

THE MEANING OF CHRONIC PAIN

by

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I declare that The Meaning of Chronic Pain is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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ABSTRACT

Chronic pain sufferers are frequently misunderstood and stigmatised. The aim of this investigation was to provide a description of the lifeworld of people with chronic low back pain, using the phenomenological method. Themes which emerged were that the persistent nature of chronic pain makes it particularly difficult to endure, arousing a profound fear of the future. It causes a disruption in the relationship between the person and the body, in which the person is forced to function within the constraints of pain. Sufferers are unable to fulfil social roles as expected and are forced to revise their goals and activities. The distress of their experience is mediated by the ability to make sense of their condition, finding meaning in the pain itself.

The study highlights the value of the phenomenological method in health psychology. Recommendations are made which may be of benefit to people with chronic pain and their families.

Keywords: Chronic low back pain; coping; meaning; phenomenology; health psychology.

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CHAPTER ONE

INTRODUCTION

Pain may be either a blessing or a curse. To illustrate this point, imagine what life would be like without pain. One would feel no pain from injuries, operations or dental fillings. However, one would also be unaware of the dangers of burning oneself, diseases or other instances of harm to the body. Usually pain serves an important protective function. The aversive nature of pain motivates individuals to take action to avoid worsening the damage or to initiate the process of healing. Nonetheless, the value of pain as a warning signal is limited. It is generally assumed that pain is a symptom of injury or disease which will diminish as healing or recovery occurs. The reality is that many painful conditions do not resolve and many are only treatable up to a point (Eimer, 1998). Pain which is uncontrolled or prolonged causes enormous suffering which may greatly compromise the quality of life. From a medical point of view, a chronic illness (as distinct from an acute condition), is a disease process which is progressive, enduring or recurrent (Gregg, Robertus & Stone, 1989).

The International Association For The Study Of Pain (IASP) offers the following definition:

Pain is an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. It is unquestionably a sensation in a part of the body, but it is also unpleasant and therefore an emotional experience. Many people report pain in the absence of tissue damage or any likely patho-physiological cause; usually this happens for psychological reasons. There is no way to distinguish their experience from that due to tissue damage if we take their subjective report (Shipton, 1993, p. 1).

Pain is a puzzling phenomenon. Although it is a universal experience, it is still poorly understood and is often difficult to control. It can span an enormous spectrum of intensity from mild discomfort to agony. Equally puzzling is the fact that responses to pain, even within an individual, may vary at different times and under different circumstances. Pain may be creative or destructive. It may be linked with survival or with disease and

death. It may serve as a warning sign that something is wrong or compromise the quality of life. It may be regarded as a challenge or diminish the will to live. In short, it may take on a variety of meanings which greatly influence the way in which it is tolerated and perceived (Autton, 1986).

Types of chronic pain.

“Pain is regarded as chronic if it persists for a month beyond the usual course of illness or time for an acute injury to heal, if it is associated with a chronic pathologic process, or if it recurs at intervals of months or years.” (Bonica, 1990, in Eimer, 1998, p. 9)

Pain is further classified into:

- Objective pain; pain associated with a medically verifiable disease or injury
- Psychogenic pain; pain which is disproportionate to objective measures of the underlying disease or injury.
- Chronic benign pain; pain of non-cancerous origin.
- Chronic malignant pain; pain associated with cancer.
- Progressive pain; pain associated with a worsening disease.
- Recurrent chronic pain; pain which recurs intermittently such as headaches.
- Continuous pain; pain which is always there although the intensity varies.

These syndromes may differ in important ways. For example, cancer patients experiencing chronic pain also face psychological crises related to fear of bodily decline and death (Eimer, 1998). In view of this, the current research will focus on one group of patients namely, those with benign low back pain.

Incidence

Chronic pain is one of the great health problems confronting modern society (Bishop, 1994). Little attention has been paid to researching chronic pain in South Africa. So far the incidence of chronic pain in this country has not been determined (Katz, 2000). However, it seems likely that a significant number of people in South Africa suffer from chronic pain (Katz, 2000). There are two thousand patients currently receiving treatment for chronic pain at Hillbrow Hospital (Shipton, Personal Communication, 2000). It is

estimated that 30% of the population in economically developed countries suffer from chronic pain (Fordyce, 1995, in Eimer, 1998). A survey conducted recently found that 7% of the adult population in households in the United Kingdom were in pain. In the United States of America, it is estimated that 3,3% of the population are permanently disabled due to pain (Shipton, 1993).

“Second to the common cold, back pain is the most prevalent affliction of man” (Hawthorn & Redmond, 1998, p. 63). 80 % of persons are likely to be affected by back pain at some time in their lives. Of these, 4 % are likely to develop chronic pain (Hainline, 1995). Back symptoms are the second most common reason expressed by patients for visiting the doctor in the United States (Cypress, 1983). The majority of back pains resolve spontaneously. Although this may imply that many patients will not need any active intervention, this conclusion must be tempered by the fact that the earlier the intervention is received, the better the prognosis. Once back pain has been present for six weeks, it is likely to become chronic. Once it has been there for six months, there is only a 50 % chance of return to work (Hawthorn & Redmond, 1998). The leading consumers of disability pensions, sick pay and insurance benefits are patients with back conditions. Consequently it appears that about ten per cent (or less) of patients with back pain account for approximately 50 to 75 % of the costs (Linton, 1987). Pain does not only have economic repercussions in terms of workdays lost, disability, compensation and treatment. In addition, when back pain develops into a chronic state, part of the problem for the patient may be a lack of occupation rather than the pain itself (Linton, 1987). Chronic pain may be the result of minor trauma and become a complex phenomenon over time, incorporating biological, psychological and social aspects.

Patients with chronic illnesses, including chronic pain, will probably never regain the full levels of health and activity they enjoyed prior to the onset of their affliction. It is sobering to note that, although some patients learn to live with pain in more appropriate ways, they seldom return to the pre-pain state of function. Linton (1987) noted that, after treatment, the final level of functioning of patients with chronic back pain was still clearly below that of their peers without pain. Although some patients may enjoy periods of remission during the course of the condition, most people with chronic health problems are confronted with the possibility of incapacitation, rising costs, long-term medical management, and the constant threat of deterioration (Gregg et al., 1989). This may have

repercussions on a person's self concept, behaviour and well-being as well as on the family and society. Yet "the greatest cost of chronic pain must be measured in the untold suffering it causes" (Eimer, 1998, p.2).

The effects of chronic pain

The following epiphenomena have been described in relation to chronic pain:

- Changes in mood, particularly dysphoria.
- Drug dependence or abuse, with all the associated side-effects.
- Multiple surgery and medical treatment, with their own side-effects, separate from issues related to drug dependence.
- Social withdrawal and loss of gratification from normal social interaction.
- Conflicts with significant others.
- Increasing hopelessness and helplessness as a result of failure of a number of new and different therapies.
- Decreases in self esteem, self worth and self-confidence.
- Decreasing ability to take pleasure from life, contributing to profound demoralization and, at times, depression.
- Escalating physical incapacity, because of the fear of worsening pain and the fear of causing bodily harm based on the belief that pain is a signal of increasing bodily damage.
- Conflicts with health professionals with resulting dissatisfaction or hostility.

(Pinsky, 1989, in Roy, 1989). The chronic pain patient has been described as "certainly the victim of misunderstanding and perhaps even mistreatment." (Roy, 1989 p.4)

Adjusting to chronic pain

Adjustment to chronic illness is not a single event which occurs when the condition is first diagnosed. Patients have to adjust repeatedly as changes occur in their life situation as well as in the condition itself. The ability of individuals with chronic pain to adapt to new circumstances may be challenged many times over the course of their lives (Gregg et al., 1989). Sufferers may benefit immensely from psychological interventions. Although

the overlap between mind and body is apparent in chronic pain syndromes, psychological interventions for pain relief have been under-employed. As a result, many people whose pain is medically untreatable “do not have access to the psychological healthcare that could afford significant relief” (Eimer, 1995, p. 3).

There appears to be a widespread perception amongst chronic pain sufferers that no one understands chronic pain like another sufferer. The experience of chronic pain has been described as one which “includes a sense of social isolation and the feeling that one is suspended in an ongoing experience, which makes no sense, which no one else can share or comprehend” (Hilbert, 1984, p. 370). Indeed, no one can feel another's pain on a physical level. However inability to find understanding suggests an additional form of suffering which extends beyond the physical pain itself.

Aim and rationale of the study

Although chronic pain is widely acknowledged to be a subjective experience, several researchers have pointed out that the patient's experience of chronic non-malignant pain has received little attention (Large & Strong, 1997; Seers & Friedli, 1996; Carter, 1999, in Walker, Holloway & Sofaer, 1999). Most studies of chronic pain to date appear to have been quantitative and correlational in nature. However, disability of any kind is never encountered in isolation but in the context of a particular life with unique circumstances, goals and dreams. Price (1996) points out that the range and impact of chronic illness is frequently underestimated by healthcare professionals, who are usually afforded only brief glimpses into their patient's world. It is recognized that “there is limited utility in measuring persistent pain in isolation from other related factors” (Walker, Akinsanya, Davis & Marcer, 1990, p. 1161). Getting inside the patient's experience may be the key to understanding the distress, needs and coping strategies of those who face the unenviable prospect of “living in pain.”

Ferrel and Dean (1995) cited in Hawthorn and Redmond (1998) suggest that an important intervention for those who construe pain in a negative way is to facilitate a more positive view of the meaning of pain. Successful management of chronic pain may lie in changing the meaning of pain (Eimer, 1998; Segal –Andrews, Altschuler & Harkness, 1995). Before the meaning of pain can be changed, it must be understood. The purpose of

this research is to provide a holistic description of the meaning of chronic pain, as experienced by the sufferer, using a qualitative rather than a quantitative paradigm. This study may be used to complement the existing body of medical and psychological knowledge of this phenomenon. Such information should be useful to those involved in the lives of sufferers including family members, health care professionals and the patients themselves and may provide important insights into the meaning of chronic pain on which effective intervention may be based.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The literature review will show that much has been learnt about the causes and management of pain. Up to now most research has been conceptualised within the biomedical and psychosocial models in which cause and effect relationships to pain have been sought. It appears that the linear causal models employed for conceptualization, diagnosis and treatment of chronic pain have yielded contradictory research findings and incomplete explanations and descriptions, as will soon become evident. Despite the fact that pain is acknowledged to be a subjective experience, Seers and Friedli (1996) point out that there has been very little research identifying patients' perspectives of chronic non-malignant pain.

Melzack (1990) observes that "prolonged pain destroys the quality of life. It can erode the will to live, at times driving people to suicide. The physical effects are equally profound. Severe, persistent pain can impair sleep and appetite, thereby producing fatigue and reducing the availability of nutrients to organs. It may thus impede recovery from illness or injury, and, in weakened or elderly patients, may make the difference between life and death" (p.19). This quotation illustrates that chronic pain has both physical and psychological effects. The boundaries between the sensory and emotional components of pain are not rigid, but fluid, functioning like parts of a whole. Reducing either has the capacity to reduce the whole (Fernandez, Clark & Rudick-Davis, 1999).

Although acute and chronic pain may arise originally from similar tissue damage or disease, chronic pain is not simply acute pain which has become unusually long standing. Acute pain subsides with healing, whereas chronic pain does not. Therefore, chronic pain appears to have no relation to demonstrable tissue damage or disease and seems to take on a life of its own. Such pain is characterized by unrelieved suffering (Bishop, 1994). It is recognised that chronic pain may precipitate widespread changes in the person's life. Such changes are known to extend even to the neurophysiology of the body, so that previously innocuous stimuli cause pain in the chronic pain sufferer (Hawthorn & Redmond, 1998).

Psychological and behavioural factors are also known to affect the way chronic pain is presented, as well as its severity and course (Katz, 2000). The relationship between mind and body is particularly salient in the study of chronic pain. Pain is both a physiological and a psychological phenomenon. For this reason, "An understanding of the anatomy and physiology of the body is central to understanding the psychology of pain." (Thomas, 1997, p 1) With this in mind, current research pertaining to both the physiology and psychology of chronic pain will be reviewed.

The gate control theory of pain

Early models of pain were primarily physiologically based (Robinson & Riley, 1999). A breakthrough occurred when the gate control theory was proposed by Melzack and Wall in 1965. This theory has been the most influential theory in the pain field ever since (Elton, 1995). It has been tested and modified in the light of new knowledge and technological advances but has remained essentially unchanged since its inception. This theory provided a useful framework for understanding pain phenomena which were inconsistent with purely biological explanations. One of the key contributions of the gate control theory was that it suggested a plausible mechanism by which psychological and social factors could be incorporated into the pain experience (Bishop, 1994). As a result, the gate control theory paved the way for the entrance of the psychologist into the field of pain management.

According to this theory, free nerve endings act as pain receptors, known as nociceptors. These receptors are widely distributed throughout the body. Three types of nociceptors exist: chemical, mechanical and thermal. Chemical receptors are irritated by agents such as 5 hydroxy tryptamine (or serotonin), histamine, potassium or acetylcholine. Mechanical receptors respond to squeezing, crushing and pressure. Thermal receptors respond to extremes of heat or cold. Stimulation of the nociceptors results in the generation of nerve impulses. These impulses from the periphery are conveyed to the brain via the spinal cord.

The gate control theory proposes that there is a group of cells known as transmission cells or T cells in the substantia gelatinosa of the dorsal horn of the spinal columns which act as a pain gate (Elton, 1995). Pain impulses arising from stimulation of

free nerve endings in the target organ are conveyed to the spinal cord. These impulses are carried in two groups of nerve fibres. The first group are myelinated A delta fibres which have a rapid conduction rate. The second group are unmyelinated fibres, known as C fibres which have a slower rate of conduction. Both groups of fibres respond to mechanical trauma, lack of oxygen, inflammatory cell products and thermal injury (Shipton, 1993). Nociceptive (pain conducting) fibres synapse with motor neurones (to facilitate withdrawal from the painful stimulus) as well as with the sympathetic and parasympathetic neurones associated with the internal organs. The latter give rise to the nausea, dizziness or and other vasomotor responses familiar to anyone in severe pain (Charman, 1989). The nociceptive fibres also synapse with the T cells in the substantia gelatinosa. It is proposed that these cells are able to increase or decrease the flow of impulses from the peripheral nerve fibres to the central nervous system. In this sense the T cells act as a gate. What is important is that the T cells do not only receive nociceptive input. The A delta and C fibres, which carry pain impulses, are proposed to have reciprocal activity with another group of fibres known as the A beta fibres, which also synapse with the transmission cells. The A beta fibres convey more innocuous stimuli. This implies that impulses from the large, fast conducting A beta fibres compete with impulses from the A delta and C fibres at the level of the transmission cells. If impulses from the A beta fibres are transmitted, they inhibit the transmission of nociceptive input thereby "closing the gate." This decreases the effectiveness of painful stimulation, lessening the pain experienced. Many pain relieving modalities such as rubbing an injured part, massage, the application of warmth, or the use of stimulating electric currents are based on this principle (Charman, 1989).

The gate control theory postulates that both body and mind are involved in the experience of pain as well as the response to it. There is no specific pain centre in the brain, but a number of structures are involved in the interpretation and response to pain (Bishop, 1994; Jabbur & Saade, 1999; Charman, 1998; Robinson & Riley, 1999). These pathways will be reviewed briefly.

The pathway from the spinal cord to the thalamus

The peripheral nerve fibres, carrying painful impulses divide into two bundles as they pass into the spinal cord. One of the systems has a faster conduction rate than the other. The fast pain tracts terminate directly in the thalamus (Bishop, 1994).

Nociceptive information which is relayed to the thalamus by fast pain tracts is in turn relayed to the parietal lobe where it is localised. The type of pain and probable cause is assessed. This phase of pain recognition has little emotional effect. Information is relayed to the temporal lobe where a memory search is conducted to determine whether this is a new pain or a repeat of previous pain experience (Charman, 1989).

The slower bundles of pain conducting nerve fibres relay information to the brainstem, thalamus limbic system and frontal cortex. These parts of the brain allow emotional responses to pain. Consciously experienced pain, ranging from ache to agony is elicited. Feelings of suffering, depression and anxiety may be generated (Hawthorne & Redmond, 1998). The neurological basis for the distress associated with pain seems to be the generation of abnormal patterns of neuronal activity in the cortico-limbic systems which drive our instincts and emotional states. The limbic system imparts emotional weighting to all thought processes, experiences, and memories (Charman, 1989; Jabbur & Saade, 1999).

Information is also transmitted to the frontal lobes, where states of anticipatory anxiety, dread and fear are generated as a result of previous pain conditioning. The frontal lobes seem to be associated with the motivational and affective dimensions of pain. These pain pathways also have connections with other brain centres that are involved with descending pathways, autonomic reflexes and the short-term memory. In this way opportunities are provided for complex interactions between pain, autonomic responses and emotions. Although these interactions can occur, it is not obligatory that they do so (Hawthorne & Redmond, 1998).

Other influences on the spinal gate

Of interest to psychologists is the fact that the spinal gate is not influenced solely by incoming impulses, but descending pathways may facilitate or inhibit the transmission

of nociceptive input. It seems that there are successive gates throughout the system. This mechanism has been postulated as an explanation for the influence of emotional, cognitive and cultural factors which mediate the chronic pain experience. For example, a person experiencing fear or anxiety may experience increased pain since the brain's message is "prepare for danger" (Barlow & Durand, 1995). The influence of cognition was demonstrated in a study of soldiers during the Second World War. A surgeon, Henry Beecher, observed several severely wounded soldiers in hospital during World War II. Despite serious wounds, many denied being in pain and only a third requested morphine for pain relief. In contrast, Beecher noted that in his post-war surgical practice four-fifths of the patients complained of severe pain and requested morphine, even though the tissue damage was less than that of the soldiers. These discrepancies were attributed to differences in the meaning of pain. To the civilians surgery was a depressing and calamitous event. The soldiers were thankful to be alive and saw their injuries as a means of escape from the battlefield (Bishop, 1994).

Several factors have been hypothesised to influence the way in which pain is perceived due to their influence on descending pathways. One such influence is sympathetically mediated arousal. Another is stimulation of the serotonergic and noradrenergic neurotransmitter pathways, A third is stimulation of the body's production of endogenous pain-relieving substances known as endorphins and enkephalins. A fourth factor is cognition (Eimer, 1998). These influences will be reviewed.

Biochemical influences on the experience of pain

Several researchers suggest that chronic pain may be a reflection of dysfunction in the neuro immune and endocrine systems (Jabbur and Saade, 1999; Charman, 1998; Elton, 1995). These mechanisms are poorly understood, but current thinking is that the experience of pain may be modulated by the release of neuropeptides within the central nervous system. The central nervous system produces its own range of endogenous polypeptides with analgesic properties, known as endorphins and enkephalins. Although these chemicals are structurally dissimilar to morphine, they bind to the same receptors as morphine and other opiates (Elton, 1995). (Opioid type drugs such as morphine and heroin are used in pain relief.) Release of the endogenous opioids appears to be boosted by "fast pain sensory stimulation" such as acupuncture and transcutaneous electrical stimulation. It is interesting

to note that these chemicals may be released in response to classical conditioning (Bishop, 1994). Bandura and co-workers (1987, in Barlow & Durand, 1995) found that individuals with a high sense of self efficacy and control exhibited higher tolerance of pain and actually increased production of their own endogenous opioids when confronted with a painful stimulus, compared with individuals with low self-efficacy. It is postulated that when a person is ill or depressed the background level of some neuropeptides may be lowered, resulting in increased susceptibility to pain. Learned inability to express negative emotions such as anger may suppress the effect of opioids which are produced by the body to moderate the experience of pain. This may lead to reduced pain tolerance (Beutler, 1986, in Kerns, Rosenberg & Jacob, 1993). Laughter and joy may have the converse effect (Charman, 1989). However, the relationship between endogenous opioids and chronic pain is not a simple one where increased opioid production is followed by a decrease in pain (Charman, 1989). Opioids seem to act mainly at the spinal level. Some, such as beta endorphins, may require nor-adrenalin to act (Elton, 1995). There is evidence of a link between hypnotic analgesia and endorphins. Hypnosis may have analgesic effects due to unknown endogenous substances, since naloxone, (which reverses the effect of opiates), does not reverse the effect of hypnosis (Elton, 1995).

Recent findings indicate that there is a relationship between chronic pain and the immune system. As an illustration, recent work has demonstrated that thymulin, a thymic hormone known to activate the immune system, can produce hypersensitivity and inflammation in the body. This hormone has also been shown to increase reactivity in certain receptors in the peripheral nervous system. It can also increase reactivity in the dorsal horn which can be reversed by morphine. It was concluded that chronic pain is a reflection of the cross talk between the nervous, immune and endocrine systems. This reflection of homeostatic imbalance does not depend upon specific pathways or cerebral centres. "Like other limbic functions it can emerge at the conscious level in humans in the form of an unpleasant experience with psychological and behavioural changes" (Jabbur & Saade, 1999, p.90).

Plasticity of the nervous system and the development of chronic pain

There is evidence that the nervous system is more dynamic and malleable than had previously been supposed (Jabbur & Saade, 1999; Robinson & Riley, 1999; Hawthorn & Redmond, 1998). This is known as plasticity. Nerve cells are able to modify the function in response to different circumstances. Various sensory modalities appear to share pathways and interact with each other. Plastic changes in the nervous system are understood to underlie the production and maintenance of chronic pain. Short-lived and long-lasting inflammatory processes can lead to changes in function of the peripheral nerves which can trigger a cascade of functional and possibly structural changes at all levels of the central nervous system. "In addition, inflammatory mediators and other factors can act directly on peripheral and central neurons leading to changes in the function of the hypothalamic-pituitary axis which in turn lead to the behavioural and psychological changes characteristic of chronic pain" (Jabbur & Saade, 1999, p. 90).

An important concept in neuronal plasticity is that of wind up. If a series of stimuli are applied in rapid succession to a nerve, the size of the impulse generated will increase. This has important clinical implications. If pain is present for a long time, it will become increasingly more painful and may lead to changes in the nociceptive pathway (Hawthorne & Redmond, 1998).

Acute and chronic pain differ in important ways. Acute pain is associated with a well-defined cause and terminates once healing has occurred. This implies that acute pain is actually a symptom of another condition. Chronic pain, on the other hand, is the disease itself (Katz 2000). Acute pain has a rapid onset, a phasic component and a subsequent tonic component. Biochemically, acute pain is similar to an anxiety state (Elton, 1995). In the case of chronic pain, the tonic component persists long after healing has occurred. From a biochemical point of view, chronic pain is similar to depression. There is a habituation of responses, lowered sympathetic activity, sleep disturbance, feelings of hopelessness and somatic preoccupation (Elton, 1995). Eales (1999) states that "when pain persists, one effect is a mood of depression that results in part from changes in the monamine metabolism of the brain." (p.13)

Central sensitisation

A process known as *central sensitisation* may play an important role in the generation and maintenance of chronic pain. What happens in these circumstances is that the central processing of information from peripheral nerves is altered so that fibres which are not normally nociceptive, generate impulses which are interpreted as pain. Injury to a nerve (as in compression due to a prolapsed disc in the spine, inflammation due to arthritis or compromise to the nerve's blood supply) results in the generation of abnormal impulses. The molecular constituents of the nerve dam up at the sight of the injury making the nerve hyper- excitable. Such damaged nerves are able to generate their own pattern of firing independent of the sensory apparatus and are called "ectopic pacemaker sites." Cross excitation with other neurones occurs, so that other sensations, such as light touch, are interpreted as pain. This is known as allodynia. This sensitivity spreads to adjacent dermatomes, so that pain becomes increasingly widespread. This phenomenon spreads progressively to other pain relay stations, resulting in central pain (Shipton, 1993; Hawthorn & Redmond, 1998).

Pain memory

An important notion which helps to explain the persistence of pain is that of *pain memory*. The word *memory* is used in this context to denote the persistence of a trace of some kind within the central nervous system, probably in many cases, in the spinal cord. When pain persists beyond the time needed for an acute injury to heal, there seem to be lasting changes within the central nervous system itself. The precise nature of these changes is not known. They may be chemical in nature or may be due to self-perpetuating circuits of nerve impulses. It follows that operations or similar measures directed at the spine itself are unlikely to succeed in such instances. Acupuncture, electrical stimulation and manipulation, all of which appear to alter the pattern of nerve impulses entering the central nervous system sometimes succeed (Campbell, 1992). The underlying assumption is that patterns of excitation within the central nervous system tend to perpetuate themselves or tend to be triggered by activity or other forms of stimulation. An interesting question is why this phenomenon does not always occur. No answers have been found as yet. One plausible explanation is that pain patterns are inhibited by activity in other parts of

the central nervous system. In line with this reasoning it is possible that pressure on a nerve root produces pain not because it generates ascending abnormal impulses but because it blocks beneficial impulses needed to prevent pain (Campbell, 1992).

Is chronic pain due to psychological or physical causes?

Chronic pain is said to be disproportionate to tissue damage or to persist after healing is complete. Chronic pain patients are known to exhibit psychological distress (Mersky, 1978). One of the central debates in the chronic pain field is whether psychological illness causes chronic pain or vice versa.

One group of researchers showed that psychological distress was secondary to pain. Their findings did not support the notion that chronic pain patients share a pre-morbid disposition to a characteristic psychological profile which underlies their pain complaint. A clear temporal relationship between pain and psychological distress was found. Whenever pain was relieved by medical treatment, psychological distress resolved. When pain recurred, it was accompanied by psychological distress. These researchers concluded that such distress was a consequence of the chronic somatic pain experienced by these patients (Wallis, Lord & Bogduk, 1997). Similarly, Thompson (1999) asserted that chronic pain almost always has a physical basis. She suggests that many psychologists inflict a great deal of damage on chronic pain patients' minds by telling them explicitly or implicitly that their pain is not physical. She believes that such judgements are made by relying on a set of incorrect or inaccurate concepts, whereas many chronic pain syndromes conform to the patterns found in neuropathic or myofascial pain syndromes. Thompson (1999) challenges the notion that normal radiological studies confirm the absence of medically explained pain. She asserts: "This is wrong. Pain cannot be visualised on X rays, CT or MRI scans" (p. 110).

