The presenting symptoms associated with arachnoiditis and the experience of living with them in everyday life

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Abstract

A qualitative study was undertaken to explore and describe the symptoms associated with arachnoiditis and the experience of living them in everyday life. Using guide questions developed from the study's objectives, eleven people who believed they had arachnoiditis were interviewed to elicit descriptions of their symptoms and experiences. Research data revealed a broad range of symptoms, including severe pain in various areas of the back, headaches, sudden weaknesses leading to falls, fatigue, bowel and bladder problems, feelings of depression, suicidal feelings and plans for suicide, unexplained sweating, various sensations of pins and needles, electric shock, numbness, cramps, and spasms. Experiences identified as associated with living with these symptoms include mobility difficulties, problems in gaining understanding from others, the development of coping strategies, the search for relief from symptoms and enforced changes in lifestyle. The study revealed that nurses had played no recognised therapeutic role in participant's experiences. A change in focus is proposed, from a biomedical perspective of arachnoiditis as incurable and the symptoms, particularly the severe pain described by participants as intractable, to a Rogerian focus which emphasises the potentials in life. New possibilities for nurses to develop therapeutic practices, in particular, those focusing on pain management needs, are identified and linked to current opportunities for practice development.

Acknowlegements

With grateful thanks to the participants who
shared so much,

to my wonderful husband, family and friends
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and encouraged me.

Contents.

Chapter One: The aims and context of the research and an introduction to the participants

Introduction

In this chapter, the researcher introduces the study aims, outlines the background to the study and describes the researcher's initial involvement in the lives of those with arachnoiditis. A brief consideration is given to the choice of methodological and theoretical frameworks and the participants are introduced.

Study Aims

This qualitative descriptive study aims to:

- explore and describe the symptoms associated with arachnoiditis

- explore and describe the experience of life with those symptoms

Analysis of the data will provide, through the description of the symptoms and the understanding gained of the experience of living with those symptoms in daily life, information from which appropriate nursing practice options can be developed and/or further research undertaken that will enable those with arachnoiditis to live lives of greater comfort and opportunity.

Background to the research

In the latter part of 1995, a television programme (A shot in the back, 1995) and a number of newspaper articles (Doctors unsympathetic, 1995; Myodil group, 1995; Myodil group wants, 1995; Myodil sufferers may number, 1995; Myodil victims, 1995;

Myodil victims band, 1995; Myodil victims urged, 1995; Spinal dye used, 1995; Sufferers join, 1995; Wanganui Myodil sufferers, 1995), brought to public attention the existence of a pattern of symptoms which, for those featured, included a severe intractable pain centred in their spines that they had come to believe was related to a disease process known as arachnoiditis. Those interviewed believed that their symptoms had developed as a result of the introduction of a radiographic dye known as Myodil (see Appendix One) into their cerebro-spinal fluid for the purpose of myelographic x-ray examination, reaching this conclusion as a result of their own personal investigations into the medical literature.

Initial involvement of the researcher with those with arachnoiditis

The response to the ongoing publicity was such that those featured, particularly those in the television documentary, were unable to handle replies to all the correspondence and the telephone requests for help and information they received from people around the country. The Whanganui Disability Resources Centre (WDRC) was asked by one of the participants in the television documentary to assist in replying to these requests, and the researcher was asked by WDRC to coordinate a response to inquiries. This was a voluntary position, as no funding was available for a coordinator. However, WDRC was able to meet the costs of photocopying, telephone and postage as part of their mandate to provide support and information to those seeking it.

Establishing support links and information dispersal

By January of 1996, over 600 people had contacted WDRC seeking information because they felt they may also have arachnoiditis as described in the various forms of publicity. Accessing information to build an information pack proved difficult. Although there were a number of articles on Medline, it was not easy for the researcher, who at that time knew very little about the condition, to know which were likely to be the most helpful articles before ordering them. Eventually, some articles of a general nature were obtained and all those who contacted WDRC were sent an information pack containing the names and contact phone numbers of people who had agreed to be local contacts, the titles and authors of relevant articles and a brief summary of the articles on arachnoiditis that the WDRC had accessed to that point, an outline of symptoms linked in those articles to arachnoiditis and a questionnaire allowing for expression of their feelings and needs concerning the situations that had developed for them since their symptoms appeared.

Emergence of areas of concern relating to symptom management

The questionnaire included in the WDRC information pack was not intended as a research tool, but simply as an in-house way of assessing the most urgent needs. Over 200 people responded to the questionnaire. Others wrote detailed letters. Responses were compiled but not statistically analysed (Whanganui Disability Resource Centre, 1996) and indicated that difficulties in getting a diagnosis, not being believed about the pain, not receiving adequate relief for the pain and not receiving help for difficulties they experienced in their day-to-day lives as a result of the pain, were the major areas of concern. Some respondents reported having been told by their doctor that the pain was 'all in their head' (ibid). Others reported being told by health professionals that they would 'just have to learn to live with it,' without support as to how to do so, or any explanation as to cause or likely future outcomes.

Individuals stated they had felt demeaned and helpless when told it was 'all in their head.' There were reports from relatives of people who felt loved ones had committed suicide as a result of such attitudes. In excess of twenty people who contacted WDRC indicated they were actively considering suicide, mostly because of the unremitting pain. Initial support for those people was provided throughout the country by field workers from the Multiple Sclerosis Society. There was a perception expressed by a number of respondents that specialists and the Accident Rehabilitation and Compensation Insurance Corporation of New Zealand (ACC) were in collusion, and were 'covering their backs' because they had ordered the tests knowing there was a linkage to the subsequent onset of the arachnoiditis. Individuals expressed their concerns about a perceived lack of choice in accessing specialists. After receiving copies of their hospital and medical notes, a number of respondents stated their objections to the content of some of the entries in their medical histories, to letters written about them without their knowledge and to the lack of information they felt they had been given at many points during their contact with the health care system.

Formation of local and national support groups

Because so many people wanted support and understanding from others who shared their problems, efforts were made to establish self-help support groups. The willingness of individuals to act as contact people led to the formation of groups throughout the country. However, many initially active local groups ran into problems because of the ill-health and disabilities of the members. Attendance at meetings was erratic and problematic, since a number of people had difficulty sitting for any period of time, which also limited car travel and thus actually getting to meetings. There were disputes over the purpose of the groups. Some wished to concentrate on seeking compensation from pharmaceutical companies, while others wanted support and information. Since then, those seeking legal redress have formed a completely separate group and are working with two lawyers for that particular purpose.

WDRC does not have a mandate to fund support groups for those with disabilities and was pleased when a local support group was formed. Members of that local support group also became the founding executive of the national body, the Arachnoiditis Support and Monitoring Society (ASAMS). ASAMS faced a huge task and the provision of information and support for members initially taxed the resources of the newly formed national group.

Since that time, ASAMS has continued to evolve. Links have been made with other arachnoiditis support groups overseas, members coincidentally discovering the distractive therapeutic value of computers as they became computer literate. ASAMS has its own web site. Members have scoured the Internet and joined chat pages for those with arachnoiditis. Information from Medline abstracts has led to the acquisition of journal articles on a wide range of aspects concerning arachnoiditis, from aetiology to treatment, including research on specific dyes and their side effects. Copies of many of these journal articles have been accessed through libraries, the Ministry of Health and other national groups, especially the British Arachnoiditis Trust. Video's from Dr Burton of the Minnesota Back Pain Facility, an acknowledged and widely quoted expert on arachnoiditis, were obtained. Some ASAMS members are now very knowledgeable about arachnoiditis related information.

ASAMS has developed a collective awareness of just how poorly served some of their members felt they had been in the area of pain management. What had been isolated individual experiences have been shared. ASAMS also reported an ongoing perception among members who receive payment from ACC that ACC appointed doctors they were required to see to maintain their payments have been particularly unsympathetic and unhelpful.

Recently, ASAMS held a regional get-together for members in the lower North Island, at which the researcher was an invited guest. This meeting allowed members to meet and discuss many of the above issues and to clarify their goals for the National organisation. They also met their new patron, a South African doctor who has recently moved to New Zealand. Some of those who attended had never met anyone with their particular difficulties before and had felt extremely alone, so the meeting proved very fruitful in terms of personal support networks.

Rationale for selection of arachnoiditis as a topic requiring nursing research.

The idea that the researcher might undertake her Master's thesis research on some aspect of arachnoiditis was suggested to her by the executive of ASAMS. This request reflected the concern of members, who had expressed disquiet that so few health professionals appeared to be knowledgeable about the condition, and seemed unable to validate members' experiences by saying what symptoms people 'should have.' There was concern that the kind of support needed to live with their pain, particularly their back pain, was not recognised as being different from that associated with acute pain or chronic pain of other causation. Members had reported feeling that the personal devastation they had experienced on finally getting a diagnosis, only to be told their condition was an untreatable one they would have to learn to live with, had not been recognised and appropriate support had not been offered.

The problems outlined above indicated a number of systemic issues, not all of which related directly to nursing. However, there is a linkage with a number of issues discussed in nursing literature over the years. These include nurse-patient advocacy (Johnstone, 1989), the rights of individuals to informed consent provided under the Code of Health and Disability Services Consumers' Rights Regulations (1996) and the leading role nurses have had in developing new approaches to pain management programmes for acute pain and cancer associated pain. (McCaffery & Beebe, 1989).

In particular, realisation of the scarcity of readily accessible, comprehensive, recent information on arachnoiditis for nurses emerged. A search of the international literature on Medline and Cinahl, the literature available from ASAMS and sources referenced in other articles, did not find any published, researched nursing studies on arachnoiditis. Study of nursing texts available to the researcher through university and hospital libraries did not discover any nursing information explicitly about arachnoiditis. Nor was knowledge of the symptoms much more readily accessible in the medical literature and crossover links between the arachnoiditis literature and the literature on central pain syndromes were not found. These gaps confirmed the need for an exploratory descriptive nursing research study to provide a base on which to build further research. The choice of this topic was thus spurred by the request of those who experience the symptoms and by 'curiosity and compassion' (Rogers, 1970) on the part of the researcher.

Choice of a Rogerian Nursing Framework

This study, in seeking to explore and describe the symptoms and experiences of people who believe themselves to have arachnoiditis, requires a theoretical perspective that can encompass analysis of the descriptions revealed at interview within a nursing framework. People who believe themselves to have arachnoiditis are usually community-based, not hospitalised, and a framework that encompasses the open systems within which they live, such as family and community systems, enables the nurse to work from the person's perspective to maximise potentials within their individual life circumstances. Such a framework is provided by the science of unitary human beings (Rogers, 1970, 1980, 1986, 1988, 1990, 1993, 1994), which gives nursing an organised, abstract system encompassing people and their environments (Rogers, 1986).

Wider applications of the study results.

It was felt by members of ASAMS that the descriptions arising from an exploratory descriptive study could be used both as an educative tool for themselves, their families and friends and for health professionals who are eager to help but have little available information on which to base their care. The findings of a descriptive exploration framed within the science of unitary human beings is seen as being able to meet this goal and to provide professional nursing knowledge that is both independent of, and yet complementary to, medical diagnosis and treatment. This will hopefully open the way for innovative, mutual care options for an erstwhile ignored problem that seems to be largely considered incurable and intractable.

The participants

Of the eleven participants, eight were men and three were women, ranging in age from their early thirties to early seventies. They came from a wide range of work backgrounds. All the participants, except one, are in an ongoing relationship with a partner. All the participants have children from either their current relationship or previous ones and all but three of the participants currently have children living at home. Two participants are in part-time paid employment, one is self-employed, one is retired, and the others are involved in various voluntary organisations. All are members of ASAMS and, at the time of entry to the study, all believed they had arachnoiditis. The following historical data was revealed at interview. Participants were asked if they had a confirmed diagnosis, whether it had changed over time, how long they had had symptoms and whether those symptoms had changed over time.

Brief introduction to participant's histories.

Participant's recounting of the events they relate to the development of their back problems, including arachnoiditis, did not always clearly fix events to dates. For some participants the sequence in which events happened was given, but only vague dates. Others, who had accessed their old hospital notes, were able to be more specific with dates, which have been included in the data. They related the following histories at interviews.

Greg

Greg officially injured his back at work by twisting as he stood up but he inclines to the view that he initially injured it during a rugby match during his teenage years. Since that time he has had several exacerbations of low back pain, for which he was treated with bedrest. He had a myelogram in 1983. He has not had any surgery. Most recently, he has been told that his lower lumbar discs have degenerated and that this is affecting the exiting nerves leading to his legs.

Jack

Jack had a rugby accident in 1986 that compacted his neck down into his shoulders and compressed the vertebrae. Initially told he was a *"nutter,"* he was eventually found to have a cervical bone splinter, which was removed during surgery in 1987. Surgery relieved the headaches, dizzy spells and tendency to collapse and fall and he returned to full time work. In 1988 he suffered another accident at work when a heavy piece of machinery fell on him, causing lumbar back pain. His symptoms were initially thought to be *"in his mind"* but were eventually diagnosed as two collapsed vertebrae. After a spinal fusion in 1989, he was told he has large areas of scar tissue at the lumbar injury/surgery site. Jack has had two myelograms, one of which required seven attempts to insert the needle. He does not know which radiological contrast agents were used for his tests. Jack has not asked his doctor about arachnoiditis, despite deterioration in his mobility, for fear of being disbelieved again.

Jane

Jane had an accident in 1986, in which she slipped over. Despite the pain, she continued heavy lifting in her work at the time. Eventually, the pain became so severe she could not straighten up properly. She gradually decreased her hours of work from full time down to none because the pain down her leg was so severe. Jane now feels she was *"a fool"* and should have *"given in"* earlier. She attended physiotherapy and a rehabilitation programme and then had a myelogram in which the radiographic contrast Iopimiro (Appendix One) was used. This showed a prolapsed disc. Two weeks later, she had a laminectomy. The pain was relieved for three months after surgery but sciatic pain returned as her mobility increased. There has since been an increase in *"deferred"* [sic] pain and the onset of headaches and weakness in the legs, leading to a clinical diagnosis of arachnoiditis by her operating surgeon and her general practitioner. She has never had a Magnetic Resonance Imaging (MRI) scan because ACC does not fund a *"peace of mind"* diagnosis. Jane also has a diagnosis of fibromyalgia.

Jim

Jim's problems began in 1980 when he suddenly found himself unable to get out of bed one morning. He could not relate this to any particular movement or trauma. He was given a series of hydrocortisone injections in the spine, and a laminectomy for *"jammed nerves"* in 1981. Five weeks after his laminectomy, he was in a car accident. No x-rays were taken at this time because he said he felt all right. Between 1981 and 1986, he had two myelograms for investigation of back pain, in which the radiological contrasts used were Pantopaque (Myodil) for the first and metrizamide for the second. In 1986, Jim had a bone graft to his spine. During this surgery they *"nearly lost"* him because of excessive bleeding and difficulty *"getting in"* to the site because of large amounts of scar tissue. His symptoms were much worse after that surgery and he was unable to walk far because of a tendency to collapse. In 1989 he had further bone grafts and a metal implant in the lumbar spine area, which was replaced in 1993 with a titanium implant. No mention was made by any of the operating surgeons of the possibility of arachnoiditis. He subsequently discovered that an MRI he had had in 1989 in the United Kingdom had confirmed a diagnosis of arachnoiditis. Since 1986, he has also been told he has arthritis, fibromyalgia and raised cholesterol and blood pressure. He was also admitted to a psychiatric ward at one period because his doctor at the time attributed his symptoms to depression. At the time of interview he was being investigated for either *"tuberculosis"* or *"a blood clot on the lungs"* for chest symptoms occurring after a long air flight overseas.

Mary

Mary was left holding the full weight of a heavy person when a hoist broke, leaving her with a sudden pain, like a *"broken arm*", in a very localised area of her back. She received epidural steroids for pain management, after which she had sciatica down one leg. In 1989, she had surgery, with improvement for about six weeks, followed by loss of function and numbness in her legs. The *"broken"* sensation continued. A second series of epidural steroids was followed by a sensation of burning. Surgery in 1990 showed webbing and scarring that she, as a result of her reading on the subject, considers indicative of arachnoiditis but she has not had this clinically or radiologically confirmed. Although her current diagnosis is nothing more definitive than *"chronic back pain,*" she reports being told she will become paraplegic.

Mick

Mick, prior to 1983, had a truck accident, after which he immediately went back to his work, which involved heavy lifting, because he *"felt all right."* Next morning, his back *"started to play up."* In 1983, he was injured when he jumped off the back of a truck and *"squashed the vertebrae."* He had a period of traction in hospital and bedrest for three months at home while waiting for a Computed Tomography (CT) scan, eventually opting for a radiculogram in 1984 because there was less of a waiting list. In September of 1984, he had a laminectomy for a large lumbar extruded disc fragment. This improved his walking but left continued pain in his back. He was given psychotherapy, which he considered inappropriate. His current diagnoses are tinnitus, sugar diabetes, and old back injury.

Paul

Paul has had no injury that he recalls. In 1987, he had a laminectomy L2-5 for *"a lot of back pain"* over the previous two years that his G.P., physiotherapist, chiropractor and acupuncturist had been unable to relieve. His operating surgeon said a disc had clamped off his spinal cord and without surgery he would be in a wheelchair in a few years. He had a myelogram prior to the surgery. Surgery went well and he healed *"beautifully."* In 1993, he visited his doctor because of deteriorating mobility. An MRI report stated that *"the appearance is highly suggestive of post-operative lumbar arachnoiditis."* In 1997, he had a worsening of his mobility, accompanied by a tendency to fall and he now uses a walking frame. He has been advised against further surgery.

Rose

Rose's original injury was in 1987, when she had an accident while carrying a heavy wood basket. This was diagnosed as a prolapsed disc, with 15% disability. Her first intervention was a steroid injection of Depo Medrol in 1989, after which there was a permanent sensation of cramp in one leg, with increased mobility problems. A subsequent CT scan showed the nerve root to be grossly enlarged and she had surgery for nerve root decompression. A second series of steroid injections in 1994 was followed by the development of an arachnoid cyst. Rose has had a diagnosis of arachnoiditis from some doctors, but not from others. She also has a diagnosis of osteoarthritis in both knees.

Terry

In 1973, Terry had an operation for hiatus hernia, in which a lower rib was removed to gain access to the operation site. After this surgery, he had a major reaction to the iodine skin paint used and developed a raw, weeping rash. In 1978, he had *"quite a big fall"* at work, which split his sternum open when he landed on his back on the breathing apparatus he was wearing. He had another fall in 1987, in which his feet were knocked straight out from under him and he landed on his *"bum and compacted my coccyx."* Two months later, after a briefly successful epidural steroid injection for pain relief, he was invalided out of his job.

Tom

Tom has had five surgeries since 1979, when he deflected a piece of heavy equipment that fell off a crane on to him. He was initially told by one specialist that his symptoms were due to spondylolisthesis and by another that he would come *"right"* in twelve months. In 1982, after no improvement, he had a laminectomy for *"compressed L3, 4 & 5,"* followed eight months later by a second laminectomy. Tom is unclear about the exact dates but in about 1984 he had a *"double sided fusion."* This fusion was broken during an x-ray in 1985, followed by a *"triple fusion"* which left him with loss of the use of his right leg, a *"drop foot"* and some numb areas. Further surgery in about 1987 has been followed by increased problems with his mobility. In 1993 he was given a diagnosis of arachnoiditis, which was shortly afterwards rescinded in favour of psychological explanations. In 1996, the conclusion from an *"expert in the field"* was that he is totally paralysed from the thoracic region down. In 1997, one month before interview, he was given a confirmed diagnosis of adhesive arachnoiditis. Tom's health has continued to worsen and he was too unwell for a second interview to take place.

Will

Thirteen years ago Will fell backward from a height at work, landing on his back on a pile of metal rubbish. An x-ray at that time showed no damage but his back continued to be sore afterwards. He had physiotherapy and acupuncture without relief and then had a myelogram with metrizamide dye after which *"chemical meningitis"* developed. He was hospitalised for five days. He has subsequently developed a number of so far unexplained symptoms and currently has no diagnosis to explain those in his back. He has had no surgery.

Chapter Two: What is arachnoiditis?

Introduction

This chapter reports on the results of examination of the literature and gives consideration to historical background, pathological and pathophysiological changes associated with arachnoiditis, etiological factors, epidemiology, methods of diagnosis, differential and associated diagnoses, prognosis and medical treatments. Only brief reference is made to clinical presentation in this chapter, as symptomatology is dealt with in more detail in Chapter Five.

Anatomy

Arachnoiditis is defined simply as 'inflammation of the arachnoidea' (Dorland, 1988). The arachnoidea, more commonly referred to as the arachnoid membrane, is a delicate, avascular membrane which envelopes the central nervous system. Composed of fibrous and elastic tissue, it is superimposed between two vascular membranes, the dura mater and the pia mater. Scanning electron microscopy reveals that the normal arachnoid membrane has a fenestrated surface embossed with parallel fibres (Guyer, Wiltse, Eskay & Guyer, 1989). The name 'arachnoid' refers to the similarity of the arachnoid membrane to the fine, closely woven webs spun by some spiders. The pia mater, the arachnoid membrane and the intermediate subarachnoid space are together considered as a functional unit known as the leptomeninges.

Historical perspectives

Arachnoiditis has been a recognised disease entity since the turn of the century. At that time, it was largely associated with infections such as tuberculosis, viral and bacterial meningitis, and syphilis (Long, 1992; Jackson & Isherwood, 1994). Arachnoiditis associated with infections tended to occur in the thoracic and cervical regions and had a relentlessly progressive course, leading to paraplegia and death (Bourne, 1990; Guyer et al., 1989). The introduction of antibiotics reduced the risk of arachnoiditis from infection (Long, 1992), although there has been a recent increase in cases associated with spinal tuberculosis in Western countries with high immigration rates from countries such as India (Chadwick, Cartlidge & Bates, 1989). Tuberculous spinal arachnoiditis is still an important clinical problem in India (Phadke, Kohli, Jain, Gupta, Kumar & Gujral, 1994). It is now recognised that the vast majority of cases seen today are iatrogenic cases associated with diagnostic and/or surgical intervention (Burton, 1978,1985, 1991; Guyer et al., 1989; Grahame, Clark, Watson & Polkey, 1991; Johnson, Ryan & Roche, 1991; Long, 1992; Dolan, 1993; Laitt, Jackson & Isherwood, 1996).

Since medical recognition of the condition, there has been confusion as to what should be called arachnoiditis, its relationship to myelography and spinal surgery, the frequency with which the disease occurs and with its diagnosis (Long, 1992). Termed adhesive spinal arachnoiditis in 1927 (Long, 1992), it has also been known over the years as chronic spinal meningitis, granulomatous meningitis, lumbar radiculopathy, meningeal inflammation, aseptic meningitis, chemical arachnoiditis (Arachnoiditis, 1996), meningitis serosa circumscripta spinalis (Guyer et al., 1989) and sclerosing spinal pachymeningitis (Walton, 1985). The older term 'pachymeningitis', associated with infectious origins such as syphilis and tuberculosis, referred to involvement of both the dura and the arachnoid. Most commonly today, it is termed chronic adhesive arachnoiditis (Long, 1992) or chronic adhesive spinal arachnoiditis or CASA (Grahame et al., 1991). Seigfried (1990) uses the term lumbo-sacral spinal fibrosis. The majority of the modern literature centres around adhesive arachnoiditis in the lumbar region and makes little mention of occurrence in higher regions of the spine.

Pathology

Arachnoiditis involves a non-specific, inflammatory process which gives rise to an exudate involving the leptomeninges and nerve roots. The avascularity of the arachnoid is thought to prevent the eradication of the fibrous bands that proliferate during the second stage of the inflammatory process. Fibroblast proliferation then gives rise to fibrosis and hyalinization of the arachnoid membrane, which becomes thickened and adherent to both pia and dura mater. (Laitt, Jackson & Isherwood, 1996). Changes range from clumping of nerve roots and blunting of nerve root pouches to multi-segmental transverse obliteration of the subarachnoid space. Atrophic, devascularised nerve roots become enmeshed in scar tissue (ibid). In advanced cases, a surgeon will encounter a nonpulsatile mass of matted nerve roots and a partial or complete block of spinal fluid flow (Dolan, 1993). In the majority of patients studied by Burton (1978), loculated cysts containing spinal fluid and/or Pantopaque were present. When large, these cysts can compress local nervous tissue. Small areas of calcification commonly occur within the collagenous tissue (Long, 1993).

Pathophysiology

It is only relatively recently that techniques for studying pathophysiological mechanisms have been available. Walton (1985) notes that spinal cord compression, such as that linked to excessive scar formation in the spinal canal, affects the cord in several ways, indicating that a number of neuropathophysiological mechanisms may be involved. Overt pressure may interfere with conduction in spinal roots and in the cord itself. Pressure on the ascending longitudinal veins may lead to oedema in the cord below the site of compression. Compression of longitudinal and radicular spinal arteries may lead to ischaemia of the segments of the cord they supply. These vascular disturbances possibly create a local oedema and/or degeneration of ganglion cells and white matter. Areas of softening may develop (myelomalacia). Obstruction of the subarachnoid space can interrupt the flow of cerebro-spinal fluid (CSF). CSF can become trapped in small cavities (loculation) with changes in its composition.

The role of CSF in cord nutrition and the correlation of the resultant malnutrition with the presence of symptoms was not discussed in any of the literature examined. Pathophysiology associated with interference in CSF flow in arachnoiditis was noted as significant in the development of syringomyelia subsequent to arachnoiditis (Klekamp, Batzdorf, Samii & Bothe, 1997), in which impaired CSF flow is believed to initiate a series of events that ultimately lead to an increase in the extracellular water content of the spinal cord. This fluid is visible within a cavity in the spinal cord itself. Usually thoracic, it is associated with progressive symptoms and can be relieved by surgical procedures. As such, this late pathophysiological development in some people with arachnoiditis requires recognition.

Walton (1985) saw the association between cord compression from the scarring and the experiencing of symptoms as probably less important in itself than the ischaemia related to interference with the blood supply of the cord. Guyer et al. (1989) cited studies drawing an analogy with cancer in which the condition is painless unless a nerve is entrapped against a rigid structure or interferes with vital organ function. Most recently, Burton (1997) attributed the pain of arachnoiditis to a nutritional, vascular nerve impairment of variable severity induced by the encapsulating collagenous scar tissue creating neural tissue anoxia similar to that associated with causalgia.

Research into central pain syndromes investigated the importance of the thalamus, the significance of lesion location and changes in membrane receptor function (Casey, 1991), and deficiencies in Aß-mediated inhibition of denervation sensitivity, and the role of substance P (Price, 1991) in pain that appears to have no direct correlation to, or immediate relationship with, an injury. No literature was found that specifically considered central pain syndromes in arachnoiditis.

Aetiology

Aetiology is a medical term relating to the study or theory of factors that cause disease and the method of their introduction to the host; the cause(s) or origin of a disease or disorder (Dorland, 1988). In a minority of cases, the development of arachnoiditis can be idiopathic, with an increased likelihood of misdiagnosis (Vloeberghs, Herregodts, Stadnik, Goossens & D'Haens, 1992). Roeder, Bazan and Jinkins (1995) report the development of arachnoiditis after the rupture of a spinal dermoid cyst. The most clinically apparent pathological forerunners of arachnoiditis have been a progressive, inflammatory reaction of the pia-arachnoid to infection, such as pyogenic syphilis and tuberculous leptomeningitis. Arachnoiditis may also be an associated complication of spinal stenosis (Jackson & Isherwood, 1994) or may arise from an exuberant reaction to meningeal injury as part of the normal reparative process (Smith & Blaser, 1991).

A number of situations related to the iatrogenic factors in arachnoiditis development are recognised. Burton (1978) related the development of arachnoiditis to a combination of etiologic factors initiating and maintaining a progressive inflammatory reaction, usually in relation to a herniated disc, amplified by the presence of blood and an irritative foreign body substance (such as Myodil/ Pantopaque) in the subarachnoid space. While Guyer et al. (1989) felt repeated trauma at the site of a protruded disc could lead to localised arachnoiditis in the absence surgery or myelography, Jackson and Isherwood (1994) found no evidence to substantiate an aetiological linkage between disc prolapse per se and arachnoiditis. Arachnoiditis has been shown to occur after extradural lumbar disc surgery independent of myelographic contrast media use (Fitt & Stevens, 1995).

The precise role of myelographic contrast agents continues to be debated. Known commercially as Myodil in Commonwealth countries and Pantopaque in the USA, iophendylate (see Appendix One) has been suspected of toxicity since the 1940's. Since that time there has been an increasing recognition of the relationship between iophendylate and lumbo-sacral arachnoiditis (Burton, 1978). Burton (1991) continues to maintain that iophendylate is the single, most significant, toxic agent in the development of lumbo-sacral arachnoiditis. Others maintained that there is no evidence that a single case of chronic arachnoiditis can be attributed solely to Pantopaque (Peterson, 1976). In Britain, evidence is also felt to be lacking that Myodil alone leads to arachnoiditis (Jackson & Isherwood, 1994). Research there indicated that adhesive arachnoiditis tended to centre on the level of surgery, suggesting synergy between Myodil and surgery (Laitt, Jackson & Isherwood, 1996) and concluded that adhesive arachnoiditis is a rare complication of Myodil myelography alone but that exposure to Myodil dramatically increases the incidence of adhesive arachnoiditis when other risk factors are present (ibid).

Disagreement also continues over the role of water soluble contrasts, some authors declaring that, without any doubt, water soluble contrast media for myelography may produce arachnoiditis (Jorgensen, Hansen, Steenskov & Oveson, 1975) and others believing the side effects are only significant in the immediate period post-myelogram. Long (1992) found no evidence to suggest that the incidence of arachnoiditis has reduced since the introduction of water soluble agents, particularly the early ones, which were all as reactive, or more so, than Pantopaque. He sounds a note of caution for those making any predictions that newer agents, such as metrizamide, can definitively be declared safer. Even so, Long (ibid) believes the paucity of reported cases in the literature in the face of millions of myelograms done throughout the world suggests that the actual incidence of symptomatic arachnoiditis related to myelograms alone is less than 1%.

The reasons why arachnoiditis develops in some individuals, and not in others, remain unclear. The role of autoimmune factors has yet to be established but may be important (Burton, 1994; Guyer et al., 1989). There is the possibility that this process only occurs in those who have a fibrinolytic defect, affecting fibrotic processes which are self-limiting in most cases, but which potentiate in others. Research in England is reported as focusing on the nature of the abnormal scar tissue and factors leading to its development, as well as on abnormal amounts of substance P production in those with arachnoiditis (Jayson, Information sheet). The Fact Sheet (Arachnoiditis - questions, 1994) produced by the Back Pain Association of America and the Arachnoiditis Trust of Great Britain leaflet (Arachnoiditis Trust Leaflet, undated) declare that arachnoiditis is an autoimmune disease but offer no supporting references for this assertion.

Recently, concerns about the role of epidural anaesthesia and analgesia in relation to the subsequent development of arachnoiditis (Arachnoiditis: What is, 1996) have been voiced. Reasons for the development of arachnoiditis after epidural administrations are unclear, with possibilities including unintentional injection of drugs into the CSF, use of large volumes of anaesthetic causing temporary compression ischaemia, the action of vasoconstrictors such as epinephrine, and the effect of contaminants such as parabens (Rosenberg & Stacey, 1996). Epidural Depo-Medrol, while it can be effective for the treatment of pain continuing despite back surgery (Shipton, 1989), is implicated in the development of arachnoiditis. There is the suggestion that the polyethylene glycol Depo Medrol contains is the likely irritant responsible (Nelson, 1993; Johnson et al., 1991). The makers state in their product information data sheet that Depo Medrol is not recommended for intrathecal use.

Epidemiology

The actual incidence and prevalence of arachnoiditis is not known. Burton (1994) reported that very little incidence and prevalence data has been accumulated. If studied per se, arachnoiditis would probably be common, since it occurs as a normal response to traumas and infections in the subarachnoid space (ibid), making arachnoid adhesions a very common entity that typically are of no clinical significance (Burton, 1997). Opinion on the incidence of symptomatic arachnoiditis varies. Danish authors in the seventies described chronic arachnoiditis in the spinal canal as a rather well known condition (Jorgensen et al., 1975). Burton (1991) considered arachnoiditis to constitute 11% of failed back surgery syndrome patients since 1981. Using extrapolations from United States statistics of spinal surgeries performed per annum, this indicates 1,659,090 cases of lumbo-sacral arachnoiditis worldwide (Burton, 1997). However, variably long latency periods and confusion with other conditions, particularly concurrently present spinal stenosis, confuse the issue and lead to delays in diagnosis (Long, 1992). Improved surgical and radiological techniques should have decreased the potential incidence (Burton, 1997) but this view requires balancing against the speed with which countries adopt new, safer technology and surgical techniques, the increasingly frequent use of epidural anaesthesia and the ongoing use of intrathecal and epidural steroids and other medications. In areas without access to advanced imaging techniques, the most important measure in reducing the incidence of arachnoiditis development is the avoidance of routine myelography prior to surgery (Dolan, 1993). Dolan (ibid) maintains that recognition of the clinical picture associated with classical lumbar disc protrusion and the findings of physical examinations should be sufficient to make a diagnosis indicating the need for any surgery.

Diagnosis

The wide range of opinions as to which clinical signs and symptoms may properly be considered to be those of arachnoiditis, and the possibility that arachnoiditis has been used as a scrapheap diagnosis for failed back surgery (Burton, 1978, 1985, 1991; Shipton, 1989), has meant that a diagnosis of arachnoiditis, if not confirmed by direct surgical observation, has often only been considered valid when radiological evidence was present. It is ironic, therefore, that myelography has been both the test by which the diagnosis must be confirmed and the procedure implicated in its development.

Radiological evidence consists of radiculographic/myelographic findings of obliteration of nerve root sleeves, and/or thickening of nerve-roots, and/or irregular distribution, fixation and/or loculation of contrast medium (Grahame et al., 1991). Myeloscopy has been recognised as having a valuable but limited role, particularly in avoiding unnecessary surgery when CT myelogram is not diagnostically conclusive (Peek, Thomas & Wiltse, 1993). MRI is now the most commonly used diagnostic tool (Laitt, Jackson & Isherwood, 1996). The noninvasive evaluation it offers is considered to excel at both diagnosing arachnoiditis and minimising the need for invasive procedures, which might potentiate its development (Gundry & Fritts, 1997). Advances in MRI permit recognition of mild or even minimal cases (Fitt & Stevens, 1995) at a level of near perfect agreement between myelographic and MRI diagnosis. A lack of correlation between the severity of radiological change and clinical status (Jorgensen et al., 1975) has led to the belief that the essential assessment in diagnosing arachnoiditis must be clinical (Johnson et al. 1991), supported only if necessary by radiological evidence.

Differential and/or associated diagnoses

There are a number of conditions various authors believe need to be differentially considered. These include cauda equina claudication, prolapsed intervertebral disc, failed back surgery, prolonged postoperative pain, recurrent prolapsed intervertebral disc (Shipton, 1989), disc herniation (Johnson et al., 1991), spinal stenosis (Long, 1992), spinal cord atrophy (Donaldson & Gibson, 1982), spinal intradural arachnoid cysts (Kriss & Kriss, 1997) and multiple sclerosis (Arachnoiditis, 1996). Other concomitants of arachnoiditis requiring differential diagnosis include syringomyelia, (Guyer et al., 1989; Brammah & Jayson, 1994) and calcific or arachnoiditis ossificans (Kitagawa, Kanamori, Tatezaki, Itoh, & Tsuji, 1990; Toribatake, Baba, Maezawa, Umeda & Tomita, 1995). Differential diagnosis is considered necessary because arachnoiditis may be masking other more treatable pathologies (Grahame et al., 1991).

Prognosis

Studies of arachnoiditis occurring in the lumbo-sacral region have tended to be short term with little followup (Guyer et al., 1989). A longer study (ibid) followed fifty patients for ten years, and concluded that the natural course of the disease was mildly progressive in only a few, and that increased neurological deficits were more frequently linked to surgical intervention than to arachnoiditis itself. For the majority of people, the symptoms, disabling and painful though they may be, would wax and wane over the years without clear evidence of progression. People may function well in a sedentary lifestyle but few would return to full-time work. Alcohol and drugs could become a problem for some. Authors who mention prognosis tend do so in terms of incurability (Shipton, 1989; Guyer et al., 1989). The pain is mentioned as disabling and intractable (Guyer et al., 1989) or ineradicable (Shipton, 1989). Johnson et al., (1991) recognise the temptation to assign these patients to an untreatable category, with few practitioners feeling able to look after them. The poor prognosis may be a reflection of the lack of consensus over appropriate treatment for arachnoiditis, which mirrors a divergence of opinions over the management of neurogenic pain (Davies, Crombie & Macrae, 1993).

Treatment for arachnoiditis

A number of possible treatments have been researched and attempted. Pharmocological approaches include d-Penicillamine (Grahame et al., 1991) and epidural administration of bupivacaine and methylprednisolone, clonidine, buprenorphine, morphine, and intrathecal baclofen, combined with psychological support, evaluation and psychotherapy (Shipton, 1989).

The operative approach remains controversial. Dooley, McBroom, Taguchi and MacNab (1988) found that those with arachnoiditis posed a special problem, with a poor response to surgical intervention. Carroll and Wiesel (1992) noted that no surgical technique has been proven successful in either eliminating the scar tissue or significantly reducing the pain. Dolan (1993) considered that when all other approaches had been exhausted, any surgical treatment that offered a chance of improvement, even if for a variable time, might be justified, at the same time emphasising the expertise needed for such surgery if the situation was not to be worsened.

Tasker, DeCarvalho and Dolan (1992) noted that steady pain, the most common type suffered by people with cord central pain, the type present in arachnoiditis, responds poorly to destructive surgery and better to chronic stimulation of the cord or brain, which induces paraesthesia in the area of pain. However, this technique is recognised as only working in a relatively small proportion of patients (Martin & Yuan, 1996). Overall, the results of many surgical treatments have been discouraging, and are now reserved for specific circumstances, such as acute cauda equina syndrome and syringomyelia.

Clinical presentation

Previous literature reports that clinical presentation ranges from nonspecific back pain to definite signs of radiculopathy or myelopathy (Rosenberg & Stacey, 1996). Radiologically evident arachnoiditis can be asymptomatic (Johnson et al., 1991). Arachnoiditis occurs most commonly in the lumbar spine (Guyer et al., 1989) but can also occur in the cervical and thoracic regions, either from primary traumas in those areas or ascending from lumbar origins. Clinical presentation varies accordingly. The symptoms detailed in clinical presentation are the aspect of medical writings most pertinent to this study. They have, accordingly, been considered separately in Chapter Five.

Chapter Three: Theoretical rationale - the Science of Unitary Human Beings and arachnoiditis.

Introduction

This study, in seeking to explore and describe the symptoms and the experience of living with those symptoms in everyday life, requires a theoretical perspective that can encompass the descriptions revealed at interview within a nursing framework. Such a framework is provided by the science of unitary human beings (Rogers, 1970), which gives nursing an organised abstract system encompassing people and their environments (Rogers, 1986). Within this system, it is the nurse's role to work with people in a mutual process to maximise potential well-being throughout their lives.

Martha Rogers, 1914-1994: a brief biographical note.

Martha Rogers, Professor Emerita at New York State University, Doctor of Nursing, Doctor of Physics and holder of nine honary doctorates, advisor to the NASA space programme, is proclaimed by those who support her work as a nurse visionary, prophet and risk taker (Barrett, 1994). Prior to 1970, Rogers' works concerned themselves largely with the need for a change in the education of professional nurses (Rogers, 1961, 1963a, 1963b, 1964), with a reiterated insistence that preparation for professional practice required a nursing programme with its own university based faculty leading to qualifications comparable to those of other faculties. Rogers (1970) then published a seminal work proposing the science of unitary human beings as a fundamentally new framework for a scientific knowledge base that was unique to nursing and on which education in such a faculty could be based. Concepts and principles were subsequently further refined and developed by Rogers (1980, 1986, 1988, 1990, 1992, 1993, 1994) to maintain internal consistency within the framework and congruence with new scientific thinking, such as chaos theory. Often spoken of as Rogerian science, the science of unitary human beings provides a scientifically based framework allowing nurses to express new thoughts and to develop new ways of creatively practising their profession. Both during Rogers' lifetime, and since her death, colleagues, known as Rogerian scholars, have undertaken basic and applied research to test and develop principles and theoretical perspectives so as to expand the growing body of nursing knowledge framed within the science of unitary human beings. Such development was considered by Rogers (1986) to be a never-ending process, providing nursing with an organised abstract system encompassing people and their environments. She maintained that research should be done in relation to theories and that theoretical perspectives should be commensurate with new realities (Rogers, 1994).

The Science of Unitary Human Beings

The science of unitary human beings as a world view utilises its own abstract concepts and principles in a conceptual system specific to nursing, (Rogers, 1970, 1980, 1986, 1988, 1992, 1994). Underpinning this conceptual system is a humane and optimistic view of life's potentials, postulated as a capacity for people to participate knowingly in the process of change, with the nature and direction of that change embodied in the principles of homeodynamics. Key concepts and principles basic to the science of unitary human beings are as follows.

Energy fields.

