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**Living with
Occupational Overuse
Syndrome -**

A phenomenological study

*A thesis presented in partial fulfilment
of the requirements for the degree
of Master of Arts in Psychology
at Massey University*

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ABSTRACT

The incidence of Occupational Overuse Syndrome (OOS) has been increasing significantly in industrialised countries since the late 1970s. Research is revealing more about its causes, and the physiological and anatomical nature of the condition. However, little research has been done into the experience of the person with OOS as they work towards recovery. In the current study thirteen people with OOS were interviewed. An interpretive phenomenological approach was used, with the aim of gaining insights into the lived experience of OOS. Findings suggest that the experience of OOS is essentially paradoxical in nature. It comprises of four main processes - 'Coming to terms with an OOS diagnosis', 'Seeking a treatment that works', 'Trying to do the right thing' and 'Learning to co-exist positively with OOS'. These processes occur concurrently and there are many inter-relationships between them. Each of these processes involves a major paradox that the person with OOS must attempt to resolve. These all involve, in one form or another, the fundamental paradox for the OOS sufferer, that of finding a healthy balance between keeping tight control and letting go - between 'working hard at getting better' and 'releasing into relaxation, acceptance and attitude change'. Implications for therapy and future research arising from these findings are suggested.

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CHAPTER ONE

INTRODUCTION AND BACKGROUND

INTRODUCTION

An increasing incidence of occupational overuse syndrome (OOS) within a wide range of occupations, but particularly among computer or keyboard users is exacting an enormous cost, in terms of personal pain and disability and the resulting lifestyle changes for sufferers of OOS. It also has huge financial implications for employers and compensation organisations. An increased understanding of how people adapt to the experience of OOS and work towards recovery is important in terms of developing appropriate treatment and support strategies. My study takes a phenomenological approach, involving interviews with 13 OOS sufferers about their personal experiences of “living with OOS”.

A wide range of issues relating to Occupational Overuse Syndrome (OOS) are discussed here, and while these extend far beyond the parameters of the current study, they are included in order to portray the complexity of OOS as a phenomenon. It is against this backdrop of competing explanations of cause and exacerbating factors, lack of well-designed research on treatment effectiveness (Bammer & Blignault, 1988, Quintner, 1995; Silversides, 1997; Dorland & Hattie, 1992) and the highly political nature of the debate, that people with OOS endeavour to ‘find their way’ and learn to manage and live with OOS.

There is very little literature available relating directly to the experience of the person “living with OOS” - the subject of the current research. Few published articles acknowledge the thoughts, feelings or experiences of the person with OOS. Reid & Reynolds (1990) noted that medical articles on OOS turned individuals into ‘subjects’ with the effect that:

“As always in the pages of professional medical journals, patients become a shadowy presence behind the abstractions of their doctors, their illness experiences marginalized by their irrelevance to the ‘inductive’ process of clinical research” (p. 181).

I was able to find only two articles which focussed on the experience and effects of OOS on the sufferer - ‘More than just a pain in the arms: a review of the consequences of developing occupational overuse syndromes’ (Bammer & Blignault, 1988) and ‘Pilgrimage of pain: the illness experiences of women with repetition strain injury and the search for credibility’ (Reid, Ewan & Lowy, 1991). Bammer and Blignault (1988) reviewed published anecdotal evidence as well as the few empirical studies relating to the affective, social, financial and legal consequences

of developing OOSs and the pain and disability consequences and recovery prospects. In almost all areas of their review, Bammer & Blignault identified lack of quality research. Little has been done in recent times to address this situation. Reid, Ewan and Lowy (1991) conducted an interview study with 52 women employed as telephonists engaged in keyboard work or workers in a chicken processing plant. Through the extensive use of excerpts from their interviews, Reid, Ewan & Lowy paint a vivid picture of the experiences of these women. They identified three phases in the experiences of the women they interviewed - symptom evaluation, illness action and adaptation. In this article they focussed on the second phase (illness action), but provided some data on the first stage (symptom evaluation) to provide context. They found that the dominant issue for the women in their study was establishing credibility.

A BACKGROUND TO OOS

Occupational Overuse Syndrome (OOS), also known as Repetitive Strain Injury and Cumulative Trauma Disorder and a range of other names, is a concern in many parts of the industrialised world. These are umbrella terms for a range of conditions which in the occupational setting, occur mostly in the upper limbs. In this thesis I will use the shorthand term OOS, except where I am quoting a writer who uses one of the alternative labels. OOS occurs in people whose jobs involve repetitive movements or sustained muscle contraction such as word processors, hairdressers, musicians, signers for the deaf and process workers.

In 1996 OOS was the second highest injury cost for new claims (\$8,161,000) in New Zealand following 'Strains and Sprains', and third highest in terms of cost of ongoing claims (\$26,234,000) following 'Strains and Sprains' and 'Fractures' ("Injury Statistics", 1996). In 1997 OOS was third highest for new claims (\$6,851,000) following 'Strains and Sprains' and 'Fractures' and second highest for ongoing claims (\$39,856,000), following 'Strains and Sprains' ("Injury Statistics", 1997). According to ACC's Injury Prevention Division, new claims dropped by about 25% between 1997 and 1998 due to "prevention programmes, early intervention and better management" of OOS (OOS, Consumer, March 1999). Trade unions say that many cases go unreported as people are afraid they will lose their jobs, or that their claims may not be accepted. They also wonder whether ACC's statistics are affected by changes in ACC policy on the acceptance of OOS claims. New Zealand's decrease in incidence contrasts with the situation in U.S.A. where OOS is now claimed to be responsible for 60% of all reported occupational illnesses. The increased incidence is thought to be due to several factors, including "improved accuracy of reporting, heightened awareness of the problem by both employees and employers, advances in diagnosis, and the ever-accelerating pace of work." (Gilbert, Tick & VanEerd, 1997, p. 53). Despite the fall in cost of new claims in New Zealand, OOS is still a very costly condition.

OOS is also a significant problem in other countries. Large increases have been documented in the U.K., Australia, Norway, Sweden, Japan and elsewhere (Yassi, 1997). Repetitive strain injury is claimed to affect 11% of the population in the U.K. (Abbasi, 1998). In British Columbia OOS accounts for over 50% of all industrial disease (Gilbert, Tick & VanEerd, 1997).

The phenomenon that we now know as OOS has been noted as occurring as early as 1713 when Ramazzini documented similar conditions in craft workers, tradesmen, scribes and notaries. In 1892 William Gowers, a prominent neurologist, used the term 'occupation neurosis' to describe this type of condition. In 1908 telegraphists cramp was included in the schedule of diseases covered by the British Workman's Compensation Act of 1906. Within a three year period 60% of the workforce of telegraphists was reporting symptoms of muscle weakness, cramp or pain that they attributed to the new technology (Tyrer, 1994). In Japan in the late 1960s, Maeda and others (cited in Tyrer, 1994) noted "cervico-brachial disorders" in cashiers, industrial workers, film rollers, nurses, keyboard and telephone operators. An "outbreak" of upper limb problems was identified in the late 1960's and 1970's in an Australian telecommunications-electronics factory (Tyrer, 1994). Other episodes of similar conditions were also reported earlier this century (Gilbert, Tick & VanEerd, 1997). Clearly, OOS is not a new phenomenon.

However, public awareness and debate relating to OOS (RSI) increased dramatically during the 1980s, during what has been termed an RSI "epidemic" in Australia. The sudden rise in incidence, or reporting of RSI, from 980 new cases in 1979 to 4550 new cases in 1984, caused a great deal of speculation as to the real nature of RSI. During this time there was also a (relative) proliferation of articles on OOS in medical, psychological, sociological and other academic journals. I have drawn heavily on this material as it provides a comprehensive overview of the many conflicting ideas relating to OOS. In my search of the literature I found that, in more recent years, the issues being debated have changed little.

THE POLITICAL NATURE OF OOS

Compensation and political agendas significantly influence the debate about the causes of OOS, and because of the major impact of such factors, these issues will be discussed briefly before other topics are addressed. If OOS could be disproved as a physical condition caused by work-related factors, work-related compensation may not be payable. Consequently there has been pressure from the compensation sector to prove that OOS is largely caused by non-work factors and is not a 'real' (ie physical) condition.

Because of the legal and compensation issues surrounding OOS, any research relating to OOS may be used as supporting evidence by either sufferers (or their advocates) or insurers. Although

researchers and writers may see OOS as a complex phenomenon which is not readily explained within the Cartesian mind-body dualism paradigm, in an adversarial compensation environment findings may be summarised by readers in simplistic terms to suit their case. Hopkins (1989) states that regardless of whether authors disassociate themselves from the 'RSI as neurosis' stance, unless they very clearly place themselves in 'RSI as Injury' camp (that is, as a definite physical condition) their work is likely to be used "to support the insurance companies in their efforts to blame the victim" (p 250).

Medical practitioners play a difficult dual role in relation to OOS. Their diagnosis legitimates (or otherwise) a patient's claim for compensation and treatment. This legitimisation role does not always sit easily alongside their role as healer / medical advisor. Specialists are often called upon to give expert opinions as to the cause and nature of OOS in legal cases over compensation. Increasingly, compensation organisations question the ability of general practitioners (GPs) to diagnose OOS, and refer clients to specialists who they contract specifically. These specialists are often seen by the OOS sufferer as being more sympathetic to the insurer's agenda than to their own needs. A recent television documentary reported on an Auckland specialist who assessed cases for the insurer, often without seeing the patient (Newland & Kenna, 1999).

Lay people look to the medical profession assuming that they will provide an 'objective' truth about ambiguous medical matters. The fact that these professionals are also subject to the same cultural influences as the rest of society is often forgotten. Their individual beliefs, prejudices and stereotypes influence their views. Commentary written from the stance of 'medical expert' can appear to give these views more authority, and thus help to entrench stereotypes amongst both medical practitioners and the general public (Reid & Reynolds, 1990). Such views not only relate to the nature of the condition itself, but also to the patient. During the OOS 'epidemic' in Australia stereotypes relating to women became intertwined within the debate because more women than men worked in the occupations most at risk of developing OOS. Similarly, as many of those effected were immigrants, these stereotypes also became part of the debate. The term 'migrant arm' was coined, and later 'kangaroo paw' as the epidemic spread more widely within Australia (Quintner, 1995). Emotional responses and accusations within the medical profession were also aired - one commentator (Pilowsky, 1986, cited in Dorland and Hattie, 1992) coined the phrase 'malingrophobia' - he suggested that doctors were suffering from "an abnormal fear of malingering", and were wary of being tricked, so were fearful of making a diagnosis of OOS at all. As Dorland and Hattie point out, these sorts of comments in both the "professional and not-so-professional print" are not only read by medical practitioners, but also by OOS patients themselves, "with expected detrimental effects on their self-efficacy" (p.45).

Such emotionally loaded and subjective views also appear from time to time in New Zealand publications. Welch (1998) believes that OOS is a psychological condition rather than a physical one, and in a somewhat emotional article in the NZ Herald stated that bodily symptoms and sensations were interpreted as being caused by work factors because of the influence of occupational health professionals suggesting such a relationship. He believes that this effect is reinforced by the discomfort that medical practitioners have with psychological explanations and that this leads them to tend towards a physical diagnosis. He states that various support systems, including compensation systems, reinforce the person's view of their condition as being physical rather than psychological. He states that OOS is a psychogenic illness which may be caused by "stress which is adding to personal difficulties" and concludes, "... to claim that OOS is produced by actual physical work is a delusion." In a similar 'broad brush' style, Dr W Turner, a specialist in occupational medicine, is quoted in an article in the Listener (O'Hare, 1997) as saying that delayed recovery from OOS happens because the patient has invariably been raised in a dysfunctional family environment and subjected to emotional neglect or abuse. Views such as these are lent credibility by the status of the writers as 'medical experts', regardless of whether there is supporting research evidence. The effect of such articles on members of the public is seldom helpful.

Within the medical fraternity the debate continues through articles, editorials and letters in medical journals. Views are often expressed in emotive and highly subjective terms, and assertions are not always backed up by research or with references (Quintner, 1995). The issues raised are not dissimilar to those that arose during the Australian "epidemic" in the 1980s. Even the issues of whether OOS exists as a separate medical condition (Brooks, 1993; Brahams, 1993) and whether OOS is "real" (ie a physical injury as opposed to being purely psychosomatic or iatrogenic) are still being hotly debated. Whether specific conditions such as Carpal Tunnel Syndrome and Epicondylitis should be lumped together with 'non-specific' occupational overuse syndromes and whether OOS is caused by repetitive actions or is necessarily work-related also continue to be debated. These issues feed into the continuing debate about an appropriate diagnostic label with both those espousing that OOS is not work-related, and those who believe that it is largely psychosomatic or iatrogenic favouring diagnostic labels such as 'regional pain syndrome' (Helliwell, 1997; Yassi, 1997b; Shanahan 1997, Harrington, Gompertz, & McCaig, 1997; Gilbert, Tick & VanEerd, 1997).

These debates occur within the larger context of society in the late 1990s where the dominant ideology values individualism and sees individuals as the masters of their own fate - that their own choices and behaviours will determine whether they win or lose. This ideology permeates medical constructions of OOS, and is evident in treatment strategies, and in medical practitioner's

views of their patients. This dominant ideology tends to deflect attention from organisational and societal factors that have led to large increases in the numbers of people developing OOS (Reid & Reynolds, 1990).

PHYSICAL ASPECTS OF OOS

Occupational overuse syndromes include localised conditions such as rotator cuff, epicondylitis, carpal tunnel and other nerve entrapment syndromes as well as the diffuse symptom type of overuse syndrome. Localised fibromyalgia, myofascial pain syndrome and regional pain syndrome may not be separable from overuse syndrome, though not all imply overuse. In some cases fibromyalgia may be a symmetrical more severe variety of the same basic disorder (Wigley, Darby & Brown, 1997).

While OOS includes a number of specific localised conditions, due to the fact that this condition has developed as a result of ongoing repetitive or sustained muscle contraction, the treatment may need to differ from a similar injury (for example a rotator cuff injury) sustained during a sports match. In the case of the sports injury, traditional physiotherapy treatments such as rest, heat, ice and strengthening are likely to be effective. In the OOS injury there is often a failure to improve once strengthening exercises are introduced. It is important to bear in mind the more complex contributing factors in an overuse syndrome when planning a treatment strategy (Gilbert, Tick and VanEerd, 1997). Similarly the tendency to treat chronic conditions such as OOS as if they were recurring acute conditions can also be counterproductive (Potter, 1998; Baszanger, 1989).

Symptoms related to occupational overuse syndromes may include disabling hand, arm, shoulder and neck pain, numbness, paraesthesia, headaches, fatigue and discomfort. OOS often starts as aching and weakness or 'heaviness', mainly in the shoulders, arms and hands, and is often accompanied by fatigue. It is usually triggered by repeated actions, or having to hold positions which involve sustained muscle contraction - in both cases muscles do not have the opportunity they need to recover fully. Physical signs such as local tenderness, swelling, hardening, or crepitus (a crackling sound when the tendons are lightly pressed) may or may not be present (Bammer & Blignault, 1988; Gilbert, Tick & VanEerd, 1997). Symptoms may not be accompanied by physical signs, which provides scope for debate as to whether OOS is 'real' or not. Electromyograph (EMG) testing usually indicates that affected muscles take an abnormally long period to relax after contraction, and the time taken is an indication of the severity of the condition.

Non-occupational factors have also been associated with OOS as either causes or predisposing factors. Those which have been frequently reported include systemic diseases (e.g., diabetes,

hypothyroidism, sarcoidosis), congenital defects, wrist size and shape, acute trauma (e.g., fracture) to the wrist, pregnancy, oral contraceptives, gynaecological surgery, rheumatoid arthritis, obesity and vitamin deficiencies (Armstrong & Lackey, 1994).

There is a great deal of scepticism about OOS and controversy over whether it is iatrogenic, a form of 'hysteria', psychosomatic or simply malingering. However there is increasing evidence that there is a physiological basis to OOS and the majority of medical practitioners believe that OOS is predominantly a physical condition, but is influenced by stress (Dorland & Hattie, 1992). The hypothesis that sustained muscle contraction causes capillary compression leading to ischaemia with release of pain-producing substances which can cause a self-sustaining chronic pain syndrome (Wigley, Darby & Brown, 1997; Gilbert, Tick & VanEerd, 1997) is fairly widely accepted.

A number of recent discoveries relating to the physiology of OOS would appear to be promising in terms of increasing understanding of both the causes and appropriate treatment. Work by researchers from the University College of London has found evidence of minor nerve damage, particularly in the median nerve ("RSI caused", 1998; Abbasi, 1998; Fricker, 1998). This study compared patients with RSI, office workers whose jobs involved intensive keyboarding, and controls who did not use keyboards intensively. This study also noted clear changes in sensitivity to vibration in many in the 'office workers' group, a finding that may prove to be useful in early detection of RSI. Work relating to thermographic changes (Sharma et al, 1997; Colles, Pusey & Brooks, 1997) may also prove to be useful for diagnostic purposes and to monitor treatment progress although it is noted that thermographic changes result from pain, and are not specific to OOS.

Research on muscle fatigue and recruitment is likely to significantly inform both prevention and treatment programmes. Initially it was thought that fatigue occurred in muscles at 30 - 50% of maximum voluntary contraction, whereas more recent research suggests that this fatigue occurs at a rate as low as 5 - 10% of maximum voluntary contraction (Gilbert, Tick & VanEerd, 1997). This finding is consistent with the fact that 'light' work such as word-processing or intricate assembly tasks are among the high-risk occupations for OOS. It is now thought that the central nervous system learns new ways of recruiting muscles in the neighbouring area once a muscle fatigues. These muscles are not biomechanically designed for such work, and are therefore also likely to fatigue, resulting, in turn, in other muscles being recruited. New assessment and treatment protocols have been developed to retrain muscle recruitment patterns in OOS patients (Gilbert, Tick & VanEerd, 1997).

Work relating to myofascial pain and associated trigger points also appears promising for the treatment of OOS. A trigger point is

“a focus of hyperirritability in a tissue that, when compressed, is locally tender and, if sufficiently hypersensitive, gives rise to referred pain and tenderness, and sometimes to referred autonomic phenomena and distortion of proprioception” (Travell & Simons, 1992, cited in Gilbert, Tick & VanEerd, 1997, p. 57).

Gunn (1989, cited in Gilbert, Tick & VanEerd, 1997, p 57) links “wear and tear on the spine, even when it is pre-clinical” with effects on the nerve and muscle leading to a shortened muscle syndrome, which he believes is an underlying cause in all myofascial pain syndromes. One study of a treatment programme which worked on myofascial pain reported an 80% success rate in getting patients back to work, even after up to two years off work (Rosen, Sharoff & Khana, 1985, cited in Gilbert, Tick & VanEerd, 1997).

Recent research that shows brain scan changes in monkeys that were trained to do repetitive hand motions may also prove to be useful in the understanding of OOS. It was found that the area of the brain that represented the hand was markedly degraded in these monkeys. These changes are reversible, but require extensive training. (Byl, Merzenich, and Jenkins, 1996; Hadley, 1999).

Research also sheds light on the role of stress in OOS suggesting that this is not just a psychological issue, but is directly linked to the physiology of the damaged muscles and nerves. Evidence suggests that personally stressful situations result in symptom-specific elevated muscle tension for people who suffer from chronic musculo-skeletal pain problems (Flor & Turk, 1989, cited in Spence, 1998). Moulton and Spence (1992, cited in Spence, 1998) also found evidence of this occurring amongst a group of musicians with OOS. This would seem to indicate that the effected muscles become a ‘repository’ for personal stress, which has important implications for treatment. This finding would appear to be consistent with work by Hubbard and Berkoff (1993) and Simons (1993) (both cited in Gilbert, Tick & VanEerd, 1997) in which they speculate that trigger points are innervated by sympathetic nerve fibres (that is, the fibres which are dominant in the ‘fight or flight’ reactions provoked by emergency conditions).

In addition to research developments relating to OOS specifically, it is also important to be aware of developments relating to chronic pain, as there is still strong debate as to whether OOS is a discrete diagnostic entity, or a form of chronic pain syndrome. The most important shifts in thinking about chronic pain in recent years relate to the development of the ‘Gate Control Theory’ by Melzack and Wall (Anderson, 1999; Turk, 1996; Wall, 1996) and identification of the ‘Wind-up’ phenomenon (Anderson, 1999; Coe, 1997; Dickenson, 1996). Although medical practitioners

may be well aware of the Gate Control theory of pain, and the practitioners guide for the treatment of OOS published by OSH and ACC (1997) acknowledges this body of work, little effort appears to have been made to explain the implications of these to the OOS sufferer.

A number of researchers have strongly suggested that the aetiology of OOS is unlikely to be fully encompassed by either a straight biomedical or biomechanical explanation, but also requires the consideration of psycho-social factors. Gilbert, Tick and VanEerd (1997) suggest that not only are both biomechanical and psychosocial factors involved but that different risk factors are important at different stages - as antecedent, precipitating and perpetuating factors. Such an analysis is likely to prove useful in designing treatment strategies. It would appear that OOS is a much more complex phenomenon than some writers would suggest.

PSYCHOLOGICAL ASPECTS OF OOS

As already stated, there is continued debate as to whether OOS is real (that is, a physical condition), or whether it is 'all in the head'. Clearly such a duality is too simplistic. Many researchers and practitioners accept that, in addition to the physical factors, there are social, psychological, organisational, and societal factors involved in the development of, and recovery from OOS. A number of psychological factors have been implicated in the development of OOS. One argument sometimes put forward is that OOS indicates some form of pre-existing psychopathology. Yolande Lucire (cited in Hopkins, 1989) is perhaps the best known proponent of this idea. Lucire saw the increasing incidence of RSI in Australia in psychoanalytic terms, as a process of 'hysterical contagion'. According to Lucire people with RSI suffer from "unresolved psychological conflicts which may be work-related but may also originate in domestic or other areas of life. These conflicts are, for some reason, too painful to consciously acknowledge and are 'converted' to acceptable symptoms with absolutely no physical basis" (cited in Hopkins, 1989, p 241.) She holds to this view even in situations where medical practitioners have diagnosed patients with specific types of RSI which involve observable medical signs such as carpal tunnel syndrome. According to Lucire (cited in Hopkins, 1989, p. 241) "the choice of symptoms is determined by considerations of psychic or even financial profit". Hopkins (1989) points out that Lucire's view is very close to that of straight out malingering, the only difference being that malingering assumes a conscious motivation whereas Lucire's theory implies an unconscious motivation.

The psychopathology most frequently associated with OOS is depression. Several studies have identified a high incidence of depression in people with OOS, but the study designs do not allow legitimate conclusions to be drawn about whether depression predates the incidence of OOS. Wigley, Darby and Brown (1997) are convinced that where depression occurs it is generally as a

consequence of OOS. Spence (1990, cited in Feuerstein, 1996) compared acute and chronic patients with work-related upper-limb pain, with people with chronic accident-related injuries of the upper limbs, and non-injured keyboard operators. She reported an absence of differences in depression, anxiety (state and trait), neuroticism, and psychoticism between these groups.

Research has also been done to try to determine individual traits that make people 'prone' to OOS. Social psychologists are generally strong proponents of the idea that situational variables are a more important influence on behaviour than individual differences (Cioffi, 1996). Skelton (1996) however, points out that 'personological drift' tends to occur in psychosocially oriented research in the workplace - that is a drift towards identifying individual traits or dispositions at the expense of focusing on environmental and social factors.

There is a common perception that people who are 'prone' to OOS are those who are ambitious, hard working, perfectionist, conscientious and often high performers - attributes commonly associated with Type A behaviour. However Dannatt (1993) found relationships between OOS and only two of the type A subscales: speed and impatience, and job involvement. These relationships were relatively weak but significant. He did not find a relationship between the subscale 'hard-driving and competitive' and OOS. Anecdotal evidence supports a stronger link with the tendency to work too hard, but this may not be related to competitiveness. Further research in this area would be valuable. In a similar vein, Feuerstein (1996) proposes the concept of 'workstyle' - "an individual pattern of cognitions, behaviours, and physiological reactivity that occur while performing job tasks." (p. 179). This pattern may pre-exist and/or be triggered or exacerbated by a set of work demands or beliefs or feelings about a work task. He suggests that workstyle "may be associated with alterations in physiological state that, following repeated elicitation, can contribute to the development, exacerbation, and/or maintenance of recurrent or chronic musculoskeletal symptoms related to work" (p.179). The behavioural component of workstyle includes the manner of movement, posture and activity. The cognitive factors are the thoughts, feelings, appraisals and evaluations relating to the work task and the individual's personal sense of threat or achievement related to the task. The physiological factors may include such things as muscle tension, force on tendons, and stress-induced changes to the immune system. A high-risk workstyle is one where the person exerts excessive levels of effort, which may also be accompanied by unnecessarily high levels of physical force (for example in the use of keys on a keyboard), causing strain on muscles and tendons. Retraining relating to workstyle can be included in treatment programmes (Feuerstein, 1996).

A more common school of thought suggests that people who develop OOS have suffered a large amount of stress in their lives that leads to the development of OOS. While this is commonly

believed, there is no research evidence to support the idea that stress 'causes' OOS. Study designs in this area of research often do not allow the separation of confounding factors. However, one thorough study of subjects with fibromyalgia (a condition which is often considered to develop following severe unresolved OOS) failed to show any relationship between previous adverse life events and symptoms. Another study did show more adverse events in those seeking medical help than in those with the same medical symptoms who had not sought medical help, but the researchers concluded that the previous life events were not causal but merely affected the decision to go to the doctor (Wigley, 1998). In spite of the lack of well-designed research evidence supporting the idea that OOS is caused by stress, there has been a tendency by compensation organisations to attempt to identify sources of stress other than work on which to 'blame' the occurrence of OOS. Except in cases of unusual levels of workplace stress, compensation organisations tend to see this stress as something that employees are expected to adapt to. Failure to do so is interpreted as inadequacy and inherent weakness on the part of the employee.

ORGANISATIONAL FACTORS RELATING TO OOS

Much research has been done on the relationship between the incidence of OOS and organisational factors such as job satisfaction, relationship with immediate supervisor, organisational climate, low job autonomy, high work pressure, 'pushing oneself', missed rest breaks, frequent deadlines, low job clarity and boredom (Stephens & Smith, 1996; Hopkins, 1990; Spillane & Deves, 1988). Poor ergonomic design of equipment and tools has also been associated with OOS. There appears to be a complex interplay between ergonomic and psychosocial factors. Interestingly, there have been examples where companies that invest in upgrading ergonomically have not seen the expected reduction in incidence of OOS, possibly indicating that job satisfaction and work relationship issues have not been satisfactorily addressed. Kilbom (1988, cited in Yassi, 1997) reviewed 14 intervention programmes in a range of industries and concluded that "job redesigns are most effective, but as the physical environment improves, work organisation and social factors become more important" (p. 945).

Work practices have been strongly linked with OOS. Kiesler and Finholt (1988, p 1011) point out that the introduction of new technology elicits new thinking among managers, "who sometimes use the inevitable chaos as a cover to implement nontechnological changes in staffing, organization, and work procedures". The trend towards fewer staff, heavier workloads, more task specialisation, faster pacing of work, fewer breaks, and more performance-based pay or appraisal systems exacerbates any effects which may be attributed to new technology. All of these factors have been implicated in the increase in the incidence of OOS (Gilbert, Tick & VanEerd, 1997). In Australia the conversion to new technology occurred more suddenly and with greater

magnitude and rapidity than other countries, which may have contributed to the RSI epidemic there (Kiesler and Finholt, 1988). While such factors have been acknowledged in some quarters, with some companies making positive changes in line with these findings, the trend towards leaner and meaner organisations is one that appears to predominate.

Surveys in the U.K. show that 3 out of 5 people work more than their scheduled hours, with 2 out of 5 indicating they work on average up to 10 hours per week extra. A survey carried out in 1998 on people who work long hours in the U.K. found that half of the respondents reported they had difficulty sleeping or complained of mental exhaustion or always feeling drained, one in three had experienced unpleasant feelings of being unable to cope or under too much pressure, and one in four had chronic headaches (The issue of long hours, 1999). Almost 25% of the 1000 employees interviewed (ranging from cleaners to surgeons) in a government backed survey claimed that they had suffered physical or mental ill health as a result of workplace stress (Sylvester, 1999). Such findings have led to the British government planning to introduce a legally binding code. The Ministers involved in preparing this code believe that workplace stress "is fast becoming a major health problem". The draft states:

"Stress is not the same as ill-health, but in some cases, particularly where pressures are intense and continue for some time, the effects of stress can be more sustained and far more damaging, leading to psychological problems and physical ill-health" (Sylvester, 1999).

The implications of such a code, if legally enforceable, are enormous - as are the difficulties involved in resolving the complex issues to the satisfaction of employers, trade unions, insurance companies and others.

SOCIAL AND ECONOMIC ASPECTS OF OOS

There are many social and economic factors that affect the development of, and recovery from OOS. Many of these are 'structural' in that they are intertwined in the infrastructure involved in treatment, compensation and employment. The issues of secondary gain (including possible gains from the compensation system), and medical and social legitimisation will be briefly outlined, along with notions relating to OOS as a social movement. These issues were part of the debate during the Australian "epidemic". Economic issues will also be briefly addressed. These issues are not all central to the current OOS debate or directly relevant to people 'living with OOS'. However they are included here as they emphasise the fact that OOS is not simply an issue of individuals being injured, but also involves many forces at a social and societal level.

Secondary Gain: The role of secondary gain (that is, the gain or advantage a person experiences through being ill) is one factor which invariably affects a person's perception of their condition,

and may well affect their rate of recovery. Often issues of secondary gain are over-simplified when compensation organisations consider OOS clients. An assumption is often made that the client either has a 'real' physical condition or they are 'faking' or 'malingering' in order to gain potential benefits from having OOS. This oversimplification often alienates clients where-as an appropriate exploration of secondary gain issues may lead to better outcomes. Dr Turner, a specialist in occupational medicine is quoted (O'Hare, 1997) as urging doctors to:

"...determine barriers to recovery at an early stage - e.g., employee [might be] avoiding an unpleasant work environment, seeking attention, wanting financial compensation, [or find] injury allows for a more socially acceptable reason for failure."

Secondary gains relating to claiming compensation (often referred to as 'compensation neurosis') are seen by some as playing a major part in the increasing incidence of OOS. According to Kennedy (1946, cited in Mendelson, 1995, p. 695) "A compensation neurosis is a state of mind, born out of fear, kept alive by avarice, stimulated by lawyers, and cured by a verdict". Mendelson (1995) in reviewing research on recovery following the conclusion of compensation cases, found that "the overwhelming majority" of studies which investigate the return to work of accident victims after their compensation cases have concluded indicate that there is no basis for the concept of 'compensation neurosis'. Mendelson's own study involved 760 subjects whose legal claims had been settled. These people came from a wide variety of occupations and ethnic groups and were categorised into 2 accident groups - automobile accidents and industrial accidents. Of the 264 people traced at follow-up, 75% were not employed after a mean of 23.1 months following settlement. This gives further support to there being no real basis to the concept of 'compensation neurosis'.

Medical legitimisation of OOS: Another common argument is that OOS is iatrogenic (defined in Collins English Dictionary as "an illness or symptoms induced in a patient as the result of a physician's words or actions") and has been socially validated. Reilly (1995) describes the typical diagnostic and treatment process of OOS as a "person with a problem" being transformed into a "patient with pathology", following which "the next logical step is to become a litigant with a claim" with the patient then "having to constantly prove disability to a succession of medical experts acting for one side or another". He states "Once the first sickness certificate is issued, the whole ghastly scenario ... is bound to follow." (p. 786). Claims that OOS is iatrogenic are often sweeping and emotive as in this example. There may be some aspects of the medical process that (often inadvertently) lead to some people with OOS seeing themselves as more 'disabled' than is necessary, and these aspects need to be improved. However, there is no evidence that OOS is purely iatrogenic.

Social legitimisation of OOS: Kiesler and Finholt (1988) maintain that the RSI 'epidemic' in Australia was due to 'social legitimization' of RSI, and that this was due to four factors: historical precedents for RSI-like conditions on the job in Australia; RSI becoming "a cause celebre of unions and feminist groups"; RSI receiving official validation by the Australian medical establishment; and detailed coverage of RSI by the press. This legitimisation was further supported by the Australian workers compensation scheme which Kiesler and Finholt (1988) see as having 3 distinguishing features -

"(a) RSI is considered an occupational injury even though the victim may have worked on the job in a 'normal' office environment for months or years without developing it; (b) RSI is compensable with or without physical indications; and (c) certifying physicians believe office environments are dangerous." (p. 1012).

Kiesler and Finholt (1988) believe that it is the quality (or lack of it) of work life, which results in higher reporting of symptoms, which is then validated as a compensation claim. While putting a strong case for RSI being a socially constructed phenomenon, Kiesler and Finholt believe that it does have a physiological basis. However, in their view:

"Once a socially valid health problem is created, it becomes an avenue and occasion for workers to express and reveal pain - and in some cases negative feelings about their jobs - without fear of reprisal." (p.1013).

OOS as a social movement: The rapid increase in incidence of RSI during the Australian 'epidemic' led to suggestions that the epidemic was a form of social movement rather than a medical epidemic. There was often an implication that RSI was not a real physical injury in these views (Spillane and Deves, 1987, cited in Hopkins, 1989). RSI was seen by some as a form of resistance by workers (Willis, 1986). In the context of work place changes such as the introduction of incentive, bonus or productivity schemes, Willis (1986) states:

"Occupational injury or illness mediates the social relations of work in that it provides a means of resisting 'managerial prerogative' by arguments about the consequences of a particular form of work organisation for the health and safety of workers" (p. 215).

Perhaps the most unusual explanation for OOS as a social movement is that of Hocking (1996). He states:

"Lewis (1976) has described 'possession' states in some cultures in which unusual symptoms manifest in socially subordinate people. For example, in Somalia women may be possessed by a spirit that requires appeasement, such as by gifts. Lewis suggests that possession states are a milder and less radically challenging assault on authority than a charge of witchcraft and may be employed against persons whose authority is begrudgingly accepted by the powerless to bring about change. It is possible to interpret the

RSI epidemic as also fulfilling this social function of conflict resolution, given the deskilling of work subsequent to the introduction of VDT systems and concomitant symptoms of arm pain.” (p. 150).

Hopkins (1989) points out that ‘social movements’ which are constructed on real underlying problems develop differently from those based on ‘mythical’ constructs, and clearly puts RSI in the court of a real injury. He uses the analogy of the growth of the women’s movement which “has grown rapidly in recent years even though there has presumably been no increase in the extent of gender inequality” (p.256). In other words, the rapid growth of the movement does not prove it to be based on mythical causes, but relates to an increase in awareness and, in the case of OOS, an increase in reporting of symptoms. In terms of OOS, improved information and compensation options have made it more feasible for those suffering from symptoms to report these, and many workplaces have responded to a growing awareness of the consequences of new technology and productivity schemes by facilitating early reporting of OOS and referral for treatment. This serves to bring out into the open what may otherwise remain a hidden problem.

Economic factors: The state of the national economy also has implications for the incidence and reporting of OOS. The high level of unemployment over the past 10 years has meant that where, previously, a worker experiencing discomfort and pain relating to their job may have decided to change jobs, this solution is not so readily available. In addition to reduced labour market mobility in a tighter economy, the increase in incidence of OOS in New Zealand in the 1990’s may be attributed to the many rounds of restructuring and down-sizing in many organisations, inevitably resulting in smaller numbers of staff and higher work loads.

LINKS BETWEEN OOS AND OTHER CONDITIONS

There are many important similarities between OOS and chronic back pain - both conditions involving chronic pain and often involving no observable physical signs. Literature relating to chronic pain conditions of this nature will not be discussed here, except to point out that reading across these areas provides further useful insight into OOS.

Links are often made between OOS and fibromyalgia, and it is commonly thought that OOS which does not resolve may develop into fibromyalgia. This is a hot political topic because of the compensation implications. Some medical specialists, such as Wigley propose that Fibromyalgia is a more generalised and severe variation of OOS (Wigley, 1997; OOS, 1999) while others such as ACC see fibromyalgia as an illness unrelated to OOS and not compensatable (OOS, 1999). Links have also been suggested between OOS and Chronic Fatigue Syndrome and between Fibromyalgia and Chronic Fatigue Syndrome (Wigley, Darby & Brown, 1997; Gilbert, Tick & VanEerd, 1997). Again, it is useful to read across these areas because of the complex inter-

relationships between them, and the lack of agreement about whether these are definitive diagnostic categories.

Wigley, Darby and Brown (1997) suggest that it depends on which symptoms are dominant as to which medical specialisation a patient will be referred to -

“... many cases of fibromyalgia have fatigue and many chronic fatigue syndrome cases have fibromyalgic features (Bayliss et al, 1996) so that pain and rheumatology clinics will receive cases with pain and a psychologically based clinic will receive patients whose predominant symptom is fatigue. These may not be separate conditions” (p. 2).

Hotoff (1994) outlines similarities between repetitive strain injury and myelgic encephalomyelitis (also commonly associated with chronic fatigue syndrome). He suggests that these conditions have many factors in common, particularly, in his view, the need for a rehabilitation strategy which “acknowledges their suffering with sympathy and yet challenges their attributions of cause [as being purely external]” (p. 659). The ‘fuzziness’ of the diagnostic boundaries of OOS and related conditions, combined with limited lay understandings of OOS, makes for lack of clarity and even confusion amongst those suffering from OOS, particularly those with a long-standing condition.

TREATMENT

In view of the non-specific nature of OOS, the many different interpretations of the condition, and the vehemence of the debate, it is not surprising that there is little common agreement on what constitutes ‘the best’ form of treatment. In addition to creating a confusing environment for the OOS sufferer, this situation also effects the relationship between OOS sufferers and doctors (Quintner, 1995). Quintner points out that the lack of clarity relating to the pathophysiology of OOS caused problems relating to treatment:

“When the medical debate did not quickly resolve the fundamental issues of diagnosis and pathophysiology of RSI, many primary-care physicians did not possess the scientific knowledge necessary for them confidently to prescribe appropriate and effective treatment for their patients. In addition, uncertainty over treatment outcome made it impossible for them to give an accurate prognosis to their patients and to other interested parties...” (p.257).

Pirie (1993) identified the following treatment methods as being used with OOS patients: acupuncture/acupressure, relaxation, rest, postural advice, general exercise, medication, splinting or binding, heat treatment, physiotherapy, massage, surgery, and job modification. Pascarelli and Quilter (1994) identify the following additional treatment methods: the use of drugs (NSAIDs, Aspirin, Acetaminophen and Cortisone), spinal manipulation, and vitamins. The Wellington

OOS-Busters programme includes workshops on the alternative therapies of Alexander Technique and the Feldenkrais method which address posture and movement patterns. Being faced with such a wide array of treatments may appear to be advantageous, but can leave an OOS patient feeling confused by the choices available, and may encourage an attitude of 'waiting for an "expert" to fix me' rather than taking a more active approach to the lifestyle changes or work / activity modifications which may be required to improve the condition. Kiesler and Finholt (1988) comment on the range of treatment options available: "What is noticeable about this list [of treatment options] is its length, which suggests that RSI can be alleviated by anything or that nothing works" (p.1009). Anecdotal evidence tends to support the latter position. Straker, a speaker at the International Symposium on Global Rehabilitation Trends (quoted in Silversides, 1997), in criticising the lack of solid research relating to treatment effectiveness states:

"What is clear from discussion with people with [work-related neck and upper-limb disorders] is that these treatments are remarkably ineffective and sometimes even exacerbate the problems - this seems particularly true of surgical interventions" (p. 1460).

Straker stated that treatment of OOS is usually recommended to have four components:

"...treatment of symptoms (preferably through conservative management); analysis and change of work conditions (to identify likely risks and reduce these as much as possible); continued work, or early graduated return to work (to avoid or minimize detrimental consequences of prolonged absence); and recognition and assistance for social and psychological problems, whether related to work or not" (p.1460).