These views are tempered by other findings. Mersky (1978) examined 141 chronic pain patients with respect to their life experience, both pre-morbidly and currently. Upbringing, neurotic traits and personality disturbance were assessed. "The data supported the view that a significant proportion of the emotional disturbance associated with chronic pain is a secondary effect" (Mersky, 1978, p.173). Nonetheless, in 50 % of subjects without demonstrable lesions, (n=35), psychological factors precipitated or exacerbated the

pain, whereas this was true of only 13%, (n=9), of patients with organic lesions. The researcher observed that pain which is due to physical causes tends to produce secondary psychological disturbance. However, he also concluded that chronic pain could follow from psychological illness.

Eimer (1998) has pointed out that there are several widespread misconceptions that chronic pain is purely a physical problem, or, alternatively that it is caused by an underlying psychiatric disorder. He maintains that understanding chronic pain should not involve an either/or position with regard to physical or psychological mechanisms. He views chronic pain as a complex multidimensional problem (Eimer, 1998). The psychological and social dimensions of chronic pain will now be reviewed.

Behaviour and chronic pain

Fordyce (1976) postulated an often-cited behavioural model for chronic pain, focusing mainly on an operant conceptualization of pain behaviour. The term *pain behaviour* refers to behaviour which develops in response to pain. The failure to reduce pain behaviour is usually related to failure to restore function or to rehabilitate the person. This model suggests that, initially, pain behaviour such as avoidance of activity, wincing and health care utilization develop in response to acute pain. However, such behaviour may be maintained once the tissue damage has healed due to reinforcing environmental contingencies. Rewards may include rest, attention, affection and financial compensation. Pain may allow a dissatisfied worker to “retire with dignity” (Chapman 1984; Robinson & Riley, 1999). Chronic pain patients’ social environment, specifically, spouse reinforcement has been shown to reinforce patients’ pain reports (Flor, Kerns & Turk, 1987, in Robinson & Riley, 1999).

The operant model has received considerable support. Examples of successful coping with pain have suggested a learning contribution to the expression of pain, as demonstrated by subjects’ ability to endure pain during cultural rituals. Robinson and Riley (1999) concluded that “it is clear that social influences, especially significant others’ reinforcement or modelling of pain can influence patients’ pain report and other pain behaviour in both directions. It is also evident from the literature that selectively reinforcing well behaviours can increase pain patients’ responses to treatment” (p. 29)

The cognitive behavioural model

More recently, attention has been paid to the cognitive processes which influence the development, maintenance and modification of behaviour. According to the gate control theory, pain perception was thought to be largely a cognitive process which was influenced by a number of factors such as neurochemical, physiological, situational, contextual, behavioural, affective, as well as religious, spiritual and motivational variables. However, cognitive factors were thought to play the primary role in opening or closing the pain gate. A strictly cognitive model of pain was outlined which suggested that specific thought patterns account for the problems encountered by persons with chronic pain. The model suggested that individuals draw the meaning of sensations from the past knowledge of stimuli, especially painful stimuli, which function as schemata. These schemata are proposed to contain incorrect beliefs which are assumed to be the basis for dysfunction in patients with chronic pain (Ciccone & Grzesiak, 1984). In this model, cognition is proposed as the central component of the problems associated with chronic pain. Other researchers have warned that cognition should not be considered in isolation with respect to chronic pain since it is multidimensional in nature (Turk & Flor, 1984). Thoughts may evoke or influence emotions, as well as affecting physiology and behaviour. Behaviour and physiology can initiate and influence thoughts. The experience of pain is a reciprocal interaction of these factors (Robinson & Riley, 1999). The cognitive behavioural model has been widely used by psychologists in the treatment of chronic pain (Eimer, 1998). The general assumptions of this model with respect to pain have been outlined. These are as follows:

The cognitive behavioural model focuses on the way in which people *think* about pain. Pain cognitions are broadly defined as thoughts, self-statements, evaluations of pain, beliefs, attributions and memories regarding the painful condition (Katz, 2000). Pain perception is postulated to comprise three dimensions: the sensory-discriminative, cognitive-evaluative and motivational-affective dimensions (Melzack & Wall, 1965, in Eimer, 1998). Pain is sensed and perceived through the sensory –discriminative dimension. Pain is evaluated, and its implications judged, in terms of the person's cognitive constructs through the cognitive-evaluative dimension. Motivational forces influence the sufferer's emotional reactions through the motivational-affective dimension (Eimer, 1998).

The cognitive-behavioural model proposes that people develop idiosyncratic belief systems from their life experiences. Unlike models employing operant conditioning, behaviour is not proposed to be contingent purely on the influence of reinforcement. According to this model, it is the way in which events are interpreted which determines the way people will behave and how they will feel in various situations. Individuals process information and develop organised schemata. Everyone is proposed to be an active seeker of personal meaning. The way in which a person construes personal events enables him or her to abstract their meaning. Behaviour is seen as the outcome of a reciprocal interaction between the person and his or her environment. Thoughts are able to influence emotions and physiology and may motivate behaviour. Similarly emotions, physiology and behaviour may initiate and influence thoughts. The experience of pain is seen as the result of the interaction between these variables (Eimer, 1998; Robinson & Riley, 1999).

Mood states are postulated to affect the perception of the quality and severity of pain directly due to the activation of automatic thoughts, self talk, beliefs and underlying schemata. For some people, increasing levels of pain may be viewed as a sign of disease progression and may be interpreted as a metaphor for impending death. Such an interpretation may result in increased pain levels since the severity of pain is positively associated with how people interpret the significance of pain (Hawthorn & Redmond, 1998). Many individuals learn maladaptive ways of behaving, thinking and feeling. This biases the person's perception and recall of events. It also affects the pain patient's response to treatment interventions. Personal beliefs influence which memories may be activated in response to certain stimuli. These stimuli might become stressors if they are associated with feelings of vulnerability or threat. This may account for the association between chronic pain and post traumatic stress disorder (Eimer, 1998).

Patients are understood to participate in the development and maintenance of maladaptive behaviours and thought patterns and should be involved as active agents to bring about change.

According to the cognitive behavioural model, behaviour is seen as an indicator of a person's predictions. For example, patients who believe that the pain is constant, permanent and mysterious, are unlikely to comply with treatments that might otherwise explain or reduce it and therefore disconfirm the pain beliefs (Robinson & Riley, 1999; Turk & Rudy 1989; Eimer, 1998). A hallmark of the cognitive behavioural model is the

concept of cognitive distortions. This concept refers to the idea that a person's thoughts, memories and perceptions are cognitive representations of reality, not reality itself, and are therefore subject to distortion, which may be either adaptive or maladaptive. People with chronic pain may develop distorted cognitions. The review presented by Eimer (1998) is summarised here because such cognitions may influence the way chronic pain is experienced as indicated in the overview:

- **Dichotomous thinking:** This distortion manifests in the thought "I am either in pain or without pain". These patients tend to be extremely sensitive to any physical indications that their pain may be worsening. Such patients are unlikely to acknowledge signs of progress and behaviours tend to be correspondingly extreme such as avoidance, withdrawal and over-reaction to events.
- **Disqualifying the positive:** Patients who think in this way are often unable to acknowledge success or progress. This distortion can lead to loss of motivation and anhedonia.
- **Selective abstraction:** Patients who display this cognitive distortion tend to be preoccupied with pain and misery. Such patients tend to expect and anticipate further pain or injury.
- **Should statements:** Many chronic pain patients believe they should and must do things in certain ways. Many such patients overdo things, such as exercising to get better, and thereby trigger a flare-up. The belief "I should be much better by now," may lead to the related cognitive distortion: "I can't stand it." This may lead to low frustration tolerance.
- **Low frustration tolerance:** This cognitive distortion may lead patients to give up easily. Such lack of persistence often prevents them from making progress in rehabilitation.
- **Perfectionism:** Perfectionist beliefs are associated with the tendency to believe that things should be perfect or they are not worth doing or having at all. Many people with chronic pain admit to striving for perfection or achievement which may really be "overstriving". Although the concept of a pain prone personality is the subject of considerable debate, Eimer (1998) states that a

perfectionistic, stressed-out personality type appears to be a significant co-variate with chronic pain syndromes.

- **Pain based emotional reasoning:** Pain based emotional reasoning is reflected in statements such as “because I am in pain, there must be something wrong” or “If I am in pain now, I will never get better,” or “no one can get rid of my pain, so no one cares about helping me”. Such erroneous, illogical conclusions may exacerbate the suffering of many people with chronic pain.

- **Mind reading:** Mind reading refers to the erroneous belief that one person can know what another is thinking. Examples of such reasoning are “I know my doctor is tired of treating me” or “They want to deprive me of compensation”. These thoughts may intensify angry or depressed feelings. They may lead to withdrawal or angry retaliation.

- **Negative prediction:** Negative predictions are often related to pain-based emotional reasoning. They relate to the tendency to predict bleak future consequences based on inadequate information, which are very upsetting for the person concerned.

- **Catastrophizing:** People who engage in catastrophizing are apt to interpret negative events as far more negative than they really are. Related to this is the tendency to misinterpret the probability of negative events occurring or treating the possibility as if it is already a reality. Such beliefs are associated with dysfunctional pain coping strategies, perceptions of poor self-efficacy, depression and emotional distress.

- **Overgeneralization:** Most of the cognitive distortions discussed may cause pain to generalise into a dysfunctional chronic pain syndrome which affects most aspects of a person’s life. Chronic pain patients who continue to think in terms of the preceding cognitive distortions tend to become stuck in a spiral of negative thinking which keeps them from behaving adaptively, managing pain successfully and feeling better. This may lead to a state of global disability and impairment due to pain (Eimer, 1998).

It has been suggested that an important intervention for those who see the experience of pain in a negative way, is to facilitate a more positive construal of the meaning of pain (Hawthorn & Redmond, 1998). The meaning of illness in North American

culture may be classified as challenge, enemy, punishment, weakness, relief, strategy, loss and value (Liposkwi, 1970, in Hawthorn & Redmond, 1998). No studies on the meaning of pain to South African patients could be found.

Cognition and avoidance behaviour

Pain which is benign, recurrent and intractable has been described as a “false alarm” which serves no protective function or purpose (Sternbach, 1968). Nevertheless, many patients with chronic pain continue to respond to sensations of pain as warning signals, as if “hurt is harm”. These patients usually respond by avoiding pain-triggering situations. Such behaviours are adaptive when persons are faced with threats to their health. However, when little or no organic pathology is present, the cessation of activities which are not damaging may lead to de-conditioning of the body, which may exacerbate the pain (Waddell, 1991).

In one study chronic pain is recognized as the most frequent cause of disability in the United States (Chapman, 1984). Avoidance of work, exercise and social activities is a useful index of disability. It appears that avoiding “is the most prominent component of pain behaviour” (Phillips, 1987, p. 274). Although patients may view themselves as avoiding pain there is little evidence that it effectively reduces chronic pain. In fact, the growth of avoidance behaviour was associated with reduced feelings of control over pain. It has been suggested that pain behaviours are partially determined by the cognitions which a person forms as pain persists. Behaviour may sustain such cognitions (Phillips, 1987).

Expectations that a person has about the effects of his actions as well as his or her beliefs about the capacity to control pain episodes have been shown to influence avoidance behaviour. In a study conducted by Cipher and Fernandez (1997) chronic pain sufferers were able to predict their pain tolerance well. They did not necessarily try to evade a pain-producing compulsory activity, but when the activity was not obligatory, they preferred to avoid it in the first place. They were shown to associate pain with damage.

Patient’s beliefs were shown to be related to activity level and psychological well being in a sample of 121 patients with chronic musculo skeletal pain (Jensen, Romano, Turner, Good & Wald, 1999). Physical and psychological dysfunction was predicted by specific beliefs, namely, that pain signals harm, that one is disabled and that solicitous

responses from others are appropriate. These findings indicated that successful rehabilitation may depend on changing the meaning of pain.

Perceptions of pain

Pain may be perceived as an area of significant loss and disempowerment.

Perceived losses may include:

- Loss of self-efficacy
- Loss of physical function
- Loss of independence
- Loss of control over both pain and treatment progress
- Loss of the ability to cope.

Patients may perceive the pain experience as beneficial. Possible gains include:

- Relief from responsibilities in the professional, personal and social areas of life
- Deserved punishment for crimes
- The opportunity to receive attention and nurture
- A means of avoiding stress
- The opportunity to avoid conflict, or to resolve conflict (Katz, 2000).

Religious beliefs

Religious beliefs may influence the way people think about pain. Some people believe that pain has positive qualities. Pain may be seen as a test, as a means of purification or an opportunity for redemption. The endurance of pain associated with the disease may be believed to raise moral stature and guarantee a swift entrance into the afterlife. Such beliefs facilitate acceptance and foster a sense of hope (Hawthorn & Redmond, 1998; Autton, 1986).

Conversely, religious beliefs may cause pain to be seen in a more negative light. Pain may be viewed as a punishment, or a sign of divine retribution. Such beliefs may be particularly frightening to someone who is terminally ill (Hawthorne & Redmond, 1998).

Perceptions of control

It is possible to avoid many unpleasant experiences in life. For example, it is usually possible to turn away from unpleasant sights or walk away from other unpleasant sounds. It is even possible to avoid many instances of pain by withdrawing from the painful stimulus. However, in the case of chronic pain, the stimulus is internal and there is no possibility of escape from one's own body. Nevertheless, it is possible to change the level of pain experienced by giving the person the feeling that they have control over the pain even though in fact they may not (Melzack & Wall, 1982; Weisenberg, 1987; Walker, Akinsanya, Davis & Marcer, 1990). A person gains a sense of control if they believe they can influence a stressful event. These findings have been used to assist patients to cope with chronic pain.

People with chronic pain frequently report that their pre-pain sense of control over life in general has been altered by the experience of chronic pain. Moreover, people with an external locus of control report more pain than those with an internal locus of control (Hawthorn & Redmond, 1998). In one study, participants were able to regain their sense of control over life circumstances despite the fact that they still had chronic pain. The authors were unable to say why this happened. Their results indicated that personal idiosyncratic strategies were important in maintaining control over pain. The researchers concluded that there is limited utility in measuring persistent pain in isolation from other related factors because the impact of pain on the patient's life is not investigated (Walker et al., 1990). These findings highlight the need for further qualitative research into chronic pain coping strategies.

A lack of knowledge seems to diminish the extent to which people believe they can control their pain situation. This suggests that training programmes may be useful in reducing pain perception (Walker et al., 1990).

Self-efficacy with respect to chronic pain has been defined as the expectation that one has the ability to engage in specific pain coping behaviours. Self-efficacy has been found to be related to exercise tolerance during rehabilitation, as well as the ability to carry out activities of daily living.

Beliefs, coping efforts and adjustment to chronic pain

Wellbeing and activity level have been shown to be related to patients' beliefs in personal control over pain and the strategies they use to manage pain. In some cases, this relationship varied as a function of pain severity. However, it was not clear whether people who believe they can control pain feel better because a heightened sense of control has a direct effect on well-being, or whether a strong belief in control over pain leads people to initiate and persevere in the use of adaptive coping strategies (Jensen & Karoly, 1991). Walker and co-workers (1990) observed that people with at least one active interest were better able to cope with chronic pain than those who had only passive pastimes. Past experience with pain may profoundly influence a person's sense of control of the chronic pain situation. Prior ability to master the situation can enhance the person's sense of control in the current situation (Walker, Davis & Marcer, 1989, in Hawthorn & Redmond, 1998).

The cognitive behavioural model has stimulated a vast amount of research into chronic pain. This model has made an important contribution by drawing attention to the viewpoint of the patient regarding the health-care system, their understanding of their medical condition, their behavioural responses and their own capabilities and beliefs (Turk & Rudy, 1986). The multidimensional nature of the patient's response to pain is emphasised. It provides an integrated perspective from which coping with pain is viewed as a process wherein attitudes and thinking mediate emotional and behavioural responses to pain. This implies that pain perception is regarded as a complex interpretive process rather than a stereotyped response to predetermined stimuli (Robinson & Riley, 1999; Turk & Rudy, 1984). However, explanations tend to be incomplete, as only the relationship between cognition and other specific variables is sought. As a result only the cognitive aspect of patient's subjective experience is emphasized.

Affect and the experience of chronic pain

Pain is intrinsically aversive and, as a result, also encompasses an emotional quality. In fact, The International Association For The Study Of Pain (IASP) has formalised the recognition that pain is both a sensory and emotional experience in the definition of pain which states "...It is unquestionably a sensation in a part of the body, but

it is also unpleasant and therefore an emotional experience.” (Shipton, 1993, p. 1). The sensory and affective components of pain are proposed to influence each other, functioning like parts of a whole: Reducing either has the capacity to reduce the whole (Fernandez, et al., 1999). A model describing the dynamic relationship between pain and affect has been proposed by Fernandez and co-workers (1999). In terms of this model, cognition, affect, motivation and behaviour are linked in the response sequence to pain. Affect is regarded as a general category which encompasses emotions, moods and temperaments. These affective responses vary in duration. Emotions tend to have a phasic quality whereas moods are relatively continuous processes. Temperament is used to refer to the domain of individual differences modulating a person’s reactivity to emotional events. Therefore, temperament represents an affective bias.

Fernandez and co-workers (1999) state that “all emotion is preceded by some cognitive appraisal or interpretation that may be conscious or controlled or else automatic and below the threshold of awareness”(p.128). Appraisals may range from attributions regarding the cause of pain to expectations regarding the consequences thereof. Cognitive appraisals ascribe meaning to pain. Cognitions do not possess intrinsic pleasantness or unpleasantness in themselves, whereas the resultant affective responses are valenced. Cognitive appraisals govern the particular emotion that is experienced. Fernandez and co-workers (1999) suggest that pain which is viewed as a discouraging setback is apt to produce sadness or depression, pain viewed as an enemy may produce anger, pain perceived as a punishment is apt to trigger guilt, and pain thought of as a disgrace would lead to feelings of shame. Such emotions, according to these authors, also lead to specific motivational processes:

Anger is likely to result in aggression, fear may lead to help-seeking, depression may result in withdrawal, shame is apt to lead to concealment, and feelings of guilt may culminate in penance or sacrifice. In each case, actual behaviour is governed by what the individual would like to do as well as what is possible or practical in the situation.

This model presumes that pain precedes affect. However, as shall become apparent, the precise relationship between pain and affect appears to be highly variable and has been the source of considerable debate.

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Depression and chronic pain

In their frequently cited paper, Blumer and Heilbron (1982) formulated the concept of “pain-prone disorder” which they regarded as a variant of a depressive disorder. They suggested that a muted depressive state gives rise to somatic pain. They hypothesized that chronic pain sufferers display global pain-prone characteristics, including a self-image as a “solid citizen” a history of difficulties in childhood and current depression (Blumer & Heilbron, 1982). The initial response to this proposal was favourable.

More recently, these suggestions have been challenged. Nonetheless, a strong correlation between chronic pain and depression has been reported consistently, with typical figures indicating that 50-65% of patients with chronic pain are depressed (Averill, Novy, Nelson & Berry 1996; Rudy, Kerns & Turk, 1986). Gamsa (1990) examined the relationship between emotional disturbance and chronic pain to see whether psychological disturbance precipitates or perpetuates chronic pain. A measure, based on Blumer and Heilbron’s (1982) solid citizen description of the chronic pain sufferer, as well as measures of unmet childhood dependency needs, parental bonding, current emotional disturbance and depression were used. One of the strengths of the study is that chronic pain patients were compared with a non-pain control group on current emotional disturbance and antecedent events, which have been identified by other authors as significant in the etiology of chronic pain. Results of this study suggest that emotional disturbance in pain patients is more likely to be a consequence than a cause of chronic pain. Conversely, the results of a study conducted by Stalling (1992) suggest that affect can function as a causal antecedent of reported pain. Gaskin, Green, Robinson and Geisser (1992) found that chronic pain affects mood states, as opposed to mood states perpetuating chronic pain.

Other authors have pointed out that it is not always pain per se which affects mood. Other problems such as work difficulties, or single status may place chronic pain patients at greater risk of becoming depressed. For example, Averill and co-workers (1996) found that a low level of education was significantly correlated with depression in a sample of chronic pain sufferers, (including a number of people with chronic low back pain). Low education was associated with employment in the manual

labour force, so alternatives for these people were limited by low educational status. Single status was also significantly related to depression, as was unemployment. Patients in contradictory roles such as working whilst planning litigation, or not working while not planning litigation, also experienced depression. These findings suggest that depression associated with chronic pain may be associated with a third variable which is part of the total chronic pain experience. Maintaining one's working role or having sufficient education to find an alternative, as well as being married, appeared to be important buffers against depression in people with chronic pain.

Biological models of chronic pain suggest that there is a link between chronic pain and depression since similar neurochemical mechanisms may operate in both disorders. For example, abnormalities in the levels of biogenic amines such as catecholamines and serotonin and endogenous opioids have been postulated to contribute to the development of chronic pain and depression. The usefulness of tricyclic antidepressants in the treatment of chronic pain is cited as support for this hypothesis. These findings have been challenged.

Rudy Kerns and Turk (1988) studied a sample of 100 patients, 36 % of whom complained of back pain. Although depression and chronic pain co-existed in over 50 % of the sample, the direct link between chronic pain and depression was not significant, as a biological model would suggest. Measures of life interference and self-control were significant intervening variables.

High depression scores have been associated with more pain behaviours and lower activity levels in chronic low back pain patients (Keefe, Gil & Rose, 1986, in Fisher & Johnston, 1991). In chronic pain patients, disability is only partially explained by pain levels. Emotional distress has been postulated to moderate the relationship between chronic pain and disability. Such a relationship was demonstrated in a study of 50 patients with chronic low back pain. Experimental mood enhancement was associated with reduced disability, while mood depression resulted in increased disability (Fisher & Johnston, 1996).

The experience of chronic pain appears to affect the way that pain and mood-related information is processed. When chronic pain patients were asked to remember lists of words, some of which were pain-related and some not, pain patients recalled more pain words than people without chronic pain. Chronic pain patients are also

more likely to interpret ambiguous words in a pain-related manner than control subjects without pain (Eccleston, in Thomas, 1997). These findings indicate that chronic pain patients are biased towards processing information in a way that will serve to maintain suffering.

Depression in chronic pain sufferers may be influenced by other affective states. The relative contribution of frustration, fear, anger and anxiety to chronic pain-related unpleasantness and depression was investigated (Wade, Price, Hamer, Schwarz & Hart, 1990). Anxiety and frustration predicted unpleasantness of the chronic pain experience, while anger and depressed mood itself predicted clinical depression. ✓

Gaskin and co-workers (1992) showed that several discrete emotions, mainly anxiety, ✓
anger and depression, relate independently to the total experience of chronic pain. ✓

Their results confirm that a variety of negative affective states are important ✓
determinants of the subjective experience of pain.

Anxiety and chronic pain

The fear of pain is a universal phenomenon. This is understandable because pain is an unpleasant experience which is usually associated with illness or damage to the body. When pain disrupts a person's life, with little prospect of relief, many sufferers live in a state of tension and anxiety (Eimer, 1998).

Anxiety may be present along four dimensions. These dimensions are:

- Cognitive anxiety, encompassing racing thoughts, agitation and impaired concentration.
- Fearful appraisal, which includes catastrophic thinking and apprehension.
- Escape and avoidance which is associated with avoiding activities for fear of worsening pain.
- Physiological anxiety which includes symptoms of increased ✓
somatic awareness and autonomic physiological arousal. ✓

Anxious sensitivity to pain, coupled with attention to pain, has been shown to predict ✓
distress, disability and reported pain intensity (Eimer, 1998). In fact, increased somatic awareness was the most important aspect of distress in a sample of people with low back

pain which “completely overshadowed other psychological measures of personality traits, fears or beliefs about illness” (Eimer, 1998, p. 85).

Some researchers have suggested that somatic hyper responsiveness may characterise people who display alexithymia. The concept of alexithymia refers to observed restrictions in a person’s ability to label and communicate affective experiences. People who are alexithymic are proposed to express emotional arousal through the body. Such individuals are proposed to be somatically hyper-responsive (Eimer, 1998). Pain may serve as a communicative function in such individuals (Catchlove, 1987). These concepts have been raised repeatedly by investigators of pain-proneness (Blumer & Heilbron, 1982; Engel, 1989).

Catchlove (1987) suggested that a diagnosis of alexithymia in patients with chronic pain is supported by certain characteristics, which the researcher regarded as strikingly similar to alexithymia. For example, he contends that chronic pain sufferers recount the history of the pain in monotonous detail. The cause is ascribed to circumstances beyond the patient’s control. Dreams are infrequent and the cause of the pain is ascribed to circumstances outside the patient. “Despite clinically evident anxiety depression and several work and social disruptions, the patient denies all affect except that directly attributable (by them) to the pain” (Catchlove, 1987, p.96). This researcher was able to demonstrate that chronic pain patients had more difficulties than controls with the expression of anger and anxiety, which he attributed to early learning experiences. He suggests that a lifelong pattern emerges characterized by the suppression of emotional communication, coupled with a tendency to value work and activity. These concepts resemble Blumer and Heilbron’s (1982) “pain proneness.” They are also related to early emotional deprivation as noted by Violon (1980, in Eimer, 1998). Related ideas that pain-prone individuals may be self-reliant, relentlessly active, have an external locus of control and engage in self-sacrifice have been raised (Grzesiak et al., 1996 in Eimer, 1998). More research is needed in this area to determine whether psychotherapy directed towards remediating emotional restriction could facilitate recovery from chronic pain (Eimer, 1998). Catchlove (1987) suggests that this is indeed so.

In addition to increased somatic awareness in general, pain and anxiety have been associated with each other. Many pain-reducing techniques involve anxiety reduction, for example, hypnosis, relaxation and biofeedback.

Fear of pain combined with a tendency to avoid noxious stimuli has been proposed as the mechanism underlying long term exaggerated responses to pain (Weisenberg, 1987). Anticipation of pain has been shown to lead to a habitual bias towards processing pain-related information (Eccleston & Crombez, 1999).