Energy fields are the fundamental unit of the living and nonliving universe (Rogers, 1986). Field is a unifying concept and energy signifies the dynamic nature of the field (Rogers, 1986, 1988, 1992). A field is in continuous motion and is infinite. Objects, whether living or non-living, do not have energy fields, they are energy fields (Rogers, 1992). Although there can be millions of fields (Rogers, quoted in Malinski, 1986), within the science of unitary human beings two energy fields are identified. These are human fields and environmental fields (Rogers, 1986).

Environmental fields

The environmental field is an irreducible, pandimensional energy field identified by pattern and integral with the human field (Rogers, 1992, 1994). The environmental energy field is everything within which the human energy field is embedded, including political systems, medical systems, spiritual systems and social systems. An environmental energy field is specific to its given human field (Rogers, 1986).

Human fields (Unitary human beings)

Basic to the science of unitary human beings is the unitary human being as an energy field integral with the environmental energy field. Unitary human beings are perceived as irreducible, indivisible, pandimensional energy fields identified by pattern and manifesting characteristics that are specific to the whole and which cannot be predicted from knowledge of the parts (Rogers, 1992).

Negentropy

Negentropy is the term used by Rogers to replace the concept of entropy. Entropy is a measure of disorder (Knight, 1989) within closed systems, which eventually run down. In human beings, entropy equates with inevitable death (ibid) which may be held in check for a period of time if equilibrium and homeostasis is maintained. Within a negentropic perspective, human beings are not closed systems that decay in increasing disorder. Integral with an environment of constant changes, human beings are dynamic, capable of increased order and complexity, and constantly evolving new and innovative ways to live with those changes.

Open systems

The science of unitary human beings reflects a universe of open systems in which acausality replaces causality (Rogers, 1986). A universe of open systems postulates the infinite nature of energy fields and the integrality of human and environmental fields. Energy fields are open continuously and the change manifested in them is innovative, homeodynamic and negentropic, rather than homeostatic and entropic.

Pandimensional

Pandimensional (Rogers, 1992, 1994), termed four-dimensional (Rogers, 1970, 1986) and then multidimensional (1990) in earlier Rogerian writings, is the postulate evolved to replace the three dimensional concept prevalent in older world views (Rogers, 1970). It is defined as a non-linear domain without spatial or temporal attributes (Rogers, 1992) and characterises the growing diversity of human and environmental fields in a universe of open systems. The use of a pandimensional pattern recognition creates an awareness of conscious energy patterning utilising energies from a wide range of sources.

Pattern

Pattern is the distinguishing characteristic of the human-environmental field process and manifests as unpredictable, diverse, continuous changes in pattern profiles which reflect the unique integrality of each unitary human being within their own unique environmental field pattern (Rogers, 1986). Although pattern is not directly observable, manifestations of field patterning are observable events in the real world (Rogers, 1992) visible as experiences of greater or lesser diversity, of time and motion, of greater or lesser pragmatism, imagination and vision, of longer or shorter periods of sleeping and as variations in the rhythmical patterns of life (Rogers, 1992). Field patterning not only changes over time in any individual, but also differs markedly between individuals, always reflecting how a person is in their world at any given point in time. The continual reshaping of patterns reflect the events of the past, hopes for the future and the interactions between the person and their environment in the relative present.

Pattern appraisal

In Rogerian research, pattern appraisal is the process of acquiring information and knowledge about phenomena that manifest human and environmental field patterns in a unitary context. Change is a feature of pattern manifestation. Because constant change is inevitable, it is the nature of the pattern that is important (Rogers, quoted in Malinski, 1986). Rogerian scholars have developed the concept of pattern appraisal in studies and in practice. Such appraisal must reflect the person's experiences, perceptions and expressions (Barrett, 1990). The person's expression is the reflection of the integration of their experience and perception (Cowling, 1990). Pattern appraisal is the continuous process of identifying manifestations of the human and environmental fields that relate to current health needs (Barrett, 1988).

Unitary

While Rogerian science can be deemed 'holistic,' Rogers (1970, 1983, 1990, 1994) uses the word 'unitary' instead, because of her belief that holism is a concept that has plagued a great many people unable to consider the segmented world in which they grew up as more than the sum of the parts. Rogers (1994) is adamant that one can no-more get a holistic human being by adding up the parts than a cake can be got by adding up the various ingredients and proclaiming them a cake. A unitary perspective does not focus on the physical, psychological, cultural, social or spiritual parts of a holistic person, instead viewing these aspects as open systems involving a constant mutual process of change.

The principles of homeodynamics

The principles of homeodynamics are three in number and postulate the nature of change. The principle of helicy states that there is a continuous, innovative, nonprobabalistic and increasing diversity of the human environmental field that is characterised by nonrepeating rythmicities. The principle of integrality postulates the continuous mutual human field and environmental field process. The principle of resonancy postulates pattern change and organisation of the human and environmental fields as a symphonic life process of rhythmical variations, in which people are united with the rest of the world in a resonating wave of complex symmetry.

Arachnoiditis and the science of unitary human beings

In light of Rogerian concepts and principles, it is clear that there are major incongruities and inconsistencies between a disease orientated medical framework relating to arachnoiditis as set out in chapter two and a nursing study framed in Rogerian science. Within a Rogerian framework, disease symptoms need to be placed within a perspective focusing on the experience of unitary human beings integral with their environment. Entropic concepts, such as incurability and intractability, can then be considered in a negentropic way that highlights life's potentials.

Chapter Four: Research methodology.

Introduction

Chapter One introduced the aims and objectives of the study, discussed the background to the research and briefly introduced the participants. Chapter Two provided information on arachnoiditis. Chapter Three introduced the theoretical framework for the study. Chapter Four provides the rationale for the choice of an exploratory descriptive methodology, briefly revisits the research context in relation to the background to the study and sets out the processes of the research, including ethical considerations, access to participants, care of the research data and data analysis.

The aims of exploratory descriptive research

Nursing research which seeks to enhance nursing practice needs to be science based and to use substantive nursing knowledge developed through logical analysis and quantitative and qualitative modes of inquiry (Barrett, 1990). When undertaken to shed light on an area about which nursing has little theoretical or factual knowledge, an exploratory descriptive methodology is appropriate (Abdellah & Levine, 1965). Such a qualitative approach, in which the researcher can use intuition and insight to explore what is there, meanings attached to the discoveries, and how these can be organised (Cormack, 1991), provides an avenue for exploring patterning by elucidating the characteristics of an experience from the participants themselves (Malinski, 1991b). Exploratory descriptive studies are never a final product (Abdellah & Levine, 1965), simply a first step from which further research can branch out to look at particular aspects of the situation, refine initial knowledge or look at the effectiveness of the various therapeutic modalities used in nursing practice.

Exploratory descriptive research and a Rogerian framework

Research designs that generate descriptive knowledge are seen as relevant to studies based in a Rogerian framework (Cowling, 1986). This methodology provides a qualitative methodology that allows for exploration of events from a nursing perspective by seeking descriptions of those experiences through interviews with the participants (Malinski, 1991b). Reflecting the unitary nature of the researcher, the participants and the environment, self-reported perceptions and other expressions of experiences revealed to an investigator in a research situation are seen as providing nurses with critical links to an individual's unitary pattern (Cowling, 1990). The descriptions revealed within a Rogerian framework uncover features of emerging patterns. Knowledge of these patterns can then be used to develop therapeutic strategies to facilitate the negentropic possibilities of a situation in ways that enhance individual well-being (ibid). This combination of a Rogerian theoretical framework and qualitative descriptive methodology is seen by the researcher as particularly suited to a study of the symptoms and experiences related to arachnoiditis, both because so little was known about arachnoiditis from a nursing perspective, and because the literature provided a very discouraging, entropic prognosis for those with symptomatic arachnoiditis.

Research Context

This study looked at the symptoms 'associated' with arachnoiditis, not at the symptoms 'of' arachnoiditis. The distinction was considered necessary by the researcher for two reasons. Firstly, there was an awareness of the difficulties some potential participants may have had in accessing radiological tests, particularly MRI's, to confirm a diagnosis of arachnoiditis. There was a possibility that very few people in the proposed study region would have a radiologically confirmed diagnosis, thus limiting the number of potential participants. Secondly, the researcher believed that such a limitation was not relevant to a nursing study in which the person, rather than the disease, was the focus. Experiencing symptoms of such a nature that the person had come to believe they had arachnoiditis, and had become a member of ASAMS because of that belief, were therefore considered valid criteria for entry to the study.

The research proposal was shared with the ASAMS committee members, who endorsed the research aims of exploring and describing the symptoms and the experiences associated with life with arachnoiditis. They hoped the study would ultimately assist in meeting one ASAMS' aims, namely, the enhancement of professional health services' knowledge of possibilities for those with symptomatic arachnoiditis. This sharing of the aims of the research was felt to be important by the researcher because of her belief that, just as people do not exist independently of their environment, there was an artificiality in considering the research as if it was somehow independent of the lives and dreams of those experiencing what it explored. This belief, reflecting as it does the principle of integrality, is believed to be particularly relevant in the case of this research, because the suggestion that it take place on this topic initially came from those with arachnoiditis.

Locating participants

Criteria for entry to the study were membership of ASAMS, and either a confirmed clinical or MRI diagnosis of arachnoiditis or the belief on the part of the potential participants that they have arachnoiditis. While this created the possibility that some of the participants might have a spinal condition other than arachnoiditis, the researcher believed this would enhance rather than invalidate the study by allowing description of any experiences that had led such participants to believe they might have arachnoiditis.

People who have, or believe themselves to have, arachnoiditis live throughout New Zealand. WDRC had a list of addresses to which the researcher had access in her role as coordinator for enquiries about arachnoiditis, but no mandate to allow its use for the purposes of research. ASAMS had their own separate membership, which had evolved out of, but was separate from, those who had contacted WDRC. Seeking participants from among this group ensured no potential participants felt pressured in any way to take part, because the invitations to participate, and the collection of responses, was handled by an independent third party. Only the list of those who agreed to participate was passed on to the researcher.

The national secretary for ASAMS was approached and, after consultation with the ASAMS management committee, agreed to address supplied invitations to participate, and to receive and collate responses. The ASAMS members, living within the region for which Ethics Committee approval had been obtained, received an open invitation to take part in the study (Appendix Three). It was intended that a convenience sample of the first twelve respondents would be chosen. Fourteen responses were received, of whom three expressed regrets to the ASAMS secretary that, although they wished to participate, their health was so bad at that particular time that they felt they could not take part. The final sample thus consisted of eleven participants. The eleven who accepted the initial written invitation to participate were contacted by telephone by the researcher to arrange a meeting to further discuss the aims of the study. At that meeting, confirmation was gained that they wished to continue as participants, and consent forms (Appendix Four) were supplied. Informed consent, in a three step process consisting of discussion between participant and researcher, reading of the information sheet, and signing of the consent form, was obtained. All participants wished to proceed straight on with the first interview after signing, rather than rescheduling another time.

Ethics Committee Approval

Study approval was granted by the Massey University Human Ethics Committee and the Ethics Committee in the region from which the participants were to be drawn.

Ethical concerns

Because of the small pool of potential participants and the possibility that they might know each other personally, identifying data, such as occupation and age, has either been removed or the context blurred, so as to protect individual identities. Some data concerning highly personal aspects of life with arachnoiditis have been reduced to a summation, genderless where possible, to further protect identities. Because informed consent is a process (Johnstone, 1989), the right to turn off of the tape at any point during interview, and participants' rights to disallow the use of certain pieces of data, were discussed both prior to signing the consent form and during interview when particularly personal issues, such as impotency and incontinence, arose. Throughout the interviews, participants continued to affirm their willingness for their symptoms and experiences, as told to the researcher, to be used in the study. They had no concerns about data identifying them personally and would have been happy to have their own names used.

Participants frequently mentioned health professionals by name, or locations by which health professionals might potentially be identified. To protect their anonymity, these names and locations have been replaced or omitted, and specialities retained only if it was felt there was sufficient protection of the identity of the professional concerned.

Interview tapes, transcripts and data were coded by pseudonym. Consent forms and identification code were kept in a locked place separate from the tapes and transcripts. The researcher transcribed the tapes personally. Participants were given the option of having their interview tapes returned to them or wiped on completion of the study.

For participants who might have felt the need for further discussion concerning personal issues raised at interview, support was available through the field worker of the Multiple Sclerosis Society and participants were supplied with her phone number. Participants were also supplied with the researcher's and the research supervisor's contact number and contact address and the number of the regional Advocacy Service, as required by the 1996 Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations (Health and Disability Code).

Interview protocols

Symptoms and experiences were sought by means of audio-taped, face-to-face, semistructured interviews with the participants, using guide questions. Semi-structured interviews were selected as the research tool that would enable as wide a possible exploration of the symptoms and experiences participants linked to life with arachnoiditis. Interviews were held in the participants' homes, with the exception of one participant who elected to come to the researcher's home. Initially, it was anticipated that two, one-hour interviews would be required for each participant, so as to allow for rest and/or movement for those who found it difficult to remain in one place for long. In practice, some participants were able to say what they wanted to say about their symptoms and experiences in one interview. No participants formally withdrew from the study but two second interviews were not completed because of the ill-health of the participants. However, due to the integral nature of the information sought, many of the areas covered by guide questions at second interview had already been partly described in the first interview, so this was not felt to have seriously affected the study.

Data Collection Method

Face-to-face interviews were selected as the data collection method that would elicit the richest and most diverse data. These interviews were semi-structured, with open-ended guide questions (Appendix Five), leaving it to the participants to decide which of their symptoms they considered were related to arachnoiditis. There was an awareness that participants might have co-existing medical conditions, such as asthma and diabetes. These conditions could have other symptoms that also reflected in participants' life experiences. The chosen guide questions created the possibility that some symptoms linked in the literature with arachnoiditis might not be discussed because the participant did not link them to arachnoiditis, while others more likely to be medically linked to co-existing medical conditions might be associated in the participant's mind with arachnoiditis. No attempt was made at interview to validate or invalidate any of the symptoms presented as those of arachnoiditis.

Data analysis

The interview questions were centred around two aspects of the human field. The first interview focused primarily on the human field (the participant) and manifestations of pattern within that field (symptoms). The response to the inquiry as to what the word 'symptom' meant to participants was analysed. Human field patterns were explored by reading the transcripts and collating a list of symptoms given by participants as those they associated with arachnoiditis. A compilation of the descriptions of each participant's experiences of these symptoms was then prepared for each of the symptom categories and a brief description of the known pathophysiological reasons for that symptom was given. Symptom experiences were of two kinds, physical manifestations of pattern, such as pain in a limb, or unitary manifestations of the whole person, such as falling or depression. Participants' responses to the ways their symptoms had altered over time, and how they expected them to alter in future, were described. In each instance, constant reflection of physical manifestations of pattern as integral with the unitary whole was maintained by using the individual participant's words as much as possible.

Consideration was then given to human and environmental field patterns, reflected as the experience of living with those symptoms. Exploration of these experiences centred around some of the problems or difficulties participants have had in living with their symptoms and how having these symptoms has affected their family and married life, friendships, work life and spiritual life. Each participant was asked what they saw as the personal strengths that helped them to live with their symptoms and to consider, through the use of a verbal rating scale, how they felt at their best and their worst. Like experiences were collated, again using transcriptions of individual participant's words as much as possible. Participants were originally asked to identify the five symptoms that caused them the most difficulty. However, at interview they were not able to separate out their symptoms in this way, either by number or by difficulty, instead reflecting the unitary nature of human beings by seeing their symptoms as integrated experiences.

Chapter Five: Literature search - the symptoms associated with arachnoiditis.

Introduction

The literature search accessed as wide a range as possible of the writings on arachnoiditis available in New Zealand. Reference lists were used to access further literature. ASAMS permitted the researcher to use the contents of their library, thus providing access to many articles not available through interloan sources within New Zealand. These articles had been acquired through contact with American and British support groups. All the available information was reviewed to explore current understandings on the recognised symptoms of arachnoiditis.

Findings

Nursing literature on arachnoiditis is sparse. The pain literature by prominent nurse pain specialists, for example, Carroll and Bowsher (1993), Jacox (1977, 1994), McCaffery and Beebe (1989), and Watt-Watson and Donovan (1992), does not mention arachnoiditis. An initial search on Cinahl in 1996 using the keyword 'arachnoiditis' found only two journal articles. Brownrigg's (1992) otherwise informative article had only the briefest mention of the qualities of the symptoms. The other nursing article (Sadler, 1993) graphically described the pain and the difficulties experienced by a nurse after a myelogram was performed, but made no mention as to what these symptoms meant in terms of pain classification and treatment options. When visiting that keyword again a year later, Sadler's entry had been deleted and replaced by a medical journal article concerning a rare complication of arachnoiditis (Toribatake et al., 1995). In January 1998, Cinahl listed eight articles, six of which were not from nursing journals. Of the two nursing journal entries, one focuses primarily on syringomyelia. To gain a fuller understanding of the symptoms considered to be associated with arachnoiditis, it was necessary to turn to the medical literature.

International interest

Articles on arachnoiditis were found mainly in specialist medical literature, in particular radiology, neurology, anaesthesiology and orthopaedic sources, and were available in journals from countries as diverse as Russia, Spain, Malaysia, South Africa, South America, New Zealand, Scandinavia and Germany. This diversity of countries of origin illustrates the worldwide nature of the problem. Not all of these articles were available in English translation but the listings on Medline with English abstracts gave notice of the foci of interest. For example, considerable research had been done in Russia on sinus and optical complications of arachnoiditis, something rarely mentioned in Western literature, but of concern to some of those who contacted WDRC in 1995-1996.

Historical perspectives on the symptoms associated with arachnoiditis and concomitant diseases and conditions.

Symptoms have not commonly been expanded upon in the medical literature. There has been little agreement over just which symptoms can be attributed solely to arachnoiditis (Guyer et al., 1989). Abnormal morphology is not always associated with symptoms in individuals with degenerative spinal conditions (Lander, 1996), and some people with radiological changes indicating adhesive arachnoiditis may have no symptoms at all (Johnson et al., 1991). It is recognised that spinal cord damage commonly accompanies arachnoiditis (Donaldson & Gibson, 1982). People with symptomatic arachnoiditis often have a history of spinal injury, spinal surgery or surgeries, and of various invasive spinal diagnostic tests, all of which are now recognised as associated risk factors for arachnoiditis but which may also have a number of symptoms of their own. It is, therefore, perhaps not surprising that there has been a lack of agreement as to which symptoms can be attributed specifically to a particular anatomical abnormality, such as the adhesive scarring of arachnoiditis.

When considered in chronological fashion, examples of earlier research (Davies, 1956; Smith & Ross, 1959; Mason & Raaf, 1962; Howland & Curry, 1966) made no mention of symptoms at all, focusing on aetiology, or on pathology in animal and human studies.

Even into the 1970's and 1980's the focus remained on aetiology and diagnosis, making no mention of symptoms as experienced by the patient, and looking particularly at the role of myelography and contrast agents in the genesis of arachnoiditis (Mayher, Daniel & Allen, 1971; Peterson, 1976; Burton, 1978, 1985, 1991; Gelmers, 1979; Junck & Marshall, 1983; Killebrew, Whaley, Hayward & Scatliff, 1983; Elliot, Wild & Snow, 1984) or at the effectiveness and side effects of radiological procedures for diagnosis (Jorgensen, et al., 1975; Carella, Federico, Di Cuonzo, Vinjau & Lamberti, 1982).

Jorgenson, et al. (1975) noted the scarcity of reports dealing with the clinical symptoms and the lack of a distinctive complex of signs and symptoms related to either the radiological or the surgical picture of arachnoiditis and concluded that the symptoms in those with radiologically diagnosed arachnoiditis were indistinguishable from those of other chronic diseases of the lower spinal canal and were probably related to previous disc herniation and/or surgery. Burton's (1978) widely cited landmark paper on arachnoiditis dealt mostly with a description of the pathological processes of unequivocal lumbar arachnoiditis, and simply noted that the presenting symptoms were constant low back pain and/or leg pain markedly worsened by activity. Of the earlier studies available the symptoms, when mentioned, were most consistently given as low back pain and leg pain in one or both legs, sometimes mentioned as radiating down one or both legs in a mono- or polyradicular fashion.

Recent studies confirm the view that symptoms vary. This may be according to the level and/or type of arachnoiditis, which can be focal (confined to one level) or diffuse (Fitt & Stevens, 1995). This study confirmed earlier findings that there was no correlation between the severity of arachnoiditis shown on MRI and the severity of the clinical symptoms and associated disabilities. However, in noting that similar clinical features were present in a number of patients who did not have arachnoiditis, they did not state what those similarities were.

By the 1990's, when people who had arachnoiditis had begun legal action against Glaxo, the makers of Myodil and, more recently, Upjohn as the makers of Depo-Medrol, literature reviews and retrospective studies had been undertaken (Hughes &

Isherwood, 1992; Rowland-Hill, Hunter, Moseley & Kendall, 1992; Wilkinson, 1992; Nelson, 1993). While recognising that there was a large body of evidence that implicated oil based dyes, small sample sizes, incomplete records, lack of access to the cohort for adequate study and the role of pre-existing pathologies were seen as problems in reaching accurate conclusions as to the role Myodil played in the development of any person's symptoms (Rowland-Hill, et al., 1992). These authors did not delineate those symptoms.

However, during the late 1980's and the 1990's there also emerged a new focus and attitude in some arachnoiditis literature, as physicians began to report more of the effect of the symptoms on both the person and society, using words such as "a most distressing condition for the patient" (Dolan, 1993). Arachnoiditis was described as the "greatest enigma" in spinal surgery with the "ruination of productive lives at great cost to society" (Guyer et al., 1989) and as a "scrapheap diagnosis for failed back surgery" (Shipton, 1989). Failed back surgery is the term used when low back surgery fails to alleviate pain or reverse neurological deficits (Burton, 1985). Only 11% of failed backs are due to arachnoiditis (Burton, 1991), with many other failures being linked to poor or inadequate evaluation and standardised protocols leading to ill-advised surgical intervention (Burton, 1985; Calliet, 1988; Shipton, 1989). Burton (1991) described the study of foreign-body-induced lumbo-sacral arachnoiditis over the last fifty years as "fascinating but also frightening" and the condition as "constant and unrelenting" and "particularly disabling." The associated back pain is described as "agonising" (Dolan, 1993). The disease was seen as "especially cruel" (Burton, 1994), because the associated, constant, incapacitating pain so resistant to therapy occurred mostly after interventions for spinal problems at an average age of 40, thus leaving about half the person's life in "functional disarray." The "bizarre" symptoms were commonly dismissed as neurotic or functional or confused with sciatic and rheumatic conditions (Bourne, 1990; Burton, 1991).

It is the literature from the late 1980's onward that gives recognition to a clearer clinical syndrome, with characteristic complaints including burning pain in the back and lower limb and sensory disturbance (usually numbness) in the lower limbs (Guyer, 1989;

Johnson et al., 1991; Long, 1992; Brammah & Jayson, 1994). Although these descriptions still tended to be very brief., the wide variation in symptoms among individuals with confirmed arachnoiditis was recognised (Guyer et al., 1989; Bourne, 1990; Smith & Blaser, 1991; Long, 1992; Carrol & Wiesel, 1992; Burton,1997), as was the sometimes progressive neurological impairment and the disability related to the constant and incapacitating pain.

Bourne (1990) highlighted a grouping of certain symptoms that could serve as clues to indicate the presence of adhesive arachnoiditis. These symptoms, as described by patients, might include a burning sensation in the sacral area, gripping or clawing pains in the calves and ankles, severe pain down the back of one or both legs that did not match a sciatic distribution, a tingling pain in the insteps, and a burning at the inner aspects of the knees. Recognising these symptoms and their exact location was seen as important, as no other disease is linked to constant burning pain at the insteps, the inner aspects of the knees and in the lumbo-sacroiliac area (ibid). Long (1992), who between 1967 and 1992 saw in excess of 300 patients with diagnosed arachnoiditis, found no consistent clinical syndrome. 94% had back pain, aggravated by activity in virtually all. 81% had leg pain. In 40% it was radicular and in 41% it was diffuse and apparently nonradicular. 14% reported major bowel and bladder dysfunction. 94% had chronic muscle contractions and 91% had impaired range of motion of the trunk, with backward and forward bending producing pain in all. All his cases reported sensory abnormalities but this could only be demonstrated in 81%. 74% had demonstrable motor loss. Long (ibid) also enquired into functional loss and impact on daily living. 92% found a claudication syndrome limited their walking. 52% could no longer work, although their complicated back histories did not allow direct attribution of this inability purely to arachnoiditis. Only 8% did not have problems with sexual function. However, this study did not describe what the symptoms were like.

The most expansive numbers of symptoms were not found in published studies, but in news sheets or fact sheets for those with arachnoiditis. The symptoms given included constant back and leg pain; paresthesias, including burning or stinging pain, numbness, tingling in the back and one or more limbs, a tightness or banded feeling around the calves; spasms in the back, legs or feet; headaches; bladder, bowel and /or sexual dysfunction; burning and aching in the feet with a feeling of walking on rocks or broken glass; visual impairment or disturbances and, in rare cases, blindness. Spastic jumping or jerking of the limbs occurred, as well as seizures and paraplegia. (Arachnoiditis - questions, 1994; Whanganui Disablity Resource Centre, 1995; Arachnoiditis: What is, 1996; Arachnoiditis Trust Leaflet). No attempts were made to explain the reasons for the presence of any of these symptoms, a lack also apparent in the majority of the journal literature.

Burton (1994) puts forward the view that, from the 1970's onward, a real knowledge and educational void has existed, which has failed to recognise that arachnoiditis represents a serious and astonishingly little appreciated world-wide clinical problem. It is not surprising, therefore, that the Back Pain of America Newsletter (Arachnoiditis: What is, 1996) can claim that physicians and nurses do not know all the problems that arachnoiditis causes. The variability of the symptoms from person to person, the episodic nature of some, and the permanency of other, symptoms confuse the picture presented. Thoracic and cervical arachnoiditis with upper neurone involvement may be associated with a much wider and more serious range of symptoms about which very little is mentioned in the literature at all. Symptom development needs to be considered in the context of past history relating to spinal problems (Tasker, De Carvalho & Dostrovsky, 1991).

Pain emerged in the literature search as the dominant symptom and the one of most frequent concern. The presence of pain is likely to be idiosyncratic, not affecting all those with known cord lesions. Pain onset, as with the onset of other symptoms, is delayed in most cases and needs to be considered in the context of past history relating to spinal problems (Tasker, et al., 1991). The most important factor relating to the pain is consideration of the types of pain involved which, when associated with lumbar spine disease, often involves several different types of pain of neurogenic, central, and nociceptive origin (Meyerson, 1990).

Pain arising from stimulation of nerve receptors is known as nociceptive pain. Pain arising from within the nerves independent of nociceptors is known as neurogenic or neuropathic pain. The spinal pain associated with arachnoiditis is pain arising from lesions within the central nervous system and is known as central pain. 'Central pain' has replaced 'neuropathy' as the preferred term for pain arising in the brain and spinal cord (Lindblom, 1991), and is defined as pain due to lesions or disease of the central nervous system that activate central pain mechanisms (Casey, 1991). However, much variation still occurs in the usage of the various terms.

The reviewed literature rarely distinguished between nociceptive, neurogenic/neuropathic and/or central pain, although central pain is the aspect of pain management that causes the most difficulty for the person who has it and the practitioner caring for them. Bourne (1990) noted the constant burning nature of the pain as suggestive of an element of causalgia and that its poor localisation and diffuse nature linked it to central paleospinothalamic pain rather than to nociceptive pain.

However, the lack of reference to classification of the pain types involved in arachnoiditis is perhaps unsurprising in light of a report by Casey (1991), who undertook an extensive literature search on electronic sources, in major textbooks and in review articles and found very scant data on the incidence and prevalence of pain in various central nervous system diseases, with some reports failing to differentiate between various types of pain, and others using a variety of classificatory systems. Casey (ibid) concluded that pain was just not considered important enough to incorporate into study protocols in order to obtain data on the incidence and prevalence of pain and its characteristics. This is reflected in the failure of arachnoiditis literature to identify the pain as central pain and link it to spinal cord lesions.

Pain associated with arachnoiditis may also include a mixture of deafferentation, radicular, and musculoskeletal pain and the characteristics of the pain may change dramatically with time. Pain characteristics noted in the literature include steady, spontaneous, pain, intermittent, lancinating pain and evoked pain. Most of the steady pain is likely to be burning in quality, with some associated numbness and tingling. The pain may be diffusely referred to the parts of the body where sensation is affected by the area of the cord lesion, but there is also often a localised component to the pain. Concurrent musculoskeletal pain may be due to over use syndromes as people overcompensate for imbalance and mobility problems (Davidoff & Roth, 1991).

Chapter Six: Symptoms and human field patterns.

Introduction

The previous chapter examined the symptoms of arachnoiditis as presented in medical and nursing literature and noted that difficulties in determining which symptoms related specifically to arachnoiditis prevented presentation of a definitive list. This chapter describes the human field patterns revealed at interview through the process of pattern appraisal, in which participants were asked to describe the experiences and perceptions they believed were symptoms related to arachnoiditis.

A symptom is defined as any circumstance, event or condition that accompanies something and indicates its existence or occurrence (Webster, 1997). Medical terminology identifies a symptom as subjective evidence of disease or of a patient's condition (Dorland, 1988). Although symptoms are taken-for-granted concepts for health professionals, who usually consider them in particular groupings 'belonging' to a specific disease, it was not known if participants in this study understood the concept in the same way. Because this study asked participants to identify and group their own symptoms in association with arachnoiditis, the researcher felt it was important to establish just what their understanding of the term 'symptom' was in comparison with dictionary definitions. Accordingly, each participant was asked to say what the word 'symptom' meant to them. They were then asked to describe the symptoms they had that they related to arachnoiditis. Where possible, the data is presented under the names participants gave their symptoms. An overview of the symptoms has been abstracted from the transcripts and included as a symptom summary (Table 1) for each participant.

Table 1:

Summary of symptoms[*]

Greg	Low back pain; numbness and funny sensations in leg muscles; knee pain; pain in top of the foot; periodic pain in various sites up and down the back; soreness of shoulders and arms; loss of power in the hands; headaches; depression; sensation of warmth on one side of the body.
Jack	Severe fatigue, swollen glands and general malaise (diagnosed as ME); bright yellow perspiration from axilla; deep, burning pain in lumbo-sacral region; tingling in lumbo-sacral region with coldness to touch; severe headaches and knotting pain in old injury site in neck area; sciatica since surgery; numbness; pins and needles in legs on sitting.
Jane	Constant burning, stabbing pain in lower spine referring up to shoulders and into legs; sciatica; frequent, severe, explosive headaches; numbness in ball of left foot; tendency to suddenly fall; fatigue; painful joints; muscle weakness; mood changes; loss of patience.
Jim	Mini electric shocks shooting up through body; painful bones; numbness in right leg and right arm; head pains coming from back of neck to above the eyes; deep, splintered, burning pain in spine and scarococcygeal regions; pain through chest like a spear causing shortness of breath; right knee pain (diagnosed as arthritis); cramp in calf muscles; pins and needles and burning in the feet; insomnia; spasms of neck muscles preventing movement of the head; visible tightening of muscles in right lower leg; depression; overwhelming fatigue necessitating lying down for several hours; nightsweats; memory loss; swelling of joints in hands; abnormal sensations of hot and cold.
Mary	Sciatica down both legs like hot electric shocks; lower lumbar pain like an ice burn radiating out to hips; migraine headaches; pain gradually extending down the front and sides of the legs; bladder and bowel dysfunction; numbness of legs and feet; sudden falls; overweight; depression; memory loss.

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[*] excludes suicide and impotency

Mick	Dull, aching back pain at operation site; hip pain on standing too long; sciatica; leg pains; tinnitus; insomnia; pins and needles; burning feet; spasms in legs; overweight.
Paul	Mobility problems from weakness in calf muscles; lack of strength below the knees; problems with balance and falling; loss of feeling in the feet; inability of legs to hold him upright; sciatica.
Rose	Continuous, burning, cramping sensation in back and legs, extreme in the tailbone; numbness in left leg and back; giving way of legs leading to falling; bowel problems; depression; osteoarthritis in knees; premature menopause; sensation of tight band across waist.
Terry	Headaches; neck pain; back pain; numbness in left leg; sciatic pain in left leg; feeling of stone bruise on heels; burning, tight cramp in middle of upper back; left sided back pain in kidney region; sharp grabs of pain flicking down lower back, pelvis and leg on leaning forward; fatigue; sudden feeling in feet of standing on hot coals; cold sensation in left arm and shoulder; depression.
Tom	Constant, freezer burn pain from middle of back up radiating out into muscles and over shoulders; burning sensation just below rib cage; spasms and knotting up of back muscles; history of falling; numbness in lower limbs followed by gradual paralysis leading to use of wheelchair; pain in shoulders and arms; bladder and bowel problems; 'ironing board' spasms; chest pains diagnosed as angina; spasms in legs; electric shocks through body.
Will	Burning back pain; headaches; electric shocks; cough; pins and needles; numbness in various parts; burning feet; impaired healing/clotting responses; deep, internal itching; problems with heat/cold mechanisms; spasms; fatigue; swollen glands; bladder problems; impatience; jaundice; yellow perspiration; insomnia.

Participants' definitions of a symptom

Two participants did not define the word, instead offering *"mini electric shock"* and *"back pain and pins and needles."* Two participants used the word 'sign'. For one, a symptom was *"an outward sign that something is not right"* and for another, a "*sign that something is wrong.*" Three participants described a symptom as indicating something "*wrong*" with themselves - "*something's wrong*"; *" . . . what's wrong with you or what makes you think something is wrong with you"; " that there's something wrong down in there."* Two participants linked the term to what they were feeling - " *it's something that's distracting you from feeling okay"* and " *how you are feeling."* For another it was *"one of the effects of his condition."* One felt it was *"a thing that makes you aware of what is going on in your body."* Another stated it was *"probably a problem associated with the condition."* One participant summed up symptoms as "*what you'd describe."* For another, it was *"something you can relate to that you're telling someone you've got, that makes you feel unwell."*

Pain patterns associated with arachnoiditis.

This section provides a description of the symptom identified by participants as pain. It was difficult to be exclusive about the location of various pain experiences, as pain experiences in other parts of the body seem to be all related to, or concurrent with, back pain. Experiences of back pain fall into three groupings: no pain, intermittent pain, and constant, severe, remittent pain. Descriptions are presented within these three subcategories.

No pain

Paul

Unique among the participants is Paul. He has an MRI confirmed diagnosis of arachnoiditis, weakness and mobility problems in his lower legs, but no pain. He is very much aware of his good fortune in this regard.

> *I have no pain or don't suffer these horrendous things that some of the other folk* [in arachnoiditis support group] *do... I think I'm one of the lucky ones, that I've got no residual pain, really.*

He did have back pain prior to his spinal surgery, but has had none since. He worries more about a close relative, who has had four spinal operations and is still in "*quite a bad way*" with a lot of pain.

Intermittent pain

For two participants, neither of whom have medically confirmed arachnoiditis, the pain is more aching or sore than anything else.

Greg

Greg's back pain occurs in various sites *"up and down my back at different times"* with soreness of his shoulders and arms, and loss of power in his hands. There has been a change over time to his pain.

> *I actually have more pain in the back than I used to. It's sort of constantly there. I can go through a few days where I don't feel it. But then it's like this. I mean, if I stand up I get a twinge or something. Mostly, it seems to be in the back. And I'm sort of finding that now it's moved down the bottom ... there is a conclusion from the x-rays and things that the bottom disc in my*

> *back is, has completely gone. And the one above it is going. I think it's that particular second disc that's causing the pain.*

Mick

Mick's back *"plays silly buggers"* on sitting or standing for too long.

> *Always got sore hips. It just aches there all the time, sort of style . . . It's always there . . . about where I had the operation, roughly, or just below it. And round about the, just above the buttocks itself.*

This leads to restrictions in his activities. *"You know, I'm sort of growing used to it now. But if I get out in the garden for any length of time, it starts hurting worse. Or stand over the bench too long, it'll get worse."*

Severe, remittent, burning pain

Jack

Jack, with two major accidents and surgeries had, at the time of interview, a diagnosis of myalgic encephalitis (ME) but no explanation for his back symptoms. Pain was not relieved by his initial lumbar surgery, but he had thought that was to be expected after surgery and would gradually disappear. Instead, there has been increased pain and tingling. A burning area has increased in size from halfway up his buttocks, to *"above L4 to L5"* and out to the sides of his hips. The burning sensation has intensified, feeling like an *"over hot, hot-water bottle"* is resting in his spine. He cannot remember whether the burning started months or years after his surgery.

There is an aspect to his burning pain not mentioned by any of the other participants.

> *I get not only the burning sensation, but my back goes numb and cold . . . the rest of my body could be hot. I could be sitting here at night with my shirt off, with the heater on, and feeling really nice and warm, and the*

> *whole area that I've just described will be numb and cold. And the wife will put her hand on my back and she'll take her hand away, because it's so cold, physically cold. It's cold,* [but] *it feels burning. Hot burning* [but] *if you touch it, it's cold.*

Jane

Jane, whose G.P. and specialist are both convinced she has arachnoiditis, despite lack of MRI confirmation, has back pain centred over her lower spine, spreading up to between her shoulders. Her thoracic pain has a *"burning, stabbing"* quality and is *"deep in the vertebrae"* but not in the muscles around it. Although she initially said it was intermittent, she later qualified this. *"I think you learn to ignore it. You know it's there. It's there all the time. It's dull, and then it flares."*

The quality is therefore remittent, having periods of abatement without any actual cessation, alternating with exacerbations lasting two to three hours in which it flares *"like somebody with a match in there"* and becomes intolerable. In her lower back, it *"transfers over my left hip and down to my leg. It follows the sciatic nerve."* Sometimes, the pain extends outside the sciatic nerve distribution, usually as a burning pain around her knee.

Jim

Jim's back pain is constant. *"Pain's there all the time. You take it for granted."* His diagnosis of arachnoiditis was made in 1989, on MRI evidence. His back pain is all around the middle of his spine and *"sometimes it feels actually as if it's splintered."* He, too, has a burning quality to his pain, like *"a fire."* This has been with him for the last eleven years, developing gradually and spreading outward from his spine to a wider area.

"The other pain area, very much so, is the neck," along with aches and pains in his shoulders. His clavicular area is also painful *"and you can touch any of your bones* [indicating his clavicles] *and they are, in fact, extremely sore."* The pain in this area is

compounded when the back of his neck goes into spasm *"from time to time and can be very painful."*

Jim also finds the bones in both his left and right legs get very sore on walking. This is not a muscular pain, although his calf muscles do also ache. *"It's deep in the - it's definitely a bone thing and sometimes, in fact, I have to stop walking . . . x-rays have been taken and there is no abnormality on the bone scan."*

Mary

For Mary, who does not yet have any diagnosis, pain became permanent in her life after her first epidural, apparent to her from the time the local anaesthetic wore off. She describes it as like an *"ice burn"* which is *"deep,"* rather than on the surface. She locates it as *"probably the lower lumbar, and it radiates both sides. And that's there all the time. It's starting to come down the front and side of my legs."* The pain also extends up her back. *"When I move. When I use it. It's not there all the time."* It is also worse on moving her neck in any direction.

Rose

Rose, who has had a diagnosis of arachnoiditis from some doctors but not from others, has continual and severe back pain. Pain is synonymous to her with cramp. The *"muscles feel like they are going to spasm, but they are not, they're actually relaxed, because there is no lumping of the muscles."* Lying on her side worsens it by adding numbness to the experience. The pain has a constant, strong, burning quality, particularly on the left, and extends down into the pelvis, into the coccyx and into the groin.

> *Nothing gets rid of it. The cramping, the burning and just the constant - oh, there's a sharp, a very, very sharp nerve pain that goes down the tailbone and across to the hip. But it just doesn't relieve.*

There have been a number of changes over time in both the type and the severity of her pain, which she links to medical interventions. Prior to each change she thought her pain was as bad as it could get and agreed to further procedures because of assurances that the pain would be relieved by that procedure.

> *I thought I was in pain when I first had the accident. But I had no inkling at all of what pain was like. Yeah, at that stage it was, thinking back on it now, it was annoying, more than anything else.*

This pain altered markedly after her first epidural steroid injection.

> *It caused severe pain and I've never known anything like it. And I went to hospital within three months and had to be operated on. And there was no disc protrusion or anything - just the badly swollen nerve root.*

Rose had high expectations of this surgery, which aimed to decompress the nerve root. Unfortunately, the surgery did not have the expected results.

> *He said to me that he could guarantee the pain in my legs would go. But the pain at that stage was the first time I'd ever experienced the cramping. I couldn't move my leg, it was just cramped.*

Rose reflected anger and despair as she related how the doctor had promised a second lot of steroids, given in 1994, would alleviate this cramping pain.

> *The doctor had promised me that I had nothing to lose - at worst I'd be no worse than I was. At best I'd be pain free for two months . . . I'd walked into the hospital and I haven't been able to walk properly since and the pain is just - I thought I had cancer* [since the day] *of the injection. Pain that I'd never had before in the tailbone.*

Rose sought explanations for her pain and was told the nerve was dead.