Gilbert, Tick and VanEerd (1997) outline an assessment and treatment sequence which, they claim, has resulted in "significant improvements by a large majority" of their caseload. This process involves a full physical, medical and psychiatric assessment of the patient followed by as many of the following treatments as are deemed appropriate for the individual: treatment of any underlying illness, IMS dry needling, trigger point manual release, physiotherapy, movement awareness, traditional or shiatsu massage, surface EMG muscle retraining, biomechanical appliances (orthotics, hip lifts), home awareness programme (education, tools, stretching, exercise), aerobic exercise, stress management, ergonomic assessment, corporate seminars, management-employee conflict resolution and outside consultation.

In spite of much of the debate in medical journals giving the impression that little has changed since the 'Australian Epidemic', in the mid '80s, there have been important developments in understanding of the physiological and psychological components, and the treatment of OOS which would appear to offer real hope to OOS sufferers, and the possibility of greater clarity in terms of options.

IMPLICATIONS FOR 'LIVING WITH OOS'

While the academic literature on OOS does not directly affect OOS sufferers, the views contained in it are representative of the views held amongst a wide range of medical and para-medical personnel, insurers and employers with whom they must interact as they negotiate their way towards recovery. Sufferers of OOS find themselves attempting to make sense of their condition and deciding on the course of behaviour that is most likely to facilitate their recovery in a complex environment:

- in a political environment which holds the individual responsible for the fate which has befallen them
- in a medical environment in which there is lack of agreement as to the most appropriate form of treatment and where there appears to be a natural propensity to separate the mental from the physical
- in a compensation environment where cost cutting appears to be the main agenda, and where there is a high level of suspicion of those who do not make a rapid and smooth return to work.

WHY THIS STUDY IS NEEDED

My study attempts to gain a greater understanding of how people make sense of their experience of OOS and seek to negotiate and manage OOS in everyday living within this environment. There is a need for research that puts the person with OOS 'back in the picture' - makes them visible, and accounts for their experience in a way that legitimates and seeks to understand. There is need for research that takes account of the social context in which people with OOS live. There also appears to be an absence of research that focuses on the experience of people with OOS over the period during which they are attempting to regain their health. OOS is a condition that involves gradual improvement, and people generally return to work before fully 'recovering' from the condition. Other aspects of their lives may be 'on hold' (hobbies, voluntary work, family or household responsibilities etc) in order to remain well enough to continue in full-time work. This project attempts to address these three needs:

- to make the experience of people with OOS visible
- to gain further understanding of this experience, looking at their experience in a 'whole of life context' not just looking for causal factors or confining the study to people's work lives
- to gain an understanding of their experiences as they work towards recovery.

CHAPTER TWO

INTERPRETIVE PHENOMENOLOGY: THE THEORETICAL PERSPECTIVE BEHIND THIS STUDY

The methodology used in this study is interpretive phenomenology. Phenomenology was chosen primarily because it involves developing a rich description, and distilling the essence of a phenomenon without stripping the phenomenon down to concepts that over-simplify it. Interpretive phenomenology goes a little further than this, aiming to discover meanings which are not explicitly given in the data, but for which the data provides clues and signposts. Very little has been published which describes in detail the phenomenon of OOS as it is experienced by the person with the condition. It was felt that without such work, there is a significant gap in the understanding of OOS.

I have drawn my perspective largely from the work of four writers. van Manen (1990) provided me with an in-depth and readable description of interpretive phenomenology. From Crotty's critique (1996, 1998) of what he feels is not being adequately addressed in the 'new' or 'humanistic' phenomenology I gained further understanding of the aims of phenomenology. From Benner (1994) I adapted analysis methods to apply to my own work. The analysis by Spiegelberg (1969) of the essential elements of phenomenology helped me to put these various ideas into some overall schema. I padded out my understanding of some of the many pre-suppositions of, and approaches to, phenomenological research through reading many other articles, theses and edited book chapters (particularly Munhall, 1994; Colaizzi, 1978; and Valle, 1998). Without a depth of study that is outside the scope of a Masters thesis, it is not possible to fully grasp the complexities and subtleties of phenomenology, either as a philosophy or as a methodology. However, the above reading gave me an adequate foundation for my current research. A brief outline of the assumptions, aims and methodology of phenomenology as relevant to my work will be outlined below. My research method will be described in the following chapter.

Phenomenology has as its focus the study of the objects of human experience (Crotty, 1996). Objects of human experience are whatever is experienced by a person (an experiencing subject). Phenomenologists hold to the idea that object and subject cannot be separated and refer to this as 'intentionality'. Intentionality involves a very close and interactive relationship between the experiencing subject and that which they are experiencing (Crotty, 1998). Meaning is generated through this interplay between the person and that which they are experiencing. The person

constructs their own interpretation of the experience, and the experience influences the way that this interpretation is constructed. In common with social constructionists, phenomenologists believe that meaning is constructed within a shared system of symbols. However, although this enables us to make and communicate meanings, it also limits our ability to see phenomenon from a new perspective. Over time we start to assume that the sense we make of things is 'the way things are' (reification), and we add layers of interpretation on top of each other (sedimentation). These processes can blind us to what is really going on (Crotty, 1998). The aim of phenomenology is to get beyond the cultural overlay of meanings to a new or different interpretation.

Phenomenology developed as a protest against reductionism as it was felt that human experience could not be adequately studied using the traditional scientific method. This approach was seen as perpetuating preconceptions and prejudgments whereas phenomenology makes a determined effort to see the phenomenon as if for the first time, returning 'to the things themselves' - the objects of immediate experience (Spiegelberg, 1969). Phenomenologists also do not restrict themselves to sense data, as positivist scientists do - they also acknowledge intuition as a source of data. Traditional science, in reducing human experience to 'constructs' and in recognising only sense data, aims for simplicity and economy. In contrast, phenomenology aims for rich description, meaning and understanding.

"Simplicity and economy are instruments that are both blunt and blunting. The genuine will to know calls for the spirit of generosity rather than that of economy, for reverence rather than for subjugation, for the lens rather than for the hammer." (Spiegelberg, 1969, p. 657).

Phenomenology becomes attractive to many researchers as a method because of its focus on understanding the meaning of experiences, as experienced by individuals in the context of their lives. Many other methodologies attempt to remove the context and reduce experience to abstract constructs (Plager, 1994). However, although phenomenology focuses on the experiences and understandings of individuals more than many other methodologies, the aim is still to maintain a strong focus on the phenomenon (the object of the experience) and it is important to avoid the possibility of focussing too much on the subjective experience of the experiencing individuals. As the aim of phenomenology is to attempt to peel away the layers of cultural understanding, by focussing only on individuals' ideas and feelings about the experience being studied, it is likely that an account will be generated which simply reflects culturally accepted meanings. This results in a lack of critical analysis, which is an essential element of phenomenology (Crotty, 1998). Instead, the aim is to tap into individuals pre-reflective thoughts (that is to have participants talk about what they experienced in as much concrete detail as possible) rather than to present their

abstract, reflective thoughts about their experience. Doing this helps to maintain a strong focus on the *object* of human experience (the phenomenon) being studied.

Despite their divergences, all schools of phenomenology have the core elements of the phenomenological method in common (Spiegelberg, 1969). Firstly, phenomenology involves investigating a particular phenomenon using the processes of phenomenological intuiting, analysing and describing. The intuiting of a phenomenon involves intense concentration on the phenomenon in question, while still maintaining a stance that enables critical analysis. It requires opening up to the phenomenon in a way which allows more than just sense data, but without being seduced by the detail of the content or any emotions and thoughts which may arise. The process of phenomenological intuiting is difficult to describe in specific detail. Much to the frustration of the beginning researcher, even those who have studied phenomenology in great detail appear to have difficulty in defining and describing this process other than to use phrases such as 'opening up your eyes', 'not getting blinded, and 'looking and listening' (Spiegelberg, 1969, p. 660). One way that this 'phenomenological intuiting' can be achieved in order to grasp the uniqueness of a phenomenon, is to pay attention to similarities to and differences from related phenomena. Phenomenological analysing involves an intense and methodical examination of the structure of the phenomenon. While this process involves identifying the elements of a phenomenon, it does not imply dissecting the phenomenon into separate parts. Any description must of necessity be selective but the key to good phenomenological description is that it focuses on the essential characteristics of the phenomenon, and sifts out and leaves behind that which would distract us from the understanding of the essential experience. While others, for example gestaltists, would support this approach the distinctive quality of the phenomenological approach is its deliberateness with the process, and its conscious rejection of reductionism (Spiegelberg, 1969).

The second element of the phenomenological method involves identifying what is the essence (or essences) of a particular phenomenon. Phenomenology has been referred to as 'the science of examples' (van Manen, 1990). Identifying the 'essence/s' of a phenomenon begins with an in depth study (and intuiting) of particular examples of the phenomenon. By identifying what the particular examples have in common, it is possible to grasp possible unifying themes or essences that are essential to the example being an example of the phenomenon being studied. For example, by studying the 'red' of a particular red rose, this can be seen as an example of this particular shade of red. This example exemplifies both 'redness' and 'colour' in general (Spiegelberg, 1969). A useful strategy, having identified similar examples, is to ask 'what are these examples of?' Another useful strategy in identifying essences is to 'line up' related examples or particulars based on how similar they are to each other, and see which naturally

group together. The 'common ground' of the examples that group together in this way is an 'essence' of the phenomenon. Spiegelberg (1969) suggests that

"the configuration of phenomena thus belonging together in a 'natural' group is comparable to that of a genuine good gestalt" (p. 678).

The third element of the phenomenological method involves grasping the meaning of the essential relationship both within and between essences. When looking at the relationships within each essence, the key question is whether each component is essential to that essence for it to still be the essence as it is identified. The technique commonly used to achieve this understanding is 'free imaginative variation' as proposed by the founder of phenomenology, Edmund Husserl. This method involves using the imagination to leave out certain components of the phenomenon, or to replace components by others, to see if the essence (or theme) is affected by the variation. The same method is also used to gain an understanding of the relationship between essences.

The strategy of suspending belief in the existence of the phenomenon is not common to all schools of phenomenology, but is a widely accepted process (Spiegelberg, 1969). The procedure of 'bracketing' is commonly used to do this. Phenomenologists aim to deliberately put aside theoretical constructs, cultural understandings and personal pre-suppositions (van Manen, 1990) in an attempt to look at the "original encounter of subject with object, seeking, as it were, to re-experience that encounter so that its possibilities for meaning may emerge afresh" (Crotty, 1996, p.131). In doing this the aim is to suspend belief in the reality of the phenomenon being studied - to ask ourselves, 'Is this really as it seems?'. We aim to peel away the common understandings of our culture, and to look at the phenomenon in a fresh way (Crotty, 1998).

Of all the aspects which are unique to phenomenology, one of the most important is the manner of approaching the study of phenomena in a manner of reverence. Also of great importance is the phenomenological method's systematic approach and its determination to stay true to the object of the experience being studied. Spiegelberg, 1969 describes this as:

"the unusually obstinate attempt to look at the phenomena and to remain faithful to them before even thinking about them" (p. 700).

The above presuppositions and methodological elements are common to phenomenology as a whole. Interpretive phenomenology aims to go further than this, in that it aims to interpret concealed meanings (Spiegelberg, 1969). Heidegger, Merleau-Ponty, Sartre and Ricoeur are some of the most well known interpretive or hermeneutic phenomenologists (these two terms are often used interchangeably). The interpretive phenomenological approach aims to interpret the 'sense' of the phenomenon in question. The researcher uses that which is given in the data as a

pointer towards meanings that are not explicitly given. However while such ‘hidden meanings’ are brought to the fore, the aim is to do this in a way which differs from constructive inference, or from the explanatory hypothesis of positivist science (Spiegelberg, 1969). A well-known proponent of interpretive phenomenology is van Manen. His approach can be seen to include the elements discussed above. It involves ‘a dynamic interplay’ between the following six research activities (van Manen, 1990).

Turning to a phenomenon which seriously interests us and commits us to the world: In contrast to traditional science the researcher is encouraged to select a topic of strong interest and to ‘live’ the question. There is no suggestion that a value-free, unbiased stance should be (or indeed can be) taken, although the researcher is encouraged to make rigorous efforts to be aware of their own pre-suppositions, values and culture and how these may effect the study. van Manen (1990) describes it in this way:

“To truly question something is to interrogate something from the heart of our existence, from the centre of our being” (p. 43).

Investigating experience as we live it rather than as we conceptualise it: This refers to the goal of getting as close to the experience as possible, rather than settling for abstract or theoretical concepts. The aim is to tap into pre-reflective accounts of experience.

Reflecting on the essential themes which characterize the phenomenon: The phenomenon can be thought of as being made up of meaning units, themes (or essences). Gaining an understanding of the essences or themes of a phenomenon is not a matter of following a set of rules, but of ‘seeing’ or intuiting the meaning. van Manen describes the process as one of “insightful invention, discovery or disclosure”. Through our intuiting we aim to gain a deeper and more reflective understanding of the phenomenon and its structure. When phenomenologists talk about identifying the ‘structures of experience’ they are referring to identifying themes and how they inter-relate. A particular challenge of phenomenology is to determine which are essential themes - that is to identify both the unique and the characteristic qualities of a phenomenon.

Describing the phenomenon through the art of writing and rewriting: Writing enables the researcher to reflect on lived experience in a way which is not otherwise possible. Writing is seen as being intertwined with phenomenological reflection in the process of the research. The importance of writing is in anchoring thoughts in order that they can be reflected on (in writing). Once ideas are in writing it is possible to dialogue with them.

Maintaining a strong and oriented ... relation to the phenomenon: To be oriented as researchers or theorists means that we do not separate theory from life, the public from the private. Instead we 'live' our orientation. van Manen (1990) goes so far as to say,

"Nothing sound can come out of work that is not animated by the desire to orient to its topic of study in a strong, original and thoughtful manner' (p.172).

Through this oriented relation, we aim to create a text that is strong, rich and deep. A rich text is concrete, is embedded in lived experience and explores what is unique and particular to the phenomenon. Descriptions with depth have explored the meaning structures beyond what is immediately experienced. It is important to avoid over-simplifying, and to reflect the natural ambiguity and mystery of the lived experience.

Balancing the research context by considering parts and whole: Interpreting accounts is a circular process, involving moving back and forth between the part and the whole. By sensitive appreciation of one person's account, we gain various insights. We can then look at detailed aspects of the account (the part) for further understanding of these insights or compare them with other accounts, and consider the whole (the bigger picture, gained from analysing all accounts). It is clear that there are many levels of 'parts' and 'wholes' within a study of this nature. This part-whole strategy is pursued until the researcher is satisfied with the depth of their understanding. It is sometimes difficult to persist with a theme and systematically explore its meaningful aspects, but if this is not done, it is likely to result in a description with no depth or overall structure.

EVALUATION OF PHENOMENOLOGICAL RESEARCH

It is important to remember when evaluating interpretive accounts that there is no such thing as an interpretation-free, objectively "true" account of "things in themselves" (Leonard, 1994). It is therefore inappropriate to look for techniques that will prove or measure reliability and validity of an interpretive account. However, there are clearly better or worse interpretive studies, and therefore it is appropriate to consider what criteria may be used to make this judgment.

Many research writers have considered this question. Munhall (1994, p. 189) proposes 'One P and 10 Rs' as appropriate criteria (the phenomenological nod, resonancy, reasonableness, representativeness, recognisability, raised consciousness, readability, relevance, revelations and responsibility). Burns (in Munhall, 1994, p. 186) proposes descriptive vividness, methodological congruence, analytical preciseness, theoretical connectedness and heuristic relevance. These many criteria deal with issues that are internal to the text, issues relating to contextuality, and issues relating to usefulness and accessibility to the reader.

For the current study I have condensed the concepts addressed by these writers into 5 evaluation criteria which I made reference to through all stages of the research, and which I would view as useful criteria against which readers might evaluate this study.

- 1) How well it serves to answer the original concern of what is the nature of OOS as a lived experience. In phenomenology the object or experience being studied is seen “not as a problem in need of a solution but a mystery in need of evocative comprehension” (Marcel, 1950, cited in van Manen, 1990, p. 50).
- 2) The degree to which it opens up new possibilities for engaging the problem.
- 3) Accessibility to the reader: It is important to me that my work can be read by a wider audience than just the academic community.
- 4) Richness: This incorporates representativeness, descriptive vividness and comprehensiveness.
- 5) Methodological congruence: This incorporates systematic and detailed examination of the data, considering the parts and the whole, and intuiting as well as ‘analysing’ the data. It requires resolute determination to remain focussed on the phenomenon and to avoid getting caught up in the detail of the experiences of the individuals.

These are the aims I have held to in this research project. The reader will ascertain the degree to which I have reached them.

PHENOMENOLOGY AND HEALTH RESEARCH

Phenomenology, and specifically interpretive phenomenology has been used extensively in the field of health, particularly by nurse researchers. In the discipline of psychology, there is relatively little published which makes the lived experience of people with chronic illnesses / conditions visible. A phenomenological account has the effect of countering “medicocentrism” (Baszanger, 1989, cited in Bendelow, 1996) where clinical aspects of an illness are privileged over experiential aspects, and instead returns attention to the experience of the sufferer (Kotarba, 1983, cited in Bendelow, 1996).

The aim of Phenomenology is not to develop theory which will “explain and control the world” but rather “offers the possibility of plausible insights” (van Manen, 1990, p. 9). Thus, with the increasing use of phenomenological research, it is hoped that the experiential ‘story’ will be valued for its useful insights. These insights may lead to improved understanding between patients and their health professionals, and to the development of more effective treatment strategies. Phenomenologists aim to get much closer to the experience being studied than is possible (or deemed as valid) within traditional science.

In this current project my aim is to describe the phenomenon of OOS in a rich and detailed manner, identifying the essence/s and structure of the phenomenon. I aim to keep a balance between a strong focus on the phenomenon of OOS, and the subjective experience of the experiencing subjects, and to get beneath the layers of taken-for-granted meanings around this phenomenon. I aim to understand the lived experience of people with OOS, rather than psychological constructs which have been developed to understand cause and effect relating to illness and injury.

CHAPTER THREE

METHOD

RECRUITMENT OF PARTICIPANTS

The participants were a theoretical sample, rather than a random sample. Phenomenological research does not aim to have a representative sample, as generalisation of results to a larger population is not the goal. Instead the goal is to create a 'rich description' of the phenomena. After 11 interviews had been conducted, it was felt that little new material was being introduced. At this point, two further participants had already been recruited, and these interviews were completed, bringing the total number of interviews to 13.

Most participants were recruited through two local physiotherapy practices and one occupational therapy clinic. One participant was a personal contact. The only criteria for inclusion in the study was that the participant had been formally diagnosed as having OOS by a General Practitioner (GP), physiotherapist or occupational therapist. In the majority of cases participants had had a claim accepted with Accident Rehabilitation and Compensation Insurance Corporation (ACC), which requires certification by a General Practitioner.

Although people with OOS seek treatment from a wide range of sources, those who have been diagnosed by a GP are likely to be referred to a physiotherapist and/or an occupational therapist who specialises in relaxation training. GPs may refer to other treatments, but usually not before one or both of these options has been tried. For this reason, recruiting through these sources should provide access to a wide cross-section of people with OOS. The group which I did not obtain, however, were those who had suffered from OOS for very long periods of time and who had experienced little or no recovery. Although some experiences and understandings will be common to both groups, many will not. The experiences of people in this situation warrant a separate study. It is possible that some people who notice symptoms related to OOS self-treat successfully and therefore would not have been included in this study. However, now that workplaces are more aware of problems related to OOS and the advantages of early treatment, it is likely that the majority who suffer symptoms at work will be referred to a GP and / or to a physiotherapist or occupational therapist for specific treatment.

Participants were recruited in three ways within the clinics. The first method involved leaving copies of the Information Sheet (Appendix A) relating to this study in the waiting room, (and in

some cases, clients were alerted to these by clinic staff). Participants could either leave their name with the clinic, or contact me through Massey University or at my work phone number. The second method involved the clinic speaking with their clients about the study, and if the client was interested in participating, their name and phone number was passed on to me. I then contacted them by phone, outlining the study in more detail, and sent them an information sheet, or gave them one when we met in person. The third method involved the clinic sending a letter to clients with OOS (Appendix B) which contained the same information as the information sheet, and a response form that they could return to me by mail.

This study was approved by the Massey University Human Ethics Committee. Thirteen adults participated in the study, ranging in age from early 20s into the 50s. All but one of the participants were women. The majority of participants had been diagnosed with OOS for approximately 3 years, but time since diagnosis ranged from 2 months to over 6 years. Ten participants were working in jobs that required the use of computer keyboards at the time they first experienced OOS symptoms, although for one of these, keyboard use was not considered to be the exacerbating factor. The types of jobs held by participants varied a great deal and included tele-sales, engineering, mail sorting, lecturing in a tertiary institution, youth work, working in a library, working as a bank teller, and accounting. Approximately half had a break from work due to their OOS and during this time received earnings-related compensation from ACC. More than half experienced periods where they were forced to reduce their working hours because of OOS.

At the completion of the study, participants were sent a brief summary of the findings of the research. (See Appendix E).

THE INTERVIEWS

“The qualitative research interview attempts to understand the world from the subjects’ points of view, to unfold the meaning of peoples’ experiences, to uncover their lived world prior to scientific explanations. The qualitative interview is a construction site of knowledge. An interview is literally an *inter view*, an inter change of views between two persons conversing about a theme of mutual interest.” (Kvale, 1996, p.1, emphasis in the original)

Kvale contrasts two metaphors for research interviewing - the researcher as a miner, and the researcher as a traveller. He describes the miner as searching for “knowledge nuggets” which “remain constant through the transformations of appearances on the conveyor belt from the oral stage to the written stage” (p.4), contrasting this with the traveller:-

“What the travelling reporter hears and sees is described qualitatively and is reconstructed as stories to be told to the people of the interviewers’ own country, and possibly also to those with whom the interviewer wandered. The potentialities of meanings in the original stories are differentiated and

unfolded through the traveller's interpretations; the tales are remoulded into new narratives, which are convincing in their aesthetic form and are validated through their impact upon the listeners." (Kvale, 1996, p.4.)

As the goal of phenomenological research is to get as close to lived experience as possible, narrative accounts are seen as desirable, and to encourage this, participants were encouraged to 'just talk' about what it is like living with OOS. However, it is important to think about what 'just talking' may mean. Cornwell (1984, cited in Radley & Billig, 1996) distinguishes between the 'private' and 'public' accounts people give about their health. Public accounts are given when people are concerned that what they say will be acceptable to other people. Private accounts are given when talking as if to people like themselves - using terms and making assumptions that are normally shared within this group. Cornwell reported that the type of account given depended on the interviewer - interviewee relationship. Where people felt they were being questioned by an 'expert,' 'public' accounts were given and where they were being asked to 'tell stories' there was a shift in control which allowed them to give a 'private' account. In this study I am interested in people's 'private' accounts of their experiences. Because of the many perspectives and the degree of suspicion of OOS as a 'real' condition, there could be a tendency for an OOS sufferer to give an account closer to a 'public' than a 'private' account. It is possible that my disclosure that I also have OOS helped to create a dynamic where an account which is closer to 'private' than 'public' was more likely to be given. By encouraging participants to talk about their experience rather than using a 'question / answer' format I hoped to increase the likelihood of this occurring.

Narrative accounts are considered to be the best way to get to the "lived experience" in a direct, pre-reflective way. It is therefore also important to be aware that with some participants, stories may be told for the first time, whereas others may have told their story many times before (Benner, 1994). Also, some people are more naturally reflective than others, and their accounts may therefore contain more abstract ideas and be less concrete or 'pre-reflective' in nature. Some participants told me that they found the interview experience very positive, as they had never really talked about their experience of OOS in any depth before.

I am very aware that each interview is a 'sample in time' of how people choose to relate their experiences. Their choices of what they relate, or their 'slant' on what they relate will be dependent on a large number of factors - for example whether they had a stressful day before seeing me, are in greater pain than usual, or whether they have just had a difficult meeting with their ACC case manager. Situational factors relating to the interview will also affect the accounts they give - for example whether they feel intimidated, cynical, in awe of, eager to please or any number of other feelings about being involved in a research project.

When participants have talked easily, without prompting, it is tempting to assume that I, as interviewer, have had little role in the 'construction' of their account. Likewise, in the cases where participants have not spoken so freely, and I have therefore asked more questions, there is some concern that the issues I ask them to address are not necessarily the issues which are of most concern to them in their daily lives living with OOS. It is important to acknowledge that "no one precise story exists, but rather multiple stories that are shaped by the particular clearing created by the interview situation" (Benner, 1994, p. 111).

Participants were offered the option of being interviewed in their own home, at my office at Career Services Rapuara or at any alternative venue they wished to suggest. Most of the interviews were held in the participants' homes, three were held in my office, and one in a participant's office. Interviews ranged from approximately three-quarters of an hour to approximately an hour and a half. The interviews were taped with a good quality tape recorder - this ensured that neither the participant nor myself needed to focus undue attention on the recording equipment, but could 'just talk'.

Before each interview, I outlined the purpose of my research, and discussed the points made in the information sheet, and invited questions. Once participants had signed the Consent Form (Appendix C) I would set up the tape recorder, and chat while doing this. Generally this acted as an 'ice-breaker' time. While I do not claim to have put in a lot of time and effort into 'building rapport' before we started the interviews, through my counsellor training and work experience as a career consultant I have become reasonably skilled in putting people at ease.

While the participants were encouraged to tell their story, the interaction would still be most accurately described as a semi-structured interview using open-ended questions. A set of 'prompt' questions was drafted. This was reviewed after several interviews, and the revised set of questions (Appendix D) was used for the remainder of the interviews. Guided by Kvale's (1996) metaphor of the interviewer as traveller who 'wanders together with' participants getting them to tell their stories, rather than a miner who is digging for 'truth nuggets', the interviews were begun with an invitation for participants to just talk, as they might over a cup of coffee, about what their experience of OOS had been like for them. I added that I would occasionally throw in a question if/when they ran out of things to talk about, or to help me further understand the experience they were speaking of. Interviews varied from those which required little prompting, to those where there was more of a question / answer style (when participants were not so inclined to talk freely or elaborate). As the need arose, I quickly scanned my list of issues/questions in order to see which areas had not yet been covered. Due to this less structured approach, at times I missed

areas I would have liked to have addressed, and not all interviews journeyed over the same territory. However the richness of the landscape we did cover more than compensated for the roads not travelled.

TRANSCRIPTION OF TAPES

All tapes were transcribed verbatim. I transcribed the first tape myself but this exacerbated my own OOS, so I hired typists to transcribe all the other interviews. Typists were required to sign a confidentiality agreement prior to beginning this work. Each participant was assigned a code name. Typists used only the first letter of the code name. Any other identifying features such as first names of family members, or names of employing companies were omitted or changed in the final typed material. In re-listening to the interview tapes I am aware of how 'naked' the typed transcripts are - or perhaps it would be truer to say, how 'chameleon' they are. The pauses, tones of voice, and hesitations change the sense of the information that is being exchanged. In black and white, on paper, a sentence may look like a clear and firmly held view whereas in the spoken context it constituted a wondering... a self-questioning... I used question marks, hyphens, or exclamation marks, where this helped to make the intended meaning clearer. It is not possible to portray all the subtleties of spoken language in a transcript. Thus it was important, during the analysis of transcripts, to re-listen to the tapes from time to time, to recapture more of the 'live' interview.

It is important to remember at all times that a phenomenological account is an interpretation (by the researcher) of interpretations (by the participants). It is also important to remember that experiential accounts, whether oral or written "are never identical to the lived experience itself" (Van Manen, 1990, p. 54).

PHENOMENOLOGICAL REDUCTION OR BRACKETING

In phenomenological research the aim is to experience the phenomenon of interest in a very direct and immediate way, to take off the 'culture-coloured' glasses through which we view the phenomenon. We aim to peel away the common understandings of our culture, and to look at the phenomenon in a fresh way (Crotty, 1998). Part of the process of bracketing is making explicit our beliefs, theories, expectations, feelings, biases and assumptions, and from this awareness, to try to hold them at bay during the research process. My personal beliefs, feelings and experience in relation to OOS are outlined below.

Why I was interested in studying OOS: My interest in this area began in late 1995 when I developed OOS. While working in my current job as a career consultant I have had several OOS clients who have been referred by ACC or self-referred as they wish or need to make a career

change. I have developed a number of thoughts and suppositions relating to OOS, both through my own experience and from hearing similar themes in accounts given by my career guidance clients. The following account illustrates how these ideas link with my experience. I am aware, however that not all people with OOS fit all of these patterns, and some may not fit any. My suppositions before beginning this study were:

- OOS occurs with intensive repetitive work (but not for all people doing this type of work)
- underlying tension (for example as experienced in an organisation under review) may be an exacerbating feature
- anger and resentment may be an exacerbating feature
- positive excitement may also be an exacerbating feature (but not a feature that I would advocate should be eliminated from one's life!)
- perfectionist / over-conscientious / workaholic attitudes appear also to be an important factor in developing OOS
- continuing with behaviour patterns which appear to exacerbate the condition is common
- people's mental pictures about what is happening in their bodies, and their views about their chances of recovery, are important in how they manage their OOS

At the time that I developed OOS (1995) I was working 4 days a week in a job which involved a lot of editing and hence a great deal of mouse work with a computer. The organisation I worked for had been under review for most of the year, with the new organisational structure announced late in the year. Our department of four staff was 'merged' with another small department, and I was the only staff member from my old department to retain my job. Two management-level staff and the secretary were made redundant, and the plan was to hire two new staff at my level. The appointment of these staff did not happen before I left this job late in March 1996, but the redundant staff left very shortly after the announcement. The redundancies had a strong negative impact on the staff affected, and as these people were friends as well as colleagues, this exacerbated the negative feelings that I had about the restructure. In addition to the emotional impact, there was still the same amount of work to do, with insufficient staff to do it. I felt tired and overworked and the job was less satisfying without the positive input of my previous manager. In spite of being owed many hours 'time in lieu', a request I made to attend a short training course was turned down because we were short-staffed. I felt huge rage and self-righteous indignation. Concurrently with this difficult period in my paid work, I began working towards setting up a part-time private practice in career counselling. I was working intensively on this each Friday, as well as doing a considerable amount of work on it in the evenings. I found this very stimulating and enjoyable. Following a few 'twinges' at work, in my wrists and forearm, I consulted my Doctor who diagnosed OOS and referred me to relaxation therapy. Shortly after beginning this therapy, I experienced increased pain one evening, and found when I got up

the following morning that I was unable to hold things with my hands, or carry even very light weights. I couldn't cut meat on my plate or eat properly with a knife and fork. For approximately two months I was unable to type or hand write without significant difficulty. Secretarial support was hired, which enabled me to continue in my job without taking any sick leave. Many ordinary self-care tasks were difficult. Because of this turn of events, I had to give up all my interests and 'extracurricular activities' over the course of the next year or so. However, I continued to do one paper per year at university. I was constantly tired. For at least a year it felt that my job and studies were all there was in my life, (apart from my relationship with my partner who was very supportive). I particularly enjoy gardening and found that very difficult to give up. After several weeks of doing nothing in the garden I would get fed up with the situation and 'binge' garden, feeling the after effects for some time. I found it very difficult to know what was 'safe' or 'not safe' to do, and my frustration often led me to do things I knew were unwise. In the course of my treatment, I had been told on a number of occasions that I would need to learn to manage my condition and to adjust. I knew of many people who still had severe cases of OOS after a long period of time, and I had a feeling that this was something that I would have to live with forever. A year or so after I began treatment, a chance conversation changed my outlook. The person I spoke with had had a severe case of OOS, but had fully recovered although she was careful not to overdo things, to avoid a re-occurrence. The prospect that recovery was possible made a huge difference to how I felt. I have been fortunate in that I was able to change jobs into an area which I enjoy and which requires less computer use. However I still get some symptoms, and need to be careful not to do too much computer work in one 'sitting', and to manage my stress levels. I have been able to return to almost all my previous interests. As yet I have not been on any long bike-rides or any overnight tramping trips (that is, I haven't carried a heavy pack), but believe that these will yet be possible. I am unsure whether I will be able to play badminton again, but remain hopeful (or perhaps it is more correct to say 'wishful').

These experiences have inevitably influenced my approach to this research project. However in making some of my thoughts, feelings and experiences explicit I attempted to be more aware of how and when my own experience may have been 'getting in the way' of me seeing the OOS picture as the participants were painting it. The above brief account also enables readers to take into account how my own experience may have shaped the research. At all stages during the research I constantly 'returned to the data' and allowed the data to reshape my assumptions and perceptions about the phenomenon of OOS.

Throughout the research process I had to challenge myself to look carefully at the data. I was aware how easy it was to 'see' what was not there. For example, having identified common themes, when writing up my analysis, I would carefully check just how common a particular

experience was amongst participants. I was aware that it was very easy to be strongly influenced by particular participants because their account matched my experience or pre-conceptions, or evoked a strong emotional response. When checking across participants I sometimes found some themes which I had begun to 'see' as common to many participants were in fact only experienced by a small number of participants, and on more careful thought, it became clear that the theme was not 'typical' of OOS, and not part of the 'essential experience' of OOS. The analysis presented in the following chapters contains many verbatim quotes from interview material to help to bring the material 'alive' to readers and to allow readers to evaluate for themselves the appropriateness of my analysis. I have found that this study has challenged my thinking about OOS in many ways, particularly in the realisation that there are no easy or clear cut answers in terms of 'finding one's way' through the experience. The paradoxical nature of OOS became more apparent as the research progressed and this learning process reflected Benner's (1994) comment:

"Throughout the interpretive project the researcher asks, 'What do I now know or see that I did not expect or understand before I began reading the text?' If the interpreter's own views have not been challenged, extended, or turned around, the quality of the account is questioned and the danger of just reading in preconceptions must be considered" (p. 101).

DATA ANALYSIS

Phenomenologists aim to reduce the data in a way that does not strip away the context and the rich detail. It is important to avoid oversimplifying the phenomenon being studied, yet at the same time, identify the 'essence' of the phenomenon with enough detail to describe it well. I have drawn methodological components relating to data analysis primarily from three phenomenological writers - Benner (1994), Van Manen (1990), and Spiegelberg (1969). I also found reading about Colaizzi's (1978) method to be helpful to my general understanding by providing an example of a different method of data analysis.

My analysis consisted of 5 phases - writing paradigm cases, identifying themes, identifying clusters, returning to the raw data, and writing up the analysis. The first two phases occurred in tandem. My interviews with participants were spread out over approximately 6 months, and each interview was transcribed shortly after the interview was completed. Once I received the transcribed interviews I wrote the paradigm case and then identified the themes within these. However, I could not move onto the next phase until I was satisfied that no significant new themes were emerging. This occurred after 11 interviews. The five phases of data analysis are described in more detail as follows.

Writing paradigm cases: The first phase in my analysis involved writing 'paradigm cases' for interviews (Benner, 1994). My 'paradigm cases' were summaries of the interview, the aim being to condense and concentrate the interview (ie to reduce the level of extraneous detail) rather than to eliminate any main ideas which arose during the conversation. Benner (1994, p.113) identifies the goal of paradigm cases as being to present as fully as possible "puzzles, incongruities, and mysteries" of the case.

This condensation allowed me to 'see' the data more clearly, without losing a lot of detail. On average the summaries were about 1/3 the length of the transcripts, and given the space taken by interviewer questions, false starts to sentences, ums and ahs etc, a good amount of detail was still included. The content of the interview was re-arranged in the summarising process to make it easier to follow as a coherent story and to assist with the process of gaining a full understanding of the participant's situation.

While Benner (1994) suggests doing this only for selected cases, I prepared paradigm cases for the first 11 interviews that were transcribed. Doing paradigm cases for so many interviews was a very effective way of immersing myself in the data. Van Manen (1990) emphasises the importance of writing in the process of analysis and theorising, and the process of writing paradigm cases could be seen as an example of this principle in operation - it proved to be a very helpful process.

Identifying themes: The second phase involved identifying themes. I did this by reading each paradigm case carefully, and identifying significant issues or topics of concern to the participant. This method appears to be similar to what Van Manen (1990) calls the "selected reading approach" in which the researcher asks themselves "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described" (p.93). Benner (1994) refers to themes as "meaningful patterns, stances, or concerns" (p. 115).

Using the paradigm cases rather than interview transcripts for the purpose of identifying significant issues had the disadvantage of being distanced from the original data. However it had the advantage that the unnecessary 'background noise' of the original interviews had been removed, but the context and meaning had been kept intact, making it easier to identify the issues of significance. This approach was chosen in preference to 'line by line' coding for themes, which I tried with 3 interviews beforehand. I found that with line by line coding it was more difficult to get a good grasp of the 'big picture' or overall situation as experienced by the participants, and even when I coded larger 'chunks', I did not find this as effective as the two step

approach of preparing paradigm cases, and then identifying significant issues. I therefore believe that the advantages of this two-step approach far outweigh the disadvantages.

As significant issues or themes were identified in the first paradigm case, I added them, with notes, into a word-processing file. As each new paradigm case was analysed, further themes were added, with notes, into this file, producing a cumulative record of all themes identified. At this stage of the analysis many of the 'themes' being identified were quite mundane, and many of them could probably be more accurately described as 'topics discussed' rather than themes. There were many of them (approximately 65), and it was not easy to see how they might come together in a coherent analysis. Once eleven of the interviews had been 'thematized' in this way, no new themes appeared to be emerging.

Identifying clusters: The third phase involved examining the themes which had been identified to find clusters which were related. I did this by physically cutting up the word processing document in which the themes had been compiled. I 'shuffled' these around to explore which themes logically 'went together', forming about 20 separate groups, including a 'miscellaneous' group. Upon further 'shuffling' these were organised into 10 groups of themes that appeared to 'go together'. I then gave each group a heading (which named the larger theme represented). The next step I took was to create a 'map' of these clusters by writing down the major theme titles, with each of the 'subthemes' under their respective titles, and then drawing lines between each theme or subtheme which seemed to relate closely to each other. Through this process I identified three main groupings, which I identified as 'Coming to terms with OOS', 'Seeking a path through the unknown', and 'Adapting to living with pain'. Through doing this I identified some subthemes which were more appropriately included under a different heading than the one under which I had originally included them, and the final groupings were different to what I had originally envisaged.

I see this 'clustering' process as somewhat similar in logic to identifying factors in the quantitative process of factor analysis. As with factor analysis, 'naming' my themes (factors) appropriately at each stage of the clustering was not an easy process. The subthemes within each theme had links that clearly indicated that they should be together, but while the groupings made some sort of intuitive sense, they were, in the early stages, not easy to name or to explain. This became clearer as time went on, although in some cases, some further regrouping was necessary before clarity was reached.

Spiegelberg (1969) suggests a method of lining up phenomenon in order, based on their similarities, and then looking at groups of phenomenon which seem to naturally 'belong together'

in distinct groups. This process has strong similarities with the process I used. He suggests that there is

“nothing arbitrary about this belongingness, for it is based on ‘natural’ affinities. Arbitrary incisions have their place only in the transition areas between several such clusters, where indeed any boundary is essentially artificial” (p. 678).

While many themes clearly ‘belonged together’ there were others that had links with several other themes, and their initial placement was somewhat arbitrary. However a clearer picture gradually began to emerge as the themes “in the transition areas” were placed within groups in which they ‘made most sense’ and created a greater sense of clarity.

Returning to the raw data: As a safeguard against the ‘distancing’ from the original data which occurred in identifying themes from the paradigm cases rather than the transcripts themselves, an additional phase was included in my data analysis. Once the structure of the analysis had been identified, I returned to the original interview transcripts. In this stage of the analysis I used the NUD*IST computer programme to code for the themes which I had identified in the steps described above. At this stage, the two interviews for which I had not prepared paradigm cases, and which therefore had not been thematised, were brought into the analysis.