The role of anxiety in the experience of chronic pain is controversial. For example, Wade and co-workers (1990) found that anger and frustration as opposed to anxiety were important factors in the perception of chronic pain. In contrast to this, Gaskin and co-workers (1992) demonstrated that anxiety contributed significantly to the unpleasantness associated with pain. Anxiety has been proposed to increase pain, by some researchers and to decrease it by others (Weisenberg, 1987). Anxiety may increase arousal, thereby intensifying pain (Groves & Thomson, 1970, in Arntz, Dressen & Merckelbach, 1991). Conversely it has been reasoned that fear and anxiety are mutually exclusive so fear may decrease pain (Bolles & Fanselow, 1980, in Weisenberg, 1987). This has been proposed as the mechanism whereby severely wounded, anxious soldiers appear to feel no pain (Arntz et al., 1991). Others have argued that anxiety increases sympathetic activity. The resultant release of epinephrine at sympathetic nerve terminals may sensitise the nociceptors (Chapman & Turner, 1986, in Arntz et al., 1991).

These contradictory findings indicate a lack of empirical consensus on the influence of anxiety on chronic pain. It has been suggested that a third variable may exert a modulating effect. For example, Eccleston and Crombez (1999) proposed that pain demands attention. They suggested that chronic pain could be defined as chronic interruption. Likewise, Arntz and co-workers (1991) postulated that attention may modulate the relationship between pain and anxiety. Their study showed that attention to pain was related to stronger pain responses but anxiety was not. However, the opposite hypothesis that anxiety is related to lower pain responses was not supported either. This does not imply that anxiety is never relevant to the clinical experience of pain. Anxiety relating to the course or cause of pain may motivate individuals to pay more attention to pain, thereby increasing the intensity of the pain experienced. These findings suggest that distraction could reduce pain. This would provide patients with a sense of mastery and control which may reduce feelings of helplessness with respect to chronic pain (Arntz et al., 1991). Other researchers have found that distraction can be effective when pain is of low intensity, but not with severe pain (Eccleston & Crombez, 1999).

Anger and the experience of chronic pain

Anger stands out as a salient emotional correlate of chronic pain, even though past research has focused largely on depression and anxiety. A review conducted by Fernandez and Turk (1995) indicates that anger is an important, relatively unexplored correlate of chronic pain. The limited empirical data available suggests that anger is at least as prominent as depression and fear in the experience of chronic pain (Fernandez & Turk, 1995).

Fernandez and Turk (1995) proposed that anger is related to reproach, that is, disapproving of someone else's blameworthy action and being displeased about the undesirable events. De Good and Kiernan (1996) suggest that patients with chronic pain who blame someone for their predicament are often unresponsive to treatment, and appear less motivated to become invested in the process of recovery. This weakens the therapeutic alliance. Perception of fault was significantly correlated with self-reported mood, pain-related behaviour and self-perceived response to treatment. Importantly, the researchers concluded that if one feels victimised by someone else's error, the range of suffering experienced increases relative to non-fault related pain. Looking for fault appeared to arise from a search for the meaning of the experience, falling within the realm of "a natural human tendency to look for reasons why, when one feels a loss of control in one's life" (De Good & Kiernan, 1996, p. 158). Despite the apparent primacy of cognitive activity in the production of emotions, there are times when anger may be unmediated by thinking. In these instances, anger is a mood disturbance, as is free-floating anxiety.

Anger is not always expressed. Some researchers have suggested that inhibition of anger may be responsible for increased pain (Braha & Catchlove, 1986, in Fernandez & Turk, 1995). Wade and co-workers (1990) found that measures of anger significantly predicted depression, but no attempt was made to determine whether such anger is suppressed or expressed.

Indications are that anger can be a complicating factor in the treatment of people with chronic pain as it may reduce compliance. If treatment failure follows, it may aggravate levels of frustration and anger. Covert acts of aggression may include acts of non-co-operation. Angry patients may disrupt the group processes commonly

employed in pain management. Anger which is expressed may be detrimental to social relationships, whereas anger which is inhibited may increase depression, lead to increased pain and increase the risk of cardiovascular disease. In short, anger is a relatively unexplored aspect of the experience of chronic pain which warrants further investigation.

Culture

A person's cultural background is thought to influence the meaning that a person attributes to the pain experience. Cultural values are known to play an important part in the way a person perceives and responds to pain (Melzack & Wall 1982). There are many dramatic examples of people who show no visible evidence of being in pain during culturally bound rituals. Melzack and Wall (1982) describe such a ritual known as trephination which is carried out in East Africa for the relief of chronic pain:-

Men and women undergo an operation entirely without anaesthetics or pain-relieving drugs – called *trephination*, in which the scalp and underlying muscles are cut in order to expose a large area of the skull. The skull is then scraped by the *doktori* as the man or woman sits calmly without flinching or grimacing, holding a pan under the chin to catch the dripping blood. Films of this procedure are extraordinary to watch because of the discomfort they induce in observers which is in striking contrast to the apparent lack of discomfort in the people undergoing the operation. There is no reason to believe that these people are physiologically different in any way. Rather, the operation is accepted by their culture as a procedure that brings relief of chronic pain. The expectation of relief, the trust in the skill of the *doktori*, as well as other psychological factors appears to alter the experience of pain (pp. 29-30).

The ability to tolerate pain is subject to wide variation. It may appear that differences in pain experience between different individuals are due to different pain thresholds. However, there is considerable evidence that the threshold at which pain is perceived is remarkably constant across ethnic groups (Bishop, 1994). Melzack and Wall (1982) conclude that differences in pain tolerance amongst members of various cultural

groups are a reflection of different ethnic attitudes towards pain. Such differences in ethnic attitudes towards pain are described in Roberts' (1993) account of North American Indian tribe, the Apaches. He describes the Apaches' attitude towards pain as "altogether different from the [white] American's. Pain was a fact of life and to greet it stoically and endure it silently was a mark of character" (p. 48) From early childhood Apache boys were taught not only to endure pain but also to inflict it. What was often regarded as torture by other cultural groups had, for the Apaches, the character of a sacramental act (Roberts, 1993).

It seems that the meaning and emotional significance attributed to pain may have changed, particularly in Western cultures (Illich, 1976). Menges (1984) states that "the Western world has become increasingly sensitive to pain, particularly in the last century" (p. 1257). With advances in Western medicine, people have become less tolerant of pain and have great expectations of altering it. Consequently, unrealistic expectations regarding the potential for healing and curing pain have emerged. Thus contemporary Western society does not regard pain as acceptable and it is viewed increasingly as an abnormal and unnatural part of life (Hilbert, 1984). Waddell (1991) argues that "chronic disability due to simple backache is a relatively recent and peculiarly Western epidemic"(p. 733).

Cultural differences of this kind indicate that the meaning of experience to a particular person, including the meaning of illness and pain, will depend in part upon the meaning assigned by the person's social group. Studies with respect to chronic pain in particular were not found, but research indicates that symptoms of illness have different significance according to particular ethnic and cultural backgrounds, as well as according to personal meanings ascribed to the condition (Toombs, 1992). Cultural definitions of illness may be a source of suffering for the sick person. Such definitions frequently involve a value judgement. They influence the behaviour of others towards the sick person as well as influencing the behaviour of the person who is ill. Cultural norms determine whether the sick person will be considered acceptable or disgusting, whether they are to be pitied or censured, or whether he/she should be isolated or not. Toombs (1992) observes that the suffering which accompanies disability is not solely the result of loss of function, but includes the recognition by the handicapped person of a devaluation in their status, which reflects cultural values. Therefore, there appears to be a link between the degree of suffering and meaning of pain. Furthermore the ability to find meaning in a particular situation appears to be partially culturally determined (Hawthorne & Redmond, 1998).

Early learning, the family and chronic pain

↳ cognitive patterns

The evidence that the experience of pain is influenced by cultural factors leads naturally to an exploration of the role of early learning experience in adult behaviour and attitudes towards it (Melzack & Wall, 1982). A critical question is: do chronic pain sufferers come from families who have members who also suffer from chronic pain? Interest in the relationship between family factors and disease has a long history. Wolff (1937) studied migraine sufferers and concluded that “sustained tension, with excessive striving and frustrated ambition, and anxiety about family, financial or personal security, to which might be added an unsatisfactory sex life appear to furnish optimal conditions in these subjects for the precipitation of attacks of migraine” (Wolff, 1937, in Roy, 1989, p. 6). Such claims were not validated in subsequent research (Roy, 1989).

An explanatory model for the development of chronic pain based on psychodynamic theory has been proposed. Psychoanalysts consider pain to be a conversion symptom, wherein bodily pain is a symbolic translation of unpleasant affect. This model suggests that certain sufferers may be “pain-prone patients.” It suggests that people who suffered abuse in childhood may be more susceptible to the development of chronic pain than those who were not abused.

Abuse in adulthood may be equally significant. One survey indicated that 53% of women evaluated at a chronic pain clinic had suffered abuse. The abuse had occurred in adulthood in 90% of cases (Haber & Roos, 1985, in Block & Callewart, 1999). It appears that patients who have experienced physical, sexual or emotional abuse are less likely to respond well to spinal surgery (Block & Callewart, 1999).

An extensive review of the literature was undertaken by Roy (1989), who found that a causal relationship between childhood abuse and chronic pain could not be demonstrated. Furthermore, “there appeared to be an absence of recognition in the child abuse literature that pain proneness could be a consequence of child abuse, neglect or maternal deprivation” (Roy, 1989, p. 11).

Chronic pain patients have been studied with the aid of personality tests in an effort to establish a relationship between chronic pain and personality. In a study of 117 low back pain patients, the hypochondriasis, depression and hysteria scores on the Minnesota

Multiphasic Personality Inventory were significantly raised in chronic pain patients compared with those with acute pain (Sternbach et al., 1974, in Violon, 1990). However, in a study of cancer patients, pain was associated primarily with extraversion and lack of pain with introversion (Bond, 1976, in Violon, 1990). The psychological profiles of seventeen patients with chronic pain following whiplash injuries were examined before and after neurosurgical intervention. It was shown that psychological symptoms were a consequence of pain, not a cause. The researchers disputed the notion that chronic pain sufferers share a premorbid disposition to a characteristic psychological profile (Wallis et al., 1997).

Fordyce (1976) considered pain behaviour to be sensitive to environmental reinforcement. He believes that pain becomes persistent as a result of environmental conditioning. Pain behaviours were identified as comprising speech, posture, facial expression, seeking healthcare, taking medicine and missing work. Using behavioural methods, he demonstrated that such pain behaviour may be diminished. This implies that chronic pain may be learned.

Violon (1990) attempted to integrate these findings into a model outlining the processes involved in becoming a chronic pain patient. She argued that labelling ^{stigma} plays a role in perpetuating pain problems within families. She points out that parents and children share language and meaning, including language for illness and pain (Violon, 1985, in Roy, 1989). Words which refer to pain may be used to express emotions and suffering as well. Families may answer to the emotional or mental complaint as if it were the body, that is, as if it were disease and physical pain. Consequently the child may express emotional distress as physical pain. This model suggests that modelling and observational learning play a central role as a mechanism for family transmission of chronic pain (Roy, 1989).

The Family Systems Model

The role of family characteristics in the etiology of somatic complaints has been examined using the structural family systems model. According to this model, a physiological vulnerability is considered to be a pre-requisite for the development of a somatic complaint. Five family characteristics are proposed to activate the disease process. These include enmeshment, over-protectiveness, rigidity, lack of conflict, resolution and

the child's involvement in parental conflict. However, attempts to replicate this model have failed to validate it (Roy, 1989).

The strategic perspective is based on a circular notion of etiology, in which symptoms in one member of a system are seen as a reaction or adjustment to the behavior of another. According to this theory, all symptom expressions, including pain are viewed as a form of communication. Unfortunately, this model does not explain how pain symptoms develop in the first place (Roy, 1989). However, chronic pain is recognized to play a variety of roles in family functioning. As Fordyce (1976) has demonstrated, pain behaviour is subject to learning principles and may be reinforced by family members simply by persistently responding to the pain behaviours manifested by the patient. In contrast to this, families do not always reinforce pain behaviour, but have been shown to play a facilitative role in the process of coping with chronic pain (Bush & Pargament, 1997).

The systems perspective has contributed to answering the question of how symptoms are perpetuated and what the roles and functions of symptoms may be within the family. When pain behaviour is considered from an interactional perspective, the functions of pain in a relationship assume a degree of complexity which is not apparent from a linear perspective alone. Pain may be a scapegoat to seek intimacy; it may provide homeostasis in a marriage or be used to avoid sexual relations (Roy, 1989). Roy (1988) compared twelve people with chronic back pain and twenty headache patients using the Mc Master Model of Family Functioning. Results relating to the group with back pain were as follows:

- 75% had problem solving difficulties.
- 50% showed pathological communication.
- Nurturance and supportive roles were ineffectively performed by 75% of the group.
- Marital and sexual gratification was reduced in 75%
- Occupational roles were compromised in 50%
- Affective responsiveness was impaired in 83%
- Behaviour control, which refers to the rules by which families live, was flawed in 83% of the sample (Roy, 1992).

These findings indicate that family functioning of chronic pain patients tends to be impaired when examined in detail. Chronic pain places extra demands on spouses who may assume more responsibility, deal with anxiety about the spouse's health, loss of intimacy and often a reduction in sexual activity. Clinically it has been noted that children often complain of losing access to the parent with chronic pain. Often parents have high expectations of them. Sometimes the level of stress is such that children become symptomatic. However, very little research has been conducted on the impact of parental chronic pain on children. Roy (1992) states that "nothing is known about the children"(p. 93). It has also been noted that studies relating to social support networks do not exist. "Research into this vital area is urgently needed" (Roy, 1992, p. 94).

Chronic pain and work-related disability

Etiological issues

Chronic back or neck pain is the leading cause of disability due to work or civil accidents (Tunks, 1990). Usually family and occupation are the primary significant objects in a person's life. A person's commitments or deeply held beliefs influence what is meaningful to them. Work and family usually involve the greatest investment in terms of time, energy and dedication and are deeply meaningful (Bush & Pargament, 1997). These aspects of a person's life may be profoundly affected by chronic pain. The experience of chronic pain has been described as more than pain – "It is everything associated with pain" (Seers & Friedli, 1996, p. 1166). For many people with low back pain, part of the problem may be the inability to work rather than the pain itself (Linton, 1987).

Individuals with chronic pain have to evaluate the effect of their condition on issues which affect well-being, such as health, work, finance, family and community involvement (Bush & Pargament, 1997). It has been shown that people who continue to work despite showing signs of the disruptive effects of pain in their personal and family life are likely to do better in a treatment programme (Tunks & Roy, 1990). It has been noted that when claims for compensation for injury rise above 55% of nett income, the number of claims rise. Conversely, it is also known that lower levels of income can compel workers to continue working, despite compromising their health to do so (Nachemson, 1983, in Craig, Hill & McMurtry, 1999). Return to work is obviously desirable and may influence the patient's

experience related to chronic pain. However, it may be necessary to make adjustments in the type of occupation or the way it is performed. Risk factors in the workplace which are associated with back injuries include bending, lifting, heavy work, repetitive work and static work, and exposure to vibration, including vibration in motor vehicles (Linton, 1982). Accommodating changes in the environment of work routine may facilitate the injured person's return to gainful employment, significantly altering the meaning of pain in the person's life. Further research into effective preventative programmes, including those aimed at secondary prevention, have been called for (Linton, 1982). It may be impossible or inadvisable for some patients to carry out certain activities, once injured (Tunks & Roy, 1990). However, subjects who complain of chronic pain are frequently dissatisfied with work as well (Tunks, 1990). The obvious problem is establishing the validity of their pain complaint. Regrettably, strategies for distinguishing genuine and deceptive pain reports are currently unavailable (Craig, Hill & McMurtry, 1999). Even though some chronic pain conditions, such as fibromyalgia and myofascial pain lead to vague symptoms which may vary in intensity, duration and location, suspicion is aroused when a patient's verbal report of pain lacks clarity and consistency. However, such inconsistency may reflect the vague and changeable nature of the symptoms associated with some painful conditions (Craig, Hill & McMurtry, 1999). The challenge of detecting deceptive messages about chronic pain relates to a long-standing problem in the field of pain management, namely, distinguishing the subjective experience of pain from its behavioural manifestations.

The operant model proposes that pain behaviours may be maintained by avoidance of undesirable activities such as work. Working may not be satisfying and therefore prove not to be reinforcing, so according to this model, pain behaviour may be maintained (Turk & Flor, 1984). There are numerous other incentives for dubious chronic pain reports. The person may claim to have chronic pain to increase the likelihood of receiving financial compensation, access to controlled drugs for illicit use or other less tangible benefits such as manipulation of others, avoidance of work or evasion of other responsibilities. Conversely, pain behaviours may be suppressed to avoid adverse consequences such as prescriptions of feared medical procedures, loss of work or imposition of the sick role on the person. Purposeful exaggeration of pain is usually treated with alarm and resentment by health care providers and institutions. However, suppression of pain complaints has received less attention (Craig, Hill & McMurtry, 1999).

The role played by compensation and litigation in the course of chronic pain is extremely controversial, especially on the North American continent (Craig, Hill & McMurtry, 1999; Fordyce 1979; Chapman, 1984). It has been popular to speak of “compensation neuroses” as a mediating variable in cases of persistent pain after injury where litigation is present. Mendelson (1995) cites Kennedy (1945), who stated “a compensation neurosis is a state of mind, born out of fear, kept alive by avarice, stimulated by lawyers, and cured by a verdict” (p.695). The implication is that symptoms will disappear once compensation is received.

In one study, the suggestion that litigants’ symptoms tend to improve after payment is received was amply supported. In a sample of fifty patients, all but one returned to work and were symptom free when followed up two years after settlement of their claims (Miller, 1961, in Mendelson, 1995). The claim was made that patients who receive compensation are less responsive to treatment than those who receive no payouts, but that patients’ symptoms resolve once compensation is received. This study has been criticised for being nonrandomized, uncontrolled and based on a biased sample (Miller, 1961, in Hadjistavropoulos, 1999).

Mendelson (1995) followed a total of 760 subjects whose legal claims had been finalized. 75% of subjects were not employed after a mean of 23.1 months following settlement of their claims.

The implication that symptoms will disappear once compensation is received has not been supported by the majority of studies. In fact, there appears to be a fair degree of consensus that, for most claimants, disability from injury does not resolve following the settlement of litigation (Hadjistavropoulos, 1999; Mendelson, 1995; Rohling, Binder & Langhinrichen-Rohling, 1995). Mendelson (1995) points out that the term *compensation neurosis* and its synonyms have no demonstrable diagnostic validity and should not be used.

The Task Force on Pain in the Workplace of the IASP released a report in which it was suggested that the number of claims relating to low back pain have increased without a parallel increase in evidence for specific back injury. This report characterised patients with non-specific low back pain as “activity intolerant” and recommended limiting wage-replacement benefits after six weeks. Such recommendations clearly have implications for the experience of chronic pain. The task force implied that chronic low back pain is a result of operant and societal factors. This report was extremely controversial

(Hadjistavropoulos, 1999; Wall, 1996; Thompson, 1996; Mersky, 1996). The Canadian Chapter of the IASP dissociated itself from this report and its policy, describing its recommendations as “not following from the knowledge base informing our understanding of chronic pain” (Hadjistavropoulos, 1999, p.62). It was asserted that the task force’s recommendations may cause a great deal of suffering for honest workers with chronic, mechanical low back pain.

It is recognized that clinicians need to be alert to the possibility of malingering or misrepresentation of chronic pain, even though the base rate appears to be low (Hadjistavropoulos, 1999). An analysis of the techniques by which this may be accomplished is beyond the scope of this study, but readers are referred to Craig and co-workers (1999), for a review of procedures such as the use of subjective reports, psychometric tests, verbal behaviour and non-verbal cues.

Claims of chronic pain are frequently de-legitimised if objective evidence is not found on diagnostic tests, even though a large proportion of chronic pain complaints have little or no relation to organic pathology (Waddell, 1991; Thompson, 1999). In a study of the perspectives of people seeking help from pain clinics, patients expressed the distress about the power invested in doctors, based on diagnostic tests. This was particularly relevant to those engaged in any form of claim related to their pain. The benefits system is closely linked to the medical system and many patients were aware that medical opinion about their condition was particularly influential. Participants expressed the feeling that “life is no longer your own” (Walker et al., 1999 p.625). The influence that the benefits system has on the return to work amongst patients with low back pain has been the focus of some debate. Fordyce (1995, in Walker et al., 1999) believes that payouts could decrease motivation to return to work since they constitute secondary gain for pain. Contrary to this view, Holloway (1994) described how claiming compensation is often a secondary concern to those with a genuine health problem who often desire to return to work. He suggests that the victims are often blamed for the condition by the medico-legal system. Many patients believe that the doctor did not believe them once they saw the tests (Rhodes et al., 1999; Seers & Friedli, 1996; Walker et al., 1999). In one study, the majority of patients who described negative experiences of testing “turned away from medicine to some extent, expressing anger or resignation about its failure to help them” (Rhodes et al., 1999, p.1196). This response is echoed by the many descriptions of chronic pain sufferers

offered in the literature as patients who are frustrated, disillusioned or disappointed. An overview of the literature regarding the system of compensation for injury suggests that the adversarial system of compensation claims may disrupt the trust that traditionally exists between patients and health care providers. Professionals who engage in assessments for third party or other claims may be suspicious of the patient. A helper who is perceived unsympathetic, or as other than an advocate for the patient is unlikely to be well-received (Hadjistavropoulos, 1999). Dissatisfaction with the medical system is frequently encountered in patients with chronic pain. Patients value relationships with doctors which are based on trust and mutual respect. They find those in which the patient is powerless, anonymous and insignificant in a large system the least ideal (Ley, Bradshaw, Kincey & Atherton, 1976). In a study of people with low back pain, some of whom were involved in compensation claims, the researchers found that none of the participants were satisfied with the medical process. From the time of injury, the medical system assumed a central part in the lives of participants. Most felt insignificant. Participants felt the treatment that they had received had not been beneficial (Rhodes et al., 1999). In a study by Seers & Friedli (1996), participants felt that doctors lost interest and began to blame them when their condition became long-standing. These subjective experiences by patients may be related to a belief in the notion of "compensation neurosis" on the part of the doctor. Such beliefs may be widespread amongst medical practitioners who may not know how to deal with the chronic pain patient (Kleinman, 1998, in Walker et al., 1999; Seers & Friedli, 1996). The nature of the encounter between patients with chronic back pain and the South African medical and legal systems has not been investigated.

Tunks and Flor (1984) reviewed the literature with respect to biological causes of back pain and found that most traditional explanations were not supported. There were a variety of organic factors which may lead to back pain such as damage to the intervertebral disc, arthritic changes in the joint, (spondylosis) spondylolisthesis (which occurs when one vertebra slips forward on another due to a defect in the bony arch, or a disc lesion), congenital bony malformations, rheumatoid arthritis, fibromyalgia, ligamentous damage, muscle spasm, or neural tension (in which mobility and nutrition of the nerve tissues and dura is impaired). A full discussion of these different syndromes is beyond the scope of this dissertation, but may be found elsewhere. However, it should be obvious that these conditions differ in important ways and should be managed differently, despite the fact that

“pain” may be a symptom which is common to all. Turk and Flor (1984) point out that “the back pain uniformity myth needs to be discarded” (p. 227).

Disruption of occupational performance

Tunks and Roy (1990) investigated the occupational role and the stresses imposed on it by chronic pain. Roles are fairly stable behavioral programmes carried out by individuals according to society’s rules and expectations. Much research has focused on outcomes of treatment in terms of analgesic intake, levels of activity, and so forth but few studies have examined the psycho-social situation and how it changed. The assumption is frequently made that if pain becomes intractable, all role function may be abandoned while the person assumes the “sick role” (Tunks & Roy, 1990). This is not necessarily so. Pain may affect a person’s ability to work to varying degrees. It has been noted that people who continue to work but still show disrupting effects of pain in their personal and family life, are likely to do better in a treatment programme. In the case of chronic pain, the person may never be able to completely move out of the “sick role”. This does not imply an absolute loss of function in all areas.

Disruption of occupational performance may result in loss of pay, promotion, recognition and security. Employers may regard the worker as unmotivated or a poor risk. Loss of the occupational role leads to loss of the provider role as well. The injured person may be treated by the partner as an additional dependant. Relationships with children may be altered, with the disabled parent being sidelined (Tunks & Roy, 1990). The injured person frequently regards the events leading up to these role shifts as catastrophic and irreversible (Tunks & Roy, 1990).

Interaction with the healthcare system

When pain becomes unusually severe or persistent, most people consult a doctor for assistance. Interaction with the healthcare system is an important aspect of the chronic pain patient’s life, which can influence the course of the condition both physically and psychologically. The experience of chronic pain may be affected significantly by interaction with the healthcare system. Chapman (1984) maintains that many chronic pain

problems are in part the result of medical mismanagement. This author states that “the treatment of chronic pain as if it were an acute pain that has been neglected is dangerous and can lead to iatrogenic problems for the patient. Many acute pain therapies fail to reduce chronic pain and in addition they make it worse” (p. 1270). Drug addiction and surgical iatrogenis were cited as two major problems arising from patients’ overuse of the healthcare system and doctors’ tendency to treat chronic pain as if it were acute.

The effectiveness of spinal surgery has been questioned. About 70% of adults in the United States of America experience back pain at some time. About 280 000 spinal operations are performed annually in that country. Unfortunately the results from spinal surgery are far from uniform. One review suggested that the outcome of 68% of operations produced improvements of 16-95%. Another review suggested that 75% of patients experienced short term relief from sciatica (leg pain), with a 10 % re-operation rate (Block & Callewart, 1999). Waddell (1987) asserts that “disc surgery has stood the test of time because 70% to 80 % of properly selected cases are cured. *But* such dramatic surgical successes only apply to 1% of patients with low back pain” (p.727). He believes that the remaining 99% of patients with back pain do not have prolapsed discs and therefore do not benefit from operations. He adds that “every study for the past 30 years has shown the association of surgical failure with psychological disturbance” (p.727). It was not clear whether such disturbance followed or preceded surgery. In another study, a total of 212 patients (with no previous spinal operations) were assessed and followed up one year after the first surgical intervention these patients had received for lumbar disc herniation. The postoperative handicap correlated highly significantly with the pre-operative handicap. Just over half (57%) the patients returned to work within two months of the operation; and 7% retired within the post operative year (Alaranta, Hurme, Einola, Kallio, Knuts and Torma, 1986). Maitland (1986) has suggested that patients who have surgery for low back pain which is unsuccessful are often worse off post operatively than they were before.