> *We queried that, because in our way of thinking, if a nerve, if it's dead, why is there still so much pain? And he - the way he explained it was like a dam. You've got a dam. You build a dam and heavy rain and that, it fills up and then it overflows, and it was the overflow from the dam of the dead nerve that was causing the pain.*

This search for an explanation has led to further confusion. *"It doesn't make sense, Everyone tells me something different."*

Terry

Terry's pain varies through the day. A *"dull ache"* when he isn't doing anything, it intensifies with activity. Terry feels pain in his neck, his thoracic region, his lower back and in his left leg. He has had multiple injuries and surgeries to his spine, starting with an operation for hiatus hernia twentyfour years ago, in which a rib was removed to gain access to the site. *"I always knew I had a weak side where that rib had been taken out."* His *"burning sensation and that cramp business all comes from that area."* That *"cramp business"* refers to the burning cramp that spreads across the middle of his upper back *"by the time I've walked 10 minutes ... It just becomes like a tighter and tighter burning feeling."* He thinks falls on his back, the first nineteen years ago and the second ten years ago, while wearing breathing apparatus during his work, have resulted in further injury to the operation site. *"That burning, tightness thing that comes across my upper back just below my shoulder blades . . . that's where the breathing set was resting on my back."* Although the pain originates in his spine, he feels it primarily in the muscle tissue and finds it very hard to describe.

> *It's not like a scald burn or a hot touch burn . . . It's not like any other sort of pain I get. It's just a burning, painful sort of cramp sort of thing . . . like a crampy, burning sensation that just sort of locks up your whole upper back. But only on the back. It doesn't come round the sides, or anything.*

When he is not walking, the pain is less.

> *It's more prevalent in the left side, slightly out toward the kidney. In fact, there's some times when I think it must be a kidney infection, except that, where you've got a slight leaning forward motion, there is a definite sharp grab of pain that seems to flick down my leg and though my pelvis and lower back.*

Tom

Tom's pain had been of gradual onset, but has become a *"constant pain,"* with him "*all the time,"* and extending higher up as *"a burning sensation just below the rib cage."* This is much higher than the site of his original injury and surgery, and now involves a degree of intermittent chest pain. There has been disagreement among doctors as to Tom's diagnosis, with the medical verdict one month prior to interview finally confirming a diagnosis of arachnoiditis. With or without a diagnosis, he finds his spinal pain hard to bear and hard to describe. *"The pain is really hard to describe. When it's really bad, it's excruciating and you can't do anything about it; nothing eases it."* The quality of his pain is *"like a freezing cold burn"* coming from the spine and *"going all through your muscles around your back, and it comes right up and over your shoulders."* Tom cannot feel below his waist. *"I can only feel it from the middle of my back, up."* However, he has an awareness that many of the sensations he feels higher up his back extend from that insensate region below waist level.

Will

Will has *"lots of back pain."* As well as *"burning,"* Will describes his back pain as a tightness in which *"it's like being in a vice and somebody's doing the vice up and it just gets tighter and tighter."*

This painful sensation first occurred after a Metrizamide myelogram twelve or so years ago, after which he developed what his medical notes describe as *"chemical* *arachnoiditis."* He had gone home following his myelogram, only to become unwell during the night.

> *I got rushed into hospital in the middle of the night with, you know, I was hyperventilating, my hands were all pulled up really tight, my feet were pins and needles and I had no feeling. I was there for five days, I think. But I think it was the next night. It was the middle of the night. I woke up in pain and it felt like they had my chest and my heart and my back in a vice. It was really excruciating pain. And my vision was all funny and my hands were funny. And my feet were funny.*

Usually a dull ache he *"can live with,"* his back now sometimes gets so sore he has to stop what he is doing and rest a while. These exacerbations are similar to the vice-like pain he had at the time of his chemical arachnoiditis and are like *"a constant squeeze, tighter and tighter and tighter"* up and down his spine, including in his neck, his head and his lower back. Sometimes they last only an hour; other times they continue all night or all day *"and then they'll just go away."* This is quite different to the pain he had had initially. *"The pain in my back was way down the bottom where I actually had my fall. I think it was L3 or something, was where I hurt it."*

Will has no medical diagnosis for his symptoms *"The scan* (MRI) *says it's in real good condition, and they reckon there's no need for me to get backaches. But I get them. So?"*

Sacrococcygeal pain

Of what sounded to be a particularly excruciating nature is the pain in the sacrococcygeal area experienced by two of the participants.

Jim

Jim struggled to describe the sensations he experiences in the sacrococcygeal area of his spine. *"Pain, just pure, burn pain right the way through."* The burning *"raw, raw, raw, raw"* nature of the pain leaves him wanting *"to freeze. What ever you do, hurts."* He finds that, *"when that tailbone gets - there's just no way out of it. You've just got to wait."* He has to be wary of the type of seating he uses, preferring a La-Z-Boy chair at home.

> *And sometimes even, because this is soft really* [seat he was sitting on during interview], *I would find if I was sitting up straight, I would be putting the pressure on it. If you lie like this* [sitting slightly on to one buttock] *you put pressure off it.*

This difficulty with sitting interferes markedly with some of his activities.

> *Like, when you are driving a car, I've actually had it where, when the driver of a car, the tailbone is just fire. You just cannot, there is nothing you can do to stop it. There is no where you sit, how you sit. If you take your bum off the seat it just doesn't matter. You cannot move. You cannot move. You just take your foot off the accelerator and hold on to the wheel and lift yourself off the seat and wait for it to stop.*

He had been searching for information about it. *"I've been looking, because I don't know too much about it. I've recently learned that it's called a cauda equina"* and this knowledge has helped him access more information. He had asked his doctors but *"all I've ever got from any of them is, I don't know."*

Rose

Rose describes it as *'right in the centre of things, as if it's going to come through the tailbone"* and *" sharp, a very, very, sharp, nerve pain that goes down the tailbone and* *across to the hip."* Bad as it may be while sitting on it, for Rose, this pain is far worse when she lifts herself off her seat. Rose sometimes tries to play a game of cards.

> *Just to break the monotony and it hurts like hang but it's okay, while you - the pain in my tailbone is so bad while you are there* [sitting on it], *but it's worse trying to relieve it, take that pressure of it*

It seems to be this pain at the base of the spine that explains the sideways sitting noted at meetings with people with arachnoiditis and the need for large meeting rooms so people can lie or sit on the floor if they choose. Rose sat on a sofa with her feet tucked up beside her during her interview. Mary lay on her bed. Jim chose a soft chair and walked frequently, as did Jane, although neither she nor Mary distinguished a particular problem with pain in the coccyx.

Sciatica

Five participants experience what they term as sciatica. Medically, this term is given to a syndrome characterised by pain beginning in the lumbar region and spreading down the back of the lower limb to the ankle and, sometimes, the foot. It is most commonly associated with disc protrusion and involves little weakness and sensory loss (Walton, 1985). Sciatic pain associated with arachnoiditis can be distinguished from that associated with disc protrusion by assessing several distinctive keypoints (ibid). The onset will be more gradual in arachnoiditis, the nerve will not be tender on pressure, and a progressive muscular wasting and sensory loss will be apparent. In contrast, sciatica associated with disc protrusion will maintain a stationary course or will show improvement.

Chronic sciatica is recognised as a difficult pain problem in individuals who have been operated on many times for spondylitic or lumbar disc herniation, with postoperative continuation of pain in the distribution of the sciatic nerve, often with an associated reduction or absence of sensation in the painful areas of the leg. Further surgery to relieve this pain may convert the painful sensation into a burning dyaesthesia, which is probably of central origin (Nashold, Bullitt & Friedman, 1989).

This study made no assessment of the category of sciatic pain experienced by the participants.

Jack

The use of medical terminology created confusion for Jack.

> *The doctors used to say to me, have you got any sciatica? And I said, "What's that? I don't know what sciatica is." And I just had localised, severe pain in my L4-L5 region. But since the operation, I do now get sciatica. I know what sciatica is.*

Jack did not enlarge further on what his sciatica was like for him.

Jane

Jane has sciatica across her hip and right down to her toes on the left side. This pain started during the period in which she continued to work in a job which required heavy lifting after she had sustained a back injury. *"Severe pain. I mean, I couldn't straighten up. I couldn't straighten up."* There were subsequent major repercussions on her work life and Jane still berates herself for this.

> *I took myself from full-time down to half time. Down from five days a week, from four, to three, to two to nothing. Because I just couldn't - I had no - the pain down my leg was so severe. I was a fool. I should have given in earlier.*

Eventually she had surgery, but this only relieved the pain for about three months, a relief she now attributes to the post-operative enforced inactivity.

> *Because I wasn't moving around very much anyway. And once I started to get more mobile, the symptoms were coming back. The sciatica was coming back. And the pain was getting worse, and worse, and worse. Same as I had before. Not as severe. For the first six months, not as severe. But after six months, I was just about back to square one.*

Now she gets sciatic pain three or four times a day, particularly after work, at which time pain is *"deferred"* [sic] from the lumbar region into her upper back as well as to her leg. A burning, stabbing pain *"transfers over my left hip and down my leg"* and the doctors have confirmed it *"follows the path of the sciatic nerve."* However, she believes it also sometimes extends to places where the sciatic nerve does not and manifests as an area of severe, burning pain, rather than a line of pain.

Mary

Mary has had *"bad"* sciatica down both legs, worse on the left, for the last seven and a half years. Sciatica was her first symptom after an epidural steroid injection for her initial injury, and she describes it as *"like hot electric shocks."* At that time it was intermittent. Following her second spinal surgery in late 1990 or early 1991, in which the nerve roots were bathed in the same drug, Triamcinolone (Kenacort A-40, see Appendix One) that she had had in both epidural steroid injections, it became continuous, with no breaks or cycle to its occurrence. *"It was actually worse. Once I came out, then I had the permanent sciatica and that's when everything was really sort of set in."*

Mick

Mick presumes that what he experiences as *"pains down, right down the leg itself, the back calf muscle area"* is sciatica. The pain is a throbbing pain *"more or less"* and seems to travel down deep in the bone itself.

Paul

Paul's experience of sciatica happened in March, 1997, at a time when his leg symptoms became worse. Like Mick, he is not absolutely sure that what he experienced was sciatica.

> *When this first happened, I thought I must be developing sciatica or something of the sort. I had a, well, you know, these things happen at night when, like toothache, they come to the fore when things are all . . . Not that I - I really don't know what sciatica is, but I guessed a sort of a pain from the groin down the leg. It settled down after a while, after copious amounts of Panadol and Digesic and things which didn't really seem to do any good at all and eventually I was able to phase out of them. And I don't take any medication now at all, and fortunately it doesn't happen now.*

His pain was only on the right and suddenly *"just went as it had arrived, and I've had no problem since."*

Terry

Terry experiences sciatic pain in his left leg, which he describes as *"right at that point where the sciatic nerve starts. It's, to me. it's like a toothache pain."*

Headaches

The majority of the participants have severe and frequent headaches of various types that they did not have prior to the onset of their back problems. The generic nature of the word 'headache' does not give any indication of the variation of the experiences participants described. Participant's variously ascribed their headaches as a symptom they associate with arachnoiditis, a side effect of Depo Medrol injections, or a result of surgery. The literature review did not find a mention of headaches as a symptom of arachnoiditis.

Mick and Rose did not mention headaches. Paul and Tom do not believe that the infrequent headaches they have are connected to arachnoiditis.

Greg

Greg finds *"there are specific occasions when I've overdone something, and I've hurt my back. Along with the sore back, comes the headache."* Greg supposes the majority of his headaches

> *are reasonably mild. Every now and again, I get a fairly sharp one. From my understanding of headaches, I haven't suffered a migraine as such, but I have had quite severe headaches, periodically. It's probably basically too much bending, or lifting, or something. It's no one particular activity that sets it off.*

Jack

Jack links his headaches to problems in his neck arising from his surgery. *"I get really bad headaches through my op., where I've had the operation on my neck. And that's probably causing the bad headaches."*

Jane

Jane links her headaches to surgery.

> *I never had the headaches when I, before my laminectomy. It is the post laminectomy back pain that causes the problems . . . Usually if I've got severe pain in my back or up into the middle of my back, I get these headaches. They, sometimes I have to go to bed.*

Although her headaches are migraine-like, she does not believe that they are migraines. *"I don't get migraines. I've never had migraines in my life. And it all comes from, I'm* *sure, my back"* These headaches can occur two or three times a week and are very severe.

> *I get these headaches just on the top of my head* [and] *can barely see out of my eyes.* [It] *feels like it's exploding, as if the top of my head's going to explode. There's pressure inside that just needs to be released. They're basically all on the top of my head. I don't know. It's a tightness. It's like there's not enough room. It wants to expand and it can't . . . it's just on the top of my head and I can sometimes, can barely see out of my eyes. So, I just go to bed.*

These headaches can last for a couple of hours, or for three days on end. *"They just seem to have to take their course."* Jane also made a linkage between some of her headaches and stress. *"If I get stressed, you know. I'm not a stressful person but in our life we do go through stress and I find that brings it on."*

Jim

The duration of Jim's fleeting attacks that can be *"as quick as that* [snaps fingers]. They were evident during interview as a brief, grimacing wince, an involuntary movement of the hand towards the forehead and a slight lapse in concentration, occurring up to every five minutes. His comment was, *"Yeah. Oh, it's coming and going."* He dryly summed his headaches up with *"You do wince, it's so strong."*

Mary

Mary has headaches *"all the time. They're like migraines. Well, they are migraines. They've been diagnosed as migraines. I'm on medication for that."*

Terry

Terry knows that if his neck is out, his *"head starts to ache."* He describes the pain he gets as neuralgic in nature. *"The neuralgia thing's in the right side. And that just gets to* *a point where my whole scalp and side of my face are just crawling. I can't - it's jangly, I guess is the best description."* Touch emphasises the pain. Untreated, *"it'll ultimately turn into a migraine. If I don't do anything about it, they just go on and get worse, and worse, and worse."* His headaches may last for a whole day, getting extremely severe. Frequency has decreased since he had some manipulative treatment on his neck.

Will

Will cannot relate his headaches to anything specific.

> *Sometimes I'll get a headache half way through the day. And it's, like it doesn't seem like anything else is wrong. I'll just suddenly get a headache. There's not a lot of noise. Or I'm not doing anything that should give me a headache.*

The head pain is of an exploding nature. *"As if they're going to explode . . . Like, even when it's like a heart beat, if feels like if it got any bigger, my head would explode."* Will has problems with his eyes, as well as his head. *"It's inside my eyes are sore. Inside my eyeballs are sore, yeah. Right inside."*

Headaches linked to myelograms

Three participants mentioned the headaches they experienced at the time of their myelograms.

Jane

Jane does not remember being told about headaches as a possible side effect. *"I was told nothing. That there would be no complications. I wasn't really told - I was told very little about what they were doing. Just that I had to lie flat."*

Tom

Tom felt sick and had blinding headaches with double vision which came right after a couple of days, along with difficulty in standing, which continued for a *"period of time."*

Will

Will was warned he might get a headache after the test, but remembers a rather mixed message. *"He said, there are no side effects. He said, you'll get a headache and you might be sick. That's it. And I got both."* Will then became very ill with what was diagnosed as chemical arachnoiditis.

Headaches linked to epidural steroids

Two of those who had epidural steroids administered for pain management developed severe headaches afterwards.

Jane

Jane had severe headaches, along with other pains, immediately after each epidural administration of Depo Medrol. She learned that this is a side effect of the treatment and that the manufacturer recommends that *"epidurally, Depo-Medrol should never be given, because of the horrific side effects."* She then elected to have Depo Medrol intramuscularly instead, but found the headaches and other pains that still seemed to accompany the treatments so unacceptable in terms of subsequent benefit that she has currently discontinued them. She did question her doctor about these problems but *"he never answered me. He said it was part of what I had to go through. That was his answer. Or else he would ignore me."*

Mary

Mary is certain her migraine-like headaches are clearly linked to the epidural insertion of transinilone. *"Migraines came after the injection. Not the first injection, the second"* and she has had no explanation she considers satisfactory for the onset of these migraines

> *They just said, "Well, it could be a twinge, umm, allergy." They've given sort of everything around the part, but they're not prepared to even acknowledge that it could be - ah, connected with the injury or the treatment.*

Pain in the feet

Four participants have painful sensations in their feet.

Jim

Jim's feet burn. *"And that applies to both the feet, on the underside."*

Mick

Mick finds his toes and the bottom of his feet burn all the time, but he is not certain whether this is back-related, or because of diabetic complications.

> *How can I put it? Oh, it's just a burning. A very hot . . . it's a hot burn. I can . . . it can be cold, yet my feet will be burning. And then they go the opposite way, and they get cold. I'll put me slippers on. I'll put them on for about an hour. And my feet'll be back to burning again.*

Terry

Terry has two sensations, one of burning, and the other of bruising.

> *It feels like walking on hot rocks, right in the middle of my feet, it gets really hot, burning feelings . . . I can be standing at the sink, doing something and suddenly it feels like, in my left foot, I'm standing on hot coals.*

The bruising is like a stone bruise. *"They're stone bruised on the heels. If you've ever had a stone bruise, that's what it feels like on my heels and in the middle of my feet for 95% of the time I'm walking around."*

Will

Will reports that it feels like *"walking on hot rocks or something"* in his feet. *"Like, in the middle, it goes right through the middle here* [indicated soles of feet] *and it gets really hot burning feelings. And in the end, it'll just go away."*

Painful joints

Jane

Jane has unexplained joint pains. *"I didn't understand why all my joints were sore. Because it wasn't - it was different to my back. Totally different. And I was tired and just not myself.*" Referral to two rheumatologists brought a diagnosis of fibromyalgia as an explanation for these pains. *" I've had two rheumatolgists tell me it was that. Straight away. Recognised it straight away."*

Jim

Jim has pains that shoot down to his leg and knee. *"There are pains around the knee area. From here down to the knee area. That can develop. But I think they've covered* *that with arthritis. It travels down at the side, and it sort of goes around the knee."* He is not sure whether he agrees with the diagnosis of arthritis.

> *I mean that's what I've been diagnosed as. And fibromyalgia. I don't know. I mean I'm so confused by it all, really, that - Because I actually asked the specialist what is the connection with, if any, and he said there is none whatsoever. With either arachnoiditis or anything else. You know, it's got nothing to do with your back. So he said.*

Jim also gets swollen joints in his hands. Arthritis medication helps with this but, again, Jim is not sure at the sharp delineation between diagnoses.

> *Oh, yes. It certainly helps, Yes. Because, I mean, there's no doubt about it. My hands were swelling up and I was definitely having trouble with those joints* [in hands]. *Of that, you know, there's - but to say there's no connection is, I feel, possibly a grey area.*

Rose

Rose has pain associated with osteoarthritis in both knees. This is showing up on x-rays and stems from surgery for cartilage tears occasioned by hurdling when she was a teenager.

Tom

Tom has shoulder pain but is uncertain whether it is primarily connected with wheelchair use or to his back.

> *I started having problems with my arms. My hands were locking. Swelling, and you just couldn't move them. And my arms were really painful to me. I could move them but they were very, very painful in the shoulders to move. And it aggravated any time I wheeled any great distance, it was aggravated.*

Chest pains

Tom has chest pains, diagnosed as angina, and, at one time, as a myocardial infarction. These attacks can be severe enough to cause collapse and, initially, before he knew what the problem was, hospitalization. *"The first one was just in the centre and it was like indigestion, really. It was just a bad pain in the middle and I couldn't get rid of it. Shortness of breath and I felt cold and clammy."* This episode led to his referral to a physician who, on learning Tom had no true diagnosis for his back problems, decided to write to a *"specialist asking whether or not my heart problems could be related to my back. And they pulled me in and started doing tests. MRI's, the works."* The orthopedic specialist ordered the MRI and on the basis of the MRI wrote back to the physician and said *"No, that it wasn't related."* Tom has had several more of these attacks and is now on Anginine.

Tom believes his heart problems are linked to his back, at least in part.

> *I started having problems with my heart. And they started looking in to it very seriously then, to find out why I was in a wheelchair and so on. Two years after I'd ended up in the wheelchair. OK. I started having heart problems. When I was first admitted, it was query MI. They did all the group, blood groups and everything and it came back that it wasn't, and it came back that I had a very high cholesterol. I had 13. They suggested a diet, and I went on the diet and that. About six months later, I had another one. They gave me anginine and so on at the hospital, and that didn't work. And so they put me in to ICU for three days. It just gradually went away. There was no damage to my heart the first time. The second time, there was. That was an MI.*

Pain tolerance

Although the researcher did not mention it, five participants spoke of their ability to tolerate pain.

Jane

Jane feels she has always had a high level of pain tolerance.

> *I have a very high tolerance to the pain anyway. Which I'm probably lucky I have got that. I've always had it and I think that's how I -* [orthopaedic specialist] *said to me, I originally were* [sic] *able to keep working. Because of my high tolerance of pain.*

Even so, there are times when she finds it can get *"really intolerable"*

Jim

Jim mentioned he just keeps *"tolerating the pain"*

Rose

Rose feels her tolerance levels have increased. *"What I was suffering then, my tolerance level had got pretty high."* and links this with an ability to endure. Rather than take extra medication, *"I'll put up with it."*

Terry

Terry believes the rise in his tolerance levels are a characteristic of chronic pain. *"I think the pain tolerance goes up. You get a better pain tolerance if you are in pain all, or a lot of, the time. And people's pain thresholds are higher than others, or less than others."*

Tom

Tom, like Terry, believes his pain tolerance has increased in the face of ongoing pain. *"Like, my pain tolerance is a heck of a lot higher than somebody that doesn't have pain all the time. So you adjust to it."*

Paraesthesiae

Spontaneous abnormal sensations, including electric shocks, pins and needles and tinglings, are called paraesthesiae. They are the result of disordered function in the pathways conducting the finer and discriminative aspects of sensibility (Walton, 1985). When they occur in people with lesions of the posterior column of the spinal cord, they may also include a sensation of a tight, constricting band, or a feeling of swelling of the part which is not apparent on inspection of that part.

Pins and needles

Four of the participants spoke of pins and needles.

Jack

Jack feels them in his legs on sitting down, with the area going *"numb and you can't move, and you get pins and needles"* after which he can't recommence movement easily.

> *I can't move my leg, I can't move, you know? I've got to lift my knee over, and the whole of my legs. I've got to sort of crawl over to the couch, and get myself up, and straighten my leg out. All this type of nonsense.*

Jim

Jim, as well as a burning sensation, gets pins and on the underside of both feet.

Mick

Mick gets *"a funny type of pins and needles"* in the thigh, and in the back of his legs on standing for long periods. *"You run your fingers up and it feels all horrible."*

Will

Will has pins and needles, which can manifest at any time and in almost any part of his body. He describes them as *"funny little things. All different places. In my head. In my back. In my legs. Down at my feet."* They are not necessarily stationary in one spot. *"The moving pins and needles are a real pain."* The size of the patch varies, as does the time of day or night they occur and the activity he is doing at the time.

> *I'll get them in the middle of my back. And it will feel like there's a spider or something walking up and down my back . . . I'll probably get them when I'm asleep, but I don't notice them because I'm asleep. But when I'm awake, it just about drives me nuts.*

They are intermittent.

> *Sometimes I don't get them for ages. And I'll just be sitting at home doing something, and my feet will have pins and needles in them, or my arm. Sometimes, when I'm at work, I'll be walking round at work and get a patch in my head.*

He has never been given an explanation for these sensations.

Electric shocks

Four participants experience what they describe as electric shocks.

Jim

The first symptom Jim mentioned was *"mini electric type shock . . . They're so inconsistent, I couldn't - there's no pattern I could put to it."* These have occurred *"since about 1986, I've had all these episodes, things."* The shocks occur in an upward direction and can be accompanied by unexpected movement of body parts.

> *They are, are something like, in this finger, for example -it is just like a little shock - and it straightens up on me. And the other symptom of it is, you can be walking along, and suddenly you'll get this sensation, and it shoots right through your body, and your jaw goes* [demonstrates jaw clunking shut and chin down to chest]. *You feel as if, you know, it travels right up from your feet around, and sort of goes like that and just, and just - You don't necessarily have it as bad as that. Sometimes, it's just, you just feel the sensation of tingling going upwards. Always upward."*

Mary

Mary links her seven and a half year experience of electric shock to her sciatica, which she describes as *"like hot, electric shocks down my legs. And they're continuous. There is no actual break in them, or there's no cycle."*

Tom

For Tom, the shocks power through his whole body.

> *They're like electric shocks through your entire body. Even though I can't feel below my waist, it actually just locks everything out. It's like being electrocuted. The pain is unbearable. I wouldn't wish it on my worst enemy. It's excruciating.*

He likens the sensation to that of the dentist touching a nerve in a tooth, but *"double it and imagine it running though the whole body, arms and everything."* Tom cannot place a direction on his sensation. He does know when it is coming because it is preceded by feeling *"really, really bad. My muscles are spasming and I can feel them going up my back. You know, rippling. Going up my back. And my legs will take off involuntarily."* The shock itself then occurs *"like a bang"* and locks everything else out. His electric shock sensations are linked to myoclonic spasms that throw him out of his chair.

Will

Will's first shock occurred during his myelogram. *"It was like something was running high speed up my back, like an electric shock in my spine."* Twelve years later, similar sensations still occur.

> *I can just be walking along and it's like someone has zapped me with some leads or something. I don't visibly move. Somebody wouldn't see me but I can feel it inside me. I'll just be sitting somewhere sometimes and I'll jump like I've had a fright. That's the sort of thing it is. It doesn't blow me out of bed or anything like that.*

He has no idea of direction of current. *" I've never really worked it out."*

Numbness

Numbness is one of the terms commonly used by people to describe a disorder of sensation, and to them it can have many meanings (Walton, 1985), including abnormal sensation, clumsiness and weakness. In this study, it was mentioned by all participants except Mick, and to all those who experienced it, it was related to abnormal sensation.

Greg

Greg has numbness and funny sensations down the legs, through the muscles, mostly in his right leg. This started right back at the time of his injury and still happens intermittently nine years later, particularly in the thigh muscles, which just "*go dead*" occasionally. The sensation has also recently started to occur in his left leg.

Jack

Jack finds sitting leads to his legs feeling numb and tingly so he has to manually move his legs before getting to his feet. This has been a recent, progressive deterioration.

> *Like now, I've noticed that when I sit down - as you notice where I'm sitting now* [on the floor with his legs tucked sideways], *I sit like this because I feel comfortable. But, if I sit here for too long, whereas like, even as far back as six months ago, I've had - could move my legs after about say sitting here for about an hour, I could move my legs by myself, now, if I sit like this, in this position, I've got to manually move my legs. Because I can't - my legs go all numb and tingly, and I go all tingly, and no feeling right through my - especially my left leg.*

He also has an area of numbness in his back that, as mentioned earlier, goes icy cold to the touch.

Jane

Jane's numbness is in her left foot *"under the ball of my foot and in my toes"* which feel *"funny to walk on, like you've got no foot, that there's nothing there."* This numbness initially led to problems when she burned her foot several times in the bath, before she got into the habit of feeling the water with her hand instead of her foot.

Jim

For Jim, from time to time down his right leg it is *"as though it's going hot to cold, then absolutely nothing."* He also gets *"numbness in the right arm down to about the elbow."* This feeling comes and goes. *"Suddenly you've lost the use of this arm . . . it's a dead weight"* and he cannot use it.

Mary

Mary experiences numbness in both legs, which leads to problems in detecting injuries.

> *It seems like - the pain's on the inside, but it feels like the outside is numb, like it's - like a sort of nonsensational. I can even scratch myself or cut*

> *myself and I feel very little. It's as if all the nerve endings have gone. That comes and goes. It's like a dull, dullness all the time. On the surface.*

Paul

Paul hasn't *"got a terrible amount of feeling in my feet. I haven't for a long time* [and] *it's worse* [recently]*."*

Rose

Rose's numbness is in her left leg, which is numb down the outside, and also in her back which has big patches that are completely numb all the time and *"never come back."* When asked if this meant she could not feel touch on the area, she disagreed. *"It's a different sensation. It's like there is nothing there."* The closest analogy she could find was as if a dental injection had put the nerve to sleep. The area of numbness in her leg is *"both burning and numb."*

Terry

Terry remembers the doctor's concern about the lack of feeling in his left leg.

> *They were concerned about the fact that I had the sciatic pain and the numbness. The lack of reaction to needles and things when they pricked the soles of your feet. I didn't like it on my right foot but I couldn't feel it on my left, sort of thing. And still can't.*

Tom

For Tom, there is now total numbness in both legs. This numbness includes feeling no pain in his legs. After his second fusion operation he woke with *"severe numb patches in the legs."* The numbness progressed from losing all feeling from the waist down when sitting for a long time but with a return of sensation overnight, to a permanent loss.

Will

Will, like Rose, uses the analogy of a nerve asleep at the dentist. He locates the numbness at a deeper level than Mary who describes it as a surface dullness. His attempts to describe his numb sensations have lead to mixed reactions from doctors.

> *Like numb. But it's numb and pins and needles together. Right. So, is it sort of like that feeling you get when your tooth's been anaesthetised? You know, your nerve at the dentist? It's like that. But, it's like that in the middle. And round the outside of it, it's pins and needles. Like, when I first tried to explain, I didn't know how to. If someone asked me if it was numbness, or if it's pins and needles, I said, well, it's like both. It's like there's numbness in the middle, pins and needles round the outside. And the doctor looked at me like I was stupid.*

Banded sensation

Rose was the only participant to mention this symptom. She did once tell a doctor, who had asked what sensations she was feeling, about it, but it was dismissed by the second doctor present as irrelevant.

> *I said, "Well, it feels like a tight band right across my waist, as if there's something like a bit of string tied tight." And he mentioned that to* [the other doctor]. *And he said, "Oh, don't worry about that." were his words. "Don't worry about that at the moment."*

Cramps, spasms, fasciculations and myoclonic contractions.

Spasms and cramps play a major part in the symptom experiences of the participants, with different types of spasms and cramps occurring in different parts of their bodies. In association with arachnoiditis, cramping sensations and painful muscle spasms suggest ventral root involvement that may be later followed by atrophy and fasciculation.

Painful spasms of the extremities may also indicate spinal cord involvement at a higher level. Guyer et al., (1989) noted frequent cramps or spasms in the legs on activity. Spasms in the back, legs and feet, along with spasticity (jumping or jerking) of the limbs are given as symptoms of arachnoiditis in the Back Pain of America Newsletter (Arachnoiditis: What is, 1996). Paraspinal muscle spasm or contracture and limitation of range of motion of the trunk were considered characteristic symptoms of arachnoiditis by Burton (1978) and by Quiles, Marchisello and Tsairis (1978). Auld (1978) gives a sequence of symptoms that includes cramp: *radicular pain - operation - increased radicular pain and severe bilateral leg cramps - temporary improvement - chronic bilateral pain,* which he considers indicative of the possible development of arachnoiditis. In this syndrome, severe cramps and spasms in both legs, sometimes accompanied by fever and chills, begin on the first, second or third post-operative day and last for four to twenty days. There is usually some improvement but then signs of chronic arachnoiditis develop over the following months or years, with new neurological deficits and relentless bilateral back and leg pain.

Myoclonic spasms

Myoclonic spasms are experienced by one participant, Tom, who calls them *"ironing board spasms"* in which his whole body arches back and actually throws him out of the wheelchair, as if he is having an epileptic fit. *"When I ironing board, that basically takes the whole body. It actually throws me out of the wheelchair."* These spasms are extremely painful, so much so that, although fully conscious at all times, Tom cannot talk because of the pain. He can only hope that someone familiar with his needs will put him in the recovery position and stay quietly beside him until he is well enough to be assisted back into his chair.

Fasiculations

Jim

The muscles in Jim's lower leg are always in motion and both he and an observer can watch as each muscle successively tightens and relaxes, following a circle around his lower leg. *"It's always in spasm - I could pull them up* [trousers] *and you could just watch it happen right now."* He did so, and each muscle in turn visibly tightened and relaxed in a continuous circle around his lower leg. The associated pain varies. On the day of interview it was *"acceptable, you know, ... but sometimes it starts going like this, that can get more - it can do it much harder and closer then, where you've sort of like pulled a muscle."* This can become severe enough to be cramp-like in intensity, and can wake him *"in the middle of the night for no reason. You're doing absolutely nothing, you're asleep and suddenly you wake up with it."*

Known as fasciculation, this phenomenon usually only involves individual motor units in a muscle, but when associated with compression of the spinal cord, ventral roots or anterior horns of grey matter, affects whole muscles innervated by the affected segments (Walton, 1985).

Spasms and cramps

Six participants noted muscular spasms, in various areas of the body.

Jim

Jim experiences periodic, very painful spasming in the back of his neck. It interferes with his range of motion, so he cannot turn his neck far enough to reverse the car. He describes it as *'locks up from time to time'* and he must hold his neck *"just so"* and manoeuvre it around to keep it out of spasm.

Mick

Mick gets jumping spasticity in his legs when he sits down; this is not a bother when he is walking around. He links these jumps to his *"nerves playing up."* He does not describe them as cramp, nor does he mention pain as part of the sensation.

Rose

Rose's lower limb cramps have also been described under the section on pain, because she links them more to pain than to actual cramp, as they are more a sensation than linked to apparent spasm. Her muscles feel as if they are cramped, but there is no visible evidence, such as lumping of the muscles, and the muscle tissue is relaxed on palpation. Lying on her right side worsens it, and the area goes completely numb as well. If there is any pressure on the bowel, the cramping, along with the burning, becomes a lot worse. Since she is prone to constipation and must take laxatives regularly, this is a considerable problem for her. In fact, she rates cramp, along with the burning, as her two major problems. Rose expresses a great deal of anger about this cramping sensation, as she links it to two epidural Depo-Medrol injections. *"The pain at that stage* [the first epidural injection] *was the first time I'd ever experienced the cramping. I couldn't move my leg, it was just cramped."*

She was particularly angry about the second injection, as she feels that if the specialist who administered it had read the Adverse Reactions insert he would have seen that cramp and bowel and bladder dysfunction were known side effects and not given that second injection. *"Now, if he'd gone back and looked at that, he would have found it, and I can't see why he gave it to me again."*

Three months went by, during which medication failed to relieve this cramping pain. *"The pain was so severe and I'd gone from before that injection, I'd gone from just Panadol and they'd actually put me on Valium and Actopen."* She then had a laminectomy, reporting that the surgeon who performed it told her,

> *it's the one thing it would do, would completely get rid of the pain in my leg. He could more or less guarantee that. And yet when I come out of theatre they had to get hot water bottles on my leg. Every part of my leg felt, just the cramp was so bad. And I thought, "Oh, oh, hasn't worked."*

Terry

Terry, like Rose, links his cramp to pain. For him, it comes on after walking, and is felt as a burning cramp across the middle of his upper back, in which the muscles actually get gradually tighter and tighter. He found there was a paucity of words to describe the feeling. " *Oh, it's really hard to describe it. It's not like any other sort of pain I get. It's just a burning, painful sort of cramp sort of thing.*" In his job, he was well acquainted with burns and scalds and was able to state clearly that " *it's not like a scald burn or a hot touch burn. It's a big, a general pain. You know, like a crampy, burning sensation that just sorts of locks up your whole upper back.*" To him, it feels as if it comes from the muscles into the spine and also spreads out over the back but does not spread round to the anterior ribs.

Tom

Tom, as well as his *"ironing board"* spasms, experiences chronic spasming that started at the time he lost all the feeling in his lower limbs and had to go into a wheelchair. These spasms radiate up, not down, his back and have an icy burning sensation to them. During them, his back muscles all *"knot up"* and actually *"visibly protrude."* It is difficult to know whether these back spasms are part of the pain-spasm-pain cycle, or directly linked to neuropathic changes.

He also has uncontrollable leg spasms that occur when he has "*overdone*" things. These spasms alternate with his legs being completely *"floppy."* In association with electric shock sensations in his body, they make him

> *feel really, really bad. My muscles are spasming and I can feel them going up my back. You know, rippling. Going up my back. And my legs will take*

> *off involuntarily. And I know I've got to turn round and tip back and try and ease the pressure. Or it's going to get worse. But sometimes I know there's nothing's going to stop it.*

On being asked how he kept himself reasonably safe when he knew such spasms were going to occur, he reported that he stayed home if he was feeling really bad, although *"couple of times, it's caught me off guard."*

Spasming has caused problems with further MRI tests, because he cannot lie on the bed without sedation. *"It's too hard and it's painful and it puts me in spasm straight away."* This led to his refusal to have another MRI recently, a difficult decision in view of his worsening thoracic symptoms.

Will

Will's spasms are different again to those of the other participants. Some mornings, he wakes with his hands clenched tight shut and *"all pins and needles."* His legs feel the same from the knees down.

> *I just worked on it for a while until I got my hands open. And then worked on my feet. And then I got out of bed and it was all right." He has "had a lot of that, of late, where they're clamping shut."*

His doctor told him he had poor circulation, but he disagrees, as he has no coldness or colour changes in his extremities that would support that diagnosis.

The squeezing, cramping pains he experiences in his chest began immediately after his myelogram, in which metrizamide was used. These cramping chest pains have occurred intermittently since that time. In his back he feels as if the paravertebral muscles in his upper back are being squeezed. He describes it thus: *"sort of the best way to describe it is, it's like being in a vice and somebody's doing the vice up. And it just gets tighter and tighter. And then they'll just go away."* These sensations can occur at any level in his spine or neck and also as headaches. He has no explanation for any of these symptoms, except that they are *"not due to arachnoiditis."* He links the sensations to pain and does not use the terms 'spasm' or 'cramp'.

Falling

Five participants linked their falling to arachnoiditis. Of the others, Terry and Will's symptoms occurred after falls but neither have had falls as a result of their symptoms. Greg, Jim and Mick did not mention falls. Jack used to have falls but does not at present. In those who do fall there were indications of power loss, or motor weakness. The collapse tended to be sudden and in two resulted in further injury.

Jack

Jack does not have problems with falling now but did when he had his first injury, which was eventually diagnosed as a bone splinter pressing on the cervical cord. He was having dizzy spells and falling over as he collapsed. He is rather bitter about this because nobody believed him when he complained of these symptoms.

> *And they were telling me that I was, the doctor was telling me, I was a thirty year old man, that I was overworking, and I worked myself too hard. I'd built myself a home and uh, spent too many hours working on the weekends. And I had* [a seriously ill child] *and that was causing the stress and that was causing the dizzy spells and headaches.*

Surgical removal of the bone splinter alleviated the falls. Now, despite constant numbness below the knee in one leg, he has no problems with walking and falling, although the potential is there because, increasingly, he has to manually move his legs after sitting down for a period of time before he can move freely again.

Jane

Jane sometimes just feels *"that my legs aren't going to hold me and I've had several falls. Falls, you know, I don't know why. And I just feel that something's not holding me there, and I just go."* Jane has the distinct sensation that the loss stems from her back. *"It's my back. There's no power to hold me up, no strength, that's the word, no strength there to hold me up. All of a sudden, I've got no strength."* She does not get sufficient warning to protect herself, and has sustained significant damage in a recent fall.

> *I fell out the back door, June last year, and I've done quite a bit of damage to my knee. I'm waiting to go and have some surgery there. I had no warning that my back was not going to hold me up to get me down the steps.*

This knee injury has had a flow on effect in that it severely limits the cycling she does on her exercycle to relieve her sciatic pain. It is her left leg that gives way and she has had to learn not to step out on her left side. *"If I step out on my left side, I'll go. And it has happened quite regularly."* Matter of factly, she added, *"But most times I can pick myself up very quickly and keep going and not be hurt. But I have been hurt several times."*

Mary

For Mary, both legs suddenly and unexpectedly go numb and give way while standing, and she falls. She used to fall over things left on the floor when her children were younger, because she could not look down. She had *"a bad fall in November. My daughter has got a shop and I fell down the back steps"* which significantly worsened her pain. *"It just sort of exploded from there."*

Paul

Paul's only symptom was a sudden lack of strength, which causes his legs to suddenly give way, necessitating the permanent use of a walker frame.

> *Just basically, I've no strength below my knees. That is the main thing, and that, of course, affects my mobility and my balance. I've no balance. If you stood me in the middle of the floor there, well I don't know whether I'd fall over, but I'd certainly be rooted to the spot.*

Paul was puzzled that there was no obvious reason as to what might have initiated this lack of strength.

> *I hadn't had a stroke or a bad fall. I've been very careful right from day one, really, . . . about how I went and I've never had, well, I've had a few tumbles on the grass, but I haven't had a bad fall, you know, that might trigger this, so I can't really account for why this sort of happened. And, as I say, that was back in March, which was four months now.*

It was his daughter who insisted that he get a walker because, even with a walking stick, he still wasn't able to move round comfortably and yet be supported when his legs suddenly wouldn't hold him.

Rose

Rose feels her power loss occuring between her hip and the back of her knee and doesn't think it is the muscle. She describes it as a *"weird feeling"* in which she *"will be walking, and suddenly my leg just seems to give way, and no weight can be put on it."* She must then grab something or, if nothing is handy to hold on to, very slowly see if the leg can take the weight. There is a great deal of pain with this for her too, and sometimes the leg is so bad it cannot be moved and she must call for someone to bring crutches so weight can be taken off her legs on to her arms.

