10.626, p= .005$), neuroticism ($F(1,19)= 23.205, p< .001$) and fear of failure ($F(1, 17)= 8.384, p= .01$). They were also significantly lower in self esteem ($F(1, 19)= 6.249, p= .022$). People with other pain showed fewer significant differences. Other-pain controls reporting higher levels of average pain were low in their Belief in a Just World ($F(1, 12)= 9.536, p= .009$) and self esteem ($F(1,14)= 5.094, p= .041$) and higher in neuroticism ($F(1, 13)= 13.864, p= .003$). However, there were some differences between the two groups, which may explain why the other pain group showed fewer significant differences. As the fibromyalgia group was larger, each quartile was made up of eleven participants, compared to only eight in the other pain group. Also the difference in mean pain ratings was very different between the two groups. The lower quartile of the fibromyalgia group reported a mean average pain rating of 8.8, while the upper quartile reported a mean average pain score of 31.8. The lower quartile of the other pain group reported a mean average pain rating of 1, while the upper quartile reported a mean average pain rating of 15.6. Interestingly, for both the fibromyalgia group and the other-pain group, there was no significant difference on scores of perfectionism between the upper and lower quartiles. This may be indicative that perfectionism is unique to fibromyalgia, while neuroticism and low self esteem increase pain experience in all cases.

Based on the evidence found in this study, it is possible to conclude that there are a number of ways in which fibromyalgia patients differ from healthy people and people with rheumatoid arthritis, in terms of personality. Perfectionism, as suggested by the patients

themselves, was only one of four differences found here, the other three being social anxiety, self esteem and neuroticism. However, it is unclear whether these differences are simply a function of the higher levels of pain reported by people with fibromyalgia. This should be investigated in further work.

The findings here suggest that the label that some people with fibromyalgia appear to have adopted, that of being perfectionists and workaholics, has some truth to it, and is not merely a counterpoint to the negative associations of fibromyalgia with malingering or laziness. This suggests that having a perfectionist personality, as well as being neurotic, having high levels of social anxiety and low self esteem could, along with labelling, be important contributing factors to the high levels of disability seen in people with fibromyalgia.

Limitations

There were certain weaknesses to this study, which should be remedied in further research. These weaknesses primarily concern the sample. There were significant differences between the mean ages of the three groups, with the fibromyalgia group having a mean age of 49.5, the other-pain controls having a mean age of 59.9 and the pain-free controls having a mean age of 62.2, a difference of over 12 years between the oldest and youngest groups. Paired comparisons showed that the fibromyalgia group were significantly younger than the two control groups, who were not different from each other. The decision to use an older control group was made to ensure that all groups were made up of a very high percentage of people who were group joiners. It was thought that there was the potential to be considerable personality differences between fibromyalgia patients who join and attend support groups and

those who do not. As the patient samples were recruited through the support community all pain-free controls were recruited through women's groups, with the aim of minimising any personality differences due to the personalities of group joiners and non-group joiners. The nature of many women's social groups led to a higher mean age in the control group.

A further limitation was self selecting nature of the sample. It may be that only fibromyalgia patients who were already open to the idea of a "fibromyalgia personality" filled in the questionnaire, which may have lead to a biased sample. As participants volunteered to fill in both the consent form and the questionnaire after being given basic details of the study, it is difficult to obtain an estimate of how many people refused to fill in the questionnaire for these ideological reasons, as the majority of people who asked for a consent form were presumably happy with the basic premise of the study. Both this and the previous problem could be somewhat remedied by posting the consent form to much larger numbers of participants from NHS patient lists, rather than working through support groups. This would not only allow general return rates to be calculated, it would also mean that a more age-matched control group could be recruited, as there would be no need to match group-joiners and non-group joiners.

Finally an important limitation was the significant difference in pain scores between the fibromyalgia group and the other pain control group. Rheumatoid arthritis patients have been compared with fibromyalgia patients in many studies (for example Dick, Eccleston & Crombez, 2002; Nordenskiold & Grimby, 1993; Ahles, Khan, Yunus, Spiegel & Masi, 1991). However,

future work investigating fibromyalgia personality and fibromyalgia in general would potentially benefit from including controls with a significantly higher level of general pain.

Further research should use larger groups of patients, recruited through postal invitation to patients on lists, rather than members of support groups. Personality traits such as fear of failure and social anxiety should be investigated further as the preliminary finding reported here suggest there may be significant differences between the fibromyalgia population and controls in these. Differences in perfectionism between support group members and non-members should also be investigated.

Conclusion

Fibromyalgia questionnaire respondents were higher in perfectionism than pain-free and other-pain controls. They also scored significantly differently on a number of other traits including social anxiety, personal satisfaction and neuroticism. Future research should compare fibromyalgia patients with control patients suffering from a comparable level of general pain.

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Appendix Eight

Fibromyalgia Personality Questionnaire

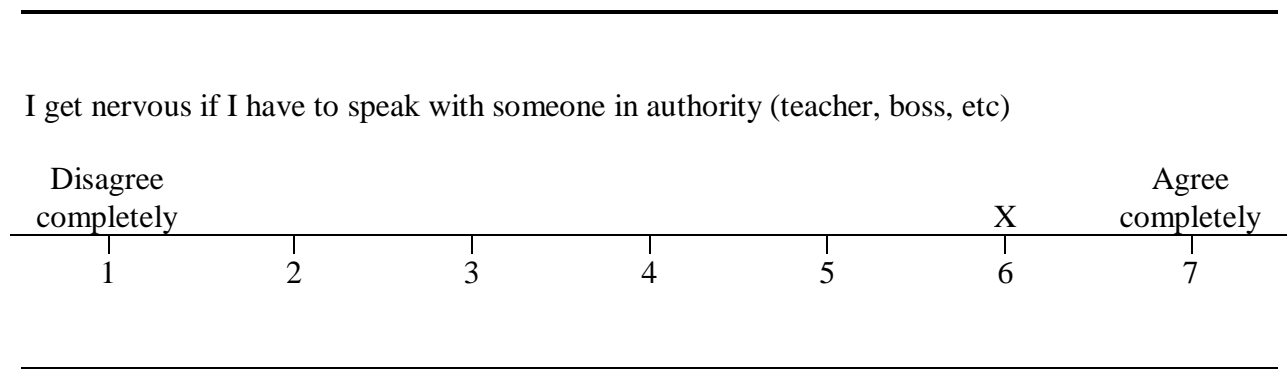
THE FIBROMYALGIA PERSONALITY QUESTIONNAIRE

Thank you for agreeing to take part in this study. Please answer the questions on the next page as honestly as you can. Always go with your gut answer. Try not to spend too long thinking about any of the questions.

Remember you have the right to withdraw at any point. You may stop answering the questions whenever you want to. You do not have to send the questionnaire back.

If you have any questions please contact the experimenter:

The majority of the questions are statements followed by a 7 point scale and you are to mark your response on the scale with a cross (X). For each of these questions placing your X above 1 on the scale indicates that you disagree completely with the statement. Placing your X above 7 means that you agree completely with the statement. For example:



The person answering this question mostly agrees with the statement “I get nervous if I have to speak with someone in authority (teacher, boss, etc)” as shown by the X above the number six.