I incorporated this step in the analysis for three reasons: 1) to aid the retrieval of direct quotations from the transcripts (which Benner, 1994 refers to as exemplars), 2) to check more carefully to what extent each theme was common across all the participants, and 3) as an opportunity to re-examine the original data to identify whether any ‘significant ideas’ (themes) could be identified which were not captured through the original process of thematising from paradigm cases. This did in fact result in the identification of a small number of subthemes which had not emerged previously. These themes were then incorporated into the final ‘cluster layout’ within groups with which they ‘went together’. As anticipated, this stage of the analysis indicated that not all of the identified themes were part of the experience of all participants, but the majority were experienced by the majority of participants.

The write-up process: The fifth stage of my analysis involved writing up my interpretation of the data. Some further refinements were made during the writing process, with a few of the subthemes being ‘reboxed’ as it became clear that this made more logical sense and enabled a more cohesive story to be presented. In addition one of the 3 main themes - “Seeking a path through the unknown” was divided into two - “Seeking a treatment that works” and “Trying to do the right thing”.

Throughout these five phases, and particularly during the process of 'refining' clusters, main themes and subthemes, greater clarity was achieved, and as Spiegelberg (1969) suggested this resulted in a "genuine good gestalt". It is important to remember, though, that the account produced is my interpretation of the participants' interpretations of their experience. It points to the 'lived experience' but is not identical to it. There is no one definitive account of OOS. However, it is hoped that this account will provide useful insights for both the OOS sufferer and practitioners who work with them.

Although the above description may give the impression of a relatively straightforward process, there were many challenges in it. There were many times when I felt somewhat 'stuck' - things did not seem to be fitting together the way I thought they should. This often became evident in the process of writing up. On further thought, in many of these situations it became evident that by attempting to fit a particular example or excerpt where I had, I was trying to make it do work that it could not do - by trying to incorporate it as an example of something it was not. Having realised this, and thought further about what this excerpt was 'really' an example of, new insights were gained, and a greater clarity achieved. A recurring problem for me was that of being 'seduced' by the experiences / stories of the participants, and finding the material so interesting that I had difficulty focussing on the 'object' of human experience. I found myself wanting to insert more of each individual's story, which resulted in less clarity about the phenomenon of OOS. Fortunately my supervisor provided ongoing feedback which enabled me, with some difficulty, to 'get into my helicopter' and see the 'bigger picture', thus distilling out the essences of OOS. This was a gradual process, and was occurring concurrently with that of refining the themes and subthemes mentioned above. As van Manen had predicted, it can be difficult to persist with a theme and systematically explore it. I feel that I have achieved this, and that these five phases of analysis have resulted in a description of both depth and overall structure.

CHAPTER FOUR

INTRODUCTION TO PARTICIPANTS AND OVERVIEW OF FINDINGS

In this chapter the participants are introduced, and a brief outline of the findings of the analysis are given in order to help orient the reader to the following analysis chapters. A separate chapter has been dedicated to this as it was felt that the participants are not just a part of the research method, but rather are the foundation on which the whole study is based. In the spirit of qualitative research, which aims to keep the context of the study as intact as possible, brief details are given of the participants age, work, treatment experience, and the degree to which they were affected by OOS at the time of the interview. The family situation of some participants is also given, as where participants have children at home, this generally involves additional responsibility and in some cases, additional stress. Some participants made reference to the stress or additional work involved in bringing up children on their own, so this detail is also included, where relevant.

INTRODUCTION TO PARTICIPANTS

Anthea: Anthea has had OOS for approximately four years. She is in her 40s. Anthea has grown-up children who she brought up on her own. Anthea first noticed symptoms related to OOS when she had been working for a year in her current job as a tele-sales / computer operator. This is the only job she has ever had. After a period of time off work, followed by reduced hours, she has built up her hours but then experienced relapses. She is currently working three and a half hours per day in this job. She has received treatment with physiotherapy, relaxation therapy, acupuncture, osteopathy, chiropractic and medication. Anthea is still very limited in what she can do.

Barbara: Barbara has had OOS for more than six years. She first developed symptoms in August 1992 (within a year of her starting work after being out of the paid workforce while she raised her son for 11 years). She reduced her hours while receiving treatment for her OOS - she went down as far as working half days, and has gradually worked her way back up to full-time. She does not know why she got OOS but thinks that it may have been because of the amount of change in her life at the time. The treatments she experienced were physiotherapy, relaxation

therapy, and medication. Barbara is now able to do some of the active outdoor activities that she used to enjoy, for example she is now able to bike half way to work.

Connie: Connie developed OOS approximately three years ago. She is in her late 40s and works as a lecturer. She first noticed symptoms related to OOS after pruning roses. She was diagnosed as having carpal tunnel syndrome and her wrist and elbow were operated on. Symptoms improved initially but returned nine months later. Connie's job requires her to do a lot of handwriting and word-processing. Although she completed her Masters thesis with no problems, when doing her PhD thesis she began to notice OOS-related symptoms. In addition to surgery, Connie has also had physiotherapy. Connie did not stop work or reduce her hours. She still has ongoing pain, but having OOS does not limit what she does significantly, although she has to take care driving, and can not sit comfortably in one position for long periods of time.

Donna: Donna was diagnosed with OOS approximately four years ago. She is in her early 20s. She had been doing telesales work where she had been cradling the phone on her shoulder while entering orders onto a computer. She went off work for three months, then returned at two hours per day, gradually building up to four hours, then had another flare up. During the following year she had three periods of three months off work. She built up to six hours per day back in this job and was no longer suffering from any pain. When this position was made redundant she gained a full-time data entry job, but suffered another flare-up and was off work for five weeks. The position was then made into a part-time position for her. She worked four and a half hours per day which worked well for her, but this company closed down. Following a three-month work trial in a retail position, she now works full-time as a retail assistant. The treatments she has received are physiotherapy, relaxation therapy, chiropractic and anti-inflammatory medication. Donna is still very limited in what she can do and suffers ongoing pain.

Erin: Erin has had OOS for approximately three years. She is 45 and works in a bank. She has two children who she has brought up on her own for many years. Following diagnosis, Erin reduced her hours to 20, and then gradually built up to 34 hours per week, but was unable to increase past this point for quite some time. She found physiotherapy, acupuncture and counselling helpful, and was finally able to increase her hours back to full time once she learnt to use relaxation techniques effectively. Erin appears to have 'come out the other side' of her OOS.

Frances: Frances has had OOS for approximately three years. She is 40. Following a break from work Frances had made a career change from accountancy into library work, but after only two weeks in her library job was diagnosed with OOS. She left this job after approximately six weeks, and after a break of two to three months began a part-time accountancy job (three hours

per day). She found this a struggle, but managed to keep going. She left this job about six months before our interview when the nature of the job changed. Frances has had physiotherapy, relaxation therapy, chiropractic, and Bowen technique treatments. She is finding her current physiotherapy treatment more helpful than her initial treatment. However Frances is still suffering a significant amount of pain, and is still very limited in what she can do.

Gaylene: Gaylene has had OOS for over three years. She is 38 and married with three daughters aged thirteen, eleven and nine. Gaylene was working evening shift in a job involving repetitive hand movement with one arm and a static position with the other when she got OOS. She reduced her hours to two hours per evening, and after six months her hours were increased to three, which led to a flare-up. She had a month off work and went back to two hours per evening, four evenings per week. For Gaylene constant tiredness has been a major part of her experience of OOS - this preceded the development of OOS, and continues to be a feature. She has received physiotherapy and relaxation therapy treatments. Gaylene is gradually improving and can identify things she can do now that she couldn't do six months ago. However, she is still quite limited in her activities, and finds she is easily overloaded.

Hamish: Hamish developed OOS approximately ten months ago. He is a fit and active 26-year-old engineer. He was spending a lot of time doing programming, and started noticing symptoms mid-1998, but kept on working until October or November. He went to his doctor following which his training manager at work referred him to relaxation therapy. The relaxation treatment over three or four months led to a relatively rapid recovery. He did not have to drop his hours at any stage. Hamish can now do everything he used to do, including rock wall climbing. However he notices that if he has a week of solid computer work, by Friday he is tired and sore.

Janine: Janine has had OOS for approximately 13 months. She is 43 and is married with one daughter. She works in a library where the majority of her work is doing cataloguing at a computer. She developed OOS following her return to work after a break following an operation. She reduced her hours to half time and gradually built them back up to almost full-time, at which point she had a relapse. She had two weeks off, and reduced her hours to three hours per day, gradually building up again. Janine has had physiotherapy, relaxation therapy, and acupuncture treatments. She now gets less tired than she did when she first got OOS, but there are still a lot of things she can not do like driving and swimming.

Karen: Karen was diagnosed with OOS approximately 11 months before our interview. Karen has two teenage children. She was working two half-time jobs, and several other smaller part-time jobs doing data entry and accounting work at the time that she first noticed minor symptoms

in her arms. Following her resignation from the more stressful of her two part-time jobs, Karen suffered an acute OOS flare-up. She continued to work for about six weeks before she was forced to stop working because of the pain. She was off work for a few weeks, then gradually began building her hours up from about five hours to 20 hours per week. She did not want to work more than 20 hours at that point, so went off ACC. Karen has had physiotherapy and osteopathy treatments, which she did not find helpful. She has had more success taking fish oil, Calmag, and vitamin B. At the time of our interview Karen was able to do most things around the home again, although found this a challenge on top of working. However she was not yet able to drive, and had to be careful about how she approached things such as gardening.

Leanne: Leanne has had OOS for approximately four years. She is 25 and is fit and active and currently working in a youth co-ordination role in secondary schools. Leanne attributes her development of OOS to playing the piano when she was a student. She has had physiotherapy treatment, both at the time of initial onset, and when she has had flare-ups. She found that a couple of weeks after starting physiotherapy she was significantly better - she was no longer at the point where she couldn't hold things. Leanne did not take a break from her studies and has not had to reduce her work hours due to OOS. She has had months on end where she has been pain free, but has occasional flare-ups, which she now feels she knows how to handle. Leanne is able to do everything that she used to do except rock climbing. She had a recent back injury while white-water rafting which seems to have caused her OOS to flare-up again, and this is proving slower to resolve than she expected.

Maxine: Maxine first experienced OOS symptoms approximately two months before our interview. She is 40 years old, married and has two teenage children. She is working in a position where she needed to carry quantities of product. Maxine attributes her OOS to carrying too much at once as part of her job. She has not had to take time off work or reduce her hours. She has been having physiotherapy treatment and is finding this very effective. She is in less pain and has few limitations in terms of what she can do, but has to be careful about how she does things. She has to be careful of actions that jar her arms, and not do too much at a time.

Nadine: Nadine has had OOS for over two years. She is married with a teenage daughter. She works as an administrative assistant, and at the time she got OOS was doing intensive word-processing. She has not taken a break from work or reduced her hours. She has received physiotherapy, and acupuncture treatments, and has also found taking Dolomite (calcium and magnesium) to be helpful. Nadine has ongoing pain and is still very limited in what she can do. She is determined to do what she needs to do in order to be able to continue working.

OVERVIEW OF FINDINGS : LIVING WITH OOS

The analysis of my data suggested that the experience of living with OOS involves four major processes - 'Coming to terms with an OOS diagnosis', 'Seeking a treatment that works', 'Trying to do the right thing' and 'Learning to co-exist positively with OOS'. These processes occur concurrently - they are not phases or stages and there are many inter-relationships between them. The analysis gives insight into the experience of a 'typical' OOS sufferer with a relatively severe and long-standing OOS condition, although each person's experience differs, and not all the issues addressed were part of each person's experience.

These four major processes will each be addressed in a separate chapter. The first addresses the process of 'Coming to terms with an OOS diagnosis'. This begins with first noticing symptoms, seeking help, and receiving a diagnosis. For many participants this occurred over a period of several months, and most were surprised at the diagnosis of OOS. This is followed by a period of trying to make sense of why they may have got it, and gradually, over a period of time, realising the many losses that OOS involves. For many, coming to terms with the full implication of having OOS involves a lengthy struggle.

The following chapter addresses the experience of 'Seeking a treatment that works'. Many participants felt that few people really understood how to treat OOS, but that everyone was willing to give advice. The process of seeking treatment involved establishing a working relationship with doctors and a range of therapists, and in many cases finding that the initial treatment did not result in satisfactory progress. Participants had to cope with the fact that almost all forms of treatment are either painful during the treatment process, or result in additional pain for a period following treatment. The participants' understanding of what was happening physiologically and their beliefs about whether recovery is possible are also discussed as these impact on their approach to treatment. Factors that affect the 'compatibility' between patient and treatment modality are also examined.

The next chapter deals with the process of 'Trying to do the right thing'. The areas addressed include modifying work practices, building up working hours (if participants have taken a break from work or reduced their working hours), doing 'homework' set by therapists and getting exercise. While most participants appear to have quite specific ideas about what they 'should' be doing for their OOS and what constitutes 'the right thing to do', few claimed a high degree of success in carrying out these measures, many of which required constant vigilance and strong self discipline or motivation.

The final analysis chapter addresses the issues involved in 'Learning to co-exist positively with OOS'. This includes participants' experiences of accepting a level of pain in their lives and learning to cope with it, and the need to develop new strategies for noticing the needs of their bodies rather than relying on pain as an important signal. Learning to positively co-exist with OOS also involved participants developing a more caring attitude towards their bodies. This included moving from a short-term view of health to a longer-term view, accepting the limits of their bodies and learning to push the limits in a healthy way, getting adequate rest and relaxation and avoiding unhealthy stress levels. These are all aspects of moving towards a more holistic approach to self-care, where the emphasis moves away from only attending to symptoms, towards a broader concern for health and wellbeing.

CHAPTER FIVE

COMING TO TERMS WITH AN OOS DIAGNOSIS

'Coming to terms with an OOS diagnosis' and successfully adjusting life around OOS occurred over a period of time for most of the participants in this study. For some this process is not complete. Analysis of the data suggested that coming to terms with an OOS diagnosis is comprised of four important processes. The first involves recognising symptoms as an indication of a problem and making sense of a diagnosis of OOS. The second process involves the OOS sufferer finding an answer to the question 'Why me, why now?' and reaching an understanding, or coming to an acceptance of why and how they may have developed OOS when many others doing similar work do not.

Coming to terms with the consequences of having OOS and the loss of their old life is the third important process. The most significant losses include the loss of independence, the ability to contribute to families or workplaces, the ability to pursue personal interests or recreational activities, and the 'taken-for-granted' ease of use of one's body. The loss of independence in the sense of being able to maintain all one's previous roles without assistance is felt keenly by many, and highlights the importance of support. Job prospects may also be severely affected for those whose main employment asset is the skilful use of their hands.

The fourth process is that of struggling to come to terms with OOS and involves a wide spectrum of emotions, commonly including frustration, anger and guilt. Dealing with these emotions is part of the process of adjusting to living with OOS. Each of the above processes involves making adjustments and these are explored in more detail in the following sections.

FROM SYMPTOMS TO DIAGNOSIS

The process of moving from first experiencing symptoms, to seeking medical help, to getting a diagnosis, occurred over a relatively long period for many participants. It often started with symptoms of pain, tingling or tightness. For the majority of participants, the sequence was as follows:

- noticing pain and unusual sensations but ignoring them, minimising their importance and not realising their significance
- 'soldiering' on regardless of the pain, in order to get the work done
- a sudden onset, or a sudden change from moderate symptoms into an acute phase (for most participants it was following this development that they sought medical help)

- a reaction of surprise at the diagnosis of OOS once medical assistance was sought
- regret over their prior lack of awareness about the seriousness of OOS

Most, though not all participants followed this sequence, minimising initial symptoms and pain and not seeking help until provoked by an acute episode. These issues are elaborated in turn to show the detail and complexity within each.

Minimising or ignoring symptoms: Many participants experienced some form of early aches, pains or ‘tingles’ which were noticed but not deemed to be important or to have any sinister meaning. Some, even when the symptoms became more severe continued to believe that they did not constitute a problem, and had an expectation, or wishfulness that they would go away.

Participants experienced a wide range of different symptoms. These included tightness in the neck and shoulders, numbness in the arm, no feelings in the fingertips, tingly fingers, very weak arms and an inability to lift things, and a tendency to drop things. In a few cases participants experienced their hand swelling, but it was much more common for there to be no visible signs, as is common with OOS. The parts affected included the neck, shoulder, arm, elbow, forearm, wrists, and thumb. Many participants spoke of waking at night with the pain or pins and needles.

Most participants experienced symptoms for many weeks and often months without seeing them as a problem that should be looked into. Several participants referred to having a high pain threshold, which resulted in them not seeking help sooner. Many participants referred to their initial symptoms in terms that indicated that they were of minimal concern - “niggles”, “very light, it was just a little ache”. Often participants appear to have simply not been paying any serious attention to their symptoms. In some cases, participants had been thinking about their symptoms, but were hoping that they would go away or get better. Hamish, the only male participant, compared his deskwork job to other heavy physical jobs and this led him to minimise the significance of his symptoms. He put up with symptoms and “*sort of soldiered on*” for about 4 months before seeking help. He suffered discomfort for several months, but sought help after this developed into pain.

“but I only battled pain for about a month, so I guess I’m a bit of a blouse like that. I mean I stuck my hand up pretty quickSome people would probably be tougher, but I sorta didn’t ... I just honestly thought that I was useless, really, I was working at my desk and I was getting pain and I was thinking well there’s people out there working on building sites and stuff who soldier on every day, and I’m

sitting in my chair. I've got no right to complain at all, really, air-conditioned office and stuff..."¹
(Hamish)

This type of stoicism and determination while generally considered an asset by employers can result in people sustaining more serious injury, and consequently greater problems for employers when employees may later lose hours from work.

Even Nadine, who had worked as an orthopaedic nurse for seven years, 'put up with' symptoms for a long time, in fact, longer than any of the other participants (approximately 9 months) before consulting a doctor. Nadine describes herself as having been 'in denial' about OOS to some extent.

"...when I think back now I think ..., but I really didn't know enough about OOS. And I probably didn't even want to go down the track of it maybe being that ... I actually am quite involved in [organisation] and have some friends in there that have had OOS and gone off work and haven't been able to continue and stuff and they used to sort of always look sort of all hunched up and pale, and always talking about the pain in their arm and stuff, and I'm thinking, na, na, na, I haven't got that, na, na, na. I think it's called denial! Yes, so that's what it was there." (Nadine)

There are many possible explanations for why people ignore their initial symptoms. These include being strongly goal focussed to the point of not noticing their bodies 'communications' with them, not wishing to be seen as a 'whinger', and an awareness that OOS is not considered to be a 'real' problem in some circles. Whatever the reasons for the delay in seeking help, the consequences are unnecessarily long periods of exacerbation of the condition which may negatively affect treatment outcomes.

Sudden onset of an acute episode: The majority of the participants experienced either a sudden deterioration into an acute phase of OOS, involving a sudden loss of function or in the case of one participant a sudden onset without any prior symptoms. For those who had put up with a range of symptoms beforehand, including pain, there was a change in the intensity and nature of the pain.

¹ When using extracts from transcripts within this analysis, occasionally a few words are omitted within the extracts where these did not interrupt the flow or meaning. These are signalled with dots Where quotations on the same topic but from separate parts of the interview are combined, this is signalled by more dots Where information has been removed to protect confidentiality, the replacement of this information with a general term within square brackets is made, e.g. [my doctor]. This notation is also used on a few occasions when a participant is referring to something which occurred previously in the conversation, where this additional information is necessary or helpful for the reader to make sense of the excerpt.

"When it was just painful, it was, it was more of a, sort of a localised pain just in my wrists... And then I think it, when it changed it, it was more like a burning sensation, right up my arm ... it was a different sort of pain, it was more unbearable than just kind of a, y'know ache." (Leanne)

"I couldn't use my thumb at all. It wouldn't behave." (Barbara)

"I put my hand up and I couldn't move it, the pain was just so severe..." (Erin)

In some cases there was a specific situation which participants saw as precipitating the situation, for example additional workload or a specific hand-intensive activity such as pruning roses. However, for two participants, the change in the intensity of symptoms experienced does not seem to relate to any identifiable changes in the use of their arms, but rather seems to be one of 'meaning' or 'interpretation'. In Janine's case her condition suddenly deteriorated as soon as she saw her doctor. She suggested that this was due to the stress of the situation coming to a head (reaching a point where her condition was so bad that she had to go to the doctor). This is an interesting reversal of the usual situation where one's symptoms get worse, resulting in a trip to the doctor.

Karen had had sore wrists for quite some time. After coordinating a national conference as part of one of her jobs, she felt burnt out and *"ready to collapse"*. She resigned from this job and took a break for a few days. She found her arms getting sorer and sorer when driving, and realised at this point that she *"had a serious problem"*. Karen likened her experience to the 'retirement syndrome' - the phenomenon of sudden deterioration of health following retirement (as epitomised in the popular belief that teachers often die shortly after retirement). Again, Karen is commenting on an unusual discontinuity in her experience - that her symptoms suddenly deteriorated once a major source of stress had been removed. One would expect, if anything, that symptoms would improve in this situation. In both these cases, it is almost as if the body suddenly decided it was time to stop. These participants had been experiencing some aches and pains, but were still functioning relatively normally until this sudden onset of an acute episode.

A smaller number of participants did not experience a sudden onset of an acute episode. For these participants the onset was gradual with pain initially intermittent, but as time went on pain was noticed every day. Often the pain would reduce or disappear over weekends but worsen on return to work. In addition to experiencing pain more often, for many the intensity of the pain also increased.

"I'd find myself holding my arm during the day, okay, so it was, it was bad enough, it wasn't crippling but it was bad." (Hamish)

The progression from experiencing 'niggles', pain and other symptoms, to a full-blown acute episode indicates a move into a more 'serious' stage of OOS. At this stage the condition is seen as serious enough to activate the sufferer to get help, but probably also indicates that the OOS has moved to a stage where progress towards recovery will be slower and more difficult.

OOS diagnosis a surprise: The diagnosis of OOS came as something of a surprise to most participants. Although OOS has been 'around' for many years, and most people knew or worked with people who had had it before their own first symptoms developed, the majority had not made the link between the symptoms they were experiencing and OOS. This is in spite of the fact that they all had at least a vague awareness of the existence of OOS, and that most of them worked with computers, a known risk area for OOS.

"Yeah, it was a totally foreign concept to me when the doctor even suggested it. It hadn't even entered my head..." (Donna)

Many acknowledged that they knew of OOS but thought it would never happen to them. Donna was quite explicit about this -

"I'd heard of it but I guess I didn't know a lot about it. Mum had worked on a computer and still does and she's been doing that for 20 years and um I suppose I looked at her and thought well you know you must be able to work on a computer for all those years and never have any problems and so I, it never registered to me that I should even be cautious of it so yeah." (Donna)

For some, OOS only occurred to them as a possibility by default. Unfortunately, this thinking can lead to unnecessary delay in seeking treatment. In two cases, participants were concerned about more serious possibilities and this prompted more immediate seeking of help. Connie had a history of heart disease in her family and when her right arm went numb and her fingers got very tingly, she immediately went to the emergency doctors, because of the similarity with the shoulder and arm pain a relative had experienced as symptoms of a heart problem.

One participant had worked as an orthopaedic nurse for 7 years and in spite of this, did not recognise her symptoms as indicating OOS.

"You know, I just couldn't think what the heck it would be. It might have been the case of a little bit of knowledge um, being a nurse..." (Nadine).

The fact that so many participants did not suspect their symptoms as indicating a possible overuse problem, and that many were surprised by an OOS diagnosis indicates that education about OOS, how to prevent it and its possible effects was not very widespread or effective. While some OOS

commentators would caution against creating an environment that encourages hypervigilance of symptoms, clearly, the lack of awareness of OOS has equally serious consequences.

Soldiering on: Consistent with the tendency to ignore or minimise symptoms, was the determination of some participants to 'soldier on' with their work following diagnosis. Some went to, what would appear to be quite extreme measures to keep working. When Erin first noticed pains in her shoulder and wrists she ignored them "*and kept on overworking*". When one day she was suddenly unable to use her right hand at all, she decided she would key with her left hand instead.

"I actually had to put my right hand behind my back cause it automatically would come up to the keyboard, automatically." (Erin)

Karen's doctor recommended she take a break from work, but she persevered for several weeks, firstly with the help of anti-inflammatories, then with a wrist rest, but after a few weeks of trying those things, she "*went down fairly fast and quickly, but in the end I had to give up and do what they suggested and take a break from work*".

Unfortunately when people are first diagnosed with OOS, they are often not in a mental space where they can calmly and objectively weigh up the pros and cons of taking a break from work. The majority of the participants in this study had little idea of the seriousness and long-term chronic nature of OOS, and many were emotionally enmeshed in their work in a variety of different ways, as well as having practical issues relating to the handing over of their work to other people.

If only I'd realised how serious OOS is...: Generally, participants had been unaware of the seriousness of OOS, and felt they would have done things differently if they'd realised it wasn't something that would just get better like a sprain or strain. Many participants were unaware of the degree of pain and weakness that OOS can involve, and the extent to which this affects ordinary daily living activities. Many were also unaware of how long it can take to recover from OOS.

"I just thought the pain in my wrist was it when I first got it. I thought 'I can live with that. I've done a stupid thing, I'll cope with the consequences'. I didn't realise how serious it could get." (Karen)

"If I had known that it was going, it was, it had a possibility of being a damage that wouldn't go away by some physio and doing some exercises, that it would keep coming back, I think I would have done something about it. If I thought right, I might get a bad bout of pain for six months but then I can fix it, I probably wouldn't have done anything about it. It's the fact that it's long term that I don't yeah. Because I'm pretty sensible about things to do with my body long term." (Connie)

Because of their own lack of awareness prior to being diagnosed with OOS, many participants developed strong feelings about the importance of education about OOS and early intervention to deal with it. Only two had received any previous formal education on OOS. There was also a strong acknowledgment that people generally do not take much notice of such education programmes, thinking 'it won't happen to me'.

"It's the same with anything I think, that unless you are going through it personally, that it's affecting you personally, you know, you sort of like, you mentally don't think about it because you're just doing your job, and you're doing your job the best that you can." (Maxine).

"but I sort of thought it happens to other people not me, and I saw it happen to a few people around me in the work place, and I still thought it happens to other people." (Janine).

Some felt that using the personal experiences of people with serious cases of OOS would be an effective way to break through the ignorance about how serious OOS can be, and the ease with which people can decide that it doesn't happen to 'people like me'.

"Maybe people who have been through it need to, need to be brought into the situation to, to talk to people and tell people what happens once you get into that situation and how much of a struggle life is, and how much you go through to get back out of that hole, if you ever get back out of it. I don't know if you get out of it yet." (Frances)

WHY ME? WHY NOW?

A common question asked by anyone diagnosed with a serious or difficult chronic condition is 'Why did this happen to me?' In doing this, the individual is trying to gain some sort of perspective on their experience that will help them to make sense out of it. Occupational health seminars, and most self-help information suggests that: a) OOS is caused by repetitive action or sustained muscle contraction; b) that it is often the people who are hard working, conscientious, etc who get it; and c) stress is often a factor.

Most participants attributed their condition to the type of work they were doing, or ergonomic or work design factors relating to their job. All of the participants in this study had jobs that involved either repetitive work or sustained muscle contraction or both. The majority were involved in jobs which required extensive keyboard work, but others did work which included repetitive, manual, mechanical tasks. However, this does not fully explain the development of OOS. Several participants commented about the fact that not everyone who does their type of work ends up with OOS.

"...it does annoy me when I see a room full of people doing the same job and a handful have this problem and the rest don't." (Anthea)

A small number of participants identified other factors as possibly contributing to their OOS - these included hormonal factors (menopause and hysterectomy) and having taken a break from work. Many participants also made reference to having poor posture. In many cases these latter explanations were framed tentatively, as a wondering, as part of the attempt to find an explanation that made sense to them. Not being able to clearly identify the actual cause of OOS, and answer the question 'Why Me, Why Now?' was a source of stress and frustration for some.

"So I couldn't pinpoint it which I think is the frustrating thing about it, you can't actually, I mean if I went to work and I broke my arm I could say, 'Well', you know, 'I broke my arm at work', but I can't do that". (Gaylene)

The following section explores more fully the participants' perceptions of an 'OOS personality' and the role of stress in their lives at the time that they developed OOS. These factors were identified by many participants as contributing to their OOS.

An OOS personality?: People who 'get OOS' bring with them a variety of understandings about OOS, and these will affect their expectations, decisions, and experience of the condition. There is a commonly accepted notion that there are particular personality attributes that characterise the 'typical' OOS sufferer. These include attributes or tendencies such as conscientiousness, perfectionism, over-working, being excessively 'busy', and going the 'extra mile'. The idea that there is an 'OOS personality' is promoted widely through a range of media, including self-help literature and OOS and occupational health seminars. This concept has not been validated by research, but some aspects of this 'constellation' of characteristics have been studied, and some relationships found, although these are not necessarily strong. For example, Dannatt (1993) found a relatively weak relationship between OOS and two of the Type A behaviour subscales. Regardless of whether this concept can be scientifically proven it is commonly accepted by lay people and therefore it is important to consider its implications.

Some of the participants in the current study had a strong identification with such characteristics, highly valuing such things as hard work, honouring commitments, being selfless and keeping busy. Such attitudes have implications for the treatment and recovery process. Thought patterns which self-reinforce such attributes are likely to get in the way of progress towards recovery in OOS, as the ability to relax the affected muscles and reduce stress levels appear to be an important part of recovery for many people. It thus becomes important for treatment providers to look at two 'layers' relating to the 'OOS personality' - firstly whether the sufferer has any of the attributes of the 'OOS personality', and if so, how this may be affecting their approach to

treatment and self-care, and secondly, the degree to which they positively identify with this profile, and are thus, possibly, valuing these characteristics and reluctant to modify them.

A number of the participants strongly agreed that there was a pattern in terms of the sort of people who get OOS.

"... but then I realise we all have the same characteristics. We are very analytic, we are perfectionist at heart, we like things done the right way or not at all, um, we would rather walk away and leave it. We hate somebody else to do it if it's only half done, and we do not like to give in, um. And we probably, I wouldn't say have blinkers on, but we don't like to change our habits." (Erin)

"I've heard that they're all conscientious types, and thinking of the people I know that sounds pretty dead right." (Janine)

However, the participants could also recognise exceptions to this.

"... and like a couple of the other ladies [who got OOS] are very similar, very similar personalities, you know, like they were uptight and they're running women. But saying that, at the same time there are other people at work who are the same, but they haven't got it." (Gaylene)

Hamish also contradicted the notion of a specific OOS personality.

"I'm not the kind of person who works incredibly hard, and goes in all hours of the night and stuff like that, which is just what strikes me as the funniest thing because, really I would think this is really the kind of thing a dedicated person would get, and I'm possibly not really as dedicated to work as I should be. I like really enjoy my home time. That's what makes me laugh, is that, I've gone and got this, and it looks good on my record, y'know cause, he's overworked himself and I was thinking that's just not the truth at all." (Hamish)

Frances also disagrees with the idea of an OOS personality. She knows two people with OOS, one who has the aforementioned characteristics but the other person is quite the opposite.

"So yeah, I don't know about this um, sort of OOS character at all... I think its more to do with our, with our environment and our, the way, the way we live now than, than a particular personality. Um, computers, our sort of working life, expectations, yeah... I think we just generally, we just don't have a healthy lifestyle. And Western Civilisation is just sort of pushing us further and further down that track, it's um, y'know, technology that has supposedly been developed to help us, is, it's not doing us much good at all." (Frances)

For many participants, however, the idea of an 'OOS personality' provided them with a part of the explanation for why they developed OOS. While this is helpful in that it is a popular concept that validates their experience, it may also have some negative consequences. In particular it may hinder sufferers from moving towards a greater degree of 'self-care'. Proudly wearing the 'OOS

personality' label of being hard working, perfectionist, and conscientious may make it more difficult to move towards an attitude of self-care which involves relaxation, and learning to let go of unnecessary responsibilities and putting options that favour personal health ahead of options that involve hard work and effort.

Stress as a contributing factor: Many of the participants identified stress as a contributing factor to them developing OOS. Ongoing stress is also likely to affect progress towards recovery, and how people conceptualise stress is likely to affect their decisions about possible self-help and self-care² strategies.

Participants identified a wide range of sources of stress. These included both work and personal situations such as restructuring, difficulties with the after-school arrangements for a child, the introduction of performance indicators which were not considered to be realistic, and death or illness of a parent. A small number of participants described themselves as naturally tense people, but also identified particular sources of stress.

For some, the experience of OOS made them aware for the first time of the extent to which stress does affect them.

"I also had quite a bit of stress in my life at that time. I was doing the job for 8 hours per day. I lost my dad and I had my daughter and um, my son-in-law home so it was quite a stressful time. I was also - I started off in my job doing doing 3 1/2 hours a day, and I changed and went to full-time, so with that and everything that was going on I sort of crashed - I think it was not just emotionally but physically as well.....I found, and I never realised this, that I get stressed out quite quickly. Very quickly... Sometimes I don't think I'm stressed and I'll end up with one of these headaches and I'll think 'Now what's going on', and I'll talk to some-one about what's going on in my life and what's happening around. Maybe I am stressed". (Anthea)

It should also be noted that Anthea works in a position where the work output is monitored constantly, and where those with the highest outputs are rostered on for additional work (or conversely those with lower outputs are rostered off during slow periods). While personal stress may have been an exacerbating factor, this stress was laid over the top of a high level of ongoing work pressure.

² In this analysis I make a distinction between self-help and self-care. I use the term self-help to refer to specific techniques or strategies directed towards the alleviation of symptoms, which may have been recommended by therapists (such as doing micro-pauses or using a 'fat' pen), or been discovered by the OOS sufferers themselves (such as changing to a power-steering car). The term self-care is used to refer to an attitude and actions that reflect being kind to oneself, being concerned about one's health in a more holistic way, and looking beyond just the immediate symptoms of OOS.

One participant believed that the combined stress of a relationship break-up some 6 months before she was diagnosed with OOS, and the year of relationship difficulties preceding this break-up, and a 60 hour working week was what caused her to get OOS.. The build up of stress over a long period of time is also evident in Gaylene's case. She had been tired and unwell for at least a year before getting OOS. She described a life that had left her exhausted.

"What I see it as now, is that my body just got so stressed like, um, yeah, it just got so stressed by the amount of work I was doing. I was working all day and I was working all night, and it just didn't seem to be able to cope and everything was tight.....I was stressed to the max when I got it you know, I just wasn't, I wasn't sitting, I wasn't doing anything I enjoyed, I was running from kids to work to kids to sleep to kids to school and it was just like that - continuous all the time - even the weekend was diabolical..." (Gaylene)

The term stress means many things to many people. Hamish makes an interesting distinction when talking about how he is affected by stress.

"So, yeah, in all honesty I'd say I'm um laid back in um attitude, okay - I'm going to make some strange distinction - in attitude, but by like basic nature I'm fairly, probably fairly um, tight, highly strung" (Hamish)

Hamish thinks that for a 26 year old to get OOS probably indicates that he must be "pretty tense." He also explains that he has a pretty high metabolism and doesn't like to sit around doing nothing for very long which leads to fidgeting.

"I'll be sitting up and I'll be twirling a pencil or something, so this, the muscles, the muscles just never stop." (Hamish)

As with the idea of an 'OOS personality', stress provided many participants with a part of the explanation for why they developed OOS. For those participants who had experienced significant stress prior to developing OOS, they were entering this challenging period of their lives when they were already, to some extent, 'running on empty'. People in good health looking in on the lives of those with a condition such as OOS sometimes wonder why they do not 'rise to the challenge' and 'work hard' (and in a logical and consistent way) to get better. They may fail to take into account that the condition (and exacerbating stresses) may have been building up over a relatively long period of time, thus depleting the personal reserves of the sufferer.

THE LOSS OF THEIR OLD LIFE - A WAITING TIME

After the realisation that OOS is not something that goes away after a few weeks of taking care of themselves, the consequences begin to become more evident. The severe weakness of the affected upper limbs and/or pain on the use of those limbs has a major affect on the ability to participate in everyday life, including recreational and social activities. As in other studies

(Bammer & Blignault, 1988) participants in this study reported significant difficulties with housework and with driving. Asking for, and accepting help was also an area of difficulty for many. However most participants appeared to have good support from their families, spouses or partners. Research by Shadbolt (1985, cited in Bammer & Blignault, 1988) reported that most OOS sufferers were satisfied with their family relationships, but were less satisfied with how they used their spare-time, and gained less enjoyment from social activities. This finding appears to be consistent with the experiences of the participants in the current study. Many participants in the current study were unable to work for periods of time, but even for those who were able to continue working, the inability to fully use their arms resulted in a major disruption in everyday life and a significant sense of loss.

"You're never going to get right so you'll never be able to do this, and your list of 'never going to be able to do this' got bigger and bigger and you sort of got squashed by the fact there's this great mountain of 'never going to be doing' - and you sort of think, what on earth's the flaming point."
(Barbara).

Losses most keenly felt by participants were the loss of independence and autonomy, the loss of the ability to contribute to normal family or household life, the loss of the ability to pursue interests and recreational activities which gave meaning and pleasure to their lives and the loss of the taken-for-granted ease of use of their bodies. For many of the participants these losses were still very much to the fore at the time of the interview although a small number of participants had 'come out the other side' of their OOS and had been able to return to past interests. The dominance of the losses as part of participants' stories was, in most cases, strongly related to their current level of disability.

The following excerpt illustrates the feelings of helplessness that may result from severe OOS symptoms and the inability to contribute fully.

"Just that, just the frustration and the, um, yeah, cos it, y'know the feeling is that you are, well I feel that I am, y'know I'm not much good for anything. I'm not, I don't contribute to anything, and within my home life, my partner who works full-time, has a full-time job, y'know has to come home and do things for me, and I've been here doing nothing all day. And that's not a very nice feeling. Um, situations like, my sister lives in Wellington, and ah, y'know I go down there from time to time and stay, and she runs around and does everything for me, and on other occasions she comes up here, and likewise she runs around and does everything for me. Y'know I don't, I feel like I don't give, or I don't reciprocate it, I, I'm just sitting here taking, yeah, and that's not a very nice feeling." (Frances)

Karen lost the ability to drive. She felt this loss particularly strongly, as she has to rely on her new partner to ferry her children around, and also to help with the heavier tasks around home. Her

partner's support was important, as Karen believes that if she had had to drive herself, she probably would not have recovered or been able to build up her hours of work as well as she has.

"I'm totally reliant on John to take me anywhere and ... to pick my kids up too, and they're not his children and if I go to work, if they need picking up, or Sam needs to go to gymnastics or something John has to do it, and if we need something from the shop, he has to do it.....I was totally reliant on John who was only going out with me at the time, to come in and clean my gardens up for me." (Karen)

One of the difficulties with a condition involving the hands, arms, and often neck, is that it eliminates, or makes difficult, a wide range of activities. Even holding a book open while reading is difficult or impossible in the acute stage. Anthea commented on the fact that even activities that are considered quite sedentary pose difficulties.

"You know, people say, why don't you play indoor bowls? Well, hey, I can't get down with my head to bend down cos it's sore." (Anthea).

The types of activities that participants spoke of having to give up because of their OOS included playing guitar, knitting, needlecraft, patchwork, embroidery, dressmaking, baking, gardening, sports (swimming, golf, tramping, cycling, gym work, rock wall climbing), helping out with children's school activities such as sausage sizzles or sports, and home decorating work.

Some spoke of a changed sense of identity from no longer being able to do the things which they used to spend much of their time doing.