Tom

Tom is now in a wheelchair, but his motor paralysis began as falls. *"I started falling. I was originally on crutches. I'd be walking down the street and - using my crutches - and then, suddenly, I'd be on the ground. And everything had just given way."* He tried to rationalise these falls. *"I couldn't figure out why. I thought I was being clumsy, to start with. Tripped on a crack, or something like that."* These falls led to a specialist visit and an unwanted outcome, the use of a wheelchair. *"And every time I went down, just about, I broke a pair of crutches. And ACC were getting very annoyed. And I went to see the specialist. And he ordered a wheelchair for long distance.*" It was *"about two years after that last operation* [second spinal fusion] *that I started falling and ended up where I am now* [in a wheelchair]. *"*

His problems have compounded recently, as his arms have suddenly started giving way when he uses them to throw himself into and out of his wheelchair. His first interview had to be postponed because he fell getting in to his chair that morning. *"Just as I shoved, bang. And I bit the dust."*

Fatigue

Five participants used the word fatigue in their descriptions of their symptoms.

Jack

Jack spoke of fatigue as the worst of his symptoms.

> *The worst thing is the chronic fatigue. It's quite bad. I mean, I can sleep. I can go to bed at 11 o'clock at night - if I'm lucky to get to sleep at eleven, and, you know, I'll have an unbroken sleep all night and then get up in the morning and I'll like to go back to sleep. And it's not that I'm a lazy person. It's just that I'm so tired. And I don't know what to do about it.*

He described this tiredness as through his *"whole body. A just tired feeling right throughout my body"* associated with a feeling of heaviness. Although not constantly present, this feeling requires prolonged rest.

> *It's not all the time. It's like, umm, if I can have 16 or 18 hours sleep, and the next couple of days I'll probably feel really good, and I'll be back to normal. But then it'll slowly just drain me again.*

He has felt like this for the last three years and it is gradually worsening. Jack is unsure what to make of his fatigue.

> *Plus the - like, I've got the pain with it, but I don't know whether, you see, I'm not sure whether what's happening to me is the result of the injury, or the operation, or is a subjective thing. I don't know. Because I don't know how to tell the difference between what's been the result of the operation and what's the result of that dye being injected into me and just getting old and getting tired. I don't know.*

His doctor has diagnosed him as having *"ME"* [myalgic encephalitis] and he has other symptoms that accompany the fatigue. *"I'd get, sometimes I'd get a feeling of unwellness, sort of - temperatures, just not feeling well"* during which his glands are swollen in his neck. The doctors have given no explanation for these symptoms, nor any treatment. Jack doesn't *"know how you get it. But they actually said I had it. And I asked them if there was anything they could do, and they said there was nothing much that they could do."* He finds it one of the most difficult aspects of his situation, because his wife cannot understand his need for sleep.

> *I can't do the things I used to be able to do. And she can't relate. And she can't understand why that, if I go to bed and sleep for eight hours, that I should have to go back to sleep. She thinks that I'm a bit lazy."*

Despite the limitations of his fatigue and pain, he coaches children's sports and has slowly renovated parts of his house.

> *I mean, a lazy person wouldn't have done this* [referring to newly extended and decorated room]. *I mean, it's taken me months and months. But I'm really fussy and I do a lovely job.*

Jane

Jane also has a diagnosis that connects her tiredness to a disease other than arachnoiditis. *"I have fibromyalgia, too. And that comes with fatigue. And the pain from the shoulders and things. That's all contributing. That makes you awfully tired."* This fatigue has developed since her back problems began, and she was diagnosed with fibromyalgia three years ago.

Jim

Jim has no medical explanation and relates his fatigue to the effort of living with his pain.

> *I'd call it fatigue, which is arrived at through the pain and the physical effort required to keep going with the ahh, the strain of it all. It's just tiring, simply tiring, you know. Even putting on a brave face. You know, you get home and you go ohhh* (relaxing down), *you know? And you've kept this face going - I'm fine. You know? You're not fine, but you can't explain it to everybody.*

This fatigue requires frequent rest. *"If it gets that bad, I have to take time out and lie down and that can be anything from an hour to three hours, two or three times a week, perhaps, yes."* He had driven for an hour to the interview with an awareness that *"Tomorrow will be the effect. Some of it will be now, but the majority of it will be upon me tomorrow."* This was his choice because he had another meeting to attend after the interview. *"But I don't mind that, because today is - you know. I know that I don't expect to do anything after having done this* [attend an afternoon meeting]." This careful balancing of activity with the opportunity to rest has become his way of living with this symptom.

> *That's basically how I try and do it so that, umm, at least I can try and achieve something. Totally half negative all the time, if you like. It's better to be - try and get a bit of positive.*

Terry

Terry links his tiredness to the effort of living with pain. He works part-time and does most of the housework, as his partner is also unwell and cannot manage it after her full-time job. Terry knows he has *"a certain amount of things* [to do] *and I do them."* Like Jim, he has a limit to how much he can achieve, although his absolute need for rest comes on the same day, rather than the next day.

> *At 2 o'clock, things are slowing down for one reason or another, The jobs have sort of been done, and I guess it's that thing, when you sit down, it sort of washes over you. You know? You think, I really need to sit down. I sit down and then I'm, phooff. I mean, I can sit in the chair in the lounge and sleep for 20 minutes, at that sort of time.*

He likened this need for sleep at one point in the interview to a sudden switching off, rather than a gradual tiredness *"Just switch off the lights."* At another point he likened it to a wave. *"It's just like a huge wave that just comes over me. Like, I've just got to feel that I've absolutely run out of every sort of energy that I've got."*

He sees an interconnectedness between his fatigue and the pain he has, but he is unclear as to the interplay between the two. *"It's not something that I've actually put together . . . it's maybe the pain that's worn me down to that point. I'm just tired of dragging myself around, yeah."*

He has found that allowing for that sleep, when it is needed, makes a difference.

> *Like, about 2.30 - 3 o'clock, not every day, but some days, I go and lie down, and I'm probably asleep for 20 or 40 minutes. And that time just goes*

> *in an instant. It's a really deep sleep. And that actually gets me through the rest of the day quite well.*

Will

Will also struggles with an overwhelming fatigue that is more than just tiredness. There are various aspects to this fatigue. He finds he falls asleep without warning if he sits down. *"If I get home from work and I sit on the couch . . . in about five minutes, I'll be asleep."* He has not been struggling with tiredness before this happens. *"I'll be walking around, running around. And as soon as I stop, as soon as I sit down, I'll just go to sleep."* On being woken up, *"I'll just get up and walk around and be as good as gold."* These sleeps don't prevent a deeper fatigue that also troubles him. He describes a weariness and a heaviness in his limbs. Fatigue affects activities he used to do without a second thought.

> *Like I, because we've got a baby at the moment, I'm going to* [the supermarket] *and getting groceries. After I've done about two aisles on a Thursday night, I feel like I'm dragging myself round the rest of the shop to get to the other end.*

Will, who is only in his mid 30"s, went to the doctor about this tiredness because he felt it was abnormal for his age and desired activity level. *"When I was under Dr X, I went to him lots of times because I thought I was tired. But he didn't do anything about it. Didn't know what it was."* He has accessed his medical notes from that time. *"I had a look through all my old medical notes and things. And it's got, 'tired, thinks doing too much at work'. Or 'tired, no explanation', 'Tired'."* He feels his other symptoms are worse when he is feeling so tired, but is unable to remedy this tiredness by going to bed earlier.

> *When I go to bed, I'll go to bed at midnight, then I'm tired. If I go to bed at nine o'clock, I'll be in bed for an hour and I still won't be asleep. And I'll be wriggling around and getting up and getting drinks of water and walking round the house.*

Being busy at work can also make things worse for him. " *If I'm not real busy at work and doing a lot, I'm usually pretty good.* " This fatigue is not because of pain, which Will does not rate as his worst symptom and which has not interfered with his life as much as the fatigue.

> *I've not had a lot of days off work with the back pain. But I've had days off work, where I can't get out of bed. Too tired, yep. Can't even open my eyes. Usually, it's, luckily, it's been at the weekend. Like I've had a Saturday and a Sunday and then it's been the Monday as well.*

He still doesn't have a reason for this tiredness. *"Whatever it was or whatever it is, I didn't have any other symptoms."* He does, however, have unexplained swollen glands, healing difficulties and other symptoms that are similar to those of ME.

Sweating

Three participants, all of them men, mentioned problems with excessive perspiration. Known variously as hyperhydrosis, hyperidrosis or polyhydrosis, excessive perspiration is indexed in Walton (1985) under 'sweating, excessive, post-spinal cord lesions' indicating that knowing and searching for the technical terms in an index can be misleading.

Disturbances of sweating mechanisms are considered rare after partial cord lesions, except in syringomyelia, a recognised complication of arachnoiditis. Usually, loss of sweating may occur when the sympathetic ganglion cells in the lateral horns of grey matter are destroyed (Walton, 1985) but excessive sweating may also occur, sometimes spontaneously and sometimes excited reflexly when the person eats hot or highly seasoned food. None of the accessed literature on arachnoiditis mentioned sweating problems.

Jim

Of the participants who linked undue perspiration to arachnoiditis, Jim has irregular, unpredictable, drenching night sweats. The perspiration is colourless and does not stain his clothes. *"You can feel the water running off, you are sweating so much ... In fact sometimes I have to get out of bed and put a towel down for it - because I freeze after that."*

The other two share a phenomenon that had also come to light amongst those contacting WDRC over the last few years - bright yellow colouration of their sweat.

Jack

Jack had previously only sweated during heavy physical exercise, like rowing and rugby, but since the injections has sweated out a yellow substance, particularly from the axilla area. His perspiration is *"an absolutely bright yellow... Since I've had these problems, being related to the injections or not, or the operations, I've sweated out yellow substance out of my body.*" He has not noted any particular odour to it. He was, however, sufficiently concerned to seek medical advice. *"I have actually taken shirts to the doctors' and actually showed them, it's been so yellow. I mean, if it's a white shirt, it's been absolutely bright yellow, coming out."* His perplexity was not resolved and he is left wondering.

> *I used a little bit of deodorant for years, but never, ever, ever, never, ever, ever come across this. And since I've had - you know, well, I can't relate it to the dye, because I don't know whether it's the dye. I don't know whether it's the food I eat, or age. I don't know, I don't know. All I know is, all of a sudden, I started, umm, you know, like with all these problems, you know, getting rid of this stuff out of my system.*

The perspiration is sometimes accompanied by feeling unwell. *"Sometimes I'd get a feeling of unwellness sort of - temperatures, just not feeling well. And sort of, nothing I could describe*" accompanied by swelling of the glands under the neck. This, coupled with his extreme fatigue, has led doctors to give him a diagnosis of ME, but with no explanation as to why he might have it, or why his perspiration is yellow.

Will

Will is also puzzled by a similar strange symptom.

> *When I sweat, which I do really often, anything that's white, turns yellow. Like, if you look at our bed at home, it's not hard to see which side I sleep on. Because it's got a woolrest on it and it's yellow on one side . . . It's like iodine kind of yellow.*

Onset is unpredictable. *"It can be, like, I don't even have to be hot. Like, well, it can be a cold night, and I'll start sweating real badly."* He is not sure how long this problem has been with him and measured the time in relation to how long the bed mattress had lasted. *"Oh, I don't know* [how long he's had excessive sweating]. *The bed we had before the one we've got now had a foam mattress on it, and the foam mattress fell apart. It went rotten."* He is pretty sure either he or his wife would have noticed and commented if it had been happening before the injection. *"I don't sort of remember having it before I had the injection. I don't remember having it before then but I really don't know. Yeah. I would have noticed."*

For him, sweating is also a warning sign that he is running out of steam.

> *First of all I start to sweat, even if I'm not, you know, it's not a hot day or something, I'll start to sweat. And then I'll get a sore chest. And then I know it's time to stop . . . My chest gets really tight. I don't cough or anything. I don't sneeze. I just get a really tight chest, so I stop straight away.*

He has had his heart checked for problems and has no explanation for these symptoms. His wife tells him he smells funny *"But she nevers says, like, what it smells like. Because I've said, "Oh is it grease?" and she says, "No. It isn't grease, it's different. You smell of something different.""* He works with machine oil, so she is used to that smell. While he links it to iodine, he does not know if that is the smell. *"I don't know what iodine smells like."* He no longer wears any white clothing. *"I used to wear white T-shirts. I don't wear white, I wear all dark coloured T-shirts now. Don't wear any light colours."*

He has spoken to fellow sufferers from other parts of New Zealand who contacted him. One has *" got all the same things that I've got. He sweats real bad."* This sweat is also bright yellow and *" he didn't relate the yellow sweat until I said to him. And his wife also notices the smell . . . I must have talked to him about the smell because his wife said he smelled funny too."* Another man he spoke to *" was a business man, and his shirts were all going yellow. And his wife was accusing him of all sorts of stuff, getting yellow stuff on his shirt."*

There was a sense of shared embarrassment, relieved by hearing that another shares the problem. *"It was brought up at one of the meetings I went to. I didn't bring it up, some one else brought it up. And he was really embarrassed about bring it up."*

Interestingly, at a recent arachnoiditis group meeting to which the researcher was invited, one lady asked another whether she had just got out of the shower or whether her wet-looking hair was due to sweating. Embarrassment turned to shared relief as three other ladies, including the questioner, said they had the same problem. Two were on medication for it. Three had cloths with them to constantly mop their brows. One mentioned that she often felt that water was running down her legs. Another noted that any uncovered areas perspired. Her doctor had said it was because the nervous system was too active and set off the sweat glands. These ladies had all had metrizamide and attributed the onset of their sweats to its use, since they had not had any problems before and were too young at the time of onset to link it to menopause. One of the study participants then commented that she also had that symptom but had not mentioned it at interview because she did not think it was anything to do with arachnoiditis. All agreed that they found it very embarrassing and that it, on top of the problems relating to pain, further limited their desire to go out in public.

Depression

Four participants, Greg, Jim, Mary, and Terry had 'depression' and had been prescribed medication for it.

Greg

Greg is not at all surprised that he has depression.

> *I'm suffering from depression because I'm probably dissatisfied with my life. I wasn't getting anywhere. And then the back injury sort of came up and became a major problem. But the back injury and being off work for so long is not terribly conducive to a happy and settled state of mind. That's for sure.*

He alternates between getting *"very, what's the word, self-centred, or something, and feel miserable and sorry for myself"* and looking round and recognising that

> *there's people a hell of a lot worse off than I am . . . There's too much to do. You can't sit round all day moaning about what you haven't got and all your injuries. It's best to get out and do something.*

He takes medication for this depression.

> *I think it's a fairly mild antidepressant. And I'm taking them for depression. I appreciate in some situations they use antidepressants to relax the muscles as well. But mine are antidepressants and I've been on them for, before this* [any knowledge of arachnoiditis] *came up, two and a half years, I suppose. And I can appreciate I'm probably going to be on them for the rest of my life.*

He is unsure if this medication actually makes any difference to his depression and considers it as *"just another medicine that I take, basically."*

Jim

Another participant with a diagnosis of depression is Jim. His diagnosis creates problems for him as he feels it was considered by some health professionals to negate any other symptoms that he experienced and sought help for. His physical symptoms were *"attached to the depression, blaming the depression."* He had just been through a marriage break-up and acknowledges that this was a factor in his depression. He also found the loss of his career depressing, as he had held an important and well-paid job prior to his back problems developing and his symptoms have deteriorated to the point where he is now considered by ACC to be unemployable. Like Terry, he sees a linkage between living his life with the disabilities associated with severe pain and being depressed. He recently went overseas and noted an improvement in his depression. *"Now I've come back, I just feel as if I've gone totally backwards and that's a bit disheartening."* What he vehemently disagrees with is the implication that his pain is due to the depression.

The ironic thing for Jim was that he had a diagnosis of arachnoiditis all along, but was not aware of it. Originally diagnosed in England, he brought copies of his doctor's notes to New Zealand but did not read them until recently. It was then that he discovered he had been diagnosed as having arachnoiditis back in 1989. No-one made a similar diagnosis in New Zealand. His back problems seemed to him to have been discounted whenever he was receiving any other treatment. He was initially given Valium which, he feels, did no good and caused him problems in discontinuing its use. He has also had extensive therapy from psychologists and mental health personnel but has not found that particularly helpful.

> *They haven't got the time . . . they seem to make a quick diagnosis* [of what he was never quite sure] *and "How are you?" and, " OK, fine?" and, "Do you need another prescription?" Basically, that's how it feels.*

An extremely low point in his life saw him go to a unit for what he thought was rest and relaxation, so as to give his wife a spell from looking after him.

> *But it turned out to be the psychiatric department. And, of course, there were so many other patients there which were, oh, so bad, you know, we - and - that was - I mean they - the back was not - I was not in there for treatment of my back or consideration of my back at all. They were concentrating purely on my head. The times that they did pay lip service to the pain etcetera I was basically laughed at and told to move.*

He remembers the staff as extremely unhelpful and eventually, unaware that, as a voluntary admission, he could have just discharged himself, determined to play things their way.

> *I organised within myself to get out of there. That place . . . by saying how much better I was and that, yes, yes, I fully understand now where I went wrong, and that sort of thing. I promise, you know, that I'm OK, and all that sort of thing. It took me about ten days, I should think.*

Mary

Mary has had problems with depression, mainly in the last year, coinciding with a marked deterioration in her physical condition. She links her depression to "*the way that it has been*" for her and feels her outlook on life at present is affected by the depression. She worries about how much worse she will get, but does feel the medication she is on has helped a lot with the depression.

Terry

Terry experiences intermittent depression. *"At the moment, no. But I've got Prozac, Serapax, something like that, in the cupboard up there . . . I do get depressed."* He has given some thought to the reasons for these depressive episodes and sees positive benefit from medication, which he requested from his doctor.

> *I don't know why it comes on. Perhaps there's a propensity to move into that sort of thing as part of my nature. I don't know. But I certainly feel I*

> *know when it's starting to come on. I feel very down. I feel like the pain's getting worse, and bits and pieces, and I actually asked the doctor for the antidepressants, because I read somewhere about it being a part of pain management or pain control. And we tried it and I certainly had an improvement in my, by lifting my depression, the pain didn't seem as bad.*

He, too, sees the pain he experiences and the depression as interlinked. *"I think it's a grinding down of your everyday sort of* [resources]. *You know, you're sort of battling the pain all the time."*

Being depressed.

Being depressed was seen by participants as distinct from depression. Being depressed was considered a human response to their situation, whereas depression was a state that came on unbidden and was not removed by actions of the participants.

Jack

Jack found the terminology used by health professionals confusing and unsatisfactory.

> *They used to say to me, "Are you depressed?" and I used to say, " No, I'm not depressed." But I used to say, "I don't know what depression is." And I used to say to them, excuse me* [aside to researcher] *"I'm pissed off. I'm really angry and I'm pissed off, but if that's what you guys call depression, then I'm depressed. But I'm really angry that I'm not well."*

Rose

Rose rejects a diagnosis of depression but finds life very depressing at times. *"It's not depression. It's not that at all. but you sort of think there's got to be something better out there, than to go on for the rest of your life like this."* At this point she became rather weepy and, on being asked what she usually did when she was feeling down like that, said she would *"just spend the day crying."* unless someone happened to distract her in some way. *"Somebody will ring me up"* She does not have an active strategy herself.

> *No. There's no one here I can ring. So I just shut myself in my room* [and cry]. *And try and sleep. And sort of wait until the night pills are due. And if that doesn't do anything, well - another bad night.*

Doctors have tried to persuade Rose to take antidepressants but contact with others on antidepressants and dissatisfaction with relationships with the doctors concerned influence her attitudes to medication. *"He* [specialist] *sort of said, he wanted me to try Amitriptyline and I said no. And he actually wrote in the report that I'd had it before. And I've never, ever had, and he knows that."* She was unclear whether this was intended for pain management, or for management of depression, and ultimately refused it because she had *"seen other people, what dosage they're on. And they're just like zoombies"* and told the doctor, *"My body's pretty well packed up. I'm not having my mind go as well."*

Tom

Tom's experience is recent and depressing, but not called depression by him. It relates to having recently found out for certain that he will never walk again. *"I'd really build my hopes up. When I got the phone call* [from ACC], *I must admit, I really broke down. It just knock me and still does at times."* The method by which this information was broken to him appears to have had a major effect on his reactions and he repeated the point later in the interview. *"Just to be rung up like that, that threw me. And it still does."*

He had been told that his paralysis was psychological and he had actually hoped that was so and he would be able to walk again after appropriate psycholgical help. He had said at interview that he was *"adjusting to it"* but *"it's had a very bad detrimental effect."* Tom is not on antidepressants and has not had *"any counselling ... all the way through."*

Two participants, Will and Jane, did not mention either depression or being depressed. Of the other two, Mick gets *"a wee bit down"* but likes fiddling around and making things, so he usually gets out and *"mucks around"* to keep himself occupied until his mood lifts. Paul, when his lower limb weakness first began, *"wasn't depressed. I don't suffer from depression, but I was a bit taken aback."* Now, he feels that, in the absence of any pain, things are not actually much different to what he expected life to be like once he was retired, anyway.

> *Perhaps it's all my lazy genes have come to the top. I've quite accepted, you know, I'm quite happy. I do a lot of reading, which is a great - especially in this sort of weather, it's pretty easy to settle in with the radio and a good book.*

Suicide

Suicide is a recognised outcome of arachnoiditis (Guyer et al., 1989). As with depression, there is a differentiation made by participants between two aspects of the same symptom, being suicidal and having plans to commit suicide. The former is seen as undesirable, linked to depression, and requiring treatment. The latter seems closer to euthanasia, a total method of pain control if pain ultimately becomes unbearable. Although the participants who spoke to this subject said they did not mind if small sample size, and the fact that most of the participants know each other, meant they could potentially be identified, the researcher made a decision to further protect anonymity by not using any names for this section.

The guide questions did not directly seek to ask participants if they were suicidal. Suicide was mentioned spontaneously by four participants. For one, it was part of their past, before their surgery, at which time alcohol was also a factor in their pain management. It was not a consideration at the time of interview. One participant spends long periods during extreme flare ups of pain feeling actively suicidal. These feelings are seen as quite distinct from depression and this person does not see themself as depressed.

Two other participants, while they do believe they also have problems with being suicidal because of depression, see the two as quite distinct - suicide, referred to as euthanasia by one, is a future option for pain control, not an outcome of depression. As one put it, *"I don't see how it* [euthanasia] *can avoid being there. Because you get to the point where you seem to be fighting survival on every front. There's no ease for what you are dealing with."*

For the other, it is also constantly there. *"It's something that's constantly in the back of my mind and I thought that if I ever got to the point where my strategies don't work any more, that's an option I'd seriously consider."* Accordingly, plans have been made.

> *I know what I would do and how I would do it. So I've actually got a strategy that I've got in place now, that I think that if I got to a point that I thought it was not going to improve any more, or that I felt that my quality of life was such that I can't be bothered any more, I would use it.*

Both these participant's views seem to reflect the sheer effort they have to daily expend on coping, so they see suicide/euthanasia as a choice for the day when they just cannot live with their situation anymore.

> *Up until now, there has always been that 'tomorrow might be better'. But if it got to a point where tomorrow and the next day and the next day aren't, well, probably over a period of time, I would certainly consider it a serious option.*

It is this coolly planned, long-term aspect that seems to distinguish this kind of suicidal thinking from that linked to depression. At the same time there is a recognition that suicide seems more desirable at times of depression, and that this kind of thinking is not the same as that of suicide as a clearly planned choice for the future. *"I think that's* [suicidal desires] *probably one of my alarm bells, and I go on the Serepax, or whatever"* This takes about three days to *'get back up again'* with the danger point for suicide being seen as *'those first couple of days when I actually accept that I need to take* [the medication]. *"*

All have children. Two of the three have close family and partners. One has found immense strength and support from that partner. *"If it wasn't for* [x], *yeah, I wouldn't be here now.* [x] *is my life. Even for the* [children's] *sake, I still wouldn't be here. I must have met* [x] *at the right time."* The other feels an ambivalence about the whole complex integrality of family and self.

> *. . . the other thing that keeps you from doing that, I guess, isn't only the hope that the next day might be better, or whatever. It is the effect it would have on your family ... And I actually feel a bit angry at times about that ... What would they think? How would they be left? And it annoys me, because those attachments are still there that prevent you from doing your own thing.*

The third has no close links with family and few friends of long standing close by. Support during depressive suicidal thinking is therefore not readily available. This person copes alone until *"Finally, I have to pick up the phone and phone* [overseas]. *A very good friend of mine over there. That's as much as I have."*

Support from health professionals has not altered their views. One participant did approach a general practitioner about his plans. The doctor opted not to handle it herself.

> *She sent me off to talk to someone about it, but that was some time ago. And because it's never come up again, she's never mentioned it, so it's probably in the too hard basket. If you're not talking about it, it's not happening.*

One participant felt if would be impossible for a support worker to know when to be worried as to the actual risk of suicide at any given moment. Another, during discussion concerning the warning signs of impending suicide, commented *"I'm smoking* [figuratively], *because I've actually given a lot of stuff away. I don't know if it's for that* *reason. It's just happening. Why it's happening, I don't know, but that's what's happening."* Despite these current feelings, euthanasia is still *"in the future. But not at the moment"* for that person.

Interestingly, all three of these people have current input as support workers, where they deal with people who are suicidal, and two have had some training in working with suicidal people, through Samaritan's courses and counselling courses.

> *When I get a case like that, I always ask the person's permission, if I think it's really desperate, if I can, if they will ring the field worker in the area. And if they can't, I ask their permission for me to ring them. And I do. I get in touch with them.*

However, they do not appear to have the same strategies in place for themselves, when actively contemplating suicide, as they try to put in place for those they support. One participant does not consider actively ringing someone as an option, at the same time welcoming calls from others if they happen to ring. This person sees a need for a much more active counselling role in pain management, especially for the crisis situations.

Bladder/bowel dysfunction

Mary

Mary has serious incontinence. For three years she has had to *" catheterize myself every four hours, and wear an incontinence pad all the time"* She takes enemas every second day because of *"Just having no idea when I need to go, having no sensation of needing at all."* The bowel problems developed two years ago. *"That sort of came later."* Since the fall that occurred between interviews, she has had a worsening of her bladder incontinence. *"And my incontinence has completely gone. I get no warning at all, nothing."* Accordingly, she has had to increase the frequency of her catheterizations to six times a day.

Paul

Paul is aware, through his doctor, that these problems can occur, and is grateful that *"that's never been a problem, so that's another thing to be thankful for small mercies."*

Rose

Rose finds any pressure from her bowel makes the burning back pain worse and her leg cramp really badly. *"I know if there is any pressure on my bowel, the burning and the pain is a lot worse. That makes my leg really cramp badly, so the bowel has a lot to do with it."* To try to prevent this she "*takes laxatives all the time. And if they don't work, or if they work too well, the problems still there either way, so . . .*"

Tom

Tom, at the onset of his paralysis, lost both bowel and bladder function.

> *At that stage, I'd lost my bowels as well, and bladder. And that was a new one for me, because I'd never had that. I was having problems going to the toilet. And I was having to pound my bladder to make me go. But I hadn't had any problems holding it. Like, I knew when I wanted to go. I couldn't start it, but I knew when I wanted to go. And I wet myself and everything. And I couldn't figure out why.*

He was in a rehabilitation unit at the time, and still remembers the fear and horror he felt when he wet himself and had to be changed by the nurses. He currently has no problems with incontinence, provided he is able to get to the toilet quickly and regularly. He also gets diarrhoea, despite medication designed to prevent it.

> *I don't get constipated. Even with the drugs, I don't get constipated. My problem is the opposite, diarrhoea. And I haven't been able to stop it. I've used bulking agents, and everything, and it doesn't seem to work. So what I've done is, I've made a regimen and I go the same time everyday. And I sit there and I press.*

Tom sometimes has *"help"* from an enema, which clears his bowel out and improves the diarrhoea. It was unclear from the interview whether this diarrhoea is due to constipation with overflow or to abnormal frequency and liquidity of bowel motions.

Impotency

Two of the male participants had problems with impotency. One participant had been told the "*message was not getting through.*" This, not surprisingly, affects his *"marital relations."* One female participant mentioned problems with sexuality, including being told by her doctor of the time that she could expect her husband to seek his *"gratification"* elsewhere.

Cough

Will now has a constant, embarrassing, irritating cough which he attributes to arachnoiditis.

> *I was coughing until I was sick, I just wouldn't go anywhere. In case I had it when I was out. Because it was really embarrassing. All since the test. I get, I was coughing until I was vomiting. Even though I didn't feel sick, or if I had nothing to eat, and I was dry retching. And driving round town and I'd have a little cough and then I couldn't stop.*

Will still has no idea why this coughing occurs. There is no tickle associated with it. *"You just start coughing for no particular reason."* The coughing paroxysms last for *"a couple of minutes. It's annoying. You know, if people are around, you feel really embarrassed."* The cough is not usually a productive one, but he became seriously ill at one time because he ignored it.

> *Sometimes I can bring up phlegm. But even when I have that, all that was taken to the lab and analysed and they said, "Well, there's nothing wrong*

> *with it." And one summer, like, when I had the bad cough - I get chest pains as well, and sore round my arms, and stuff like that. I got used to that and I left it. And I ended up getting pneumonia. Because I thought it was just normal. Something that was just happening, and I left it and I left it. And* [wife] *said, 'Oh you'd better go to the doctor. You don't look very well." And I said, "No I'm all right. There's nothing that's different." Then I started getting a temperature and she took me to the doctor and I had pneumonia.*

Shortness of breath

Jim gets shortness of breath, associated with shooting pains in chest.

> *One of the areas I get pain, is from the chest. It feels from the back. It's like a spear, or something, going right through you to the front. And you eventually get so short of breath with it, as well, it all feels so tender.*

Impaired healing mechanisms

Will, since his myelogram, has had problems with his healing processes. His glands in his neck are swollen. He bleeds easily, and wounds fail to heal.

> *If I have an accident, if I cut myself at work, it bleeds for ages. It makes, a small cut will leave a big scar on my hand or my leg. There's one there. It was only a real shallow cut. But it took probably a month or six weeks to heal up. It was all open. It looks like it's poison. But it never gets infected . . . . It wasn't pus-y looking. But it went white. And all horrible looking. My mother-in-law said, "Oh! You've got poisoning in your hand." And I said, "No. It'll heal up." I've got one there. I've got one on the back of my foot I did at home where the kids shut the door on my foot. That took, I don't know, six to eight weeks to heal up. I don't know if it's anything to do with it*

> [his other health problems]. *They haven't really got an answer. No. The doctors don't know what it is.*

Itching

Will experiences deep, internal itching.

> *I get itchy bits. Itchy legs and itchy hands and itch till I pull all the skin off my legs and, particularly in the summer time, when I get into bed at night. That'll be sort of warmish nights, and I'll get an itch in my back and I'll scratch. And then, that isn't on the skin. Like that, I sort of itch that, but it feels like it's further inside there. The ones on my legs, I'll itch them till I've got big scratch marks on my legs and they don't go away. They're deep, they're inside. They're not on the skin, or anything.*

Premature menopause

Rose believes the onset of premature menopause was related to steroid injections she was given for pain.

Memory loss

Jim mentioned that he had memory loss but did not elaborate on what this meant for him. Mary also has memory loss, which she attributes to medication.

Disturbances of heat-cold mechanisms

Disturbances of heat/cold mechanisms are a recognised symptom of nervous system disorders. Three participants described sensations of this kind.

Jim

Jim's sensation is, as mentioned earlier, partly associated with numbness in his leg. "*It feels as though it's going from hot to cold, and then absolutely nothing.*" He also has heat changes elsewhere in his body. *"There are parts that fluctuate. But, generally, it's the whole body. You know, you just feel hot, or you feel absolutely freezing."* Although Jim has night sweats, there is no perspiration or clamminess associated with his heat/cold changes. *"It's a dry heat or a dry cold."*

Terry

For Terry, this is a relatively new sensation. *"The other thing that I've got is like a cold sensation in all my left arm and shoulder side. And that's something that's only happened in the last six months."* He has *"no idea"* why this happens.

Will

Will also finds his awareness of heat and cold has changed.

> *Sometimes it can be a warmish day and I'll feel cold, and on a cold day, I'll feel hot. So, I don't know. It's like, it's almost like there's something wrong with the temperature control in my body, at times. And I shouldn't be feeling hot.*

Mood changes

Jane

Others have commented to Jane on the way her temperament has changed.

> *My partner knew me twenty two years ago, and he couldn't believe how I have changed. How moody and very quick tempered, I'm very quick tempered, which I was never that way. I was always very placid. But I try to*

> *control myself, but sometimes I can't. I actually would like to understand why I'm like that. And probably control myself better.*

Jane is troubled by her mood changes because of the way they impact on those around her.

> *I try very hard not to sort of fly off the handle, but sometimes I - for no reason- I do it. And I have thought at times of having some counselling, because of that. Because I don't think it's very fair on these little children. Oh, I'm kind to them, don't worry about that, but instead of me saying, "Now, you shouldn't do that," my voice is raised. And that really isn't me.*

Mick

Mick does not feel that his symptoms have affected his mood *"I try not to let it sort of get me."*

Will

Will has also found it increasingly difficult to maintain an even mood as his symptoms have developed.

> *I'm not very patient now. I'm not as patient as I used to be, put it that way. I don't know whether it's because I'm getting older, or what it is. But, like if I'm doing something and it's not going right, I lose patience real quick. And I never used to be like that.*

Jaundice

Will

Will had an episode of unexplained jaundice. *"I'd been to the doctor with bright yellow feet and he thought I had hepatitis. But I passed all the tests. Didn't have hepatitis. He* *doesn't know what that was."* The yellowness appeared on the bottoms of his feet, on his hands and in his eyes and was the same colour as the yellow perspiration he gets. *"Same colour. Really, really yellow. And then it just went away. I had it for two days, I think."* This happened about six or seven years ago and has not recurred.

Insomnia

Jim

Jim feels lack of sleep is part of the overall situation he is in. *"Lack of sleep, that comes with all of these. This morning, I've been awake since four o'clock. It's sometimes just pain, but other times it's - I don't know - stress, I suppose, you get things on your mind."*

Mick

Mick gets tired through his inability to sleep well because of his hip pain when lying in bed. He often only has three hours of sleep per night. To make up for this he'll *"nod off on the couch"* although this is dependent on him not being *"annoyed"* by other family members.

Terry

Terry used to have trouble sleeping but *"since I've started the job, I've actually slept better. Maybe because I'm just exhausted."* He feels he maybe *"wasn't sleeping so well, because I was spelling myself through the day."*

Will

Will has frequent nights of lying awake, and has had to structure a strict bedtime routine. If he goes to bed early, no matter how tired he is, he tosses and turns. If he goes at midnight, he usually gets off to sleep without difficulty.

> *If I go to bed at twelve, it's good. I'll more or less go straight to sleep, most of the time. But if I don't get to sleep, then I'll still be awake at 2 o'clock, 3 o'clock. And then the alarm goes off at half past six.*

Weight problems

Two participants spoke of their need to lose weight, and the difficulties they have in doing so when their ability to exercise is so limited.

Mick

> *Oh, weight issue, yes, that's an ongoing thing, that one. I mean, I can do a lot of walking, I can do a lot of, a certain amount of exercise that I can do. But I still don't seem to lose any weight and I don't eat a lot of fatty foods or anything.*

Mary

Mary's doctor tells her she is unable to have an MRI until she has lost weight. *"I've got to lose a lot of weight first. It's unlikely to be - to give a good result to anyone over a 100kg. So I'm losing it at the minute."* She finds this very difficult, since she can barely walk. *"Because I can't get any exercise."*

Vision problems

Will has an ongoing problem with deteriorating vision.

> *Every time I go to the optician, I need stronger glasses. Which he* [the optician] *thinks is a bit funny, because my eyes should have stopped getting any worse. There's supposed to be a period where your eyes don't get any worse. And then when you get older, they start getting worse again. But*

> *mine get worse all the time. Every time I go. So there is nothing - I haven't got glaucoma, or anything like that, causing it.*

Tinnitus

Mick is troubled by "*ringing in the ears. Or, in the head actually, not ears. It's more in the back of it.*" This started suddenly in about 1990 when he was driving through a forest and he

> *heard this buzzing. And said, "Oh, yes, it's the locusts." And got out of the forestry and, still with me, you know. And it's sort of been with me mainly, on and off, all the time. Occasionally, it stops, but not very often.*

He has had an investigatory MRI and has had tinnitus explained to him but is unsure if he really has tinnitus because *"it's not in the ear itself. It's in the middle of the head."* He does not associate it with other symptoms, such as neck pain.

Chapter Seven: Human and environmental fields: the experience of living with arachnoiditis.

Introduction

The previous chapter discussed symptoms, or manifestations of patternings, relating to particular systems or organs, and to the unitary whole. This chapter presents descriptions of the experiences that make up the overall experience of life with arachnoiditis. These patternings reflect the integrality of each participant's unique human-environmental field, in which the individual human experience is inseparable from the environment in which it occurs.

Mobility difficulties

Described as the quality of being mobile (Tasman Dictionary, 1985), difficulties with mobility reflect as a manifestation of the human-environmental fields, arising from previously described symptoms which affect the ability of the person to move readily in their environment. These difficulties also reflect the ways in which the environment restricts individual's ability to make full use of the mobility they do have.

Because of pain, numbness, muscle weakness and fatigue, all participants had varying degrees of difficulty when it came to living a life involving any degree of activity. Problems had two aspects. They altered and restricted the way a person did things for themselves or they forced participants into unwanted dependency on others. Nine participants described lack of mobility or freedom to move easily in their world as a major problem of their life with the symptoms of arachnoiditis. Two other participants did not describe lack of mobility as a major problem, but noted some mobility difficulties related to their symptoms.

Greg

Greg is able to walk without too much trouble, unless his leg gives way. *"I mean, the other weekend, I went to the supermarket and all of a sudden my left leg just sort of, for no reason, it sort of felt all funny and had no strength and I was about to collapse."* He finds this very *"frustrating."*

Jack

Jack has no problems with his walking, which he describes as *"excellent."* Increasingly, he finds it hard to get to his feet after sitting. These difficulties were described earlier in relation to numbness, which is linked to his mobility difficulties after sitting. He also has problems with keeping still while standing. *"I get pain with standing. I've got to be moving round."*

Jane

Jane's mobility is limited by pain, fatigue and a tendency for her legs to suddenly give way, leading to falls. She used to be an avid gardener and do-it-herselfer, but now does all her gardening on her knees because of her back. Even so, every little digging motion jars. Not one to give up on doing things herself, she recently got stuck on her roof when she climbed up to inspect the guttering, and had to be rescued by a neighbour. She cannot stand for long periods, but nor can she sit in a car, so she finds travelling "*absolutely dreadful.*" She determinedly went to Auckland for a seminar several months ago. *"The whole weekend was sheer hell."* She had to stop every 40 minutes to get out of the car, because sitting was so painfully uncomfortable. As a result of this experience, she has decided that she will not drive that far again. Jane has difficulty getting in and out of the car because of swinging her legs over into position by the pedals but found ACC would not do anything with the seat in her car. She believes she could travel a lot better if she had a decent seat, rather than just a swing cushion. Her brother-in-law, an upholsterer, took the wings off the seat and made it a lot better. *"Because if your seat's like that you can't get out of it."*

Her legs also give her trouble using the clutch, which led to an embarrassing time in town when she could not find the clutch because her feet had suddenly gone numb. Unable to proceed, she was warned by the policeman who came to her aid that she must only use an automatic car or risk losing her license.

Once a professional in training, she knows that she couldn't go back to complete her education in her preferred profession because she could not be on her legs long enough. Instead, she has a job providing home support personal cares, showering clients in their own homes and spacing her day to allow rests between clients. She works with people who have flat bottomed showers and who do not require any lifting. While Jane finds this very fulfilling, it is not what she had in mind in the days of unlimited mobility when she envisaged achieving a professional university degree.

Jane had been a keen swimmer, but she now dislikes going in the water because her mobility problems make her feel conspicuous, *"You try and swim and everybody's looking over and things like that. I don't like swimming in public."*

She remembers how difficult life became when she also got a frozen shoulder. *"I didn't realise what it was like, not to be able to use your arms. Oh! It was cruel."* Basic things, like lifting trays and dishes in and out of the oven, are still beyond her strength.

Attending activities for her children, such as school interviews and sports events, creates problems.

> *I make myself go. The only thing that I won't go to is rugby matches, because they're too long. But most things are pretty short and, if you - the teachers know I have a bad back, so the interviews are sort of - they'll usually stand up with me. But if they've got a long session, well,* [husband] *is actually more comfortable sitting than me, so he'll go.*

Jim

Pain and fatigue limit Jim's mobility. He had experienced being left standing in the shower for long periods of time because family had to go and attend to customers in their business, which was attached to their home, and he could not get out by himself. At various times, he has also been unable to manage getting dressed and undressed because of difficulty with raising his arms. Other days, he is just unable to get up out of bed at all, because his symptoms are so bad. Resident in a small town, he finds it hard when friends suggest they all go out for a meal and elect not to take a car because, although distances are short, he finds the walk too much for him, but doesn't like to make a fuss.

Mary

Mary has very little control over her legs and must lift them manually for all but the simplest of flat walking exercise. Numbness affects her joint movement and her mobility. Even though walking is a real problem for her, she persists in doing a small part of one of her children's paper round once a week just for the exercise and as part of her weight loss programme.