You may place a cross anywhere on the scale (i.e., it does not have to be directly above a number)

After these statement questions there are series of YES or NO questions; please tick the box (YES or NO) you feel applies most to you.

The final questions ask about your pain experiences. Please tick the appropriate boxes.

Thank you for your participation.

Demographic Information

1) How old are you?

2) Are you (please tick the appropriate box):

Female

Male

3) Are you:

Married/in a civil partnership

Living with a partner

Single

Divorced

Widowed

4) Have you been diagnosed with:

Fibromyalgia

Rheumatoid Arthritis

Neither

5) If you indicated “neither” please tick if you suspect you may have:

Fibromyalgia

Rheumatoid Arthritis

Neither

6) Has your partner been diagnosed with:

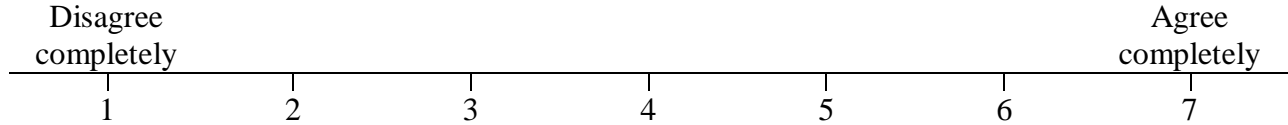
Fibromyalgia

Rheumatoid Arthritis

Neither

Please answer these questions by writing an X on each of the seven point scales, using 1 as “completely disagree” and 7 as “completely agree” depending on your beliefs about each statement above the scale.

I get nervous if I have to speak with someone in authority (teacher, boss, etc)



I have difficulty making eye-contact with others



I become tense if I have to talk about myself or my feelings



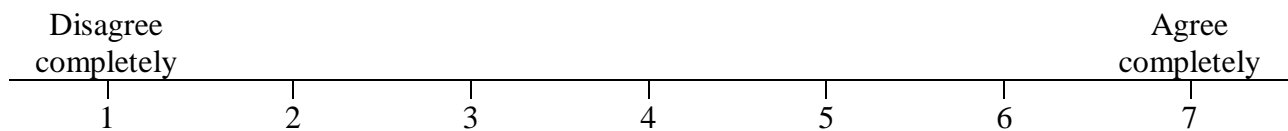
I find it difficult to mix comfortably with the people I work with



I tense-up if I meet an acquaintance in the street



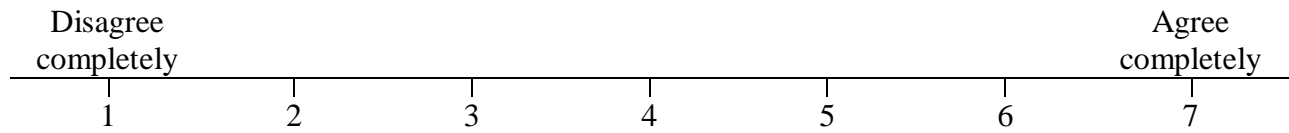
When mixing socially I am uncomfortable



I feel tense if I am alone with just one other person



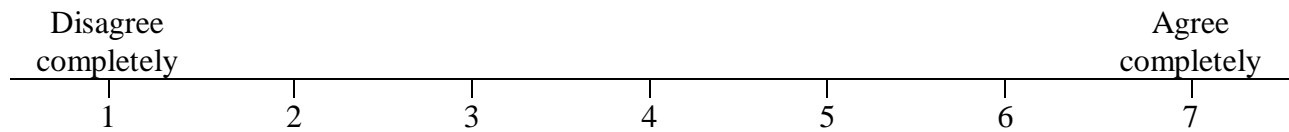
I am at ease meeting people at parties, etc



I have difficulty talking with other people



I find it easy to think of things to talk about



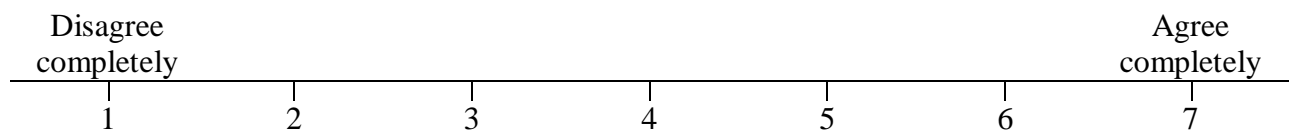
I worry about expressing myself in case I appear awkward



I find it difficult to disagree with another's point of view



I have difficulty talking to attractive persons of the opposite sex



I find myself worrying that I won't know what to say in social situations



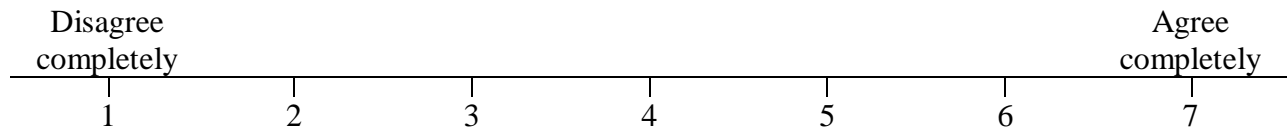
I am nervous mixing with people I don't know well



I feel I'll say something embarrassing when talking



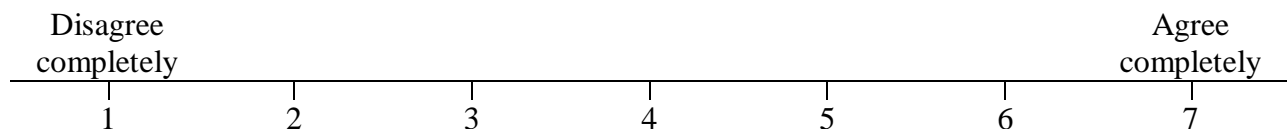
When mixing in a group I find myself worrying I will be ignored



I am tense mixing in a group



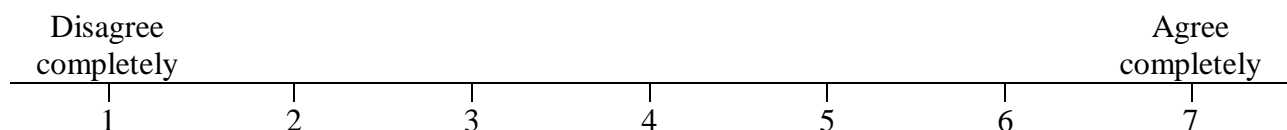
I am unsure whether to greet someone I know only slightly



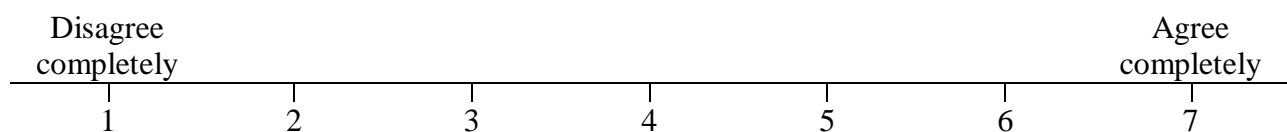
Most people spend too much time in unprofitable amusements