It has been suggested that in Western society the expectation exists that pain will go away if a correct diagnosis is made and treatment instituted (Hilbert, 1984). Unfortunately this is not always the case. Interaction with the health-care system on the part of patients with chronic pain appears frequently to be unsatisfactory.

Consultations appear to be motivated by a search for diagnosis and cure. Researchers note that diagnostic tests prove to be a powerful source of comfort or distress to patients with

chronic pain (Hilbert, 1984; Rhodes et al.,1999). Testing is frequently used for diagnostic purposes. Patients also seek a category by which they can describe their experience and the nature of their condition to others. Diagnosis also provides reassurance that the condition may be shared by others and that the problem is not “in the mind”. Tests may provide objective evidence to both patient and doctor that pain is legitimate. Most patients with chronic back pain undergo x-rays or scans. Finding correspondence between an objective visual image of the inside of the body and one's subjective experience is a new task for man (Rhodes et al.,1999). If tests provide objective evidence of causative factors which may precipitate pain, both doctor and patient may see the patient's experience as validated. It is as if patient and doctor are on the same side looking through the window of the tests at the body and sharing an understanding of the pain. This in turn may encourage patients to align with their physicians. If, on the other hand, no objective cause is found, patients may feel that their pain is de-legitimized. This may lead to feelings of frustration and alienation. When the alignment between tests and the patient's subjective experience does not occur, patients are caught in the dilemma of seeking to find legitimate reasons for their experience, without the support of confirmation from test results (Rhodes et al., 1999).

It seems that one source of tension between doctor and patient may lie in the way meaning is assigned to the patient's symptoms. Balint (1980) explains that physicians often try to reassure the patients that there is nothing wrong if objective evidence of pathology cannot be found. Patients however are likely to assume that what has in fact happened is that the source of the difficulty has not been found yet. Balint believes that “there is a dangerous confusion of tongues, each party talking in a language not understood and not understandable to the other” (p. 26). Miscommunication between patients and medical practitioners, appears to be a real problem – 95,7% of urban medical practitioners and 82,5% of rural medical practitioners who took part in a study conducted by Papaikonomou (1991) “believe that there is a communication gap between medical practitioners and their patients, where information is not understood or is understood in a different way, by the medical practitioners and patient”(p.101). Thus far, it seems that nothing has been done to eradicate the problem. Similarly, Toombs (1992) suggests that there is a tendency towards distorted communication between patients and physicians. She examined the way in which meaning is assigned to symptoms from the perspective of patients and their physicians, drawing from her own experience as an multiple sclerosis patient, as well as

phenomenology. She argues that the biomedical model is an inadequate model for medical care. She explains that, from the phenomenological point of view, illness is understood from different perspectives by patients and medical practitioners. The patient experiences illness in its immediacy as the disruption of his or her life world. This experience is a pre-theoretical one. In contrast, the physician focuses on the disease process itself. In this sense illness is regarded as a dysfunction in the biological body (rather than a disruption of the lived body). The patient's subjective report is re-interpreted in terms of the physician's understanding of disease processes. This involves an abstraction from the patient's pre-reflective experience to a scientific account of causal structure of such experiencing. Although it may appear that the patient and physician are talking about the same reality, from a phenomenological viewpoint these realities are distinct (Toombs, 1992). She states that therapy is less likely to be successful if the meaning of illness to the patient is not taken into account. Such meaning is not apparent from clinical data alone, but the lived experience represents the reality of the patient's illness. Critics of modern medicine suggest that such subjective data is often discounted. Toombs (1992) argues that distortions in communication can only be remedied once the differences on which they are based are understood. Such differences with respect to chronic pain in particular have not been explored. However, provision of phenomenological description of pain from the patient's perspective may provide the basis on which communication between patients and physicians may be clarified.

Coping with chronic pain

Adjustment to chronic illness is a process rather than a single event which occurs when the condition is first diagnosed. Patients have to adjust repeatedly as changes occur in their life situation as well as in the condition itself. The ability of the individual with chronic pain to adapt to new circumstances may be challenged many times over the course of their lives. Reactions to chronic illness depend on the individual's specific stage of adjustment to the condition. Some emotional reactions seem to be particularly prominent at particular stages in the course of the illness. (Gregg et al., 1989). These include the following:

- Shock: following the diagnosis the individual may experience a feeling of numbness.

- Realisation: as the individual realises the implications of his or her predicament feelings of anxiety and fear may be prominent.
- Denial: the individual may question the accuracy of the diagnosis and refuse to accept it or the seriousness of the situation.
- Mourning: the individual may acknowledge the presence of the condition and then undergo a period of grieving for his or her lost health. At this time signs of depression anger, irritability and frustration may become prominent.
- Acceptance: the person may accept the fact that they have a chronic condition. The limitations which the condition imposes on their life are realistically perceived and accepted.
- It must be noted that complications or relapses may cause the individual to re-experience many of the emotional responses which had previously been worked through.

Well-being and activity level have been shown to be related to patients' beliefs in personal control over pain and to the strategies they use to control pain (Jensen & Karoly, 1991; Haythornthwaite, Menefee, Heinberg & Clark, 1998). Coping strategies are cognitions or behaviour intended to manage a specific stressor such as chronic pain.

Examples of coping strategies which may be adopted include:

- The use of coping self statements.
- Diverting attention.
- Ignoring sensations.
- Re-interpreting pain sensations.
- Increasing behavioural activity .
- Praying and hoping. (Haythornthwaite, et.al., 1998).

Coping strategies may be active or passive. Active coping strategies are those used when patients attempt to function in spite of pain. Passive strategies are characterised by helplessness and reliance on others. Active strategies have been linked to greater levels of activity and an inverse relationship to psychological distress. Passive coping strategies have been linked to psychological distress and depression (Snow-Turek, Norris and Tan,

1996). Haythornthwaite and co-workers (1998) suggested that collapsing coping strategies into two categories may be misleading because specific coping strategies cannot be identified. These researchers point out that little is known about the specific coping strategies that contribute to the perception that pain is controllable (Haythornthwaite, et. al., 1998).

Jensen and Karoly (1991) found that psychological well-being was related to three specific coping strategies, namely ignoring pain, using coping self-statements and increasing activity when in pain. In contrast to this, Haythornthwaite, and his co-workers (1998) found that ignoring pain predicted lower perceptions of control over pain. Results obtained by Large and Strong (1997) had definite similarities to those of Haythornthwaite and his co-workers (1998). Flexibility in coping strategies was shown to be important. Additionally, bodily awareness was a pre-requisite for successful coping. The latter finding was opposite to what is commonly expected. It contradicts the proposal that heightened somatic awareness may predispose people to chronic pain or that it may perpetuate such pain, as suggested by Eimer (1998) and by Catchlove (1987).

The coping constructs of people with pain were studied by Large and Strong (1997). Coping appeared to be an important means of preserving self-esteem in the sample of low back pain sufferers whom they studied. A number of constructs emerged which emphasised the limitations or costs of coping. Coping was seen as a necessary evil in that being a "coper" was less desirable than being pain-free. Coping was seen as obligatory. Being dependent was regarded as a luxury. Coping also meant limiting activity or being cautious about it. Similar findings emerged in a study conducted by Schmitz, Sailie and Nilges (1996). These researchers postulated that people orient their actions and strivings towards the attainment of personal goals. Individuals are proposed to evaluate their life situation with respect to progress towards these goals, or movements away from them. Chronic pain is associated with a perceived threat to goal attainment. This circumstance may lead to a discrepancy between an actual and desired state. Such discrepancies trigger coping processes to neutralise the threat or minimise loss. In this model, two modes of coping were distinguished, namely, assimilative coping and accommodative coping. Assimilative coping is characterised by active attempts to change the situation. Conversely, accommodative coping is directed towards a revision of goals in accordance with perceived deficits and losses. Results of their study of 122 chronic pain patients, 59% of

whom had back pain, indicate that the negative effects of chronic pain are buffered by flexible goal adjustment strategies. These findings are similar to those of Large and Strong (1997), as well as Haythornthwaite and co-workers (1998), who also cited flexibility as a factor which was associated with greater perceptions of control. These studies indicate that it may be beneficial for patients to be able to shift strategies when one strategy is unsuccessful. Assimilative coping may be more important at the onset of pain but accommodative coping may become more relevant as chronicity progresses (Schmitz et. al., 1996).

Another important question arises as to whether coping is related to less pain because less pain makes coping possible, or because coping reduces pain. One study suggests that active coping is related to psychological well being while more passive strategies are related to psychological stress (Snow, Turek, Norris & Tan, 1996). These findings contradict those of Schmitz and co-workers (1996), who suggest that overemphasis on assimilative coping may impede the transition to accommodative forms of coping, leading to feelings of helplessness when the individual is confronted with factually irreversible problem situations. At such times, accommodative coping may be adaptive. These findings challenge the claim that active coping strategies are superior to accommodative processes. The researchers point out that there is a tendency for researchers to favour active or offensive coping efforts (Schmitz et. al., 1996). Similarly, Large and Strong (1997) state that “the gap between the expectations of the therapists and expectations of sufferers needs to be better understood” (p. 251).

Conclusions

Chronic pain is a complex, poorly understood phenomenon. Although chronic low back pain is usually not life threatening, the literature expounds the large number of sufferers, the high cost to the person involved as well as to society in general, as well as the detrimental effects the condition may have on personal and family life. Much research has been devoted to uncovering the causes and course of chronic pain in the hope that a cure or effective treatment may be found. Unfortunately, progress has been slower than desired.

Therefore many people are confronted with the prospect of living with pain, in other words, they have to cope. Thus far research attempts at understanding the nature of chronic pain and the coping strategies used have been largely quantitative in nature. This approach may not do justice to the finer nuances of the coping strategies used, the changes which they encompass over time, or the way coping strategies may vary with the particular situation (Large & Strong, 1997). Furthermore, the suggestion has been made that successful management may lie in changing the meaning of chronic pain. Personal constructs of this kind are dynamic, ever-changing reflections of the person's adjustment to the environment. The meaning of chronic pain and coping mechanisms used are best known to persons who have this condition themselves.

Although the literature reviewed in this chapter offers different views on chronic pain, it is apparent that, generally speaking, the world of chronic pain from the perspective of the person with such pain is a relatively unexplored field. This is surprising because chronic pain is acknowledged to be a subjective experience. Therefore, the purpose of this study is to describe the meaning of chronic pain from the perspective of those who live with this experience.

CHAPTER THREE

METHOD

Introduction

The literature review demonstrates that chronic pain is not only a noxious physical experience but that it impacts on a person's life. The way in which it does so, depends on the context in which it occurs. Each person occupies a particular biographical situation in the world, with its own relationships, special interests, motives, aspirations and commitments. When pain becomes chronic, it becomes part of an already unique context. Viewed this way, each person's encounter with chronic pain is uniquely his or her own. The experience of chronic pain is subjective and is available to no one but the individual concerned. Consequently, it cannot be measured. Prior research on chronic pain using conventional quantitative models of illness has not provided an adequate understanding of the meaning of this experience in the life of an individual (Walker et. al., 1990; Carter, 1999, in Walker et. al, 1999, Price, 1996; Large & Strong, 1997). Thus far, little attention has been paid to the patient's perspective (Seers & Friedli, 1996). This implies that a different approach is needed. The present dissertation differs fundamentally from conventional quantitative studies in terms of its research objective, namely, to provide a holistic description of the meaning of chronic pain. This study does not focus on finding an explanation, cure or treatment for chronic pain. Neither does it seek to define specific relationships between chronic pain and intra-psycho variables or other factors. Instead, the meaning of chronic pain is described from a phenomenological perspective, using an alternative paradigm, that is, a qualitative rather than a quantitative method. Quantitative and qualitative research will now be compared briefly to elucidate the rationale for the use of a qualitative method in this dissertation.

The difference between quantitative and qualitative research methods

From an ontological perspective, quantitative and qualitative research methods are based on different assumptions about the nature of reality. They also have different research objectives. Quantitative research is based on a positivist philosophy which

assumes that an objective reality exists independent of the observer (Firestone, 1987). Within this paradigm, reality is assumed to be driven by immutable laws and mechanisms (Guba & Lincoln, 1990). With respect to the social world, the assumption is made that “there are social facts with an objective reality apart from beliefs of individuals” (Firestone, 1987, p.16). When research is carried out within this paradigm, all entities that may be studied, including humans, are conceptualised as objects and the natural laws which they obey are sought (Guba & Lincoln, 1990; Romanyshyn, 1971). Questions and hypotheses are stated in advance and subjected to empirical testing in an attempt to uncover relationships between variables of interest. Probability sampling and randomisation are used to ensure that results are generalizable (Moon, Dillon & Sprenkle, 1990). Testing is carried out under controlled conditions to prevent bias or confounding which may obscure or distort the relationships which are the focus of the enquiry. Researchers reduce data acquired in this way into units stripped of the subject’s larger context in order to understand reality (Rapmund, 1996).

In contrast, qualitative research is concerned with the view of man as an experiential being, that is “man as man,” rather than “man as an object.” Qualitative research is based on the notion that reality is subjective and that it is socially constructed through individual or collective definitions of the situation (Firestone, 1987; Creswell, 1994). Qualitative research methods are concerned with comprehending the meaning of psychological life as presented in real world contexts, including the purpose and significance that people attach to their behaviour (Stiles, 1993; Firestone, 1987). The emphasis on understanding human experience as perceived by the subjects themselves, is one of the essential differences between quantitative and qualitative research methods (Rapmund, 1996; Moon et al., 1990). Criterion based selection techniques are used to select a few cases for intensive study (Moon et al., 1990). Rather than trying to control variables, they are included as part in the context (Rapmund, 1996). Researchers use data acquired in this way to provide rich descriptions of the subject’s world.

A qualitative paradigm has been chosen for this study for several reasons. Chronic pain is not encountered in isolation, but within the context of a particular life, with unique relationships, goals and dreams. Therefore, each person’s encounter with chronic pain is uniquely his or her own. Romanyshn (1975, in Kruger, 1979) makes the point that the study of man as an intentional being (not man as a thing) requires that qualitative data be

accepted for the investigation. The impact of chronic pain and, therefore, what it means, will depend on the particular context in which it is encountered. It is an experience which cannot be measured. A qualitative paradigm, with its emphasis on understanding meaning in a particular context, is deemed to be the appropriate means by which the experience of chronic pain may be studied.

The phenomenological method in particular is a qualitative research approach which provides a means by which the way reality as experienced by a particular person can be explored in a rigorous fashion (Cleaver & Pallourious, 1994; Toombs, 1992). A phenomenological analysis focuses on events and occurrences *as one experiences them*, not focusing on the event itself, but on how it is perceived. The task of phenomenology is to study the essence of experience (Giorgi, 1997). The emphasis in phenomenology is on meanings rather than facts, particularly what events mean to the subjects of the research (Giorgi, 1983). Meanings are discovered by examining the individual's personal perception or account of an object or event (Giorgi, 1983). Phenomenology argues that true reality is both unknown and unknowable to us. Instead, that which is experienced by us as being reality is subjective. It is inextricably linked to our mental processes in general and, in particular, to our inbuilt, innate capacity to construct meaning (Spinelli, 1989). It should be noted that objective reality is not denied in phenomenology. However, "real meaning, for a phenomenologist, is to be derived by examining the individual's relationship with and reactions to these real world events" (Penguin dictionary of psychology, 1985).

The emphasis in an explicitly phenomenological approach is on describing the phenomenon precisely as it presents itself, without engaging in interpretation, or speculation as to how it came to be (Giorgi, 1992; Giorgi, 1994 ; Toombs, 1992). The phenomenologist seeks to understand a phenomenon on its own terms, rather than seeking an explanation by "going behind" phenomena via hypotheses or operationally defined terms. Reliance on such constructs is undercut in phenomenology. In a phenomenological analysis, experience is studied in and of itself, in order to understand the meaning of experience as it is actually lived (Toombs, 1992; Barrell, Aanstoos, Richards & Arons, 1987). The preconceptual roots of the phenomenon are sought in the lifeworld. Operationally defined constructs are regarded as abstractions (Barrell et al., 1987). To illustrate this point, Barrell and co-workers (1987) use the example of "anxiety." They state: "The term anxiety is already an abstraction; it refers to an object-like reification, a

“thing” one “has” - like a disease....A phenomenological researcher must begin pre-conceptually in order to elucidate the original experiential meaning to which the concept “anxiety” refers” (pp.446-447). Phenomenology makes what is hidden in ordinary, everyday experience manifest (Toombs, 1992). The essential features of events and occurrences as experienced by the individual are described, in order to determine the essential character of the experienced phenomenon. This enables the researcher to arrive at a description of the invariant features of the phenomenon of interest (Toombs, 1992; Giorgi, 1983; Giorgi, 1992). In this way, the essence of experience may be disclosed (Giorgi, 1997).

Despite the emphasis on subjective experience, Giorgi (1983) observes that phenomenology is not the same as introspection. The phenomenologist is able to detect meanings of which the subject is unaware. This is because of the particular perspective afforded by the phenomenological analysis. Giorgi (1983) explains that “it should be remembered that the meanings that the researcher can detect in descriptions have for their reference points the totality of the subject’s lived experiences and that totality exceeds the subject’s explicit awareness. In other words, just as in traditional research, the subject communicates more than he or she knows, the researcher, because of his different perspective on the situation, is able to discern some of these meanings more deeply than the subject himself” (p. 162).

When conducting research, the paradigm chosen should be the one which would best provide the information required to answer the research question (Kruger, 1979; Romanyshyn, 1971). The paradigm chosen defines both the method and, by implication, its subject matter (Romanyshyn, 1971). Therefore, if one is interested in finding out about pain thresholds, a quantitative approach would be most appropriate. If one is interested in human experience, such as guilt, anxiety or pain, this will be more fully comprehended by ascertaining what experience means to the person who feels guilty, anxious or is in pain (Kruger, 1979).

The phenomenological method has been chosen as the means by which to study the meaning of chronic pain. This method is deemed to be coherent with the research question for the following reasons –

- Chronic pain is not “something,” which a person “has.” It is an experience with which a person *lives*. Phenomenology provides a means

of exploring experience as it is lived. The research question is concerned with man as an experiential being. Therefore, a research method has been chosen by which experience itself can be explored.

- The phenomenological research approach provides a means by which the way that different individuals assign meaning to illness can be disclosed (Toombs, 1992). Phenomenological studies are able to show how different individuals think about a phenomenon so that commonalities and discrepancies between them can be revealed. This implies that phenomenology can reveal meaning from the viewpoint of patients, therapists and families and provides a basis on which communication between them may be clarified (Toombs, 1992).
- Reality as experienced by the individual is subjective, and this reality may change over time. For example, coping strategies may be adopted and discarded later, if no longer appropriate. It is not possible to state an invariant truth once and for all regarding the human condition (Kruger, 1988). Phenomenology provides the means by which changes in people's responses to chronic pain can be explored. Qualitative methodologies, such as the phenomenological method, help to illustrate the particularity and adaptability of such responses and coping strategies. As such, it is a useful means of examining changes in the way people perceive chronic pain and deal with it.

Smith (1996) believes that “qualitative research has the potential to supplement, expand and greatly enrich the existing corpus of research in health psychology” (p. 265). He describes the phenomenological method as an under-represented approach in health psychology. It is suggested that health psychology and phenomenology could form a useful alliance, since health psychology is concerned not only with the occurrence of illness in communities, but also with individually diseased bodies. While some accounts may provide valid explorations for the distribution and transmission of health problems, the individual body remains the unit for determining the existence of and boundaries for illness.

People also think about their bodies and assign meaning to their experiences. Phenomenology provides a means of exploring how individuals assign meaning to their

experiences, so that discrepancies and commonalities can be revealed. A phenomenologist may focus on the way two people speak differently about what is – medically speaking – the same condition – shedding light on the subjective processes, which are operating in the person’s interpretation of his or her health status. Using a phenomenological method, one is able to obtain a rich account of what the person is thinking about and how the person is dealing with health-related issues. As such, it is an appropriate method by which the research question can be answered.

The role of the researcher in qualitative research

Quantitative and qualitative paradigms differ on the epistemological question of the relationship between the researcher and that being researched. Quantitative paradigms hold that the researcher should adopt a distant, non- interactive stance so as to eliminate bias during the research process. The qualitative researcher becomes immersed in the phenomenon of interest in an effort to understand or describe it (Firestone,1987). In qualitative studies researchers interact with those they study, using empathy as a means of enquiry (Stiles, 1993). Researchers act as measuring instruments. Kruger (1988) states that “of course, the human being is not a measuring instrument in the natural scientific sense; rather he is a highly sensitive recipient of meanings” (p.7). Because of their involvement in the data gathering process, researchers using this paradigm, acknowledge their biases to ensure validity (Rapmund, 1996). For the same reason, the research process is described in detail. In keeping with this principal, the personal orientation of the researcher will now be revealed.

The researcher’s orientation

My interest in exploring the meaning of chronic pain stems from my own experience as a physiotherapist and a chronic pain patient. My training as a medical professional was based on the positivist philosophy of classical science which assumes that all phenomena can be explained through the postulates of objectivity, causality and reductionism. Consistent with these assumptions, Western medical professionals are trained to search for specific causes of the patient’s condition, whether physical or psychological, and develop treatments to eliminate the cause and solve the problem. The

problem at hand is defined in terms of diagnosis and cure and the effectiveness of treatment is judged by the extent to which symptoms are reduced. I believe that research in this tradition is essential and has been of great service to people with chronic pain. Every effort should be made to eliminate and cure illness of any kind. However, at the present time, when confronted with chronic pain, these goals of treatment and cure are thwarted, because chronic pain is, by definition, resistant to treatment. Patients often express the perception that no one understands chronic pain like another patient. In discussing my own condition with physicians it has often seemed that there is an inability to communicate, despite a shared knowledge of medicine, which does not stem from inattentiveness or insensitivity on the part of the physician. It seems that chronic pain has a different meaning to patients and medical professionals. The patient's experience extends beyond the borders of symptoms and their causes. In dealing with an intractable condition, it seems to me that the goals of medicine need to be redefined so as not to be limited to cure of the condition, but to include understanding the patient's subjective world.

Sampling and selection of research participants

Physiotherapists and medical doctors were asked to refer patients who had agreed to be participants for the study. Only participants with pain which medicine has failed to relieve were approached to take part in the study, that is they were people who have to cope with pain. To avoid confusion between unique features of different chronic pain syndromes, participation was restricted to people suffering from chronic benign low back pain. Participants were not excluded on the basis of race or gender. Convenience sampling was used. Subject selection was purposive. Subjects were included on the basis of certain criteria:

- They experience chronic pain, that is suffer from the condition, so as to be in a position to describe it.
- They expressed willingness to discuss the matter freely and openly.
- They were capable of providing rich descriptions of their experience.
- They were naïve with regard to psychology to avoid the possibility of their accounts being influenced by prior theories or knowledge.

- Subjects were willing to commit sufficient time to the interviews (Kruger, 1979).

Data collection

In this study, data was obtained during open-ended unstructured interviews. In qualitative research, data is frequently collected in this manner. Several objections are commonly raised against the use of interviews in research. Qualitative interviews are sometimes dismissed as not being scientific. However, Kvale (1994) observes that science may be defined in a number of ways, and that there is no unequivocal, generally accepted definition of science. "The characterization of qualitative research as scientific or unscientific will depend upon which definition of science is used" (Kvale, 1994, p. 150). He states that if science is understood as the methodical production of new, systematic knowledge, science becomes the creative search to understand better, and it uses whatever approaches are responsive to the particular questions and subject matter addressed. Any method which produces understanding which is deeper, fuller and more useful than the previous understanding is acceptable as being scientific (Kvale, 1994). Therefore, the automatic dismissal of qualitative interviews as unscientific is unwarranted, and reflects a specific, limited conception of science.

It is commonly claimed that qualitative interviews are subjective rather than objective. However, Kvale (1994) points out that objectivity may refer to reflecting the true nature of the object investigated. He states that "in phenomenological philosophy, objectivity is reached through the intentional acts of consciousness and is an expression of fidelity to the phenomenon investigated" (Kvale, 1994, p.151). In qualitative research, this method of data collection is regarded as more objective than the methods of the natural sciences when "the object of the interview is understood as being within a linguistically constituted and interpersonally negotiated world" (Kvale, 1994, p. 153). The qualitative interview is able to provide privileged access to such a linguistically constituted world. Lastly, it is often claimed that the results of the interview are affected by the biases of the interviewer. The impact of interviewer bias may be countered by efforts on the part of the researcher to formulate and reflect upon his or her own presuppositions and prejudices. In a specifically phenomenological analysis, the researcher actively "brackets" or sets aside

any preconceptions regarding the phenomenon of interest (Kruger, 1990). This enables the researcher to remain true to the phenomenon of interest (Kvale, 1994).

Unstructured interviews were used in this investigation to gather the data because the phenomenological method requires that the researcher should put aside all preconceptions regarding the phenomenon of interest, so as to observe it as it presents itself (Kruger, 1979). Imposing a structure on the interviews would interfere with this process. For the same reason, no pilot study was conducted, so as not to bias the researcher's thinking prior to commencing with the study.

Questions were posed which encouraged subjects to describe their experience. Leading questions, suggestive of particular answers were not asked, although the researcher did ask for clarification or further elaboration by the subject (Barrell et al., 1987). One advantage of an unstructured interview is that it is flexible, allowing the researcher to grasp the subject's experience more fully than would be possible, using a more rigid method (Kruger, 1979). The duration of each interview was self-determining, depending on what the subject wished to relate. The number of interviews conducted with each participant depended on when the subject had explicated his or her experience fully. Interviews were tape recorded and transcribed. At the end of all interviews participants were telephoned to supply any missing biographical data. Participants were asked for information which had not come up in the interview so that a complete record of the following details could be obtained.