Getting in and out of the bath was a real problem and ACC put in a shower for her. Unfortunately, her house has such poor water pressure that washing her hair, a difficult procedure anyway, now takes nearly forty minutes. Her inability to look down to see if her pathway is clear has led to some nasty falls on children's toys. If she does look down, the pulling effect on her spine results in a complete loss of balance making it *"difficult to move at all."* Movement of her back is associated with an extension of the lower back pain to areas higher up the spine.

Mick

Mick sometimes walks *"very, very funny. I flop me leg, more so than the other. I seem to lift it, I think, but when I come back down, I seem to come down a lot heavier."* Before his surgery, his leg had a tendency to give way and still does occasionally and he *"goes down"* on the leg a bit. He has not had problems with falling in association with this. He does have trouble getting dressed, bending over and putting *"me undertrousers on, things like that. I've usually got to sit on the bed and then I still can't at times. I can get them on, but it's bloody awkward."* because he cannot stand on one leg and bend forward. He has extra cushions on the seat of his couch so he does not have to sit low to the ground. Driving is occasionally a problem and he has to let someone else drive. He has no problems bending over to pick things up, nor on walking up stairs. Exercise does not worsen his symptoms, which are more evident when he relaxes, sits down or lies down at night.

Paul

Paul considers difficulties *"in my mobility"* his main problem. His lack of strength below his knees affects both his mobility and his balance and mention has already been made of his inability to move if stood in the middle of the floor without his walking frame.

His mobility gradually deteriorated over a period of time, Firstly, he started having to use a walking stick. *"I couldn't sort of get around safely without some support."* He needed to use his lawnmower *"as a bit of a walker."* Further deterioration involved a few tumbles and his daughter insisted he get a walking frame. Initially a temporary loan, he now has a permanent one. He can no longer mow the lawn, but can do the edges. Once a regular driver for voluntary support organisations, this all came to a halt after his first major collapse and fall. He is now driving again, although unsure whether he would tackle a long distance drive with the confidence he once had. He has found the increased freedom from driving again has given him *"quite a psychological boost really."*

Nonetheless, he still sees his decreasing mobility, especially with the change from a stick to a walker, as the main problem of his situation because of the restrictions it has imposed. *"My theme song is that I don't get around much any more."* He no longer goes weekly to the Club where he used to meet a friend. He had earlier attended a gym to try and improve his initial weakness and feels that *"six years of it didn't really do any good"* as far as the weakness was concerned. However, he is aware of disuse *"atrophy"* and the value of keeping as fit as possible to maintain his mobility at as high a level as possible. Even though no-one had encouraged him to continue with any activity, he is considering asking the doctor's advice about going back there, choosing a time when fewer people would be present. Unfortunately, he faces a further barrier at the gym itself, because some of the equipment most suited to his use is on a mezzanine floor and climbing the stairs presents *"a challenge."*

Rose

Rose tries to do all she can for herself. *"I'll push myself to do what I can, because I don't like relying on others. That's the most degrading thing of all."* She has a home help during the week for heavy housework and assistance with shopping, but is likely, during the weekend, to *"turn around and vacuum,"* which *"puts"* her in bed. This upsets her husband and family but they have come to realise that *"it's my peace of mind and it's more important to me to feel useful."*

Rose sees immobility as her biggest problem, mainly because of the effect she believes it has had on her family. *"The inactivity, the things I can't do . . . they've missed out on so much that I couldn't do with them. Sports, that sort of thing."* Her children were very accepting of her problems and would ask *"If you're feeling OK, could you take me here?"* For some activities, other parents *"knew what was wrong* [with Rose] *and they did take them"* She found it hard to attend school parent/teacher interviews and tended to speak to teachers on the phone instead.

Rose is unable to sit on the floor in her most comfortable position, with her legs out to the side of her and her weight off her coccyx, because she cannot get down there or get up again. She is able to drive an automatic car but, because of the pain generated when she sits on her coccyx, cannot do so for long periods. When travelling to specialist appointments out of town, she therefore needs to be driven by someone else and spends such trips with *"the front seat right down"* so she can lie flat. Shortly after this interview, she had a seven hour car trip to a specialist appointment. She was approaching this with mixed feelings. *"Pleasure, just to get out of the house for a while. And dread, for the trip, because I know what it's going to be like."* Time away from home is lengthened by the need to break the travel by having stopovers on the way there and back. For this trip *"we're making it this time, that we're away for three nights"* because the afternoon appointment has caused a difficulty as *"there's too many hours from when you've got to get out of the motel until the appointment, and that's sitting in the car."*

Eating out is also a problem because restaurants *"take too long"* for the meal to arrive and she cannot sit for that period. Rose was a very social person and she'd like *"to be able to go out more. You get very lonely."* She is torn between going to do things, like the supermarket shopping *"because it's one time I get out,"* and hurrying the experience once there *"in case I get bashed"* by someone else's supermarket trolley.

Terry

Although walking exacerbates the pain in his back, Terry is still able to walk short distances, provided he can take frequent rests. If fences or benches are available, he sits on them. When walking his dogs in the area designated for that purpose, there is nowhere to sit and he must bend down to rest his back. *"I can walk for probably 10 minutes."*

Terry is aware that the majority of his mobility problems are not an initial physical incapability to actually do the tasks; rather, it is the effect the movement has on him that is the problem. *"I can't even carry the firewood in from the back yard, you know. I can do it, but it's painful, let alone chop the damn stuff."* The gardens at his house have become neglected and he is distressed at his reliance on others, particularly when those others are people he feels he should be helping, rather than them helping him.

> *I've stopped doing that a lot now* [gardening]. *This week, I've felt really bad about it. I don't know if you noticed when you walked in, it's a bit weedy out the front and that. But one of them there's half weeded. My 70 year old mother-in-law came over and did four hours in the garden and I felt terrible about that. Because I can't get out there and do bloody five minutes.*

Terry has assumed responsibility for the household management because his wife works. A costing of energy and pain management usage has to be constantly factored in, so he can manage household tasks. He has bought a new vacuum cleaner with a longer handle so he doesn't need to stoop forward, and a new lighter lawn mower, but they too have not been a total answer.

> *I mean, I could probably mow the front lawn and the back in one day. And then I'm buggered for the rest of the day and I'm sore, really sore, the next day. If I space myself out and do a bit, like, I'll mow the back lawn, I'll come in and have a cup of tea, I'll sit down for half an hour and read something. Then I'll do something . . . a bit of dusting. Again, I wouldn't do all those big jobs in one day. Like, I might do the vacuuming on Monday, do the front lawn on Tuesday and do the back lawn on Wednesday.*

This careful planning has been thrown into disarray since he started his own part-time job, ten hours a week. *"Like, I've only been doing that for five weeks, but even so, things have slipped."*

ACC encouraged him into this job and recognise the difficulties it causes. They have reviewed his needs for home help and *"I might get four hours a week."* This would be *"a big help."*

Terry also described what he believes is a typical walk used by those with arachnoiditis.

> *What we called a broken arse walk. You know? Sort of stooped and stiff legged. And I know that walk because when I'm tired and I'm really stuffed, that's how I picture I must look like when I'm walking, because I tend not to swing the hips, or I tend to bunch up.*

Tom

Tom's mobility has changed markedly over time. Initially, motion increased his pain, *"I was getting a great deal of pain. I couldn't go* [one block] *the pain was just so bad."*

Numbness, and *"everything"* giving way, led to falls which he initially attributed to his own clumsiness in using his crutches. A specialist eventually ordered the use of a wheelchair for long distances which *"helped and the pain was more bearable, more controllable."* Increasingly, the *"feeling"* in his legs lessened until eventually he had none, lost the use of his legs totally and had to use the wheelchair full time. However, he does not remember ever being taught how to use a wheelchair properly. Increasing pain in his shoulders has decreased his mobility again. He is currently awaiting assessment for an electric wheelchair to help relieve his shoulders. *"They've assured me that the RSI* [repetitive strain injury] *in my shoulders will heal if they're not used."*

Tom has found that having the incorrect equipment has had a major effect on his mobility. He *"went for a grant"* to get a vehicle he could drive.

> *I picked a van because I could lie down flat. The OT* [Occupational Therapy], *in their wisdom, decided they weren't going to let me drive a van and that was entirely unsuitable and made me take a* [car]. *I was at the time annoyed that I couldn't take the van, but grateful that I could have any vehicle. It turned out I can't drive that vehicle to* [X, one hour's journey]. *I lose the use of my arms, It's got the wrong hand controls. And the seating is wrong.*

He has since got another car with bench seating, paid himself for hand controls to go in that car, and is able to drive long distances with no problems.

Tom also has problems with mobility within his house, which has stairs to the sleeping area. He slides *"down on me bum and get me feet in line in the right place with the wheelchair and throw myself at it."* This requires a *"giant shove"* from his arms. Lately, they have had a tendency to give way without warning, causing him to fall heavily. He is now looking for a single level house to move to.

Tom was the only participant to describe unwanted and dangerous motion. When he has one of his *"ironing board"* spasm attacks, he finds himself thrown out of the chair on to the ground, totally immobilised. If others are with him, they place him in recovery position but he is unable to get into the sitting position from there and get back into his chair when he feels better. If others are not around, he's *"buggered, like a stranded whale. I lay outside in the rain for three hours one day because of it."*

Will

Will used to really enjoy outdoor sports, playing golf, running cross country, playing roller hockey. Now, fatigue quickly exhausts him. *"Ten minutes each way"* of soccer with his children leaves him *"bushed"*, requiring a couple of days to get over the fatigue such activity engenders. He can no longer dance, or move around, or stand talking to people at social gatherings. Nor can he sit still at functions, because he starts to *"fidget."* Back pain worsens as his physical activity increases, leading to interruptions in his daily activities because he must stop what he is doing and sit for a while.

Lifestyle changes

Lifestyle, defined in the dictionary as 'an individual's whole way of living' (Webster, 1998) is a term that sums up the way in which people are integral with their environment, each having a constant effect on the other as energy flows between them. Any person having to come to grips with a new life with a chronic illness may face changes in the way they live their life. This can be difficult for the person and for their families. Descriptions by participants that are reflections of changes to lifestyle include altered relationships, being a parent, alterations in financial circumstances, social life and working life.

Relationships

Greg, Jack, Mary, Paul, Tom and Will are still with their original partners, although maintaining these relationships has not been without problems.

Greg

Greg's partner has developed a chronic illness with associated disability and he finds this rather stressful and worrying. *"I mean it's fairly obvious when she has a bad day* (wry laughter). *And if I have a bad day at the same time, it sort of stresses me a bit."*

Jack

Jack finds both fatigue and pain affect his relationship.

> *One of the hardest things is not, it's not me coping with it, it's my family. My wife can't understand it. She married a very, very fit strong young man . . . and she can't relate . . . she thinks that I'm a bit lazy. But I'm not. As you can see, I've worked hard and can do - I'm an* [x] *by trade, and if I wasn't building homes, I was working on cars. And now, all of a sudden, I can't do the things I used to be able to do. I've pottered around with things and I love working when I'm able. But I'm limited to what I can do. Very limited.*

Jane

Jane's symptoms had a devastating effect on her first relationship.

> *It broke up my engagement and my wedding was called off, because my fiance couldn't cope with my disability, as he called it. It broke my whole relationship up and for many years I didn't go out . . . it really ruined my life.*

Jim

Jim's second marriage eventually collapsed. *"I couldn't manage myself. And it was obviously creating a lot of tension, because my wife couldn't get on and do what she was supposed to be doing* [running their business] *. . . So it was basically downhill from there."* He still seems stunned by the change to his second marriage. *"I never imagined for one minute that I would have been in this situation. Or that I . . . OK, I'm on my* *own, but there were two of us. And I didn't think this could ever happen."* He has not formed a new relationship.

Mary

Mary's husband has developed a major problem with his back. She finds this a point of common understanding. *"There are some aspects of these kinds of things that you can only understand when you've been there, eh?"* and had not *"thought of it being unusual"* that they both have not dissimilar health problems.

Tom

Tom, who feels his eldest son left home early because he could not cope with his father's illness, is thankful his wife is still with him, but unsure whether she chose to stay or felt she couldn't leave. *"My wife couldn't. She was stuck with it. Sure, she could have left me. And I'm grateful she didn't. But, you know, she stuck by me and fought through it with me."*

New relationships

Several participants whose marriages, or engagements, broke down after the onset of their symptoms, have forged new relationships. Some of these new partners have chronic health problems too.

Jane

Jane's new partner is actually an old boyfriend who had wanted to marry her years earlier. She chose her career at that stage, and he could not accept her shift work. Now, he possibly has arachnoiditis too, having had a series of Myodil investigations and suffering *"really really badly"* sometimes *"worse than I am"* and she considers them a good match. *"We complement each other, because we want to keep going."*

Mick

Mick has been married twice. He attributes his second breakup to his back problems, but not his first.

> *I don't think the bad back itself affected my first marriage. It was just her, I think. The second one, it definitely did, yeah. . . . It would be two or three years after the operation that things were really started going wrong, because I just couldn't - I couldn't get a job and things were, you know, sort of getting on top of me as far as that was concerned . . . I just couldn't get out and do a lot of work and that was getting my wife down and, you know, so she walked out on me, from that one. And that just turned my life into a bit of a tizz there for a while.*

He is now in a new, third relationship.

Rose

Rose's first marriage broke up, with her back problems being the *"turning point"* in an already troubled relationship. She now has a new partner who is very supportive.

Terry

Terry's current partner has a chronic illness, which also has major effects on both their lives. Both were aware of their difficulties prior to the beginning of the relationship some ten years ago, and had spent time on their own before coming together. *"That was part of the deal. It was both part of our deal. But, I'd been on my own 7 years before."* He believes both having a problem has been a strength. *"Because we both know what it's like to moan to other people, so we tend not to do it. We tend to just get on with it. And when we do say something, we know we really mean it."*

Being a parent.

All the participants are parents. Greg and Mick did not mention any concerns connected with parenting that they associated with their backs. Changes to their ability to live life as a parent in the way they once just assumed it would be was a theme in common among the other participants, relevant no matter what the age of the children, or whether they were the biological parent or a step-parent.

Jack

Jack has adult children of whom he spoke proudly and showed photographs to the researcher at interview. However, the serious illness of one of his children during the early stages of his back problems was, he believed, a factor in the way some health professionals approached his health concerns, as they appeared to link his health problems to stress rather than to organic problems.

Jane

Jane has two new step-children, which she finds gives an unexpected and welcome purpose to in her life. *"My future is a lot brighter. I've met a nice family. I've got two stepchildren - little children, at my age! So my life has to be brighter. I have to keep going for them."* Learning to cope with this instant family has not been without its challenges.

> *It hasn't been easy. You know, the relationship with children. And then we've got a boy at boarding school. But I've adjusted - we've all adjusted. I think it takes an adjusting time and, a year down the track, I think we're getting - we've got there. It's just me with my fuse* [impatience]. *And we're a good family unit.*

Jim

Jim has two adult children from his first marriage. Both now live overseas, as do his grandchildren. He feels they have *"no appreciation"* of his health problems, which have *"not helped"* but that the *"rift"* was there not because of his back problems but *"because I remarried . . . not so much with my son, but my daughter."* He rarely sees or speaks to them. *"I'm on my own and that's that."*

Paul

Paul has adult children, and young grandchildren, attending their sports events and family occasions whenever possible. Now he knows so much about arachnoiditis, he worries about one of his children, who also has major back pain problems after surgery.

Rose

Rose, until recently, raised her children as a solo parent. She is very proud of her children and thinks they have turned out wonderfully kind and thoughtful. Her regrets are not so much for the effects of the breakup of her first marriage on the children, as for the effects she feels her symptoms have had on what she could do with them as a parent.

> *Not so much for their sake. My sake. My interpretation of what effect it has on the family. They've had to grow up too quick. They haven't had the childhood that they should have . . . They've missed out on so much that I couldn't do with them. Sports, sort of thing. But they took it in their stride and they never, ever once accused me of not doing this and not doing that.*

Terry

Terry spoke proudly of his children, and stepchildren, and grandchildren, while showing his wall of family photographs. He did not mention any effects his symptoms had had on them.

Tom

Tom has major regrets about the way his life with his children has been affected.

> *My son, he's 23 and he remembers me walking. Running around. Working. And I used to pick him up, catch him when he was a toddler. My daughter, she can't remember me not walking on crutches. My twins, they're eleven. They don't remember me out of a wheelchair. My son left home early. He couldn't accept the changes. He saw me getting worse. he couldn't accept it and he left home.*

Will

Will, who has a young family, found it interferes with his desire to *"horse around"* with his sons.

> *I picked him up* [his young son] - *we were playing silly buggers and I picked him up and slipped over and I couldn't move. And I had to stay there for about ten minutes . . . so I have to be very careful doing those sorts of silly things, and don't do them.*

Faced with unexplained fatigue, he struggles with this inability to do what he feels he should be able to do as a dad of his age.

> *I used to do all those things* [play sports etc] . . . *but last year I went and played soccer with some kids. We only played ten minutes each way and I was bushed. I felt worse the next day. By four days later I was starting to come right. It took me that long to get over a twenty minute game of soccer.*

Changes in financial circumstances

People with chronic illnesses, particularly once they are no longer earning, tend to suffer financial losses. This can become a compounding problem, in which lack of work opportunities are converted into disability, handicap and poverty (McKenzie, 1996), a poverty trap of the worst kind, because no amount of personal effort will break the cycle. Lack of discretionary income is one of the most consistent factors in limiting life choices for people with disabilities (ibid).

Jack

For Jack, his change in financial circumstances started early after his first accident, before any of his current symptoms developed. At that time, he could barely walk, had dizzy spells, black outs, and loss of memory. With no diagnosis and no medical leave, his obvious choice was to resign. However, there were problems with the welfare system at the time that forced him to action that still upsets him.

> *At the end of the day, I had to do some horrible things. I was so ill . . . I had a big mortgage. I couldn't afford to have a stand down period of six weeks with no wages. So I went to work and got myself sacked . . . for the theft of* [a piece] *of second hand copper pipe. And I picked it up out of the rubbish tin and walked passed the boss and I waved it in his face and I walked out the gate. And he sacked me for theft. This was a major financial loss. I was on the permanent staff. I had a big superannuation. And I was so ill, I was forced to go to those measures.*

Once diagnosed, he sought his entitlement to ACC because the accident had happened at work.

> *We fought ACC for twelve years through the courts, to get some sort of a claim for me which, by the time I got it, I lost a third of it in lawyer's fee. So - and I lost more in wages the first year off work, than what I ended up getting in the total claim. So it was a complete financial and terrible mental thing to go through.*

Jim

Jim described very clearly the spiral down which financial fortunes can flow.

> *Before all this happened, I was extremely successful . . . I was mortgage free, owned a house. And after seventeen years, I ended up owing $200,000 . . . we had to go into mortgages and everything, since I got sick.*

He has given thought since as to how he could have avoided that situation.

> *I have thought about it since, because, I mean, now that I'm landed on my own, I don't even have those opportunities any more . . . looking back, yes. There were ways that it certainly could have been avoided. But, you see, it changed me as a person, because I used to be able to say, I could operate on instinct and impulse. You know? And not have to think. I've had to revert back to thinking, and I've gone the other way. Whereas I get quite serious . . . it's got to now, where I feel, at the moment, it's a slow painful process.*

Jim finds this downward progression very difficult to deal with, because it seems so much out of his control. Sometimes he just wants to precipitate the inevitable.

> *Am I better off just hitting the bottom, getting there straight away and then coming back? Or is there a better way to do it? Get right down there and then you know where you're at then. Because at the moment it just feels as if it's just a gradual, painful - there goes another thing, there goes another thing. Do I want to get rid of it all right now? Let's get it over and done with, so that I don't have this painful, slow, painful . . . And then I can come back from that. At least I know where I am with that.*

Terry

Property can also suffer a financial impact because of disability from the symptoms. Terry recognises the financial impact neglect of his house leads to. *"The value of your property suffers because of that."*

Social life and friendships

Social life was severely curtailed for most participants.

Jane

Friendships were affected, as Jane discovered.

> *People, if they can't see where the pain is, or see an injury, don't understand. I've had friends say to me, "Oh. but you used to be able to do that. You should still be able to do it." But they can't see. And they don't understand, it hurts, it hurts. It's mainly been friends.*

She lost her social confidence.

> *For many years I didn't go out. Because I couldn't sit or stand long enough. And people didn't understand, when you were bobbing up and down and things like that. And I probably didn't have the confidence either, just to do my own thing. If I wanted to lie on the floor, I couldn't. Now, I'll do whatever I want to do. I don't care about other people.*

Jim

Jim finds the social facade difficult too, involving acting a role he feels compelled to play.

> *It's like keeping up a brave face all the time . . . You keep doing things that you know you shouldn't be doing because, somehow, it's expected of you.*

> *You've got to do this, you're not allowed to be - you know - a failure, they make you feel.*

Rose

Rose now has a very restricted social life. She cannot sit for long enough to go to the theatre or cinema, finding that even going out for dinner takes too long and that, at events like a smorgasbord, once she sits down she can't get up to get her meal. She would love to be more involved in the community, because *"you get very lonely."* Friendships drifted away, partly because she moved towns, partly because friends couldn't *"handle it."* A close neighbour struck problems. Rose ended up being involved with those problems as well as her own and she *'just couldn't deal with it."* Her new friends are *"not from unsuffering people."* Most of all, having always been a shy person, she now feels very self conscious that people are looking at her. Her husband's protestations that it was all in her imagination were somewhat disproved when she was stopped in the street and asked if she had a bad hip. There is also the constant fear that *"you're moaning all the time"* which leads to the converse, bottling it all up.

Will

Will, who generally is better for keeping moving, finds there are limits to just how much moving he can do, especially when he is out at social events.

> *I used to get up and dance. But I can't do that either* [so] *you just don't go. I just run out of steam after ten minutes or something. But if I have to sit at a table, I can't keep still.*

Working life

Being able to undertake paid work is considered by society as an important aspect of daily living. Participants were asked how living with their symptoms had affected their work life.

Greg

Greg's original injury at work was *"accepted by ACC."* He has not been in paid employment for many years but is busy on a number of committees, holding office on many of them. He sees this work in unpaid employment as a trap when it comes to getting back into paid employment, as it does not appear to serve as sufficient work experience.

Jack

Jack is currently not in paid employment, spending his time, when able, working on his house and coaching children's sports teams. He has, however, tried very hard over the years to keep in paid employment. At other times he felt forced into remaining at work despite being unwell because a lack of diagnosis did not entitle him to appropriate benefits. Initially on an unemployment benefit, he was then put onto *"a sickness benefit and I was probably on that for about six months until they diagnosed my problem."* Once diagnosed, he *"went to a lawyer and said to him, and they transferred me on to ACC. But it took years of fighting it."*

Jane

Jane is on ACC and found their initial attempts to return her to the paid work force a less than happy experience.

> *They tried to rehabilitate me into an office. And I loathed it. Two hours and they said, "You can go." And said to ACC, "This is a waste of time." They made me sit. I had to see how long I could sit. Well, it was just cruel.*

Now working part-time for home support organisations, she has some satisfaction. *"What I'm doing, it mightn't be a glamorous job, but I enjoy it. I'm able to cope with it. If I can increase my hours, I'm going to do so. I get a lot of reward out of it."*

Jim

Jim is involved in voluntary work but is unable to undertake regular work hours because of the variability of his condition.

Mary

Mary has been told by ACC that *"there's no possibility of my being rehabilitated for work. I'm just sort of left."* When able, she helps in her daughter's shop, but has injured herself by falling while there.

Mick

Mick's working life has been *"very significantly"* affected by his symptoms. He has not been in paid employment since 1984.

Rose

Rose had to give up her own business because she could not stand for the long hours required. She has now become computer literate and has a busy time on the Internet doing voluntary work for organisations. She is not sure where her employment opportunities may lie. Her ACC file reports *"that there was no possible recovery, that my condition was permanent, that there was no possible recovery from nerve root damage."* She has subsequently been sidelined by ACC into their *"unemployable"* file.

Terry

Terry, also on ACC, has recently started part-time work with a support agency. He finds the number of hours he is paid for is greatly exceeded by the number of hours he actually works but feels that is a characteristic of that kind of job, not because his symptoms slow him down. Terry, used to very physically demanding occupations and still in the middle of his expected working life, finds his employment potentials greatly restricted through his lack of mobility, which he relates to both fatigue and pain.

Tom

Tom has been on ACC for twenty years, on and off. He has managed to find salaried work at times, particularly at first, but his deteriorating lower limb movement, increasing pain, and paralysis, have taken their toll. He had been self-employed part-time up until just prior to the first interview but ongoing problems with pain have meant he has not been able to work since.

Will

Will is on ACC's books but is working full-time and receiving no payment from them. *"I'm still under ACC. But I don't know what they're doing. They haven't been in contact with me for ages."*

Will's doctor, however, wanted him to stop work, a suggestion Will did not accept.

> *So he wanted me to give up my job. He said, "It's something you're doing at work." I said, "I don't think it's anything I'm doing at work. I had three or four weeks off on holiday and it didn't make any difference." I said, "It's all right for you to say find something else to do, but it's the only thing I've done."*

Being believed

Being believed was an issue raised by six of the participants. Three of the six have confirmed diagnoses of arachnoiditis and two have histories of major back injuries and multiple surgeries. Another participant, who felt she personally had been believed, mentioned a friend with similar symptoms who had not. Responses concerning being believed were raised in relation to descriptions of experiences in getting a diagnosis.

Jack

Jack had two long periods, prior to the development of his current symptoms, of being considered a *"nutter"*, both of which eventually ended with the discovery of valid reasons for his symptoms and subsequent relief by surgery. He found the disbelief he faced when he described his initial symptoms following his injury shattering when added to the already traumatic illness of his young child.

> *I was having dizzy spells and falling over, collapsing* [from what was later found to be a splinter of bone in his cervical spine]. *And they were telling me . . . that I was overworking . . . and I had a* [seriously ill child] *and that was causing the stress and that was causing the dizzy spells and headaches."*

Jack was eventually sent to a psychiatric unit.

> *I'd been to so many neurologists and they'd all told me the same thing. I was actually wondering whether I was, partially, making more out of it than what I - I knew definitely there was something wrong, but I was wondering in my own mind, at the end of the day, was I making more out of it than I thought. And they were sort of talking me into* [thinking that].

It was the strange nature of the symptoms that seemed to create the problems of disbelief. As Jack put it,

> *I think that some of the symptoms I was telling them, they couldn't believe were happening. I think they just didn't believe that a man of my physical size and strength couldn't use my right hand properly and I was having trouble moving my left ankle.*

He links his eventual diagnoses to what many perceive as the ultimate in good fortune. *"And I felt like I'd won the Golden Kiwi. After all the years of being told that I was a nutter."* However, as a result of these experiences he has not told his doctors of the change in his current symptoms and his increasing disability.

Jane

Jane has a friend with the same symptoms as Jane. This friend's GP told her it was all in her head *"whereas mine has never, ever . . . he knows me well enough . . . which I'm very grateful I've got a good G.P. . . . Nobody's ever disbelieved me."*

Jim

Jim was sent not to only to rehabilitation units, but also to psychiatric units. He remembers the health professionals there as determined to deny his pain and his disabilities.

> *They were trying to pretend I didn't have a back problem . . . they ignored every aspect of help that I needed, in an attempt to prove it was all in my head. The physio said that I was actually making the pain, creating the pain myself.*

He feels his attempts to explain made no difference. He found getting his food trays, which were raised on a self-service bar where he had to reach up to access them, extremely painful. He was also sent to occupational therapy, where he had to lean forward over a table, something else which exacerbates his pain.

> *I explained the difficulty* [to the physiotherapist]. *He said, "Well, just move it." My arm. I said, "I can't, I can't get it up." Oh, they just made everything so hard . . .*

He found the attitudes there *"just totally, totally degrading"* and feels he has constantly *"been struggling to be accepted."* He has a sense of a widening of the effects of disbelief, which *"makes you doubt yourself very much and starts to create doubts amongst others as well. So it just broadens the battle, if you like, for survival."* He can tell people what is happening *"and then they'll just turn around and tell me it's in my head."* He feels people have *"always attached it to the depression"* and did *"not at all"* believe he had the symptoms he said he had.

Jim noted the strangeness of his symptoms as a factor in disbelief, feeling he was the one required to provide an explanation for them *"There's more to it than just a back. I mean, there are rare things happening but, I'm sorry, I can't explain them."*

He now has a G.P. who, he feels, believes him. He attributed finding this doctor to good fortune. *"I've been lucky in that I've got a GP who will listen to what I say. And now, doubly lucky, because he has a second patient who he can compare like with.*

Mary

In seeking relief for her symptoms from a pain specialist, Mary remembers being made to feel

> *very, very odd. I really felt guilty for wasting his time. That's got nothing to do with it. The patient has to be believed. They have to have someone to listen to them and to believe them. Somebody in the medical profession has to.*

Mary is in the situation of not wanting to believe a gloomy prognosis in the absence of a diagnosis. Unable to have a confirmatory MRI until she has lost some weight, she has nonetheless been given a rather frightening prognosis in the absence of any diagnosis. *"The scar tissue was such that it would eventually cut off all sensation from the cord and I would be paraplegic. That's inevitable. There's absolutely no treatment."* On being asked whether she shares that belief, she replied, *"I don't want to.* [But] *I've went to* [two orthopaedic specialists] *and they're both of the same opinion."* Although she seems to accept their findings as a clinical diagnosis, she has decided that at this stage she does not want an MRI even when she has lost the weight, because she does not want the inevitability she feels the radiologically confirmed diagnosis will bring her. Mary's current G.P. did not, she feels, initially believe her but this changed over time.

> *Originally, I think there was a bit there. But because I kept coming back and I didn't change. And when I started with him, I'm not sure what was in the letter, but my doctor in H sent a letter down. Normally she left them open for me to read because she knew I would open them anyway. But this one was sent to him . . . It coincided with the time when I was explaining to him that I wasn't an idiot, I had some information and I wasn't going to be fobbed off. And I was actually with him for nearly an hour that day.*

Things did change *"dramatically"* from then. Mary thinks *"it may have been an informed"* letter.

Mick

When Mick was first *"complaining of me back playing up,"* his doctor linked it to stresses at home.

> *He put it down to all in my head. He started giving me psychotherapy and what have you. He just thought it was - you know, I was having problems with boys at home and things like that and he just thought well, that's what it was that was causing the* [pain]. *I don't think that was the problem.*

This experience has made him slow to seek further help, despite having *"got a lot more symptoms as things have gone on."*

Rose

Rose felt she was not believed right from the start and wonders if that was because she waited for her back to get better by itself and continued to work in the period immediately after her injury. Her husband of the time did not believe she had a problem and she remembers the specialist as patronising. He diagnosed a prolapsed disc, told her the pain would fluctuate but not get any worse and sent her for an epidural injection of Depo Medrol. Expectations of the efficacy of epidural steroids were, Rose believes, such that, when her pain worsened afterwards, nobody would accept her description of her pain. *"The pain I had after that was just unbelievable. And, well, on the day that he decided that I needed surgery, he actually wrote that I was worse after the epidural."* Because she felt no one believed her, she accepted a repeat of the procedure. *"I felt I had to go through with it because he didn't believe me. That was the only way I could prove that it was true."*

Rose has recently found a doctor who believes her - *"he's been marvellous."* Even so, Rose has withheld her old notes from this doctor because she does not wish them to influence his belief in her and she feared he would think she was *"jumping on the bandwagon"* because of publicity on arachnoiditis in the news media at the time when she first visited him.

Terry

Terry expressed a belief that one of the consequences of not being believed is that you are receiving financial support on false pretences.

> *Neighbours over the fence saying, "Dole bludger, get a job" because there is nothing visible. You might be sort of be walking around with the broken arsed walk but there's nothing that people can tangibly see. You haven't got a crutch. You haven't got walking stick. You haven't got a bandage on it. You haven't had a leg torn off or whatever.*

Being with those who implicitly believe because they share the same experiences has been a factor in the experience since the publicity in the mid 1990's. As Jim said, *"I could relate to just about everything they were referring to and I thought, "Oh, my God! Thank God for that.""*

The support groups that have developed since then have reinforced this feeling of implicit belief. Jim expresses it thus.

> *Some of it is just pure camaraderie, but it's knowing that, if I say something relating to my symptoms, somebody knows what I'm talking about. I don't have to go through a long process. You know, I don't feel I'm having to justify my existence.*

Tom

Tom has had intense emotional experiences dealing with the reactions of health professionals to the very serious symptoms affecting him. Not being believed made him feel *"very, very scared"* during a period when he desperately wanted help because of all the changes that were happening to him. *"Having them say it was psychological when you knew you were in a lot of pain and you couldn't walk, drives you up the wall."* He was sent for tests because his doctors had attributed his symptoms to psychological factors. *"And they sent me to* [a] *rehabilitation centre. To be tested. Because I had told them about it, and they didn't believe me."* He found it unhelpful to instead be told things he already knew only too well, as if they were a diagnosis, for example, *"you are paralysed,"* and *"you've got no control over your bowel and bladder."*

The feeling of not being believed continued throughout his tests at the rehabilitation unit. *"I kept saying, I can't feel it . . . And they didn't believe me"* He has had a sense of embattlement ever since. *"from then on it was a constant fight. turning round and saying, "I'm not in a wheelchair for fun. There's something wrong. Please, what is it?""*

Another side of disbelief for Tom was coming to hope that maybe it was psychological. *"That my mind had actually stopped me from walking because of the pain. And that they'd, you know, be able to treat me, and I'd be able to walk."* This made eventual diagnosis a double edged sword. On first being given a diagnosis of arachnoiditis he *"felt like a whole weight had been lifted off my shoulders"* because *"Phew, someone actually believes me."* But, at the same time, he had to accept that he may not walk again. Then the diagnosis was changed again to *"nothing"* and *"then came the quandary. What the hell is wrong with you. And I thought, "Oh gosh. Ten years down the tubes and here we go again.""* When he did eventually get reconfirmation of adhesive arachnoiditis as a diagnosis just prior to the first interview, he found the implications very hard to cope with. *"It just knocked me, And it still does at times."*

Will

Will has never had anyone say they disbelieved in the presence of his symptoms. However, he believes they are attributable to arachnoiditis linked to metrizamide myelogram even though his doctors do not believe that could be so. He would not mind if doctors could prove he doesn't have arachnoiditis, provided they could tell him what it was. What does irk him is their rationale that he cannot have arachnoiditis because of a conviction that metrizamide does not cause it and their apparent lack of interest in any of the literature he could show them that indicates otherwise.

> *No one seems to want to tell me what I have got, but everyone wants to tell me that I haven't got arachnoiditis. But they don't know what I have got. But it's definitely not arachnoiditis. Because you don't get that from metrizamide . . . I even took a whole lot of stuff to* [the specialist] *with me. And he said, "No," and he wrote in the letter to them* [ACC] *that the people in his - the neurologists in New Zealand, in his circle, said that you can no way get it from metrizamide. And I said, "Well, what about all the information that's printed about it?" And he said, "Oh, I haven't seen any of that." I said, "I've got lots of it at home." And he said, "I don't want to see it."*

This attitude led to a forthright opinion from Will. *"He just struck me as being an ignorant sort of a person who didn't want to know what I had but he just wanted the money that I was paying."* Will bases his belief that he has arachnoiditis on his MRI report. *"One of the things on my* [report] *I've got, it says I've got a thickened membrane . . . it's the thoracic part of my spine, Something in there is thicker than the rest."*

Hopes for the future

Within a unitary framework, time is not linear. Each moment is a relative present as a person's thoughts move back to their past experiences and memories and forward to their future hopes and fears when contemplating their situation. Having a condition considered 'incurable' and 'intractable' is not considered indicative of strong future possibilities. Participants tended to endorse this view when talking about their envisaged futures. The consistent theme in treatment possibilities was that all that could be done has been done and there was nothing more that could be tried. Societal expectations reinforced those views. ACC had moved four of the participants to what several participants termed the 'backburner' file, that is, not expected to ever return to paid employment.

Greg

Greg has recent MRI confirmation that he does not have arachnoiditis. While pleased that he does not, he is still uncertain whether things are that simple.

> *I don't really know. I mean, these - I sort of wonder if it's always this cut and dry. I mean, is it you've got it or you haven't got it. Or, is that you haven't got it today but you could have it in a week's time. Or, you didn't have it six months ago so we'll have another look now. Oh, yes. You have got it.*

Jack

Jack sees things in a despairing way.

> *I think that things are getting worse . . . the bottom of my back, the ME, and the things that are happening to my legs . . . They've virtually told me there is nothing more they can do for me - the vertebrae above the operation site will probably end up collapsing and getting worse and I may have to have*

> *that fused at some point in time . . . they can't do anything more in my neck area and they can't, probably, do anything more to the operation site, That's finished, like, whatever I've got, I've got. I'm stuck with.*

Jane

Jane, happy with her new young family and partner, is optimistic.

> *Hopefully, I won't get any worse and I'll be able to carry on like I am, or even be better. I'm pretty sure once they do something with my knee and I get back biking, I'm going to be that much better with the pain, rather than be sitting around.*

Jim

Jim feels all his options have been tried, leaving a bleak future.

> *I've had so much surgery already that there's nobody left who can do any more. But I'm aware of that and really I don't want any more. I'll keep what I've got and live with that. I honestly feel that the future is not good.*

He hasn't hit *"rockbottom"* yet but *"it's backwards, it's beyond my control."* He no longer feels he can change that progression because he has *"lost a lot of trust in necessary people."*

Mary

Mary is determined she is *"going to be 96. And I'm going to be able to walk, maybe not very far."* Apart from that, she is hesitant to *"put anything in concrete. I just want to keep going."* She has been told that the original damage to her spine is such that the pressure on her cord will increase. *"The longer it goes, the tighter the constriction and soon or later there will be nothing . . . Nothing can be done"* to prevent this outcome.

Mick

Mick is unsure of his future. He wishes he could *"get out and do some work"* but otherwise considers himself *"one of the luckier persons that's had the injections,"* at the same time mindful that *"it could still get worse."*

Paul

Paul is fairly philosophical and cautiously optimistic that he won't get worse. Being past retirement age, he has no problems with knowing he won't work again. *"I'm not terribly hopeful of getting any better. As long as I don't deteriorate too much further, I'm quite happy. I still haven't any pain."*

Terry

Terry finds it hard to accept he will not, in the future, be a major contributor to family income.

> *I guess, in time to come,* [wife] *is going to be the breadwinner and I'm going to be the full time domestic - which I am anyway. But I guess ACC is not forever. Somewhere down the track they're going to boot me off it and* [wife] *is going to be the major earner in this house. And I've got trouble accepting that.*

Tom

Tom has a young family and he find his future is full of fears.

> *I think the biggest fear is not knowing what's going to happen and you always fear that. And I have three fears. One is not knowing what is going to happen. The other is what the medical profession is going to do. They're a lot better that what they were. They actually explain things now. In the past, you put all your trust in them and they didn't explain anything. So, you didn't know. And there's always the fear of the unknown. And the other fear*

> *is, the worst one is, am I ever going to be able to, and how much more am I going to lose. That is the worst fear.*

Will

Will, also father of a young family, has had to change his plans for his working future.

> *The business that I'm in, that I rent, I've got an option of buying into it. But, because of what's wrong with my back, I haven't done anything about it. Because I don't know whether I could buy into it and then it* [his back] *could give out and then I'd be stuck with it. The fact that I don't know if it's going to get any worse or if it's going to get any better. Or what it is, or if it is that. So the whole uncertainty is the whole thing.*

The uncertainty is worsened by the way his symptoms come and go. *"For quite a while, I'll be really good, I'll have nothing. And then, all of a sudden, I'll get heaps of pins and needles or heaps of eye things"* He is pessimistic about the future. *"If they* [the symptoms] *are arachnoiditis, they'll get worse, I guess."*

Arachnoiditis and spiritual meaning

Spirituality is a reflection of the pandimensional nature of human life, postulated as an integral element within the principles of homeodynamics (Malinski, 1991a). Participants were asked how faith and/or spiritual dimensions played a part in their lives with their symptoms, and what effect their experiences had had on their spiritual perceptions and beliefs. This was not meant as an indepth discussion of their perceptions but to offer an opportunity for those who felt strongly about this aspect of their lives to voice their thoughts. Two did not find this question particularly relevant. Mick considered himself a *"practical"* person and Paul also considered himself *"not really a spiritual person."*

Jane

Jane has questioned her experiences but had not directly related them to religious beliefs.

> *I probably question that all the time in my mind, And especially when I see people run, and walking and jogging, and things like that. I always say, "Why isn't that me?" But not in a nasty way. I just envy them. Because that used to be me.*

Jim

Jim, brought up a *"strict"* Catholic who served as an altar boy, is not now a *"practising Christian or anything like that. But I believe there's something there"* and he has an internalised practise which is *"unnoticed. And, I think, that's more important than to be seen to be practising."* Someone once said to him *"You must have been a bad little bugger when you were younger, and it's come back to haunt you"* but he rejects that view and any theological thinking that pain is developmental for the soul. *"I don't think that's the case at all."*

Mary

Mary married into a Catholic family. She considers herself a Christian *"as in believing in God and the way I like to live"* but she feels the odd one out as far as Catholic teachings and attitudes go and that it provides her no personal support. *". . . you get totally different attitudes. When you think you're getting support, they tell you other things . . . it's not something I can hold on to."* Nonetheless, she hopes an afterlife will be there for her at the end. *"I just sort of hope, when my time comes, my parents will be there and my grandmother will be there."*

Rose

Rose used to be *"what they call a born again Christian."* However, she had a frightening experience that left her alienated from that church.