"I used to see myself as a cycling, swimming person who did crafts and gardening. And I lost all of those for a while. I'm gradually regaining them. I haven't really started anything new." (Barbara)

"I used to be quite a good swimmer and I still want to be able to swim like that but I can't, so it was pretty frustrating for me." (Janine)

The degree to which participants identify as 'disabled' varies. Karen saw herself as permanently disabled. For others, their relatively lower level of pain and other symptoms and/or their ability to cope with the pain enabled them to carry on 'business as usual' to a large extent, by adapting how they approached tasks. Leanne is now able to do most of the things she used to be able to do. She comments:

"I really sort of see myself as not, yeah, not 'not being able to do things'. The only thing I can't do is rock climb, which I, I don't mind, because I don't really like it that much,... I mean, yeah, there are times when I've had to say no, but most of the time it's pretty much life as normal." (Leanne)

Very few of the participants indicated that they had developed new interests to replace the things they could no longer do. Frances was one of the few participants who was using her time to take

up a new activity. When she stopped working recently she began thinking about a change in career direction, and has taken up art studies. Most others were able to pursue some of their previous interests though often in an adapted way. However, some participants indicated that they were gaining some benefits from the time that would previously have been spent either on household tasks or recreational activities.

"I suppose in a way it was quite nice just to be at home and to be relaxed at home more - it makes a home seem more like a home, doesn't it." (Janine)

Gaylene, while still unable to do much cross-stitch, which was one of her strong interests, commented that in the past she had had very little time available for her own enjoyment. However her OOS has forced her to re-evaluate her situation, and make changes in her life which include some self-nurturing. She now makes a point of keeping afternoons free.

"I listen to my music now. I don't do a lot of things, yeah, I listen to my music. I go to craft group on Tuesday mornings which is not a high powered craft group - if you want to sit there all morning, which I did yesterday, the day before, you're allowed to - it's for the little old ladies, and it's lovely - I do that and um, yeah what else do I do? I've gone back to my cross stitch, and I watch the cricket, I don't feel guilty about watching the cricket at all - actually, no. So that's quite good, so yeah, I've definitely gone to doing a few things for myself... I have that time in the afternoon set aside when it's quiet time sort of thing. I read the odd book, I read the odd magazine, yeah, I can't bust my boiler any more." (Gaylene)

The loss of ability to be involved in shared interests with their partner or spouse, and the loss of choice are a part of living with OOS for some. Frances expresses resentment about the losses to her lifestyle, including the loss of choices. In the context of discussing her partner's outdoor activities, she states:

"...and I get quite jealous about that, y'know I feel really, I get quite angry about it at times, so not that I'd, I don't stop him from doing, from going and doing these things. I think it's great that he does those things, but, um, for myself I feel quite, it upsets me that I can't go and do those things as well, yeah. Or that I don't have the choice to do those things, too." (Frances)

Another of the major losses is the 'ease of life' that taken-for-granted health allows. This is discussed by Frances, who finds the constant vigilance that is required because of having OOS, to be very intrusive in her life:

"And that's something that I, that I find, yeah, that's one of the things that I find really annoying is that, y'know to do a pause every five minutes for a few seconds and drop your arms and flop your arms about, and all the other things, it's this deliberate thinking about everything you do. Analysing the way you do everything. It drives you mad. Y'know, when you're, when you're okay, you just do things, you just get on and do things, but when you've got this sort of problem, you, yeah, you think about everything you do, every single thing you do." (Frances)

Connie talks about another example of the loss of the taken-for-granted.

"Ah, its now quite difficult to find comfortable chairs cause I can yeah our couch is quite uncomfortable when it never use to be. I find it quite difficult now to get to find a position where I can sit comfortably for any length of time. Sort of fidget around. Yes, that's a great loss actually."
(Connie)

The loss of the 'taken for granted' ease of use of their bodies acts as a constant reminder of their condition. Even when OOS does not stop them from doing a particular activity, it reminds sufferers of its presence on an almost constant basis. Every activity must be approached with thought in order to over-ride habits which are so ingrained that they seem to be the natural way to do things. It takes a long time before adapted ways of doing things become automatic.

The need to ask for or accept help is a difficult issue for a number of people with OOS, particularly those who have characteristics in common with the 'OOS personality'. Prior to developing OOS, Erin had felt that things weren't worth having unless she had earned them. This made asking for help even more difficult but in time, she learnt the importance of support.

"I was offered help, but didn't want to take it, wouldn't. I was told I could have somebody in the house but I wouldn't have it. I came home, sorted out my problems, and I said to the kids the two things I can't do, I can't mow the lawns and I can't use the cleaner. Anything else I can do. When I first got it, it was literally impossible to peg clothes on the line, but I did it. And I survived it and I got through it."
(Erin)

"So, what I'm saying, you've got to have support, and people like me don't like support. People don't like relying on anyone else, people with my characteristics like to do it their own way, so you're breaking a very hard mould, you're you're, it's very, very hard..." (Erin)

For single people with OOS, particularly those with children, getting help was more difficult, and had to be more consciously sought. Karen's experience of relying on her new partner for her family's transport needs illustrates this. Many of the participants spoke of having supportive spouses, partners or families. Several had spouses who would give them a massage when they were sore, and others who helped with vacuuming, supermarket shopping and driving. While this help is clearly appreciated, some felt that it placed an unfair burden on their spouse / partner.

"Now Jack starts [work] at 4.30 every morning, and doesn't get in till, what is it now - it's just on five now and he's only just walked in the door, and that's five days a week, and then he's also doing the vacuuming and stuff like that." (Nadine)

Being able to ask for and accept help is an important part of coming to terms with OOS. It is difficult to move towards an approach of greater self-care if one is stoically determined to remain independent and autonomous.

Although the above excerpts indicate a range of responses by participants, there is still a strong sense for most that the losses dominate. It would seem that many were in a 'waiting time' until their condition improved so that they could begin to resume more of their past interests and lifestyle.

Job Prospects: The negative effect on job prospects was another loss for some participants. For sufferers of OOS there are generally two options, to stay in their current job, or to change jobs. If they decide to stay, they are staying in a job in which they may be vulnerable to further injury. If they attempt to apply for jobs they are competing against uninjured people for these jobs. In the current environment, most job application forms, even at a professional level, ask whether the applicant has ever had an injury that will effect their ability to do the job. Some specifically ask about OOS, and a few even ask for the applicant's permission to check with ACC.

Donna, one of only two participants who have made a career change since they got OOS, has experienced many of the major pitfalls involved in a job change following OOS - the loss of a loved career, reduction of salary, having to start at the bottom in a new career, and coping with a job which does not suit her need for constant activity. The loss of her career in data-entry and computing was a hard blow for Donna, who was quite ambitious and career focussed. This was a job she expected to keep for the duration of her working life.

"... and so yeah mm, it's ruined my career, well and truly it really has... I'm um really unsettled I don't know what I want to do. I don't know what I can do until I try it and yeah mm, big thing, cos like I say I wanted to be doing that job until I retired, I was quite happy there, you know, I had no plans whatsoever to do anything else, didn't even think of anything else and you don't really get a say in these things unfortunately." (Donna)

In addition to the loss of the job she loved, Donna has suffered significant financial loss through a progression of job changes in the process of finding work she can do that will not result in a recurrence of her OOS. She has moved from a salary of \$30,000 in a data entry job to \$22,000 in her job as a retail assistant.

"And um each time I've had to take cuts, um, through ACC because um you know, you like, get out and you try something different that you think you can do to get off ACC. It doesn't work so they cut your wage by 20%, so you try something else, that doesn't work, they cut it again, and again, and it just feels to me like I'm being penalised for trying." (Donna)

In Canada it has been found that when an injured worker cannot be accommodated in their previous workplace, they drop an average of 15% in their wages (Silversides, 1997).

Donna is a high achiever who needs to be constantly busy. She found that her new job did not satisfy this need.

"I sort of always had in the back of my mind that I wanted to be in a [retail position], it was something that I always wanted to try and um I thought, you know, my ship's come in. It's not me, standing around waiting for people to come in, it's not me, and I'm finding it really hard on, you know, a lot of nights in tears, crying myself to sleep, not wanting to go to work in the morning, not even wanting to get up because I don't have anything to do when I get there." (Donna)

She also finds it hard starting from the bottom again in a new job.

"... just coming in at the bottom is just really hard, from what I was doing to what I'm doing now, you know, everybody else gets told things and given jobs and so yeah, mm, it's ruined my career, well and truly, it really has." (Donna)

Several participants expressed fears or a sense of hopelessness about the possibility of job change, which is not surprising in view of the difficulties involved.

"...even just trying to find, the thought of trying to find another job is just terrible." (Gaylene)

"And my doctor keeps telling me, change my job. Well, I mean, that's easier said than done." (Anthea)

The potential difficulties involved in applying for a new position, and the possibility of having to 'start at the bottom' in a new job may have been some of the fears which prompted Erin to her view:

"... I still reckon you're best to stay where you are to work it through than to move on, I still feel 150%. Instinct is to run away from a problem, but you are better to face it, rather than sweep it under the carpet or run away from it, because it gets bigger and it follows you." (Erin).

Of the thirteen participants, three have 'chosen' to reduce their work hours as they can afford to do so, and one has accepted a permanent reduced hours position with their employer. It is unlikely that these choices would have been taken if they had not developed OOS.

Having OOS clearly has had negative impacts on participants' careers, and their future career options. Good quality career guidance would be beneficial to people with OOS but to be effective a good working relationship with the ACC Case Manager is necessary in order to navigate the constraints of the ACC system to find the best possible solution for the OOS sufferer.

STRUGGLING TO COME TO TERMS WITH OOS

As with other chronic conditions, the process of moving from noticing symptoms, seeking medical advice, getting a definitive diagnosis, and becoming aware of some of the consequences of the condition seldom leads on to a quiet acceptance of the reality of the situation. Some writers portray acceptance of such conditions as having parallels to Kubler-Ross's stages of loss and healing - shock, denial, bargaining, depression, resolution and acceptance (Anderson, 1999). Bammer and Blignault (1988) however, pointed out that this idea has yet to be demonstrated. One participant, Erin, knew of this parallel and discussed it briefly in her interview. In the case of OOS, the shock stage is not generally clear, as most participants have little idea of the possible serious consequences of OOS until they personally experience them - in some cases this is due to lack of information, and in others may be a matter of denial.

For sufferers of OOS 'denial' can occur over a prolonged period. Because there is often an absence of physical signs accompanying the symptoms of pain and weakness, sufferers may have difficulty accepting that this is a condition that will not just go away. Others not believing that OOS is real can exacerbate this situation. Many of the participants expressed anger, depression and a sense of hopelessness, which might be interpreted as feelings which would accompany 'bargaining' and 'depression'. The issues of being believed, dealing with frustration and anger, and moving towards a point of acceptance will be elaborated in the following sections to show some of the detail and complexity involved in each.

Being believed: In Reid, Ewan and Lowy's (1991) Australian study, being believed was a big part of the participants struggle to find a pathway through OOS. In the current research, comments relating to being believed arose spontaneously in only a small number of instances, and it was not an issue that I questioned participants about. The major difference between the situation in Australia in the late 1980s and the situation for participants in this study is that the GPs in all cases believed the participants' symptoms to be 'real' and believed that OOS was a valid diagnostic entity. There is some evidence that having their condition accepted as real, and receiving validation that their pain originates in their bodies and not from psychological need, secondary gain or sin, helps people with chronic pain to progress towards recovery (Howell, 1994; Seers & Friedli, 1996).

Frances was one of those who commented on the issue of being validated. She was referred to a physiotherapist when she was first diagnosed, and it was the support and validation which she received which was most helpful

"...probably more than anything the person I went to was very supportive in terms of the, the work environment, probably more. He helped me more in that respect than he did in terms of dealing with

the physical problem... in particular, um, telling me that this was a real thing, and that it does happen to people, and you're not imagining it, which is really what I was getting from work." (Frances)

Some participants, as in Frances' case, received little support from their supervisors. On the other hand several participants did receive good support.

"What helped me was that I had a very supportive work - all my jobs, and that they believed in what I had and that they did everything to keep me at work, so that sort of support helped me to make the decision that I wanted to do the same back for them." (Karen)

Although most GPs (and all those consulted by the participants) are in agreement that OOS exists, there is still a perception by many employers that OOS is not a 'real' workplace injury. Because of the subjective nature of pain and the lack of physical signs, both employers and sufferers alike are unsure how to judge who is 'real' and who is 'faking', and this can lead to speculation or suspicion.

"One of the other ladies, hers was a bit mysterious because hers miraculously disappeared. As far as I'm concerned it doesn't do that, like one day its there and the next day it's gone." (Gaylene)

"But the majority of people I met with OOS, their employers have been the opposite. They just don't want to know that the person has got it. They don't believe they've got it and I think that is the other thing, is the visual thing, that you look absolutely fine. And even myself looking at OOS people, I don't know which one is actually more worse than the other and you are taking their total word for it and we know that humans are inclined to say that pains - some people are inclined to sit on pain and say it is the end of the world and other people can walk around and cope with it without even complaining. So it's a really hard thing to decide whether the person is actually honest or not. You've got to take their personality and the person and if they say that they're an honest sort of person you've got to believe them. But its really hard because until I had that doctor's assessment it was really my word telling the doctor that I had it. So maybe they need to do the doctor's assessment right at the beginning when you're sore anyway... That would have been the first exercise with ACC was to have a full assessment straight off by somebody who knew what they were doing ..." (Karen)

Clearly, although the issue of being believed is not as problematical for the participants in this study as it was for those in Reid, Ewan and Lowy's (1991) study it is still an issue which does affect participants as they move towards acceptance of their OOS, and ultimately, towards recovery.

Dealing with frustration and anger: Following diagnosis, once the gravity of the situation is realised, there ensues a process of coming to terms with having OOS. In people with a relatively severe or long-term condition, this often involves a real 'struggle', with periods of worry, tension, depressed mood, guilt, feelings of hopelessness and helplessness, inferiority and anger (Bammer

& Blignault, 1988). Some sufferers experience resentment, rebellion, and frustration and this is sometimes overlaid by a feeling of fatalism - that if they're the sort of person who thrives on working hard and being busy, they are stuck with their condition.

Erin spoke on a number of occasions about the anger she had experienced on the road to recovery, giving insights into several different faces of anger in the experience of OOS.

"...but it was learning to cope with something that you expected to go away and expected to solve and you got angry, with yourself, you got wild, you got frustrated." (Erin)

"I can see how I became so aggressive and so assertive, um, you've got to do something with that pain, you've got to do something with that energy. You've got to - it's sheer frustration, and um, some people would cry, crawl into a corner, other people fight out of the cage, and I, yeah I fought out." (Erin)

Erin also felt anger towards her employer for not being more supportive. She felt under pressure to resign from her job and had made up her mind that if she had to leave, she wouldn't be leaving quietly.

"...and employment-wise, I'd made a lot of decisions, that if I was going I was going out with a bang, and if it wouldn't help me it would help everyone else." (Erin)

Anger about ACC was also expressed by some participants. For these there was a deep sense of injustice that while they had done 'all the right things' in terms of furthering their recovery and taking as little time off work as possible, ACC was not providing the necessary supports. For some there is a sense that they would have been better off, in some senses, to have left their jobs and lived on weekly compensation from ACC (80% of their wage).

"...and this is what gets up my nose - this is on the damn tape - you know, I really am quite angry probably, at the fact that I haven't gone off on ACC and they're still saying you know, [you can only have] thirty six bloody treatments, you know." (Nadine)

For Nadine, the irony is particularly strong as she once worked as an occupational nurse.

"I can see where they're coming from. I mean I used to be the nurse for[company] and I used to say to the guys, ACC stands for Accident Compensation Corporation not Another Con Caper. And they'd go 'Go on, go on,' and I'd say 'No', you know - so that's what really gets up my bloody nose, the fact that I was actually backing them all the way and now it's my turn and I've sort of tried to play by all the rules ..." (Nadine)

For a small number of participants there was a strong sense that their employers were not taking sufficient responsibility. There is some evidence that recovery levels of workers is affected if they believe that their problem was caused by the work they do, and the employer did not "care

enough” to address the problem (Anderson, 1999). One participant had very strong feelings about the work practices that had led to the development of her OOS. She feels angry that her employer does not accept responsibility for their work practices or acknowledge that they have a problem with OOS amongst their staff.

“Well, if I could turn back time I wouldn’t have taken that job. Y’know looking at it now, it was just set up to fail, that situation, shocking situation, and I’m just sort of sorry that there was nobody there to say to me, look, this is potentially a very bad situation, and I’m y’know, at the time in particular, I was not very happy with (my employer), that they put people into that environment, into that situation, without any advice about, y’know, you’ve got to be set up, you’ve got to do this, you’ve got to take pauses, this is a potentially bad situation, we’ve had problems with people in the past. I know they have. They won’t admit it, but they have.” (Frances)

In addition to anger and resentment of OOS and the limitations it places on participants’ lives, there is also a sense of rebellion and frustration surrounding the actions required in order to get better.

“Deep down I probably think, okay, I didn’t sit with my shoulders back when my mother told me I should. So now I’m paying the price. It’s actually difficult to keep pulling my shoulders back, you know, my habitual posture’s here and to keep retraining my body all the time to do this, um, it’s a nuisance. I have a sense of rebellion about it.” (Connie)

Given the situation that the participants found themselves in, such anger and frustration is almost inevitable and unavoidable. Coming to terms with their situation such that these emotions are felt less keenly is likely to be important to their recovery. Exactly how this acceptance occurs is not clear and further research into this area would be useful. Clearly, for a condition which is generally acknowledged to be exacerbated by stress, the ongoing experiencing of these emotions is not helpful.

The path to acceptance: For some participants there was a long period of internal struggle before coming to terms with the reality of living a (changed) life with OOS. Gaylene described this struggle in some detail. It involved a period of rebellion - of acting as if the OOS didn’t exist, ignoring possible consequences, and then suffering the painful results.

“Well, um, [I was] very anti for a long time, but I’ve sort of got used to it now. Yeah, I’ve got used to it and it’s just something I have to do now, if I want to be - I mean, I’m not pain free, but I’m certainly not in the pain that I was in, and I can do so much more now than what I could do even 6 months ago.” (Gaylene)

For Gaylene it took her about 2 years to reach this point of acceptance.

"You seem to go through a period where you just would prefer to be in pain and do what you want - I mean I get sick of people telling me what to do.....I'm not allowed to do that, I must do this that way and I must do that that way and it was just really weird - it was really weird at the beginning, and I just got really anti. In the end I would do what ever I liked. Ha - I would always pay for it mind you. But um yeah, so that took a lot of getting over and accepting that I actually had it, you know, I actually had it and um it was getting worse, um, my condition travelled and it even travelled down my legs, and it just travelled everywhere and um yeah, but finally I sort of said you know, I sort of got used to the idea of having it and I've learnt to live within it, I think that's the thing, so, perhaps you know, that has definitely helped. I don't tend to push it very much now whereas I used to push it all the time at one stage, yes, when I was a bad girl" (Gaylene).

The resolution of this struggle may occur to different degrees - while Gaylene speaks of no longer being 'anti' her acceptance is passive and there appears to be some remaining resistance and reluctance in her acceptance.

"I can't afford to do that, and I haven't got the energy to do it anyway. You know, and as soon as I start doing those sort of things, I tend to pack up, so I don't do them any more." (Gaylene)

On the other hand, for Erin, there was more of a sense of rebellion in her acceptance - the following excerpt was expressed in the context of a heated discussion with her boss:

"I don't like what I've got, I don't like where I am. I would give anything to be anywhere else, but hey, this is where I am. If I have to accept it, so does everyone else. And it's much, much harder for me to accept than anyone else, believe me." (Erin)

For one participant, coming to terms with having OOS, involved a very conscious acceptance of the seriousness and permanence of the condition:

"That's the other thing. It took me a while to recognise that I was permanently disabled. It didn't feel like a disability - it was just a short term pain thing that I was going to get over but it's not. It's actually a permanent disability that you're never going to get completely [over], you learn to live with it but not...." (Karen).

Until Karen reached this point of accepting what she calls the "permanence" of the condition, she did not begin to take the necessary steps to help improve her condition. Karen ignored the initial symptoms for a long period of time, and continued to work after she was diagnosed in spite of her doctor advising her to take a break from work. Conceivably, her belief that OOS is a permanent disability may have resulted in her not thinking about the possible help that could be available to her. Her belief that she has a serious disability could allow her to position herself as a 'disabled person', becoming less active, and more disabled as time goes on. Karen does not, in fact, do

this. She appears instead to 'wear' this statement about OOS being a serious and permanent disability as a mantle that reminds her of the need to treat OOS seriously, and to look after herself better.

For some there is a sense of inevitability about their OOS - that they are who they are, and if a consequence of that is ending up with OOS, then that is their lot. If they decide to make changes this will involve a great deal of effort because of 'the way they are'.

"I could say all the things that people have said to me like, um, not to stress so much and to um, you know, cut down on things that you do and try not to be so busy at work, but I honestly think that if you're that type of person you'll never change because I know that I'll never change, like I know that I shouldn't, you know, um, be like that and try and get all the work you possibly can but that's me, that's my nature and that's how I work so I know all the things I should do, but its easier said than done, and you know, maybe over years of telling myself and having other people tell me I might change but, yeah"
(Donna)

For Erin, overcoming her 'natural tendencies' has also been a struggle.

"So it's something I work on. I can see a sale and I could go for it hammer and tongs, but I put on the reigns and sit back, and think, well hey, do you always have to be the tall poppy that everyone wants to chop down? Do you always have to be the best? Um, very, very hard for me to change, so it's, yeah, it's caring, it's consideration, it's um, it's like a new start, um, but I still, every so often, like the thrill, the adrenalin rush, the thrill of, oh, of going for something. Y'know, it's a turn-on, it's um, it's, you can't change a winner, you can't change a characteristic of somebody that's had the taste of winning in top sport, and, but I've tried, yeah I've tried to mellow, and it still comes at me, oh, y'know, and it's really hard to, um, pull yourself back, um. It gets easier as you go on, yeah but you, yeah you think back, but then you realise, this is where I'm at." (Erin)

The path from struggle to acceptance appears to involve both coming to terms with the reality of OOS and what changes this demands, and also coming to terms with one's self - accepting one's own particular tendencies, but at the same time accepting that changes can be made. The experiences of the participants give us some insight into this process.

SUMMARY

As yet there appears to be a relatively low level of awareness amongst the general population as to the warning signs and consequences of OOS. This results in long delays in seeking help, and this may consequently impact on recovery time. The concept of an 'OOS personality' was accepted by many of the participants in this study, and a strong identification with this profile, while helping to validate the OOS experience, may have adverse consequences in terms of the degree of motivation to change work practices or move towards self-care. Stress was recognised

as a contributing factor to their development of OOS by many participants, and this provided an important sign post for them in terms of treatment and self-care measures. The losses relating to OOS are many, and one area where this is felt strongly is in leisure activities. Most participants were either able to maintain some aspects of their previous leisure interests, or appeared to be 'waiting' till they got better - few indicated efforts to develop new interests. Coming to terms with having OOS was a real struggle for some, and involved periods of frustration and rebellion, but eventually a level of acceptance was reached, though sometimes this acceptance was reluctant and somewhat passive.

CHAPTER SIX

SEEKING A TREATMENT THAT WORKS

The experience of treatment was not an easy one to navigate for many participants. Many spent significant periods of time when they felt like they were floundering around in the dark to some extent. There was a feeling that no one really knows what to do, but everyone has advice. This dynamic is addressed in the following section in order to provide some insight into the OOS sufferer's experience. Adding intensity to the feeling that one is 'lost in the dark' is the very long, slow, painful course which the condition typically follows as sufferers progress towards recovery. Progress towards recovery from OOS has been much slower than expected for almost all participants, and the treatment experience almost inevitably involves pain. Whether the treatment involves strengthening or stretching muscles, relaxation, acupuncture or acupressure, the result is further pain. This can create a feeling of ambivalence to treatment for some sufferers.

Because there are still conflicting schools of thought about OOS within the medical profession and because different doctors have different approaches to treatment, the sufferer is left feeling that there is no clear path through OOS. The fact that there are so many different treatment modalities available, rather than helping the OOS sufferer, adds to the sense of confusion. Many of the participants in this study did not find their initial treatment helpful, or their progress was not as fast as they would have hoped. Often these participants were referred on to another treatment modality, or in a number of cases participants self-referred to alternative treatments. Some participants still feel that they are not yet on the road to recovery (after 3 years in one case). The participants' experiences relating to navigating through a range of treatment modalities is explored briefly.

The quality of relationship established between participants and their doctors or therapists would seem to be important in the treatment of OOS, as with many other long-term conditions. This issue is examined, particularly with reference to the degree to which participants take an active role in the relationship. In addition, the explanatory models (models of cause and effect relating to the condition) which participants have constructed relating to their OOS are likely to have a direct affect on their decisions and actions relating to treatment, self-help and self-care. The extent to which their explanatory models match or are compatible with those of their therapist would also seem to be important. However, in the current study it was found that participants' verbal explanations of their explanatory models, which often appear to have originated from their

therapists, were not always well integrated with their lay understandings of their condition. It would also seem likely that the participants' views relating to whether cure is possible would impact on their level of optimism and motivation relating to treatment. Participants' beliefs about the likelihood of full recovery are explored in further detail.

Those people who were diagnosed early and received timely and 'compatible' treatment, found their experience of seeking and proceeding through treatment was straight-forward. These people were in the minority in this study. For most, the experience involved periods of feeling lost in a world where there seemed to be no clear answers, and feeling pessimistic and fed up, with treatment pain being laid on top of the pain that they were already experiencing from their OOS. However, in spite of this, the majority of participants were progressing, albeit slowly in some cases, and were optimistic that their condition would improve.

NO-ONE KNOWS WHAT TO DO BUT EVERYONE HAS ADVICE

For the majority of participants, their experience is of being in a world where no-one really knows what to do with OOS, and for some the hardest aspect of this is that they themselves do not understand it. However, in spite of (or perhaps because of) the fact that there seems to be no clarity about the best way forward for OOS sufferers, every-one seems to have advice. Several participants made reference to practitioners not knowing what to do with OOS. Anthea's doctor initially thought the problem was related to her hormone levels, and put her on medication for that. After her symptoms got worse and she returned to her doctor, he told her he thought she had OOS. In Barbara's case, her doctor initially thought she had strained her thumb. Karen's doctor had little experience with OOS patients.

"The hardest thing was the doctor didn't know anything about how to treat it and I felt like I was a guinea pig. And nobody knows what to do, the doctor doesn't know what to do. She takes lots of notes ready for the next person that comes along, so that she knows what not to do and she's learning from each patient." (Karen)

Barbara speaks of the increase in knowledge between when she first went to her physiotherapist and now.

"I don't know whether it was lack of experience with the condition, cos I mean you know I sort of did some physio early on and it was sort of experimental at the time and they weren't quite sure what was happening and I'm going back there now and it's three years on and they certainly sussed out the sort of things that are, I mean, it's not all in the hand and it appears to be a lot more in the shoulders and the neck." (Barbara)

There was generally a feeling that there is not a lot of real understanding about OOS anywhere. Their own lack of understanding was a cause of distress for several participants. Erin talks about the first meeting she had with her employer.

"I said 'Look, now it's fine for you, you're asking me questions, it's actually happening to my body not yours, and don't you think I'm frustrated? You want to know the answers, I want to know them a hell of a lot more than you do. And I haven't got them. And it's happening to me. Don't you think that I really want to know them more than even you?" (Erin)

For participants who felt lost in the dark, support groups or talking to other OOS sufferers was an important source of information for them. However, this is seen by some as a relatively unsatisfactory default option. In response to a question about where Karen had found out more about OOS, she states:

"I've been talking to other OOS sufferers, knowing what it is and how it works, but I still think there is a huge question mark there. A massive one. I mean if some-one goes to the doctor, you usually go to your doctor and you expect the doctor to tell you what to do, not to - 'let's try this and we'll write up how it affects you' each time and um all that." (Karen)

However, although on one hand, for many OOS sufferers, it feels as if no one seems to know the best way forward, many people (both medical practitioners and lay people) are willing to offer advice. For Gaylene this experience of being given advice was somewhat overwhelming. The following is her experience of advice from the professionals she interacted with.

"I mean I get sick of people telling me what to do – there's physios, there's doctors, there's ACC and there's work, and there's your mother and your father and oh every Tom, Dick and Harry that knows what's going on and how to cure it and, but mostly physios – I mean physios and [occupational therapy] – they are both very very bossy and they will tell you, you know – you've got to change your lifestyle and you've got to do this, and you've got to do that and you know, oh, you're not allowed to make the beds before nine o'clock in the morning and you're not allowed to get up before eight and you're not allowed to lift this parcel and you're not allowed to walk with your arms swinging, and I could just go on and on – you're not allowed to get into the car frontwards, you've got to get into it sideways – you're not allowed to bend when you back out the car um, you're not allowed to lift anything up, you're not allowed to um oh it's just you're not allowed to do anything you know um and then you go to physio and they say to you um you're not allowed to walk, you're not allowed to um you're not supposed to stand this way and you're not allowed to hold your arms that way and oh it just went on and on and on and I just had to – and nothing seemed to help you see – that's what it was you know – I got to the stage where I was mentally fatigued because I was just so busy thinking well I'm not allowed to do that, I'm not allowed to do that, I must do this that way and I must do that that way and it was just really weird." (Gaylene)

In addition to what seemed like an overwhelming amount of 'advice' from therapists, Gaylene was also being offered lots of advice from lay people - from "every Tom, Dick and Harry".

"Oh yes people are very forward with advice – let me think – my father told me that I should work harder – well you can't really do that when you're exhausted and it didn't work um, oh there's just been so many snippets, so many snippets of things that you should be doing, you know, you should be working harder or you should be not working as hard, you should be giving up work or you should be looking for another job... um, a lot of people thought I should give up work... um, suggestions like you should get your husband to do more, you should get your children to do more, and, um, you should go to bed earlier – well that was all very well but yeah. Yeah even dad came around a couple of months ago and he had this cream for me to try um, but that didn't work and people can't understand why it didn't work um, yeah a lot of people thought I should try the medication um, yeah its more little bits you know like would it be more helpful if I got more home help, and then the next person would be - but if you're getting home help you're not doing things for your self so you're like invaliding yourself. Um, people would say to me, well don't do what the physio says because, you know, you do what you want to do, its your life blah blah." (Gaylene)

Gaylene found the experience of being given advice by many people difficult and here states "...So yeah, in the end I ended up annoying most of them because I had to do what I wanted to do really." Gaylene appears to live in a world where she feels that she must catch every ball thrown to her by some one else and therefore has difficulty coping with the many (professional and lay) providers of conflicting advice. The weight of this advice further overloads her when she is already struggling to cope with her day to day stresses.

TREATMENT: A LONG, SLOW AND PAINFUL EXPERIENCE

For many of the participants, the experience of treatment was that of a long, slow and painful experience, which sometimes had the effect of exacerbating the sense that 'no-one knows what to do', and leaving the OOS sufferer feeling 'lost in the dark'. Almost all forms of treatment caused increased pain or discomfort in the short term, and the majority of participants found their progress to be much slower than they expected it to be. Maintaining motivation to persevere with treatment under these circumstances is a difficult challenge for many OOS sufferers.

Good pain, bad pain, more pain: It appears that for many people, effective treatment involves pain, whether it be the pain of deep massage, trigger point work, exercises and/or stretches at physiotherapy, or the increased resting pain that results from relaxation therapy. According to therapists in this field, people often fail to complete treatment because of the increased pain.

The idea that relaxation therapy results in further pain (relaxation pain), is a somewhat strange concept to grasp. Almost all of the participants who had relaxation therapy spoke of this phenomenon.

"I mean sometimes even resting doesn't do it. If you're having a bad day, resting brings on what they call resting pain and it's just all your blood circulating and when I do my relaxation I get a lot of resting pain because the blood's flowing and yeah, funny things can happen - lots of pain come and lots of pain go. But it's good pain, they tell me - good pain, because that means it's all flowing." (Gaylene)

Pain resulting from physiotherapy is easier to understand, but no less unpleasant. Frances, while feeling positive about the physiotherapy she is currently having, and thinking that her current physiotherapist is on the right track, states:

"I feel um, quite ah, what's the way to describe it, vulnerable I suppose. My whole back and shoulders and the pain seems to move from one shoulder to the other and down my, up my back and lower back and - I feel that I have to be very careful about everything I do. Um, so it really does feel stirred up... (Frances)

The long, slow and painful experience of treatment is expressed vividly in the following excerpt.

"... then we went to physio, um, put up with all the pain that went along with those sessions and um, the same thing, started off going everyday and then, um, gradually um eased off and ended up going once or twice a week, and that again was for months and months and didn't see any real improvement....Yeah, because when I was at physio they, um, gave me a lot of similar stretching exercises like that but oh man, I'd go home and oh, just, it'd take me like the 3 days to recover and then I'd have to go back, do it all over again..." (Donna)

While some participants were able to view 'resting' pain as positive, none attached positive attributions to the pain caused by stretches or exercises. It is likely that previous experience of pain following stretching or exercise may have been related to an injury, and this close association of pain and injury may be difficult to 'undo'. On the other hand, the notion of pain associated with relaxation is so 'weird' and outside of everyday experience that clients may more readily accept the therapist's explanation that 'resting pain' is a positive sign.

Most participants have a base line of pain, with periods where the pain is more severe. They spoke of having good days and bad days, or ups and downs. At times there was a pattern to the occurrence of 'bad' days. Sometimes they seemed to occur after having 'done too much', but at other times there did not seem to be a particular reason as to why a 'bad day' was experienced.

"...it's never been pain free, but some days are worse than others..." (Nadine)

"You know, one day I seem to be sitting at my, it's all moveable - it's all proper chairs and I've got ergo rests for work, um, I seem to be fine, another day I'm not so fine..." (Anthea)

Bad days can cause OOS sufferers to become despondent. Donna acknowledges that she has good days and bad days, and speaks of not coping so well on her bad days.

" ... when I'm sore I get very tired um and I get very irritable um yeah and I find that even like sometimes I guess I have good days and bad days but on the bad days you can start to think, well, you know, I'm not being, I can't, well I mean I am working full time now but you know I can't work full time, I can't keep the house tidy to what I would like it to be um. I can't do everything that I would like to do for [my husband] and things like that. When you're really down and feeling sorry for yourself but yeah that all comes into it as well um but um yeah nothing really - everything's rosy" (Donna)

While a seemingly random pattern of good days and bad days makes progress more difficult to measure, the good days can be helpful in terms of offering hope of possibilities to come. However, it is important to have strategies for coping with 'bad days' to avoid experiencing a greater sense of hopelessness.

Participants spoke of 'bad days' and 'relapses' or 'flare-ups'. While they did not define the differences between these terms it seemed that when using the terms 'flare-up' or 'relapse' they were referring to the development of an acute episode which required further treatment (if treatment had been discontinued) and represented a step backwards in their progress towards recovery. On the other hand a 'bad day' represented a period of greater pain that was generally temporary and did not have longer-term implications. Relapses have much in common with initial onset, but the fact that they occur after a period of improvement can seem even more demoralising. Often this improvement feels as if it has been 'hard won' - there has been a long period of 'trying to do the right thing' and slow recovery, then, often seemingly 'out of the blue', a relapse may occur. This knocks sufferers' confidence in their ability to recover, and may lead to the feeling that it is an overwhelmingly difficult struggle. Similarities between relapses and initial onset include the fact that both often involve a sudden development of acute symptoms, although in some cases, there has been a gradual increase in pain experienced which then suddenly develops into acute symptoms. Relapses also seem to vary in severity, and as with initial onset, they result in some people taking a break from work and others working through. As with the initial onset, some participants were clear about the cause while others struggled to work out what may have caused the relapse.

"No, well when I was at , in my data entry job, the pain almost came on over night, like I was fine for the three months and I thought, you know, this is really good, and then all of a sudden it was there and it was bad. Yeah, and that was that. And again, this time, it's almost like it's fine, there was nothing, and then it was there, so it's not like it um you can sort of feel it coming, it's sort of there and it's there

to stay.....I'm working in [a shop] now as an assistant, um, so there's no keyboard work but, um, there's working the till which is, you know, on a basically just a computer, um, and there's a lot of like vacuuming and dusting and like, I really don't know whether that's doing it, or what, or whether it's standing tense, I don't know but something's made it flare up again..." (Donna)

One of the biggest challenges for people with OOS can be coping with the despair and hopelessness which relapses or 'flare-ups' often engender. After a period of 'doing all the right things' (and making all the sacrifices and exerting the effort which this involves) they suffer a relapse, and feel that they are 'back at square one'. It is following a relapse that the gravity of the situation may hit home, and the enormity of the task of getting well may seem too great.

" ... [I] went back to work and was in terrible pain again and so I was back at square one, so I went through the whole process again. I got quite depressed at that stage cos I felt I had done the right moves as the doctor had said and gone, gone backwards and started again..." (Anthea)

"Well, I'm not as confident about that [returning to 5 hours per day of work] as I was. Because of getting up there and going back." (Anthea)

"It just puts me in so much pain and I don't handle the pain well any more - when you put me back into pain I just tend to get all weepy and I can't cope, yeah, so, so I have to be a good girl... I think it's because - I don't know why - because I like being without little pain - I don't know, it's just the fact yeah - once you go back into pain it's like going back down, down that long road again, I suppose, and um, yeah, and you know how hard it is to get rid of it and you don't like it and it is very painful and it just feels, it just makes it so much harder to cope with everything." (Gaylene)

Nearly half of the participants experienced relapses or flare-ups and others spoke of 'bad days'. Of those who experienced relapses, only a small number of participants spoke of strategies for managing them. Nadine goes for a course of physiotherapy, which she finds, resolves the problem relatively quickly. One participant spoke of using a relaxation technique to help control the pain. Many others appear to experience quite a degree of distress and despondency relating to flare-ups. Sadler (1997) identifies having a 'flare-up action plan' as an important strategy for chronic pain sufferers. Without such a strategy it is likely that a flare-up will result in the sufferer re-experiencing (in their memories, and often in their bodies) all the difficulties they have experienced since they first developed OOS. An action plan that focuses on techniques such as relaxation exercises, and avoiding catastrophising thoughts and despondency is likely to be helpful. Given that few of the participants appear to have had any deliberate strategy to help them deal with flare-ups, research into the use of such action plans with OOS sufferers could be very valuable.

Clearly, many OOS sufferers experience involves a great deal of pain – both the ‘good pain’ involved in treatment, and the ‘bad pain’ of ‘bad days’ or relapses. Pain is often experienced as being very draining, and as evidenced in excerpts above, can lead to despondency. It is hard enough to persevere with long-term treatment without the additional disincentive that it causes increased pain. The added fact that there can be a long period before noticing any gains from treatment suggests that a great deal of faith or discipline may be required to persevere with treatment.

Slow Progress: One of the biggest challenges of OOS is living with the very slow progress towards recovery which is commonly experienced. As time goes on, the more complex the process of recovery seems. Often, after initial slow response to treatment, therapists push the time frame out progressively. This slow progress and the long time frame to recovery can be very disheartening and frustrating. Some participants’ accounts of treatment over a long period of time evoke feelings of a long slow trudge. For example, Gaylene had been going to an occupational therapist for relaxation therapy for approximately 18 months before it “kicked in” in any significant way, although she had been experiencing some small degree of improvement prior to this. Such slow progress and the lack of a guaranteed outcome make this long slow trudge even more difficult.

“It’s really hard because I often feel I would take one step forward and two steps backwards...”
(Janine)

“...the idea of getting over it has, ah, is more involved than I anticipated, yeah.....I am feeling that this guy’s [new physiotherapist] on the right track with me and he’s telling me the right things, and that this, y’know he’s talking, initially he talked about four months and then he started about 6 months, and the last thing he talked about was 18 months before it really came right, so y’know, I’ve sort of been extending out my time period of how long this is going to take to fix. But at the same time, the longer it takes to see any results, the, the more negative I get about it. Y’know I’m coming up to three years, and so, ah, the longer it goes on, the less positive I feel, and that starts impacting on a whole lot of things then...” (Frances)

“It was a long process and I was going three times a week [to physiotherapy] and it was just very long. That’s all I remember, very very long and very painful.” (Gaylene)

“... they did give me a thing of five years, you know, um, because I’d had it for so long when I went to [Occupational Therapy], they reckon it would be five years before I came out the other end, but saying that there’s no guarantee – they don’t give you a guarantee that you’re going to make it anyway.”
(Gaylene)

Measures of progress: As there are often no medical signs with OOS, there are few tangible measures of progress. For those attending relaxation therapy, the therapist sometimes retests the time it takes for their muscles to relax using an electromyograph, and this can be an encouraging measure for participants. The process most commonly used by participants to measure progress was the increase in the range of activities they were able to do.