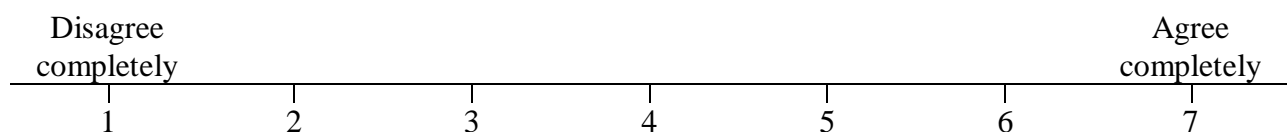
Our society would have fewer problems if people had less leisure time



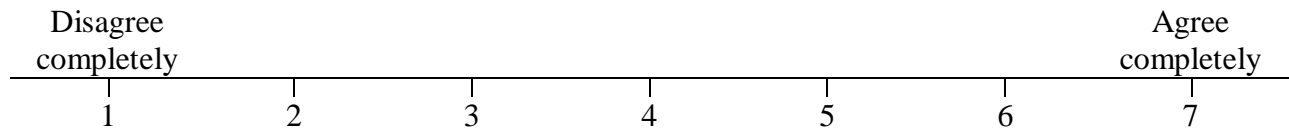
Money acquired easily (e.g. through gambling or speculation) is usually spent unwisely



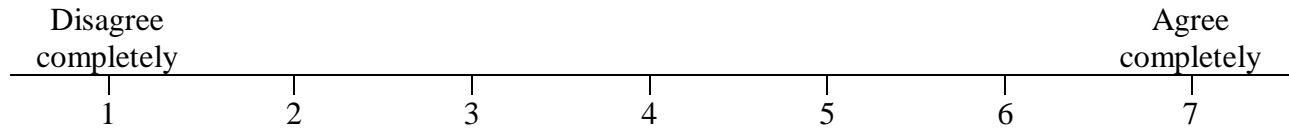
There are few satisfactions equal to the realisation that one has done his best at a job



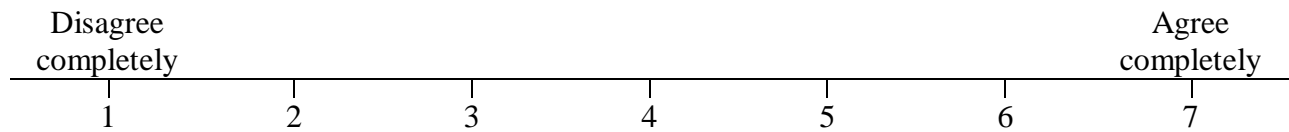
At school, the most difficult subjects usually turned out to be the most rewarding



Most people who don't succeed in life are just plain lazy



The self-made man is likely to be more ethical than the man born to wealth



I often feel I would be more successful if I sacrificed certain pleasures



People should have more leisure time to spend in relaxation



Any man who is able and willing to work hard has a good chance of succeeding



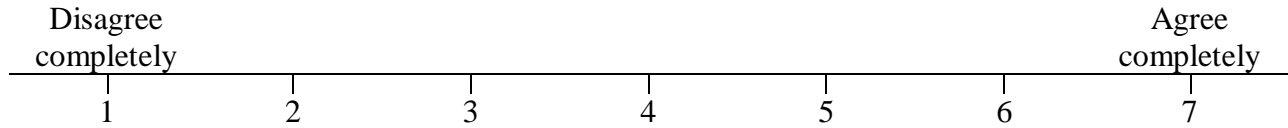
People who fail at a job have usually not tried hard enough



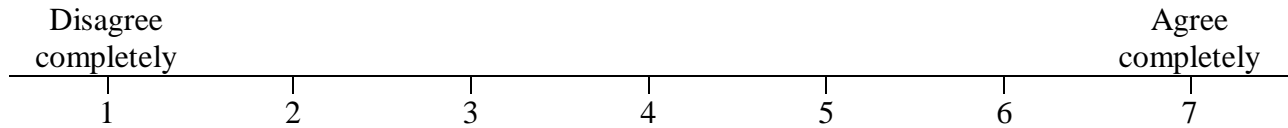
Life would have very little meaning if we never had to suffer



Hard work offers little guarantee of success



The credit card is a ticket to careless spending



Life would be more meaningful if we had more leisure time



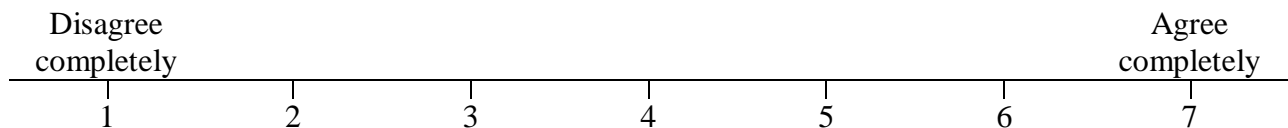
The man who can approach an unpleasant task with enthusiasm is the man who gets ahead



If one works hard enough he is likely to make a good life for himself



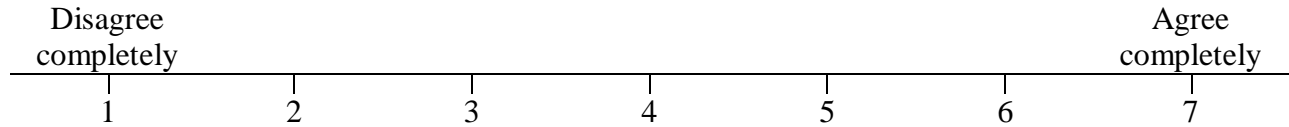
I feel uneasy when there is little work for me to do



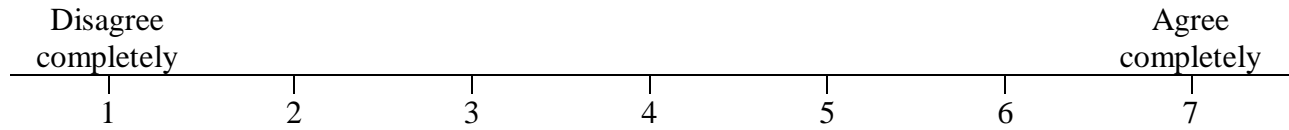
A distaste for hard work usually reflects a weakness of character



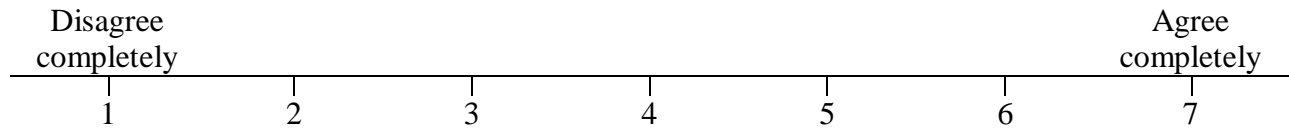
When I am failing, it is often because I am not smart enough to perform successfully.