> *I went to a healing session, after the injection. And the healer, he, I can't think of his name, he's a famous New Zealand guy, was showing the minister how to do it. And they decided they'd try it on me. And they lifted both my legs and the whole congregation was there and I screamed . . . And that's when I knew it wasn't from God. Because they would have known not to lift both my legs.*

She has since moved towns, but has not rejoined a church because of the *"way you've got to go and explain everything again"* to the new people she would meet. Nonetheless, she still retains a belief in God, and find this helps in a lot of ways. She strongly rejects the idea of divine punishment or pain as developmental for the soul. *"I can't see it. Nobody should be ever put in this position."*

Terry

Terry also sees himself as *"not a greatly practising spiritual type of person."* He attributed some of that attitude to the *"hardnosed training"* of one of his previous professions. *"If you start questioning the meaning of life when you're hosing someone up off the road after an accident, you stop doing it."* He sees avoiding that kind of question as a *"coping strategy"* and has accordingly adapted his present life to match his situation.

> *I accept it now. I wasn't so accepting of it when it happened. I thought that I'd been dealt a bit of a bad deal. But now I accept that I can't do the things that I want to do. But I'm more at peace with that sort of thing, That's the way it is, so do something else that you can do.*

There was no linkage made by those who had spoken of suicide with religious teachings or spiritual beliefs.

The worst and the best of daily life

The previous descriptions have been of particular facets of the participants lives. The researcher wished to see what impact participants felt the experience of living with their symptoms had had on their lives as a whole. This overall glimpse was considered more relevant than ratings gained by using separate measurements of particular symptoms, such as pain scales, as it was more in keeping with the Rogerian view of humans as unitary beings. Accordingly, using a simple verbal rating scale, participants were asked to rate how they felt overall at interview, if ten was the worst they could imagine themselves being and zero was the best. They were then asked to say what rating they would consider themselves to be at their worst and at their best. With one exception, participants did not find this difficult, and readily used the scale.

Greg

Greg had a sore throat at the time this question was asked and he felt this had raised his rating to a four. At his best, he feels he would be a two. The worst day he could remember was an *"eight, eight and a half, perhaps."* and that was from *"moods and everything else. You know, when you sort of allow yourself."* Greg is on antidepressants and had identified depression as a major factor in his life.

Jack

Jack could not place himself *"at the top end of the scale, because I'm not in a wheelchair."* However, he feels he is *"certainly getting toward the second half of the scale so far as just general life things,"* and relates this to increasing dependency on other people and on medication. *"I've got more dependent now. And I've got some drugs."*

Jane

Jane, who at the time of interview had both a headache and backache, rated herself as a six. This was her most common level of being. She could, at her best times, feel herself to be a three but these moments occurred only as *"parts of the day"* and were unpredictably variable as to time of day and duration. At her worst times, when she can do very little, she feels she could *"probably get to a nine."*

Jim

Jim *"wouldn't get a whole good day but I would certainly have a peak"* at which time he would be four or three. At interview, he felt himself to be *"about seven."* His worst days are a nine. *"There are days when I just can't get up."*

Mary

Mary related her good and bad times to pain. She felt she reached nine at her worst. She *"won't let"* herself reach ten. For her, a really good day would be a six and that's only on *"days when I take more medication than I should."* Prior to her interview, she had taken a double dose of analgesia and a sleeping tablet which she uses for its muscle relaxing properties and rated herself about a six and a half during interview.

Mick

Mick expressed a small variation in his level of rating, which ranged from four to five, depending on how much he could actually do. *"Like there are times when I can go into town, I could probably walk the whole street a couple of times. And there's times when I can only walk, say, fifty yards down and I'm buggered."*

Paul

Paul was the only participant who found himself unable to find any relevance in the idea of a scale. He has no pain that interferes with his life and finds *"no problem"* with his lifestyle, even with his major decrease in mobility, reiterating that he's *"quite accepting of my condition."*

Rose

Rose initially felt she was *"a seven"* at the time of interview but, after giving consideration to how she was at her worst, she lowered that to *"a five."* For her, the bad days come when her pain is at its worst and on those days she would definitely be *"a ten."* Such days occur at least three times a week. She describes those times as *"like it's out of control and I can't control it and I lose control of myself."*

Terry

Terry, a four at time of interview, can be *"a two with medication."* At his worst, he would be an eight. These ratings are linked by him to how much activity he is able to undertake. When he has a migraine he *"just can't function"* and as far as he is *"concerned, switch off, that's off the scale."*

Tom

Tom, already in a wheelchair, relates his scaling to other things that might be permanent, such as loss of bladder or bowel control, rather than to pain or loss of lower limb function. He hopes his pain is *"temporary."* At the time of interview he was *"probably about a five"* which was his most common level of being. During times of loss of control, he rates himself as *"an eight."*

Will

Will places himself in the middle, a four or a five, because he can *"still go to work, which is a good thing."* If he could not do so *"it would be a ten."* He has had to take days off work already, not with pain, but with fatigue.

Seeking relief

Pain is the foremost symptom and depression and insomnia two other symptoms for which participants were likely to have sought help and relief. Several participants were also on medication for other concomitant conditions, such as diabetes and arthritis. A wide range of self help and pharmaceutical options have been tried.

Pharmaceutical preparations

The use of pharmaceutical products for pain relief is widely accepted in the Western world, and there is an expectation on the part of those seeking it that relief will be obtained, at least to some degree. This has not been the experience of the study participants, who have found their medication for pain relief largely inefficacious. Participants also use pharmaceutical products for a range of problems other than pain management, including depression, muscle spasms and sleeping difficulties.

Greg

Greg takes medication for a number of problems, including *"pain relief, muscle relaxants for my back. I'm on medication for asthma. I'm on medication for my depression. And I take sleeping pills to get to sleep at night."* He feels his asthma is probably *"more nervous asthma than anything, really."* He has noted an inconsistency in prescribing for his medication.

> *I've been in a hospital where they're treating you for pneumonia and not treating you for the other stuff. And you get sick of telling people that you take other medication for other situations. You sort of think, oh, well, what the hell. Fix the pneumonia and when I get home, I'll take the other pills and everything will come right eventually.*

Jack

Jack spoke of an undesirable increase in his use of medication just to cope with his day.

> *I'm more dependent now and I've got some drugs there, DHC. And I mean I now have got to - I used to take them when I had something on, so I could*

> *cope with what I was doing. But now I'm taking it just to make myself feel a little bit better.*

Jane

For headaches, Jane usually takes *"a couple of Panadol, and sometimes two hours later, I have to take another two, and I can usually get rid of 90% of the pain that way. Just by lying quietly."* Even so, her headache may still be there the next morning and can last several days.

Jane is restricted in her options for medications.

> *I'm very allergic to a lot of pills. I can't take a lot of painkillers. I can't take anything with codeine or anything. All I can take with is Fortral and Panadol. I have to be content with those two. And I have to be pretty bad to take the Fortral.*

Aware of the limitations involved in Panadol usage, Jane does not usually take more than eight a day. *"Sometimes I take more, but, umm, I'm pretty careful. Because I know what can happen."*

Jim

Jim takes a number of different medications. *"There's ten or eleven darned pills, that's just the morning. There's more to come, the same again tonight."* He is on medication for *"arthritis and fibromyalgia"*, *"blood pressure"* and *"cholesterol."* He is currently on Prozac, which has less side effects for him than Amitriptyline. He has not found that any of the anti-depressants did anything for the pain. *"It doesn't contribute to any - OK, it might stop the amount of depression, if you like, but I don't think it affects - it certainly doesn't contribute to any relief anywhere."*

For pain, he takes Voltaren. *"What I have for pain is Voltaren. I can have three of those a day."* He believes the Voltaren does have a therapeutic effect because he knows what happens when he does not take it.

> *Because, I mean, I've tried to come off them, from time to time. And within five days I've had it. I'm back on them. It then takes time for it to build up again. You know. It takes well over a week to, umm, ahh, to get back.*

He has *"been on those for about 11 years now"* and does not feel he gets any side effects from it.

At one stage he was prescribed Valium for his pain.

> *At one time, I was told, "Oh, just keep taking Valium. Keep taking Valium." That was the specialist advice, take some more Valium. And I found that that was actually making me worse, and stopped on my own accord.*

He stopped it because he found it interfered with his feelings of control over his situation. *"You couldn't do anything. Yeah, you were just - because I think that was what was wrong. That was why it wasn't working. Because I couldn't do anything. Because that was in control, I wasn't."*

Jim also takes a sleeping pill at night.

> *I have the medication, Temazepam, for sleep. And the most I can get out of them usefully is four hours. I can take up to three a night if I so wished but I try and get by on two and like, when I know - with, like tomorrow, I know if I take three tonight, that's fine. Tomorrow I can have a rest day and it doesn't matter. So I do it that way.*

Mary

Mary finds that her lower back pain *"when it's very bad, seems to drag everything else as well. It just seems to roll up my spine."* When this happens, she gets *"on to the medication and hope that something will work and just keep going."* She has *"days when I take more medication than I should"* and doubles doses and mixes tablets to achieve the desired effect. She took four Digesic prior to interview and uses *"the Baclofen, which although it's a sleeping tablet has wonderful muscle relaxing properties."* She is also on medication for migraines. Mary uses *"Digesic, Amitriptyline, Paramax and sometimes the Maxolon separately, Baclofen and Voltaren D, the soluble one."* The Amitriptyline, 150mg, is for both depression and pain management and *"seems to hit two birds with one stone."*

Mary has worked out a dosage plan that enables her to cope with her day. *"I dose it into basic areas. I have my first what I call a cocktail at about 4 o'clock in the morning. And that's one Amitriptyline, two Digesic, a Voltaren and half a Zoplicone."* On really bad days, her doctor gives her Voltaren injections. She had Voltaren injections every second day for a week after a recent fall.

She has noted some side effects from her medication use. Amitriptyline causes marked short term memory loss.

> *Because that's one of the side effects of Amitriptyline - short term memory has absolutely gone. Drives* [husband] *out of his tree at times. Because something will happen at night and I'll ask him about it again in the morning. Gets really p'd off.*

Mary takes Voltaren orally and intramuscularly. Since November 1997, when she fell down some steps, she has taken soluble Voltaren D twice a day in her 'cocktail' combining it with Amitriptyline, Digesic and half a Zoplicone. At the time of her fall she had Voltaren injections every second day for a week. She also has Voltaren injections from the doctor on *"the really bad days."* While this achieves some relief for her, she is aware of a price she has to pay for that relief.

> *Personally, I think that the drugs like the Voltaren, the what-have-you, they can affect you. The Voltaren, the anti-inflammatories, I think actually reduce your ability to, for the lung function to be as good as it could be. And I know if I've had a really bad few days and I've been on a lot of medication, I'm inclined to have more difficulty breathing.*

Voltaren is contraindicated in patients in whom asthma is precipitated by acetylsalicylic acid but respiratory problems are not noted as an adverse effect (Voltaren information insert, 1993).

When talking about the possibility of opiod use, Mary revealed she now has *"an absolute fear of really needing* [opiods] *somewhere down the track and because I've had them up till then, they're not going to work as well."* Consequently, she feels she would find it difficult to know if, or when, she should start on opiod medication.

Mick

Mick takes *"pills for me diabetes. I'm taking Panadeine like, when the pain gets too bad. And that's basically all I'm taking in medications."* He has had no medication specifically for the burning in his feet.

Paul

Paul does not take any medication now, although he did take Panadol and Digesic prior to his surgery.

Rose

Rose's need for pain relief has increased after each intervention she has had. After her first epidural steroid injection she had *"gone from before that injection I'd gone from just Panadol and they'd actually put me on Valium and Actopen for those three months* [prior to surgery]." Rose has developed a deep distrust of medication and laughingly admits she must be a nightmare for any health practitioner trying to help her. *"I take it* *to ease it when it gets so bad that I can't stand it . . . And I don't believe in taking it to prevent. Because how do you know if you need it?"* She did try morphine once but was unable to bring herself to take it in an effective manner.

> *I gave in and tried it once. Just one tablet, 10mg tablet. And it didn't do anything. And I was in agony and I was too scared to take anything else . . . I was given 20 tablets. I've still got 19 left.*

She now feels uncertain about any future individually formatted regimen for opiods

> *It probably wouldn't work. Because I'd come to the conclusion that you're relying on something. And, you know, maybe you don't need it. Where probably you do need it, but in my mind, it's telling me, how do you know you need it?*

Rose also has various fears which she thinks are irrational and not helpful to her situation, which arose from a reaction she had to postoperative medication.

> *Because when I had the last operation on my knee, I thought they'd given me an overdose of Pethidine. And I just, went into, like a panic attack. And I can do that myself. If I swallow something that I don't know, if I think I've taken them too close, I just put myself into that panic attack for fear.*

Just what she is afraid of she does not know. *"I don't know. I'm just terrified of them."* Despite these difficulties, her doctor has managed to persuade her to take a combination of medications.

> *It's taken me a lot to even get onto what I'm taking. And it's, I have to have a lot of reassurance from the chemist. Not the doctor. It's the chemist I actually trust more than the doctor. To tell me what's going to happen.*

Currently, she takes *"DHC, Digesic, Valium, Imovane, Voltaren injection"* and she uses these in a cocktail combination. *"In the morning* [Dr] *put me on what he called a cocktail to try and get it under control. And that was a 5mgs Diazepam, 1 DHC and 2 Digesic all together. And again at night. The same thing."*

Rose has frequent Voltaren injections from her doctor and had to alter interview times to seek relief of her *"tailbone"* pain. During interview, she did not enlarge on her use of Voltaren.

Terry

Terry uses various medications to relieve his pains. He uses Digesic for the pain in his back. The neuralgia he experiences in the right side of his face responds to aspirin.

> *I can get rid of it, if I take a couple of disprin and go and lie down, sort of straight away, it will generally disappear in half an hour. If I don't, it'll ultimately turn into a migraine . . . they just go on and get worse and worse and worse.*

On the couple of times he has let the headache develop, he has ultimately been given an injection of what he assumed was *"morphine, I guess it is, to stop those,"* given by the doctor on a home visit. For other pains he takes a mixture of medications. He has discussed the safety of his chosen cocktail combination with his doctor.

> *Two Digesic and two Disprin together, and the doctor said that's quite a good cocktail and certainly won't do any harm. And if I do that, pull the curtain, go to bed, no radio, no TV, nothing, and just sleep, I can get rid of it.*

Now that he has started part-time work he has had to increase his medications. *"I'm having more Digesic now to manage than I would be prior to doing the ten hours. Because I'm probably on the go and on my feet more."*

Tom

Tom experiences severe pain frequently, despite his medication. *"Like I'm on DHC twice a day and occasionally I have morphine tablets in between. I try very hard not to take anything in between. I'd rather go to bed."* Like other participants, he does not have his medication plan focused on preventing pain, but on taking extra when it gets too bad. Because he cannot feel anything below his waist, he is often too late when he does take it, and *"the tablets won't stop it."*

For his chest pain, he takes Anginine at home.

> *I didn't even bother going to hospital. I just took my, I've got Anginine spray. And I take that now. I have got angina. It was very scary, the first couple of times, because they didn't tell me. What the problem was. After the third time, they actually told me. And they gave me the spray. Said, this is the problem, dude. You know? Take this, and if it doesn't take it away after two shots, then turn round and come up.*

Will

Will primarily requires analgesia for headaches.

> *When I'm starting to get one and if I take Panadol, it's all right. But if I don't, quite quick, they'll thump and I can feel my heart beating in my head and that sort of thing. If I don't take something for it, I'll have to go home. I keep Panadol at work in my toolbox.*

Otherwise, he prefers to get by without medication, if possible. *" I was given some Voltaren but I haven't taken those. I take as little medication as I have to."*

Epidural steroids

Jane

Jane was having epidural Depo Medrol, with good effect. *"Depo-Medrol did relieve the inflammation in my back. I got good results from it. And was able to get myself going again."* She then found out Depo-Medrol is not recommended for use in the epidural space.

> *I've had so many epidurals, it's not funny. But I was, again, never told what Depo-Medrol would do to my back . . . I could have been told, now that I know what was going on, that epidurally Depo-Medrol should never be given. Because of the horrific side effects, I mean, that I've learnt this through ASAMS . . . I was very distressed when I found out that, you know, it should have never been given epidurally.*

She then decided not to have it epidurally again and changed to a doctor who suggested intramuscular administration of Depo-Medrol as an option.

> *He gives me the choice. When I first met him, he explained to me all about it. First time in my life. And it is your choice. You sign a consent form. I'm not talked into having it. And he's very understanding.*

Unfortunately, this method has been accompanied by severe side effects.

> *And, at times I had, after the injections, severe pain. I mean, severe pain. I would be in bed three or four days afterwards. And severe headaches. But I just thought that was part of what I had to go through, to get my back right. Because it did come right after three or four days.*

She finds these side effects too long lasting and severe to feel she gains any overall benefit and has recently decided not to have that treatment any more.

Mary

Mary's epidural steroid injections are linked by her to a major worsening of her condition after each administration. The pain in her legs dates from the time of her first epidural injection of Kenacort-A40 (Triamcinolone acetonide).

> *It didn't set in until after my first epidural. That was just off and on, and then after the first epidural, that's when it became permanent. I had it from the time the local anaesthetic wore off. I had it before I left the doctor's office.*

Mary was also rather perturbed by the places where the procedures were performed. *"It was just done in - the first one was done in, like, a little cubicle. And the second one was actually done just in his, um, office where he had like an examination table."*

Because she felt her change in symptoms was related to the first injection, she requested a change in agent for the second.

> *He* [GP] *sent me for a second epidural - and - to the same doctor - and I asked him not for the same one. I said, look, I've - I thought I'd had a reaction to it, is all I could describe it as. And he said, "Oh no!" He said, "We've sorted it out this time. It'll be different." And I still wasn't told what I'd had. And they gave me the same thing.*

It was when Mary obtained copies of her medical notes that she discovered the same agent was used a second time and she was even more upset to discover that the same agent was also used *"at the second operation*, [surgeon] *put the same drug on my nerve roots that I'd had in both injections."*

Rose

Rose, like Mary, believes she had major adverse effects after her epidural injections. Hers were of Depo-Medrol, and afterwards she experienced *"a cramping pain. Like* *severe cramp. it was there after the epidural. That's when I first had the cramp, after the epidural."* Rose was given two separate injections of Depo-Medrol. She has since read the insert sheet that comes with Depo-Medrol and believes some of her symptoms compare with recognised side effects described in that insert, and that she should not have been given the second injection.

> *Certain adverse reactions, when it's injected epidurally or intrathecally. A lot of it was insomnia, which I had right from then too. That's when I was put on sleeping pills, when I was still in hospital. And I haven't been able to sleep ever since. The severe, the worsening of the pain. Cramping. Bowel and bladder dysfunction. It states these are certain adverse reactions. Now, if he'd gone back and looked at that, he would have found it. And I can't see why he gave it to me again.*

Terry

Terry has also had epidural pain relief.

> *"I've had an anaesthetic, a spinal anaesthetic thing, to help try and get rid of that lower back pain when I first did it. It was administered in* [hospital] *outpatients. And then I was sort of told I'd have to lie there for probably three or four hours, but I felt fine after a couple of hours so I was told I could go. I was told it would probably last from about three to six months. It actually lasted about two weeks . . . I did get a result. Yes. I got quite good pain relief. And I actually thought it was going to be good. And I don't know whether I overdid something at that time. Because I actually thought I was getting better. And then I got medicaled out of* [his job]"

Alcohol

None of the participants feel they have a problem with alcohol, either in relation to pain, or generally. Three participants mentioned their past experiences with alcohol.

Jim

Jim used to drink alcohol.

> *I had to give it up because of the medication. There was just no way you can handle it. No way you can cope with it. Because you can't take alcohol because of the medication. And I'd hate to think what would happen, if I ever did. It frightens the life out of me.*

He knows that alcohol can have a temporary relieving effect on the pain. *"Oh, for a time it does. Yes, sure. In the morning it was a different story. So, there's no mileage in that at all."*

Mary

Mary had also used alcohol at the time of her initial injury and prior to her operation. *"I took to drinking very, very heavily to numb the pain and then it just became a cycle. You know? You'd feel great, and then you'd think, oh, what's the point, I might as well end it all"* She does not drink alcohol now.

Terry

Terry has used alcohol for his pain in the past.

> *Alcohol is certainly a relaxant or a help or what ever. It seems to amplify the medication, if you - I know if you go and take alcohol - this was five or six years back when I was a little bit more unsettled than I am now, if you*

> *like. Still a non-acceptance of the way you are. It's much easier to drown your sorrows, or get some relief, or get some sort of escape, by getting, by drinking. And combining drugs and alcohol amplifies the effects of both, and it's very easy to just blot yourself out with a few brandies or something.*

He had found that *"between the pills, if I drank, I didn't need the pills. And when I needed the pills and I drank, I really got a good effect from them."* He doesn't think he was an alcoholic, because he can now have so little and that's enough. However, he feels "*there was a good chance I could have turned into one.*" He now only has *"one or two glasses of wine a week."*

Counselling

Tom mentioned that he had had no counselling throughout his progressively worsening ill-health and disability. He felt counselling would have been of value to him in his situation. He is now aware that he could have seen the field worker with the Multiple Sclerosis Society but he

> *never used her because the ASAMS society is new and at that stage, up until we formed it, she was MS and I always looked on it that I didn't have MS, so I couldn't. You know? And secondly, was that I couldn't afford a professional, because it would have meant I would have had to pay. ACC wouldn't pay. So I had no means.*

At the time of interview he was still feeling that he'd *"been sort of coping"* because he'd *"been able to help other people"* He felt seeing people worse than him, by his unstated definition of 'worse,' *"actually helped me get on top of my own problems."* These people did not necessarily have arachnoiditis.

> *Not so much in ASAMS society, although there are people worse than me, I feel. But especially when I joined DPA* [Disabled Persons Assembly]. *There*

> *were people like C and D and so on. And it helped me to turn around and see them and turn around and think, well, hey, I'm not so bad as I thought.*

Cryotherapy

Only one participant amongst those who experience burning pain mentioned applying cold to the area. Jane has an area in her back *"like somebody with a match in there."* When it gets really intolerable, she will *"usually go and grab an ice pack and whack it on the area."* Her icepack is *"peas out of the freezer"* and it does provide relief.

Distraction

The tool most commonly used by participants was distraction, although they did not always name it with this term. Distraction involves focusing attention on something other than the pain sensation (McCaffery & Beebe, 1989) and increases tolerance by 'tuning out' the pain during the time of distraction (Edgar & Smith-Hanrahan, 1992).

Jim

Jim practices distraction for much of the time.

> *I basically remove myself from what is drawing attention to it. I try and do something that'll distract, if you like, create a distraction. And, invariably I end up messing about on the computer. Or reading a newspaper. Or, if it's that bad, get out of the house and go somewhere . . . I just automatically do that. I mean, I - you allow it to happen within yourself so long and you know it's going to get the better of you. and at that point you have to do something. Otherwise, you know you'll sink.*

Tom

Tom also has a love of computers and used them for distraction. Unfortunately, pain in his shoulders possibly attributed to repetitive strain injury from wheelchair use has limited his ability to use this tool. He seeks activity as a means of relief. *"And you're moving around and doing things to take your mind off it. And help control it."*

Will

Will, who suffers from a high degree of fatigue as well as his pain, also tries to use activity to take his mind off things, and constantly seeks a balance between enough rest and the distracting power of action.

> *I've got to stop what I'm doing or sit down or. Although, sitting down will sometimes make it worse, rather than better. The best thing I can probably do, is keep moving. If I keep real busy, I don't notice it as much.*

Heat applications

Rose was the only participant who mentioned heat as beneficial. She finds hot baths definitely relieve her pain, and has had a spa installed in her back yard. Unfortunately, financial restrictions limit her use of it. After one of her surgeries, she awoke with severe cramp in her leg, which was also alleviated to a small degree by heat. *"When I come out of theatre they had to get hot water bottles on my leg. Every part of my leg felt, just the cramp was so bad."* This was the only mention by a study participant of applications of this kind by health professionals.

Natural therapies

Natural therapies is a generic term which can be used to include a range of therapeutic options, such as chiropractic and osteopathic therapy, homoeopathy, herbs, massage and acupuncture. Only Jack, Jane and Terry mentioned exploring therapies of this kind.

Jack

Jack has had relief for his headaches from chiropractic therapy and massage.

> *Where I've had the operation in my neck . . . that's probably causing the bad headaches, because sometimes I get relief from either massage or chiropractic. And that helps. So I know that, definitely, when my neck's - if I go to the chiropractor that definitely helps, so I get relief from chiropracty there.*

Jane

Jane has spent *"heaps on all sorts of things. I've been to naturopaths, I've been to herbalists, I've been to osteopaths, I've been to chiropractors. I've been to just about any - colour therapists. But the acupuncture was the best of the lot."* She had her acupuncture in China while there on holiday, but this was *"early in my back time"* before the development of arachnoiditis. Jane has also found Swedish massage helpful. *"It relaxes the muscles, that's very relaxing."* Unfortunately, she has not had ready access to such massage. Her GP sent her to an osteopath once and she found that was better than physiotherapy because it included massage.

Terry

Terry had been getting prolonged and frequent headaches arising from pain in his neck. He found a combination of physiotherapy and osteopathy helpful for this.

> *I had some treatment at physio, at the hospital and a private osteopath, which I find suits me quite well, and I haven't had the neck thing for quite a while. Even though it's quirky, and it's funny at the moment, it's never been as bad as that since I had the treatment.*

Physiotherapy

On the whole, participants have not found physiotherapy particularly useful for pain management. Nor do they have access to ongoing physiotherapy for prevention of disuse problems, which may augment that pain.

Jane

Ironically, while it was a physiotherapist, who had first hand experience with arachnoiditis through treating another lady, who first alerted Jane to the possibility that she had arachnoiditis, Jane has found physiotherapy to be *" no good at all. It stirs my back up something terrible. They put that machine on me* [and] *that stirs my back up something chronic."*

Jim

Jim also found physiotherapy did not focus on his particular needs. *"He* [a physiotherapist] *was supposed to be coming to do the back but they - I explained the difficulty, he said, "Well, just move it."* He also recalls being told he was responsible for his pain, a suggestion which makes him angry still. *"Physiotherapy! Well, there was an instance, particularly with the neck, whereby they again said that I was actually making the pain - creating the pain myself. When I was doing the exercises. Well, that's impossible."*

Paul

Paul had tried physiotherapy prior to his surgery, but had not found it effective. *"It didn't really, it didn't do any good."*

Positional changes

People with pain tend to fall into two groups – those for whom pain is worsened by movement, and those who find it gives temporary relief. Participants described lying down and/or being still as easing the pain, possibly because there is a relaxation of the tethering effect of the scar tissue on the cord and nerves.

Greg

Greg had long terms of bedrest following his first injury but does not use that strategy now.

The thing to relieve a slipped disc is bedrest. And I had about a month in hospital, or something like that. Got frowned at by the nurses for lying the wrong way or that sort of thing. Had to lie flat on my back for ever and ever. And it's just basically gone from there . . . That was ten years ago. And after the three months, I was sort of back at work, and six or eight months after that, it sort of flared up again and so I went back in to hospital for a week and I had another month off work, as it ran.

Jack

Jack's pain is much worse on sitting and sometimes, on standing, it is so severe, he must stop what he is doing.

> *If I do the dishes, standing at the bench for about two or three minutes, I've got - I get a severe pain that's that bad, it's sort of a passing out pain . . . I just want to collapse. And I'll come and lie on the floor and I've got to lie down for about twenty minutes. And then it goes away and then I can stand up, go and finish.*

Jane

Jane finds *"just sitting up and resting . . . And it's just sort of getting my posture sort of right, Or lying flat"* can all help briefly ease the pain a bit. Overall, *"lying flat is probably the best thing out."*

Rose

Rose finds lying down and keeping still the only thing that gives her a little relief when her pain is really bad and she goes to bed for the day to achieve this.

Terry

Alternating the weight bearing side can help. Terry, when sitting, chooses a hard chair with arms and sits with his legs crossed to keep the weight off his coccyx, alternating the uppermost leg. He also puts *"quite a lot of weight"* on one or other elbow. When out walking his dogs, he sometimes adopts a squatting, bent forward position to try and stretch his back region. He also finds prolonged standing difficult and must sometimes sit or lie down for a period of time.

> *As I go through the day that* [the dull ache] *generally increases to a point where, I'm getting tea, I have to spell myself by sitting down, because I can't stand at the sink for more than about five minutes. And by the end of the day, which for me is about seven pm, I can't stand on my feet another minute. I've got to go and lie down.*

Tom

Confined to a wheelchair for much of the time, Tom's options are to go to bed or to move within the chair. *"If it's moderate, you tip yourself up in the wheelchair and ease the pressure . . . When it's just bad, you go to bed. Even though it doesn't ease it completely, it's a hell of a lot better than trying to be up."*

Smoking

The majority of the participants smoked. Of those who smoked, not all mentioned it, even if they smoked during the interview. Four participants spoke of the pleasure or relaxation smoking gives them.

Jane

Jane always goes outside to smoke.

> *It doesn't relieve the pain, I'm convinced of that. I think if you're stressed, it helps the stress. I think that's why I do smoke, because I can go out and relax. That's my five minutes outside. If I'm in agony, I don't go and grab a cigarette. It's not my relief.*

Jim

Jim feels very strongly about the attitudes of those who feel he should not smoke. "*I mean, all it would take* [to upset him] *is somebody to say, "Oh, look, he still smokes." For example, I have nothing else. That's the only thing I spend my - it's the only pleasure I have, thank you.*" Jim has wondered whether to try to smoke marijuana, but has never had the opportunity to access any.

Terry

Terry used to smoke, but gave it up because *"my reading indicates that cigarettes aggravate the problems . . . I stopped smoking about four years ago."* He thinks smoking had been *"aggravating things."* He has never *"smoked marijuana or anything for pain relief."*

Tom

Tom now has heart problems, and has been told not to smoke. *"But I look at it, you've got to die of something, And I've given up a - I've lost a lot. I haven't given it up, I've lost a lot."*

Swimming

None of the participants went swimming. Apart from Jane, they did not say whether using public swimming pools psychologically, financially and physically created problems for them. Jane, once a keen swimmer, regrets the loss of access to physiotherapy pools at hospitals.

> *I actually like swimming. But I don't like swimming in public, if you know what I mean. If I had my own pool, I'd do it. I used to be a great swimmer, I was a champion swimmer. But as I've got older, I don't like getting into the water, or there's too many people around and things like that. You try and swim and everyone's looking over and things like that . . . I actually used to go to the hospital pool and found that very, very good. But you're only allowed a certain time up there and then you get better and good-bye, sort of thing.*

Chapter Eight: The role of nursing in participants' experiences.

It might have been expected that nurses would have played a leading role in helping those with arachnoiditis, especially in relation to pain management. Nurses play a prominent role in providing pain relief for those with cancer and those with acute pain. Evidence of their role in providing pain management for participants was not specifically sought at interview. However, analysis of the interviews revealed a disturbing pattern. Nurses were not mentioned in the most glowing of terms by the participants in this study. Indeed, some have downright unpleasant memories of various experiences with nurses.

Jack

Jack had a *"shocking"* experience when he had his myelogram and became visibly distressed when recounting the events of that time. The seven attempts required before the needle was successfully inserted for his myelogram caused him major pain and raised issues of concern regarding technical expertise and judgement of the staff involved and of Jack's informed consent to the procedure. Informed consent is a process, not an isolated incident, and Jack was having second thoughts about the wisdom of proceeding.

> *I just didn't want them to do it, and they had - it was a guy that did it and three nurses holding. Because I got so, I was so anxious and nervous and, I think because they were trying to push into the spine, they sort of got half way through and couldn't get in. I started getting so I was shaking and my body started going in to a sort of shock.*

He remembers the ambivalence he had, because he desperately wanted a diagnosis to explain the very distressing symptoms that had led to him having the test, so he did not actually demand that they stop. However, consent based on hope or fear is not a free decision and there were other options, such as CT and MRI which he could have been offered once it became obvious that there were difficulties with the needle insertion.

Jane

Jane had come to a rather less than flattering view of surgery and raised an interesting viewpoint in her claim that most nurses shared her view. *"You'd go to the length of the world for a cure, if you can get away from surgery. I think most nurses feel like that. You know, if you can stay away from the knife and do it naturally."* Jane had used a number of non-medical therapies over the years but had not accessed them through information from nurses.

Jim

Jim's hospital experience of nurses, in this case, psychiatric nurses, was also so vivid as to cause him distress when he recounted it.

> *The times that they did pay lip service to the pain etcetera, I was basically laughed at and told to move. And I think the final insult was, without explanation, they called me into a room at five o'clock and said they were going to do a test which consisted of umm,* [became distressed and tears sprang to eyes] *the nurse had to put a rubber glove on and they, umm -a rectal finger or some such. That's - there was no explanation as to why, or the result of it. As if they said, "Well, this will shut you up"* [Wry laugh].

It is difficult to know the reasons behind Jim's rectal examination experience, but he viewed it as a deliberate punitive action by nurses.

The lack of knowledge about the limitations of movement with arachnoiditis caused problems even in areas highly specialised at dealing with pain. Jim did not feel that nurses highly skilled at arthritis management were to support him knowledgeably, which left him feeling completely displaced.

> *I noticed even, I went to* [hospital] *after one of the surgeries, I used to go down to the* [specialist pain facility], *and the nurses just didn't know what to do with me. They'd say, get in the pool. And I'd just do what I wanted to do, because they didn't know what to do, really. Yeah. you feel different. It's just that example. Everybody else is doing it and why aren't you? So you feel terribly, totally different.*

Rose

Rose's experience at an orthopaedic clinic is interesting in that a nurse was there, but appears to only have had a role as a chaperone, despite the fact that there seem to have been serious concerns about Rose's management of her medication.

> *That was when this other doctor* [introduced as a pain specialist but later found, on accessing her notes, to be a drug abuse specialist] *and the nurse was present . . . he told me to undress, which was unusual. Because he'd only ever told me to take my trousers off before. Ever. And I said to the nurse, "Well, can't I keep my camisole on?" And she said, "Yes." She was sitting next - I was sort of sitting on the bed and she was sitting there next to me. And* [the two doctors], *while I was at the other end of the room, he was showing him on the skeleton and they were talking there for ages. And I got angry, and I said, "Look, excuse me, Do you mind talking to me." And she said, "Don't worry, they do this all the time."*

Rose believes this nurse was witness to a promise which was not kept. The doctors wished Rose to have more epidural injections. Against her better judgement, because of the poor reaction she had had at the time of the last injections, but hoping desperately for an improvement, Rose made her agreement conditional.

> *I'll agree on one condition. And he said, "What's that." And I said, "That you use a different steroid to what you used in '89." I said, "You know I had a bad reaction against it." He said, "Yes." It would definitely be different. Now, there were two witnesses* [one of them the nurse] *to that.*

Rose remembers another interaction with the same nurse as arrangements were made, in which the nurse sought to reassure her. *"And the nurse, she knew I was pretty upset as well, who booked it in for ten days later, and she said to me, she said, it will be better."* Rose subsequently discovered she had received further treatment with the same drug, Depo-Medrol. That treatment was followed by a marked deterioration in Rose's condition, particularly bowel and bladder function, mobility and pain levels.

Terry

Terry's *"bossy nurse"* was all efficiency when Terry expressed concerns about when the allergy test he had requested prior to his myelogram was to take place, urging him to get ready for a procedure he was not yet confident to undertake. She told Terry to

> *get your theatre gown on, because you're holding everybody up. And they're all waiting for you. The theatre's booked and the radiographer is there, and all the rest of it. And I said, "Well, I don't particularly care who is there and who is waiting. I want the allergy check done before I have this done."*

After consulting with the radiographer, Terry realised iodine was involved and refused to have the test.

> *This bossy sister said, "We've got the theatre booked and everything. I'm going to get the Matron." And I said, "Well, that's fine. You can get the Pope. You can do what you like, but I'm not having it done." And she said, "You are preventing other people from using the theatre." It was a big guilt trip. And I was, at this stage, was getting dressed again, in front of them still standing there. So she rushed off and got the Matron. And the Matron came back and said, "What seems to be the problem?" I said, "The problem is that the product you want to use had got iodine in it and I know I'm allergic to it. So I'm not having it done." And she said, "That's fine. You're perfectly within your rights." So this frumpy old - huh* [he became lost for words].

Tom

Tom, trying to be treated within specific guidelines he had been given, found he had to make arrangements for himself when nurses refused to support his request that his specialist be contacted after an x-ray went disastrously wrong.

> *They arched me backwards to x-ray. I don't know why. They said they had to have an extended x-ray. But me being extended, unfortunately, there was a loud crack and a big scream from me. I was put in Ward X. Now I'd been told by* [neurosurgeon] *that I shouldn't have traction because I'd had a fusion. And he said, once you've had a fusion, you can't be tractioned. They tried to tell me that they were going to put me in traction. And I kept saying to them* [nurses], *please ring* [neurosurgeon]. *But they wouldn't. So I waited till the Charge Nurse left the ward and I grabbed the phone and rung him. And she came back while I was still talking to him. And they were going mad. So I just handed her over. And she spoke to him and I was in* [neurosurgeon's city's hospital] *5 o'clock that night. And 8 o'clock next morning went into theatre.*

Chapter Nine: Discussion

The primary aims of this exploratory study were to provide a description, based within a nursing theoretical framework, of the symptoms associated with arachnoiditis and the experience of living with those symptoms. The chosen theoretical framework is the science of unitary human beings (Rogers, 1970, 1986, 1990, 1992, 1994) in which the descriptions are focused on the person and their world, a perspective considered by Rogers to be unique to nursing (ibid).

The study results describe field patterns as revealed at interview. These descriptive patternings arise from two aspects of a person's being, human field patterns, which describe the experiences identified by the participants as symptoms, and human-environmental field patterns, which describe the associated experience of living with those symptoms in everyday life.

Within the person, symptoms manifest as human field patterns, not as the property of a part. Symptoms, such as pain and physical dysfunction, manifest as reflections of the physical body. The ways in which they manifest impact on the person's opportunities in life and on their power to make choices about their lives as they live and move in their world. Because the life process of a person cannot be separated from their environment, the process involved is actually that of the human-environmental field (Malinski, 1997). The interactions between these two are expressed through the three principles of homeodynamics (Rogers, 1990). The principle of integrality reflects the constantly changing nature of the processes between the person and their environment. The principle of resonancy reflects the harmonies and disharmonies inherent in those changing relationships. The principle of helicy reflects the ways in which symptoms affect the continuity, innovation, unpredictability and diversity of the human and environmental field patterns.

The focus on symptoms required clarification of the way participants use the word 'symptom'. On being asked to say what the word symptom meant to them, two participants named specific symptoms rather than defining the term. Another named a disease. For the others, symptoms transcend the particular disease. The use of personal pronouns in their definitions place symptoms as integral with the whole person, more than simply part of a disease classification and more than just one summatory word, such as pain. Symptoms are descriptions. They are what you tell others about the way you are, key events that attract your attention and make you aware that something wrong is going on inside yourself.

For participants, therefore, symptoms are evidence of disharmony, and their presence creates an implicit understanding that some disease process, in this case, arachnoiditis, must be taking place. The disease, just as much as the symptoms, is integral with their whole person. What might be termed a confusion on the part of participants as to the accepted definitions of symptoms as subjective and signs as objective evidence of disease reflects the view that manifestations of the human field cannot be dichotomised as objective or subjective (Rogers, 1970). The insistence on signs as necessary evidence before symptoms can be accepted as valid emerges from the data as one of the primary concerns held by participants, summed up in the experiences as issues of belief.

Rogers (1994) commented that the study of anatomy and physiology might well be condensed in future nursing courses as nurses are going to be working with people, not practising physiology or anatomy. Brownrigg (1992) noted the importance of the nurses' role in providing information to those in hospital who have arachnoiditis and who had felt their concerns were not understood. Study participants experienced concerns about the lack of understanding they perceived amongst those who care for them in the community and feel it is important to know their carers are knowledgeable. In view of this identified need for specific information, pathophysiological detail relating to symptoms is considered as important, indeed, essential knowledge for nurses working with those with arachnoiditis and, as such, consistent with a Rogerian perspective of people as unitary human beings. To the people who experience them, symptoms are percepts, revealed by the senses and coming unbidden into their lives (Cowling, 1990). As revealed by pattern appraisal, symptoms symbolise vital descriptions of pattern experiences, perceptions and expressions that provide nurses with details of feelings, sensations and concerns on which to focus therapeutic nursing options.