"and like I say I can do a lot more but yeah, its not like you can see day to day, oh yeah, you know, today I feel better than yesterday and the day before – it just doesn't work like that. Its really slow and I mean some days I feel dreadful....Yeah, I can look back – like last winter I couldn't even open the top windows – I couldn't wipe down the windows with the dew on them because I can't push and I can't reach, but I can do that now, so I can see progress but I try not to think about it too much because you tend to sit there waiting all the time – waiting, waiting. Um, yeah – but hopefully in a year's time it will be– even if its just slightly better..." (Gaylene)

"I can remember walking to the Manager, saying 'Look!' at one of the meetings, 'I can actually do this!' and he must have looked at me and thought 'She's weird,' y'know. And I said 'I haven't been able to do that for 1 ½ years.'" (Erin)

"I have just very gradually but steadily increased my stamina for like going out and doing things. I'm not sort of lifting things or doing work with my hands – its like being out and watching my daughter riding um, which she competes in. I used to – in the spring – I found that totally exhausting, I was a write off by then. But now I can go out to a day like that and feel tired, but not exhausted." (Janine)

Measures of progress relating to pain were also commonly used by participants - both the type of pain and the timing of the pain. Some participants use the decrease in time between an exacerbating activity and when they feel pain, as a measure of progress and some have identified an improvement in the period of time the pain remains after they are no longer using their arms.

"...like during the day, I do tend to get a little focused on what I'm doing and forget to stop, yeah, um. And that results, that still results in pain during the day, um like I get sore during the day, but when I've come home it doesn't settle in, it goes away and when I've done something else its y'know its gone." (Hamish)

"...so I'm at the moment I will get pain but when I get to bed and sleep I don't wake up with pain whereas before I was waking up and starting off sore before I even went to the job." (Anthea)

It is important that people suffering from OOS identify ways of noticing progress in order to encourage themselves over time, and to help them remain motivated in the discipline required with treatment and self-help efforts. In most cases participants had worked out measures of pain and activity which were helpful to them.

THE TREATMENT EXPERIENCE

For some, the experience of searching for a treatment that works was somewhat like stumbling around in the dark: feeling that no one really knows what to do about OOS. Identifying appropriate treatment in this situation can seem like a 'hit and miss' process.

Which Treatment? For many of the participants, the treatment experience involved persevering with treatment(s) in spite of progress being unsatisfactorily slow (or in one case, where 'nothing has worked'). Given that progress is slow, and consequently that participants or their doctors may consider this unsatisfactory, it is not surprising that the treatment experience included, for most, trying more than one treatment modality. However, overall, given the length of time participants have had OOS, there was a relatively low degree of switching from one treatment modality to another. This limited amount of 'switching' may have been due to the commonly accepted view that there are a relatively small number of treatment options available for OOS.

"I mean there's not much that you can do for OOS. You can only go to physio, acupuncture or [relaxation therapy]. It seems to be the only things around at the moment - or medication." (Gaylene)

It is possible that some types of treatments are more suitable at different stages of the condition. Karen found physiotherapy treatment painful and unhelpful when she was first diagnosed with OOS, but feels that she would benefit from it now.

"I was referred to physio but physio made it worse. That was something that I've heard a lot from others too, that at the early stages - I think now, once you're getting better, now that physio would be helpful ... but they're not interested now I'm back at work and off ACC, so there is no payment for that sort of thing". (Karen)

The majority of participants have experienced two or fewer treatment modalities. A small number of the participants (Connie, Hamish, Leanne and Maxine) were referred, in the first instance, to a treatment modality that was effective for them. These participants did not seek any other types of treatments. The 'effective treatment modality' was not the same for each person. A further four participants have only experienced two treatment modalities. Barbara, for example, who has had OOS for six years, has had only physiotherapy and relaxation therapy (plus medication) during this time. The remaining participants had experienced up to six different treatment modalities.

Few participants spoke of seeking alternative treatments beyond the 'standard' list. Of those who did, Frances spoke most explicitly of her experience. Her reasons for trying new therapies were not always clearly defined, but each new therapy she tried inspired new hope.

"Chiropractic - I don't know why I decided on that. I was just wanting something different, and that was I suppose one of the first things that came to mind." (Frances)

"I suppose I always have a, I, I constantly feel that particularly when I'm doing some type of therapy, um, I always feel, this is going to fix it. Get down the track a few months and it hasn't. So you try something else and that sort of, you think right, this'll do it, so at the moment, y'know, I am, although I'm feeling quite in this trough of pain, um, I am feeling that this guy's on the right track with me and he's telling me the right things..... . I am constantly looking at any information that are, that are possible avenues of treatment". (Frances)

Of those participants who are making relatively slow progress towards recovery, many appeared to have moved from one treatment to another with a sense that the previous treatment has failed to deliver satisfactory results. It is possible that such judgments are founded in a belief that they will eventually find "the treatment" that will work for them. In contrast, some participants have been able to identify specific benefits received from the different treatments they have experienced, and specific uses for them. Erin's story demonstrates this well. Erin has had OOS for three years, and has had physiotherapy, relaxation therapy, acupuncture and counselling. She attributes counselling as being very important to her recovery.

"And he's made me look at me and why I do things and how I do them ... but it was trying to understand why I did things and psychologically even though I'm not terribly well educated, trying to understand what people go through, and why we put ourselves through things.....But at least I've been given the tools to survive, um. The counselling was a big part of it. A lot of people look at counselling as a weakness, but it's a strength." (Erin)

Erin also sees acupuncture as having been important for her. Erin had acupuncture for about 18 months. She attributes it as being *"the only thing that kept me at work"*. She went twice weekly, until she was feeling better, but this would only last for a couple of months, then she would have to go back. Several other participants spoke of trying acupuncture but discontinuing it as the affect was only temporary, and it therefore did not contribute towards a 'cure'. Erin, on the other hand, appears to have viewed it as an aid to helping her keep at work, rather than an unsuccessful cure.

Erin finally 'stumbled upon' relaxation therapy at a time when she had been unable to make any further progress towards full-time work - she had 'plateaued' at 34 hours per week, and her employers were threatening medical retirement. While she initially found it hard to imagine that this technique could work for her, she was encouraged by the fact that the therapist herself had had OOS, and appeared very relaxed and had fully recovered. She found this therapy very helpful, and continues to use it.

Erin appears to have identified particular benefits relating to each type of therapy she has tried, whereas most participants spoke of trying a new strategy after the previous strategy failed, and the treatments appeared to be seen as either / or options. Only a small number of participants spoke of combining therapies for their different benefits. These included Connie and Nadine who spoke of using relaxation techniques alongside their physiotherapy treatments and home exercises. Neither of these participants had received relaxation therapy, but instead had worked out their own strategies for example from books they had read.

One of the difficulties experienced by several participants is actually being able to identify whether a treatment is helping, and if they are beginning to get better, determining whether this is because of the treatment or other factors. This dilemma is magnified because of the very slow rate of progress that is experienced by a number of OOS sufferers.

"It's hard to know what's actually making it better, whether it's just that you are looking after it, and not using it as much, or whether it's the physio." (Leanne)

Similarly Janine expresses the confusion she felt about the fact that she was doing enough of the right things that her electromyograph readings were coming down, and yet her pain was spreading.

"Because I have noticed that even over the period when I was receiving the treatment [relaxation therapy] that I thought I was doing well and even at that time my muscle tension in my neck and shoulders was being measured was going down, but even at the time I could feel a pain starting to spreading down through my body and I just don't understand why..." (Janine)

Relationships with doctors and therapists: In most cases participants did not 'choose' their therapist, but were referred by their GP or rehabilitation officer. They often had no prior knowledge of the therapist or the therapy. The relationship may begin with a certain degree of suspicion or scepticism, but one way or another, the client must learn to trust the effectiveness of the therapist and/or therapy in order to persevere with the treatment. Hamish speaks of his somewhat cautious and exploratory initial approach when he was referred for relaxation therapy, and the development of his confidence in the modality due to all the 'milestones' which the therapist predicted occurring just as she had said they would.

"And um, yeah, I went along and it really surprised the heck out of me. At first of all, like I said I was sceptical, because they were just telling you to stop and do nothing, and she explained all these mechanisms and what would happen, and it might be quite hard to recognise some of them, but I have to admit that, I'm pretty open-minded and pretty um, like I do a lot of other sorts of training and stuff and I recognised the benefit of stretching and those sorts of, yoga and those sorts of exercises as well as training..... so I thought I'd give anything a crack, and I was really surprised at how everything she

said sort of came, I mean maybe it's a bit of thinking something will happen and it happens as well. I guess that's the power of positive thinking thing, I don't know. But everything she outlined and told me would happen actually happened, like it actually did get sorer for a while, even though I was relaxing, which I guess was the blood flowing to the muscles or whatever she described. Um yeah, no, I was just really surprised so that sort of gave me confidence pretty early on in the scheme, I can imagine if that hadn't happened I would have given up on the relaxation." (Hamish)

In contrast Frances' experience did not follow exactly as the therapist had suggested it would, and this may have had the effect of undermining her confidence in the relaxation therapy.

Participants' prior experiences with different treatment modalities may also determine the degree of faith they have in each modality. It is possible that peoples' beliefs about the value of both traditional and alternative medicine influence their experience of the treatments they receive. Strong beliefs about particular types of therapy could conceivably result in selective attention to either the benefits or the difficulties related to that therapy, and therefore, to some extent, pre-determine the success of the treatment. For example, Karen places high value on alternative health therapies, and has found the alternative nutritional supplements she has used more helpful than the mainstream treatment she received (physiotherapy). On the other hand, Maxine is an example of some one who placed high value on physiotherapy. Her relationship with her physiotherapist is one built on a strong faith in that modality.

"Well you see my husband went to ... the chiropractor... for his back and he'd been going there for like months and months and months, nothing was happening and he was in pain all the time and then they sent him to the physio, yeah, ... and he only went a few weeks and they did well, it got rid of his pain. So I don't mind physios because you know he was really excellent". (Maxine)

In addition to a degree of trust in the treatment modality being important, the quality of the relationship with the doctor or therapist is also important. While few participants spoke of the quality of their relationships explicitly, it was evident from comments about their interactions with their doctors or therapists that almost all participants were reasonably comfortable with their current practitioners. Janine was one of the participants who spoke explicitly about getting on very well with a therapist. *"I just clicked with her - just like that. She seemed like a really warm person and she explained to me in some detail what - she was a real sweetie"*. Although Janine clearly values a supportive interpersonal relationship with this therapist, this is not enough. She speaks of a physiotherapist that she saw - *"She's very nice - she's very bright and cheerful and everything, but."* The 'but' referred to the treatment not being helpful. Janine stressed the importance of making sure that you have the best health professionals that you can - she recommended shopping around, and asking friends and family for recommendations.

For Erin an important component of her relationship with her relaxation therapist was that the therapist had herself had OOS, and was, in effect, a living advertisement for the therapy. Erin found relaxation treatment made a big difference for her. However, initially her counsellor had given her a relaxation tape and told her to go home and use it. She could not relate to this suggestion and made excuses to the counsellor, for example that she didn't have a tape deck. Clearly, there was a mismatch between Erin and relaxation therapy at that time - Erin places importance on the 'right person to sell it'. Other factors which may have effected Erin's openness (or lack thereof) to relaxation therapy at that time could have been how relaxation therapy was described to her, or it may have been that Erin had to reach a point of crisis - her job being under threat - before she was willing to try it. At this point she had nothing to lose, and potentially, a lot to gain if she tried it. Here she describes her reaction to finding that the therapist herself had suffered from OOS.

"...I sat there and looked at [Occupational Therapist], and I thought she's not married, she's got no ring, you know how your mind just, you start from the bottom and you make, it's just cause you deal with people, it's your job and you're on automatic. And I thought this quite lovely lady, this um, serene, that's a word I never used till I met her, serene, laidback and she asked me more questions, she wrote it all down and then I said, which I always ask heaps of questions, I said, well y'know, I really am stuck and I'm a Virgo. I'm the early Virgo sign, so I know what I'm like. She said, 'So am I.' I said 'Oh, next thing you're going to tell me you've had OOS' and she said 'Yes I have' and I said 'Are you going to tell me that I can end up looking like you?', and I laughed and she said 'I was very much like you. How do you think I can help you?' And I sat there in disbelief and I thought, what have I got to lose? I have done everything else, I have nowhere else to go, and I believe this lady but I don't believe what I'm seeing." (Erin)

The degree to which OOS sufferers are active participants in the healing partnership (the partnership between the patient and the therapist) is also important. Participants in this study varied in this respect, with some being very active, and others being very passive. Nadine is an example of some one who has been very active in her desire to be involved in and understand both her treatment, and OOS itself. In fact, she was taking so much control and responsibility in the early stages, and trying to self-diagnose, that she did not consult a doctor for nine months. However, during the treatment phase her desire for responsibility and control was an asset. The following excerpt indicates a consultative relationship with her GP.

"They asked me what I'd like to do and they were all very supportive. [My Doctor] said to me that I could go off work if I wanted to, and I said I know too many people who have gone off and never returned." (Nadine)

Karen also appears to have an active partnership with her doctor. She has been seeking further information from other OOS sufferers or from any other source she can find and shares her

findings with her doctor, who makes a note of them. Her doctor has attempted to support her with some of the alternatives she is trying. Hamish also took an active role in his approach to treatment. For example, he did not find the relaxation tape provided by the occupational therapist to be helpful as he found the tone of voice on the tape to be unnatural. Instead of using the tape he took himself mentally through the relaxation steps, thus adapting the treatment principles to suit his own needs.

Those participants who are very passive in the healing relationship rely on their therapists to 'fix' them when they have a flare up, and are inconsistent or lack commitment in terms of carrying out the recommendations made by their therapists, particularly in relation to 'homework' tasks. The degree to which patients are active participants in their relationship with their therapists is also strongly influenced by the approach of the therapist. Two of the participants in this study had trigger point therapy as part of their treatment. Gaylene's physiotherapist taught her how to trigger all her own points. This contrasts to Anthea's situation where Anthea depends on her physiotherapist to 'unlock' her whenever she needs it.

One of the difficulties for people with OOS is that several practitioners may be involved in their treatment. The doctor initiates referrals onto other treatments, prescribes medication if that is considered appropriate, and is responsible for certification for time off work (and thus for directing the process of building up work hours). There is often little or no direct communication between those involved in the OOS sufferer's treatment, and often different therapists have quite different explanatory models and consequently different perspectives on what is the most appropriate treatment. In the following excerpt Janine discusses the process involved in 'juggling' the advice and pressures from several sources relating to building up her work hours and dealing with relapses.

"When I first saw her [her doctor] and she put me off – cut my hours by half- I said 'Oh gosh' and when I went back to see her she said 'Do you feel ready to increase your hours?' I said 'Oh sure'. I imagined going back to full time just about straight away, or within a couple of weeks, but she was the one who was acting really cautious at that stage, um, after that I tended to trust the judgement of [occupational therapist] who was seeing me all the time, and my doctor did say that she would take notice of what [O.T.] recommended, but they still did have rather different views. [O.T.] was really conservative, wanted me to rest lots, whereas [doctor] was not pushing me exactly, but not coming from quite the same place. ACC of course want more to see results and want people to go back quickly..... The only time I felt upset was once I had a slight relapse – I was quite sore – I felt it was not going to last long and I should have just taken the day off sick and stayed home, but I went back to the doctor and said '[O.T.] says I should take a day or two off' and she said, 'No I'm not going to do that – I'm going to put you on half time hours for a week and then you're going to build up again.' I just burst

into tears. In retrospect - the fact that the same thing has happened once or twice since then and I have just taken the day off, and just a day off just relieves things so much that I can start up again." (Janine)

Several factors in connection with relationships with practitioners have been explored here, all of which seem to be important. Participants who had faith in the treatment modality they were experiencing, were comfortable with their therapist and were active participants 'in partnership' with their therapists mostly appeared to be making relatively good progress towards recovery or were adequately coping with their OOS. However, it is also important to note that one of participants (the one person in the sample who does not have chronic OOS) is in a relatively passive relationship with her therapist and appears to be making good progress, perhaps facilitated by the very strong faith she has in that practitioner. There are also participants who are determined to have as much control and knowledge as possible relating to their OOS and its treatment, who are still struggling and making relatively slow progress.

The process of navigating from one treatment modality to another generally appears not so much a case of careful logical analysis and decision-making but rather as a process of trial and error, often without a clear evaluation of the relative benefits of each modality. For those experiencing significant levels of pain from treatment this can be even more of a problem. The OOS sufferers themselves are often 'too close to the wood to see the trees'. If they are seeking another type of treatment it is generally because they feel they are making little or no progress. They are likely to be feeling somewhat despondent and 'lost', and do not necessarily have sufficient knowledge of alternatives to make good decisions. Their doctors are likely to work through their list of preferred 'mainstream' treatments (the treatment costs of which are covered by ACC), hoping by a process of elimination to find a treatment that works. Seldom are treatments prescribed in tandem for their possible complementary benefits, and judging from the participants' experiences, no particular logic is being applied by referring doctors in terms of targeting specific types of treatments to particular stages of the development or resolution of OOS.

It is possible, in some cases, that the treatment expectations and goals of doctors and patients differ. Patients are likely to be seeking an end to their pain, the ability to lead a 'normal life' in which they are able to present themselves as competent and coping (Baszanger, 1989), to have a treatment plan that involves minimal disruption to their lives with as few side effects as possible, and which restores them to health in the shortest possible time (Putz-Anderson, 1988). On the other hand, doctors may see the condition as chronic, and if not irreversible, then slow-moving, and may see it as unrealistic that pain will end (Baszanger, 1989). The lack of a clear path towards recovery can be a daunting prospect for OOS sufferers.

FACTORS EFFECTING MOTIVATION TOWARDS TREATMENT

A number of factors affect the OOS sufferer's motivation towards their treatment. As already discussed, the pain caused by treatment, and the slow rate of progress may diminish motivation, and the quality of their relationships with their treatment providers will also affect their motivation. In addition, it is likely that the degree of match between the explanatory models of individual OOS sufferers and that of their practitioners will play an important part. How well their prescribed treatment fits with their lifestyle and their expectations relating to whether a cure is possible are also likely to impact on their progress.

Matching or Mismatching Explanatory Models: In my interviews with participants, if they had not talked about it in some way without direct prompting, I asked about the mental picture they had of what was happening in their bodies in relation to OOS. Not surprisingly, there appeared to be a close link between how participants explained what was happening in their bodies and the model their therapists were likely to have presented them with. However, these models were often not consistent or well-integrated with the participants' strategies for managing their OOS.

Connie was an example of some one who was only using one treatment modality, physiotherapy, and who had a relatively consistent and well-integrated model of what was happening to her. Her explanation of what was happening in her body was consistent with the explanation a physiotherapist might give, involving posture, vertebrae being out of alignment and 'seizing up', pinched nerves, transferred pain, waste materials not being flushed away when the muscles are tense and causing pain. Connie directly drew on the concepts given her by her physiotherapist, and added during her explanation, phrases such as "*I hope I'm reflecting this correctly*". Connie also integrated her own ideas into this model - she had identified that the muscles in her shoulders hunch up more when she is stressed, and consequently her model includes relaxation. Not all physiotherapists would incorporate relaxation in their model although several of the local physiotherapists do. She stated that this explanation "*made a lot of sense*" to her. Connie has an explanation which 'supports' her in doing exercises which will loosen her 'seized up' vertebrae and strengthen the postural muscles that need more strength. It also supports her in being vigilant about her posture and being aware of her stress levels and the need to relax. Her explanation does not provide a strong justification for the need for micro-pauses, but is not inconsistent with such a practice. Connie does in fact do the exercises given to her by the physiotherapist (but only when she notices things seizing up again), and has worked out strategies to help her to relax. She is less disciplined about micro-pauses.

Anthea and Donna both spoke in terms of a relaxation model, and also spoke of the involvement of posture. Neither of them found relaxation therapy helpful, and neither of them appear to have any strategies in place to help them to learn to relax, either generally, or to relax the affected muscle groups in particular. Also, neither of them do the home exercises prescribed by either their physiotherapists or relaxation therapists. Donna didn't do her 'homework' physiotherapy exercises because they hurt. Anthea didn't do them because she was too busy.

Gaylene's stated model of what is happening in her body in relation to OOS follows the type of explanation that is likely to be given by a relaxation therapist – that of muscle tension reducing blood flow and of waste materials not being flushed away thus causing pain. However, although the relaxation model appears to be dominant for her, she has reduced her relaxation practice to once a day, even though the electromyograph readings suggest her muscles are still not relaxing adequately.

Karen's model appears to be one of anatomical or physiological 'building blocks' and involves muscles and the spine - she speaks of these on different occasions during the interview, as follows.

"He did things like pulling your arm different ways and seeing how far it could go without pain and he definitely confirmed my doctor's prognosis that it was in my neck. And that my neck could not turn, see it still can't turn.....One of the things that led to my OOS is lack of exercise um because if I had stronger arms I probably wouldn't not have got it – if I had stronger neck muscles." (Karen)

When Karen speaks of the nutritional supplements she is using, she speaks of the involvement of bone (general, rather than specifically the spine) and muscles.

"So I mean I was treating the bone and treating the tendons with the salmon oil, so I started taking vitamin B [for the muscles] and that has helped." (Karen)

In the excerpt below, when thinking about what caused her sudden onset of OOS *after* she had given up the more stressful of her half time jobs, Karen's explanation of the involvement of adrenalin suggests a chemical and physiological component of OOS.

"There was no doubt about it, it was a stress thing. I do believe stress is very much linked to it, and the stress, being high on stress right to that point, the adrenalin in my system and that is a physical thing adrenalin, it probably kept me going and then I just let go, it was gone and I did let go, I let go in a big way – I just didn't want to know about it, so that was, um, yeah, that could have been, that could have been it, the trigger to go into an extreme state." (Karen)

Karen's 'building block' model is consistent with the use of nutritional supplements to strengthen these building blocks. Exercises and relaxation are not a necessary part of such a model, and they are not of high priority to Karen.

Erin wasn't asked specifically what she thought was happening in her body. However, the following model of 'healing from within' supports her practice of relaxation.

"So it's, yeah and you just slow down, your metabolism slows down and you do your relaxation in the middle of the day, and it takes you out of life. It, you remove yourself from life, um. It probably - you just remove yourself completely, and you heal from within... You heal and then you get back through the next day. I, I still have my relaxation, y'know. I'm too scared to give it up." (Erin)

Janine's mental picture does not have a physiological or anatomical basis. She does not appear to need a more specific understanding of what is happening in her body. She is finding relaxation therapy helpful, she has discovered that her condition is exacerbated by stress, and alleviated by holiday breaks, and she is making slow but steady progress through regular use of a relaxation tape.

"I don't know - it probably doesn't mean anything, but I thought, think of the muscles as having gone spongy or something like that. I don't know what the physical changes are, or that go with the peculiar feelings. I sort of think of it as an unsoundness of some kind." (Janine)

Only two participants mentioned trigger points, and their conceptualisation of these was a mix of anatomical fact and an imaginative extension from these facts (not necessarily accurate).

"I trigger my points which are like sore spots, yeah that's all I can describe them - people often say to me well what are they but apparently they're knots in your muscles or something or a build up of something in your muscles and you can just like - I can run my hand over my, anywhere, and I'll find a trigger spot and it's just like having an internal sore and the physio taught me how to trigger it by really pushing on it and it must like burst or something, but it does work um, and I can relieve quite a bit." (Gaylene)

It is not unusual to have mental models that have not integrated all the 'parts of the jigsaw'. The following is one example of this occurring. Although Gaylene appears to have some 'separate pieces of the puzzle' in terms of a useful mental model, these pieces have not been successfully put together to serve her to the best advantage in the management of her OOS. At other points in her interview it is clear that Gaylene realises that pain is not always associated with activity - she is aware of the phenomenon of 'resting pain'. She speaks frequently of the difficulties related to working an evening shift and caring for her family and the difficulties this creates for establishing a healthier sleeping pattern. However she believes that giving up her job wouldn't make a difference.

"I mean if I'd thought that - a lot of people thought I should give up work, but if I thought that the condition would go away tomorrow if I'd given up work, I would have given up but I didn't think that it would. People don't understand - it wasn't only in my work situation that I had it. I had it from the minute I got up in the morning to, even after I went to bed, I mean I had it all night as well. Yeah, so they always were suggesting I give up work." (Gaylene)

This would appear to indicate that she has not, as yet, integrated all these parts of the 'puzzle'. There are many forces in action in this situation - pressure from ACC, her desire not to lose her job, and it is also likely that there is some pressure being applied by her employers as well. These pressures are likely to mitigate against her making connections, as the resulting conflict would be difficult or impossible to resolve without her changing jobs.

In situations where the OOS sufferer identifies strongly with the 'OOS personality' it will be important to ascertain whether the treatment being proposed appears credible to her/him and whether she/he believes that it is likely to be effective. Without such a belief, the chances of adherence to the treatment and any 'at-home' practice that it involves are slim. Relaxation treatment or the gentle hand and arm exercises at a physiotherapy clinic may be hard to accept by clients who identify strongly with the 'OOS personality' profile and are 'go-getters' who always like to be busy. In the following excerpt one participant describes herself in terms which are very consistent with such a profile. Donna does not do either relaxation practice or physiotherapy exercises at home, but she does do approximately an hour and a half per day of aerobics and exercycle.

"The busier I was the happier I was. The more I had to do the more I threw myself into it - just loved it, so yeah... I just hated and I still do standing around or not having anything to do. I get very bored very easily. I've got to sort of be stimulated all the time and I find that when I am bored I get very down." (Donna)

In working with such clients it will be important to assist them to understand the complex factors involved in OOS, and how such personality factors may affect their feelings about treatment, as I am not aware of any type of treatment for OOS which 'matches' this 'busy, hard working' image of the 'OOS personality'. However, a degree of tenacity, determination and conscientiousness, also characteristics of the 'OOS personality' is an advantage, although, as discussed in Chapter 8, being too 'driven' is not helpful.

Hamish discussed a number of factors which he thinks predict a very good 'match' between himself and relaxation therapy, making him 'an ideal case' for the success of this treatment. Firstly, he sees himself as relatively open-minded so was willing to give what sounded like a strange type of treatment a try. Secondly, he was already in the habit of having a short wind-

down period when he got home each day, so it was easy for him to introduce 'relaxes' (formal relaxation practice) into his lifestyle.

"I do like to, like every day I used to find that I'd come home from work and I'd like to just chill out after work, have a real relax anyway, stop for 10 minutes and then go off to the gym or rugby or do whatever I wanted to do after that, and so it was, it was just an extension of what I was doing already." (Hamish)

Hamish also describes his willingness to take the advice of medical practitioners as important.

"I think maybe that might be my personality a little bit, like if someone, like if I go to physio and the guy says 'Don't run for a week...' then I'll do that pretty much as good as I can. So some people accept treatments. Other people just um say, 'Oh what does he know?' and waste the \$60 now they just spent going to see them, and don't do it. I saw it as an investment more than anything. Yeah." (Hamish)

Hamish does admit that he would not handle the situation well if he had a severe case of OOS that lasted for a long time.

"See, I'd, I'd be ruined if that had happened to me. I, I don't have the staying power I don't think. I'm really lucky that I got it as early as I did, and that the kind of treatment was sort of suited to my lifestyle anyway, and to my personality. If, yeah, if it'd been anything else I'd be, I dunno, like if there'd been some other form of treatment that I had to take that took longer, or was harder for me to do... If I'd had to go out of my way to do it, I probably wouldn't have done it and I'd be in a different place now. I'd be, not be able to do the work that I'm trained to do, sort of thing." (Hamish)

In summary, many things affect whether an OOS sufferer will accept a treatment modality, follow the therapist's recommendations, and see a treatment through to the end of the prescribed course. The degree of fit with lifestyle, the amount of effort required, how much 'faith' they had in the modality and pressure from therapists were some of the factors identified by participants in the current study. There is scope for a greater degree of exploration of the factors that will promote or inhibit a match with a therapeutic modality. There was little evidence from my interviews that therapists make any effort to explore these factors, although this is not a subject that I addressed directly. Failure to do this and to adapt treatment and 'homework' assignments to fit the client may result in a low level of commitment to the treatment.

Is cure possible? Views about the possibility of recovery from OOS appear to be very unclear. This occurs in spite of the fact that, for example, 'Occupational Overuse Syndrome: Treatment and Rehabilitation - a practitioners guide' (OSH & ACC, 1997) advocates that an "essential" part of the initial consultation process with a patient with OOS is to explain to them that "OOS is not likely to result in permanent impairment and that the prognosis is good." The majority of people with OOS do not develop severe chronic conditions (Bammer & Blignault, 1988; Spence, 1998).

However, those who do develop severe chronic conditions appear to be the cases remembered by both treatment practitioners and lay people. Hosokawa (1985, cited in Bammer & Blignault, 1988) in a study of 50 people with OOS reported that the mean time taken for recovery was 4.6 years. He found that 36% recovered within 3 years, 64% within 5 years, and that 6% had not recovered within 10 years. In this study recovery was not defined. Shadbolt (1985, cited in Bammer & Blignault, 1988) found that, of the 76 subjects in their study who had frequent (at least weekly) symptoms at the time of their initial assessment, 14% reported no progress towards recovery, 35% made some progress, 18% were near recovery, 29% had recovered but with injury recurrence, and 4% made a full recovery. This research would seem to indicate that, although recovery is slow for many sufferers, it is possible to recover. It is important to remember that there is now a great deal more knowledge available about treatment strategies than there was when these studies were undertaken.

In the current study all but two of the participants believe that OOS is a lifetime condition, and that it is necessary to learn to manage it and live with it. Barbara was the only participant who had specifically been told that a cure was possible, and this clearly affected her feelings about her situation.

"You're never going to get right so you'll never be able to do this, and your list of 'never going to be able to do this' got bigger and bigger and you sort of got squashed by the fact there's this great mountain of 'never going to be doing' - and you sort of think, what on earth's the flaming point. You may as well, may as well quit work and laze around on ACC - I mean it sort of puts you into this - can't do anything about it, its just going to get worse and you might as well blob. Whereas taking it the other way gave you, sort of, I mean, some power back." (Barbara)

Several other participants knew of some one who has had OOS and is now working full-time again. Janine stated, when asked if she knew of anyone who was coping with OOS:

"There is certainly - a lady who works ... with me - she had a very bad dose of it - she was off work for eight months I think, and she's back working - she probably doesn't do as much on the computer as I do, but I look at her as an inspiration." (Janine)

However, like several of the other participants, Janine also knows people who have not done so well. *"And another friend who had it a few years ago and unfortunately it's starting to rear its head again."* Nadine, while taking a positive approach with her own OOS, only knows people who have been badly affected by OOS, permanently leaving their jobs. She wishes she could meet some one who had got over it. For those who do not know of anyone who has recovered, the outlook can be quite bleak. When Frances was asked whether she knew anyone who had got over it she replied:

*"No, no, no I don't. Which is a bit depressing. Sorta feels like this is going to go on forever at times."
(Nadine)*

Most participants were optimistic that their condition would continue to improve to some degree, but few expected full recovery.

"Hopefully I'll be better, you know, better than what I am today - whether I'll ever get rid of it I don't know - I try not to think about it really, I don't know whether my arm will ever be a hundred percent better - hopefully the right arm will come right, but the left one I don't know, cos its just, it's weak, it's a weak link now. Yeah, so I don't really, I try not to think about it too much." (Gaylene)

"But, it's just my guess is that it's going to be ongoing and it will get worse if I don't, ah, really work at it - like sitting here now, my hands are hurting." (Connie)

"And I still had ups and down days, but I'm never going to be 100% cured. And Monday's always going to be my worst day ..." (Erin)

Leanne is optimistic that her OOS will eventually go away. Unlike others who are basing their hopes or expectations on their observations of other peoples' experiences, Leanne is basing her optimism on her own experience. Up until her current setback (complicated by a back injury), she has had periods where she was pain free for months at a time during the four years since she got OOS. She wondered, however, if it may always be "on and off", and whether she will always have to be careful. But she concluded that that would be all right - she could cope with that.

The fact that it is possible to recover appears to be one of the best kept secrets surrounding OOS. One has to wonder why this is. Do therapists realise that most people are aware of OOS only through those who are suffering relatively severe symptoms? The fact that in most cases participants only knew people who had severe symptoms, or delayed recovery does not seem to sit easily with the fact that most participants had no idea how serious it could be, prior to their own experiences of the condition. Presumably, they are more attuned to the issue now that they also have OOS, and notice other examples of OOS more readily. This apparent contradiction presents an interesting challenge for therapists and health educators - on the one hand to increase public awareness of the potential dangers of OOS, and to bring home to people how serious it can be in order that they take preventative measures seriously, and on the other hand, to make it clear to people that it is possible to recover from OOS (although in many cases this recovery would seem to be quite slow).

SUMMARY

The experience of participants in finding a treatment that works varied, with a small number finding the first treatment that they were referred to effective, and with others trying up to six different treatments. The degree to which participants were active in a 'healing partnership' with their therapists varied, and it is likely that passive relationships with therapists may have been an important factor in the fact that these participants were generally making relatively slow progress. On the other hand, taking too much control and trying to work too much by themselves may also have had a negative affect on the progress of some participants. In the case of some participants, explanatory models or conceptual frameworks regarding OOS were not well integrated and included concepts which were contradictory. There also appeared to be a relatively poor 'match' between the explanatory model as verbalised, and the actions of a number of participants. This may have been because the explanatory models being verbalised were the 'official' explanations they had been given, where-as their own ideas may not have been as easy to express, or may have been seen as less acceptable to talk about in the interviews. Most participants had experienced pain as part of the treatment process, and only two participants believed that a full recovery from OOS was possible.

CHAPTER SEVEN

TRYING TO DO THE RIGHT THING

Phrases such as doing the right thing, and 'being good' arose relatively frequently during the interviews. Participants appear to have a relatively clear idea of the sorts of things that could help them progress towards recovery. However, they find many of these ideas difficult to put into practice consistently. The following analysis examines participants' perceptions that there is a 'right thing' that they should be doing, and their experiences as they attempt to follow both their own instincts about what they think is 'the right thing' and their therapists' advice. Just as there are many different treatment modalities available, each with a different explanatory model, there are equally many approaches as to what is 'the right thing to do' outside the treatment room. These may have the effect of reducing the OOS sufferers' belief in particular 'homework' tasks, as they are aware that these approaches are not universally accepted. For all participants, their efforts to 'do the right thing' are being made in the context of a life with other responsibilities, particularly work and family. Many people with relatively severe OOS find that everyday tasks take much longer to do, and that they suffer from tiredness to a much greater degree than they did before developing OOS. All in all, 'trying to do the right thing' is a struggle for some people, particularly when they feel so uncertain about the time-line towards recovery, or in fact whether recovery is possible at all. Perhaps, under the circumstances, it is not surprising that adherence to 'homework' tasks is not always high.

The major tasks which participants had to negotiate as part of their efforts to 'do the right thing' related to building up their working hours if they have taken a break from work or reduced their hours, adapting work practices, doing therapists' 'homework' and exercising. These issues are elaborated in turn to show the detail and complexity within each. In addition, slow progress towards recovery, which is the experience of many participants, is examined.

It has been identified that adopting the 'sick role', as well as conferring certain rights, also implies certain obligations, which those who are sick aim to fulfil. If the sick do not behave appropriately and fulfil these obligations they are judged as non-cooperative, not genuinely sick, or malingerers. In this study, there was strong evidence that participants had a sense of there being 'right things to do' in relation to OOS, and these were discussed by the participants in terms of their efforts to get well. Many felt a sense of guilt about the things that they 'should be doing'

which they were not doing, and some felt a sense of rebellion about them. The following examples illustrate this sense of there being a 'right thing' to do.

Connie speaks of 'paying the price' for not 'doing the right thing' in relation to her posture - a factor which she attributes as having had a role in the development of her OOS.

"Me, that's um deep down I probably think okay I didn't sit with my shoulders back when my mother told me I should. So now I'm paying the price. Its actually difficult to keep pulling my shoulders back, you know my habitual posture's here and to keep retraining my body all the time to do this um it's a nuisance. I have a sense of rebellion about it." (Connie)

Gaylene spoke of 'doing the right thing' most specifically, and for her, this was generally phased in terms of "*being a good girl*". This meant doing her exercises (that is, using her relaxation tape) every day and keeping in control of her routine so as to keep her experience of stress at a reasonable level. However, although she finally came to terms with having OOS after a two-year struggle, she still has times where she feels rebellious.

"...yeah and you know I do get the odd weeks where I'm a bad girl because I get so anti everything and I look at [an aspect of her work] and I think, oh well, I'll just pick [it] up um, but most of the time I'm pretty good - not like I used to be." (Gaylene)

Anthea speaks of being "*really naughty*" in relation to not doing her exercises at home, and when asked about this in more detail, said "*Ooh you're making me feel guilty.*" Several participants have a strong sense of self-responsibility in terms of their OOS, similar to that expressed by Connie (above). A range of comments, acknowledging that they were not doing what they 'should' or indicating that they felt guilty was made by participants. The majority of participants have a clear sense of there being many things they 'should' be doing to further their recovery from OOS.

It is important to acknowledge the more generalised societal pressures that play a part in this dynamic. Reid and Reynolds (1990) point out that medical constructions relating to OOS

"assumed the dominant liberal ideology of the society, which sees individuals as free agents whose fate (and health) is determined primarily by their own choices, personalities, and responsible (or irresponsible) behaviours." (p. 184)

To a large extent the treatment strategy for OOS requires that individuals take full and personal responsibility - that they make changes in their work practices, that they adhere to exercise prescriptions, and change any ingrained habitual thought patterns which lead to practices which put them at risk. The participants in this research had clearly taken on board many of these expectations, thus having a clear and strong sense of 'should' about these tasks. However, several

participants were also very aware that there were environmental constraints that made desirable changes in some cases impossible, or in other cases very difficult. Karen spoke of some of the dynamics which have resulted in OOS becoming more of a problem. In the first excerpt she addressed the leaner, meaner, faster and more intense work culture which is becoming the norm, and in the second, the pressures on women trying to get off the Domestic Purposes Benefit (DPB) which may lead to working excessively long hours.

"... but I still keep going non-stop, I never, that's something that happens at work, we don't have morning tea breaks or afternoon tea breaks as such, everyone works flat tack. It's the new thing since the Contracts Act. There's no doubt about it every job I've had since then. There is no such thing as morning tea or afternoon tea. Some people wouldn't object to you taking it. You just get into a system of no one else taking it and no one thinks about it. There wasn't, I think with unions and that it was just set. You had a morning tea and it was set and everyone did it. But because it's not set no one gets around to taking it, they're too busy getting their work done. And I notice that a lot of the jobs are salary jobs and you get paid for forty hours but you do fifty or sixty..." (Karen)

"and people are working too long working hours. There's no doubt about it and that's low wages etc that do that. And this pressure to get off the benefit. They expect, I mean single parents to go out and get a job like I did and work and look after the kids and family and everything else and to get a job that got me off a low income because I hadn't worked for years, meant I had to work long hours because the wages were a pittance... And I know that I've talked to a lot of women that work full time that believe that beneficiaries can work but they are on high incomes and they pay child care, and they pay for a house keeper and a low income person doesn't get that... I worked my butt off to get off the benefit, to get off the low income. And um, and that's where I've come, I've got off it, I'm on a high income and I can only work twenty hours now." (Karen)

It is important that therapists are ever mindful that the OOS sufferer is not an individual social atom, but is part of a social and societal setting which has very strong influences, enabling some changes, and making others difficult or impossible. Without therapists exploring how these factors will impact on the strategies that they are recommending to their clients, a low adherence level is a likely outcome.