- Their age
- Gender
- How long they have had the pain
- How it started
- Cultural group
- Marital status
- Number of children
- Surgery/other treatment

Data analysis

The aim of the phenomenologist is to understand a phenomenon, as fully as possible, as it presents itself. To achieve this aim, data is analyzed using the phenomenological method. Kruger (1979) has outlined the following steps in the analytical process:

- Bracketing

“Bracketing means that the researcher suspends judgment, that is, refuses to take for granted, as correct, his or her own beliefs about the event as an objective reality, but rather attends to it precisely as the meaning that is lived by the subject. In other words, the researcher’s gaze is redirected from things to meanings in order to achieve an empathic contact with the subject’s perspective” (Barrell, et al., 1987 p.449). Phenomenological research involves the researcher in an inter-personal situation. With its emphasis on a radical reflection upon lived experience, the phenomenological approach requires a commitment to setting aside prior theoretical or common sense presuppositions in order to focus on the phenomenon of interest as it presents itself. This involves a radical disengagement or distancing from habitual ways of interpreting the world (Toombs, 1992).

- Gaining a holistic view of the data

The phenomenological approach is holistic so all the data should be read prior to any analysis to gain a global sense of the data. The researcher should read and re-read the protocols, becoming immersed in the data. During this process the researcher should suspend or “bracket” his or her own pre-conceptions and judgements (Giorgi, 1997).

- Natural meaning units

During the next phase of analysis, the data are broken down into naturally occurring units, which emerge spontaneously from the data, each conveying a particular meaning. Each natural meaning unit (NMU) is a statement made by the subject which is self definable, and self delimiting

in expressing an aspect of the subjects' experience. Central themes in the subjects' experience are sought.

- Constituent profile description

Having listed the natural meaning units, the researcher proceeds to eliminate those which are repeated or irrelevant. Only units which are obviously irrelevant are eliminated at first to produce what is termed a "first order profile." This profile is then summarized into a "Constituent Profile Description" that is a summary of the original data containing the essence that the subject expressed.

- Second order profile

The above 3 steps are repeated on the Constituent Profile Description. These steps are repeated for each subject. The elements obtained from this procedure are listed and numbered. These steps are repeated for each subject.

- Hierarchical categorization

Statements with similar meanings are gathered into categories. Each category may contain elements from one or all subjects. Categories are arranged in hierarchical fashion.

- Extended Description

Taking thematic elements from the above clusters in turn, the researcher writes an Extended Description of what these categories express about the research topic. Each additional category should add to the description or modify it in the light of new information in the additional category. This is repeated category, by category, until addition of categories is rendered superfluous, since the information is being repeated.

These procedures were followed in this study in order to disclose the core features of the experience of chronic pain. The process by which this was achieved will now be described.

CHAPTER FOUR

THE RESEARCH PROCESS

Qualitative research involves the researcher in an interpersonal situation using empathy as a means of enquiry. The research process had an impact on the researcher as shall be explained. For this reason, the description of this process has been written in the first person.

Initial contact

I contacted a general practitioner and two physiotherapists and explained the purpose of my research. I asked them to refer patients who would be willing to participate. One of the physiotherapists gave me Joyce's name and number, the other referred Gerda, and the Doctor put me in touch with Molly. I had intended to write to the participants, but telephoned them instead. All agreed to meet me. I gave each a letter outlining the purpose of the study. I also obtained written consent to tape record interviews, and, if necessary to review medical records. Participants were given the right to withdraw at any time. Signed consent was obtained to use the results for research purposes and to publish the outcome on completion of the study. Participants were informed that names would be changed should the results be accepted for publication. The letter and consent form are included in the appendix.

The acquisition of the data

Data was collected by means of open-ended unstructured interviews. Each participant was seen twice. Interviews were between 1 and 2 hours long. Each participant was asked the same initial question, namely "Please describe as fully as possible your experience of chronic pain." Participants were left free to answer this question as they chose and I listened to their account, bracketing my pre-conceptions about chronic pain, asking for clarification where necessary. The participants had agreed to the use of a tape recorder during the process. This allowed me to concentrate fully on their descriptions, without the distraction of taking notes. The tape recordings proved to be an invaluable aid when analysing the data later.

Listening to the tapes again enabled me to become immersed in the data and to recall the atmosphere of the interview in detail. None of the participants seemed to be put off by the tape recorder.

The research relationship with each participant

Joyce

Name: Joyce Watson.

Age: 58 years.

Gender: Female.

Marital status: Married.

Cultural Group: White.

Number of spinal operations: 5.

Date of First operation: 1995.

Date of most recent operation: 2001.

Onset: Pain started 42 years ago and has been continuous for 8 years.

Occupation: Retired due to pain. Formerly a typesetter.

Joyce had recently moved into an attractive new house, because her pain made it impossible to cope with the work in her previous house. She greeted me with a warm smile and we sat in a comfortable lounge in front of the cosy fire. I enjoyed Joyce's company. She has a sparkling sense of humour and the interview was filled with laughter. However, a wistfulness pervaded the interview. Beneath the laughter was a profound sadness. She would reveal the depths of her feeling, and then quickly switch to an example of something else. Often her laughter was followed by a heart-rending sigh or wistful comment. Joyce seemed so genuine and, I was astonished by her openness. I felt that she viewed me as her link with other professionals to whom she wanted to reveal the human side of chronic pain. I found it easy to listen to her, free of any pre-conceptions. I was comfortable with her and enjoyed being in her company. However, I could not escape the pathos. Joyce's story lingered in my mind, and I was left with a sense of longing, as if I was groping for answers which eluded my grasp.

Gerda

Name: Gerda van Rensburg.

Age: 67 years.

Gender: Female.

Marital status: Married.

Cultural Group: White.

Number of spinal operations: 6

Date of first operation: 1962.

Date of most recent operation: 1998.

Onset: Pain started: 50 years ago and has been continuous 39 years.

Occupation: Retired due to pain. Formerly a teacher.

When I contacted Gerda, she immediately indicated her willingness to participate in the research, especially if her experience could be of help to others. I made an appointment to meet her at her home. I was welcomed with a cup of tea and sensed an instant rapport with Gerda, despite my initial nervousness. We discovered we had studied at the same university which seemed to give us a feeling of being on common ground. Gerda has a degree in sociology. She showed me her magnificent well-organised photograph collection and then settled down comfortably in front of the tape recorder. I asked Gerda to describe her experience of chronic pain, and thereafter I needed to say very little. Gerda spoke slowly and clearly, as if she had given this matter a great deal of thought. She possessed an air of serenity and this gave the interview a philosophical tone. She explained what pain has taught her and how she has learnt to cope. She seemed to slip into her former role as a teacher which cast me in the role of a student. In fact five times she asked “Are there any other questions?” or “does that answer your question?” She seemed to control the interview. I consciously allowed her to present her perspective. I sensed any attempt on my part to delve into personal feelings was met with a subtle distancing on her part. Nevertheless, she seemed to value the opportunity to speak to me and I felt we related well. Gerda seemed to have analysed her situation. I sensed that she had a message for other chronic pain sufferers, and that she saw me as her spokesperson. I left with a feeling of deep respect for this gentle lady, who convinced me that coping with chronic pain may not be easy – but it is possible.

Molly

Name: Molly Carter.

Age: 47 years.

Gender: Female.

Marital status: Single.

Cultural Group: White.

Number of spinal operations: 10.

Date of first operation: 1985.

Date of most recent operation: 1995.

Onset: Pain started: 31 years ago and has been continuous for 16 years.

Occupation: Retired due to pain. Formerly trainer at a bank.

Molly had undergone surgery shortly before I contacted her. Nevertheless, she indicated that she was willing to speak to me right away, so we set up an appointment.

Molly welcomed me to her pleasant home and I felt at ease with her at once. However, I could see that she was in pain, and suggested that she should lie down as we spoke, which she did. Molly and I enjoyed an instant rapport. However, throughout our first meeting I was aware that she could not find a comfortable position, because she was in pain and this disturbed me. I experienced a sense of urgency in the meeting, which I needed to control. Molly, however, seemed quite at ease. She poured her heart out, starting at the beginning and describing her feelings and experiences with great openness and emotion. However, towards the end, she was clearly in pain, shifting about on the couch. When I suggested that we should continue another time, she indicated that she wanted to continue. I found it easy to bracket any pre-conceptions I may have had about chronic pain since the scope and magnitude of Molly's problem was beyond anything I had ever encountered, in fact I felt quite awed by her condition. Time passed quickly and I ran out of tape. I replaced the first tape and we finished our conversation. When I got home I was dismayed to find the second tape was blank. However, I had become so involved with Molly that I knew exactly what I had missed. I telephoned her and she happily agreed to meet again to fill in what was missing.

Molly postponed the second appointment due to agonising pain, for which she required an injection. However, she made it clear that she wanted me to return a day later. This had the effect of putting me at ease because I knew that Molly would let me know if her pain was too severe to permit the interview to continue.

When I arrived the second time, Molly was waiting for me. She seemed eager to speak. She lay down and picked up the discussion where the first tape had ended. I felt relaxed sensing that Molly was looking forward to the discussion and the interview seemed to flow straight from Molly's heart. The tone of this interview was subtly more positive than the first. Molly said she found talking about her experience therapeutic and I could sense this. We seemed to be on the same wavelength. She treated me like a friend telling me her personal life story quite openly and there was a sense of companionship in the meeting. Nevertheless, the focus was on the research, but when I got home I felt I had truly learnt something from Molly. I had great respect for her. I felt as if I had been spurred on to help others who live as she does with unrelenting pain.

Working towards saturation

The interviews continued until the researcher felt that a point of saturation had been reached. Shantall (1996) states “when a sense of agreement that enough has been said is reached between researcher and participant, the research can be accepted as closed.” (p. 272)

The interview with Molly seemed to reach a natural point of closure. Molly felt she had “talked herself hoarse.”

After the first interview, as Gerda printed out her medical history from her computer, she told me about the termination of her job and current physiotherapy treatment. It seemed inappropriate to start the tape recorder again, so I returned later to follow up this casual conversation. The second interview seemed to lack the intensity of the first, and towards the end, no new information seemed forthcoming. Gerda appeared to turn to me to think of questions to keep the discussion going. I sensed that she had exhausted what she could tell me and accepted the data she had given me as complete. I was, however, somewhat disappointed with my grasp of the emotional impact of Gerda's condition, but she seemed unable to illuminate it further.

It was only much later that I realised that this was indicative of a powerful coping strategy which she employs.

In Joyce's case, when the first interview was being transcribed, there was a point which required clarification, so the second and last interview was conducted. During this interview I sensed that a saturation point had been reached. The conversation seemed to reveal not new insights and it seemed that the discussion was becoming repetitive. This sense of closure was taken as indicative that saturation had been reached.

The explication of the data

All the interviews were transcribed fully. The researcher immersed herself in the data, reading and re-reading the transcripts and listening to the tapes in order to gain a holistic view of the data.

Once a holistic intuitive grasp of the data had been gained, the transcripts of each participant were broken down into natural meaning units. These meaning units were appraised by the researcher's supervisor.

Thereafter, those meaning units which were repeated were eliminated in order to construct a first order profile. This in turn was converted into a constituent profile "which is a condensed summary of the original data in the words of the researcher containing the essence of what the subject expressed" (Shantall, 1996, p. 273). The constituent profile for each subject is presented in the following chapter.

This process was repeated on the constituent profile to yield a second order profile. In the next stage of the analysis, statements with similar though not identical meaning were gathered into categories which were arranged in a hierarchical sequence, describing the characteristics of chronic pain.

The themes arising from this process were used to write an extended description, from which the researcher could gain an overall view of the experience of chronic pain, capturing the core qualities of the phenomenon.

Reliability and validity

It is imperative to consider the reliability and validity of a study such as this to establish the credibility of the research findings. The criteria by which this is judged

should be appropriate to qualitative research, which has a different epistemological foundation to quantitative methodology (Osborn & Smith, 1998). Such criteria have been detailed by several authors (Stiles, 1993; Osborn & Smith, 1998).

Reliability in this study

According to Stiles (1993) reliability concerns the procedural trustworthiness of the research. The report should convey what another person who was observing would have seen. With this in mind, the context of the research has been described, as well as the researcher's orientation. Verbatim evidence has been included in the report to allow the reader to assess the interpretation. Full transcripts of the interviews have been included in the appendix. Thus the data is open to inspection (Osborn & Smith, 1998; Stiles, 1993). In order to ensure that interpretations were grounded in the data, the researcher's supervisor read the transcripts and continually checked the emerging analytic account, not to produce a simple definitive reading but to ensure that the analysis presented is supported by the data.

During the interview itself, Stiles (1993) states that reliability is enhanced by keeping the focus of interviews on questions which subjects can answer that is, on what they experienced rather than why. Reliability is strengthened by reflecting the researcher's understanding back to participants and by repeated interviews. These procedures were followed during the study. Secondly, Stiles (1993) believes that qualitative research is facilitated by immersion in the material reading and re-reading the transcripts, moving between extracts and the unabridged form and discussion with mentors. This was done, especially during the phase of explication of the data.

It must be noted that the researcher and participants shared a cultural context, therefore results may be culturally bound. Notwithstanding this, strenuous efforts have been made to ensure that the study is reliable.

Validity in this study

“Validity concerns whether an interpretation is internally consistent, useful, robust, generalizable or fruitful” (Stiles, 1993, p. 607). Validity in qualitative research refers to the presentation of an account which is sound and grounded in the data. The aim is not to produce a single true account of the material (Osborn & Smith). The

emphasis is on understanding by people, including the readers of the study, rather than on facts. Misinterpretation is a particular danger in qualitative research, and this risk is augmented by reliance on a limited range of information sources. The solution is to ask many questions and expose oneself to multiple perspectives (Stiles, 1993). In this study triangulation was used to achieve such exposure. Several participants were interviewed and their perspectives were probed in depth in order to negotiate meaning. The researcher sensed strong empathy with each participant and believes the necessary trust was there to enable them to communicate freely with her. Secondly, a literature study was conducted in which both psychological and medical perspectives of chronic pain were reviewed. Some critics may object to the fact that, in keeping with the researcher's course requirements, the literature study was conducted prior to the collection of the data, a procedure avoided by phenomenologists lest the literature should bias the researcher's perceptions. However, Shantall (1996) argues that a literature study need not lead to theoretical bias and may in fact enhance understanding and empathy, by opening the researcher's mind, and revealing existing pre-conceptions. The researcher is of the opinion that the literature survey served to heighten her sensitivity to participants.

The validity of qualitative research may also be assessed by its impact on the researcher, participants or theory. Did it produce change or growth?

The researcher's own ideas were changed by the study. As a physiotherapist, who has been intensively involved in rehabilitation, she valued active coping strategies and tended to equate "coping" with restoration of function, getting as close to the same lifestyle and activity level as one had prior to the onset of disability. The research participants quickly made her aware of the value of passive and accommodative coping strategies in the case of chronic pain. Secondly, as a chronic pain sufferer herself, deep down the researcher entered the research hoping that some means of eliminating chronic pain may be found within the realm of psychology. In the absence of a medical cure, could chronic pain be beaten using the mind? The researcher was left woefully aware of the inadequacy of both medical and psychological explanations of pain. Her focus changed from seeking ways to cure pain to understanding how to cope therewith. Thirdly, the researcher's awareness was expanded by the participants who challenged her to consider the spiritual dimension. Stiles (1993) refers to such changes in the researcher's thinking as "reflexive validity".

The validity of qualitative research may also be assessed by its impact on the participants. Two of the participants commented on the fact that they found participating in the study therapeutic. Stiles (1993) refers to the degree to which the research process reorients, focuses and energises participants as “catalytic validity”. Participants may feel empowered and may change by taking control of their lives. One participant, Joyce, seemed to experience such growth. Some months after the interviews she and the researcher happened to meet. She informed the researcher that she had started to visit the hospital once a week to assist other patients, drawing on her own experience, something she had considered during our first interview. The change in her self-esteem was apparent and the researcher believes that acting as a participant had served as a catalyst for growth in this regard.

The researcher’s supervisor acted as a critic and mentor to ensure that the analysis presented reflects a fit between the data and interpretation. Participants were invited to read and comment upon the interview transcripts. However, they were not asked to comment upon the interpretations because a phenomenological analysis yields an explanation which is beyond the awareness of the participants themselves (Giorgi, 1983).

Validity is also established by the coherence of the report which can best be assessed by the reader. This refers to the internal consistency and comprehensiveness of the account. A better interpretation encompasses its rivals, at times confirming them, supplementing them or superceding them (Stiles, 1993). The research should enhance understanding of the phenomenon in question. This study confirmed many aspects of the literature review, but also transcended it by offering insights gleaned from entering the life-world of the sufferers themselves. Their accounts will now be presented.

CHAPTER FIVE

CONSTITUENT PROFILE DESCRIPTIONS

Joyce's story

Joyce suffered a great deal of stress, physical abuse and trauma in childhood. She wonders whether this precipitated her chronic pain. She developed severe degenerative changes in the spine and by the time she was 51, she had to relinquish her job and underwent surgery. Prior to the first spinal operation, Joyce had worked for twenty years as a typesetter. Unfortunately, the operation had disappointing results. The pain became progressively worse. Joyce has lived with relentless pain for eight years. She has had five spinal fusions, one to the back and four to the neck. In all, eight vertebrae have been fused.

Life before and after chronic pain.

Joyce compares herself now with the way that she was before surgery, the way that she "should" be. She recalls her former self with a sense of grief and nostalgia:

I was a dancer. I used to dance on stage in competitions and I was very good when I was small. And now I am like a jolly invalid!

She used to be able to control the pain by stretching into her spine in her mind's eye and switching the pain off. However the pain has worsened and this does not work any more:

I cannot switch off any more. It is too much. The pain does not go away. It stays there. Before I could actually wipe it out, and four hours later it would be back. But now I cannot wipe it out any more. It is there constantly. Constantly.

Joyce compares her role as a grandmother before and after the onset of her condition, regretting that pain has denied her the opportunity to be the kind of

grandmother she wishes to be. Formerly she looked after her grandchildren regularly, but, because she cannot give her second daughter the same help with her newborn baby, she feels upset and guilty:

I don't carry things. I have got another little grandchild now, a little baby. I don't hold him, I can't. I can't hold him and walk. So I don't. I have not looked after him. I had to apologise to my daughter the other day because I have never asked to look after him. I can't."

Joyce has been forced to learn "a whole new way of life."^{coping}

You adjust yourself and your way of thinking and everything to your situation. You have to. Otherwise you just make your life an absolute misery.

Joyce related that chronic pain has aroused a consciousness of her body which did not exist before. The body which used to function spontaneously, cannot be trusted. Things that were taken for granted previously have to be placed under her conscious control. The damage to her spine causes her to fall frequently. She has to think about everyday activities such as shopping, walking, dressing, bathing and even turning over in bed or getting out of the car:

^{no self esteem}

You lose confidence. You find you are concentrating on walking because you are so scared that you are going to fall. So when you walk you are watching your foot, one foot in front of the other. I can walk past people I know because I am so busy trying not to fall. You also find you walk against a window. You don't walk up and down stairs. At the mall, you walk down those slanty things so that you have got something to grab. Your whole life changes...being obsessed with this pain all the time makes you old.....

A pain that cannot be seen: The response of medical practitioners

Joyce had great difficulty communicating her experience to others. At first, the validity of her complaint was denied by medical practitioners. This has caused her a great deal of distress. Joyce resents the authority which is invested in the medical

profession, which has the power to deny or confirm the legitimacy of one's complaint. Her doctor's assessment had a negative impact on the treatment and compensation which she received. When the specialist refused to believe her, she experienced a profound sense of powerlessness. She had the feeling that her honesty and integrity as a person were being questioned. The implication was that she was either "mad or bad."

You've got no power and you've got no proof...What do you do? He says to you "You've got no pain" And you sit and look at him. Now you think you've become a hypochondriac. But, you realise "I have got pain!" -"No, you haven't – there's nothing showing up on this X-ray. Lady, do you want to be sick or do you want to be better?" "No, no I want to be better." "Well then, there's nothing wrong with you!"

Joyce rejected the notion that her pain was unreal. Convinced that it had a physical origin, she changed doctors until she found one who acknowledged the reality of her pain and was prepared to treat it. Joyce believes that the patient will engage in a relentless search for a medical practitioner who will understand and treat the chronic pain sufferer. This quest is born from the sincere desire to be rid of the pain permanently and to get back to normal life

The disbelief which she encountered left Joyce feeling dehumanised. This sense of dehumanisation did not end when she went in for surgery. Joyce was outraged by the rough treatment she received postoperatively. She was treated as if she was a nuisance. This callous treatment has aroused a lurking fear of what might lie in store in the future:

When I had my back operation, I came around wishing for death because it was unbelievable! They would come and turn you in the bed and they wouldn't warn you, they would just turn you. And you would scream like an animal because the pain would be so bad..

... In the hospital, when the staff used to wash me, they were so rough! It worries me. You can't believe how they treated me! As if I was an absolute burden on them. And that hurt me. Terrible! You cannot believe it!

Isolated by the fear of rejection

Fear of rejection has had a profound effect on Joyce' relationships. She believes that complaining ^{Keeping Quiet} will drive others away. She stifles any cry for understanding or sympathy from those close to her, even though deep down she is longing to reveal her suffering. Joyce acknowledges that she hides her inner anguish beneath a cheerful exterior. She is acutely aware that others are unable to handle pain, especially pain which never resolves. She is convinced that people who have not had pain cannot understand the chronic pain sufferer. She admits to reacting that way herself previously, which heightens her anxiety that she too may be ignored. Whilst she longs for support and understanding, Joyce chooses to hide her pain rather than risk rejection. As a result, she endures isolation which is an integral part of her suffering. In the particularly moving moment, which seemed to touch the core of her anguish, Joyce revealed her enormous need for compassion and support:

I can't say anything. Yes. Most confusing. Most upsetting. I actually am very unhappy that they don't know because I put on this huge act. "Oh come inside sit down how are you? How about tea?" Nobody ever helps me. I make the tea, put biscuits on the plate, or cut the cake, carry this massive tray, and everybody sits and chats, nobody knows and they won't know because I don't want them to know.

Joyce fears that she will be stigmatised because of her pain. She does not want to be a "spoilt sport" and strives to live up to the expectations of others:

I just like people to like me. I want them to come and visit me, and be here, but if they come here and you are complaining, there is enough sadness in the world and people do not want to go and associate with pain and suffering. They want to go somewhere where they can relax, enjoy themselves, lose their worries, and just sit and have a good evening. So you don't want to sit and say "oh I am sore!" or "oh I can't stand up!" I want to be accepted as someone who is healthy, normal, someone where they can come and enjoy an evening...People don't click with someone who is always complaining.

Much as she wants to be treated as normal, she is in an “abnormal situation” and believes that others cannot deal with that. This impairs communication, leaving her isolated and afraid that if she opens up, she will be abandoned: — no soc. support

I think people are scared of illness. I don't know what they are scared of but they are scared of it and they don't want to come and see it. Maybe they don't know what to say. It is like when you go to somebody and they say "I have got cancer" so what happens? Nobody mentions cancer. Ever again. They just don't talk about it.

A bleak future

The future seems daunting and devoid of pleasure. The realisation that the chronic pain is permanent is particularly upsetting to Joyce. At first she had hope, but “that hope is just going.” Failed surgery and repeated disappointments have suddenly taken on an ominous character. All attempts to alleviate the pain have failed and, most distressingly, it is getting worse:

It is a bleak future. When you sit and feel sorry for yourself. It is a hell of a bleak future...It is just one terrible thing to live with. I just wish somebody could come and take it away! But they are not going to take it away. I have realised lately that this is a permanent thing and I do not know what to do about it... If I am going to be in bed constantly and unable to do anything, people are going to switch off from me and just push off...So maybe I'm scared of rejection...You know that the thought of living with pain for another 20 years is not a good thing. It is scary. It is very, very scary. external locus of control

She compares herself now with what she may become in the future and is terrified by the prospects. The future is too much to bear all at once. Joyce has found that she can only cope by dealing with short periods at a time:

I know how I am now, what am I going to be like in ten years time? It is so scary. And what has been happening is that I wake up at about 3 o'clock in the

morning in a panic, panicking about what is going to happen to me in ten years time.

The fear of becoming a burden

She dreads the thought that she may become dependent on others and lose her value as a person: ^{self-worth}

I think I am a very independent person and I have always done everything for myself. And I do not like relying on other people. And I am scared that I am going to be bed ridden, or in a wheelchair, that I am going to have to rely on somebody to do things for me. I think it will kill me. Really.

Repeated disappointments have almost driven Joyce to the point of despair. In fact the realization that the last operation was a failure drove Joyce to contemplate suicide. Joyce would rather die than depend on others because her worst fear is being a burden. She has experienced what it is like to rely on others and it was an intolerable and humiliating experience. She says that she fears this more than death itself. She believes that her sense of personal worth would be undermined if she was forced to depend on others, particularly if they became irritated with her:

I like people to want me for who I am. Not for what I need from them.

The fear of becoming a drug addict

Joyce described how she delays taking pain medication because she is afraid of becoming addicted:

For the whole day, or the whole weekend, I take a painkiller and I put it on the table and I think "I am so sore I am going to take it now." But I am scared, because these things are addictive. Then in an hour's time I think "it is not too bad, I will wait another hour." And I am busy watching that painkiller the whole day. I am so proud of myself when I can go 24 hours, and not take a painkiller. It is so terrible. My whole life is centred around pain, painkillers, anxiety,

depression, trying not to appear weak to others, so I am always smiling, you know, laughing,...

Getting her mind off herself

Joyce believes that it was due to Divine intervention that she started studying for a degree in theology prior to her first spinal operation. This has become her lifeline. She looks forward to a period in front of her books which enables her to escape the consciousness of the pain:

You are constantly thinking of yourself all the time. That is why I study. When things get too much, I go upstairs, get out my books, and I'd start learning. And it is so wonderful that for about two hours I forget myself.

distraction, gives meaning to her life, safe place, can relax
 Studying enables Joyce to avoid taking pain medication. She believes that pain medication actually impairs the ability to control pain, because it dulls the mind:

Pain makes you sorry for yourself, which is a bad thing. You get depressed, which is bad. So you are totally self-centred when you are in pain. So you have got to get your mind off yourself, and on to something else. But when you take a painkiller, you cannot control it. You take that painkiller, and you cannot concentrate.

Pain has robbed life of many joys, but studying has given Joyce something to look forward to: *goal, do-able*

It (studying) became so important to me I would get up in the morning and I would say "what am I going to do today?" I am going to do this and this, and then I am going to learn. I look forward to it. It is something to look forward to and I would work towards it, and that gave me something to live for. Each day I took one step at the time.