Eliciting the presence of predetermined symptoms was not a focus of the interviews. Participants described only the symptoms they associated with arachnoiditis. In hindsight, this interview technique led to some confusion as to which symptoms participants felt they should describe. This deficit was revealed by two incidents. One participant emailed further symptoms and experiences to the researcher after interview. At her request, this communication was included in the interview data. Another incident reflected evolving group awareness of associated symptoms when discussion at a support group meeting attended by the researcher revealed excessive sweating as a symptom common to several women present, including a study participant who had not mentioned it because she had not linked it to arachnoiditis until that moment. Overall, these shortcomings of interview technique are not thought to have seriously compromised the study and such omissions would be remedied in a pattern appraisal related to therapeutic care, the ongoing nature of which would reveal all symptoms over a period of time.

Study participants have many symptoms they associate with arachnoiditis, but no two have identical ones. Even those with confirmed arachnoiditis have differing combinations of symptoms. The range and variation of symptoms described by participants is consistent with the view that in arachnoiditis the distribution of lesions is so haphazard and specific to each individual case that no two cases will have the same distribution and location of pain (Bourne, 1990). It is also consistent with Rogerian perspectives on the uniqueness of each individual.

Of those with confirmed arachnoiditis, the only two symptoms shared by all four are lower limb weakness and mobility problems, neither of which are definitive symptoms of arachnoiditis. Of these four, three have problems with falling, the fourth does not. The three who fall also have numbness in areas of their feet. Three have constant burning spinal pains, one has no pain. Of those with unconfirmed arachnoiditis, four also have constant burning pain in their spines.

In addition, there are other unexplained symptoms, such as the yellow perspiration experienced by two and the night sweats of a third, the fatigue that overwhelms and severe migraine-like headaches. These symptoms perplex and concern those who experience them. There appeared to be a strong need to understand why various symptoms occur.

Of the symptoms described at interview, pain emerged as the predominant concern for all but one of the participants. The difficulties in researching pain using rigorous scientific methods were recognised by Rogers (1970). Even in assessment, anyone other than the person with the pain cannot be truly aware of what it is like and must rely on the person's description. Those in the study perceive the qualities of the pain associated with arachnoiditis as largely unknown except to those who experience it.

The majority of the pain experiences described fall within the broad category of chronic nonmalignant pain for which no truly satisfactory or generally agreed upon definitions exists (McCaffery & Beebe, 1989). Chronic pain is simply an operational term specifying a symptom and its duration (Terenius, 1992). It is, however, recognised as one of the most pervasive and expensive health care problems of modern times, an entity in its own right noted for its highly destructive effect on the person's life (Baquie, 1989; LeFort, 1992; Melzack, 1992; Hitchcock, Ferrell, & McCaffery, 1994; Coe, 1997).

The 'back pain' mentioned in the literature reviewed emerges from participants' descriptions as a burning spinal pain. This spinal burning is a distinguishing quality of the pain the majority of participants associate with symptomatic arachnoiditis and is described as burning like a match, a fire or an overhot, hot water bottle. For two, it has an ice burn or freezer burn quality. For some, it proved incomparable with anything in their experience and they were lost for words to describe it. This spinal pain is remittent in nature, constantly present, but with flare ups of extremely severe exacerbations, often brought about by ordinary everyday activities, such as sitting, standing or walking, and relieved only by lying down for a period of time. The pain is mostly of a radiating nature, spreading outward from the spine into the pelvis, hips and thighs in those with lumbar region symptoms and out into ribs and shoulders in those with symptoms in the thoracic area. It is described by one as a passing out, and by another as a cancer like, sort of pain. Other descriptors include stabbing, grabbing, vice-like, sharp, tight and splintered. For two, there is also a particularly burning, raw pain centred in the coccyx, identified by one participant as cauda equina pain. Bourne (1990) links the bizarre, diffuse, constant, causalgic burning of the intractable pains associated with cauda equina lesions to the poorly localised patterns of paleospinothalamic pain.

Trying to attribute single cause and effect is inconsistent with Rogerian science. Medical perspectives also urge great caution in prematurely attributing simple peripheral or central factors as explanations for the puzzling variability of pain in relation to nerve damage (Wall, 1992). This puzzle is deepened by the fact that chronic pain is never present in 100% of the cases with the pathology to which the pain may be attributed (ibid), as was indicated in this study by the participant who had no pain.

The referral of pain to other areas of the vertebral column and surrounding musculature is noted as a component of intractable pain of spinal cord origin (Tasker, DeCarvalho & Dolan, 1992) and by Bonica (1991) as a component of central pain. Symptomatic arachnoiditis is therefore likely to have a multi-site pain experience and this is borne out by the findings of this study. The multi-faceted nature of their pain experience is marked. As well as the burning back pain, there are also headaches of an incapacitating nature, musculoskeletal pain from injuries from falls, further pain from the cramping and spasms, and secondary musculoskeletal pain from pain-spasm-pain tensions in the postural muscles of their torso. Bone pains, joint pains, myofascial and referred pain patterns, burning foot pain and angina are also described. In light of this variability, unless a detailed pain history is taken for each person, it is likely that health professionals may have an inaccurate understanding of the pain experience of individuals with symptomatic arachnoiditis. For those in this study, their pain is certainly much more than the 'low back pain' noted in much of the literature examined.

Although the literature review identified mono- and poly-radicular pain as a possibility in arachnoiditis, no participants used those terms. However, five experience shooting nerve pains in their legs that they term sciatica. The distribution of this pain is not always in the sciatic area, indicating the involvement of other nerves. No participant described the pattern of burning pain at the insteps, the inner aspects of the knees and the lumbo-sacral area noted by Bourne (1990) as found only in lumbo-sacral arachnoiditis, but a more focused inquiry may have elicited such a description.

That pain experiences can overwhelm the individual and consume every aspect of their lives (Ferrell, 1995) is borne out by this study. Five participants think their pain tolerance levels are higher than those of people without constant pain. Pain tolerance levels are defined as the greatest level of pain the person is prepared to put up with (Bowsher, 1993). Twenty years earlier, Bonica (1973) noted that people with chronic pain do not become accustomed to it but instead seem to become more sensitive and suffer more, with prolonged disabilities that could be obviated with proper management. Participants may tolerate their pain but that seems to be because they feel they have no option. Eight daily tolerate levels of pain that are clearly disabling. For seven participants, the pain is sufficiently severe to interfere with the most basic of activities such as sitting and standing. Full-time work is possible for only one participant. Only two others have part-time, paid employment. Others require help at home with aspects of their housework and yet persist in undertaking tasks that they know will make them feel worse, purely for the satisfaction of feeling briefly useful. This desire to be useful is reflected in the literature on chronic pain. Not being able to work or do chores was seen as the worst problem associated with chronic pain (Hitchcock, et al. 1994).

Through the presence of their symptoms, particularly pain, marriages and relationships with friends, family and children have been impaired. Educational plans and career options have been broken. Financial security has been lost, affecting many of the choices participants can make that might maintain their health or relieve their pain, a finding which supports research showing that disabled people become poor and that, once poor, disability is likely to increase (McKenzie, 1996). Simple pleasures like playing with their children or enjoying a game of cards are not possible without significant consequences in terms of pain, energy loss or risk to personal safety. As in some other painful conditions, the majority of problems seem to be associated more with the disabling effect of the pain than with the underlying pathology (Moran, 1994).

While pain has been seen as an initiator of positive changes in life, providing an enhanced sense of purpose (Ferrell, 1995), for those with arachnoiditis, pain is simply not relieved sufficiently to allow participants to experience a life that reaches anywhere near their full potential. The greater part of their energies are focused on getting through the day. Participants identify the strength that enables them to live day by day with their symptoms as determination. It is determination that helps them achieve a degree of involvement in activities the able-bodied could undertake without a second thought.

However, determination alone, especially in regards to pain, is not always enough. Determination has not enabled participants to realise their dreams, satisfy their needs and respond positively to environmental challenges, as was suggested by McWilliam, Stewart, Brown, Desai and Coderre (1996). Instead, participants spoke of a loss of control when their pain reached high levels. Keeping in control was important to them and maintaining that control was the focus of their determination. Wells (1994) investigated the relationship between control beliefs and distress and disability in relation to chronic nonmalignant pain and found support for the hypothesis that the greater control one perceives themselves as having, the better a person adjusts to chronic symptoms. However, adjustment is not a concept consistent with Rogerian thinking. Even the term 'control' implies a reining in, rather than a transcending of, the symptom and, as such, is not consistent with the science of unitary human beings.

Fatigue was the next most disabling symptom, with nearly half of the participants experiencing an extraordinary degree of fatigue. Fatigue is a recognised concomitant of pain (McCaffery & Beebe, 1989; Hitchcock, et al., 1994), although not of arachnoiditis. The participant with no pain did not mention fatigue as a problem for him. The overwhelming nature of the fatigue described by other participants was striking, but it is less clear to both the researcher and to the affected participants whether their fatigue is associated primarily with the pain, as two participants believe, or with other factors, such as chronic fatigue symptoms and fibromyalgia (Bohr, 1995).

Piper (1994) outlines various attempts to classify fatigue, with the most useful classification for nurses seen as acute or chronic. Piper (ibid) also reports on a physiological classification of central fatigue which may result from impaired transmission down the spinal cord. Further investigation into this possibility may establish a link with arachnoiditis which could be of relevance when considering a choice of therapeutic possibilities.

Fatigue, like pain, is a symptom which health professionals must usually accept as being as severe as the person says it is, because there may be little objective evidence to validate the experience. To be clinically valid, measures must analyse patient's descriptions. Potempa (1994) notes that most of the fatigue instruments currently available were developed for non-clinical populations, particularly in the area of sports medicine relating to muscle fatigue, and that the development of tools for clinical populations had been so difficult as to lead to abandonment of the construct as too difficult to measure. As with pain, it seems the most helpful nursing assessment or pattern appraisal of fatigue is likely to be a description using the person's own words (Piper, 1994).

One tool, used in nursing research and which could be useful in clinical practice, is the Pearson Bryar's scale, which rates fatigue on a lay language scale ranging from 'extremely peppy' to 'ready to drop' taken at various points over a twenty four-hour period (Cohen & Hardin, 1994). This scale's focus on the whole person makes this a measure consistent with a unitary perspective.

Fatigue is recognised as multidimensional, with some specificity to disease states (Potempa, 1994). Finer & Melander (1985) describe the interwoven links between pain, fatigue, medication, lack of exercise and lack of mental stimulation. Ferrell (1995) notes that the extent to which pain results in extreme fatigue is particularly impressive. Why this should be so is still unclear. Sleeplessness is a major factor in fatigue in people with painful rheumatoid arthritis (Crosby, 1994). However, sleeplessness was not noted by participants in this study, even by those who sleep poorly, as a major factor in their fatigue. The effects of lack of exercise on fatigue is another consideration. Study participants did not, on the whole, take part in regular exercise programmes. While there is a recognised correlation between lack of exercise and fatigue, the difficulties of exercising with the severe pain participants report and the recognition that exercise does worsen their pain, makes maintaining fitness very difficult. Swimming causes embarrassment and difficulty in accessing the facility. Physiotherapy pools are not readily accessible for maintenance programmes.

The physical effort spoken of by participants in relation to the accomplishment of even quite simple activities and the relentless nature of their pain can be compared to other literature relating to pain, for example, in those with rheumatoid arthritis (Crosby, 1994). For those with arachnoiditis, the benefit to be gained from forcing oneself to exercise through increased pain and the possibility of increased fatigue, in the hope of improving general fitness is hard to determine at present. Only effective pain management allowing pain-free exercise is likely to reveal any correlation between pain, lack of exercise and fatigue, and fatigue and arachnoiditis per se. If arachnoiditis has an autoimmune component, then there may be a shared biophysiological correlation between fatigue as a symptom of arachnoiditis and fatigue associated with other autoimmune diseases such as multiple sclerosis, rheumatoid arthritis, and chronic fatigue syndrome. The possibility of an admixture of these two components of fatigue indicates that effective pain management alone may not relieve some participant's fatigue.

Living with both pain and fatigue creates a dilemma for participants expending energy in a forced interaction with their world to distract themselves, mostly from the pain. This creates a balancing act of sorts, since they must juggle the need for distraction against the limitations of fatigue, the exacerbation of pain and the limitations of mobility problems. The nursing literature notes both the advantages and disadvantages of distraction. One disadvantage is that others may doubt the existence of the severity of the pain if the technique is successful (Edgar & Smith-Hanrahan, 1992). Another disadvantage is that the fatiguing nature of distraction techniques indicates their use for short periods of less than two hours (Edgar & Smith Hanrahan, 1992). Participants have devised distraction activities to use throughout their day, but may not be choosing the most beneficial options. The exhausting nature of some of the distractive activities chosen reflects a lack of mutuality in the flow of energy, which is predominantly from the human field to the environmental energy field in people who already seem to have reduced energy, manifested as fatigue, in their field patterns.

Techniques, such as rhythmic breathing exercises, music (McCaffery & Beebe, 1989; Edgar & Smith-Hanrahan, 1992) which may allow for a mutual energy flow less fatiguing to participants are not mentioned by participants. Piper (1994) suggests that unnecessary energy expenditure can be decreased by an increase in dependency on others. To a certain extent, this is already evident in participants' lives, through provision of homehelp by ACC, but such dependency has other unwanted effects such as feelings of uselessness. A lack of obvious or recognised reasons for inactivity can, as several participants reported, lead to accusations of laziness from others. None of the participants reported their pain as being worse in the morning, a linkage to emotional upset, as compared to worsening pain throughout the day, which is seen as more likely to be due to organic causes (Srivastava, 1994).

Other expressions of symptom experiences included feeling depressed, having a diagnosis of depression, feeling suicidal and planning for suicide. Such feelings are field functions manifested as integrating forces that encompass the totality of the individual (Rogers, 1970). Depression is a recognised concomitant of chronic pain (Ferrell, 1995) and the prevalence of depression in those with chronic pain is recognised as being substantially higher than in those without pain (Hitchcock, et al., 1994). Because of its constancy, lumbo-sacral arachnoiditis pain is considered more depressing and debilitating to patients (Bourne, 1990) than other back pains. However, although 'depression' as a pathological label (Tuyn, 1994) was accepted by some participants, it was specifically denied by others, who instead felt it was perfectly reasonable to feel depressed in their situation.

A linkage between depression and suicidal feelings which respond to pharmaceutical intervention was made by two participants, supporting the need for early detection of suicidal ideation in people with chronic pain (Hitchcock, et al., 1994). The planning for suicide as a fully knowing life choice spoken of by some participants appears more akin to euthanasia than to depression-associated suicide. The prevention of such actions may be impossible if the person truly feels a continuation of their incurable and unbearable state is all the future has to offer. It could be argued that, far from a knowing choice, such a decision is made because no other options are apparent. Suicide or euthanasia then becomes no choice at all but an expression of the ultimate in extreme powerlessness.

Changes in human-environmental field patterning reflect in the interactions participants have with their worlds. Foremost among these changes for participants are mobility problems, which have had far-reaching effects in their lives. An inability to move freely in their world is linked to a number of symptoms, including a tendency to fall unexpectedly, pain, fatigue and, sometimes, depression. Mobility problems reflect a major imbalance in an individual's sense of integrality with their environment. A lack of resonancy is engendered by those around them either disbelieving the presence, or the severity of, their symptoms, or not understanding the ways in which the symptoms affect their ability to undertake physical movements. The helical patterning of their lives reflects a lack of forward movement relating to an apparent closing down of the number of opportunities open to them as future life choices. Mobility difficulties affect peoples' abilities to function in household and employment tasks. They alter their ability to interact with their family, participate in social events, use cars, go for walks, play sport and enjoy hobbies such as gardening. Unwanted lifestyle changes occur in relationships, in parenting, in work opportunities, in financial circumstances and in hopes for the future as a result of those difficulties.

However, these difficulties appear to occur less because of motor impairments alone, than through associated pain, which further limits movement. The participant who has no pain, although the eldest of the participants, has remained largely independent and has few difficulties in living his life much as he expected he would in retirement. For others, pain and mobility difficulties create a ripple effect flowing as energy changes throughout every aspect of their lives. Descriptions of reasons why and how participants seek relief focus largely on pain management strategies, although relief is also sought for decreases in lower limb function, bladder and bowel problems, sweating, depression and problems with sleeping.

Social isolation is a marked feature of participant's lives with pain. It is recognised that many people do not leave their homes when their pain is uncontrolled, isolating themselves rather than be seen in pain (Ferrell, 1995). Although concealing their problems is a feature of several of the participant's lives, this is not necessarily for reasons of pain alone. Changed financial circumstances contribute to a decreased ability to enjoy activities, such as a meal out or using the spa bath, because the cost always has to be factored in. Participants dislike constantly having to relate their problems instead of enjoying general conversation of an everyday nature. Managing the information relating to a chronic condition is therefore a factor in determining participant's attendance at social activities. They must cope, not only with the pain and associated disability, but also with deciding whether to tell people why they cannot sit, walk, dance or collect their meal from the buffet. Admi (1995) compared the historical perspectives on the decision to reveal disability or not as concealment because of immaturity in dealing with the problem, or as denial of the disease, contrasting with a third option of total public visibility as a self-empowerment technique against discrimination. In this study, those who spoke of telling others about their condition tended to a fourth option, not telling unless absolutely necessary because they do not see it as anyone else's business.

Relationships had foundered, reflecting the impact of chronic pain on partners and families. Several participants mentioned the difficulties partners had, or currently have, in understanding their symptoms and needs. No participant mentioned counselling support for partners during these relationship crises, supporting Schwartz and Slater's (1991) claim that spouses of chronic pain patients may represent a population in need of support in their own right.

Quality of life is a term commonly used in reference to those with chronic conditions, but particulate views which identify variables of a biopsychosocial being are not considered congruent for the study of unitary human beings and their lives (Parse, 1994). Instead, asking participants to consider themselves at their best and their worst placed the assessment as a unitary percept centred in the life of the person. This brief review of the worst and best of daily life with arachnoiditis tended to have a common link, namely, participants' perceptions of their ability to function independently in daily life, reflecting, most disturbingly, a high level of disability linked largely to pain, as an immobilising factor in their lives. Eight of the eleven participants perceived themselves as closer to the worst they could imagine being for most of their waking hours than to the best they could imagine, with seven frequently reaching between eight and ten at their worst. To be feeling this bad for most of the time creates great personal costs in, as Baquie (1989) put it, forging ahead while feeling awful. On a pain scale such high levels as this would indicate an unacceptable level of pain and suffering. As a general indicator of disharmony in their field patterns, the levels of distress and disability revealed by this study attest to the need for consideration of a whole range of different options for those with arachnoiditis.

Although participants manage to get through each day, they are relatively pessimistic as to their hopes for their futures. They all hope not to deteriorate further but are uncertain as to the likelihood of not getting any worse. Nursing studies on uncertainty in illness indicate people have difficulty making sense of their illness events when they are marked by ambiguity, complexity, informational deficiencies and unpredictable outcomes (Mishel, 1988, 1990), all of which have been features of participants' experiences. Uncertainty is also seen as consistently associated with emotional distress, reduced quality of life and poorer adjustment to life with illness (Mishel, 1995) and as a pervasive, stressful accompaniment of illness that strongly influences the ability to reach their greatest potential in their circumstances (Mast, 1995). Whether this is specifically so for the participants was not a focus of the study. However, there is an overall sense of uncertainty in their situations, revealed by participants' general lack of plans, apart from suicide, for their futures. For some, this relates to a lack of explanatory information about their mobility problems and how much worse they might get, and for others to a general pessimism, tinged with a further uncertainty as to whether any potential medical advances will occur in time to be of benefit to them.

Pervasive in Rogers' writings, and in those of her followers, is a perception of people as integral with a spiritual oneness of creation that transcends particular religious traditions. Three participants mentioned ongoing spiritual beliefs as important in their lives. While it has been stated that pain has a tremendous influence on spirituality, and that particular religious traditions influence perceptions of the meaning of pain (Ferrell, 1995), this is not apparent in this study. There is no acceptance of the idea of their situation as a punishment. Instead, there is a perception of aloneness felt by participants, who sense that others, including health professionals, do not understand their situation. In face of this sense of aloneness, a pragmatic attitude seems to have developed. Pragmatism is considered to be a manifestation of lessened diversity in field patterning (Rogers, 1990). Participants reflect a pragmatic acceptance of the incurability of their situation, even though that acceptance remains tinged with hope that medicine may one day offer an effective answer. They accept, with regret, their enforced isolation. They endure the intractable nature of their pain. They accommodate the need for long periods of rest. These thoughts and actions are based more on getting through each day than on finding spiritually based ontological meanings in their pain experience.

This study indicates there is something more to living with the symptoms associated with arachnoiditis than with many other chronic health problems in which a high degree of normality in everyday life can be maintained. Indeed, some participants have been diagnosed with other conditions, for example, asthma and diabetes, which do not impact on their lives in anywhere near the same overwhelming way. The differences would seem to be centred around the pain and, for some, the fatigue. Pain and fatigue are more disabling than the muscle weakness, lower limb motor problems or even the paralysis of one participant. It is these symptoms that send them to their beds, prevent them from working and interrupt their enjoyment of family and social life.

The study findings also indicate the complexity of the situations in which those with arachnoiditis find themselves. The reported lack of success of most therapeutic options appears to leave health professionals who would seek to work with those with arachnoiditis little in the way of therapeutic answers. It is this general sense of helplessness and hopelessness that an altered world view based on a Rogerian perspective would seek to change. Instead of being seen as incurable and intractable, their situation reflects a need for planning for mutual repatterning that seeks to re-establish positive helical movement and a new harmony and integrality in their lives. Possibilities for the implemention of this optional view will be discussed in the next chapter under implications for nursing.

Chapter Ten: Implications for nursing

This study has raised a number of concerns that have implications for nursing. Of primary note was the absence of nurses as therapeutic practitioners in the care of those with arachnoiditis, particularly in relation to the management of chronic nonmalignant pain. Of equal concern was the apparent lack of any mentioned advocacy role taken by nurses in relation to participants' needs. While a lack of diagnosis and/or a lack of readily available information about arachnoiditis may have created difficulties for nurses working with study participants, it could also be argued that an effective nursing presence is inherent in the choice of theoretical framework on which practice is based. An entropic view, which sees conditions such as arachnoiditis as incurable and its symptoms as intractable, leaves nurses with little to offer, leading to therapeutic and professional burnout (Kodiath, 1991). By contrast, a negentropic view, which sees people as individuals capable of making numerous choices in the arranging of their environment and lives, provides nurses with possibilities for developing a researched-based foundation of knowledge that can expand the choices available.

The absence of nurses in therapeutic positions in relation to the care of those with arachnoiditis is, as noted earlier, of major concern and is contrary to the view expressed in the recent Taskforce on Nursing (Report, 1998) that nurses are a continuing presence across the whole spectrum of a client's care. Participants in this study did not have a positive image of services nurses could offer. Practice nurses were not mentioned as offering support or advocacy in the general medical practices participants visited. Nurses at hospital venues and clinics did not have an identified nursing role in symptom management that was obvious to participants, instead appearing to function as tacit supporters for the hospital medical system. These experiences position the nurse very much alongside medical personnel as assistants in diagnostic, consultative and treatment procedures, a positioning noted by Chinn (1996) as resulting from nurses continuing to place themselves within a frame of reference oriented toward cure. In this entropic positioning, once a cure is no longer considered possible, or effective treatment is not available, nurses do not appear to have an obvious professional role in the lives of those who must continue to live with seriously incapacitating symptoms, such as the nonmalignant pain associated with arachnoiditis.

Currently, nursing in New Zealand is not well positioned as a profession to offer independent and valued therapeutic services to those with nonmalignant chronic pain. The hegemonic social and political processes shaping the development of health care services in New Zealand have side-lined nursing as a science and an art in its own right, not only for those with arachnoiditis, but for many people with health concerns. The focus is currently on medical care, commonly called primary health care, from GP's, who serve as the first entry point to the health system, whether public or private. The Taskforce on Nursing (Report, 1998) delineates the various changes and the barriers to developing innovative practice strategies and provides information on which nurses can base their efforts to create new therapeutic options.

If nurses are to provide an independent, useful service to those with chronic pain, there is a need to carefully consider just what form that service might take. Participants in this study voiced a desire for health care professionals to believe them, to listen to them, to be knowledgeable about their condition, to provide ongoing support and to explore further avenues for symptom management, most particularly, of their pain. There are indications (Vallerand, 1991; Ferrell, McCaffery & Rhiner, 1992; McCaffery & Ferrell, 1996; Wenley, 1998) that current nursing practice often fails to meet peoples' need for pain relief. While individual nurses may well have provided aspects of such care to participants in this study, this was not done in a manner that created an impression in participants' minds that nurses were independent and useful health professionals who had skills and knowledge to offer. Advocating for effective pain management, including the use of pharmaceutically-based options and working with people to ensure the most effective management of that medication, is a recognised role in the work of acute pain and oncology nurse specialists. The development of such nurse specialists in community based nonmalignant chronic pain management programmes appears to be the logical next step.

Supporting people in their search for adequate symptom management is an aspect of nursing advocacy. 'Advocacy' has become a catchword in Western nursing (Johnstone, 1989) and an advocacy role has been seen as part of the daily work of the expert nurse (Segesten, 1993). New Zealand has had, since 1996, an independent nation-wide advocacy service, headed by the Health and Disability Commissioner. Its function is to empower people with consumer dissatisfactions and complaints regarding health services, rather than replace nurses in the on the spot advocacy that would meet the needs indicated by participants' experiences within the health services. These needs included information that might have ensured informed consent, support during procedures, and support in their search for adequate pain management. The findings of this study indicate that nurses, rather than advocating for their patients in support of voluntariness in relation to informed consent (Etchells, Sharpe, Dykeman, Meslin & Singer, 1996), instead appear to have sought to support medical opinions and enhance efficiency. Whether this is because those nurses felt vulnerable to intimidation from medical staff, a point noted after the release of the Report into the Cervical Cancer Inquiry in 1988 (Johnstone, 1989), or were trying to avoid interpersonal conflicts between themselves and physicians, is unclear, but these are issues that had important consequences for participants. New consideration of the advocacy role of nurses seems timely, particularly of processes that empower nurses to avoid similar problems in future.

The new legal requirements demanding informed consent (Health and Disability Code, 1996) constitute an important aspect of any such consideration. Nurses who assist with medical therapies and tests, or work with people about to undergo such procedures need to clarify their role in the provision of supplementary information over and above that on the official consent forms, both in response to people's direct questions and to people who ask no questions. As regards arachnoiditis, this is particularly so in helping people with back injuries to make an informed choice between procedures, such as MRI or myelography. A number of the factors which may have been associated with the development of arachnoiditis in study participants have now been eliminated. Oil based dyes are no longer available, having been replaced with purportedly safer water-soluble options. Myelography itself, especially just prior to surgery, is used much less commonly. However, myelograms are still performed and fully informed consent would require disclosure of the comparative safety and excellence of MRI scanning as an option (Gundry & Fritts, 1997). The role of nurses in this process is as yet unclear.

There is also a need for nurses to give serious consideration to where their role as providers of nursing services links into other community based organisations. Service providers, such as the case managers employed by the ACC, come in regular contact with those with chronic pain, including arachnoiditis sufferers, and important decisions about clients future lives are partly based on case manager reports. The conservative treatment of acute back injuries has changed, from the prolonged bedrest spoken of by some participants, to early mobilisation. A system of 'red and yellow flags' indicating high physical risk factors and psychosocial risk factors (Kendall, Linton & Main, 1997) has been developed and is being used by ACC in New Zealand to instigate early management targeted toward preventing chronic back pain and disability from developing. As yet, there seems to be no specifically recognised role for nurses in this protocol.

For those with disabilities linked to arachnoiditis who are not on ACC, needs assessors within the new Health and Disability Services structure perform a similar function to ACC case managers, assessing individual's eligibility for Health Funding Authority services, such as home help and personal care. These case managers and assessors also assess for and coordinate services provided by health professionals such as physiotherapy assessment, occupational therapy assessment, and complex assessments involving various specialists for those with long term disabilities, including those arising from pain. Some case managers and assessors are nurses but they have no direct therapeutic role in this position. They could, however, refer people to specialist nursing services. Assessment services are required to inform the funding authority of service gaps in meeting people's needs. This creates an opportunity for nurses to create specialised services targeted to meeting the wider needs of chronic pain management in the same way that nurses have led the way in developing care for, and becoming accepted experts in, cancer and acute pain management (McCaffery, 1990).

Pain management emerged in this study as an area of prime concern, and therefore, a most useful focus for new nursing activities. While there is increased interest in the management of chronic nonmalignant pain from a nursing perspective (McCaffery & Beebe, 1989; Kodiath, 1991; Watt-Watson & Donovan, 1992; Carroll & Bowsher, 1993; Hitchcock, et al., 1993; Matas, 1997), management strategies for central pain are less evident. Central pain affects up to 30% of people with lesions of the cord and its medical management remains difficult (Tasker, et al., 1992).

The recognition that there is a great similarity between participant's symptoms and the clinical features related to spinal cord injury (Tasker, et al., 1992) may prove significant as a focus for nursing, since it obviates the necessity for a precise diagnosis of a disease before nursing therapies can be utilised. In giving consideration to changes in specific areas of the body, field pattern appraisal and ensuing plans for therapeutic options are of a greater degree of relevance to nursing because they centre on the symptoms within the person, instead of on the disease. Understanding the physiological processes that may be linked to those symptoms provides an important extra understanding to expectations regarding various therapeutic options.

Pain management concerns for those with arachnoiditis raise ethical issues relevant to nursing. Those who used the term 'excruciating' to describe their pain have used a term that denotes immense suffering (Champagne & Weise, 1994). Health care professionals have not always seen it as their role to be concerned about pain (Somerville, 1994). Bourne (1990) notes that in many instances, doctors, relatives and friends fail to realise the pain of arachnoiditis can be as bad as that of cancer but without the prospect of death as a release. It is considered unethical to let cancer patients live out their life in unrelieved pain (Cain & Hammes, 1994; Somerville, 1994), but similar ethical and therapeutic issues have only relatively recently been addressed for those with nonmalignant chronic pain, particularly in regard to the use of opiod medications (McCaffery & Beebe, 1989; Vallerand, 1991; Hitchcock, et al., 1994; Large & Schug, 1995). Nurses, working closely with those with chronic pain, can be prime instigators in advocating the use of effective analgesia, including opiods.

Cancer pain is now commonly treated with opiods and there is a recognised need to educate those, including nurses, with unjustified concerns about the risks in using opiods for long periods in the community (Ferrell, McCaffery & Rhiner, 1992; McCaffery & Ferrell, 1996). For those with arachnoiditis and no expectation of death in the near future, misunderstandings concerning the dangers of addiction may be preventing access to opiods. Opiophobia, a customary underutilisation of opiod analgesics, is thought to be as common in New Zealand (Wenley, 1998) as in other countries in the world. Guidelines for opiod use have been developed for clinical practice in New Zealand and nurses can support those with arachnoiditis to find out if they fit the criteria.

However, the value of such opiod therapy for those with arachnoiditis also needs to be specifically evaluated. Meyerson (1990) reports on a study in which he found that those with chronic, neuropathic pain were resistant to opiods. Large and Schug (1995) raise issues centred on whether opiods liberate and extend autonomy or create dependency handicaps in already limited lives. There is a need for further nursing research to see if opiods work effectively because of their action on other types of pain than that of central origin. Lowering the overall pain burden sufficiently to enable the person a better ability to participate in life may be sufficient justification for the use of opiods even if there is little effect on the central pain. Similarly, peripherally active substances such as carbamazepine and tricyclic antidepressants, particularly Amitriptyline, were only occasionally effective (ibid). Nursing research looking at factors indicating when such medications are effective, and recognising when they are not, may also be required.

As well as pharmaceutical products, there are a number of other non-pharmacological techniques which are recognised for their effectiveness in pain management. Unfortunately, the lack of mention by participants of any nursing input using these methods for their pain management, indicates a disparity between nursing practice and educational claims that nurses are uniquely prepared for the effective use of non-pharmacological pain management technique (Edgar & Smith-Hanrahan, 1992). These authors indicate that such techniques are used less than 25% of the time. Nonetheless, they see nurses as having a responsibility to try various therapies, such as cryotherapy, superficial heat application, massage, acupressure, transcutaneous nerve stimulation, relaxation cognitive strategies, imagery, music and distraction and to incorporate them into people's individual pain treatment programmes if successful (Edgar & Smith-Hanrahan, 1992). However, it is already recognised that physiotherapy and TENS are not effective therapies for arachnoiditis (Bourne, 1990), indicating that the neuropathophysiological aspects of the arachnoiditis experience may require research into the effectiveness of all these strategies specifically for those with arachnoiditis.

A choice of therapeutic options is meaningless if an effective service to provide those options does not exist. Successful use of these therapies in practice can be achieved either by nurses gaining specialist knowledge for themselves or by building networks that link people with other specialists who can perform them safely and knowledgeably. Jacox (1994) makes the point that nurses, who provided leadership in studying children's pain, need to be more aggressive in insisting on their ability to practice professional nursing, and more assertive and creative in trying some of the numerous interventions suggested in nursing research literature for those with nonmalignant chronic pain. The lack of perfect answers available for those with arachnoiditis, suggests a need for nurses to innovatively heed what Donovan (quoted in Champagne & Weise, 1994) described as 'successive approximation', that is, to try various therapies, evaluate their effectiveness, revise the plan if necessary, and try again.

To meet the needs of people with arachnoiditis, nurses can chose between two perspectives. These perspectives arise from Rogers' (1970) recognition that body image and human field image provide two different views of persons with disabilities which lead to two markedly different approaches to practice. The body image perspective sees nursing focusing primarily on dysfunction of the parts. The human field image perspective focuses on the potentials of the person. By using a body image perspective, participants lives can be viewed in entropic fashion as a downward spiral of unmanageable symptoms, psychological dysfunction, broken dreams, shattered careers, family tensions and marriage breakups. Not only is their disease and, therefore, they themselves, incurable but their pain is intractable and prevents their participation in the activities of normal life. As a result, their lives have ground to a halt.

It is possible to view the study findings in this way, and to find that entropic perspective supported by the literature review. However, a deeper analysis of the study data revealed an embryonic negentropic perspective on which to build nursing interactions. Integral with pain and hopelessness in participants' lives have been bright areas of change. New relationships have been forged. Two have started new, part-time jobs. The publicity in 1995 has been a spur to self discovery and to new outlooks on life. There has been an immense sense of integrality and belonging that has come about through joining the support groups, and of finding others who knew absolutely and without question what they were talking about when they discussed their symptoms. This research illustrates, within itself, the integrality of the researcher and participants as a part of that forward motion, that uncovering of new possibilities. The national support group (ASAMS) is eager to advance knowledge of pain management and plans are being made for a conference in 1999, which will include a focus on central pain syndromes (personal communication with ASAMS patron, Oct., 1998).

The choice of perspective thus has crucial implications for nurses, because choosing to work within an entropic, body image perspective focusing on symptoms appears to leave little in the way of therapeutic options. By contrast, practice from within a Rogerian perspective requires that participants be seen, not as incurable, but as capable of infinite possibilities. Identifying barriers in the patterns of relationships between events and experiences, as seen through a negentropic, human field image perspective, gives an ordering of knowledge (Rogers, 1970). This knowledge allows a recognition of new possibilities in care options and an indication of areas where future research can be done to enhance the pool of knowledge from which nurses and those with arachnoiditis can select potentially helpful options. All the currently available information on arachnoiditis and, since it is the predominant symptom of concern to those with arachnoiditis, information about chronic nonmalignant pain and central pain, can be reframed in terms of potentials. The nurse and the person can, by focusing on those potentials, work together to find helpful ways to relieve symptoms, enhance physical and social activity, maintain wellness at as high a level as possible and generally seek to find ways to enjoy life to the maximum degree possible. Individuals may achieve some of these goals by themselves, but an experienced nurse can facilitate the search by bringing a wealth of expert knowledge to the encounter.

The expertise required to work as a nurse in practice based on a Rogerian framework is not easily gained in New Zealand. The value of such innovative practice is already evident in the work done by nurses working in a Rogerian framework in the United States, both in private practice and in hospital settings. There are increasing numbers of practice-based reports in the literature that could serve as guides. Pain management strategies using creative approaches based on a Rogerian framework have been developed and utilised in practice by various practitioners. In particular, Cowling's (1990) experience of working with a person with phantom limb pain, also a central pain phenomenon, indicates the possible usefulness of the approach in those with arachnoiditis. Kodiath (1991) offers a Rogerian view of chronic pain management and Garon (1991) has developed a model for the delivery of pain management care in the community based on a Rogerian framework. Matas (1996) has used Rogerian science to explore the nature of chronic pain as a pattern manifestation. Other useful literature that could be adapted to pain management includes nurses' experiences in instituting a Rogerian nursing perspective in a service organisation (Caroselli, 1994), developing pattern appraisal as a guide to nursing care for children with heart variations (Morwessel, 1994), using various unitary human field practice modalities (Boguslawski, 1990), and developing private nursing practice settings (Cowling, 1990; Barrett, 1990).

People requiring a nursing service should be able to influence the type of service offered. The importance of a person's ability to participate knowingly in change was identified by Rogers in 1970 and developed by Barrett (1986), who defined the person's capacity to participate in the nature of change by repatterning their human and environmental fields as power. This study indicates that a person's inability to participate knowingly in their own life changes and to create their own new realities may be the true nature of disability. Power, as the capacity to knowingly participate in change and to make choices, is a reflection of the principle of helicy and is integral to the mutual process of the human-environmental field (Barrett, 1990). Pain and fatigue disempower many of the participants, preventing them from acting intentionally, allowing fewer possible choices and increasing feelings of inability to create change. The lack of harmony participants feel within their environment, and their sense of not being fully part of life in their communities, adds to their sense of powerlessness. Essential to an ability to utilise that power is awareness of the situation, knowledge of the choices available, freedom to act intentionally and an involvement in creating change. These abilities also meet the enablement and empowerment criteria set in place in New Zealand by the framework for health and disability service provision (New Zealand Framework, 1994).

The study results revealed that participants had very little of any of these attributes of power until the news media presentations in 1995. Since that time, a number of events have occurred that have altered the environment within which they live. They have an increased awareness of the situation and also of the choices that should have been given to them and that are available to them now. Legal changes have empowered them with more freedom to act intentionally (Health and Disability Code, 1996), although monetary and health system issues of service availability have counter-balanced some of these apparent gains. The most limiting factor in making choices is the lack of availability of services other than those within the medical model. Those with arachnoiditis, working through their support organisation, ASAMS, are seeking to increase those options. However, in New Zealand, almost all of the therapeutic options that are consistent with Rogerian thinking are offered by wellness practitioners other than nurses.

One option for New Zealand nurses, in keeping with Rogers (1990) view that health services are properly community based, is the development of autonomous, community based nursing services funded by the Health Funding Authority. In the United States, nurses are already entering an increasingly entrepreneurial world in practices that are primarily characterised by non-invasive modalities that are based in nursing science, not medicine. Ministry of Health officials (personal communications, Sept., 1998) confirm that there are funding openings available for innovative community based services in New Zealand, and the Ministerial Taskforce on Nursing (Report, 1998) outlines a number of potential strategies by which nurses can build the structures through which practice can evolve to maximises health in difficult circumstances.

Limitations of the study

The limitations of this study were shaped by the broad sweep of information sought in a two hour interview period. While this strategy allowed a wide-ranging description of the patterns of symptoms and experiences to be revealed, it also meant that any one aspect of the overall pattern has not been explored and described to its full potential. The symptoms and experiences described by participants would all bear further exploration. Such a process would occur during individual pattern appraisal in therapeutic practice, in which the uniqueness of each individual participant's personal pattern would emerge in greater detail.

A secondary limitation was the difficulties for the researcher in using a Rogerian framework with limited practical experience in its application. However, the potentials inherent in using a negentropic framework were felt to outweigh the disadvantages of an inadvertent lack of consistency in theoretical concept application.

Further research

An exploratory descriptive study provides an introduction to an area of concern about which little is known. From that information, further research can be undertaken. The primary area requiring further research was revealed by this study is for pain management. The multifaceted nature of the pain experience, its effect on the daily life of those who experience it and their families, and the lack of effectiveness of pharmaceutical preparations, create many possibilities for nursing research into chronic nonmalignant pain management strategies. Literature providing information on the benefits of a negentropic Rogerian approach indicates potential benefits to those with such pain. Exploration into nursing strategies that would assist in the development of individual's potentials, rather than into their losses, would also be of use. Theoretical perspectives developed from a Rogerian framework, such as Barrett's theory of power as the capacity to knowingly participate in change (Barrett, 1986) may guide such research.

Appendix One

Iophendylate (Myodil, Pantopaque)

Iophendylate is an ionic monomeric contrast medium that was formerly used for myelography. Myodil is the name by which iophendylate was known in New Zealand and Great Britain. In America, it was known as Pantopaque. It had an oily consistency and was thought to slowly clear over many years. Adverse effects were of two kinds: acute and chronic meningeal reactions, with the chronic reaction usually being described as adhesive arachnoiditis. Although up to 67% of patients were thought to develop asymptomatic arachnoiditis, symptomatic arachnoiditis was thought to occur in only possibly 1 to 2% of patients. Experimental studies indicated that blood in the CSF may increase menigeal reaction. Removal of iophendylate has been a controversial issue. Centres using small amounts tended not to remove it, others using large amounts sometimes sought to remove some of it.