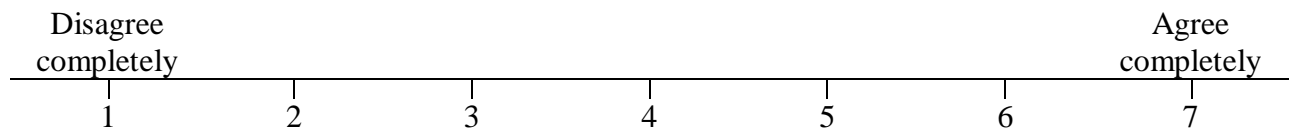
When I am failing, my future seems uncertain.



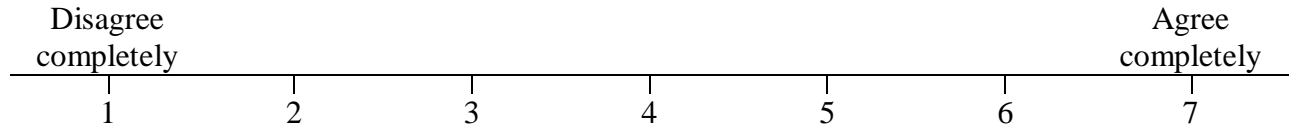
When I am failing, it upsets important others.



When I am failing, I blame my lack of talent.



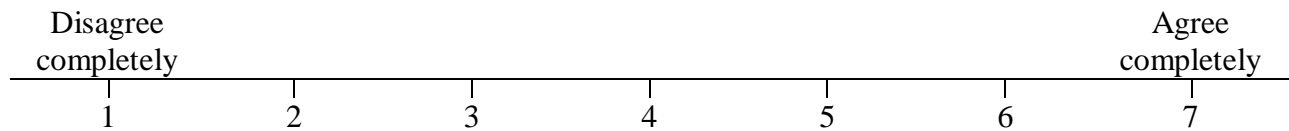
When I am failing, I believe that my future plans will change.



When I am failing, I expect to be criticized by important others.



When I am failing, I am afraid that I might not have enough talent.



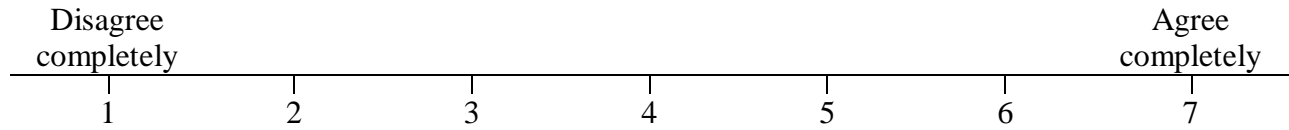
When I am failing, it upsets my “plan” for the future.



When I am failing, I lose the trust of people who are important to me.



When I am not succeeding, I am less valuable than when I succeed.



When I am not succeeding, people are less interested in me.



When I am failing, I am not worried about it affecting my future plans.



When I am not succeeding, people seem to want to help me less.



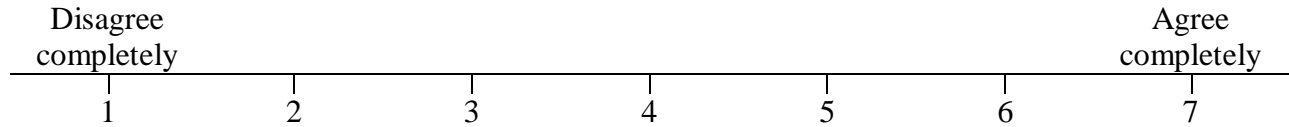
When I am failing, important others are not happy.



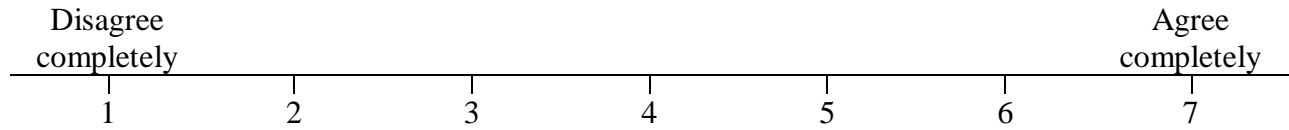
When I am not succeeding, I get down on myself easily.



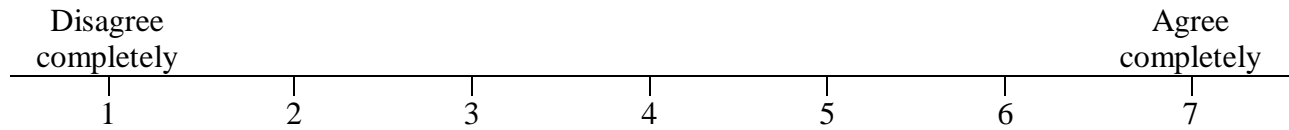
When I am failing, I hate the fact that I am not in control of the outcome.



When I am not succeeding, people tend to leave me alone.



When I am failing, it is embarrassing if others are there to see it.



When I am failing, important others are disappointed.



When I am failing, I believe that everybody knows I am failing.



When I am not succeeding, some people are not interested in me anymore.



When I am failing, I believe that my doubters feel that they were right about me.



When I am not succeeding, my value decreases for some people.



When I am failing, I worry about what others think about me.



When I am failing, I worry that others may think I am not trying.



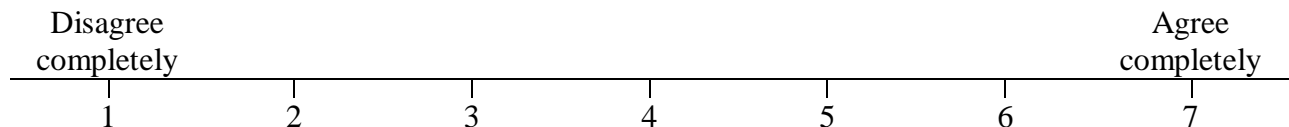
I think that I deserve the reputation I have among the people who know me



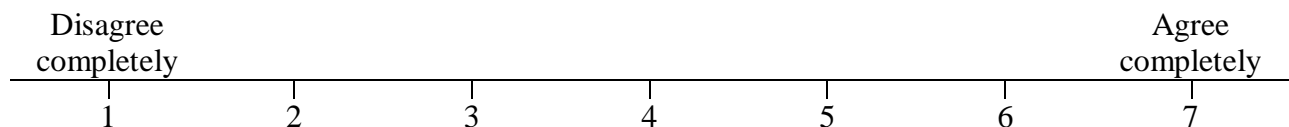
When I get “lucky breaks” it is usually because I have earned them