The meaning of pain

Joyce related that the failure of medical science to relieve the pain has forced her to look for a purpose in the pain experience itself. She wonders why it happens. The reason is not entirely clear to her yet, but she believes that her studies are preparing her for a task in which her experience of pain can be useful. She found herself alone in learning to deal with pain. She feels that she may be able to draw on her own experience to help other sufferers. She experiences a sense of satisfaction that she has managed to cope. The prospect of using her experience to help others is a ray of hope which has given her pain a new meaning. It has given her a sense of anticipation that she can fulfil a purpose and that her suffering may not be pointless after all:

That is another reason why I carried on with this, (studying) because my idea was that I could go to people in hospital and tell them about my experience, not tell them what to do, but to tell them how I coped. Maybe they could try it, and it would make it easier for them... Because you know, you think to yourself "why did God do this to me?" And then you think, "there must have been a reason." Maybe He wants to use me somewhere else. I am waiting to see.

Gerda's story

Gerda has suffered with chronic pain for a period of 50 years as a result of osteoarthritis and disc disease. She is aware that structural changes have appeared in the spine, with the result that her condition is deteriorating.

The need to control the pain

Gerda emphasises that although pain dominates one's life, one must control it. She is willing to fight it and she is also willing to "co-operate" with it. Reaching a point of acceptance was the first step in coming to terms with chronic pain. This does not imply a passive acquiescence. Gerda will use every means at her disposal to minimise pain, such as regular exercise seeking medical assistance, pursuing her hobbies, going to physiotherapy or taking medication. However, there are times when she finds it more beneficial to say "no," cancelling appointments, or resting. She has learnt to be realistic and honest in dealing with the expectations of others. This taught her an important personal lesson:

It's not easy because one has a lifestyle of giving and now you're having to learn to receive.

Gerda believes that the mind plays a key role in the control of her chronic pain. When she left work she had to go through the usual rounds of tests to prove that the pain was real. Establishing that there was a physical cause for a problem was very important to Gerda:

That is the most important thing. I know it's not my mind.

She is in the fortunate position of having a doctor who does not doubt her complaint, who is willing to support and assist her:

I think this is vitally important. More needs to be done for the patient to help you understand why things are happening to your body, then you can cope with it. I found that in my own experience. Fortunately I have a very good relationship

with my doctor. If I say "Please explain," then she will take time to explain to me why something is happening, because then she knows I'll be able to cope better.

As far as possible, Gerda likes to know about the underlying mechanisms of the pain. This enables her to adapt her activities so as not to exacerbate the pain. She displays much insight into her physical condition. Gerda emphasises the importance of having an intact mind in order to control the pain and how the pain affects one. Her worst fear is the loss of her mind.

Letting pain have its own way

Gerda believes that if the chronic pain sufferer does not have hope, the relentless nature of the pain may drive the sufferer into a state of despair or suicide. She can understand that. The persistent nature of pain gives it a quality that is particularly hard to endure. One does get desperate. It imprisons one. The freedom to do what one wishes to do is curtailed. That is frustrating. Pain controls your life and, paradoxically, the way to cope is to let it have its way. She finds that questioning only adds to the tension and worsens the pain:

I'm having to learn to say "no." I am not a person that can easily say no. I've got to listen to my body's needs...I'm learning to say to myself "Okay, relax, let go, move out." Now, that's restrictive. It gets to your psyche, and it says to you, "Why? Why? Why?" Why the pain? Why the tension? Getting you to this state, I find the moment I get tense, then the pain gets worse.

inner awareness, 45 of relaxation

The importance of having faith

It is not possible to understand how Gerda deals with chronic pain without reference to her personal faith:

This, I think, is vital with chronic pain. If I can understand something of where my pain is coming from, and if I can understand something of what it can do to me and to those around me, then I can work at it through God's grace.

Psychologists help up to a point, but can't go beyond that point.

She emphasises that each person's response is unique. In her case faith is her anchor, a theme to which she returned continually. She is unperturbed by the fact that many would challenge her faith, or regard her spirituality as a form of escape, because she has found her faith to be the best way she has of dealing with chronic pain. She is not interested in defending the truth or falsehood of her beliefs. Her aim is simply to explain how her faith in particular helps her to cope with the pain:

To me, God has a purpose in all that I am, all that I do, and in all that I experience, and in that I am able to cope. So, if there is a God I'm happy, because one day I'll be with him, and there will be no more pain. There will be no more heartache. What happens to that person for whom he doesn't exist – well that is their choice. To me, that (faith) is the answer, to my need, and the answer to my pain, and I'm able to cope with it

When pain mounts she will try by all means to decrease it. If that fails, she withdraws physically from the situation. Importantly, in order to cope with both physical and emotional pain she distances herself mentally from the situation. This is achieved by withdrawing into the spiritual realm. She will draw aside, praying, ^{cuping} singing, and reading her Bible. This enables her to calm herself, which relaxes the body and reduces the pain:

There was a time when I was afraid of it. There was a time when I was extremely afraid of it, and I would ask for an injection for the pain. But now I am able, by His help, by prayer, by reading the Scriptures and by singing, to reduce that tension...If I get into a stress situation, I try to remove myself from that situation. I will go to my room and start praying and quietening my mind and my spirit. To me, there's a very close correlation between the body, the mind and the spirit. If I am able to control my mind and my spirit, then I'm able, with the help of medication and whatever, to control the pain to a degree. I don't think we can ever take the pain away, but we can control it. It can become a pain that we can put up with.

Transcending the body and assisting it in its pain

Gerda conceptualises herself as being made up of a body, emotions, mind and spirit. Although these dimensions are distinct, she sees them as intimately related and capable of communication with each other. She admits that pain could become too much to bear and that it could overwhelm her. She strives to maintain control by keeping the body subject to the mind and the mind subject to the spirit. Gerda has learnt to use her mind to keep in touch with her body. She has learnt to read its signals and takes responsibility for responding to its needs. She believes that her body will warn her of any threat of impending, unbearable pain. In this way she has been able to reinterpret her body's signs as messages and cooperate with them, for example, by taking medication. She then engages in "self talk" as if to soothe a troubled inner child and to teach it how to cope. This has enabled her to overcome a sense of alienation from the body. The certainty that pain need not be overwhelming is a crucial factor in being able to live with chronic pain:

But I've learnt with this situation to be able to know when my body reaches a certain stage, when if I don't take something now, then in an hour's time I'm going to have so much pain, that I'm not going to be able to cope. So knowing that my body tells me beforehand, I take two painkillers, nothing major, just two Stillpane tablets, and that eases the spasm. It eases the mind, because the mind now tells the body "it's okay". Well, that's how I see it myself, personally.

Minimising the monopoly of pain: Fleeing into the arms of the Father

Gerda indicates that physical pain is only one aspect of her distress. She has learnt to deal with each dimension. She copes with physical pain by minimising it if possible. She had received a nerve block just prior to our discussion, and was delighted that it had reduced her current pain to a level, to what she described as "discomfort."

For Gerda the tyranny of chronic pain lies in its capacity to render one helpless - this is what she fears most. The one time when she was totally unable to control the situation followed a back operation. It is apparent that on this occasion the dominant pain was emotional. This is the one occasion on which she admits to praying "through

tears." She was shocked and utterly humiliated by the experience, in which she had to surrender control of even her most basic body functions to her husband. Despite the fact that she has confronted life-threatening illnesses during which she almost died, it was in this situation of utter helplessness that she felt most alone. Pain is a burden which one bears alone. Support is valued, but ultimately one suffers alone and no one can take your place. It is in this description that she presented a picture of what having faith means; her faith is a relationship. She flung herself into the arms of another, her Heavenly Father, who would not abandon her, One who knows the full extent of what she is going through and who will not turn away:

I think my biggest shock came about with my last back operation in 1998. I was totally helpless, and I had to allow somebody to bath me, to shower me, to wash me. I was unable to wipe myself when sitting on the toilet, because I couldn't reach with my shoulders and with my back. That hits at one's self esteem. It hits at one's ego, and unless one has that relationship with God, you get totally blown over. There were many nights when I didn't have a moment's sleep. Beside my bed I would have my Bible and my Hymn Book. Through my tears I would sing through the night, or read through the night, or pray through the night. But by the end, I was able to cope. I would fall asleep in tears, but I would sleep. So, basically, it comes back to that point where one has to have faith, and again faith is not something that comes from you. It's an experience, a relationship that you can build up. My relationship with God, is much like my relationship with my late father. I thank God every day for a father like him, because he is a gentle man, a person who used to pick me up and put me on his lap. I could relate really anything to him. Now, my God-Father is the same. I'm able to go to Him and talk to Him. No one else will understand, but he will understand. He does comfort and he does strengthen me. I think in one's awareness, where one has gone through situations of lungs collapsing, and not knowing, in total delirium what's going to happen, having a heart attack, where you are unconscious, having a heart operation, which you're not sure you're going to come out of, and having a stroke and not being sure of what's going to happen, one is so aware of the fact that the person is so alone.

Keeping a distance

Gerda views chronic pain as a learning experience. She seeks insight into her physical condition, which in turn enables her to control it. She is able to clearly explain how she deals with the spiritual dimension. Mentally, she is able to rationalise and to think positively. She is far less explicit about emotions. It is apparent that Gerda distances herself from the emotional aspects of pain. Without exception, any direct reference, which she made to feelings, such as desperation, helplessness or torment, was immediately followed by reference to the spiritual realm. Whenever she spoke of feelings, it was either in the third person or in general terms. Any probing in the area of feelings, was met with a subtle distancing, and Gerda would answer either by generalising, or in philosophical, spiritual or metaphorical terms. Gerda explained that she avoids looking inward. She seemed to deal with emotional pain by intellectualising or using her faith to shield herself from painful feelings. Dwelling on emotions would undermine that defence:

One must keep one's eyes outward. To me the most important thing is not to become introspective. The moment I become introspective, I tend to lose hope.

Gerda wanted to enable other sufferers to cope by applying the lessons she has learnt:

This is what I would really like you to stress, that there's no self-edification here. It really is God's grace that enabled me to manage and to cope. I'm sure others could also find that grace.

On her own

Gerda believes that only someone who has had pain can understand the chronic pain sufferer but, even then, no one can fully understand one's experience:

You're totally on your own. Only a person that has gone through pain will really understand, and even then your pain differs, and your understanding differs. I have learnt to say I have empathy, I have an appreciation of (another's pain) ,

but not to say that I totally understand. No one will totally understand what another is experiencing from the point of view that they're not in your situation. They do not have your psyche. They do not have your emotions. They do not have your body. They are totally unable to have a deep comprehensive understanding. To say you have a total understanding is a no, no. It's just not there, because we are all so different.

Gerda emphasises that chronic pain is a private experience, known only to the sufferer. One has to trust oneself, regardless of the expectations and criticisms of others, much as these may hurt. She has found that chronic pain does not make sense and makes one vulnerable to the criticism of others:

I had to learn to accept myself, regardless of what everybody thinks or says. That doesn't mean to say I don't take notice of what they think. You know one can think you are cut off from people and that you don't allow people to affect you by their thoughts and their mannerisms, and by their approach to you, but I don't think there is anyone of us who is able to withstand what others around us say and do. We all think about it.

Gerda revealed that people around one are not able to cope with one's pain. One is unable to control that. Gerda knows that she is getting weaker physically, she knows she is stronger mentally and spiritually, but she is less sure of her emotional strength. However, others may not realise that it is support that is most needed. Gerda believes that others feel helpless, which adds to the patient's burden. The sufferer feels guilty:

Emotionally, I think I am stronger, but physically I'm not as strong. Spiritually I am stronger and I'm stronger in my mind. There are moments when one needs the physical comfort of another human being. There are times when you want someone just to come and hold your hand.

The dilemma of helplessness

Gerda is embedded in a network of supportive relationships. In fact she believes that her chronic pain worries others more than it worries her. Despite the fact that others are so willing to help and support her, Gerda admits:

I think the one thing we all fear, is helplessness. *→ we fear, fear.*

All the same, Gerda revealed that chronic pain forces the sufferer into a position of vulnerability. She has experienced periods of helplessness following surgery and has found that, rather than weakening relationships it has in fact strengthened them, but she admits that dependence on other people does put them under stress. This places the chronic pain sufferer in a dilemma between revealing their experience and hiding it, in which case the openness in the relationship may be impaired, having a detrimental effect. This is the reason why it is important to become vulnerable:

It (depending on others) does add stress to them though. The result is that it does affect one's relationship with them as well, because you're trying not to show always what you feel and what you're experiencing... The thing is you have to come to a point basically, where you are prepared to be vulnerable. And if you're an independent spirit, being a vulnerable spirit isn't easy. Vulnerability is something that, if you want to build a relationship, is absolutely vital, because you can't build a relationship without it.

The need for independence

Gerda points out that chronic pain places contradictory demands on the sufferer. On the one hand, one needs to be vulnerable. Sometimes one has to restrict one's activities and withdraw. There are times when one needs to ask for help. On the other it is vital to retain one's independence. Both independence and dependence enable one to adapt.

Despite her handicap, Gerda has not allowed pain to prevent her from enjoying life. She was obliged to give up work because of her pain, but had anticipated this and had built up hobbies and interests which would enable her to cope. She emphasises the importance of adapting and finding new ways of doing what she wants to do. Most important of all is retaining a sense of personal worth:

Being a fiercely independent person, I think that was part of the driving force, that has taught me to adapt. I had to learn how to cope and do what I wanted to do. I knew I had to work out devices, ways and means of coping and being able to whatever it was that I wanted to do, for example, running a home, enjoying a hobby, enjoying my grandchildren and being able to help others either physically or whatever. Being able to help others has always been very important.

The power of choice

Despite her best efforts Gerda has been unable to remove her pain. However, she has discovered that there is one aspect of control which cannot be wrested from her grasp. She is free to choose how she will respond to her suffering: *humanistic*

I think something I've been made aware of, over the last number of years particularly, is the fact that one has a choice. I can choose to be miserable, or I can choose to be cheerful. I can choose to cope, or I can choose to give up, and I must choose to be satisfied with whatever the situation,

The unanswered question

Gerda recognises that chronic pain has caused her to slow down. Coupled with this she is in a phase of late adulthood, preparing for her final end. She describes herself as sitting in the "departure lounge," waiting for the aeroplane to take her to her final home. She looks upon life and reflects upon her choices, what her life has meant and in particular what pain has meant. The relentless nature of her pain has made her desperate for an explanation. She emphasises the importance of finding meaning and purpose in the pain itself, some reason for its existence that makes endurance

worthwhile. She regards her pain simply as a “training ground for eternity”. Since chronic pain cannot be eliminated she has been forced into a faith position which has been the best coping measure available to her. What kind of faith enables her to cope? She concludes that the implications of faith are this: Faith holds out hope that there is a life hereafter in which there is no more pain and no more heartache, where she will be rewarded for suffering bravely and for not giving up.

Her suffering must have a prize otherwise, it is meaningless. Some part of that prize may be experienced even now, in that she is able to feel pride in coping as well as she does. She can feel satisfaction knowing that she is able to teach others how to deal with pain. Gerda concludes that suffering makes you stronger as a person and as a believer. Pain has brought her to maturity and has increased the qualities of compassion and sensitivity. She has become better in relating to those that she loves and is able to appreciate the smallest blessings. She has been able to find purpose in the pain itself:

But one does get desperate. One does get desperate if one is lying on that bed day in and day out, and the pain never stops. You get to the stage of saying “Why, God, why?” You don’t get an answer, except the answer for me is if one looks at the eagle with its nest high up on the mountain, it kicks its chicks out of the nest. Why? To teach them to fly! But, the moment they start tumbling, the mother flies in underneath and picks them up on her wings, and she carries them back to the nest. Tomorrow she kicks them out again, until their wings are strengthened, and they are able to fly on their own. To me my pain has been that kicking out of the nest to strengthen my faithfulness, my trustfulness, and my ability to cope with my situation.

I think one needs to find a purpose. If one doesn’t find a purpose, or cannot see a purpose in one’s life, then you’re going to get lost. You’re not going to cope. And I don’t see pain as a punishment. Many people do. Many people see it as a result of sin – Oh you’ve done something awful in your life! Or they may see it as some sort of punishment for something you’ve done or your parents have done or whatever. I don’t see it as such.

To me, my life is a learning process, a school, preparing me for eternity. What I do with that learning process is vitally important. If I sit in the classroom and I don't pay attention to what the teacher or lecturer is saying to me, I will not absorb what I need to know. And so my prayer life has taught me to listen to life, listen to God, listen to people, and to listen to my body. The culmination of that has been a coming together of trust, and not looking for the cause of the problem, but the end result.

Molly's story

Molly's back pain started when she was a teenager and was ignored until twenty years later, when a tumour was discovered in the spine. The tumour had obviously been there for some time and had damaged the bone structure, necessitating both a spinal fusion and removal of the tumour. The tumour turned out to be non-malignant.

A cruel stroke of fate

Molly bitterly regrets having the operation to remove the tumour:

I should never have had the first back operation. Tumour or no tumour. If I had known then what I know now, I would never have let them touch my back. I would have rather taken the chance of the tumour being malignant. *regret, self blame*

Molly embarked on a search for relief, trying any possible option. Reluctantly, she went for further surgery which seemed to offer some hope, only to be rejected by the Medical profession, who told her "There is too much damage... there is nothing we can do." The doctor said he did not want to see her again. She felt betrayed and abandoned:

The neurosurgeons and orthopaedic surgeons all sit back and say "this has happened to you, now you've got to learn to live with it." They don't realise that 24 hours in the day is a long time when you've got constant pain.

Molly's recovery did not fit a prescribed pattern. She was particularly upset to find that she was blamed for the failure of the operation, although she had followed all the instructions to the letter. As a result of her poor recovery she was stigmatised and told that "she wasn't putting her all into getting better."

A prisoner of pain

Molly mourns her loss. ^{chronic} **“Pain took a lot away from me.”** She could not find relief and could find no pleasure in activities that used to be so enjoyable. **“The pain got in the way.”** She could not walk or drive well. She was unable to sleep for more than an hour at a time. She became allergic to medication. Her options seemed to diminish rapidly. A particularly bitter blow was dealt to her when the doctors – who had failed to help her – insisted that she should give up her job as a trainer at the bank. Molly loved her job and was not ready to leave. It was more than a job. She enjoyed it and wondered what would happen to her mind if she stopped working. She put up a fight for six months, only to be rendered powerless:

After about six months of the doctors telling me I needed to give up my job, they said to me “look, the pressure you are putting on your back is so bad, we are going to go to your company (to have you boarded). So you either do it with us or we do it!

She was pensioned off against her will. Nevertheless, Molly’s condition has worsened steadily. Her bladder collapsed, and she had to undergo surgery to insert a device like a pacemaker, to restore control. **“and of course through all this, I still have daily pain.”**

Clutching at any straw, Molly went to see a psychologist. The cause of her problem was invisible, so she thought - or rather she desperately hoped - that she was a hypochondriac:

We worked very hard to get me to realise that I had genuine pain. It wasn’t psychological...I thought it would be so much easier if I had a mental problem, because that was something I could work on...But if it was a physical problem, then the doctors were right and there was nothing I could do.

The difference between acute and chronic pain.

Molly slowly realised that her pain had a physical origin and that it would be permanent. She gradually came to terms with the chronic nature of her pain. She described the difference between acute and chronic pain, emphasising that it is the relentless nature of chronic pain that sets it apart from acute pain, making it so hard to endure:

When I was young I started with my kidney problems. I would have a kidney infection. It was acute, it was sore, but I could go to the doctor and get my antibiotics and it would go away. It was totally different. I knew that within three or four days I would be fine again. But I know, sitting here today, that in three or four days I am going to have the pain. It will not go away...

There's nothing more the doctor can do for me except to say to me you must have something for pain, rest up and take it easy. But it is very difficult when you've got to live your whole life like that.

Breaking the chain of unbroken pain

Molly found the realisation that the pain would be permanent frightening, because she was not sure she would be able to cope. She finds it essential to have respite from the pain and may go into hospital for a couple of days on strong medication just so that the chain of pain is not unbroken: *unwilling 2 accept the situation*

Having had that break enables you to cope...when you just see this a long road ahead, that you've got this pain for another 50 years, you think to yourself "I just can't cope." You do panic. That is what is frightening. You think "no! I can't cope" and it becomes too much for you...Your mind is a really strong force. A soon as your mind tells you it's too much for you then you need to get help, because it does bring you down. I believe it makes the pain worse.

The final release

Molly believes that one needs to know that pain will end one day, otherwise it may become overwhelming. Her faith has given her hope that pain will eventually be wiped out. She was very upset about two people within a support group, which she attended who lost hope and committed suicide:

Some people in the group lived for now. They didn't have an idea of eternity, that when this life comes to an end there is another life. The pain became all engulfing because they had nothing left. They had absolutely nothing. All they had to look forward to was daily pain...

It made me realise that although I've got pain now, it's not the end of everything. I've got the pain, but I've just got to persevere and get through this lifetime. I do believe in an afterlife. I do believe in Christ and God and I do believe that my pain will eventually be taken away. So I've got hope. This is where it was frightening, because when I looked at my life, I realised that without God, although I've got my friends and my family around me I didn't actually have hope because I knew my back was actually not going to get better...

She looks forward to that relief so much that she admits:

I have at times, when the pain was really bad, actually prayed that God would take my life.

Molly views her prayer that her life will be taken as an incentive to live fully. She sees it as a challenge to be prepared for that final freedom from her current pain. She feels she cannot pray for her life to be taken, unless her life is ready to be taken. This encourages her to do her best.

The turning point

Molly related that accepting the permanent nature of the pain represented a turning point in being able to cope. She stopped looking for a cure and started to seek ways of dealing with her problem:

At first I just fought it all the time thinking that I wanted it cured. Totally cured. And I came to the realisation that “Molly, no matter what you do, it is done. It cannot be cured. And you’ve now got to look for ways to help yourself deal with it more...

But it is very hard in the beginning when you've got constant pain. You don't actually realise that this is going to go on and on and on. It takes a long while for you to start realising that there isn't an op out there, there isn't a machine out there, there isn't anything out there that can help you.

Molly explains that, in order to cope, she started looking for things she could do to restore her confidence and rediscover her personal worth. She started walking, changed her style of dress, and became involved in the Church. She enjoys arts and crafts and marks papers for a Bible college:

You’ve got to learn to say “yes.” That is number one. The more you say “no,” the deeper you go into yourself.

An ongoing battle

Molly related that coping with chronic pain is an ongoing struggle:

You have to fight it daily. It is not something that you have fought and it’s over with... The day you stop and think “the pain has got the better of me. I am just going to do nothing,” the pain has won. You can never let that happen...It is a hard walk. Every now and again I want to stop, and say, “oh no, I just want to give in” But then I'm right back to square one, and all the hard work that I did to get myself out of it, is lost. That in itself is an impetus to me to realise I cannot

lose. It was a hard battle. I can't have done all of that for nothing. I've got to carry on...

Molly experiences an ongoing battle between her mind and her body. First and foremost the pain is real and it restricts one. Too much activity carries a price – more pain. Total inactivity carries a price as well – a loss of personal pride in one's accomplishments, a loss of self worth. **“You cannot live your life just not doing anything. That's not living.”** Her body no longer works with her will:

I think this is what makes pain so difficult – there's absolutely nothing wrong with your brain. Your brain is still active, your brain still wants to do things, your brain still wants your body to do things. But your body, because of the pain, just cannot work with your brain. And it is very frustrating. Very, very frustrating. You've actually got a little war going on inside you. Sometimes I will push myself then I know I have gone too far I actually get mad at the pain and I think “you won't stop me doing what I want to do.” And unfortunately, the pain is very real...

Molly acknowledges that there are times when she does have to give in to the pain, when she has overstressed the back and then the only thing that helps is total bed rest. Contrary to current opinion, she finds bed rest beneficial. **“I know the medical profession have said that the bed rest doesn't work, but the bed rest does work for me. It really does. But that is when I've pushed myself too far.”**

The impact of pain on relationships

Although Molly is single, she has strong support from friends. She has learnt to distinguish between friends who don't really want to hear about her pain, and those that truly care. She knows who will be willing to help and has built up a circle of solid friends. Molly acknowledges that it is difficult to admit that she cannot cope by asking someone to do something for her. She had to *learn* to ask for help, which is difficult because **“one is scared of rejection.”** Even if you do ask for help **“you feel you are a nuisance.”** However, she has learnt from experience that there *are* friends

around her who are in fact only too willing to help. Nevertheless, she tries by all means to hide her pain whenever possible:

If somebody asks me how I am, I will never say “I’m in pain to day” Never...I just feel I am a weakened person if I admit to the pain all the time.”

Molly feels that chronic pain has destroyed her confidence in social interactions: **“I must be a pain to be around.”** Social gatherings, which were once a source of pleasure, have become a source of stress. At a party, Molly says she may be fine for an hour or so, but then she may need to lie down or go home. During outings, Molly will cry in private at times. She desperately needs understanding and acceptance and yet **“you don’t want to dampen the day.”**

Molly feels that she cannot blame others who do not understand what she is going through and she believes that admitting to pain constantly is socially unacceptable:

I get the feeling that people must think, “oh, here she goes again. She is in pain again. She is never not in pain!”... I feel that is not acceptable. I think they must get tired of it. Even my family, I think surely they must get absolutely sick and tired of hearing me saying “I’ve got pain, my back hurts.” As a result when my back really is sore I try to hide it.

Opening new doors

Molly finds it therapeutic to help others who are having a difficult time with their health or with bereavement. She has endured her pain and is unafraid of dealing with suffering:

The pain has actually given me an assurance that I can understand people because I have been through it. I have travelled that road. And that road has opened up doors to me.