Junck, L. & Marshall, W. (1983). Neurotoxicity of radiological contrast agents. *Annals of Neurology*, 13, 469-484.

Metrizamide.

Metrizamide (Amipaque) is a radiographic contrast medium used for lumbar, thoracic, and cervical columnar myelography, CT cisternography, ateriography, phlebography, urography and body cavities. It was introduced in 1974 and was hailed as a marked improvement over iophendylate in regard to neurological toxicity, including the development of arachnoiditis. Distribution in New Zealand ceased in 1986-7 and the product was noted in Ministry of Health files as being formally withdrawn in 1992, by which time it had not been distributed in New Zealand for a five year period (Private Communication, Department of Health, 1997). The Medical Adverse Reactions Committee (MARC) had no occasion to consider metrizamide and the Department of

Health did not communicate anything to practitioners or specialists about metrizamide (ibid). Although short term effects have been reported, metrizamide is still widely considered to have no role in the subsequent development of arachnoiditis after its use, despite its development in high dose animal trials. The manufacturer, Winthrop, notes the most frequently occurring adverse reactions as headache, nausea and vomiting, usually occurring within 24 hours. Aseptic meningitis syndrome (chemical meningitis) is reported as rare, less than 0.1%, and usually preceded by pronounced headache, nausea and vomiting. Onset is 12 to 18 hours after the procedure and clears spontaneously about 10 hours after onset, with complete recovery over 2 to 3 days.

Metrizamide is absorbed from the cerebrospinal fluid into the blood stream. Approximately 60% of the administered dose is excreted unchanged through the kidneys within 48 hours. It is noted that between 12 and 24 hours after administration, the surfaces of the cerebrum and cerebellum in contact with the subarachnoid space will develop a "blush" effect on the scan which will normally disappear in 36 to 48 hours. Metrizamide is contraindicated in people with a known hypersensitivity to metrizamide or other iodine-containing contrast media, and precautions are necessary in those with allergy histories, but sensitivity to iodine itself is not mentioned. Fatal reactions associated with water-soluble contrast media have mostly been attributed to chemical, allergic or idiosyncratic effects.

Reference

Amipaque: An advanced concept in contrast media for myelography and ventriculography. *Information sheet.* Ermington, N.S.W.:Winthrop laboratories. (Undated).

Iopamiro

Iopamiro is a tri-iodinated, non-ionic, water-soluble, contrast medium suitable for intravascular, intrathecal and body cavity administration in radiographic procedures. It is indicated for lumbar and thoraco-cervical myelography and for CT enhancement.

Although a number of adverse effects are mentioned on the data sheet, arachnoiditis is not among them.

Reference

Iopamiro Data Sheet, Rhone-Poulenc Rorer, New Zealand Ltd., 1995

Appendix Two

Depo Medrol (methylprednisolone acetate USP)

Depo Medrol is an anti-inflammatory steroid that exerts its influence locally by preventing or suppressing the development of inflammation. It is used intra-articularly and intramuscularly as an adjunctive treatment for pain relief in osteoarthritis, rheumatoid and other arthritic conditions, bursitis, tenosynovitis and epicondylitis. Such local therapy does not alter the underlying disease process. Spinal joints are not recommended as sites for administration because of their inaccessibility and the sacroiliac joint because it lacks a synovial space.

The Upjohn Data Sheet (1988) specified that Depo Medrol is not recommended for intrathecal or epidural administration. Adverse effects possible when these routes are used are noted as including arachnoiditis, meningitis, paraparesis/paraplegia, sensory disturbances, bowel/bladder dysfunction, headaches and seizures. Side effects of its usage include muscle weakness, menstrual irregularities, osteoporosis, vertebral compression fractures and pathological fractures of long bones.

In 1990 a television programme on Depo Medrol was aired in Australia, which the medical director of Upjohn referred to as "an Australian tabloid television programme, which has been described as sensational, biased and unbalanced." The director also noted that the "advent of contentious television is regrettable." As a result, correspondence between UpJohn and the New Zealand Pain Society (1990) ensued. Upjohn noted, and asked the Society to share with its members, that it does not, and cannot recommend, epidural or intrathecal use of Depo Medrol because sufficient scientific data regarding the safety and efficacy of this use does not exist. In the same letter, Upjohn notes that the decision to use a specific treatment in a specific situation remains the prerogative of the doctor, in agreement with, and after discussion with, the patient. The letter also pointed out the impossibility of ever conducting an unbiased clinical trial because, by the time all the potential problems were listed for informed consent, only truly committed people would volunteer for such a study. Obtaining a random and objective sample of either doctors or subjects would not be possible. Since 1991, Upjohn has changed the data sheet to include an underlined warning that epidural use is not a recognised usage of Depo Medrol. Subsequently, it has been recommended that patient information sheets should be given to people prior to epidural injection of Depo Medrol.

References

Upjohn Data Sheet, 1988.
Correspondence from Upjohn to the New Zealand Pain Society, 1990.

Kenacort-A40 (Triamcinolone acetonide)

Kenacort is recommended for the same inflammatory joint conditions as Depo-Medrol. The data sheet notes that it will ameliorate symptoms but has no effect on the causes of the inflammation. Intramuscular and intra-articular administration are the recommended routes. No mention is made of intrathecal or epidural administration, or of arachnoiditis as a possible side effect.

Reference

Bristol-Myers Squibb Fact Sheet, 1991.

Appendix Three

Information Sheet

My name is Chris Hopkins and I am a Registered Nurse studying for my Master's Degree in Nursing at Massey University. I am proposing to undertake research relating to the symptoms associated with arachnoiditis. To do this study I will need to interview people who believe they have arachnoiditis. I should like to invite you, as a member of ASAMS in the [x] region, to participate in this study. If you wish to take part, could you please forward your name and a contact phone number to:

The Secretary,
ASAMS,
[x] St,
[x].

Your name will then be forwarded to me, along with the names of others who wish to take part. The first twelve people on the list will be selected as potential participants. In the event that one of the selected twelve should, after further discussion, no longer wish to take part, the next person on the list will be selected.

The purpose of the study is to provide a description of the symptoms associated with arachnoiditis as you experience them and of your experiences of living with your symptoms in everyday life.

The information gained from this study will be made available to those with arachnoiditis through the national arachnoiditis support group, ASAMS, and will also be used as an information source for other groups and health professionals.

If you agree to be in the study, you will be interviewed by me (Chris) at a place convenient to you. The interviews will discuss your symptoms and how they have affected your life. They will also explore whether you have a confirmed diagnosis of arachnoiditis and how that diagnosis was reached, including whether you have had an MRI. Total interview time will be two hours, broken into either two one hour sessions or as is most suited to your needs. Interviews will be held at a place and time suitable to you.

The interviews will be audiotape recorded. You have the right to request that the audiotape be turned off at any time. The tapes will be transcribed by me or by a professional transcriber who has signed a confidentiality agreement. Upon completion of the study your tapes will, by your choice, either be returned to you or destroyed.

Confidentiality and anonymity of participants is an important part of this study. Pseudonyms will be used for all participants. However, because of the small sample size, total anonymity and confidentiality cannot be guaranteed.

If you feel you would like to be a participant in this study, these issues can be discussed further with me and again if you have any questions later. You have the right to decline to participate and to withdraw from the study at any time and can refuse to answer any particular questions.

Throughout the study, I can be contacted at Ph [x] between 10 am and 4pm. My thesis supervisor is Charmaine Hamilton. If necessary, she can be contacted at (06) 357 0724 during office hours.

If taking part in this study raises issues that are painful for you and which you may wish to work through further, [x], the Multiple Sclerosis fieldworker will be available to assist you. She can be contacted at Ph [x].

This project has been approved by the [x] Ethics Committee. This means that the Ethics Committee may check that this study is running smoothly and that the study has followed appropriate ethical procedures. The Committee assures you of its complete confidentiality.

Appendix Four

Consent form.

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission and that this information will be used only for this research and publications or conference presentations arising from this research paper.

I understand that the information given at interview is not available to other participants.

I agree to the interview being audiotaped.

I also understand that I have the right to ask for the audiotape to be turned off at any time during the interview.

This project has been approved by the [x] Ethics Committee. This means that the Ethics Committee may check that this study is running smoothly and that the study has followed appropriate ethical procedures. The Committee assures you of its complete confidentiality. I understand that if I have any ethical concerns about this study, I may contact the [x] Ethics Committee on [x] (phone/fax).

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed: ....

Name: ....

Date: ....

Appendix Five

Guide Questions.

The presenting symptoms associated with arachnoiditis and the experiences of living with them in everyday life.

Interview One. Questions (pattern appraisal) reflecting the human field.

1. Can you tell me what you think a symptom is?
2. Do you have any symptoms at the present time?
3. Can you give me a general picture of your symptom or symptoms
4 Do you have a confirmed diagnosis?
   How was this diagnosis reached?
   Has your diagnosis changed over time?
   Do you feel comfortable with your present diagnosis?
   What do you think this diagnosis means for you?
5. How long had you had symptoms before you got a diagnosis?
6. Are the symptoms you have now different to any you had when you first felt something was wrong?
   In what way are they different?
   Do you think your symptoms will alter as time goes by?
   In what way do you think they might alter?
7. Do you think some symptoms make other symptoms feel worse?
8. How would you rate the way your symptoms make you feel generally with 10 being the worst you can imagine and 1 the best

How would you rate the way you feel right now with 10 being the worst and 1 the best you can imagine ?

When your symptoms are at their worst, how would you rate the way you feel on a 1-10 scale?

When your symptoms are at their best, how would you rate the way you feel on a 1-10 scale?

Interview Two: questions (pattern appraisal) reflecting the environmental field.

After reviewing symptoms as given at last interview:

1. Could you identify the 5 symptoms that cause you the most problems

Taking each of the five that cause the most problems in turn:

2. What do you do to cope with or manage this symptom in your daily life?
3. What explanations have you been given for this symptom?
4. What do you see as your current problems or difficulties in living with this symptom?

   How do you think they could be best solved?
5. How has having this condition affected your friendships, your work life, your family life, your partnership/marriage.

   How has having this problem affected your views of the meaning of life and your spiritual thinking?
6. What do you see as your personal strengths that help you to live with these symptoms?

Glossary

arachnoid cysts - arachnoid cysts are outpouchings of the arachnoid lining. They are usually considered to be idiopathic and possibly congenital. If they compress the spinal cord, the cauda equina or individual nerve roots, they can be associated with pain, sensory changes, urinary dysfunction and weakness. The intensity of these symptoms can alter dramatically with postural changes.

arachnoiditis - inflammation of the arachnoidea.

causalgia - disruption in normal flow of sensory information along nerve to brain creating confusion for the brain which is interpreted as a uniquely disabling pain state, constant and highly resistant to normal forms of medical therapy.

chronic adhesive arachnoiditis - thickening and adhesions of the leptomeninges in the brain and spinal cord, resulting from previous meningitis, other disease processes, or trauma; the signs and symptoms vary with the extent and location.

clonic spasm - rigidity of the muscles, followed immediately by relaxation.

cauda equina compression - most often due to neoplasm but also by lipoma, in spina bifida occulta, constricting fibrous band or by chronic arachnoiditis. If a complication of ankylosing spondylitis, it may also be due to arachnoiditis, but is more often associated with arachnoid cysts.

cramp - sustained spasm, or tetanic contraction of an entire muscle, which lasts for just a few seconds or several hours, causing the muscle to become taut and painful; among other causes, linked to irritability of the spinal cord.

fasciculation - a small local contraction of muscles, visible through the skin, representing a spontaneous discharge of a number of fibres innervated by a single motor nerve filament. In association with compression of the spinal cord, ventral roots or anterior horns of grey matter, fasciculation of the muscles innervated by the affected segments will occur, along with progressive wasting and weakness.

focal arachnoiditis – arachnoiditis focused on a small area of damage in the spine

myelomalacia - morbid softening of the spinal cord. Associated with tuberculosis of the spine and with paralysis.

myoclonus - shocklike contractions of a portion of a muscle or an entire muscle or a group of muscles. The term 'myoclonus' is applied to a brief, shock-like muscular contraction which may be confined to a single muscle or may involve many muscles, either successively or simultaneously. Often, contractions may occur symmetrically in muscles on the opposite sides of the body. The contraction may be too slight to cause movement or can cause such violent movement as to throw the person to the ground. The contraction does not affect groups of muscles which are normally synergistically associated, nor does it usually affect mutually antagonistic muscles.

neuralgia - paroxysmal pain which extends along the course of one or more nerves. Many varieties are distinguished according to the part affected or the cause.

neurogenic - originating in the nervous system

neurogenic claudication - syndrome associated with a narrow spinal canal. Typically, there is a distinctly unpleasant sensation in the legs, which can be frankly painful in some cases. It is variably described as numb, cold, burning or cramping and characteristically appears after assumption of an upright posture or during prolonged extension of the lumbar spine. May begin in the feet and spread proximally or vice versa. Paraesthesias often appear when the person is standing still, but typically are brought on by walking. These points help to distinguish it from peripheral vascular claudication in which cramps affect the legs after exercise regardless of posture. A useful rule of thumb is that the patient whose intermittent claudication is due to arterial insufficiency would rather walk downhill than uphill. The reverse is true of the person with a narrow spinal canal since the back is slightly flexed in climbing.

neuropathic - pertaining to or characterised by neuropathy..

neuropathy - a general term denoting functional disturbances and/or pathological changes in the peripheral nervous system. The aetiology may be known eg diabetic neuropathy, ischemic neuropathy, traumatic neuropathy or unknown. Encephalopathy and myelopathy are corresponding terms relating to involvement of the brain and spinal cord, respectively. The term is also used to designate non-inflammatory lesions in the peripheral nervous system.

radicular - of or pertaining to a root

radiculitis - inflammation of the root of a spinal nerve, especially that portion of the root which lies between the spinal cord and the intervertebral canal

remitting, remittent - having periods of abatement and exacerbation without actual cessation of the symptoms.

silent arachnoiditis - scarring process in spine before later development of symptoms different to initial symptoms

spasm - a sudden involuntary muscle twitch attended by pain ranging in severity from merely irritating to very painful and interfering with function, producing involuntary movement and distortion

spasticity - a form of increased tone or hypertonia resulting from lesions of the pyramidal and often of the reticulospinal pathway, the stretch reflexes, released from descending inhibitor influences, become hyperactive as a consequence of increased excitability of dynamic fusimotor neurones and alpha neurones. If the dorsal reticulospinal system, closely related anatomically to the pyramidal tract in the spinal cord, is also damaged, there is disinhibition of afferent flexor reflex pathways. Release of such flexor reflexes may give flexor spasms in the lower limbs in response to stimulation of the legs, or the bladder or bowel

References

Abdellah, F. & Levine, M. (1965). *Better patient care through nursing research*. New York: MacMillan.

Admi, H. (1995). Nothing to hide and nothing to advertise: Managing disease-related information. *Western Journal of Nursing Research*, 17 (5), 484-501.

Arachnoiditis – question2s and answers. (1994, February). *Fact Sheet*. Back Pain Association of America.

Arachnoiditis Trust Leaflet, author unstated, date unstated, no title. *Leaflet written for the information of doctors, consultants, physiotherapists, alternative therapists, and healthworkers*. North Tawnton, Devon: The Arachnoiditis Trust.

Arachnoiditis: What is arachnoiditis?: What is its symptoms?: What causes it? (1996). *Newsletter,* 4 (2), 1, 7-15. Pasadena, Maryland: Back Pain Association of America.

A Shot in the back (1995, Sept. 25). *20/20*, TV3, Television New Zealand.

Auld, A. (1978). Chronic spinal arachnoiditis: A postoperative syndrome that may signal its onset. *Spine,* 3(1), 88-91.

Baquie, M.L. (1989). What matters most in chronic pain management. *RN*, March, 46-50.

Barrett, E. (1986). Investigation of the principle of helicy: The relationship of human field motion and power. In V. Malinski, (Ed), *Explorations on Martha Rogers' science of unitary human beings* (pp. 173-184). Norwalk, CT: Appleton-Century-Crofts.

Barrett, E. (1988). Using Rogers' science of unitary human beings in nursing practice. *Nursing Science Quarterly,* 1, 50-51.

Barrett, E. (1990). Rogerian patterns of scientific inquiry. In E.A.M. Barrett (Ed), *Visions of Rogers' science-based nursing* (pp. 169-187). New York: National League for Nursing.

Barrett, E. (1994). On the threshold of tomorrow. In V.M. Malinski & E.A.M. Barrett (Eds.) *Martha E. Rogers: Her life and work* (pp. 271-275). Philadelphia: Davis.

Boguslawski, M. (1990). Unitary human field modalities. In E.A.M. Barrett (Ed.), *Visions of Rogers' science-based nursing* (pp. 83-92). New York: National League for Nursing.

Bohr, T. (1995). Fibromyalgia syndrome and myofascial pain syndrome: Do they exist? *Neurologic Clinics*, 13(2), 365-384.

Bonica, J. (1973). Fundamental considerations of chronic pain therapy. *Postgraduate Medicine,* 53(6), 81-85.

Bonica, J. (1991). Introduction: Semantic, epidemiologic, and educational issues. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: The Central Pain Syndromes* (pp. 13-29). New York: Raven.

Bourne, I. (1990). Lumbo-sacral adhesive arachnoiditis: A review. *Journal of the Royal Society of Medicine,* 83, 262-265.

Bowsher, D. (1993). Pain management in nursing. In D. Carroll & D. Bowsher (Eds.), *Pain: Management and nursing care.* Oxford; Butterworth-Heinemann.

Brammah, T. & Jayson, M. (1994). Syringomyelia as a complication of spinal arachnoiditis. *SPINE,* 19, 2603-2605.

Brownrigg, M. (1992). Helping lumbo-sacral arachnoiditis patients. *Nursing Standard,* 7 (4), 28-30.

Burton, C. (1978). Lumbosacral arachnoiditis. *SPINE,* 3 (1), 24-29.

Burton, C. (1985). The failed back. In R. Wilkins & S. Renachary (Eds.) *Neurosurgery* (pp. 2290-2292). McGraw-Hill.

Burton, C. (1991). Causes of failure of surgery on the lumbar spine: Ten-year follow up. *The Mount Sinai Journal of Medicine,* 58(2), 183-187.

Burton, C. (1994). *Arachnoiditis Report.* Minneapolis, MN: Institute for Low Back Pain.

Burton, C. (1997). Adhesive arachnoiditis: The global economic liability. *Newsheet*, Minneapolis, MN: Institute for Low Back and Neck Care,.

Caine, J. & Hammes, B. (1994). Ethics and pain management: Respecting patient wishes. *Journal of Pain and Symptom Management*, 9 (3), 160-165.

Calliet, R. (1988). *Low back pain syndrome*. Philadephia: Davis.

Carella, A., Federico, F., Di Cuonzo, F., Vinjau, E. & Lamberti, P. (1982). Adverse side effects of metrizamide and iopamidolo in myelography. *Neuroradiology,* 22, 247-249.

Caroselli, C. (1994). Opportunities for knowing participation: A new design for the nursing service organisation. In M. Madrid & E.A.M. Barrett (Eds.), *Rogers'*

Scientific Art of Nursing Practice (pp. 243-259). New York: National League for Nursing.

Carroll, D. & Bowsher, D. (Eds.) (1993). *Pain: Management and nursing care*. Oxford: Butterworth-Heinemann.

Carroll, S. & Wiesel, S. (1992). Neurologic complications and lumbar laminectomy: A standardised approach to the multiply-operated lumbar spine. *Clinical Orthopaedics and Related Research,* 284, 14-23

Casey, K. (1991). Pain and central nervous system disease: A summary and overview. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: the Central Pain Syndromes* (pp. 1-11). New York: Raven.

Chadwick, D., Cartlidge, N. & Bates, D. (1989). *Medical Neurology*. Edinburgh: Churchill Livingstone.

Champagne, M. & Wiese, R. (1994). Intervening with adults in pain: A discussion. In S. Funk, E. Tornquist, M. Champagne, I. Copp, & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp. 173-178). Basingstoke: MacMillan.

Chinn, P. (1996). From the editor: Living with chronic pain. *Advances in Nursing Science,* 18(3), 1-15.

Coe, C. (1997). Advances in nursing patients with intractable pain. *Contemporary Nurse,* 6(1), 32-39.

Cohen, F. & Hardin, S. (1994). Fatigue in patients with catastrophic illness. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp 208-216). Basingstoke: MacMillan.

Cormack, D. (1991). *The research process in nursing.* Oxford: Blackwell.

Cowling, W.R. (1986). The science of unitary human beings: Theoretical issues, methodolgical challenges and research realities. In V. Malinski, (Ed.), *Explorations on Martha Rogers' science of unitary human beings* (pp. 65-77). Norwalk, CT: Appleton-Century-Crofts.

Cowling, W.R. (1990). A template for unitary pattern-based nursing practice. In E.A.M. Barrett (Ed.), *Visions of Rogers' science-based nursing* (pp45-65). New York: National League for Nursing.

Crosby, L. (1994). Fatigue, depression, and sleep disturbance in rheumatoid arthritis patients. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp 299 - 302). Basingstoke: MacMillan.

Davidoff, G. & Roth, E. (1991). Clinical characteristics of central (dysesthetic) pain in spinal cord injury patients. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: the Central Pain Syndromes* (pp77-83). New York: Raven.

Davies, F. (1956, Oct 13). Effect of unabsorbed radiographic contrast media on the central nervous system. *Lancet*, 747-748.

Davies, H., Crombie, I. & Macrae, W. (1993). Polarised views on treating neurogenic pain. *Pain*, 54, 341-346.

Dolan, R. (1993). Spinal adhesive arachnoiditis. *Surgical Neurology,* 39, 479-484.

Donaldson, I. & Gibson, R. (1982). Spinal cord atrophy associated with arachnoiditis as demonstrated by computed tomography. *Neuroradiology,* 24, 101-105.

Dooley, J., McBroom, R., Taguchi, T. & MacNab, I. (1988). Nerve root infiltration in the diagnosis of radicular pain. *SPINE,* 13(1), 79-83.

Dorland, W. (1988). *Dorland's illustrated medical dictionary.* (27th Ed.). Philadelphia: Saunders.

Edgar, L. & Smith-Hanrahan, C. (1992). Nonpharmacological pain management. In J. Watt-Watson & M. Donovan (Eds.), *Pain management: Nursing perspective* (pp. 162-199). St Louis: Mosby.

Elliot, R., Wild, J. & Snow, W. (1984). Prolonged delerium after metrizamide myelography. *JAMA,* 252, 2057-2058.

Etchells, E., Sharpe, G., Dykeman, M., Meslin, E. & Singer, P. (1996). Bioethics for clinicians: 4. Voluntariness. *Canadian Medical Association Journal,* 155, 1083-1086.

Ferrell, B. (1995). The impact of pain on quality of life: A decade of research. *Nursing Clinics of North America,* 30, 609-624.

Ferrell, B., McCaffery, M. & Rhiner, M. (1992). Pain and addiction: An urgent need for change in nursing education. *Journal of Pain and Symptom Management*, 7(2), 117-124.

Finer, B. & Melander, B. (1985). Living in chronic pain. *Persistent Pain, 5, 225-240.*

Fitt, G. & Stevens, J. (1995). Postoperative arachnoiditis diagnosed by high resolution fast spin-echo MRI of the lumbar spine. *Neuroradiology,* 37, 139-145.

Garon, M. (1991). Assessment and management of pain in the home care setting: Application of Rogers' science of unitary human beings. *Holistic Nursing Practice,* 6(1), 47-57.

Gelmers, H. (1979). Adverse side effects of metrizamide in myelography. *Neuroradiology,* 18, 119-123.

Grahame, R., Clark, B., Watson. M. & Polkey, C. (1991). Towards a rational therapeutic strategy for arachnoiditis: A possible role for d-Penicillamine. *SPINE,* 16(2), 172-175.

Gundry, C. & Fritts, H. (1997). Magnetic resonance imaging of the musculoskeletal system: Part 8. The Spine, Section 1. *Clinical Orthopaedics and Related Research,* 338, 275-287.

Guyer, D., Wiltse, L., Eskay, M., & Guyer, B. (1989). The long-range prognosis of arachnoiditis. *SPINE,* 14, 1332-1341.

Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations (1996). Wellington, New Zealand.

Hitchcock, L., Ferrell, B. & McCaffery, M. (1994). The experience of chronic nonmalignant pain. *Journal of Pain and Symptom Management*, 9(5), 312-318.

Howland, W. & Curry, J. (1966). Experimental studies of Pantopaque arachnoiditis. *Radiology*, 87, 253-261.

Hughes, D. & Isherwood, I. (1992). How frequent is chronic lumbar arachnoiditis following intrathecal Myodil? *British Journal of Radiology,* 65, 758-760.

Jackson, A. & Isherwood, I. (1994). Does degenerative disease of the lumbar spine cause arachnoiditis? A magnetic resonance study and review of the literature. *British Journal of Radiology,* 67, 840-847.

Jacox, A. (1977). *Pain: A source book for nurses and other health professionals.* Boston: Little, Brown.

Jacox, A. (1994). Key aspects of comfort. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp. 8-21). Basingstoke: MacMillan.

Jayson, M. (undated). *Progress in understanding arachnoiditis*. (Information sheet). Salford: University of Manchester.

Johnson, A., Ryan, M. & Roche, J. (1991). Depo-Medrol and myelographic arachnoiditis. *The Medical Journal of Australia,* 155, 18-20.

Johnstone, M. (1989). *Bio ethics: A nursing perspective.* Marrickville, Australia: Saunders/Balliere Tindall.

Jorgensen, J., Hansen, P., Steenskov, V. & Oveson, N. (1975). A clinical and radiological study of chronic lower spinal arachnoiditis. *Neuroradiology,* 9, 139-144.

Junck, I. & Marshall, W. (1983). Neurotoxicity of radiological contrast agents. *Annals of Neurology,* 13, 469-484.

Kendall, N., Linton, S. & Main, C. (1998). *Assessing psychosocial yellows flags in acute low back pain: Risk factors for long term disability and work loss.* Wellington, New Zealand: Accident Rehabilitation and Compensation Insurance Corporation of New Zealand and the National Health Committee.

Killebrew, K., Whaley, R., Hayward, J. & Scatliff, J. (1983). Complications of metrizamide myelography. *Archives of Neurology,* 40, 78-80.

Kitagawa, H., Kanamori, M., Tatezaki, S., Itoh, T. & Tsuji, H. (1990). Multiple spinal ossified arachnoiditis: A case report. *SPINE,* 15, 1236-1238.

Klekamp, J., Batzdorf, U., Samii, M. & Bothe, H. (1997). Treatment of syringomyelia associated with arachnoid scarring caused by arachnoiditis or trauma. *Journal of Neurosurgery*, 86, 233-240.

Knight, D. (1989). *A companion to the physical sciences.* London: Routledge.

Kodiath, M. (1991). A new view of the chronic pain client. *Holistic Nursing Practice*, 6(1), 41-46.

Kriss, T. & Kriss, V. (1997). Symptomatic spinal intradural arachnoid cysts development after lumbar myelography. *SPINE,* 22(5), 568-572.

Laitt, R., Jackson, A. & Isherwood, I. (1996). Patterns of chronic adhesive arachnoiditis following Myodil myelography: The significance of spinal canal stenosis and previous surgery. *British Journal of Radioology,* 69, 693-698.

Lander, R. (1996, August). Low back pain. *Primary Health Care in New Zealand* (pp. 37-43).

Large, R. & Schug, S. (1995). Opiods for chronic pain of non-malignant origin - caring or crippling. *Health Care Analysis,* 3, 5-11.

LeFort, S. (1992). Patients with idiopathic low back pain: Physical fitness as a treatment strategy. In J. Watt-Watson, & M. Donovan (Eds.), *Pain management: Nursing perspective* (pp. 482-508). St Louis: Mosby.

Lindblom, U. (1991). New directions for basic and clinical research in central pain syndromes. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: the Central Pain Syndromes* (pp. 275-279). New York: Raven.

Long, D. (1992). Chronic adhesive spinal arachnoiditis: Pathogenesis, prognosis, and treatment. *Neurosurgery Quarterly,* 2(4), 296-319.

Malinski, V. (1986). Further ideas from Martha Rogers. In V. Malinski (Ed.), *Explorations on Martha Rogers' science of unitary human beings* (pp. 9-14). Norwalk, CT: Appleton-Century-Croft.

Malinski, V. (1990). The Rogerian science of unitary human beings as a knowledge base for nursing in space. In E.A.M. Barrett (Ed.), *Visions of Rogers' science-based nursing* (pp. 363-374). New York: National League for Nursing.

Malinski, V. (1991a). Spirituality as integrality: A Rogerian perspective on the path to healing. *Journal of Holistic Nursing,* 9(1), 54-64.

Malinski, V. (1991b). The experience of laughing at oneself in older couples. *Nursing Science Quarterly*, 4 (2), 69-75.

Malinski, V. (1997). Rogerian health patterning: Evolving into the 21st century. *Nursing Science Quarterly*, 10:3, 115-116.

Martin, R. & Yuan, H. (1996). Neurosurgical care of spinal epidural, subdural, and intramedullary abscesses and arachnoiditis. *Orthopedic Clinics of North America,* 27, 125-136.

Mason, M. & Raaf, J. (1962). Complications of Pantopaque myelography: A case report and review. *Journal of Neurosurgery*, 19, 302-311.

Mast, M. (1995). Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice,* 9(1), 3-24.

Matas, K. (1997). Human patterning and chronic pain. *Nursing Science Quarterly*, 10(2), 88-96.

Mayher, W., Daniel, E. & Allen, M. (1971). Acute meningeal reaction following Pantopaque myelography. *Journal of Neurosurgery,* 34, 396-404.

McCaffery, B. (1990). Nurses lead the way to new priorities. *American Journal of Nursing*, Oct, 45- 49.

McCaffery, M. & Beebe, A. (1989). *Pain: Clinical Manual for Nursing Practice.* St Louis: Mosby.

McCaffery, M. & Ferrell, B. (1996). Correcting misconceptions about pain assessment and the use of opiod analgesics: Educational strategies aimed at public concerns. *NURSING OUTLOOK*, 44(4), 184-190.

McKenzie, D. (1996). Broken bodies, intact souls: A holistic approach to disability services. *New Zealand Journal of Disability Studies,* 2, 115-127.

McWilliam, C., Stewart, M., Brown, J., Desai, K. & Coderre, P. (1996). Creating health with chronic illness. *Advances in Nursing Science*, 18(3), 1-15.

Melzack, R. (1992). The dilemma of morphine. In F. Sicuteri, L. Terenius, L. Vecchiet, & C. Maggi (Eds.), *Advances in Pain Research and Therapy: Pain versus man,* Vol 20 (pp. 149-159). New York: Raven.

Meyerson, B. (1990). Neuropathic pain: An overview. In S. Lipton, E. Tunks & M. Soppi (Eds.), *Advances in pain research and therapy, Vol 13.* New York: Raven.

Mishel, M. (1988). Uncertainty in illness. *IMAGE: Journal of Nursing Scholarship,* 20(4), 225-232.

Mishel, M. (1990). Reconceptualization of the uncertainty in illness theory. *IMAGE: Journal of Nursing Scholarship,* 22(4), 256-262.

Mishel, M. (1995). Response to "Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice,* 9(1), 25-29.

Moran, K. (1994). The effects of self-guided imagery and other-guided imagery on chronic low back pain. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp160 -165). Basingstoke: MacMillan.

Morgan, J. (1995a, Oct 18). Doctors unsympathetic, say Myodil sufferers. *Dominion.*

Morgan, J. (1995b, Nov 1). Myodil group wants answers. *Dominion.*

Morwessel, N. (1994). Developing an effective pattern appraisal to guide nursing care of children with heart variations and their families. In M. Madrid & E.A.M. Barrett (Eds.), *Rogers' Scientific Art of Nursing Practice* (pp. 147-161). New York: National League for Nursing.

Myodil group may be formed. (1995, Oct 10), *Wanganui Chronicle, p3.*

Myodil victims band together. (1995, Oct 19), *Gisborne Herald.*

Myodil victims sought. (1995, Oct 6), *Southland Times.*

Myodil victims urged to gather records. (1995, Nov 14), *Wanganui Chronicle, p1.*

Nashold, B., Bullitt, E. & Friedman, A. (1989). The place of neurosurgery in the treatment of intractable pain. In M. Swerdlow & J. Charlton (Eds.), *Monographs in the field of anaesthesiology: relief of intractable pain.* NY: Elsevier.

Nelson, D. (1993). Intraspinal therapy using methylprednisolone acetate: Twenty-three years of clinical controversy. *SPINE,* 18, 278-286.

New Zealand framework for service delivery: Disability support services. (1994). Wellington: Ministry of Health/Manatu Hauora.

Parse, R. (1994). Quality of life: sciencing and living the art of human becoming. *Nursing Science Quarterly*, 7(1), 16-21.

Peek, R., Thomas, J. & Wiltse, L. (1993). Diagnosis of lumbar arachnoiditis by myeloscopy. *SPINE,* 18, 2286-2289.

Peterson, H. (1976). Commentary on myelography: defense of Pantopaque. In T. Morley (Ed.), *Current controversies in neurosurgery*. Philadelphia: Saunders.

Phadke, R., Kohli, A., Jain, V., Gupta, R., Kumar, S. & Gujral, R. (1994). Tuberculous radiculomyelitis (arachnoiditis): Myelographic (and CT myelographic) appearances. *Australasian Radiology*, 38, 10-16.

Piper, B. (1994). Fatigue: Current bases for practice. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp 187 - 198). Basingstoke: MacMillan.

Potempa, K. (1994). Chronic fatigue: Directions for research and practice. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp 229 - 233). Basingstoke: MacMillan.

Price, D. (1991). Characterizing central mechanisms of pathological pain states by sensory testing and neurophysiological analysis. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: the Central Pain Syndromes* (pp 103-115). New York: Raven.

Quiles, M., Marchisello, P. & Tsairis, P. (1978). Lumbar adhesive arachnoiditis: etiologic and pathologic aspects. *SPINE*, 3(1), 45-50.

Report of the Ministerial Taskforce on Nursing: Releasing the potential of nursing (1998). Wellington, New Zealand: Ministry of Health.

Roeder, M., Bazan, C. & Jinkins, J. (1995). Ruptured spinal dermoid cyst with chemical arachnoiditis and disseminated intracranial lipid droplets. *Neuroradiology*, 37, 146-147.

Rogers, M. (1961). *Educational revolution in nursing*. Philadelphia: Davis.

Rogers, M. (1963a). Building a strong educational foundation. *The American Journal of Nursing*, 63(6), 94-95.

Rogers, M. (1963b). Some comments on the theoretical basis for nursing practice. *Nursing Science*, 63(1), 11-13, 60-61.

Rogers, M. (1964). *Reveille in nursing*. Philadelphia: Davis.

Rogers, M. (1970). *An introduction to the theoretical basis of nursing*. Philadelphia: Davis.

Rogers, M. (1980). Nursing: A science of unitary man. In J. Riehl & C. Roy (Eds.), *Conceptual models for nursing practice* (2nd Ed.) (pp. 329-331). New York: Appleton-Century-Crofts.

Rogers, M. (1986). Science of unitary human beings. In V. Malinski (Ed.), *Explorations on Martha Rogers' science of unitary human beings* (p3-8). Norwalk, CT: Appleton- Century-Crofts.

Rogers, M. (1988). Nursing science and art: a prospective. *Nursing Science Quarterly*, 1, 99-102.

Rogers, M. (1990). Nursing: Science of unitary, irreducible human beings: Update 1990. In E.A.M. Barrett (Ed.), *Visions of Rogers' science-based nursing* (pp 5-11). New York: National League for Nursing.

Rogers, M. (1992). Nursing science and the space age. *Nursing Science Quarterly,* 5, 27-34.

Rogers, M. (1993). The science of unitary human beings: Current perspectives. *Nursing Science Quarterly,* 7(1), 33-35.

Rogers, M. (1994). The science of unitary human beings: Current perspectives. *Nursing Science Quarterly,* 7(1), 33-35.

Rosenberg, S. & Stacey, B. (1996). Postoperative Guillain-Barre Syndrome, arachnoiditis, and epidural analgesia. *Regional anaesthesia,* 21(5), 486-489.

Rowland Hill, C., Hunter, J., Moseley, I. & Kendall, B. (1992). Does Myodil introduced for ventriculography lead to symptomatic lumbar arachnoiditis? *The British Journal of Radiology,* 65, 1105 -1107.

Sadler, C. (1993). Once the dye is cast . . . . *Nursing Times,* 89(2), 16-17.

Schwarz, L. & Slater, M. (1991). The impact of chronic pain on the spouse: Research and clinical implications. *Holistic Nursing Practice*, 6(1), 9-16.

Segesten, K. (1993). Patient advocacy - an important part of the daily work of the expert nurse. *Scholarly Inquiry for Nursing Practice: An International Journal*, 7(2), 129-135.

Seigfried, J. (1990). Neurosurgical treatment of neurogenic pain. In S. Lipton, E. Tunks & M. Zoppi. *Advances in Pain Research and Therapy,* Vol 13 (pp. 207-215). New York: Raven Press

Shipton, E. (1989). Low back pain and the post-laminectomy pain syndrome. *South African Medical Journal,* 76, 20-23.

Smith, A. & Blaser, S. (1991). Infectious and inflammatory processes of the spine. *Radiologic Clinics of North America,* 29(4), 909-827.

Smith, J. & Ross, L. (1959). Steroid suppression of meningeal inflammation caused by Pantopaque. Source unknown.

Somerville, M. (1994). Death of pain: Pain, suffering, and ethics. In G. Gebhart, D. Hammond & T. Jensen, *Proceedings of the 7th World Congress on Pain: Progress in Pain Research and Management,* Vol. 2 (pp. 41-58). Seattle: IASP Press.

Spinal dye used all over New Zealand, neurologist says (Sept. 27, 1995). Wanganui Chronicle, p3.

Srivastava, R. (1994). Fatigue in end-stage renal patients. In S. Funk, E. Tornquist, M. Champagne, I. Copp & R. Wiese (Eds.), *Management of pain, fatigue and nausea* (pp. 217-224). Basingstoke: MacMillan.

Sufferers join forces. (1995, Oct 19). *Manawatu Evening Standard.*

Tasker, R., DeCarvalho, G. & Dolan, E. (1992). Intractable pain of spinal cord origin: Clinical features and implications for surgery. *Journal of Neurosurgery,* 77, 373-378.

Tasker, R., De Carvalho, G. & Dostrovsky, J. (1991). The history of central pain syndromes, with observations concerning pathophysiology and treatment. In K. Casey (Ed.), *The Bristol-Myers Squibb Symposium on pain research. Pain and Central Nervous System Disease: the Central Pain Syndromes* (pp. 31-58). New York: Raven.

Tasman Dictionary (1985). Dee Why, NSW: Macquarie Library

Terenius, L. (1992). Profiles of CSF neuropeptides in chronic pain of different nature. In F. Sicuteri, L. Terenius, L. Vecchiet & C. Maggi (Eds.), *Advances in Pain Research and Therapy: Pain versus man,* Vol 20 (pp. 93-100). New York: Raven Press.

Toribatake, Y., Maezawa, Y., Umeda, S. & Tomita, K. (1995). Symptomatic arachnoiditis ossificans of the thoracic spine: Case report. *Paraplegia*, 33, 224-227.

Tuyn, L. (1994). Rhythms of living: A Rogerian approach to counseling. In M. Madrid & E.A.M. Barrett (Eds.), *Rogers' Scientific Art of Nursing Practice* (pp. 207-221). New York: National League for Nursing.

Vallerand, A. (1991). The use of narcotic analgesics in chronic nonmalignant pain. *Holistic Nursing Practice*, 6(1), 17-23.

Voltaren information sheet, (1993). *Geigy Fact Sheet.*

Vloeberghs, M., Herregodts, P., Stadnik, T., Goossens, A. & D'Haens, J. (1992). Spinal arachnoiditis mimicking a spinal cord tumor: A case report and review of the literature. *Surgical Neurology,* 37, 211-5.

Wall, P. (1992). The biological function and dysfunction of differential pain mechanisms: In F. Sicuteri, L. Terenius, L. Vecchiet & C. Maggi (Eds.), *Advances in Pain Research and Therapy: Pain versus man,* Vol. 20, (pp. 19-28). New York: Raven Press.

Walton, J. (1985). *Brain's diseases of the nervous system* (9th Ed.). Oxford: Oxford University Press.

Wanganui Myodil sufferers band together to fight for recognition. (1995, Oct 19). Wanganui Chronicle.

Watt-Watson, J. & Donovan, M. (1992). *Pain management: Nursing perspective.* St Louis: Mosby.

Whanganui Disability Resource Centre, (1996). *WDRC questionnaire responses on arachnoiditis*. Unpublished raw data.

Webster's New World Dictionary (1998). M. Agnes (Ed.). New York: MacMillan.

Wells, N. (1994). Perceived control over pain: Relation to distress and disability. *Research in Nursing & Health*, 17, 295-302.

Wenley, S. (1998). Opiophobia - the fear of addiction. *New Zealand GP*. April 2.

Wilkinson, H. (1992). Intrathecal Depo-Medrol: A literature review. *Clinical Journal of Pain,* 8, 49-56.