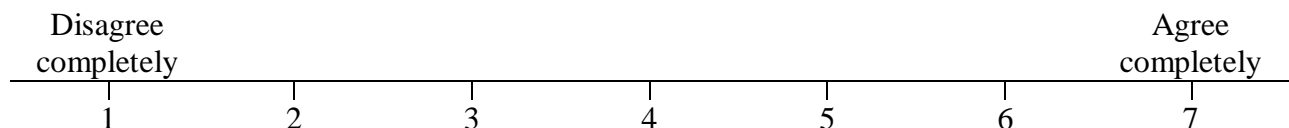
When I take examinations I rarely seem to get the grade I deserve



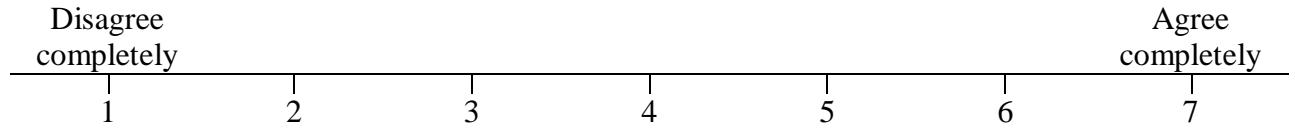
As a child I was often punished for things that I had not done



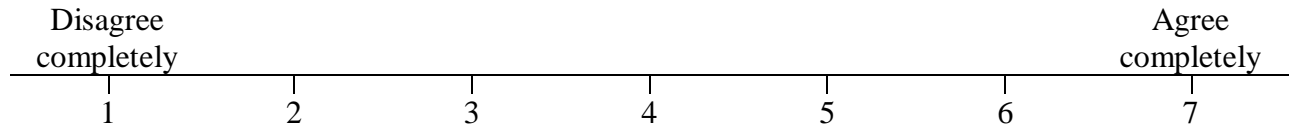
I am less likely to get hurt in traffic if I drive with caution



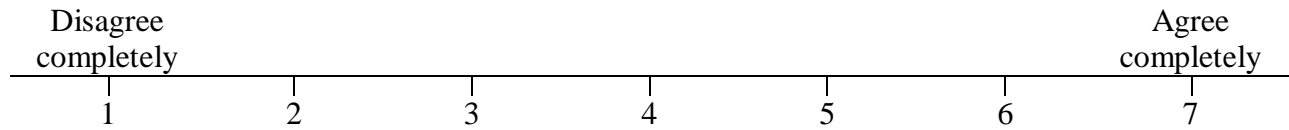
I have found that people who work the hardest at their jobs are not always the ones who get promoted



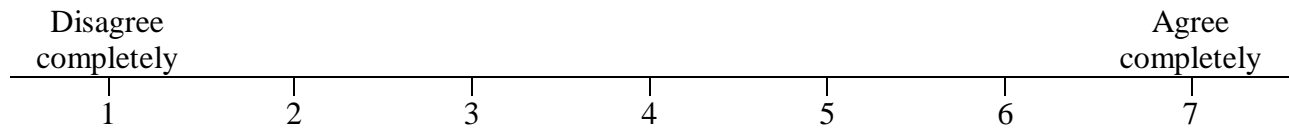
If I watch what I eat, I will live longer



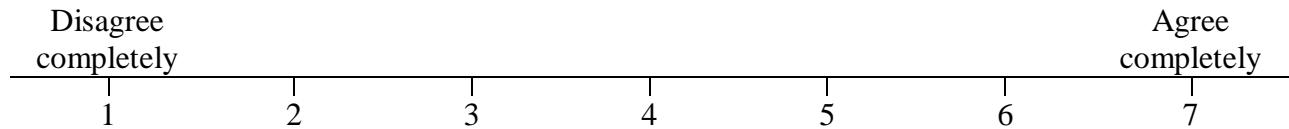
If I suffer a misfortune, I have usually brought it on myself in some way



Being nice to people will not necessarily bring me lots of friends



If I get mugged or raped, I am just plain unfortunate



In a job selection interview, the best applicant hardly ever gets the job



Parents who think of others before themselves seem to loose out on life



Parents who form good relationships with their offspring bring up more successful children



1 2 3 4 5 6 7

Friendly people have the best marriages

Disagree completely Agree completely

1 2 3 4 5 6 7

People who make the effort to invite people into their homes deserve lots of friends

Disagree completely Agree completely

1 2 3 4 5 6 7

People who offer help in times of crisis rarely find their help is reciprocated when they are the one in need

Disagree completely Agree completely

1 2 3 4 5 6 7

Lonely people are just no good at making friends

Disagree completely Agree completely

1 2 3 4 5 6 7

People who divorce have only themselves to blame for the unhappiness they may suffer

Disagree completely Agree completely

1 2 3 4 5 6 7

The group leader who prefers to solve group problems in democratic fashion is less successful

Disagree completely Agree completely

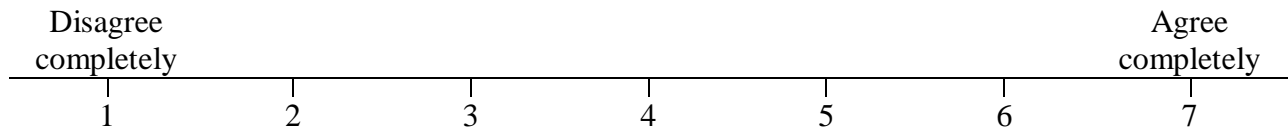
1 2 3 4 5 6 7

Outward-going, sociable people deserve a happy life

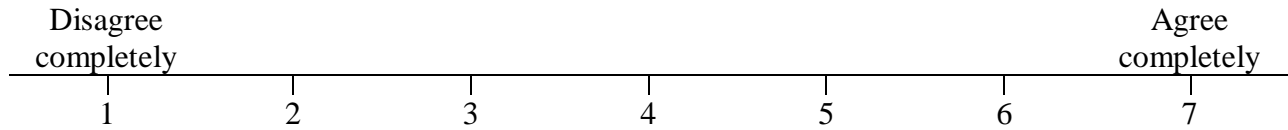
Disagree completely Agree completely

1 2 3 4 5 6 7

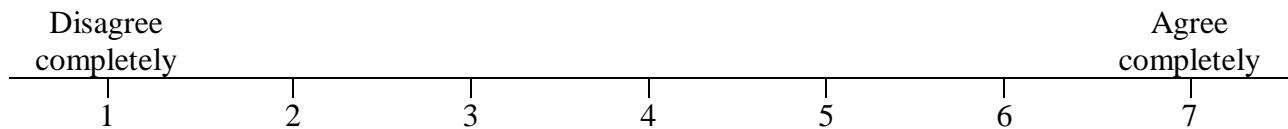
The political candidate who sticks up for his principles rarely gets elected



It is rare for an innocent man to be wrongly sent to jail



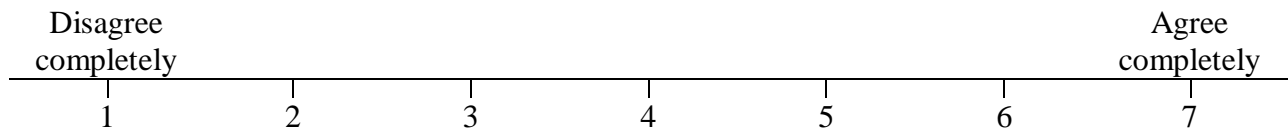
Although evil men may hold power for a while, in the general course of history good wins out