Molly related that the real struggle in coping with chronic pain has been in discovering how to lead a valued life in spite of pain. She has allowed the experience

to enrich her as a person, increasing the qualities of sensitivity, compassion and openness. She is able to appreciate what she has. Molly has been able to come to terms with pain to the extent that she sees it as having created new opportunities. She compares her life before and after the onset of chronic pain and shows how she has been able to find purpose in the new way of life imposed upon her. She concludes:

I can do things now that I wouldn't have been able to do when I was working because of time constraints. It has created different opportunities. Before I would not have had the same empathy with somebody with pain as I have now. I have learned, as I have said, that I can go and visit people who are sick, and it doesn't bother me. Before, it would have got to me. Work took up my time and I was not able to do a lot of things. So my life has changed. It's like two different lives in a lifetime. It is like the life before pain and the life after pain. They are very different. Very different. But I can say now that I am content with life, and the things I am able to do now. At first I was not. I really battled. I battled tremendously. But as I got more into it, and more involved, I realised that it was just as rewarding, as what I was doing before, if not more so. I can do something else now. It does not mean that everything was taken away from me.

My life is different, but I'm still useful. - coping, adapting, finding meaning

CATEGORIES DISCLOSING THE CHARACTERISTICS OF CHRONIC PAIN

The ongoing nature of chronic pain gives it a quality that is particularly difficult to endure.

Pain is a noxious stimulus. Chronic pain is a noxious stimulus which is there for the rest of one's lifetime. One must either cope or escape. The realisation that chronic pain will not resolve forces sufferers to regard death as the only release from pain. Patients are able to understand why some commit suicide, viewing their peers who choose this option with trepidation, knowing that for some, chronic pain is so intolerable and inescapable, that this option makes sense. Controlling the level of pain which has to be endured is critical in enabling sufferers to cope.

The person with chronic pain does not realise initially that the pain is permanent. Expectations are such that the pain "should get better". In addition, the sufferer is often confronted with a problem that no visible signs can be found to validate one's complaint. The difficulties encountered in proving the reality of one's pain makes one vulnerable to judgement by others. This may lead to the sufferer being labelled "mad or bad", creating a fear that one has an even worse problem, namely a problem "in the mind."

Pain takes over your life

The person with chronic pain feels powerless and victimized. Chronic pain seems to take on a life and character of its own. The affected body seems "separate" from the person and may be personified. The body no longer obeys spontaneously and has to be placed under conscious control. The painful body dominates the person's life. It seems to imprison one and too much effort to escape may be severely punished. One is forced to function within pain's constraints.

Chronic pain causes interpersonal difficulties

Not only is the sufferer vulnerable to judgement by health professionals, but also by significant others. Chronic pain does not make sense to relatives and friends

who believe it “should” be curable. However, precisely because the pain does not resolve, sufferers have a need for ongoing social support. Chronic pain sufferers are sensitive about divulging their experience, being aware of the limits of others’ compassion. They feel guilty about being a burden and are reluctant to request help. This creates a dilemma in social relationships between genuine openness and fear of rejection. Sufferers feel it is socially unacceptable to complain “all the time”. However, one cannot relate to others free of pain. This causes a shift in social roles where sufferers have to find a balance between the restrictions imposed by pain, and the demands of everyday life. One has to learn to be vulnerable, and learn to receive, and still enjoy life, in spite of pain.

When support is forthcoming from doctors, family or friends, the social world may be viewed as a sanctuary, as in Gerda’s or Molly’s case. When support is lacking, the social world may be regarded as threatening, causing the sufferer to retreat further and further from it despite a desperate need to be understood, as in the case of Joyce.

One is alone

Although chronic pain has social consequences, it is an experience in which one is profoundly alone. No one can take one’s place and sufferers realise that no one else knows what you are going through. People with chronic pain may find solace in religion. For Gerda, faith is the answer to the problem. She sees God as one who is able to share her experience, one who can look at the full extent of what she is going through without having to turn His face away. She can turn to Him at any time. In that, she finds comfort.

Chronic pain creates a bleak future

The course of chronic pain is uncertain and one’s current experience of pain, especially worsening pain, provokes a profound fear of the future. Sufferers fear being overwhelmed by pain. There is a pervasive fear of being incapacitated and dependent on others. This fear seems to be mediated by the willingness of others to provide support. Most of all, sufferers fear being abandoned and losing their personal worth.

These fears are so terrifying that sufferers prefer not to look at the future. It is too much to bear all at once. Efforts are made to live one day at a time, focusing on the good things one has now. Sufferers report a greater appreciation of what they have.

It is vital to retain hope, because losing hope may lead to one being overwhelmed by pain and even to suicide.

Coping with chronic pain

The person with chronic pain is forced into a corner where one either has to escape from a life of pain, or one has to cope. Accepting that chronic pain is permanent is the first step in learning to cope. Prior to this, sufferers engage in a search for relief and cure, which eludes them. Sufferers who find practitioners who are willing to support and advise them maintain a positive attitude towards the medical profession. Failure to do so results in the patient turning away from the profession to a greater or lesser extent, expressing anger at its failure to support and assist them.

The realisation that chronic pain is permanent forces the patient to re-evaluate the course of life. Sufferers look at the past as the way they should be or wish to be, mourning their loss. Their former activities and abilities are viewed as indicators of what has been lost. One is forced to redefine one's goals, accommodating the changes imposed by pain. Sufferers are forced to learn a whole new way of life, in which pain is the master. The outcome depends on the coping strategies adopted.

Hobbies and interests provide an invaluable respite from pain. It is essential to have something to look forward to.

Sufferers work out ways of decreasing the level of pain, including sensible use of medication or therapy. Sufferers highlight the importance of attitude and of the mind in dealing with pain. Sufferers may make effective use of "self-talk" to control pain. Another alternative is to distance oneself from pain. Joyce achieves this by using humour. Gerda is able to turn to her spiritual life.

Finding meaning in suffering

Sufferers ~~find~~ find themselves engaged in a struggle to find meaning in their pain. In the absence of any medical explanation, they are forced to find value in the pain itself, seeking an explanation that transcends the physical realm. They need to find purpose in the new way of life it imposes. The distress of chronic pain is mediated by one's ability to find personal meaning in the situation. Sufferers are able to cope when such meaning can be found. Chronic pain may be viewed as a stimulus for personal or spiritual growth. People with chronic pain may experience satisfaction in their ability to cope. Importantly, chronic pain is viewed as increasing the qualities of compassion, sensitivity, and wisdom. Sufferers feel they are better equipped to assist others. They want to help others to deal with pain. They seem less intimidated by suffering. The heart of the struggle seems to lie in the sufferer's ability to find personal worth and fulfilment in life in spite of the presence of pain.

EXTENDED DESCRIPTION

Chronic pain is an ongoing noxious physical stimulus, which by its chronic nature imposes a form of distress which extends beyond the physical pain itself. Sufferers feel alienated from the body which no longer functions as it used to and this is experienced as loss. The person feels isolated and trapped within the painful body and is forced to function within its constraints. This imposes changes in social, occupational and family roles, since the sufferer is unable to interact free of pain. *difficulties of interaction*

The relentless nature of the problem generates an ongoing need for support, yet the sufferer is isolated in a private experience which makes no sense to outsiders, placing the person in a dilemma between revealing one's distress and the fear of rejection or stigmatization. These contradictory demands for support and discretion are experienced as stressful. The course of chronic pain is unpredictable and does not allow closure. The persistent nature of the pain, coupled with variations in intensity, provoke a profound fear of the future, especially the fear that one will become dependent on others and thereby suffer a loss of personal worth. Sufferers face the threat that ultimately they will be overwhelmed by pain and unable to cope.

Sufferers are forced into a situation where it is imperative to gain a measure of control over the pain, or find some means of escape. Anxiety is reduced if the person is able to control the intensity of the pain or find some means of distancing oneself from it. The distress of chronic pain is mediated by the sufferer's ability to find a personal meaning in the experience itself, in the ability to re-interpret its impact so as to be able to live a valued life in spite of the presence of pain.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

The value of phenomenology in health psychology

The primary focus of this research was to provide a description of the experience of chronic pain from the position of sufferers themselves. The study confirms that this perspective has been poorly understood. Using the phenomenological approach it was possible to access the “insiders perspective” of living with chronic pain and to focus on the underlying processes involved in coping in a way which complements existing studies. This research highlights the value of phenomenology in health psychology. Chronic pain is experienced as a disruption of the lived body which impacts the life-world of the person. Phenomenology permits access to the lived experience of the phenomenon. People think about their bodies and assign meaning to their experiences, particularly in the absence of plausible medical explanations for their condition (Smith, 1996). Current literature has been criticised for neglecting the lived body in the search for meanings related to chronic pain (Osborn & Smith, 1998). Phenomenology provides a means by which discrepancies in the understanding of illness between individuals can be revealed. Toombs (1992) suggests that there is a tendency towards miscommunication between patients and medical practitioners, because illness is experienced by the patient in its immediacy as a disruption of the lived body, but that the understanding of physicians is an abstraction, focusing on the disease processes. She emphasises these realities are distinct and that this is frequently a source of misunderstanding between patients and their doctors. Phenomenological studies such as this one, provide a basis on which the source of such confusion can be clarified.

Chronic pain is more than a series of nerve impulses. Persistent pain is more than a physical stimulus. The way in which chronic pain is experienced is determined by the person’s specific context and the meaning which is given to the pain. The qualitative method used in this investigation permitted access to this dimension, in a way which would not have been possible, using quantitative methods, deepening our knowledge. Phenomenology discloses how this experience impacts the individual person’s unique life, goals and relationships. The themes which emerged in this study

reveal the struggles that patients live through in their pain careers. The investigation showed that people with chronic pain strive to understand the nature of chronic pain, to assign meaning to their experience and to acquire coping strategies. The study highlighted the multidimensional nature of chronic pain, which implies that a team approach to its management is required. It also reveals the implications for various role players involved with the sufferer.

Implications for the medical profession

Medical doctors

Participants' accounts emphasise the inadequate and often punitive nature of the application of a purely biomedical model to chronic pain. This model is unable to supply either an explanation or cure and sufferers are frequently stigmatized as a result. This implies that many medical practitioners need to be equipped to offer support and counselling to patients. Focusing on the credibility of the patient's complaint strengthens the therapeutic alliance, but failure to do so prompts frustration and anger, deepening the patient's distress. When doctors were able to support and listen to participants, this provided a valued form of therapy in itself.

Chronic pain can become unbearable, yet patients are reluctant to use medication. There is a prominent fear of addiction. The literature indicates that this is rare, since patients who take analgesics purely for pain relief have been shown not to develop the rapid physical tolerance that is often a sign of addiction. Indeed, unnecessary pain has been described as a "tragedy" (Melzack, 1990). It seems that more can be done by doctors in terms of educating patients about the correct and safe use of medication and alternative therapies. It is important to note that the intensity of pain seems to have a profound impact on the person's perception of their ability to cope and therefore it is imperative to assist the patient to reduce the level of pain that must be endured.

The authority invested in the medical profession as well as the confidence held in diagnostic tests in terms of compensation, treatment, disability payouts and litigation seems to warrant further careful investigation. Participants expressed distress when their pain was initially denied, based on diagnostic tests, only to be confirmed later, when it was too late to reverse legal decisions regarding their

condition. One participant has endured persistent, iatrogenic hip pain as a result of failure to be heard. Such decisions may have long term implications for the patient, which influences the effect of chronic pain on their life. The negative experiences of these participants lends support for further research into the development of more humane and effective approaches to the management of people with chronic low back pain

Physiotherapists

Physiotherapists are often doubtful as to whether it is ethical to continue to treat patients who do not recover for long periods. Treatment outcomes are frequently assessed by methods such as clinical judgement, return to work and test results. However, there has been a change in emphasis recently and the trend is towards taking the patient's perception of what is helpful into account when evaluating treatment outcomes. One of the major objectives of medical care is to improve the patient's quality of life (Eales, Stewart & Noakes, 2000). Participants in this study emphasised that the provision of relief, even for brief periods is beneficial and enhances coping. Therefore, the answer as to whether patients with long term low back pain should continue to receive pain-relieving treatment is an unequivocal "yes".

Participants emphasise that they have learnt to cope and could teach others. They indicate that education with regard to the factors and mechanisms which exacerbate pain is valuable in learning to adjust one's lifestyle. Physiotherapists are well equipped to provide such explanations. Discussion groups or back schools could be put to good use to achieve this purpose.

Occupational therapists

This study highlights the value of a combination of active coping and accommodative coping. Participants did not give up but learnt to find a balance between the constraints imposed by pain and the need to engage in meaningful activities so as to retain a sense of worth. This suggests that occupational therapists could play an important role in assisting sufferers to establish suitable, enjoyable hobbies and interests. This is particularly important because participants indicate that they are able to gain control over the pain by escaping into their interests or distancing themselves

from pain. Psychologists and occupational therapists would be able to assist patients to discover individual means by which this may be achieved.

Psychologists and counsellors

Chronic pain isolates sufferers from those around them. Participants often preferred to retreat from social situations rather than risk rejection or spoiling social interactions. They felt vulnerable to criticism. This poses the threat that the person may be cut off from sources of support. The chronic nature of this type of pain generates a need for ongoing support. More needs to be done in terms of educating close others about the nature of chronic pain and the need for empathetic understanding on an ongoing basis. Families need to be assisted to deal with the fact that chronic pain imposes changes in one's ability to fulfill social roles as expected and it seems that family counselling may facilitate such understanding.

Counsellors could assist patients through the psychological processes involved in coming to terms with chronic pain. This research has highlighted certain salient themes on which counselling could be based. Participants stated that they face a pervasive fear of the future despite the fact that their condition is not life threatening. They compared the past with the present, mourning their loss. Chronic pain does not go away and one is forced to cope. Accepting the incurable nature of the condition seems to represent a turning point in the person's ability to cope. In this study participants were able to deal with their pain by adapting their lifestyle, finding support and seeking a purpose in the experience itself. Sufferers may be assisted through this process if the themes arising from this study are addressed. The distress of chronic pain is mediated by the person's ability to make some sense of their experience. Participants in this study sought spiritual explanations for their condition. Should the person respond in this way, pastoral rather than psychological counselling may be indicated.

Strengths of the present study

One of the strengths of the study was that participants were no longer seeking a cure for their pain. They had learnt various means of coping. Since participants had accepted their condition and were focusing on coping, they were able to provide

valuable insights into the *specific* coping strategies adopted. Previous research has been criticised for collapsing coping strategies into categories, which means that specific coping measures cannot be identified (Haythornwaite et al., 1998). Participants revealed that both active and passive coping strategies are needed, confirming previous research that flexibility in the use of coping measures is valuable (Large & Strong, 1997). Participants explained how they had redefined their goals in order to accommodate the changes imposed by pain, without giving up, emphasising the value of accommodative coping (Schmitz et al., 1996). It has been suggested that there is a gap between the expectations of health professionals and sufferers themselves with respect to coping with intractable pain (Large & Strong, 1997). Health professionals tend to favour active, offensive coping strategies. This research provides a basis on which such misunderstandings can be overcome, putting the claim that active coping strategies are superior to accommodative processes in perspective.

Limitations of the present study

The participants and the researcher shared a cultural context, therefore the results may not be applicable to persons from a different culture. However, the aim of the research was not to produce statistically generalizable results.

The study was limited to participants with chronic low back pain. It is not clear whether these findings are applicable to people with other forms of chronic pain, such as pain associated with terminal illness or intermittent pain.

Only women participated in the study. It is uncertain whether their experience differs from that of men or children.

Recommendations for further research

Further studies could be undertaken to overcome the limitations of the current study, as indicated above. Furthermore, it seems that the impact of chronic pain on other family members, especially the children warrants further investigation (Roy, 1992).

Catchlove (1987) suggests that heightened bodily awareness may exacerbate chronic pain. Participants in this investigation indicate that somatic awareness

facilitates effective management of the pain. Such contradictory findings suggest that further research is warranted

Participants in this study indicated that chronic pain has stimulated psychological and spiritual growth. They have attained greater inner strength, insight and wisdom. The human qualities of compassion and sensitivity have deepened. They have been able to achieve enhanced connectedness with other sufferers. They have matured. This ability to find purpose in unavoidable suffering needs to be explored further. How can this process be facilitated?

Participants emphasise the importance of hope in coping with chronic pain. Where can such hope be found when faced with an incurable condition? The qualitative method employed in this research reveals the individuality and particularity of a person's coping responses. The experience of chronic pain may be translated into a spiritual struggle and the meaning thereof may be sought in the spiritual aspect of man which requires further investigation by methods which give access to this dimension. This theme, emerging from the current research, echoes the question raised in Shantall's (1996) study of suffering:

Do we need to further broaden the horizons of psychology as a science by an inclusion of the spiritual aspects of human nature and behaviour? Man's conscience; his moral consciousness and choices; his struggle and victories of faith in situations of unavoidable suffering, are aspects that seem to need inclusion in our consideration of what constitutes psychological maturity on the highest levels of personality functioning and growth.

We know man as a product of his environment; as a creature of need; as a social being. Do we, however, know the strengths and beauty of the human spirit? (p. 350)

Closing reflections on this study

Health professionals are faced with complex issues when serving patients with chronic pain. Talking to people with chronic pain about what their pain means to them seems to be invaluable in enabling them to accept their condition and to transcend it. Pain can reorganise one's life and change priorities and perspectives. Enabling

sufferers to allow chronic pain to have a positive impact seems to be a humbling experience, vital need and an extraordinary challenge.

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APPENDIX

TRANSCRIPT OF INTERVIEW WITH JOYCE

Researcher: Joyce, what I would like you to do for me is to describe in as much detail as you can your experience of chronic pain.

Joyce: Well when I had my back operation, I came around wishing for death. Because it was unbelievable. They come and turn you in the bed and they wouldn't warn you, they just turn you. And you would scream like an animal. The pain would be so bad. Then they got me to walk, and the pain was - it burnt, it was sore,- every move, every cough, if I'd just turned my head it was sore- it was too terrible. More or less stayed on the bed for a year. I would get up in the morning and I would cook, because I had to cook for my family, I would do the cooking- very slowly, and found I'd drop a lot of things. So I wouldn't pick up anything. I would kick it all to the middle of the floor, then my maid would come in, and she would pick it up you know every four hours or so. And since then I have heard that people walk around with braai tongs. Then I would go and lie down, and I would lie, and lie and eventually I decided what I would do. I would stretch in, in my mind into my spine and switch the pain off. So I would lie in bed, take a deep breath, breathe out, put my hand mentally into my spine, and switch off the switch. Then I would go to sleep. For about two hours I would sleep in the afternoon, and have no pain. And that got me through the year. Then I found somebody, and I spoke to them, and they were also going through severe pain, and they told me "it will last three years." Then when I knew that, it was easier to cope with the pain, because I knew, three years, it will be fine. Three years came, four years came, five years came, and it eased. But in between that I have had all the neck operations. And the neck operations have just about killed me. Choking, unable to swallow, can't turn my head, have not been able to drive the car, if I go out I can get in and out of the car maybe twice. The third time it is impossible. I am tired. I have just had it. If I'd go to the East Rand Mall, I can only walk half way. Half way - toilets. Half way - toilets. And then I am totally out of breath and I have to get back to the car as quickly as possible.

Researcher: Does the pain affect your bladder?

Joyce: Yes, it affects the bladder. The walking you know, if I walk up and down. Then pain affects the bladder. So, it's depressing. It is very depressing, specially this year, I have had my fourth neck operation. I had it in February. And for a while I felt great. But now all of a sudden am on anti-inflammatories, and it is all back again. The low back, the hips, my knees, I can't lift my right arm, I am in bad pain.

Researcher: Do you have constant back and neck pain?

Joyce: Constant back pain. But if I move my legs, then my legs hurt.

Researcher: By chronic pain, I mean long term pain.

Joyce: Long term pain. Long term. My spine - still to this day I have worked out how to turn over in bed. I have got a special way of turning. I sort of jerk over. Because turning in bed is just about impossible. I cannot sleep on my right side at all. My whole neck goes into spasm. So that I can't do. But you learn to - it is like not having an arm. You learn to live with the one arm and not with the other. You learn to do certain things with the right leg, but not with the left leg. You learn to turn, completely instead of turning your head. You learn not to look down, because you can't. And so to adjust your body. You adjust yourself and your way of thinking and everything to your situation. You have to. Otherwise you just make your life an absolute misery.

I drop a lot of things still but I go down, I have found a way to pick it up sideways, pick it up, come up slowly, and I ache like mad, and I find if I shout when I do it, it eases the pain. You are not concentrating on the pain you are concentrating on a "whaa" you know as you go down to pick it up. You learn a whole new way of life.

Researcher: Tell me more about that.

Joyce: You do you do. You get up in the morning, swinging your legs around, put your legs off the bed, then you sit up, then you wait. You can't just get up, because if you do you will be sore. It's like that cage that I have got in my back, it has to settle before I can stand up. And in and out of the car, I automatically get in, I pick my legs

up, with my hands, swinging them in, and put them down, to take the strain off the back. Carry things - I don't. I don't carry things. I have got a little grandchild now, a little baby, I don't hold him, I can't. I can't hold him and walk. So I don't. I have not looked after him. I had to apologise to my daughter today because I have never asked to look after him. I can't .

Researcher: How does that feel Joyce?

Joyce: It upsets me. It really does. Because Sarah's children, you know, my other daughter, she's got three boys, and we have brought them up because her husband left her when the babies were eight months and we have done everything for her and now I am unable to do it for Carol. And she has had to go through to Jo'burg and leave her children, if she needs help, I feel guilty. I felt unhappy, and just this morning I said to her "I am so sorry I have not done for you what I did for Sarah". I can't complain to them, they think I am normal.

Researcher: Who?

Joyce: The children.

Researcher: Your children?

Joyce: Yes. If you say "I am sick" they quickly change the subject. It is as if they don't want to accept the fact that I am getting old or that something might happen, that I am not going to be there anymore. I know I was like that with my Mom. So I don't, complain to them I have got a husband who doesn't like, complaining, so I don't, complain to him. So you can get a bit depressed. Beryl, my physio, is the only one I complain to and she has got broad shoulders, she is sweet, she is super with me. You need somebody to talk to. It is terrible.

Researcher: So who else can you talk to? Only the physio?

Joyce: Only Beryl (the physiotherapist).

Researcher: So Joyce, have you found that having chronic pain like this has affected your relationships?

Joyce: Oh yes. My sister-in-law is always asking us to go and spend the weekend, with her because she hikes. I don't want to keep on saying "I can't" so I find an excuse not to go with them, and now she thinks I don't want to be with them. And if we do join her for the morning she (says) "let's go hiking!" And she cannot understand that I can't. She thinks I'm being funny. She has never had an operation, she has never suffered pain, she does not understand.

Alan takes me out for suppers. I can't swallow since my last neck op so I can't swallow meat, I can't swallow salads, so I hardly eat my food, he gets upset, because I am not eating, so it affects - it is little things, that all build up together, that - it is easier, in fact I have done this since February, I lock myself up in the house and I never go out. In fact today is the first day that I have driven my car.

Researcher: So listening to what you have just said, it sounds to me as though the big part of your experience of chronic pain is that you feel very misunderstood.

Joyce: Yes, and you don't want to complain about it.

Researcher: You don't want to complain and so people can't understand either.

Joyce: No, they don't understand. Not at all. Even my grandsons you know they will rush up to me and hug me around the neck and "watch out. Be careful" and they say "why are you so grumpy?" No I am not grumpy, I am sore. "You are always sore"

Researcher: And that doesn't seem normal to them?

Joyce: No, to them that is not right. And in fact when they come here I am normally lying down. What I do is I get my studies together, type it all out, in a summary form, then I lie here and I study. But now I have got a problem because I cannot lift my right arm. So I put a pillow on my tummy and I put my arms on the pillow, and I look up, because if I look down I get a headache so I had to get myself on the bed, so I can look up. I also have a special stand in the office upstairs that I put the book on so I can

sit and learn straight. Then I don't have to put my head down. Your whole life changes.

And shopping is - I want to go shopping, I go to the East Rand Mall, I park my car, I get out of the car and I think "oh, I have to walk to that entrance. It is so far. I will never make it." Then I walk and I'd get to the entrance, and I think "now, I will have my hair done, and I think "okay now I feel better" I have been sitting for a while, and what do I do? Straight to the toilet, and straight home. Walk into Woolworths or Pick And Pay? It is just impossible. I would not even attempt it. We went to the show two weeks ago. The outdoor show. I walked around there with Alan. I had to go to the toilet. Walked a little bit further, had to go to the toilet. By this time now, he was upset, because I am always at the toilet. Anyway, we eventually got near the car, it was now, from 10 o'clock until one. Three hours walking around and when we got out of the place, my legs went lame. I could not put my one leg in front of the other. And I said to him "Alan, my legs have gone lame, I cannot walk!" And he thought I was joking. And he hooked me in and he actually dragged me to the car. I got in the car and I had a good cry, without him seeing, and we came home and I have been sore since then. And that was three weeks ago. Beryl could not even touch me this morning. It is all in the hip now. She said to me "go to the doctor." I do not want to go to the doctor. Because they will send me for another operation.

Researcher: Do you think so?

Joyce: Well, I did not think this guy was going to operate. In February. I went to see him, and I told him about my arm, and then they sent me for tests to see what is going on, and this Indian lady said to me "push down" and she said "push" I said "I am pushing" she said to me "no, you are not." I said "I am" and I was pushing. It is nothing - my arms are like lame you know that this worries me. I know how I am now, what am I going to be like in ten years time? It is so scary. And what has been happening is that I wake up at about 3 o'clock in the morning in a panic, panicking about what is going to happen to me in ten years time.

Researcher: The anxiety.

Joyce: I wake up and I think and I break out in perspiration I am sopping wet. And I do not want to take tranquillisers.

This whole day, the whole weekend, I take a painkiller and I put it on the table and I think "I am so sore I'd am going to take it now." But then I am scared, these things are addictive, then in an hour's time I think "it is not too bad, I will wait another hour." And you are busy watching that painkiller the whole day. And I am so proud of myself when I can go 24 hours, and not take a painkiller, it is so terrible. Your whole life is centred around pain, painkillers, anxiety, depression, trying not to appear weak to others, so I am always smiling, you know, laughing,...

Grant came to see me the day after the operation. I had make up on and I was sitting straight up in bed. I said "Hallo Grant, how are you?" And I was joking and laughing and when he left I sank back into the bed, and I was finished. But he thinks I am fantastic. But I'd just don't want people to see me lying, half dying. People don't, what's the word, people don't click with someone who is always complaining.

Researcher: So do you feel that you become rejected if you complain?