MODIFICATION OF WORK PRACTICES

The modification of work practices, both at work and at home, is an important part of working towards recovery. Participants appeared to have definite ideas about 'the right things' relating to work practices, although these ideas varied from person to person. Work practice modifications discussed by participants included taking micro-pauses, improving their posture, breaking tasks down into short episodes or steps, varying tasks, and pacing themselves. When thinking about the types of modifications which are recommended for OOS, it is important to bear in mind the work

patterns which may have contributed to OOS in the first place, and the 'OOS personality' with which some participants strongly identified. It would seem likely that making changes to work practices which require people to be gentler on themselves and slow their work down would be particularly difficult for those with characteristics in common with the 'OOS personality'.

Perhaps the most difficult strategy of all, and the one most frequently promoted as being important in treating OOS, is that of taking micropauses. This is difficult because it requires constant vigilance (or involves a constant reminder by an ergopause timer, or computer programme), and constantly interrupts one's work. Unless a person has begun moving towards a more caring relationship with their bodies such that they are putting their long-term health before their immediate deadlines, this interruption is likely to be seen as a 'disruption', and will cause frustration and additional stress. The following comment by Frances implies intense frustration, and to some extent a sense that micropauses are impractical and represent a change which will be impossible to make.

"I think they're [micropauses] ridiculous. Um, and that's something that I, that I find, yeah, that's one of the things that I find really annoying, is that, y'know to do a pause every five minutes for a few seconds and drop your arms and flop your arms about, and all the other things, it's this deliberate thinking about everything you do. Analysing the way you do everything. It drives you mad. Y'know, when you're, when you're okay, you just do things, you just get on and do things, but when you've got this sort of problem. you, yeah, you think about everything you do, every single thing you do." (Frances)

For participants who still strongly identify themselves as hard workers and fast workers, the adjustment to taking micropauses can be even more difficult. In addition, work that requires intensive thought is difficult to interrupt with micropauses and breaks.

"Then the writing of course, once you start writing something three hours can go by and it feels like ten minutes ah and you need to really work in that concentrated way to develop an argument in academic writing and its not something that you can pick up and do in half an hour and then walk away and do something else. ... and it takes enormous discipline to actually tell ones self your arms are hurting you've got to stop now and you're in the middle of writing a really difficult analysis - to hell with the arms hurting you just keep going until you've got your paragraph or what ever finished..." (Connie)

"... micropausing during the day I'm pretty bad at, um like most people who are getting themselves in that situation I guess they tend to work pretty [hard], cos I sort of get focused and forget what I'm doing." (Hamish)

In many office environments where employers have installed micropause computer programmes on staff computers, many individuals prefer to over-ride the instructions to take a break, finding

the suggested breaks a source of frustration. Janine, on the other hand speaks about ‘cooperating’ with the micropause programme on her computer.

“Yes you can ignore it and I have done so sometimes. If you are right on the verge of tapping in some keys that finish off something, it is very hard not to resist. I am pretty sure I’m doing all right with that - I’m not overly abusing it.” (Janine)

But even when one is diligently doing what one believes to be the ‘right thing’ in terms of micropauses, it is still possible to ‘get it wrong’.

“At the time when we went to the meeting to hold my job, um, [the Occupational Therapist] said she doesn’t actually think that the muscles know how to do a micropause. [I] was doing them, and everything right, but this muscle - what was meant to relax in 30 seconds was holding on to - I don’t know how many minutes. And then the other one was holding, so it didn’t matter how many times I did it, in the day or at night, it was never letting go. But I never realised that, you do everything right ...” (Erin)

This is a useful reminder that micropause programmes on computers need to be specifically set for the individual, preferably based on electromyograph readings. The instruction booklet for the ‘Ergopause’ timer suggests that, for patients with advanced symptoms, the timer should be set for 10 second breaks every 3 minutes. Clearly, this would be woefully inadequate for some one with symptoms as severe as Erin’s. If a muscle takes one minute to relax, a micropause programme set for 10 seconds is not helpful. This situation has parallels with the giving of unhelpful advice by lay persons as discussed in the previous chapter (No-one knows what to do but everyone has advice). However in this situation the ‘advice’ has been sanctioned by employers, and because of this OOS sufferers may be unlikely to seek further. Thus they can find themselves in a situation of inadvertently exacerbating their OOS.

Another work practice modification with which many participants had difficulty was in improving their posture. As with micropauses, this is a strategy which requires constant vigilance, and is therefore more difficult to implement than some of the other strategies discussed below.

“I think a lot of it came from lazy posture, I mean look at me now, slouching down in the chair. Um, yeah, that’s another thing I’m going to have to concentrate on, is lazy posture, I do that a lot.” (Hamish)

A strategy which was discussed by many participants, particularly in relation to work at home such as housework and gardening, and one which appears to be somewhat easier for OOS sufferers to manage, is that of taking breaks, and spreading or ‘drip-feeding’ their tasks.

However, even this strategy was challenging for some participants. In the following excerpt, it would appear that Erin has mastered this strategy.

"I do a couple of hours, I come in and make myself sit down and have a drink of water or a drink of orange. I won't want to, but I do, ah. Um, I used to work till I dropped." (Erin)

While Erin is using the strategy of taking breaks, generally breaks every half-hour are recommended rather than every 'couple of hours'. However, if tasks are varied, as they often are in work such as gardening, this is less important. The structure of work tasks in some jobs can also make this strategy more difficult. For others, their general approach to work makes this strategy difficult.

"This work is a bit odd in the sense that it um you don't have a certain amount of writing to do everyday you get a batch of assignments in and there is a two week turn around so you have to um, I thought okay I'll just spread this out during the day but then to fit round other things I'll end up marking for three hours at a time and I'll take breaks going to get myself a drink and people say you know you should mark one essay and then get up and go for a walk but pressure of work, you can't always afford to do that, and, ah, so I tend to mark in blocks of at least three hours." (Connie)

"... and I tend to be a person that if I've started a project I want to get stuck into it and do it, and I can't do it that way any more. I've had to have a big rethink in the way I, the way I do things." (Frances)

Varying the tasks being done is another strategy that is recommended for people suffering from OOS. Again, this is a strategy that is easier than those requiring constant vigilance are, but it still has its challenges. Barbara speaks of her son's reaction to her doing this:

"'Oh, Mum, you never do one gardening job all the way to the end' - No, well, I can't - I do a bit of weeding here and have a rose prune over here and a poke over here and go over and get the mail and find something else to do and you're changing your position. I mean, it's probably the main change that I've had ... I mean in some ways it's a right pain because you can easily forget where you put tools and all sorts of things..." (Barbara)

A range of other strategies was mentioned by participants - all were aware of the need to do things differently. Partly these modifications were motivated by a sense of 'should' in terms of 'doing the right thing' relating to their OOS, and partly they were directly motivated by the consequences (particularly pain) of not 'doing the right thing'. Specific strategies mentioned by participants included: doing more with the uninjured hand or arm, trying to be less of a perfectionist, being more willing to delegate, being more willing to ask for help, preparing simpler meals than

previously, getting a power steering car, taking breaks when driving long distances, and carrying lighter loads.

A small number of participants spoke of not just adjusting how they did their tasks, but also their approach to the way they set work (including work at home) goals. This adjustment may indicate a step back from focussing on immediate symptoms, and taking a slightly 'bigger picture' view of their situation, and also a move towards acknowledging the need to change their work style, as well as specific work practices. However, while these strategies were being used to some degree, for several they still posed significant difficulties. Barbara talks about no longer using 'a list' in the way she previously did. Several participants also made reference to trying not to let work build up. However, for one participant, Gaylene, who identified this as a strategy, it is not always easy.

"... but life is so much different now, but it doesn't take much to overload it, that's the problem and you get behind so fast. But you can't do anything extra, you can't plan to wash the windows in one day, you can't plan to wash the venetians, you can't plan to vacuum the whole house in one day, everything has got to be drip fed - that's what I learnt, everything has got to be drip fed." (Gaylene)

Working out ways to pace themselves and their workload was important for some participants. The attitude towards asking for help, or being able to delegate tasks is also important. Few participants discussed this, but in one case where it was raised, Maxine indicated a feeling of hopelessness towards delegating. In talking about her tendency to sometimes work until she gets pain, instead of chunking her work so that she avoids pain, she states

"...but it's just the fact that, like they say - the old scenario, if I don't get it done, nobody else will do it." (Maxine)

Overall, participants struggled a great deal with modifying their work practices, often with little apparent success. It appears that the success of OOS education programmes in relation to modifying work practices, and the adherence rate of OOS sufferers is far from perfect. And yet, the majority of participants have either been able to remain working full-time, return to full-time work, or make progress in increasing their working hours (although in many cases the progress has been very slow). It is possible that the increased awareness of the desirability of such modifications has influenced them to make some changes in their approaches to work, even though these are not adhered to consistently, and that these changes have been beneficial. It is a useful reminder that therapists' recommendations can not always be easily accommodated into patients' existing responsibilities, habits or mental schema. If such modifications are important to recovery, different strategies may need to be adopted by therapists to help patients make what would appear to be a bigger transition than many therapists perceive it to be.

TIME OFF WORK AND REBUILDING WORKING HOURS

The absence of one clear, definitive view on whether or not breaks from work are beneficial resulted in some participants coming to their own conclusions, for their own reasons, some regretting taking their doctor's advice, and some feeling ambivalent, as evidenced in the following paragraphs.

"I've never been totally pain free but I've never had any time off work, because I refuse, I refuse to go off work because I know so many people, I could name five right off the top of my head that have got OOS, went off work, and have never actually gone back, and I thought bugger that for a game of soldiers. I'm not going to be in that sort of, you know." (Nadine)

Gaylene did not take time off work when she first got OOS, but later wondered whether she would have made better progress if she had *"stopped pushing myself to keep going all the time"* and taken a break from work when first diagnosed. On the other hand, Frances is an example of some one who took time off, but later had regrets about this. She initially thought that the rest would help her to recover.

"So since then [end of August], I've not been working, and partly I thought that by giving up work at that point, I could really concentrate on getting rid of this problem, and now it's the beginning of March, and I'm finding I'm really not a lot better off, in fact if anything I probably feel that I've gone a bit backwards, because again, I'm not working, so I'm not used to a regular use of my arms, and yeah, as soon as I do do anything it flares up, and yeah, to get back into a system of doing things, I think is quite difficult again. So, that, that has backfired on me a little bit, that, the idea of getting over it has, ah, is more involved than I anticipated, yeah." (Frances)

As with many aspects of OOS, a number of participants experienced doubt, self-questioning and a general lack of clarity as to what was the 'right thing' for them. This was particularly true in relation to taking a break from work. They experienced conflicting pressures and advice from ACC, their GPs and therapists, which resulted in additional stresses for several participants.

Workplace support makes a big difference to the success of OOS sufferers as they rebuild their working hours. The following statement from one participant indicated the strength of her feeling about the importance of workplace support.

"And to get support at work, and after not having it, is fantastic. And if people that have got it [OOS] don't get support, which they normally don't in the workplace, they haven't got a dog show. They're not going to make it." (Erin)

In most cases it is necessary to return to work on 'light duties' and some workplaces are better than others in organising this. This process worked well for two participants, Barbara and Karen, where other staff were brought in to do the more manual aspects of their jobs, and they were

given more of a supervisory role. As Karen points out, 'light duties' are only possible where the employer has work the injured person can do.

"I only went for what work they had, so that was the problem with rehabilitation - it's okay to say you should go back and do so much but if there is no work for you it's not a possibility." (Karen)

Some participants were given alternative duties which worked well for them. Others, for example Frances, who worked in an unsupportive work environment, found her experience with 'light duties' more difficult. The concept of 'light duties' may not fit well with the work culture of some organisations.

"I probably continued working for another four to six weeks, I think, at [workplace] and that was very difficult, very stressful, um, they were not very supportive really, basically didn't want to know about it. They, ah, despite giving me these different tasks, it was very awkward, cause I didn't fit in to their very busy office, ah, where they wanted things done." (Frances)

For some, the thought of being independent of ACC weekly compensation was a strong goal. This was probably due to a combination of wanting to 'do the right thing' and of wanting to be free of pressure from ACC. For one participant, Donna, this desire was so strong that she was reluctant to tell her doctor about her current flare-up of symptoms 'in case he put her off work'.

"I certainly don't want to be off work again I'm just finally getting off ACC after 4 years and I'd hate to have to go back, mmm" (Donna)

Three participants, Anthea, Frances and Karen, have chosen to work less than full-time as they can afford to do this. However, in all cases, this appears to be a choice that has been forced on them by their health, and may have been an option chosen in order to avoid pressure from ACC. Gaylene also has accepted a permanent part-time position working considerably fewer hours than she worked before she got OOS.

DOING 'HOMEWORK' RECOMMENDED BY THERAPISTS

Another area where many participants indicated having difficulty "doing the right thing" was in relation to doing 'homework' recommended by their therapists. Most physiotherapists and relaxation therapists give their clients 'homework' to do. In the case of physiotherapy, this may be stretches or strengthening exercises, plus instruction on improving their posture. Relaxation therapists give their clients a relaxation tape, which usually takes about half an hour, with the instruction that it should initially be used twice a day. Presumably 'homework' is given on the assumption that what can be done during a treatment session (usually from half an hour to an hour in duration) once, twice or even three times per week will not be enough to significantly improve the condition, and that doing regular daily follow-up will speed up the recovery process. With physiotherapy, the exercises are generally to be done at home, but in some cases there may only

be instruction to do these at work, at intervals during the working day. Sometimes gym sessions are prescribed, where clients must go to the gym at the physiotherapy clinic two or three times a week. Eleven of the thirteen participants had attended physiotherapy and had been given exercises and / or techniques to provide relief, to do at home or work. A number of these had also attended relaxation therapy, as had the remaining two participants, and would have been given relaxation tapes to use at home. Overall, there seemed to be a low rate of adherence to 'homework'. A range of reasons was given for this: that the exercises caused 'pain', that the treatment didn't work, lack of confidence about doing exercises correctly, and not having enough time. These issues are elaborated in turn.

Gaylene is an example of a participant who did not do her physiotherapy exercises because of the pain.

"Oh yes, I've got lists and lists of exercises I should do. I'd be exhausted if I did all the exercises physios gave me, but I don't have to do any of them, I don't do any of them because they all make me hurt you see." (Gaylene)

It is hard enough for many people to be disciplined about 'homework' practices such as doing a formal relaxation session, or doing exercises, without the additional disincentive of increased pain. The added fact that there can be a long period before noticing any gains from treatment suggests that a great deal of faith or discipline may be required to persevere with treatment.

The degree to which participants believed that the therapy they were receiving was 'working' also appears to have had a strong influence on adherence to 'homework' practices. Two participants gave up their physiotherapy exercises because they believed they were not benefiting from them. Another participant, Frances, still does her relaxation practice occasionally during the week in spite of the fact that her experience with this therapy was not altogether positive. With relaxation therapy Frances' symptoms got gradually worse, reaching what may have been a 'healing peak', but then failed to improve. It is therefore, perhaps not surprising that Frances still has some commitment to doing her relaxation practices. Confidence in her ability to do the exercises correctly was a factor in the level of adherence for one participant, resulting in her being less diligent at doing them than she might have been.

Finding time to do the exercises was an issue for some participants. Anthea states that she finds it hard to find the time to do her home physiotherapy exercises. As part of her physiotherapy treatment she goes to the physiotherapy gym three times a week, and exercises there. However this adds to her feeling of time pressure in terms of doing her exercises at home.

"so I've got to do stretches to stretch them out, you know and I'm not very good at doing the exercises they give me. It's just finding the time." (Anthea)

For a small number of participants, doing their exercises at work (usually short periods of stretches) is easier for them than doing exercises at home. Maxine has exercises to do at work, in her case, to do them 'whenever she thinks of it'. She does them if she has a spare moment at work, or when her arm starts aching. She finds the exercises do ease the problem. However, doing exercises at work may also involve overcoming the embarrassment or self-consciousness of being seen by colleagues. Although in theory we could expect to see people in all computer intensive or other high OOS-risk jobs, dropping, flopping, doing arm rolls, neck rolls and other exercises, in actual fact it does not seem to be at all common.

In spite of the possible barriers, there were some participants who did adhere in a fairly consistent and disciplined way to their practices (either relaxation therapy or physiotherapy exercises). Nadine has been given stretching and postural exercises and fits them into her morning routine. As mentioned in the previous chapter, Hamish sees following the 'prescription' of his therapist as an investment.

Although many participants may not be adhering well to the expectation of their therapists that they do regular 'at home' practice, they are generally adamant that they want to get well, and have made other changes towards this goal, for example by making changes to their work practices, or by reducing the amount that they are doing. For some participants, even though they are not adhering fully to 'homework' practices, they still like the idea of doing the exercises.

"...but at the same time, it is good to have that on a daily basis, because you feel like you're, everyday you're doing something towards, towards getting better." (Frances)

The following excerpts from one participant, Anthea, illustrate the contradictory thoughts and feelings that some experience in relation to adhering to treatment recommendations. Anthea does not want the 'after-effects' of poor work practice, she wants to 'try' to 'do the right thing' and also appears to feel a strong 'should' in relation to doing her 'homework' exercises and modifying her work practices.

"Yeah, well, there's no way I want to be really sore in the evenings like I have been so I've got to do it [breaks / micropauses].....I try and keep to the posture and do the exercises that [physiotherapists] are giving me.....Definitely, definitely, very aware of it. And doing stretches, leaning back, dropping and flopping - if I have to I'll do it, you know. It's a whole new way of thinking. Totally new way of thinking." (Anthea)

Anthea has had OOS for approximately four years. In spite of her good intentions, it became evident, later in the conversation, that she was not having a lot of success in her 'trying'. Perhaps these contradictions represent the difference between a wish and a goal. When inquiring into the reasons why she does not do her home exercises, Anthea said "Ooh, you're making me feel guilty". As with participants' efforts to modify their work practices, their efforts in adhering to prescribed 'at home' exercises do not appear to be particularly successful.

EXERCISE

A basic level of general body exercise is often advocated as part of the treatment of OOS and fibromyalgia (Nye, 1999a, Nye 1999b, OSH & ACC, 1997). This section will deal with general fitness or exercise, as opposed to specific exercises for OOS as would be prescribed by a physiotherapist. Most participants did not see themselves as physically fit at present, although some had been before they got OOS. Others have never seen themselves as very sporty or 'fit' people. Most saw improving their fitness as something to aspire to as part of 'doing the right thing' in relation to OOS.

One participant was a strong proponent of the general benefits of exercise.

"I think if you're fit you handle everything much better, um, I know, well, for me I go swimming, like three times a week, and I'm swimming quite long distances.[one or two kilometres] ... I think doing that, swimming is really, really good for, for it. You're using your arms and everything, but it's in a low, what do you call, low impact, low something ... resistance, and um, but you're still building up muscle strength and, um, yeah, and just going walking, just frees everything up, so yeah, I think keeping fit is really, really good. I think that's common sense, you get over anything faster I think, if you're fit."

(Leanne)

In addition to the general benefits of fitness as enabling people "to handle everything better", Leanne had additional motivation for her exercise. She had a friend with fibromyalgia who stopped exercising and put on a lot of weight. This prompted Leanne to think about the importance of exercise:

"so, yeah, I've kind of thought about that a few times, and thought, I don't want to stop exercising, even if it hurts when I'm doing it. If it's not making it worse, I think, do it. Cause I mean sometimes when I was swimming, it does hurt a bit, but as long as it's not any worse than it was before I went swimming, then I think, it's not doing any damage." *(Leanne)*

Leanne, as the strongest proponent of physical fitness, had a tentative explanatory model for her OOS which fits well with her philosophy on exercise. In discussing why her OOS did not develop when she was playing the piano almost daily, but instead started when she was only playing three or four times a week, Leanne suggested this analogy:

"I mean if you think about, say if you go running regularly, it doesn't really hurt that much. Not that I'm a runner, I hate running. But if you do it regularly, your muscles attune to it, and you kind of, y'know you do your stretches and whatever and you're fine the next day, but if you only go running say once every two weeks or something, your body really reacts to it. So I don't know whether it's a similar kind of thing, that I was yeah, playing regularly enough that my body was just used to it and then only coming to it every now and then." (Leanne)

This sports analogy would also appear to support her in her approach to her ongoing exercise programme, in that she has decided that pain while she is swimming is probably not harmful, as long as it leaves her no worse than when she started.

Only one participant, Donna, mentioned a link between exercise and stress, although for her the link was very tentative. Shortly after developing OOS, Donna began doing aerobics and exercycle for an hour to an hour and a half every day. When asked if she thought exercise was helping her she replied:

"It probably does, um, yeah. I, I can't say for sure because I've done it right from the onset, um, but yeah, I have read and heard that exercise does help in stressed, to relieve stress, more than anything." (Donna)

Several participants spoke of the importance of movement for flexibility.

"I mean I find, y'know sometimes I wake up in the morning, I've been lying in the same place all night and I'm really achey, I find if I just go for a walk, everything just kind of loosens up, it's just getting everything moving." (Leanne).

"Well yes, I guess everything just sort of stops and locks - I don't really know. But I do know that if I get up and go for a nice long brisk walk I feel better because all the blood is pumping through everywhere ..." (Anthea).

Only one participant spoke of taking advantage of any of the special exercise programmes offered for people with OOS. Janine spoke of her experience with hydrotherapy.

"It's lovely if you're not working, but it's a bit hard to get there at twelve o'clock most days, and they had a physiotherapist in attendance there on the two days that they ran it, so its really quite excellent - and the water - it's a tepid shallow pool for toddlers and it's quite delightful actually - I used to enjoy doing that. They are gentle exercises ..." (Janine)

Another participant, Karen, who lives in a smaller city, was not aware of any exercise programmes for people with OOS, so in an effort to exercise in what she thought may have been

an appropriate way, decided to try going to the pool. However, without appropriate instruction, this proved to be an unsuccessful venture.

In spite of the fact that the benefits of fitness and movement were acknowledged by most participants in some way, exercise is another area, which presented a challenge to many. Although they see the advantages, they list many reasons why they are not able to even go for regular walks. Given the difficulty that most participants had in following advice that was focussed specifically on their OOS, it is not surprising that they also had difficulty in maintaining a level of general exercise, a strategy that may be seen as much less relevant to them. Interestingly, most participants were unaware of the exercise programmes in the community which are provided specifically for people with OOS or related problems. The hydrotherapy programme for people with OOS and the Yoga class for people with OOS, fibromyalgia and arthritis, which run locally, appear to be relatively well kept secrets.

DIFFICULTIES RELATED TO 'DOING THE RIGHT THING'

Motivation to continue to 'do the right thing' can be difficult to maintain, as one of the hallmarks of OOS appears to be the very slow progress towards recovery. This not only makes OOS difficult to live with, but also means that it is difficult to measure progress, as changes may be imperceptibly small and not recognisable on a daily or weekly basis. Generally, sufferers have good days and bad days, and again, this can have the effect of masking the real rate of progress. Doing exercises, attending treatment sessions, and adapting one's way of working are difficult enough to maintain over long periods of time, but are perhaps even more difficult when the time-line to recovery seems so uncertain, and in many cases keeps extending, and recovery is not necessarily guaranteed.

"If they gave me a yes. And if they gave me a time span. You have to keep doing this for another six months and then you would be better, I'd do it. It's the fact that I'm not totally convinced that it's not going to make a difference." (Connie)

There is no guaranteed time-line or outcome with OOS. Many participants have lived with the condition for a long time (the majority over 3 years). This is a long time over which to attempt to maintain a positive outlook or stay motivated towards 'doing the right thing' in relation to OOS.

For some people with OOS, time is an issue in terms of 'fitting in' at home exercise programmes for their OOS, general exercise and self-care strategies. Some OOS sufferers try to cram more in a day than will easily fit. Others may not be very assertive, so end up with more commitments than they easily have time for. Both of these tendencies will affect the sufferers' recovery attempts. In Dannatt's (1993) investigation into the relationship between 'Type A' behaviour and

the development of OOS, he found relationships between OOS and only two of the type A subscales, one of which was speed and impatience. This finding may indicate that some degree of a sense of urgency and time-pressure may be relatively common amongst OOS sufferers.

Added to this dynamic is the issue that, when living with OOS, things take so much longer to do than they did previously. Nadine speaks of the additional time basic housework tasks take:

"What I do now is I get up in the morning, I'll put the wash on at night so that I can get up in the morning, because it takes me quite a while to hang a wash, but I hang it in the morning before I go to work and pray like hell that it won't rain, and then I walk home from work and I'll take the wash off the line and then when I come home I'll have a cup of coffee and stuff and then I'll go down and start folding the average wash load and maybe do five or six towels and then that's it, that's all I can do, and then I'll rest for a while, then I'll go back down and fold a few undies and stuff and then I'll walk away from that task, whereas that could have been, like beforehand when I was working at [previous employer] I'd be in the house, bang on a wash, get tea organised, the wash would be done, out would go the wash, de da, de da, de da - so yeah it's really quite changed, yeah, quite." (Nadine)

Fitting in treatment, particularly if one is working full-time, becomes another factor in the time equation. Even in Anthea's case, where at the time of the interview she was working only 3 ½ hours per day, time is felt as a pressure in relation to doing her exercises.

"It's time. Time, really. And making yourself do it. At work I'll do it. I'll sit and I'll stretch at work like this, you know. But when I'm out of work I'm doing this, and I'm going here and I'm doing something else and yeah, and I just don't do it.... Also I have to go to the gym three times a week, and that means travelling down to the gym, and I mean, I'm going to physio twice a week anyway. It's all time." (Anthea)

Anthea's situation emphasises the fact that prescribing 'rest' at home, as part of the treatment for OOS is not always effective, as very seldom is this time spent 'resting' (OSH & ACC 1997).

Finding time for self-care activities is also an issue for some participants, and it becomes more so once back at work.

"Once you get back into things you find it hard to not - to go back to actually relaxing and going for a swim or making that time because the lifestyle never actually gave me that sort of time for walking or doing any exercise ..." (Karen)

It would seem that the issue of whether there is enough time 'to do the right thing' is influenced by situational factors (a single parent is likely to have more demands on their time than a single person without children, for example). However, it would also appear to be strongly influenced by attitudes and expectations. A person who tries to cram too much into their time will never

have enough time. As soon as more time is available, more activities or commitments are taken on. As people with OOS recover, daily household tasks which had become very time consuming 'shrink' back to their normal time requirement, and the sufferer becomes less tired. It would seem that as people with OOS recover to the stage that they are able to do more, the time which may previously have been used for exercises and self-care activities is re-allocated to other things. This situation is reinforced by the fact that their symptoms are then a less constant reminder of the need for self-care.

An important challenge for the successful management of OOS is to identify the strategies that will have most leverage on their progress towards recovery and focus on them. Because there are many different self-help strategies advocated for OOS, from small things such as using a fat pen, to major things such as doing therapists' 'homework', and because rest or working less may be seen as a strategy in its own right, it is possible for an OOS sufferer to feel they are 'doing the right thing', when in fact they may be failing to do the things which will have the most impact on their condition. OOS sufferers cannot possibly take on all the advice and suggestions that are made to them, and of necessity make choices as to which are the most important. In making these choices they will not only take into account the possible effects of the strategies, but also how well the strategies will fit into their life style and affect their productivity at work. 'Trade-offs' will inevitably be made.

"... just for instance on the computer there's a heap of shortcut keys that I don't bother with, I should, I just keep using the mouse, and I should learn to do that instead. And I am a bit, but then I get lazy and stop using them, y'know, it's just, just one of those things, and you, and you sort of trade off until it hurts enough so that that um, becomes sore ... and you start using it." (Hamish)

"If somebody had explained that to me [before she got OOS] I think I would have gone and done a typing course to make myself a touch typist. But once I had it, the point in actually relearning all my computer skills although I have done you know I've made some attempt to become much more of a touch typist so I don't have to do this constant look up and down. If I could have worked that into my schedule somehow I think I would probably have done that early in the piece. Now, I, just the time it would take out of my working day to do that, I just can't afford it. And it seems, well, I've got this far now. Yeah." (Connie)

While these two particular examples have been included, every participant had examples of 'shoulds' that they were not doing. All participants had reasons why they were not doing these things, although some indicated that some of these reasons were a matter of not feeling motivated or making it a priority.

SUMMARY

Most participants had a strong sense of what one 'should' do for OOS, and all indicated that they were not doing all that they 'should'. Some felt a sense of rebellion or guilt about this. Many of the 'shoulds', especially modifying work practices, were found to be difficult to implement, and those such as micropauses or improving one's posture, which involved constant vigilance and considerable self-discipline, were particularly difficult. Some participants felt that these practices were not practicable in the context of their work. Doing homework set by therapists was an area in which there appeared to be a relatively low level of commitment by participants. Most participants did the prescribed exercises to some degree, but few appeared to view them as being of central importance to their recovery. Some were not doing exercises set by physiotherapists because of the pain the exercises caused. Others indicated that not having 'enough time' was a factor. The fact that progress towards recovery, for most participants, was very slow is likely to have a negative impact on their motivation towards 'homework tasks' or continuing to modify their work practices. This creates a 'catch 22' dilemma - the less commitment to these tasks, the slower the progress, and the slower the progress, the less commitment to the tasks.

CHAPTER EIGHT

LEARNING TO CO-EXIST POSITIVELY WITH OOS

Just as the first process identified, 'Coming to terms with an OOS diagnosis', involved mental and emotional adjustments, this chapter addresses some of the mental and emotional changes required of participants as they moved into a new phase of adapting to life with OOS - that of developing a more caring relationship with their bodies, and with themselves as whole persons. Only a relatively small number of participants had made this transition fully. However, it would seem likely that many of the 'tasks' involved in this process are important to a full recovery. As with the initial process, this adjustment may occur over a long period of time, and there may be a partial adaptation by some people, as they address some, but not all, of the aspects discussed here. The adjustments involved in this process include coming to an acceptance of living with pain, pushing the limits but in a healthy way, and adopting new strategies in terms of noticing the needs of one's body rather than relying on pain as the most important indicator. Perhaps the most significant aspect of this process is moving towards a more full-hearted caring relationship with one's body. As a post-script to this section, the experience of some participants of being able to see the 'good side' of having had OOS, is also discussed. This was the experience of a small number of participants, both those who had 'come out the other side of their OOS experience', and those still suffering relatively severe symptoms.

PUTTING UP WITH THE PAIN

Research relating to patients who had been involved in cognitive behaviour therapy programmes for OOS by Spence and colleagues (cited in Spence, 1998) indicated that although subjects reported a significant decrease in pain levels and interference in daily living, the majority were still experiencing pain (on average two to five hours of mild to moderate pain each day) at two year follow-up in the first study, and at six month follow-up in the second. It is likely that this occurs with other treatment modalities also. While some people do recover totally within this time frame, the majority still have to 'put up with' pain.

Accepting that it is necessary to live with some degree of pain, and developing strategies to cope with this has been important to a number of participants in their efforts to 'co-exist positively' with OOS and still get the most out of their lives. For some of the participants in the current study this has involved a strong determination and a deliberate effort to maintain a positive attitude. The experience of pain is very subjective. Several participants made reference to their pain threshold - generally that they had a high pain threshold. Connie spoke of experiencing her

pain as “*low-grade until it gets actually quite excruciating*”. The subjectivity of pain may lead people to question their own experience and how others might interpret a similar level of pain.

“ and, um, I, I’ve been teaching for two years, and I think, um I had it on and off while I was doing that at various stages, um, but never really badly, like I write, y’know, my reports and all that, I have to take breaks, but I don’t know whether it’s any more than other people who get writer’s cramp, just from writing, um.” (Leanne)

The majority of the participants appear to have adopted an attitude of determination in coping with some level of pain in order to keep on living as fully as they can. Some participants have gone further than just ‘putting up with’ pain and have reconciled themselves with the need to accept pain as part of their lives, and have adjusted their attitudes and strategies accordingly.

“But I mean, I can’t actually these days, go around without noticing my arms, I mean they’re not, they don’t, you know, when you didn’t have it you didn’t notice your arms, but you always notice some ache somewhere but it’s only, it’s not worth worrying about, if you just sat here you’d think about it, yeah, I can feel my arms, it’s like a, its like sore muscles after a walk that you put up with but in a gentler way. It’s always there, always in my arms permanently, so that doesn’t go away but it doesn’t affect you, you can live with it.” (Karen)

“I’ve never been totally pain free, but I’ve never had any time off work..... so then I came to the decision that I was never going to be pain free - I just assumed that was what the condition was and I would never be actually pain free, so, as long as I could keep the pain at a level that I could keep on working, that’s what I wanted to do.....and I just sort of feel if I keep going – I’m actually managing the pain you know. I mean I’m aware that it’s there all the time, but if I dwelt on it all the time, then you could easily become depressed, you could easily become quite you know sort of maudlin about it you know and I don’t want that to happen, so I don’t I like to think - that today I got through and I wasn’t pain free but it certainly, I didn’t have an acute bout today – nothing happened to cause me to have an acute bout. So if I just keep on track and keep always aware of anything that might actually stir it up, um that’s how I – so I just go day to day.” (Nadine)

However, for several participants, the determination to put up with some pain in order that they could continue to work, and as much as possible, continue to fulfil their roles within their family / household, involved a significant cost. They avoided activities which put them at risk, which generally included a lot of their interests and the recreational activities that gave them pleasure and satisfaction.

“You know [I’ve lost] a lot of my life enjoyment ... I actually live my life so that I can remain at work and that’s the basic simple thing of it.” (Nadine)

The determination to live life as fully as possible but with some pain, has involved, for those adopting this attitude, the development of strategies to control their pain and manage it better. The following excerpts demonstrate this.

"You still get pain levels, but you learn to control them, you um. It's really hard to learn to control it, it's, it's standing back and reading it. It's like it's not your body, it's like you're somebody else watching it, it's um. But you watch how you react to different things..." (Erin)

"If I can feel it coming I'll, I know to, how to manage it better, I think. I think it's just management," (Leanne)

For those participants who felt that they had learnt to co-exist in a co-operative way with their pain, as opposed to fighting it, this process appears to involve accepting that some pain is inevitable, recognising the subjectivity of pain, being able to distinguish 'bad days' from relapses, and developing strategies to manage the pain when it is at its worst.

MONITORING AND RESPONDING TO THE NEEDS OF THE BODY:

In developing ways to co-exist positively with OOS, sufferers may need to adjust their strategies in terms of noticing and responding to their bodies' signals. Many OOS sufferers paid little attention to the needs of their bodies prior to developing OOS, and relied on pain as a signal that something was amiss - perhaps analogous to a car owner who relies on the oil light and temperature gauge to alert them to the need to add oil and water rather than regularly checking and maintaining the vehicle. People with OOS often have a great ability to absorb themselves in a task and lose their sense of time. They have not had to give any special attention to the needs of their bodies, and the experience of OOS changed all this, which was a great source of frustration to them. Reference to their ability to 'lose themselves' in activities was made by several participants. While this phenomenon is not specific to people with OOS, it presents an additional challenge in terms of the management of OOS. When Barbara developed OOS she became aware of the need to take regular breaks. However, getting into the habit of taking these breaks has not proven to be easy.

"Oh, it's taken ages. I mean occasionally there'll be still, there is a day where I've got to work at half past eight and I've been doing some stuff on the computer which isn't typing, analysing things, and some-one will say - hey it's coffee time, are you coming? You did all that and you didn't do any breaks at all, that was not good..." (Barbara)

Several participants spoke of paying little attention to their own bodily signals prior to, and even to some extent, since developing OOS.

"I don't take much notice of my body at any time. Let's face it. I've known for years that I'm not fit...I do it still now, I get hungry at work and I just keep working until I'm finished, and even going to the

toilet I've put off, it's not till I actually finish work and come home I realise I need to go to the toilet. It's just that's how I work, and I still do that a bit at work now." (Karen)

The ability to notice their bodily signals is also important in terms of monitoring progress towards recovery and identifying which treatments or self-help strategies are proving effective. One participant, Donna, thinks that none of her treatments have helped, except rest. It appears that she has noticed no differences in her bodily sensations following either physiotherapy or relaxation therapy. She was prescribed anti-inflammatories soon after diagnosis and she can not remember if they worked or not. It is possible that Donna is not sufficiently 'tuned in' to notice slight improvements in her condition, and therefore gives up. She does not do any 'homework', which presumably means that any progress she does make would be much slower than if she was doing follow-up exercises at home. For OOS sufferers who have difficulty noticing their bodies' more subtle signals, retesting at regular intervals with an electromyograph may be helpful

Some participants indicated a well-developed ability to minimise and quickly forget pain. While this is a strategy that may have served them well in helping them to maintain a positive attitude and continue to live a productive life, it can be problematical in terms of developing habits of self-care and taking sensible precautions.

"...and I hadn't realised exactly how much it's there. Except for my partner has commented on it recently...He probably notices me starting to do this [rubs arm] and he will say something like 'Is your arm hurting again?' and he'll yeah give it a bit of a massage for me, which helps." (Connie)

" I, the ergonomic mouse I had broke for a week last week, um, and I had to go back to using an old mouse, um, I was in, it was a short week last week and I was in agony by Friday night, ah by Thursday night. So like it taught me really quickly again, like y'know, you get blase really quickly, the human mind forgets how much trouble you were in, and um, four days later, yeah I was in pain again." (Hamish)

In many situations in our society we are encouraged to use our willpower to ignore pain. This is particularly the case in the world of competitive sports, where 'mind over matter' is a useful strategy to cope with pain. However this strategy is not necessarily helpful for people with OOS.

"And I didn't understand it myself, because if I'd ever had a problem and it was a sport problem, I've had massive injuries, I've done reps, and it was mind over matter, and in this instance it was exactly, completely the wrong thing to do, and I would go and I would say there was nothing wrong, and I thought I had a low pain level, but I realised I had a high pain threshold. So, um, and I learnt to do things differently." (Erin)

While people with OOS have often paid too little attention to their bodily signals and may benefit from paying more attention to this as part of their efforts towards recovery, it is important that they do not place too much reliance on pain as a signal for action. In OOS and other chronic pain conditions, pain, in some senses, takes on a life of its own and is no longer an accurate signal that one has 'done too much' or that 'damage is being done'. With OOS the 'meaning' of pain can vary widely. In some situations, by the time one experiences pain, damage may already have been done, in other situations there may be a long delay after 'doing too much' before pain begins, which may result in unnecessary damage being done. Several participants indicated that one of their main strategies for modifying their work practices was to use pain as a guide, and to stop work, or take a break, once they experienced pain.

"I try to do as much as I can, so, I'd say, yes, probably until it hurts. Which it shouldn't be because I shouldn't, you know, because then I've probably gone too far." (Maxine)

Given that the consequences of doing too much, or doing the wrong thing may not be immediate, monitoring mechanisms other than pain must be developed to ensure that one looks after one's body more successfully. In the following excerpts, participants spoke about their awareness of the delay that may be experienced between 'doing too much' and noticing pain.

"Cos the thing with it is if I'm at work and it's causing me pain, it's not really till the end of the day that it all catches up with me. So I sort of don't really plan my day very well in that respect, I'm just, at the end of the day I'll go, oh holy heck I'm sore today....Yeah, too late. Done, done the damage today." (Hamish)

"I mean it was probably worse when you didn't know until that evening or the next day cos there was a stage where it was like that, you know. You had absolutely no idea that you had done too much until you'd ... you didn't know until you stopped, you know, you keep waking up when you're sore.....I can remember saying, I think it was to [colleague] I did such and such at work and I felt it at afternoon tea time, which is an improvement on sort of bed-time... - I took the impression anyway that the closer it got, was actually a good thing. Whether its you're more tuned in, or quite what it is I'm not totally sure." (Barbara)

"but I think what was happening was the, the pain didn't really react immediately, I didn't get the pain immediately. It would be that night, that I'd get the problem, not at the time that I was sitting there drawing something. I'd draw something fine, but it's, it's the build up of it, through the day that would get me. So, y'know they talk about pain being your indicator to stop, but it, I don't think it really works like that for me. So, I'm going to have to think, I yeah, maybe it's more, I need to do more pauses as well. It's not necessarily reacting to pain, but ah managing, managing it before it happens." (Frances)

In addition to the fact that pain may be delayed, there is a further complication – that according to relaxation therapists, there is both ‘good’ pain and ‘bad’ pain. Pain does not necessarily signal a relapse but may be part of the path towards improvement.