Crime does not pay



It is often impossible for a person to receive a fair trial in this country



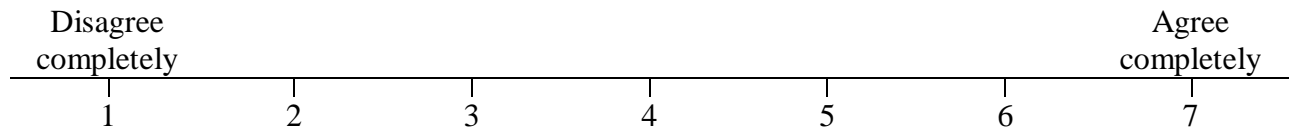
In a free market economy, the only excuse for poverty can be laziness and lack of enterprise



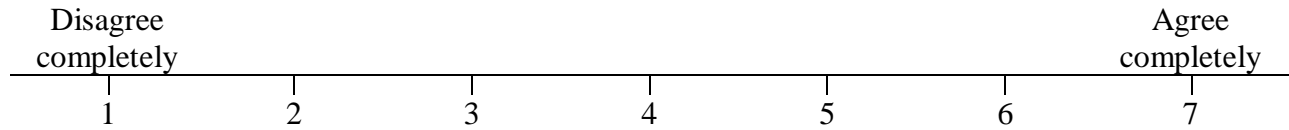
Political representatives are more interested in getting into power than representing their constituency



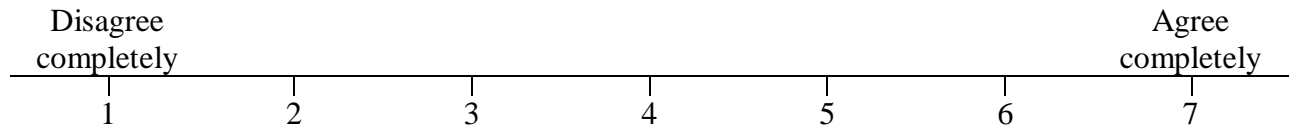
The government has ensured that every citizen has an acceptable standard of living



The forces of law and order discriminate against black people in this country



Harsh as it may sound, mass unemployment has ensured that the people in work are the ones most deserving of employment



Depending upon the people involved, I react to the same situation in different ways



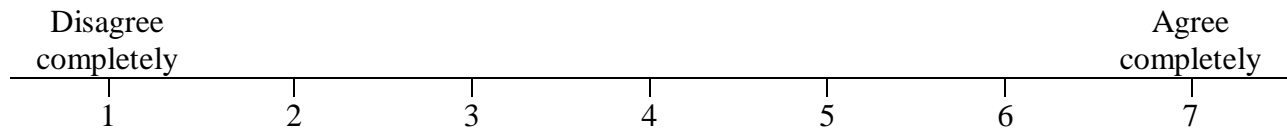
I would rather be myself than be well thought of



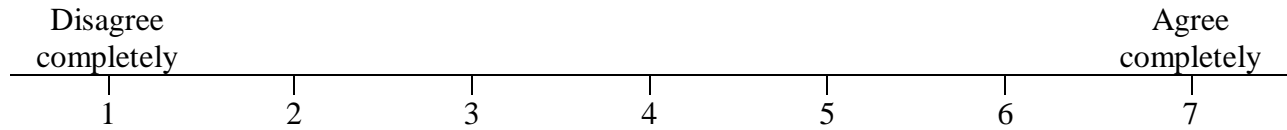
Many times I feel like just flipping a coin in order to decide what I should do



I change my opinion (or the way that I do things) in order to please someone else



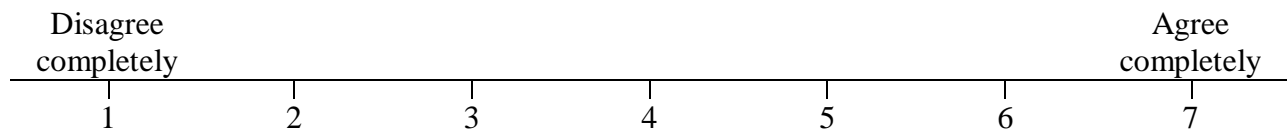
In order to get along and be liked, I tend to be what people expect me to be



I find it difficult to talk about my ideas if they are contrary to group opinion



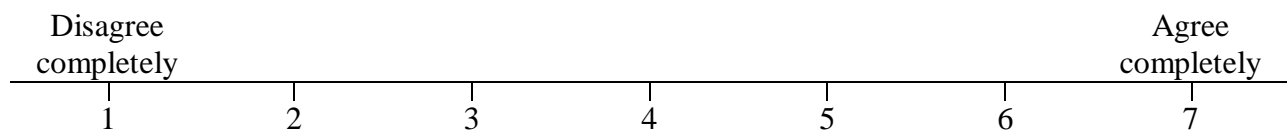
One should avoid doing things in public which appear to be wrong to others, even though one knows he is right



Sometimes I feel that I don't have enough control over the direction that my life is taking



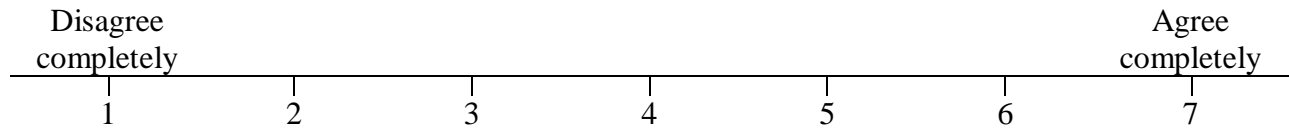
It is better to be humble than assertive when dealing with people



I am willing to argue only if I know my friends will back me up



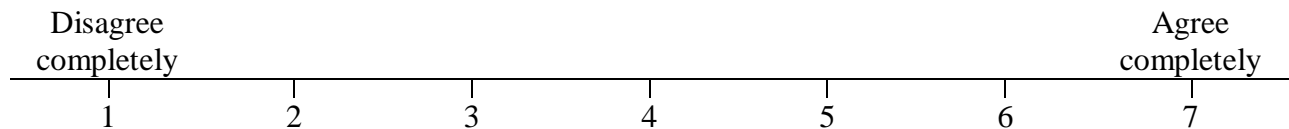
If I hear that someone expresses a poor opinion of me, I do my best the next time that I see this person to make a good impression



I seldom feel the need to make excuses or apologise for my behaviour



It is not important to me that I behave “properly” in social situations



The best way to handle people is to agree with them and tell them what they want to hear



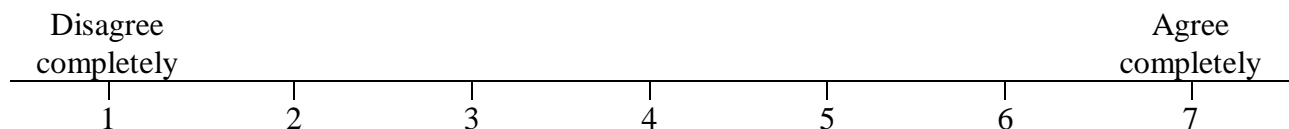
It is hard for me to go on with my work if I am not encouraged to do so



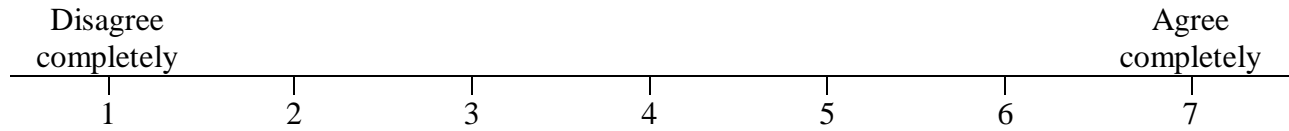
If there is any criticism or anyone says anything about me, I can take it



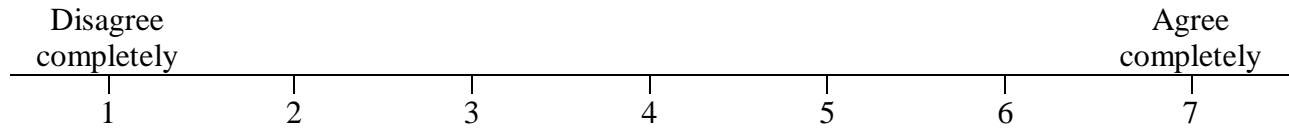
It is wise to flatter important people



I am careful at parties and social gatherings for fear that I will do or say things that others won't like



I usually do not change my position when people disagree with me



How many friends you have depends on how nice a person you are



On the whole, I am satisfied with myself



At times I think I am no good at all



I feel I have a number of good qualities



I am able to do things as well as most other people



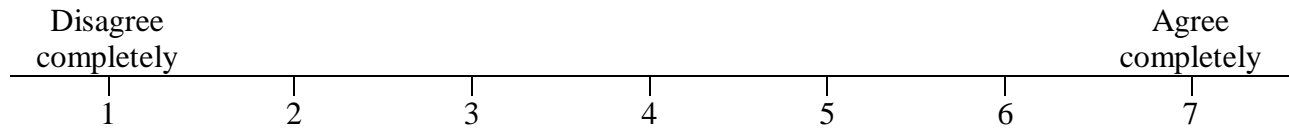
I feel I do not have much to be proud of



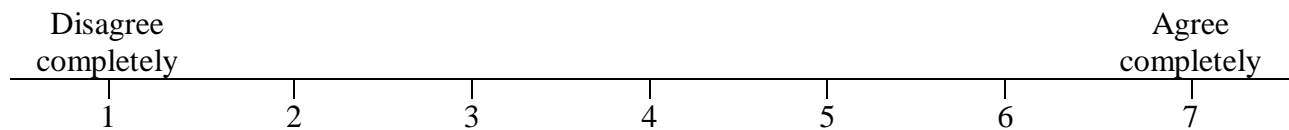
I certainly feel useless at times



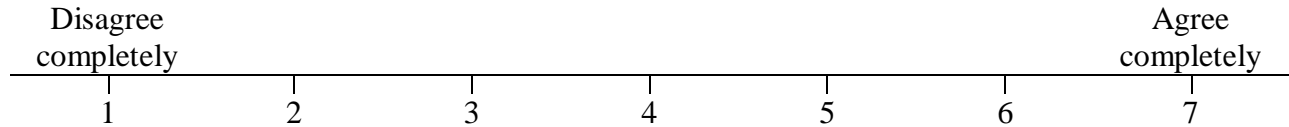
I feel that I'm a person of worth, at least on an equal plane with others



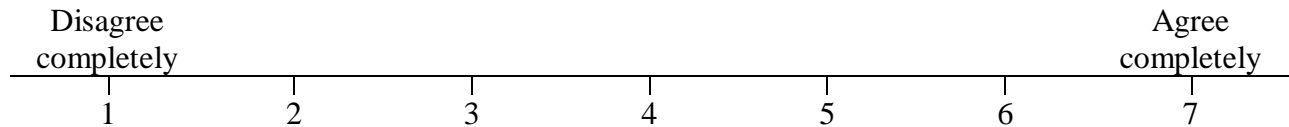
I wish I could have more respect for myself



All in all, I am inclined to feel that I am a failure



I take a positive attitude toward myself



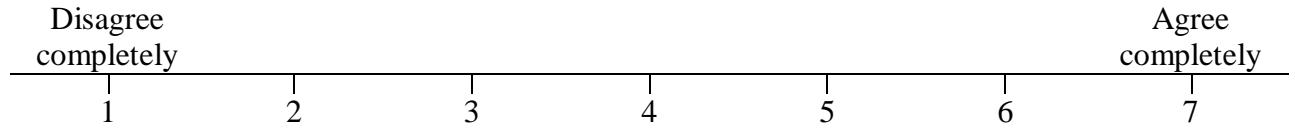
My parents set very high standards for me



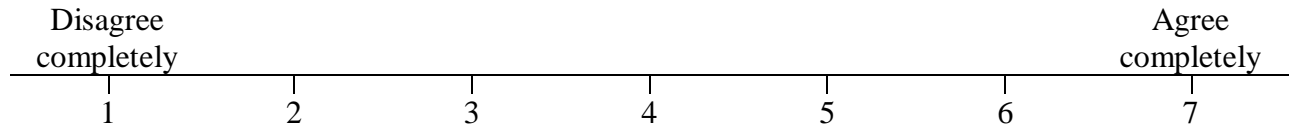
Organisation is very important to me



As a child, I was punished for doing things less than perfect



If I do not set the highest standards for myself, I am likely to end up a second rate person



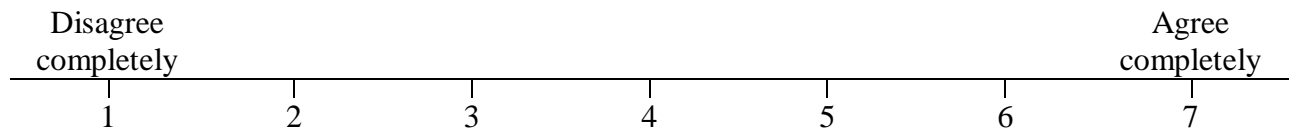
My parents never tried to understand my mistakes