An often-difficult area for people with OOS is identifying the activities or other factors that exacerbate their symptoms or cause a flare-up. The extent to which this is achieved successfully affects their ability to care for themselves more effectively, yet at the same time not limit their activities more than is necessary or beneficial to their ongoing progress. The link between pain and specific activities is often not clear, although it can sometimes be identified through a process of elimination.

“I was driving, I’d realised that, oh, right in the early stages, um, that I was trying to connect when I got worse with what I did - I wasn’t working at work, I wasn’t doing any typing, and I wasn’t doing any entering stuff [data entry]. I wasn’t doing any housework but I was still driving. And when I drove I got worse the next day, so I stopped driving - I walked everywhere.” (Karen)

When one is in the throes of experiencing relapse or increased pain, one is often not in a position that lends itself to careful analysis and strategising. In such a situation it is possible to ‘over-react’ to the situation, leading to a feeling of the need for extreme caution.

“So I said to [physiotherapist], you know, it seems that I can’t do anything, um because I didn’t want to do anything that was going to affect my ability to remain at work so I’ve really cut back on everything now, you know, that’s just what I’ve had to do.” (Nadine)

“Yeah, I talked to [relaxation therapist] about this and I was saying I’m sure it’s nothing to do with the art, but it, it has to be, y’know I was trying to, I was praying that those two things were not connected, but because, y’know, I’ve, I really want to do this, and I just can’t bear the thought of, of this stopping me from doing this thing. There’s so many things I can’t do, but ah, yes, it’s a very depressing thought if I have to give this up as well. My physiotherapist says I must do it. Says you’ve got to work your way into it, you’ve got to build up your strength to do things, so that was encouraging.” (Frances)

In addition to the possibility of over-generalising the need for caution, it is also important to bear in mind that often the fear of possible damage done by a task can be almost physical in its manifestation. Barbara illustrated this well when she stated that her thumb “doesn’t even like thinking about” a particular task. It is also important that the capacity of people to live in their heads and ignore their bodies be taken into account when designing treatment, self-help and self-care strategies for people with OOS. While these characteristics are not unique to OOS sufferers, it is possible that some OOS sufferers, particularly those who identify strongly with the ‘OOS personality’ profile, may have this capacity more highly developed than the general population. This dynamic presents an additional challenge in the treatment of OOS. In addition it is important

that health practitioners ascertain the degree to which their clients are relying on pain as an indicator, and encourage them to monitor their progress through other means.

MOVING TOWARDS A MORE CARING RELATIONSHIP WITH THE BODY

Moving towards a more caring relationship with the body involves a change of approach. While one may have reached an initial 'acceptance' of the OOS condition following diagnosis, it appears that moving towards a more caring relationship with the body involves another level of acceptance. This change may occur gradually, and may only be partially completed. It involves extending one's focus beyond physical symptoms and avoidance of pain, towards looking at one's life as a whole, particularly the balance between work, home and recreation (Broom, quoted in OOS, 1999). According to Hadley (1999): "Often improvement only occurs when an individual begins to accept the condition and rebuilds a new life with different expectations and responsibilities, and with a longer time frame for recovery." (p.16).

Aspects of this change, identified from the experiences of the participants in this study, included moving from a short-term to a longer-term view of one's health, accepting the limits of one's body, learning to 'push the limits' in a healthy way, finding a satisfactory balance between rest, relaxation and activity, avoiding unhealthy stress levels and developing a more holistic approach to one's life. Not all participants who have moved towards a more caring relationship with their bodies have addressed all these aspects.

Moving from a short-term to a longer-term view of health: For some participants, the issue of moving from short-term to long-term thinking with regard to their health was mentioned as important. For Donna this change is very recent and it will become evident in time whether this has a positive impact on her efforts towards recovery. As Donna has been relatively 'stuck' in terms of her progress to date, this could prove to be a significant turning point.

"...[I was] just trying to make up my mind last week even as to whether to tell the doctor you know that my arms were playing up again cos I'm scared he was going to take me off work, cos that's what he's done in the past, and um I said to one of the girls at work 'Oh, what should I do?' and she said 'Well, you know, you've got to think ahead' and I did and I thought, no, I'd, you know, rather be able to hold my baby than to put up with pain and have crippled arms, you know, and let it go so bad that I can never use them properly again, so yep, it has changed my outlook a lot ... yeah my um only thought earlier was short term and being taken off work again and having to go through the 2 hours a day, 3 hours a day and all that again and so it just wasn't worth saying anything but now I'm starting to look ahead" (Donna)

In Erin's case, she has 'come out the other side' of her OOS, and her longer-term thinking is evident in her overall approach to self-care.

"And it's really life teaching me to look after the body, not just hey, hang, this body's gotta hang around. Y'know, it's gotta do what I want to do when I want to do it and if you don't perform then I'll get another one. Well you don't get another one; it's not like a new pair of shoes. And, um, and I have been extremely lucky, I think that's the biggest thing. It's like being asleep and you actually wake up to this life, this is reality, um." (Erin)

Accepting the limits of one's body: Accepting the limits of their bodies was a challenge for several participants. To some extent this is similar to the challenge or struggle of coming to terms with the diagnosis of OOS and its implications. The acceptance of one's limits, which is a necessary part of moving towards a more caring relationship with the body, is a more full-hearted acceptance than the somewhat reluctant acceptance felt by some participants and expressed here by Gaylene. Gaylene's acceptance of her limits appears to be fuelled, not by concern for what her body needs in order to recover, but rather by the pointlessness of keeping on pushing the limits of a strategy that no longer works.

"I can't afford to do that, and I haven't got the energy to do it anyway. You know, and as soon as I start doing those sort of things, I tend to pack up, so I don't do them any more.....I think it was a hard lesson to learn but I just pushed it all, I pushed my whole system to the brink and I reckon that's why I got sick in the first place, um, because I was doing a job that I wasn't physically able to do - to cope with, and I wasn't giving, you know, I just wasn't having enough rest." (Gaylene)

In order to move towards a more caring relationship with the body, the acceptance of bodily limits must go beyond what the OOS sufferer has learnt from their doctors or therapists about what their bodies need. It must move to a more careful and thoughtful noticing of their own bodies, and a willingness to put the needs of their bodies before the needs of others, or their own desire to complete tasks quickly. The ability to 'listen to the body' or to 'read the body' was a feature commented on by some participants.

"You pace yourself, you, you listen to how you feel, you don't get up and say I'm going to do this, this and this..." (Erin)

...and learning to push the limits in a healthy way: There seems to be a natural tendency in humans to 'push the limits' - to see just how far we can go. In the case of living with OOS this involves seeing how much we can 'get away with'. Some participants talked about 'pushing the limits' as a positive challenge, whereas others talked only with disappointment of activities which have led to later suffering. To make positive progress it is necessary to learn to push the limits in a healthy way, without abusing the body or pushing it too far.

Janine speaks of the idea of 'pushing the limits' in a very positive sense.

"Sometimes I know I've done something that I probably shouldn't have – stretched the limits but – um, [Occupational Therapist] keeps saying to me – you're always testing the limits – it's the nature of it and if you don't, you actually never make any progress. But you keep hitting the limits and getting knocked back a bit." The sorts of things that Janine has tried pushing the limits on are "trying to drive, perhaps trying to work a little bit harder at work than I should, um, perhaps doing a few more things around home" (Janine)

The results of 'pushing the limits' are not always consistent. It is possible to 'get away with' doing something which one would expect to lead to pain on some occasions yet not on others. This situation can result in it being difficult to be disciplined in one's approach to self-care.

"You did all that and you didn't do any breaks at all, that was not good, well maybe it's all right, no, just, um, it doesn't matter whether it wasn't - according to all the things that people have been trying to teach you over the time, this is not a good idea even if you've got away with it today - you do what you can get away with, you push the limits on what you can get away with all the time." (Barbara)

Unfortunately, because of the many factors which result in 'good days' and 'bad days', it is not easy to determine the point at which pain will occur and when this will be 'just pain' as opposed to causing a 'relapse' and result in taking 'two steps backwards'. Often the 'healthy limits' can only be identified in hindsight. Frequently with long-term conditions such as OOS, particularly when sufferers experience intermittent pain levels (good days and bad days) there is a tendency to get into a 'boom and bust' cycle. This involves experiencing a good day or a run of good days and deciding one is well enough to tackle all the jobs one has been unable to do, overextending oneself, and then suffering pain as one's limbs are not conditioned for the effort they have made. Alternatively, a person may get so frustrated and fed-up with not being able to do the things they want to do that they decide to tackle them anyway, in spite of their pain and weakness. Again, this results in some form of setback. The following excerpt indicates this dynamic.

"I did some gardening, last weekend I think it was, and, oh, it was good - I got stuck in, got in there, did this gardening and that, and I felt fine on the night, but the next day it was really hurting me, and I knew I'd done too much over the weekend, so yeah, it comes later." (Maxine)

While some participants appear not to have yet found a healthy balance in pushing the limits, others appear to have learnt to read their bodies' needs and abilities relatively successfully.

Adequate rest and relaxation:

In moving towards a more caring relationship with one's body, it is necessary to ensure one is getting adequate rest and relaxation. Several participants identified closely with the 'OOS personality', and for these people in particular, developing a routine which includes adequate rest and relaxation is likely to be an important aspect of their recovery. Gaylene, prior to developing

OOS, was giving herself no time to rest or relax, and was so tired that if she did sit down briefly to rest she would fall asleep. This is an extreme example of 'overdoing it'. Those who identify strongly with the 'OOS personality' are likely to err in the direction of too little rest and relaxation and too much activity when finding their balance point between these. In the following excerpt, Karen illustrates this situation.

"... But I usually make time for myself. But I don't actually make the time for myself as far as hobbies, or interests or things I want to do other than obligations really. I'm more inclined to just sit with a book for a while or have a rest ... Resting, so that I can get on with the workload...Yeah, but even when I do something for myself I work at it full tack, like gardening or something, I just can't go out and do a little bit of gardening it has to be full tack into it, until, and I want to see it finished..." (Karen)

"I still keep too busy yeah, I don't think that's going to change but you can be too busy without being over doing it I think, if you still keep to the [inaudible]. I think you can." (Karen)

However Karen has made significant progress towards recovery, so it is possible that this balance point may be appropriate for her - time will tell whether this is a stance which is sustainable on an ongoing basis and conducive to good health.

Of all the participants, Gaylene has made the most conscious effort to schedule in re-creation time for herself.

"and in that time I tend to do my exercises [relaxation therapy tape] which take half an hour to an hour depending if I fall asleep, which I do frequently which apparently is very bad, but I just can't stay awake, as soon as I lay down I go to sleep. Um, and then I tend to watch 'Days of Our Lives' and then I will do a couple of jobs and then I'll go to school - so that time of the day is my time of the day and I don't tend to do a lot, I'm tempted sometimes but I'm probably because I've just been in so much pain that I don't do it any more, it's not worth it." (Gaylene)

It is important to make a distinction between structured relaxation exercises as taught by relaxation therapists and a lay understanding of relaxation which includes such things as taking 'time out' to read a book, spending time with friends or having a nap. The former are designed to teach the body generally, and specific muscle groups in particular, how to relax more readily. The latter while extremely important, cannot take the place of the former, and for some OOS sufferers, learning to relax their bodies more readily is one of the keys to their recovery.

In addition to rest and relaxation, adequate restorative sleep is an important factor for some OOS sufferers. Lack of restorative sleep has been linked with fibromyalgia (Nye, 1999a, Nye 1999b), a condition that sometimes develops as a result of a severe and chronic OOS condition. Several participants indicated that they were not getting enough sleep, and/or that it was not refreshing

sleep. Hamish, Janine and Karen all spoke of disturbed sleep patterns. Karen stated that her sleep patterns, prior to resigning from a stressful half-time job (shortly before she got OOS) were *"an overworked person's sleeping pattern of thinking things in the middle of the night, and waking up all the time."*

For Gaylene it takes time following her work shift for her pain to abate, then to wind down enough to sleep. She estimates that she gets six to seven hours sleep per night, but it is broken sleep. However, during the school holidays, she has a chance to establish a different pattern.

"I don't sleep all night. I haven't slept all night in ages - years. It is not as bad as it was but it doesn't seem to be the pain that's waking me up any more, I just wake up, I don't know why.....you wake up tired. I very rarely wake up non-tired. By the end of the school holidays - next week and the week after that, and by the end of that I will wake up - I'll be waking up not tired because I need to sleep till about half past eight I reckon. It sounds a very leisurely hour to me, but I don't get that when the kids are at school." (Gaylene)

In Gaylene's case the lack of sleep, because of both evening shift and child-care responsibilities, may be having a larger effect on her than the nature of her work and the hours she is employed.

"I mean people look at me as if to say, you know, you're not working very much but it's still at a time of the day when you are tired, like, I would get to five o'clock and I would - I get to four o'clock now and I have to cook tea and I have to leave here at half past five, my husband was working long hours then so I had to organise baby sitters, Girls' Brigade after school and swimming it was um, yeah and you're going out to work at a time when you're tired anyway and then you're working til eight which is fine, but it takes me, well it used to take me two hours for the pain to stop when I got home, so you're going to bed say half past ten, eleven and yeah it was just very tiring." (Gaylene)

Several participants experienced increased tiredness as a result of having OOS. Many participants spoke of the tiring and draining effect of living with ongoing pain.

"... it just drains me totally, yeah. That was my main thing, I would say, the tiredness was actually the pain draining me ... The pain drains you, it takes your energy away. You use all your energy to keep going through the pain I think all the tiredness was related to pain, even small pain, even just the aches every day..." (Karen)

However, although this additional tiredness necessitates additional rest, as with many other aspects of OOS, it is important to keep a balance between rest, relaxation and activity. In the past it was common for doctors to prescribe total rest, whereas now there is evidence that stopping work completely is correlated with poor recovery (Feely et al, 1995; Buckwalter and Hunziker, 1996; Shadbolt, 1985, cited in Bammer and Blignault, 1988). An appropriate balance must be found and it is likely that the OOS sufferer may have difficulty in gauging this balance as their

pain, weakness, and often significantly increased tiredness may appear to be signalling the need for total rest, where as their life responsibilities may be indicating the need to carry on as before. Each individual is likely to have a personal belief about what the best option is, which may or may not be supported by the therapists they work with. It is also likely that a therapist's advice may be interpreted selectively because of this personal belief. Either way, the OOS sufferer's understanding of their therapist's advice is likely to influence their personal strategies in managing their OOS.

Avoiding unhealthy stress levels: One of the necessary factors in moving towards a more caring relationship with one's self is to develop strategies for reducing the level of unnecessary stress in one's life. This may involve approaches such as making changes in how things are done, changing one's attitude to aspects of life which have previously caused stress, or learning to be more assertive, and thus deflect some of the stressful forces in one's life. Life beliefs also affect the approach to stress. Several participants spoke of efforts they were making to avoid excessive stress in their lives. However, with several of them, there was a sense of inevitability when they spoke of stress. Beliefs such as expressed by Anthea can prove to be self-fulfilling prophecies.

"I actually do try and keep my life fairly stress free [laughs] ... You can't live without stress in your life." (Anthea)

"But I mean, you know, like I say, if there's no stress in your life, you're dead, aren't you." (Anthea)

Methods used by participants to reduce stress levels varied. For example, Barbara 'engineers' breaks in her work by going off to visit somebody to borrow equipment, or walking around the perimeter of the building, when things get too much for her. Learning to handle office politics and manage work relationships was identified as important by Erin. The following excerpts indicate adjustment of both attitudes and approaches to tasks.

"Yeah, you've got to keep saying to yourself - is it really that important. I mean, hey, why are you getting stressed out about this?" (Anthea).

"So I tend to plan myself so I'm not pressured" (Barbara).

Learning general assertiveness techniques may be important for some participants. Not developing such strategies results in other people's needs coming before their own. Both Gaylene and Karen admit to having difficulty saying 'no' to people. This will inevitably be adding to their stress, or forcing them to work in a way which puts them at risk.

"But I don't always have the, I don't always have the opportunity to stop, I mean sometimes I just don't - I can't, I can't because I'm obliged to do things and I have to do them." (Gaylene)

There are many different methods of dealing with stress. In view of the evidence that there are strong physiological links between OOS and the stress response (Flor & Turk, 1989; Moulton & Spence, 1992, both cited in Spence, 1998; Hubbard & Berkhoff, 1993; Simons, 1993, both cited in Gilbert, Tick & VanEerd, 1997) it is important that OOS sufferers identify any areas of stress in their lives, and either work out ways to avoid these situations from arising or develop strategies to minimise the amount of stress experienced.

Moving towards a more holistic approach to self-care: Perhaps the most significant move towards a more caring relationship with the body involves moving beyond just attending to symptoms towards an approach of attending to quality of life as a whole. Interestingly, very few of the participants spoke of 'looking after themselves' in this wider sense. Erin is one of the few participants who did this, and the excerpts below indicate her approach. Erin is looking at the situation having 'come out the other side' of OOS. She reached the realisation that she must accept responsibility and look after herself, changing from living life at top speed to taking a quieter more balanced approach to life.

"Yeah, it's changed. It's mind, body and spirit, it's balance. I was terribly unbalanced, um....I turn off, and I wake up refreshed and different. I get up like [the Occupational Therapist] says, you stretch like a cat, you take your time, you yeah, you look after yourself, um. Cause nobody else is really going to look after you, it's your responsibility, um, and it's like y'know if you work and it's bad, what's going to happen in 10 years you can't move it, you can't work, who's going to look after you then. It's, um and it's frightening for people, it's scary for people and it's frightening, yeah." (Erin)

Erin moved from a point where she wouldn't take any time out for herself to a point where she started to care for herself in a very deliberate way.

"I would say to the kids, I'm having a hot bath, y'know, I'll be an hour, tea will be late. And I put Epsom Salts and that would kill the pain, in hot water, um. Yeah, it's learning to live with it, to, I now automatically do things differently." (Erin)

Part of Erin's journey with OOS was an increased self-awareness, a softening of her attitude towards herself, and a desire to take a more holistic approach to her life.

"You've actually got to look after all of you. And you, yeah, you've got to learn to appreciate you, you can't be so hard on you ..." (Erin)

The extent to which OOS sufferers attend to the above aspects of moving towards a more caring relationship with the body is likely to depend on many things including the extent to which their life was disrupted by OOS (the motivating factor towards change), the amount of energy and optimism which they were able to summons (the resources at their disposal with which to approach change), their awareness which they have of the effect of such factors on their ongoing

health, and, perhaps in some cases, their belief in their ability to make their own health and well-being a priority over other demands on their life. Such personal changes are made against a backdrop of work culture that, to an increasing extent, has an expectation that people will push themselves to the limits. This makes such changes additionally difficult to initiate. While over half of the participants were still relatively severely affected by their OOS, only a very small number indicated that they were acting in a way which was consistent with the idea of moving towards a more caring relationship with the body. For the majority, their main concern was to soldier on as best they could with their life, and to attend to immediate symptoms. This is not to say that the majority of participants were not doing things to try and get better. To varying degrees, all participants were doing this. However, the distinction between undertaking treatments, and trying various self-help measures, and the more holistic notion of moving towards a more caring relationship with the body may prove to be significant.

Letting Go: Following Erin's story provides useful insights into the importance of 'letting go' as part of recovering from OOS. Erin described herself as a person for whom being in control was important, as evidenced by the following excerpts - *"I like the feel of control. I like being in my own control, my own destiny."* *"We're very much time management, even though people don't realise we are, and I actually realised that I lived by my clock."* *"but if I set my goal I succeeded"* *"the flight and fight, I'm the fight person"*. Erin applied a great deal of discipline and control in her attempt to get better. She improved to the point where she could work up to 34 hours per week, but had been unable to find the key to be able to get back up to full-time hours. Her employers had put pressure on her to either return to full-time work or resign. She was desperately seeking the last pieces of the puzzle. She ended up, almost by accident, in a conversation with a relaxation therapist, and decided to try this as she had nothing to lose. She described part of her interaction with the therapist as follows:

"And she said 'You don't make it happen'. And I'm used to making everything happen. I always thought there were three sorts of people in life: people who make it happen, people who wonder what happened, people that just sit, but I can't think of the third, y'know. And I was always the person that shook the hell out of the apple tree, and made it happen, and she said, 'It'll just happen', and that's something I found hard to come to terms, but it has, it's just slowly happened, um, so her biggest job is to convince the person to have faith, that it's going to happen ..." (Erin)

Ironically, she concludes this sentence by saying ...

"and if you're not a strong-willed person and very determined, it's very easy to give up and quit."
(Erin)

These two excerpts graphically illustrate the paradox involved - the need to 'let go' on the one hand, and to 'work hard towards getting better' on the other. In the following excerpt Erin further illustrates this paradox.

"The control thing came very easily, I used to have a lot of control, but you lose control and you don't realise you've lost it, okay. And you don't, other people can see what's happening to you, but don't understand, um. And by relaxing, you gain control. That sounds weird and back to front, but it's God's honour true. You learn to relax, you're too scared to relax, cause you're scared you're going to lose it all. You're so much on the edge, you're so much on the edge of if I lose my job, I've lost everything, if I lose my job, I lose my means to support my kids, or else I'm real touchy, I don't want to be an ACC. Everything's happening at once in your whole life, and they're telling you to relax, and all your instincts are telling you, I can't, even if I want to I can't. So, but once you relax, you take steps forward and you gain control, it's automatic. But you don't understand, and you don't know it's going to happen, and even if [relaxation therapist] told me it was going to happen that way, I wouldn't have believed her, okay, um." (Erin)

In a similar vein, Karen comments on the irony of 'doing nothing' to recover.

"I spent just ages just sitting in a chair because there wasn't anything - I was bored silly because there wasn't anything that I could do, I couldn't read a book because I couldn't hold it up, there was - you know, I think also it's very hard for somebody who is a workaholic to sit down and do nothing to recover, and I think the biggest thing I did to recover was to do nothing... So I suppose I was working at doing nothing and I was working at getting better, and it was a job for me to sit there and do nothing." (Karen)

Ursula Evans, an OOS sufferer profiled in an article about OOS in "Consumer" (OOS, 1999) spoke of her search for a therapy that worked and stating that she wished she had worried less and gone to fewer therapists.

"I applied the same drive and ambition to trying to get better that I applied to my violin playing [she was in the NZ Symphony Orchestra when she got OOS]. I probably needed to learn not to be so driven, and having OOS gave me the opportunity to recognise this." (p. 17)

Finding an appropriate balance between 'letting go' and displaying determination and tenacity in 'working hard to get better' is no easy task, but appears to be important in moving towards recovery.

POST SCRIPT: FINDING THE SILVER LINING BEHIND THE CLOUD

As time progresses, the degree of disability and the slow nature of recovery become clear. Although this proves very disheartening for some, for others the process of adjusting to this reality involves positive changes in their attitude to life - slowing down and 'smelling the daisies', learning to enjoy this new way of living, and seeing it as having brought benefits to them

(Bammer & Blignault, 1988; Quilter, 1998). Erin, who feels she has finally come out the other side of OOS after a three-year struggle, made several references to this.

"Trying to stand back and look at it, instead of being in it, which is very, very hard, um. It's made me slow down. It's made me want to slow down and smell the flowers. It's made me look around me. It's made me thankful for what I've got, not for what I haven't got..." (Erin)

Erin referred to a number of changes in her life, during the interview. She saw herself as someone who used to be very critical, but now she looks for the good in others, and appreciates that we are all different. She also used to "whiz through life at top speed", and always have a list of things to do that she could never get through. Now she is able to sit back and enjoy life more. She is also able to relate to the experiences of other people more. Having OOS (and coming out the other side) has changed her perspective in many ways.

".. you realise I've missed different things in life, um, probably the biggest thing I've become softer, more caring, made me a better person, which I needed to be made a better person. Obviously I think there's a reason we all go through things, um, probably given me a lot more faith, um, I'm learning slowly to trust my own judgment again..." (Erin)

She is grateful for the crisis, which has led to these changes.

"but now I realise some people go through their whole lives and never have what I've had... so um, I've actually got to be thankful that I've been given the opportunity to turn it round. And been given the tools to turn it round, um, and there is life after death I think, um, I don't think I'll ever be what I was, but I don't think I'll grieve over that death, that death had to come at some stage. And I think it's growing up too..." (Erin)

Gaylene had not yet 'come out the other side' of OOS, and still experienced a lot of pain and tiredness. However, she also identified positive aspects from having OOS.

"But, I mean, looking back on it I think it's a good thing because it's taught me so many good things. I mean my priorities in life have changed tenfold, I mean I don't really care whether, you know, I earn big bucks or not. It doesn't worry me now, and I would rather be healthy than wealthy. You know, it's taught me those really basic things that everyone should know anyway. But you do, but you get pushed into doing things because of these strange reasons and you think, 'Oh, I can't live without that'. You know, when I was working six hours a night and we were raking in the money, yeah, we were living a good lifestyle, but I would rather live without that lifestyle if I could just, if I could be what I was before, um, and that sounds all very corny I suppose, but yeah, so it's just changed all my priorities, so it's had its advantages, it's been a very painful advantage but you know it's taught me a lot - but I would change anything not to have it because it's so ongoing and it's just so hard to get rid of when you've got it." (Gaylene)

Hamish, while his 'skirmish' with OOS was relatively short, was also, in retrospect, glad that he had been through the experience in the way that he had. When referring to the fact that if he had had more variety in his job, he may not have got OOS Hamish stated:

"I'm quite glad I didn't though, because it would never have brought it to a head, and I never would have done anything about it. Um, so I was kind of glad I was forced into the situation where I had to do something about it. Yeah, it didn't destroy my life, let's put it that way, but it could of." (Hamish)

Erin felt that not just her attitude, but her whole identity changed. However, this change was not necessarily comfortable at the time:

"You lose your identification too, you lose, to identify with what you had is gone, so the person that you're trying to identify is yourself, but that person is changing, so yeah, emotionally you're actually coming to terms with a different person. And I would say if you get through it, you never ever, nobody will ever be back to what they were." (Erin)

The positive experiences of the participants in this study were echoed by Deborah Quilter in 'The Repetition Strain Injury Recovery Book', who states:

"Repetitive strain injury has many gifts to offer people who are willing to receive them. Once they overcome the anger and depression that often come with RSI, many people find inner peace and happiness that they did not know before their injury." (Quilter, 1998 p. 203)

Although it may be difficult to imagine for those who have been living with OOS for a long period of time without making any significant progress towards recovery, some people not only 'come out the other end of OOS' but also are grateful for the experience.

SUMMARY

Co-existing positively with OOS involves accepting pain as a part of one's daily life and learning ways to manage it, particularly when it is at its worst. Learning to be more attentive to the body and its signals, and to be more accepting of its needs is an important part of moving towards a more caring relationship with the body. In many cases it is necessary to no longer rely on pain as the main means of monitoring activity levels and the needs of the body, as the pain response often develops a life of its own in OOS. Pain may be experienced without activity, or there may be a considerable delay in the pain response following unhealthy amounts or patterns of activity. Other aspects of establishing a more caring relationship with the body include moving from a short-term to a long-term view of health, accepting the limits of one's body and learning to push the limits in a healthy way. Finding a healthy balance between rest, relaxation and activity, and avoiding unhealthy stress levels are also important. These are all aspects of taking a more holistic approach to one's health, and moving the focus beyond symptoms to overall wellbeing. This

process involves a move away from fighting against OOS and one's body to working with them, and involves letting go of tight control.

CHAPTER NINE

DISCUSSION

The aim of this phenomenological study was to gain further understanding of the experience of people who are 'living with OOS', and to present a rich and detailed description of this experience.

While OOS has been known to exist for nearly 300 years, and has been an increasingly prevalent problem since the late 1970s, the level of real awareness and understanding by those with the condition is often quite limited. There also appears to be a gap in knowledge and understanding between treatment providers and those with OOS, and little evidence of a coordinated approach between the providers of the variety of treatment modalities available. While many of the participants in this study identified stress and the characteristic 'OOS personality' traits as playing a part in the development of their OOS, it is important to bear in mind that there is no one cause or one characteristic course or 'illness trajectory' with OOS, but several different patterns, with many variations. The challenges facing people as they attempt to 'find their way' through OOS are many. In the current study, each of the four major processes identified appears to be associated with a major paradox, and the successful 'resolution' of these paradoxes appears to be pivotal in progress towards recovery. The 'resolution' of each of the paradoxes involves finding a balance point on a continuum relating to a particular attitude, orientation or approach to action. For the OOS sufferer, the opposing 'end points' of these continuums constitute a 'damned if you do and damned if you don't' situation. Many advisors (therapists, family members, friends, acquaintances, and ACC case managers) see the situation in 'black and white' terms and advice is often given to favour one or other end of the continuum. Everyone finds their way to a point on the continuum which 'fits', at some level, with their personal explanatory model and their lifestyle and life circumstances. However, the point they gravitate towards does not always represent a healthy balance point that will help them move effectively towards recovery. Often, the appropriate balance point is only identified in hindsight - when the sufferer has eventually found what works by a process of trial and error. The slow moving nature of the OOS condition makes finding this healthy balance point particularly difficult. The paradox relating to each of the processes identified in my analysis are outlined in turn.

Accepting or rejecting OOS

In the process of moving from symptoms to a diagnosis and coming to an acceptance of OOS, the paradox involves the degree to which it is appropriate or beneficial to accept or reject the diagnosis of OOS and its implications. Lack of acceptance results in minimising and ignoring

symptoms and in delaying seeking treatment, and also often results in sufferers resisting the recommendations of treatment providers. This can have serious consequences for prognosis and treatment duration, as studies indicate that early reporting and preventive measures can have significant effects on treatment outcomes (Oxenburgh, 1985; Brown & Dwyer, 1983; both cited in Bammer & Blignault, 1988).

In common with many other chronic pain conditions, many OOS sufferers appear to be playing a 'waiting game' - putting their lives on hold and hoping that their condition will 'go away' and life will return them to 'normal'. This dynamic sees people not making any efforts to develop new interests or seek alternative employment within the boundaries of their condition, as they view their life with OOS as a disruption which they have to put up with 'until they get better'.

On the other hand a fatalistic acceptance of OOS as being a very serious and long-term condition can result in a cycle of depression and hopelessness, with low motivation towards taking appropriate self-help options. It is possible that for some people this fatalistic acceptance develops over time as they suffer repeated relapses or generally fail to make satisfactory progress towards recovery. Depression is not uncommon in cases of severe OOS, and this can reinforce a sense of there being no hope, and no point in either continuing with strategies that appear not to have been successful in the past, or in trying new approaches.

An interesting example of a somewhat heavy and almost fatalistic acceptance of OOS was presented by Karen, who was the only participant to verbalise that she had come to the point of seeing OOS as 'a permanent disability'. In Karen's case this does not appear to have fuelled a sense of hopelessness. Instead, this appears to have fuelled a sense of rebellion and determination to progress as well as she can in spite of this disability, and also in spite of orthodox medicine's inability to help her. However, it is possible that her belief that the 'disability' is 'permanent' may have made it more difficult for her to identify some potentially beneficial treatment options, for example, the possibility of getting further treatment for her neck. Both her doctor and the ACC specialist had identified the involvement of her neck in her OOS problem, and she also had identified her neck problem as part of her difficulty with driving. However, she had not identified the possibility of further treatment as an option, instead seeing her OOS as a 'permanent disability'.

In finding their 'balance point' between denying or rejecting OOS, some participants were also influenced by a sense of inevitability. For those who identify strongly with the 'OOS personality' there is a certain logic in concluding that 'If I exhibit many of the characteristics of the "OOS personality", and if those characteristics profile the sort of person who gets OOS, then I guess I'm

stuck with it - after all, that's the sort of person I am.' A detailed exploration of the explanatory models of those who identify heavily with this profile could prove very worthwhile. In the current study Erin was one such person, and it is probably fortunate that she had counselling as part of her treatment programme, as that appeared to have enabled her to unravel some of this dynamic. On the other hand some participants who identified strongly with the 'OOS personality' appear to have been relatively 'stuck' in their progress, and their accounts indicated a tendency to see their situation as somewhat inevitable because of the way they were, or in one case to see 'stress' as an inevitable part of life. This sense of inevitability results in a feeling of lack of personal control, and this constellation of beliefs and feelings is likely to result in a relatively passive involvement in treatment.

Clearly, each end of the continuum has both dangers and advantages, and a balance between the two needs to be found. It would appear to be important to accept the *potential* of the condition to be serious and long-term if the sufferer does not make an active commitment to treatment and self-care. Finding the balance point between a 'heavy' acceptance of the potentially severely debilitating condition on one hand, and denial or minimisation on the other, is an ongoing challenge for OOS sufferers. It is likely that the balance point for them will change over time, possibly oscillating between a tendency to minimise and reject OOS, and a tendency towards a despondent and passive acceptance. This is evident in the experience of Gaylene, who took nearly two years to come to an acceptance of her OOS condition, and still occasionally feels 'anti' and tries to do things she knows she shouldn't do. However she generally accepts her OOS and sees that it is 'not worth' doing things she shouldn't do, because she will have to 'suffer the consequences'. This dynamic is also an aspect of the 'boom and bust' pattern that chronic pain sufferers often fall into. It is likely that until a reasonably stable balance point is found on the continuum between minimising and rejecting OOS on the one hand and a fatalistic acceptance on the other, moving towards an attitude of more holistic self-care is unlikely.

Taking personal control or handing control over to the medical practitioner

The paradox to be resolved in relation to the process of seeking a treatment that works is between taking control of treatment and giving control for treatment over to the treatment provider. Some people have a tendency towards the 'taking control' end of the continuum, desiring independence, autonomy and control in relation to their treatment process. At the extreme end of the continuum this involves treating health practitioners with suspicion, believing that they know better than their medical advisors and choosing not to adhere to treatment advice. Some participants indicated aspects of behaviour that were too far towards the 'taking control' end of the spectrum to be beneficial. These included such things as the attempt to self-diagnose from initial symptoms, thus postponing seeking help from a doctor for nine months, and relying on 'mind

over matter' strategies to manage initial pain symptoms. A number of participants had a strong belief in their own ability to deal with their problems, and to be in control of their health. While these attitudes had probably served them well in the past in relation to managing their health, when taken too far they put participants at a distinct disadvantage in relation to their OOS.

Other people have a tendency towards the 'giving control' end of the continuum, having total 'faith' in their practitioners' ability to 'fix them'. Ironically, their 'total faith' often does not extend to following their practitioners' advice in terms of 'homework' exercises and self-help measures. Instead, they tend to view the practitioner as the 'expert' who can 'fix' them in the treatment room. People at this end of the continuum tend to take a passive role in their treatment, to lack commitment to 'homework' exercises and make little effort to identify what exacerbated their symptoms, or to address any factors, such as stress, that they had identified.

The healthy balance point on the continuum between 'taking control' and 'giving control' involves developing 'healing partnerships' with one's practitioners. Baszanger (1989) considers that patients' efforts towards getting well should be conceptualised as work, and that the patient should be seen as "actors in the division of medical work". The efforts they make, whether recognised or not, integrate with the organisation of the therapeutic team. Participants who take too little control in the treatment process are seeing their therapist as the only 'worker' in the relationship, and those who take too much control are perhaps not allowing their therapist to do their work. Gilbert, Tick and VanEerd (1997) believe that the sense of control that patients in their clinic are given during the treatment process is, to a large degree, responsible for the fact that the patients' conditions improve. As with other paradoxes related to OOS, the appropriate balance point may only be recognised in retrospect, when it is possible to define what works in terms of improving the rate of recovery as 'the appropriate balance point'. Some of the participants had found an appropriate balance point in that they were confident in the treatment modality they were receiving, and appeared to have accepted and acted on a large proportion of the advice of their therapists, but also felt able to adapt suggestions to better meet their needs. These participants appeared to be making relatively good progress. While these people were not necessarily adhering fully to 'homework' tasks, they were seeing these tasks as important and made a commitment to them.

Doing 'enough' of 'the right thing'

The third paradox relates to resolving the challenges involved in 'doing the right thing'. This requires that the OOS sufferer find a balance between adherence to treatment recommendations and 'getting a life' (or 'keeping on having a life'). Fanatical adherence to 'homework' and self-help tasks, and making an intensive and constant effort 'to get better' could potentially result in

one's life being ruled by what one should or should not be doing because of the OOS. On the other hand, making self-help and treatment measures totally subservient to one's 'lifestyle' is likely to result in low adherence to treatment providers' recommendations, and consequently slow progress towards recovery. The reality for many of the participants in this study was that of fitting their treatment recommendations within a life which included other areas of responsibility and which left no 'spare' room to incorporate 'homework tasks' or self-care measures. Consequently, a significant shift in priorities would be necessary in order to 'fit in' these measures, and in a number of cases this shift does not appear to have occurred. It is possible that treatment providers are not fully cognisant of the degree of attitude modification that is required for such a change. This may be even more of an issue with OOS sufferers who identify strongly with the 'OOS personality'.

An important aspect of finding a healthy resolution to this paradox is having the ability to discriminate which of the many self-help recommendations, homework exercises and self-care recommendations are going to be most central to recovery. All participants in the current study indicated that they were doing some of 'the right things'. However, all indicated that there were many other things that had been recommended to them, or that they felt that they 'should do', which they were not doing. In many cases there was no indication of a sense of the relative importance of these various measures. A lack of clarity on what is most important and what will make the most difference to progress is likely to result in effort being inappropriately focussed.

Battling against or co-operating with one's body and OOS

The paradox of battling against, as opposed to co-operating with, one's body and OOS itself appears to be significant in terms of progressing towards recovery and co-existing in a positive way with one's OOS. In a positive resolution of this paradox, OOS may be interpreted as having relayed important information to sufferers about the limitations of their bodies, the lack of sustainability of their lifestyle, workstyle, or strategies for managing their lives generally, and indicating a need for change. Viewing their bodies as their friend rather than as inadequate and having let them down badly can lead to a greater willingness to incorporate treatment recommendations into their lifestyle. This change of view also leads to attitude adjustments that involve developing a greater degree of 'kindness' to themselves as a whole. As suggested by one of the participants in the current study, part of the path to recovery may include a willingness to slow down, be less demanding on oneself and to 'take the time to smell the flowers'. To the extent that stress exacerbates an existing OOS condition (Flor & Turk, 1989; Moulton & Spence, 1992; both cited in Spence, 1998; Hubbard & Berkhoff, 1993; Simons, 1993; both cited in Gilbert, Tick & VanEerd, 1997) this attitude adjustment may be pivotal in making progress. Further qualitative research into how OOS sufferers interpret their symptoms, what they say to

themselves in relation to these symptoms, and how their interpretations of their symptoms affect their actions could be very worthwhile.

As part of finding the balance between fighting and co-operating with one's body, it is necessary to find a healthy balance in terms of 'pushing the limits'. Being 'too kind' to oneself, perhaps 'pampering oneself' to an unhealthy extreme by choosing not to make additional effort, can limit one's progress. 'Pushing too hard' and constantly trying to 'see how much you can get away with' - almost, in effect, trying to 'trick' one's body by doing something and hoping it will not notice, can be equally detrimental. Instead a balance must be achieved.