It is important to me that I be thoroughly competent in everything I do



I am a neat person



I try to be an organised person

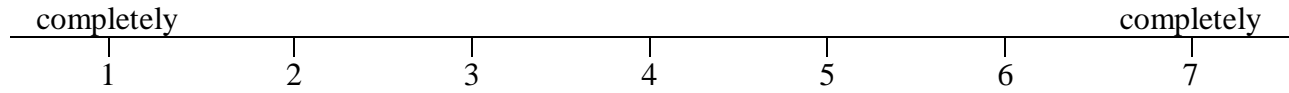


If I fail at work/school, I am a failure as a person



I should be upset if I make a mistake

Disagree 1 2 3 4 5 6 7 Agree



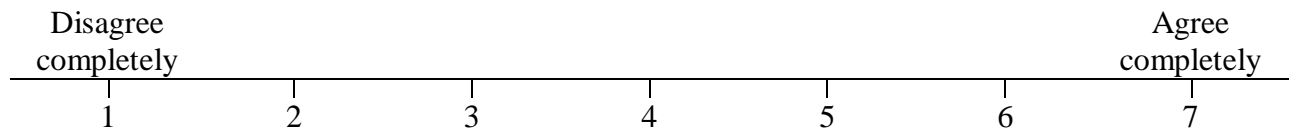
My parents wanted me to be the best at everything



I set higher goals than most people



If someone does a task at work/school better than I, then I feel like I failed the whole task



If I fail partly, it is as bad as being a complete failure



Only outstanding performance is good enough in my family



I am very good at focusing my efforts on attaining a goal

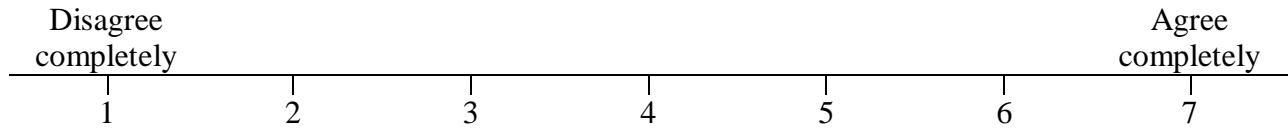


Even when I do something very carefully I often feel that it is not quite right



1 2 3 4 5 6 7

I hate being less than the best at things



I have extremely high goals



My parents have expected excellence from me



People will probably think less of me if I make a mistake



I never felt like I could meet my parents' expectations



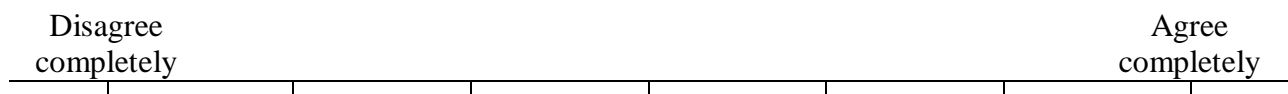
If I do not do as well as other people, it means I am an inferior human being



Other people seem to accept lower standards from themselves than I do

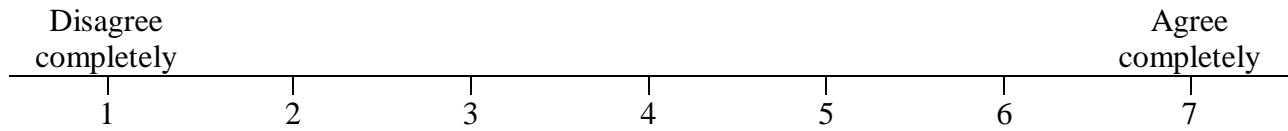


If I do not do well all the time, people will not respect me



1 2 3 4 5 6 7

My parents have always had higher expectations for my future than I have



I try to be a neat person



I usually have doubts about the simple everyday things I do



Neatness is very important to me



I expect higher performance in my daily tasks than most people



I am an organised person

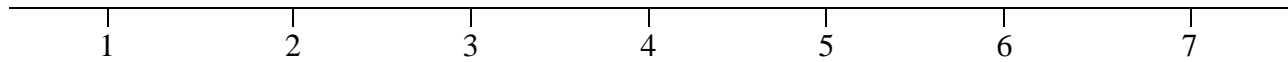


I tend to get behind in my work because I repeat things over and over

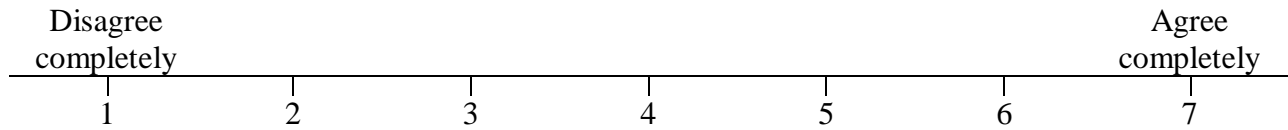


It takes me a long time to do something "right"

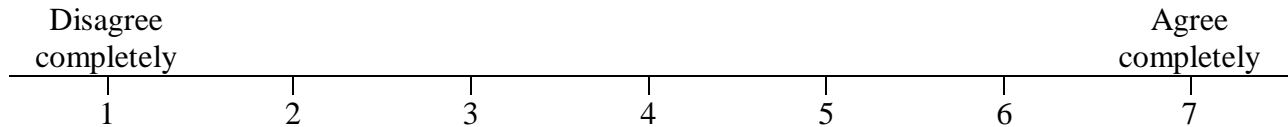




The fewer mistakes I make, the more people will like me



I never felt like I could meet my parents' standards



When answering the following questions, please tick the appropriate Yes or No box.

Do you like having a lot of things going on around you?

YES NO

Are you often uneasy, feeling that there is something you want without knowing it?

YES NO

Do you almost always have an answer ready when spoken to?

YES NO

Are you sometimes happy and sometimes sad without any special reason?

YES NO

Do you prefer to keep to the background in the company of other people?

YES NO

Do you regard yourself as happy and carefree?

YES NO

Do you often reach decisions too late?

YES NO

Do you often feel tired and listless without any special reason?

YES NO

Do you have a lively manner?

YES NO

Can you quickly describe your thoughts in words?

YES NO

Are you often lost in your thoughts?

YES NO

Do you have anything against selling things or asking people for money for some charitable purpose?

YES NO

Are you extremely sensitive in any respects?

YES NO

Are you ever too restless to sit still?

YES NO

Do you keep things to yourself except with good friends?

YES NO

Do you have any nervous problems?

YES NO

Do you like to crack jokes and tell funny stories to your friends?

YES NO

Do you usually worry a long time after a distressing incident?

YES NO

Finally please tell us about your pain experience, as it felt while you were completing the questionnaire. For example if you had severe shooting pain while filling in the questionnaire, tick the severe box for shooting. If “shooting” does not describe your pain, tick “none”. Please include a tick for each descriptor.

This first box asks about your pain as you were completing the questionnaire

Pain descriptor	None	Mild	Moderate	Severe
Shooting				
Stabbing				
Sharp				
Cramping				
Gnawing				
Hot-burning				
Aching				
Heavy				
Tender				
Splitting				
Tiring-exhausting				
Sickening				
Fearful				
Punishing- cruel				

This second box again asks about your pain but asks how it typically feels on an average day (which may or may not be the same as it felt while you were completing the questionnaire)

Pain descriptor	None	Mild	Moderate	Severe
Shooting				
Stabbing				
Sharp				
Cramping				
Gnawing				
Hot-burning				
Aching				
Heavy				
Tender				
Splitting				
Tiring-exhausting				
Sickening				
Fearful				
Punishing- cruel				