Co-operating with and moving towards a more caring relationship with one's body also involves finding a balance between putting one's own health first (but without becoming self-obsessed or paying too much attention to one's bodily signals and becoming hypervigilant) and allowing other priorities to take precedence, particularly one's responsibilities to other people. It requires the development of assertiveness skills to enable one to set limits, and the valuing of one's own health to the extent that rest and relaxation are seen as integral to everyday life, rather than 'special occasion' activities. As with the paradoxes identified above, this can prove to be additionally challenging for those who strongly identify with the 'OOS personality'.

The overall paradox

In examining the above paradoxes it becomes clear that there is a common issue recurring through all of them. This involves finding a healthy balance between keeping tight control and letting go and could be thought of as an overall paradox for OOS sufferers as they 'find a way through' their OOS.

It is important to recognise that, while the actions of the individual sufferer can enhance progress towards recovery, there is also a great deal that is outside of their control. In fact 'chance' factors also play an important part. These include issues such as whether their work place has an occupational safety and health policy on OOS which encourages early reporting, and which facilitates a speedy referral to appropriate practitioners. Chance factors such as whether their own GP is knowledgeable about OOS and has an effective referral network, whether the treatment to which he/she initially chooses to refer the individual OOS patient 'fits' with the explanatory model of that person, and whether individuals' work situations enable them to change to light duties for whatever period is necessary, also impact on progress towards recovery. We live in an age where the predominant ideology is one of taking personal responsibility for one's health, and where productivity is valued and illness or injury are often seen as an aberration. Within this framework, the answer is seen to be in the hands of the ill person who has a responsibility to take

appropriate action. The idea that luck may have a role in the process of staying healthy or regaining health is not one that is given much attention. In an ideal world many of the above factors would not be a matter of luck, but it is important to acknowledge that as yet, we have not reached the ideal.

In working towards recovery from OOS, both control and letting go appear to be important factors in improving one's situation. This is the paradox of needing to 'work hard at getting better' but at the same time 'releasing into relaxation, acceptance and attitude change'. This issue is not unique to OOS sufferers. Blumer and Heilbronn (1989, cited in Grzesiak, Ury & Dworkin, 1996) identified a group within their chronic pain patients as 'ergomaniac'. These people had a history of "excessive work performance, relentless activity, self-sacrifice and the precocious assumption of adult responsibilities" (p. 152). This profile appears to have a number of characteristics in common with the 'OOS personality'. Of particular significance to the current discussion is the fact that these people had "marked difficulty trusting their caretakers, including their health care providers" (p. 152). Parkes (1973, cited in Grzesiak, Ury & Dworkin, 1996), identifying a similar dynamic, termed this 'pathological self-reliance'. Gamsa (1990, cited in Grzesiak, Ury & Dworkin, 1996) found 'ergomania' and emotional repression to be the only two psychological variables which were consistently associated with chronic pain. It would appear from this research that some of the characteristics which are commonly associated with OOS specifically, are applicable to chronic pain generally, and that learning to let go, trust, and relax may be important aspects of moving towards improved health and wellness.

An understanding and acceptance of the paradoxical nature of OOS is important in order to assist OOS sufferers towards recovery. Many factors will affect how each individual resolves the paradoxes identified. Some of the more important factors include the degree to which the individual identifies with the OOS personality, the nature of their particular explanatory model, the degree of their knowledge and understanding of OOS, their coping strategies, their responsibilities, the degree of support available to them, and their optimism (or otherwise) about whether recovery is possible. By accepting the unique nature of each person's experience of OOS it is possible to approach each person's situation with a desire to unravel the mystery, to understand the experience and to assist the individual to adopt strategies and make changes which will help them towards recovery. Each person's path will differ, and some will require more assistance than others in adapting to the changed reality that is 'living life with OOS'.

IMPLICATIONS FOR PRACTITIONERS

The four paradoxes discussed above also have implications for practitioners. Working through these paradoxes does not occur as four distinct and separate processes, but each will be discussed separately as this provides a useful organising framework.

Helping OOS sufferers come to terms with OOS and its implications, and finding a 'healthy' balance point on the continuum between fatalistic acceptance of OOS as a permanent disability on the one hand, or rejecting it and ignoring the consequences on the other, requires acceptance and validation of the OOS sufferer by the health practitioner. Accepting the OOS condition as real, and validating it as a physical condition (rather than as being 'all in their heads') may help sufferers to accept their condition and progress towards recovery (Howell, 1994; Seers & Friedli, 1996). However, while recognising the importance of accepting and validating the sufferer, it is also important to recognise the importance of helping them to 'unravel' any beliefs that may stand in the way of their progress. This is particularly important in the case of those who either identify strongly with 'the OOS personality', or whose attitudes or behaviours are consistent with aspects of this profile. In the current study there was little evidence that this was occurring. This is important in relation to all four paradoxes, but addressing it soon after diagnosis may assist some OOS sufferers to come to an earlier acceptance of their situations and an understanding of some of the strategies they can adopt to enhance their progress towards recovery.

In addressing the second paradox, that of 'taking control' of the treatment process, or 'giving control' over to their treatment practitioner and adopting a passive role in relation to their treatment, the notion of a healing partnership is useful. It is important that the therapist or doctor takes responsibility for building an active healing partnership with the OOS patient, as such a concept may be outside of the experience of many patients. Such a relationship requires that the client take an active part in their own treatment by adhering to treatment recommendations and doing 'homework' tasks. It also implies that the practitioner will work with the client to help them build a coherent mental model of OOS. It is important that the practitioner takes into account the client's personality and lifestyle when 'prescribing' tasks, and helps them to address any barriers or resistance that may exist, or alternatively that they modify their recommendations. Practitioners may require some changes of clients that do not fit in with their current lifestyles. In such cases, achievable steps need to be identified in making lifestyle changes. Ascertaining whether the treatment modality appears to 'make sense' and be credible to the client would also seem to be important. Spence and Sharpe (1993, cited in Spence, 1998) found that what predicted the completion of a home study version of a cognitive behaviour therapy programme was the extent to which the patient believed that the self-help approach "was a credible and sensible way

to help them” (p. 37). Encouraging self-initiation (for example by offering choice, minimising controls and acknowledging feelings) enhances the degree of control felt by patients (Williams et al., 1998) and is likely to encourage and build their motivation and commitment toward the healing partnership. Given that most OOS patients have a strong desire to get well, once such groundwork has been laid, the degree of adherence to recommended treatment strategies is likely to be much higher.

In relation to the third paradox, that of finding a balance between fanatically adhering to every treatment and self-help recommendation, and not letting treatment or self-help interrupt one’s lifestyle at all, it is important that practitioners examine their current practice and ascertain the extent to which they enable or empower their patients to make the necessary changes and to incorporate treatment recommendations into their lives. It is also important that practitioners help their patients to understand which strategies are likely to have the most impact on their recovery so they can most usefully focus their efforts.

Research shows that one-third to a half of patients fail to follow their doctor’s recommendations or prescriptions (Radley, 1994) and the relatively low level of adherence indicated in the current research appears to be consistent with this finding. It is useful to consider the factors that may improve this situation. In the past ‘non-compliance’ has been seen as the patients’ failure. An alternative view is that low rates of compliance or adherence occur because the therapist’s goals are not the patient’s goals. Supporters of this view see it as the responsibility of the therapist to tap into the (sometimes latent) motivation in the patient and to enable or empower them to help themselves to achieve the (shared) treatment goals (Brown, 1997, cited in Furth, Holm & James, 1994). The nature of the relationship and the communication between therapist and patient is likely to be an important factor, and therefore it is important for the therapist to ask what they could do which would make it possible for the patient to better understand the nature of their condition, and consequently make it possible for the patient to achieve better progress (Radley, 1994).

An aspect that appears to be particularly important to the degree of adherence is the structure of the explanatory model that each individual constructs in relation to their condition. A patient’s mental representations and explanatory models are culturally driven and enable them to make sense of their illnesses and frame problems (Krefting & Krefting, 1991, cited in Moss-Morris & Petrie, 1994). Individuals develop a representation of their health problem which is made up of many components (an understanding of the identity / diagnosis, cause, time-line, consequences and cure or controllability of their condition) which are integrated into a coherent whole (Croyle & Barger, 1993; Leventhal, Diefenbach & Leventhal, 1992; Moss-Morris, 1997; Moss-Morris,

Petrie & Weinman, 1996; Murray, 1990, Weinman, Petrie, Moss-Morris & Horne, 1996). This whole fits together and makes sense to the individual. The coherence of the system involves not just internal coherence, but coherence with others in their social space - family, care-givers, friends and health-care providers. If patients do not accept their doctor or therapist's view of what is wrong with them, they are less likely to adhere to any treatment suggested. If the treatment suggestions do not fit in with the culture or systems of others in their social space, again, adherence is at risk (Leventhal, Diefenbach, and Leventhal, 1992). If one accepts this model, listening to the patient to find out about their representations or cognitions of their illness or injury becomes at least as important as giving information and advice.

Cognitive models are constructed based on individuals' interpretations of their symptoms, what they have heard from others, observed, or read, and from their own ideas (Moss-Morris & Petrie, 1994). These models determine how new information is evaluated and how bodily signals related (or otherwise) to their condition will be interpreted (Cioffi, 1996). The interpretation of bodily symptoms is by no means straight forward, and becomes more difficult because of the complex inter-relationships between the condition itself and the emotional state of the sufferer. Bodily sensations such as increased heart rate, hyperventilation, and increased temperature can be caused either by emotional states or by illness. In the case of OOS increases in pain and muscle tension can similarly be caused either by emotional states and stress, or by a 'relapse'. Emotions can either increase or decrease the intensity of symptoms experienced, can affect the way people cope with their condition, and their evaluations of the effectiveness of coping mechanisms they are using. They can also influence which information and experiences people 'take in' to their explanatory model. Information congruent with their mood may be accepted, and other information rejected. For example, a depressed person is more likely to process negative information. Distress makes it harder for people to cope, and also affects them at a physiological level through depletion of the immune system, and because their distress has resulted in them less adequately caring for themselves physically (Moss-Morris & Petrie, 1994).

In addition to determining how bodily signals are interpreted, individuals' explanatory models will also determine what actions they will take in relation to their condition and their overall approach to recovery (Schiaffino, Shawaryn & Blum, 1998). Recent studies of people with low back pain and respiratory disease indicated that illness perceptions were better predictors of functioning than medical ratings of severity and prognosis. These studies also found that a close match between illness perceptions of patients and clinical staff indicated a higher likelihood of return to work and other life roles. It seems that more accurate illness perceptions may help patients keep their symptoms in perspective and to modify work and interest activities rather than give them up (Lacroix, 1991, cited in Moss-Morris, 1994).

There is strong evidence that peoples' cognitive models are constructed spontaneously and are relatively stable (Moss-Morris & Petrie, 1994). This can present a challenge to therapists working with their patients. It is also likely that explanatory models, having been 'spontaneously constructed' are to some extent unconscious, or at the very least the patient may be unclear as to the effect that particular aspects of their explanatory models are having on their decisions and behaviours in regard to managing their condition. Although they may have been constructed spontaneously they will have been added to and strengthened by (selectively interpreted) confirming evidence often over long periods of time. There is likely to be a strong motivation to preserve these explanatory models (Moss-Morris & Petrie, 1994). In spite of the difficulties that may be involved, it is important that practitioners learn what makes up the model of each of their patients, and ascertain how it enhances or impedes their patients' progress towards recovery. It is important to accept that the patient's explanatory model is not an empty construction site waiting to be built on, but is already well formed and it is quite possible that the therapist's model may not be consistent with it. Unless a conscious effort is made to work with the patient to 'rebuild' their model in a way that makes sense to them (that is, is coherent with all the other components of their model/s), then the patient may not see the point of, or usefulness of following the therapist's suggestions.

Unless therapists make a specific effort to do so, a difference in beliefs may never be exposed, as patients are unlikely to discuss their explanatory models with their therapists, particularly if they think they will disagree with them or not accept their ideas. Encouraging patients to talk about what they think is going on in relation to their condition, and remaining sensitive to subtle 'clues' which reveal aspects of their explanatory models are likely to be important in moving towards greater adherence. To change patient's inaccurate models it will be necessary to start where the patient is at, and together, build an alternative framework for viewing the problem.

In relation to the fourth paradox, that of co-operating with one's body (and OOS) or fighting against it, OOS sufferers must develop a more caring relationship with their own bodies. Health practitioners can help OOS sufferers in this area in a number of ways. Assisting those who have attitudes or behaviours in common with the 'OOS personality' to identify the ways in which they put other people's needs or productivity targets before their own health and wellbeing is important. It may be appropriate to recommend assertiveness training or counselling. Another important aspect for OOS sufferers is that they learn to be more aware of their bodies' needs. One of the more challenging factors in relation to this is that of 'unlearning' a reliance on pain as a signal. It is important that practitioners ascertain the extent to which the individual is either 'overdoing' or 'underdoing' things in response to pain signals which are no longer directly

connected to injury. It is important also to ascertain whether the individual is getting adequate rest and relaxation and addressing any sources of stress that may be having an adverse affect on their lives.

A general awareness of the overall paradox, that of finding a balance between 'letting go' and 'working hard to recover' provides an important background to working with people with OOS. While it may not have specific and direct implications regarding practice, it is important to be sensitive to signals which may indicate that a particular client has leanings either toward 'excessive' efforts to 'work hard to recover' or to excessive passivity in relation to their condition, and to encourage practices which will help to redress the balance. As this paradox is being played out within each of the four major processes which are part of progressing towards recovery, and of each of the major paradoxes associated with these processes, it is important that the practitioner is aware of the disadvantages of being 'out of balance' in either direction.

It is also important to recognise that one of the results of ongoing chronic pain and tiredness is that those experiencing it loose clarity, especially when at times everything may seem so hopeless. It is often difficult to identify a clear association between specific activities and increased pain, as sometimes an activity causes problems and sometimes it does not. Relapses appear to occur 'out of the blue' for some. It is therefore quite conceivable that a person could begin to loose perspective and the ability to be logical and consistent in their decisions about treatment and self-care measures, thus limiting their ability to resolve the paradoxes discussed above. After long periods of time (up to 6 years in the case of one participant in this study) of persevering to get better, it can be possible to lose focus. OOS sufferers in this situation may not be in a good position to make 'links' in their thinking that could potentially result in a better strategy regarding treatment or self-care. They are often at a point in their lives where they do not have a 'high bank balance' of mental health, energy or stamina, and in fact may already be seriously in 'overdraft' through a range of work or life stresses.

Generally in our current health system each therapist works only in their own modality, and is not necessarily able to spend sufficient time to cue into the broader areas of how their clients are managing their lives with OOS. Typically there is very little communication between the various health practitioners involved in treating a person with OOS, and little or no 'case conferencing' between practitioners with the OOS sufferer him/herself involved. The practitioners who potentially could be in a position to play more of a coordinating and integrating role with the client are the GP and the ACC case manager. However, the GP's role is often largely as a referring agent to other therapies and the ACC case manager's role as a compensation administrator may not be compatible with the role as a 'healing partner' or neutral guide. There

are many choices that must be made along the way towards recovery where it would be useful to have help in sorting out the options. These include issues such as deciding whether to take a break from work, for how long, and how best to manage this process, which type of therapy to try, to what extent stress or workstyle may have contributed to the development of OOS and what needs to be done to make changes in these areas. There are many other issues and choice points where assistance to 'gain perspective' would be useful. A particularly important role would be helping the OOS sufferer to make wise decisions about which of the 'shoulds' are most important and will have the most impact on their rate of recovery. Those who have made good progress with their OOS appear to have been able to maintain or gain perspective, or at least not 'get lost in the dark' with their OOS. It is possible that the availability of a health care practitioner who is able to take the role of a 'guide' could be very beneficial (DeGood & Dane, 1996). Such a person could assist the OOS sufferer to clarify their explanatory model relating to OOS ensuring that it is built on a foundation of accurate knowledge, and address contradictions or blind spots that may stand in the way of progress towards recovery.

FUTURE DIRECTIONS IN RESEARCH

The current research project has involved gathering the accounts of thirteen OOS sufferers. By inviting these people to give narrative accounts of their experiences, the aim has been to gain an understanding of the lived experience of OOS. These accounts are constructed in a specific context, that of the interaction between myself and the OOS sufferer, at a particular time, and in a particular place. My interpretation of these accounts is also embedded in a specific context. Accepting that there is no 'one true account', the aim of phenomenology is not to develop theory which seeks to explain and control the world, but instead to "offer the possibility of plausible insights" into a particular phenomenon. This study, through its interpretation of the experiences of the participants, offers insights into their experiences. It is hoped that these insights will prove to be helpful to both OOS sufferers themselves and the health practitioners who work with them on their journeys towards recovery.

This study has taken a broad approach in its investigations, and in addition to offering its particular insights, has revealed a number of issues that would benefit from more specific research. These include more detailed qualitative research into OOS sufferers' explanatory models, what is involved in achieving a good match between an individual with OOS and a particular treatment modality, what facilitates or detracts from adherence and what facilitates the transition towards a more caring relationship with the body. Future research on these and other related areas will continue to give greater insight into OOS. A quantitative study into rates and degrees of adherence to therapists' 'homework' tasks and modification of work practices would also be useful. It would appear from the current study that adherence rates are generally low, and

further study in this area, including a quantitative study, could be beneficial, in that it may provide impetus to address the reasons for this occurring and to develop more effective strategies.

Concluding Comment

The findings of the present study add to existing research by providing more understanding and insight into the phenomenon of OOS as the OOS sufferer experiences it. These findings have implications for health practitioners who treat people with OOS, reinforcing the need to explore the individuals explanatory model relating to OOS, acknowledging and honouring their existing model and working with them to (re)-construct a model which will enable and empower them to make any changes, or adopt any strategies which are identified as being an important part of their recovery plan. In assisting them to make these adjustments, it is essential to acknowledge individual differences in terms of personality, beliefs and life circumstances, and to adapt this plan accordingly. It is also essential to acknowledge the paradoxical nature of OOS, and the fact that there appear to be no simple or easy answers. Instead it is necessary for the OOS sufferer to resolve a number of important paradoxes on their road to recovery.

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Living with OOS Information Sheet



**MASSEY
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COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES

SCHOOL OF
PSYCHOLOGY

Who is conducting this study

My name is Angela Baker, and I am a part-time Masterate student in the School of Psychology at Massey University. I work as a career consultant at Career Services *rapuara*. My research supervisor is Kerry Chamberlain, Senior Lecturer in the School of Psychology at Massey University. I have an interest in understanding the experience of life for people who have OOS with a view to contributing to improving ways of working with people with OOS to enhance their health outcomes. It is important that you understand that I am not medically trained and that I cannot offer advice on the treatment or management of your OOS.

What this study is about

This study focuses on the experience of people who have been diagnosed as having OOS, and how they see their lives and look after their health. It seeks understanding of the processes involved in managing OOS while living your life, and the place of OOS in everyday experience.

What you would agree to do

There is no obligation on you to participate. If you are willing to take part, all you need to do is complete an interview with me. In the interview we will talk about your understanding of your OOS, what you do to deal with your OOS, what sort of influence having OOS has on your daily life, and what you do to look after your health, along with any issues you want to raise about OOS yourself. I will not be asking you a lot of questions, but asking you to tell me about your experiences in the areas mentioned. The interview will be like a conversation and will take us approximately an hour to complete.

Protecting your confidentiality

I will need to tape-record our interview, in order to analyse the material we talk about. If you are not willing for this to occur, you should not participate in the study. The recorded interview will be transcribed by myself or by another person assisting me. This may be a person from a typing agency. This person will hear what you have said, but will have been required to sign a statement agreeing to keep the information confidential. My research supervisor will also have access to the tapes and transcripts, but is bound by the same confidentiality agreement that I am. The tapes (and transcripts) will not have your name on but will be identified by a pseudonym. Your tape will be stored securely and will be destroyed at the end of the research, or it can be given to you if you would like to have it. It will not be possible to identify you in any reports that are prepared about the study. I will not disclose what you have said to anyone else including agencies such as A.C.C. The information you give me will be used for my research only.

Your rights as a participant in this research

If you agree to take part in the study, you have the right :

- to ask any questions about the study at any time
- to refuse to answer any particular questions
- to withdraw from the study at any time
- to ask for the taperecorder to be turned off at any time
- to provide all information on the understanding that it is completely confidential to the researcher, transcriber and research supervisor.
- to be given a summary of the findings from the study when it is concluded.

How to contact me

You are welcome to contact me at any time during the study, for further information or to clarify any questions you may have about the study. I can be contacted

by mail : c/- School of Psychology, Massey University, Private Bag 11222, Palmerston North

by phone : 358 7413 during work hours

My supervisor, Kerry Chamberlain can be contacted at the above postal address, or phone 356 9099.

Appendix B



**MASSEY
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**COLLEGE OF HUMANITIES
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SCHOOL OF
PSYCHOLOGY

Dear SPARC client

Research Project - Living with OOS

I am a Masterate Student in the School of Psychology at Massey University. I am about to undertake a study of OOS as my thesis project.

SPARC Physiotherapy have mailed this letter out to you, inviting you to participate in the study. It is important to emphasise that SPARC is doing this mail-out, and I have no knowledge of who letters are being sent to. In this way, your confidentiality has been maintained.

You are under no obligation to participate, but if you were willing to participate, this would be greatly valued.

More about who is conducting the research

I am studying part-time towards my Masterate while working as a career consultant at Career Services *rapuara*. My research supervisor is Kerry Chamberlain, Senior Lecturer in the School of Psychology at Massey University. I have an interest in understanding the experience of life for people who have OOS with a view to contributing to improving ways of working with people with OOS to enhance their health outcomes. It is important that you understand that I am not medically trained and that I cannot offer advice on the treatment or management of your OOS.

What this study is about

This study focuses on the experience of people who have been diagnosed as having OOS, and how they see their lives and look after their health. It seeks understanding of the processes involved in managing OOS while living your life, and the place of OOS in everyday experience.

What you would agree to do

There is no obligation on you to participate. If you are willing to take part, all you need to do is complete an interview with me. In the interview we will talk about your understanding of your OOS, what you do to deal with your OOS, and what sort of influence having OOS has on your daily life, what you do to look after your health, along with any issues you want to raise about OOS yourself. I will not be asking you a lot of questions, but asking you to tell me about your experiences in the areas mentioned. The interview will be like a conversation and will take us approximately an hour to complete.

Protecting your confidentiality

I will need to tape-record our interview, in order to analyse the material we talk about. If you are not willing for this to occur, you should not participate in the study. The recorded interview will be transcribed by myself or by another person assisting me. This may be a person from a typing agency. This person will hear what you have said, but will have been required to sign a statement agreeing to keep the information confidential. My research supervisor will also have access to the tapes and transcripts, but is bound by the same confidentiality agreement that I am. The tapes (and transcripts) will not have your name on but will be identified by a pseudonym. Your tape will be stored securely and will be destroyed at the end of the research, or it can be given to you if you would like to have it. It will not be possible to identify you in any reports that are prepared about the study. I will not disclose what you have said to anyone else including agencies such as A.C.C. The information you give me will be used for my research only.

Your rights as a participant in this research

If you agree to take part in the study, you have the right :

- to ask any questions about the study at any time
- to refuse to answer any particular questions
- to withdraw from the study at any time
- to ask for the taperecorder to be turned off at any time
- provide all information on the understanding that it is completely confidential to the researcher, transcriber and research supervisor
- be given a summary of the findings from the study when it is concluded.

If you are interested in participating in this research project, please phone me at Ph 358 7413 (work hours), or complete the form below and mail it to me :

Angela Baker, c/- School of Psychology, Massey University,
Private Bag 11222, Palmerston North.

My supervisor, Kerry Chamberlain, can be contacted at the above postal address, or phone 356 9099.

Yours sincerely

Angela Baker

Research Project - Living with OOS

Name :

Address :

.....

Phone Number :

I am interested in participating in the Research Project - Living with OOS. I understand that you will phone me to discuss the project further.

Signed :



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**COLLEGE OF HUMANITIES
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Living with OOS

Consent Form

I have read the Information Sheet for this study, and I understand what it involves. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from the study at any time, and to decline to talk about any particular issues in the interview.

I agree to provide information for this study on the understanding that it is completely confidential to the researcher, research supervisor and transcriber, and it will not be used for any other purpose than the present study. I also understand that my identify will not be revealed in any reports that are prepared about the study.

I agree to the interview being audio-taped and I understand that I have the right to ask that the tape-recorder be turned off at any time during the interview.

I agree to take part in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:

Appendix D

Interview Questions

Intro/Demographic questions

- Age
- Occupation
- No of hours working when got OOS
- How long since you got it
- Progression ie reducing/increasing hours
- Tell me how OOS has affected you. (Additional prompt questions, if necessary – What part(s) of your body are affected and how? How has OOS affected your life?)

Onset

- Describe how it began, what you noticed and what you did

What's going on in your body?

- Tell me what you think is happening in your body?
- Can you be more specific
- What do you think happens to the muscles, nerves, blood supply with the treatment
- What do you think makes it better / what do you think makes it worse? Why do you think this is?
- Are there any occasions or things you do when it doesn't seem to affect you? Why do you think this is the case?

How will it get better?

- What treatments have you had?
- What self-help methods have you tried?
- What do you see as the doctors / physio's / OT's role being in your recovery
- Have your treatment providers given you tasks to do at home? If so what? How do you find this? (what would help you persevere with these tasks and be more disciplined in doing them?)

What would need to happen for you to get better?

- What stops these things happening?

Relapse / Setbacks

- Have you had a relapse / setback?
- Why do you think it happened?
- What effect has it had on you?

The future

- What is your view of your future, in terms of OOS
- To what extent do you expect to recover? How long will it take? What will you have to do for this to happen
- How has OOS affected your job / career, and what are your thoughts on your future career?

Changes

- How has your life changed since you developed OOS. How has your outlook on life or attitude to life and yourself changed? Describe how these changes have been for you. Where positive changes have been made, what made the difference in you making these changes?
- Have you started developing any new interests? If not, what is your thinking about this?

Relaxation

- Have you had relaxation therapy? Did it help? Explain why you think it did or didn't help.
- Do you still use it? Describe how you use it, how often, what prompts you to use it etc

Who gets OOS

- Why do you think you got OOS?
- Where you work, have you noticed any differences between the people who get OOS and those who don't? What are these differences? Has your awareness of these differences affected you thinking about how you cope with OOS?

Task approach

- How do you approach your work / activities / housework etc now? Is this different from how you used to approach them? (pacing / boom-bust etc)

Health / Self-care

- How important was your health and well-being to you before you got OOS? If yes, give me examples (eg exercise, balance in life etc)
- How important is your health to you now. If yes, give me examples of self-care.
- What sorts of things do you do to help to improve your comfort level or your health relating to OOS?

Knowing what you know now, would you have done things differently?

- To what extent did you listen to what your body was telling you then? Do you look after yourself better now?

Belief statements

- Explore any of these further

Describe pain / sensations

- How different from other pain / sensations in the past

How was increase in hours / time off etc decided?

November 20th, 1999

Dear

As I near completion of my research project on 'Living with Occupational Overuse Syndrome', I am sending you the following brief summary of my findings. I interviewed 13 people with OOS, and this summary is a generalised account of their experience. Because of this, there will be some things in this summary which do not relate directly to your own experience, but you should be able to recognise a lot about your own OOS experience in this generalised account. In my thesis I have used a 'pseudonym' for each person interviewed, and have also changed the names of spouses or children mentioned in the interviews in order to maintain confidentiality. Names of your employers, doctors and treatment practitioners have been removed also. I have used many 'verbatim' excerpts from the interviews to illustrate the findings which emerged - I do not write about each individual's experience with OOS but instead use excerpts from your interviews to give examples of common themes which emerge.

After my analysis of the interviews, I reached the conclusion that the experience of living with OOS involves four major processes

- 'Coming to terms with an OOS diagnosis'
- 'Seeking a treatment that works'
- 'Trying to do the right thing'
- 'Learning to co-exist positively with OOS'

These processes occur concurrently - they are not phases or stages and there are many inter-relationships between them. For the majority of the people in this study, the experience of 'living with OOS' often felt like 'finding their way in the dark'. My study has largely focussed on the experiences of these people, but has also noted the exceptions. Three of you experienced a (relatively) less difficult journey with OOS - one of you began treatment very early after first noticing symptoms, and two of you made very good progress with the first therapy to which you were referred

Tē Kūmenga ki Pūrehuroa

(in one case this was relaxation therapy, and in the other, physiotherapy). The remaining ten of you experienced a much more difficult and uncertain path, with relatively slow progress towards recovery, and many of you experienced a sense that 'no-one knows what to do'. The following provides a brief summary of the complex issues involved in each of the four processes identified.

Coming to terms with an OOS diagnosis

In spite of the prevalence of OOS, at the time that the people in this study developed symptoms, few of you were aware that these symptoms pointed to OOS, and most of you were surprised when you were diagnosed as having OOS. Similarly, few of you were aware of the potentially serious nature of OOS and its consequences. The process of coming to terms with an OOS diagnosis was a slow and painful adjustment period for some, as you adjusted to the losses associated with OOS. The most significant of these was loss of independence, the loss of capacity to work, feeling unable to contribute to the family or household to the level which was previously possible, loss of the 'taken for granted' ease of the use of your hands and arms, and for some of you, the loss of the ability to drive. For some of you there was also the loss of a satisfying career and the need to change direction, in some cases resulting in a significant reduction in wages. These factors all exerted their effects on how easily people were able to adjust to and accept the idea of having OOS.

Seeking a treatment that works

Most of you reported that few people understand what OOS is, or how it can best be treated, and for many of you, your experience involved a sense of stumbling around in the dark, making very slow progress, and believing that there must be a better way. Each OOS sufferer constructs their own unique and personal explanations (explanatory models) for what is happening to them, piecing together their model from their own experiences, from what they notice in relation to others suffering from OOS, and from information they gain from a wide variety of other sources. These models are somewhat like a jigsaw puzzle, where some of the pieces fit together well, and comprise of accurate information, and where other parts are inaccurate and don't 'fit' with the overall picture. Often the contradictions and inconsistencies in these personal explanatory models are not obvious, as until the contradictory parts actually 'bump into each other' there is no awareness that they do not fit. These personal explanatory models strongly influence the decisions and actions of OOS sufferers in terms of their commitment to doing their therapists' 'homework' tasks, self-help and self-care. A range of other factors such as the quality of relationship with the therapists and the ease with which treatments and 'homework' tasks fit into lifestyles affect the degree of 'match' between the individual and the treatment they are receiving. Commonly OOS sufferers are characterised as being very active, hardworking, conscientious, perfectionist types of people (the 'OOS' personality). For people who identify with this

description, there is no 'natural fit' with passive therapies, nor with the suggestion that they need to learn to relax. Unless therapists make a deliberate attempt to help OOS sufferers build bridges between where they are now and where the therapist wants them to be, there is likely to be a low level of commitment and adherence to treatments. As almost all forms of treatment for OOS involve increased pain levels, and because progress is often very slow, it is necessary to have a high level of commitment to the treatment being provided in order to see the treatment through.

There is evidence indicating that only a small proportion of people who suffer OOS develop a long-standing chronic condition. All but one of you, in this study, had moved into this long-standing category, and all but two of you believed that it was not possible to fully recover, although all of you believed (at some level) that it was possible that you would get better than you were at the time of the interview. This belief is also likely to impact on one's motivation and commitment towards treatment and self-help efforts. Hence, for many of you, trying to find a treatment that worked was difficult, and progress towards recovery was much slower than you expected.

Trying to do the right thing

All of you had a strong sense of what you 'should' do in relation to modifying your work practices (adopting strategies such as micro-pauses and breaks), and in terms of doing your therapists' 'homework' tasks and getting enough exercise. However, overall, adherence to most of these practices was relatively low. Although all of you had a strong desire to get better, in many cases effort was put into only a very small proportion of the things you felt you 'should do' for your OOS. In some cases this effort was relatively minimal, and effort was not always applied to the things which appeared to be most important to recovery. This occurred for a wide range of reasons and was explicable because you were trying to fit this in with getting on with your life. Trying to do the right thing turns out to be complicated, and was often a confusing and difficult process to resolve.

Learning to co-exist positively with OOS

In coming to terms with an OOS diagnosis, there is a certain level of acceptance of the condition which generally involves changing one's work practices to some degree, and making some level of commitment to therapists' 'homework' tasks and self-help strategies. However, moving towards recovery appears to require a qualitatively different level of acceptance, which is much more full-hearted, and involves not just attending to 'reducing symptoms' but also attending to one's own health and wellbeing in a more holistic way. This level involves putting one's own health before other commitments or desire for achievement, which can often mean making significant adjustments to one's lifestyle and priorities. This shift in perception involves adopting

a more long-term approach to one's health and wellbeing and accepting the limits of one's body. It also involves learning to relax, getting enough rest, avoiding unnecessary stress and getting enough good quality, restorative sleep, yet, at the same time remaining physically active. Learning to put up with a certain level of pain (which in many cases is still relatively high), and continuing to 'push the limits', but in a healthy way, also seems necessary to move forward. It appears to be important to develop a strong awareness of one's body, and its signals and needs, but at the same time, to break any reliance on using pain as a means of monitoring one's needs or progress. Previous research indicates that in chronic pain conditions (including conditions such as OOS), pain, in some senses, takes on a life of its own, and is no longer an accurate signal either that one has 'done too much' or that 'damage is being done'. In OOS, there may be a long delay after 'doing too much' before pain begins, which may result in unnecessary damage being done. There is also 'good' and 'bad' pain, so pain does not necessarily signal a relapse or problem, but may be part of the path towards improvement. For several of you who have made significant progress towards recovery, there was a sense of being able to see OOS as a gift which has forced a change in perspective which in the long-run is more satisfying.

The paradoxes involved in living with OOS

For each of the four processes identified there is a major paradox or challenge. How this is resolved appears to affect progress towards recovery. In the process of moving from symptoms to a diagnosis and coming to an acceptance of OOS, the paradox involves the degree to which it is appropriate or beneficial to accept or reject the diagnosis of OOS and its implications. Lack of acceptance appears to result in minimising and ignoring symptoms and delaying seeking treatment and results in sufferers resisting the recommendations of treatment providers. This can have serious consequences for prognosis and treatment duration, as studies indicate that preventive measures and early reporting can have significant effects on treatment outcomes.

The paradox to be resolved in relation to the process of seeking a treatment that works is that of finding an appropriate balance between, on the one hand, being very independent, autonomous and 'in control' in relation to one's treatment process, and on the other hand having total 'faith' in one's practitioner and taking a more passive role in one's treatment. Both taking too much control, and too little control in one's treatment are not helpful to recovery. An ideal 'balance' between the two involves being an active partner in a 'healing partnership'. This involves such things as actively learning more about OOS, making a full commitment to the current treatment including 'homework' exercises, asking questions to gain sufficient understanding, asking that exercises be demonstrated until one is confident enough in how to do them, finding out about further self-help and self-care measures that may help, and finding out about alternative treatments if the current treatment does not appear to be helping.

In relation to the process of 'trying to do the right thing, the paradox to be resolved is to find a balance between adherence to treatment recommendations and 'getting a life' (or 'keeping on having a life'). Fanatical adherence to 'homework' and self-help tasks, and making an intensive and constant effort 'to get better' could potentially result in one's life being ruled by what one should or shouldn't be doing because of the OOS. On the other hand making self-help and treatment measures totally subservient to one's 'lifestyle' is likely to result in low adherence to treatment providers' recommendations, and consequently slow progress towards recovery. The reality for many of you was that of fitting your treatment recommendations within a life which included other areas of responsibility and which left no 'spare' room to incorporate 'homework tasks' or self-care' measures. Consequently a significant shift in priorities was necessary in order to put your own health first.

In a 'healing partnership' the responsibility of achieving a higher degree of adherence to treatment recommendations lies at least as heavily with the treatment providers as with the OOS sufferer. The challenge for them, as OOS sufferers attempt to 'do the right thing', is in providing a treatment strategy that makes sense to you, and that involves achievable steps in relation to fitting with your lifestyles. In addition assistance may need to be given to help the OOS sufferer to make wise decisions about which of the 'shoulds' are most important and will have the most impact on their rate of recovery.

The final paradox is one of co-operating with, as opposed to battling against, one's body and OOS itself. This appears to be significant in terms of learning to co-exist positively with OOS. In a positive resolution of this paradox, OOS may be interpreted as having relayed to the sufferer important information about the lack of sustainability of their lifestyle, workstyle or strategies for managing their lives generally, and indicating a need for change. Viewing your bodies as your friend rather than as inadequate and having let you down badly can lead to a greater willingness to incorporate treatment recommendations into your lifestyle, as well as to attitude adjustments involving a greater 'kindness' to yourselves as a whole. As suggested by one of you, part of the path to recovery may include a willingness to slow down, be less demanding on yourself, and to 'take the time to smell the flowers'. Research suggests that stress exacerbates an existing OOS condition, which would tend to indicate that an attitude adjustment of this type can be pivotal in making progress. As part of finding the balance between fighting and co-operating with one's body, it is necessary to find a healthy balance in terms of 'pushing the limits'. Being 'too kind' to oneself, perhaps 'pampering oneself' to an unhealthy extreme by choosing not to make additional effort can limit one's progress as much as 'pushing too hard' and constantly trying to 'see how

much you can get away with' - almost, in effect, trying to 'trick' your body by doing something and hoping it won't notice.

Co-operating with, and moving towards a more caring relationship with one's body also involves finding a balance between putting one's own health first (but without becoming self obsessed or paying too much attention to one's bodily signals and becoming hypervigilant) and allowing other priorities to take precedence, particularly one's responsibilities to others. It requires the development of assertiveness skills to enable one to set limits, and the valuing of one's own health to the extent that rest and relaxation are seen as integral to everyday life, rather than 'special occasion' activities. As with the paradoxes identified above, this can prove to be additionally challenging for those who strongly identify with the 'OOS personality'.

The above paradoxes all represent aspects of an overall paradox in relation to 'finding a way through OOS' - that of finding a healthy balance between keeping tight control and letting go. In working towards recovery from OOS both control and letting go appear to be important factors in improving one's situation. This is the paradox of needing to 'work hard at getting better' but at the same time 'releasing into relaxation, acceptance and attitude change'. This is a difficult balance to find, but it was pleasing to see that many of you were on the road to this point.

The approach I have taken is one of many ways that it would be possible to interpret the interviews. No research project can hope to present all the complexities and possible interpretations of peoples' experiences of OOS. My interpretation has no doubt been influenced by my particular background including my personal experience with OOS, my contact with clients, friends and acquaintances with OOS, and my educational background in psychology. However, I do think it has some value in providing some insights into the experience, and offers some suggestions for how people with OOS and practitioners can try to do better in managing and treating the problem.

Throughout this project I have learnt a great deal in relation to OOS generally, and have had a great opportunity to reflect on my own experience with OOS and how I manage it. I am aware, as I write about issues such as the fact that many of the people I interviewed made a relatively low commitment to homework tasks from therapists, that this may be seen by those I interviewed as being somewhat judgmental. I wish to assure you that I do not feel judgmental about any of the issues that you discussed with me, and which I have addressed in this research. My own experience with treatment, and with therapists 'homework' was very similar to many of the participants I interviewed. With the benefit of hindsight, and the privilege of having your interviews to provide further insight into the experience of OOS, I believe that I am now in a

much better position to analyse my own situation and move further towards 'co-existing positively with OOS'. However, I have come to the conclusion that just 'knowing' the things which I have learnt through this study would not be enough - if some-one had handed me my thesis to read when I first got OOS, it may not have made a big difference to what I did. I think what would have made a significant difference would have been to have had a counsellor or 'guide' who could help me make sense of all these issues and work out how to adjust my life in view of all that is now known about OOS.

I feel profoundly grateful to you all, as participants in this study, for your willingness to talk to me of your experiences, and for the insights this has provided. Not only has it enabled me to complete this research and thus my M.A. in Psychology, but it has also helped me to gain insights to manage my own health better. I believe that this research will prove to be useful to others suffering from OOS also.

Yours sincerely

Angela Baker