Joyce: I think so. You know my mom complained continuously. And eventually it went over our heads. Not knowing that she had cancer. But she always thought she was dying. For about 20 years. So eventually it got to the stage where "oh Mom's complaining again!" I don't ever want that to happen to me. Not at all. I am independent. I try not to let people hold my arms. I fall regularly. I am for ever falling. Because I am busy. I have had two bad falls in the bedroom.

Researcher: And Joyce, the anxiety, what do you think has brought it on? This anxiety about the future, you say you wake up and you actually panic...

Joyce: Yes. I think I am a very independent person and I have always done everything for myself. And I do not like relying on other people. And I am scared that I am going to be bedridden, or in a wheelchair, that I am going to have to rely on somebody to do things for me. I think it will kill me. Really.

Researcher: What makes you think that that could happen?

Joyce: The pain. Because at night when I get into bed, and I lie in the bed, I lie ten minutes, I want to cross my legs, and I can't lift my legs. They feel totally lame.

And then I go to the kitchen, try and carry my puppies with me, kiss and love them and I can't carry them. My right arm won't do it. Then I have to put them down. I think "oh God is it going to get worse?" It is fear of the future. It is terrible. Or "will I become a drug addict?" Will I have to take these tablets more and more until eventually I will end up in a drug rehab to get off the tablets you know. And when you go to the doctor the first thing that they do is give you tranquillisers. I have been addicted to tranquillisers, before for three years.

Researcher: Because of the anxiety?

Joyce: No, this was something else. My daughter worked for us, and she had a baby. She used to bring the baby to work every day. And Alan cannot handle noise. And this kid screamed non stop and I could not take it. I went to the doctor in a panic-stricken state, and he gave me the tablets, and this was 12 years ago, and it took me a long time to get off them.

Researcher: How did you get off them?

Joyce: I used to take one at seven in the morning, one at lunchtime and one at night. So what I did, instead of seven o'clock, I would take one at eight o'clock, one at lunchtime and one at night for a week. Then nine o'clock, one at lunchtime and one at night then ten o'clock, one at lunchtime and one at night until eventually I combined the two. And that took three months. But I tell you I thought I was going to have a heart attack, you know I would get dizzy, I had fainting spells, but I got through it. I have never taken another one again. Now the doctor has given me some more. I don't want to take it. And of course the anti-inflammatory eats your stomach. I get sores in the stomach and the mouth and that is depressing because if you cannot eat, you have got all the sores, your mouth - the one thing leads to another.

And you are constantly thinking of yourself all the time. That is why I study. When things get too much, I go upstairs, get out my books, and I'd start learning. And it is so wonderful. Then for about two hours I forget myself. And it is wonderful. You don't have to think of yourself. So I'm sure I could control it in the mind. If I sit still.

Researcher: What are you studying?

Joyce: Theology. (Pause)

Researcher: Joyce, you were saying that you focus on yourself. Is that because of pain? And so you have found that one way of coping you used to find something that is very distracting.

Joyce: What I do, I make 26 sandwiches every morning. For my grandchildren. They are big boys. And then I make for my son as well, so in the morning I cook for everybody, the supper is cooked already, I make all the sandwiches, I keep myself very very busy. Then after I have done all of that, I go and I learn. I learn until Alan gets home. He does not like me learning, he likes 100 percent attention. Then I see to his lunch, we fetch the boys, the boys come here, it is their homework and everything, so I only manage to study perhaps two hours a day.

Researcher: But it is focused study.

Joyce: Focused study. And the bookwork for the company, I do all the bookwork, for two or three days a month, I just sit doing bookwork. I suffer when I get up. Because my head is sore. And with bookwork you are writing. So your head is down, and when you come up, boy, that headache is unbelievable. Then I take a painkiller. I can handle anything except a headache. I like my mind sharp. The tablets make you dizzy. You can't think, and you slur, - it is a very powerful painkiller that I've got. So that is a problem.

Researcher: Joyce, you are saying that you like your mind to be clear. Tell me more about that.

Joyce: Pain makes you sorry for yourself, which is a bad thing. You get depressed, which is bad. So you are totally self-centred when you are in pain. So you have got to get your mind off yourself, and onto something else. But when you take a painkiller, you cannot control it. You take that painkiller, and you cannot concentrate, you can't

have a conversation with people properly, I find my mouth is slurring, and they look at me you know. Do you know how often people have thought I have been drunk? I have fallen so many times at the shopping centres, and nobody helps you. You can't believe it. In fact I saw a woman the other day. She said " I saw you last week. I saw you in the car park." That was the only time I had been away and so I said "did you see me fall?" "Oh" she said and she went red. I said to her "if I drank, surely I would not be drunk at nine o'clock in the morning! And secondly I have never touched alcohol in my life! I don't even know what champagne tastes like." She went red again. People will not help you. I have crawled across the East Rand Mall to get to a window to try to help myself up. People walked past and looked at me. You lose confidence. You find you are concentrating on walking because you are as so scared that you are going to fall. So when you walk, you are watching your feet, one foot in front of the other, and I can walk right past people I know, and I am so busy trying not to fall. You also find you walk against a window, you don't walk up and down stairs, at the mall you walk down those slanty things so that you have got something to grab. Your whole life changes.

Researcher: And it sounds as if you have got to think about everything you do.

Joyce: Everything. You have to concentrate on everything.

Researcher: Things that we would take for granted.

Joyce: Yes. Yes. You are aware of everything.

Researcher: What is that like Joyce?

Joyce: It is tiring. It is tiring. You come home so depressed. But I am not a depressed person. No I'm not. And when it hits me I fight it

Researcher: How do you fight it?

Joyce: I fight it by going and doing something constructive. Or studying. Or I talk to my daughter. I try not to be a nuisance though. Perhaps three minutes, phone her, talk

to her, how are you doing, she works, so I don't want to be a nuisance, but I feel better after I have spoken to her. Even if I don't, complain, or tell her what has been happening, she doesn't know.

Researcher: Really Joyce?

Joyce: No, they don't know. I mean even bathing. You know Alan had to bath me for months. And he still helps me with my shoes, my boots. I can't get boots on. And the kids always ask me, "what are you going to do when you are old?" And I say to them "I am going to move into a retirement village." "What do you want to do that for?" I say "well, if something happens to Daddy, I have got somebody who can help me." "Help you with what?" "Get dressed" and then they say "what is she talking about?" They do not realise that Alan helps me now. There are a lot of things he has to do for me.

Researcher: Does that affect your relationship with him in any way?

Joyce: It did. It did. Alan was brought up to "have no sympathy for anybody. Pain is putting it on, it is a big act to draw attention. Give a woman your little finger and she will take your arm" and he was as hard as nails. So when I was building up to these ops, I used to lie down without him seeing. He could not handle me lying down. I was not allowed to lie down. And now, since the back op, he is slowly coming around and in fact after this last operation now or I should say since the last two operations he has been wonderful, really.

Researcher: So it has actually brought you closer?

Joyce: It has brought us closer. Very much closer. And in fact this weekend is the first time I had said to him "I don't mean to complain. But please understand I'd can't do this, I can't swallow meat," you know because they had cut through my throat three times and look at these scars.

Researcher: Oh Joyce! How many is that? Three scars?

Joyce: Four times. (Researcher: What is this?) It has fallen in. (Researcher: I see that. Is that the vertebra?). Beryl cannot touch it. But now from my right shoulder, all this, feel it, it is in total spasm. And this muscle keeps on swelling, and as I say it is just very depressing. So going to the doctor I don't know.

Researcher: What is depressing Joyce?

Joyce: I might have to have another operation? I will never get better. I will be an invalid.

Researcher: So it is that fear of not getting better and that you could get worse. Is that what makes you feel depressed?

Joyce: Yes.

Researcher: By depressed, what do you mean?

Joyce: Perhaps lonely, people don't like to come - I have got a friend, a very good friend, we have been friends since 1970, but during that year when I was on that bed she never visited me once. I think people are scared of illness. I don't know what they are scared of but they are scared of it and they don't want to come and see it. Maybe they don't know what to say. It is like you go to somebody and they say "I have got cancer" so what happens? Nobody mentioned cancer. Ever again. You know because "You've got cancer" and she just never mentions you know "how is your back?" Or your neck or they just don't talk about it.

Researcher: You feel lonely and you feel very isolated in that pain.

Joyce: Yes. I find that if I am going to be in bed, constantly, and unable to do anything, people are going to just switch off from me and just push off. But I like to please people. I am always looking after my kids and buying them little gifts, and cooking for them and make a cake and you know come and enjoy yourself I like spoiling them, and giving them things, I don't like getting presents. I always say "don't

buy me presents!" But when birthdays come I am always there to get them presents. I love it, I love it. So maybe I am scared of rejection.

Researcher: So by depression and you mean lonely?

Joyce: Yes.

Researcher: And it sounds as though you mean anxious?

Joyce: Oh yes. That is part of being depressed, very much so. Very much so. (Researcher: I understand that.) And also the pain, I am scared that pain is going to get worse. It seems to. It really does. It has got worse.

Researcher: Has it got worse? More intense? Or more widespread?

Joyce: More intense and more widespread. Even Beryl said to me today that she can't believe it. My whole lower back has now gone into spasm and if she touches it I break out in perspiration. Eventually I said to her "just leave it" she said "you had better go to the doctor" and I said "no. Just leave it". I have had enough. Because if they operate on my lower back again I would rather commit suicide. (Researcher: Really Joyce? Is that how you feel?) Yes. You know, there were two men who were done with me, both had - I had eight discs, five are in a cage at the moment and the other three are above. So from the bottom right up they are eight discs. Five are in that metal cage. The other men in the hospital each had one disc fused. Both men committed suicide. Yes. When I went back to the hospital the sisters said to me that both were dead. The one man had had an accident, and he had the back op, and was screaming with the pain. And both of them committed suicide.

Researcher: Do you often feel suicidal Joyce?

Joyce: Do you know, funny you should talk like that. Never, I never did. Because that to me is totally against my grain. Until six months ago. And now - do you know Alan is depressed - he suffers from severe depression. And I can spend up to two hours a day talking him out of committing suicide. He is on a new tablet to calm him down,

and stop the depression but it gets so bad, he even asked me if I would commit suicide with him in Cape Town. (Researcher: Oh Joyce?) He asks me regularly.

Researcher: And you have always felt fine, despite the pain, until six months ago?

Joyce: Yes.

Researcher: What changed then?

Joyce: This continual - you know this shoulder operation that I had to have? (Researcher: This last neck op?) No this was last year. (Researcher: I am not up to date with all the ops.) they cut part of my shoulder away. (Researcher: The actual shoulder, not the neck?) No not the neck. I have been cut right down look at the shoulder do you see where my strap is? (Researcher: Now that you pointed out.) My strap is here. (Researcher: I see that.) Anything that I wear falls down.

Researcher: So then what happened? That made you so desperate?

After that I thought now I am fine. Everything is fine. We kept on operating on the neck, we thought it was the neck, causing the problem, now they have done the shoulder, because my hand was pins and needles, couldn't lift my arm, I thought at last the problem is solved. I was out of hospital two months when it all started again. I could not turn my head, I had headaches, severe pain, right down the back of my spine, and I thought "no, it has started again." And that is when I started thinking "maybe I should end it." And then I thought "stop it! That is nonsense!" And when I went to see this doctor he has took all the screws and plates out of my neck.

(Researcher: have you gone to a different doctor now?) Yes. Dr.B. took nylon cording and he has threaded it right down, now this other doctor that I went to, he trains neurologists. So he knows what he is talking about, and he said to me, he didn't say there was the mistake, he said to me "you have got the pain in your arm," and I said "yes" and he said "I know what the problem is, I can fix that." So I went in and he took all the screws and plates out, again they went into the hip. Four times they have gone into my hips, fused it altogether, and when I came around, he said "pain has gone out of the arm!" And I said "yes" and he said to me "I have found the problem!"

And then the anaesthetist came and said "you had the pain in your arm didn't you?" And I said "yes" and she said "I bet you it's gone" because she had been there, and I said "it is gone" and she said "I thought so!" And now, two months ago, my arm started again and I can't lift my arm.

Researcher: So Joyce, was it that disappointment again? You were set up where you thought you were fine, and then it came back and that is what broke your heart, that you thought you were over it, and it came back and you probably just thought well? What was the point?

Joyce: Yes. You wake up thinking you are going to be fine, you are going to be 100 percent, you know I was a tap dancer. I was a dancer I used to dance on stages and in competitions and I was very good. This was when I was small, and now I am like a jolly invalid.

Researcher: So it is that disappointment?

Joyce: Yes. And when Beryl mentioned the doctor this morning I nearly had fit. I really won't go back. And that makes me more depressed because it would be better if I went to the doctor and he operated again, or would I be better leaving it alone and just becoming an invalid? Will I become an invalid?

Researcher: So it is this uncertainty that is very unsettling?

Joyce: Yes, it is terrible. It is disappointment after disappointment.

Researcher: And I suppose after having that shoulder operation for example, you must have been unsure whether it was worth it or whether it would have happened anyway?

Joyce: Yes, people said to me "you are mad!" Having had all these neck operations you know, "what are you worrying about the shoulder for?" And I actually lifted it and it burnt. But it burnt so bad that I actually cried my heart out and I must have torn something. Then my arm was completely - I never moved it. Then I couldn't do my hair or anything. So I came out of hospital, and Cathy got married, for the second time

a week after, so here I am sitting at the wedding, and I had to get somebody to come and do my hair, I couldn't do my hair. And none of the kids realised that I couldn't do my hair. And I don't want to complain to them. I really don't.

Researcher: It is almost as if you are living in a contradiction, where you need them to understand and you can't say anything.

Joyce: And I can't say anything. Yes. Most confusing. Most upsetting. I actually am very unhappy. That they don't know because I put on this huge act. "Oh come inside sit down how are you? How about tea!" Nobody ever helps me. I make the tea, put biscuits on a plate, or cut the cake, carry this massive tray, and everybody sits, chats, nobody knows and they won't know because I don't want them to know. And yet I am crying out for them to just (laughs)

Researcher: Joyce, when you say you don't want them to know, is that

Joyce: I would like them to know I think.

Researcher: Is that real or would you really like them to know?

Joyce: I think so. But I know they won't understand.

Researcher: Can you explain to me?

Joyce: I would like them to know because I would like them to come to me and say "how's things?" But they never do.

Researcher: You would like more support?

Joyce: Yes. I think so. (Cries.)

Researcher: Are you okay?

Joyce: You see I never open up. Beryl sees this quite a bit.

Researcher: Would you like a tissue?

Joyce: I have got one I went and fetched it just in case.

Researcher: That is very hard.

Joyce: I cry a lot but when nobody is around. Then Alan comes back "what is wrong with your eyes?" "I stuck my fingers in my eyes"

Researcher: Does the crying help Joyce?

Joyce: Actually yes. It does. That is when you realise that you really feel sorry for yourself. A good old cry and then you are okay again.

And what is worse is that it has gone into my fingers. It is in my fingers, in my wrist, in my elbows, so I know it is moving around. It is in my knees, my knees are on fire at night. And my knees are completely distorted you know and they are growing weirdly. You know that they have lumps on them. I go to my aunt and she has had her knee cap removed. And I looked at her and I think "oh, I hope that is not lying ahead. What is lying ahead?"

Researcher: So a lot of this is fear of the future?

Joyce: Terrible. It is not that I have not had other operations. That is what scares me.

Researcher: How many operations have you had now Joyce?

Joyce: I tried to think about it the other day. I think of between 22 and 24.

Researcher: In total? Not all on your back?

Joyce: No. Only one on my back. Four on my neck. One on my shoulder. The rest were all lumps and other things.

It is a bleak future. When you sit and feel sorry for yourself. It is a hell of a bleak future. But then I sit and I think "I have got to pass!" That is why I have been so depressed because I thought I have failed now, and if I have failed it means that it is that subject to study again, plus another three and writing an exam you know this a problem. To write the exam, I can't put my head down and leave it like that. So I have to lean on my hand. So I have to write leaning on my hand, and writing. And that is the only way I can get through the exam.

Researcher: I am sure you could request an oral. Now I am off the subject, but I'm sure they would let you to an oral exam.

Joyce: I don't know, but I find it is easier for me to go back and rub out and so on. I write in pencil always.

Researcher: I know I am off the subject, but do you know what you can use, you can use one of those bag trays. You get a tray with a bag. If you shake all the filling, you can then make a slope on the desk so that your book is raised the way that you do when you read and that will help you. Then that least you are not looking there, you are looking there.

Joyce: This is my problem. I mean it is a little desk you know.

Researcher: Why don't you try one of those bag trays?

Joyce: Will they allow me to take it in?

Researcher: I think they will if you explain. They need to just have one look at those scars and then I'm sure they will.

Joyce: Yes I was sitting here the other day and looking at the scars and thinking "I can't believe it!"

Researcher: It does not look bad Joyce, it is just that you pointed it out to me there at the back here..

Joyce: That back one is terrible.

Researcher: But this when you don't even really see it is in the crease. But you have pointed it out.

Joyce: Even your way of dressing changes. Instead of wearing low backs, I can't. Because if I stand in a queue, you hear the people talking behind you and you can watch them in the glass, you know in the mirror, and you see them (points) you know? And I, I... God made me perfect, and I still want to be perfect. As perfect as possible. So your way of dressing changes. You buy high collars, even my hairstyle has changed. I have let it grow so they cannot see the cuts. You cannot believe it! Even scarves, I have got a whole lot of scarves. If it is a little bit low at the back I put a scarf on, and I wear scarves. Even in church, you hear the people talking behind you, if your dress is a bit low. If you sit down and it pulls down then you hear whispering behind you and you know that they are talking about your neck, because it looks ugly, very ugly. It is scary because you see all these bones sticking out, these are the actual bones.

Researcher: It doesn't look ugly, Joyce. You see it that way.

Joyce: People look and oh they say "oh my God, look at her neck! Freak!"

This is why I want to pass. Then I will feel I have accomplished just something for me.

Researcher: That is important Joyce:

Joyce: Oh yes! Going off the subject, my mom and Dad were divorced. I finished matric when I was 16. I had to go out and work. My brother went to university. I had to pay for him to go to university. So all these years I have envied him being able to study. And I feel I must do it now before it is too late. (Researcher: I quite agree with you.) And the pain killers make me dull and I cannot learn with them so I am trying to stay off the pain killers until exams are over.

Researcher: So this studying is a very important part of coping with the pain?

Joyce: Yes!

Researcher: And giving you a sense of accomplishment.

Joyce: Yes.

Researcher: Because you have spoken quite a bit about the fact that it is important for you to be independent. What is it like having to depend on Alan and others for support?

Joyce: It has not been nice. No not at all. Because you hear them sigh, and then you think "oh dear, I am getting on their nerves." Sometimes he wants to watch TV, and he has to help me, and then he gets a bit rough. "Come on now, hurry up!" And if you say "oh, oh, oh," he says "stop complaining!" This is how it was with the back op, it was terrible. In fact I actually washed myself every second day so I did not have to ask him anything. So it sounds terrible, but I never washed my feet for a year! And then I bought a bath brush, which I didn't know you could get and I sit and I clean my feet with the bath brush. So that I am able to do. But bathing has changed. And I know it sounds terrible, but even going to the toilet has changed. Because you can't wipe from the back, so you have two wipe from the front. You can't sit in the bath flat, because of the screws in the bottom of your spine, so you sit sideways. In church I can't lean back, so Alan has to put his arm behind me, and I sit forward.

Researcher: So when asking for help, what worries you about it?

Joyce: That I am going to irritate someone.

Researcher: That you are going to irritate them?

Joyce: Yes and that I'm going to irritate them and they are going to get cross with me. I don't like to be moaned at, or fought with, or something like that. And it hurts. I am always trying to do the right thing. All my life I have done that. And I like people to

want me for who I am. Not for what I need from them. And that is difficult. Because I find now, that when Alan walks with me, he has to hold me and put his arm around me. Or tuck his arm in and hold me. Now he has taken to saying "Kom ou vrou"(come old woman) whew that gets me! I know I am old but I don't want to be called old!

Researcher: How do you feel when he says that?

Joyce: Resentful! Very resentful! In fact I have never thought of myself as old, even with the ops. Until we bought this house. And my son-in-law said " what do you want to buy a house like this for? You are old? You don't need a house like this.

Researcher: Oh "because you are old."

Joyce: And I said to him "it did not occur to me, I thought it was going to be small, compact and easy to handle. The fact that all these expensive houses have gone up has got nothing to do with me. And now I have started to think of myself as old and that is even more depressing. You know my hair goes grey and I think "shall I do it?" Shall I colour it? And Alan says to me I like women with white hair. So I am in between trying to think about this. Why get old before your time? But being obsessed with this pain all the time makes you old. And nobody has gone more grey than me since February. My hair has just gone white. And it is panic. See here, you can't believe it! You will see it, if I go in the sun you will see it. It is just plain unhappiness because it has all started again. I just find I cannot go back to this doctor again. I felt so good when I walked out of his office. I thought maybe they put morphine in your spine. There is a tablet that they put in your spine that dissolves slowly, for pain. And I wondered if he didn't do that, that I felt so good. It wasn't a few weeks and I could feel I was going down. And there is a muscle in my back that is alive. Moves up and down.

Researcher: And Joyce, that feeling that you want to be loved for who you are, can you elaborate on that?

Joyce: I like people to like me. I have realised that you cannot please all the people all the time. They are going to be some people who hate me. I had a hang of a life with my mother-in-law. She hated me, until the day she died. The day she died I still took her hand and said "I am with you mom" and she pulled away. That hurt. And maybe that has got something to do with it. I just like people to like me. I want them to come and visit me, and be here, but if they come here and you are complaining, there is enough sadness in the world. People do not want to go and associate with pain and suffering. They want to go somewhere where they can relax, enjoy themselves, lose their worries, and just sit and have a good evening. So you don't want to sit and say "oh I am sore!" Or "oh I can't stand up!" I want to be accepted as someone who is healthy, normal, someone where they can come and enjoy an evening.

Researcher: Joyce, with your way of dealing with the pain, with your way of getting involved with other things, how did that start?

Joyce: Actually, it was amazing. I think the Lord did that. Because before the operation, I'd enrolled at university. So I'd enrolled for one reason, and continued for another.

Researcher: Why did you enrol?

Joyce: Because at last, I realised - we had stopped working, I wasn't working any more. My back was giving me a lot of trouble. So I was not well. (End of tape) I'd enrolled in November, got my books and started studying in December. I was enjoying it thoroughly. March, I had the operation. I came out of hospital, and I looked at this book lying on the bed, and I thought "how on earth am I going to learn?" Painkiller after painkiller. I thought "no, I have got to pass!" I am the type of person, if I started something, I have got to finish it. And I warned Alan, I said "Alan, if I enrol, I will finish it!" And he said to me "no, I understand". Now he is complaining "you are always studying!" But I started learning because it is something I wanted to do. But it turned into "if I learn I forget my pain". So I was learning for an hour a day, lying on the bed, learning, learning, I wrote the exam and passed. Just passed. But that gave me the confidence to go on next year. The next year I did a second subject, which was two subjects, and then I did that for the year and I passed,

and I thought "you can do it." Still lying on the bed, third year, - third year was disastrous! I never did maths at school. I had to go for extra lessons. So I went at night for extra lessons, on how to do maths, and I went right into it and even though I was in absolute agony, I passed! Half was theory half was maths and I got 51 percent! So I passed. So the whole reason for studying changed. (Researcher: And it became?) It became so important to me I would get up in the morning and I would say "what am I going to do today?" I am going to do this and this, and then I am going to learn. I look forward to it. It is something to look forward to and I would work towards it, and that gave me something to live for. Each day I took one step at the time.

Researcher: You say that each day you took one step at a time. Was that with the studying or with the coping of the pain?

Joyce: Everything. You have to. You can't - when you are in constant pain and severe pain like that, you cannot think of tomorrow or the next day. It is too far away. And it is impossible for you to even think that you are going to get there. I think it is similar to alcoholism. You have to live one day at the time. And that is what I have found. Live to day, think of to day, and, like when my mom died, I thought I was going to die. And tonight is... (a tv show). And I would look forward the whole day to watching the TV show. And that got me through the day. And because of that, I did it with this operation as well. I would think "11 o'clock to 1 pm, I am going to study. It is exciting! Keeping my brain alive. My mother-in-law died with Alzheimer's disease and I did not want that. So I thought if I keep my brain alive, and have something to look forward to - and I mean studying is super! I love it! And so I would get up in the morning, and think "oh, I can't wait for 11 o'clock!" And I would live for 11 o'clock. Do all the things I had to do, and I would do everything. I put make-up on every day, washed my hair every day, put it in curlers, look good, I have never walked around without make up. So I have looked good, felt good, dressed properly, never ever stayed in my pyjamas, got dressed as painful as it was, Alan would put the corset on me before he went to work and I would get dressed and I would walk like that the whole day, looking forward to study time! Alan thought I was mad. But hell, what else did I have? And he says to me now "stop studying! What are you studying for?" I have to have something to look forward to.

Because I do not visit people, I do not go to church or ladies meetings. I don't like it. I don't enjoy it. I am a loner. So studying - that it is all right.

Researcher: Joyce, you mentioned that when you started studying you had just stopped working. Was that the result of pain? Did the pain interfere with your occupation? (Joyce: Yes) Can you tell me about that?

Joyce: I just could not sit any more. Because you know I typed (Researcher: What did you do?) I was a typesetter. I would work from 7 in the morning until 2 the next morning. Every night. This is our business. Since 1971. It got easier then became twelve o'clock - as we got more staff and then we would work until 10 o'clock and it was more or less 10 o'clock for the 20 odd years. (Researcher: So you worked for 20 years?) Yes. (Researcher: And then your pain?). It was unbelievable.

Researcher: Did you have pain right through that time?

Joyce: Yes. If I sat too long. I had constant tablets that sort of thing just to keep me going. I had to go into hospital. I had a bladder op, my bladder dropped. They took the stitches out, from the op, I would go straight to work! From hospital! Then I would go back a few days later to have the stitches out - this is what happened - I went back to work, and we were working and at twelve o'clock that night, I said to Alan "I am burning so terrible!" I went to the toilet, I am not lying, and I looked down and my stomach had opened! I could see right inside my stomach. I shook with fear! I went to the doctor if the next morning and they took black stuff and they poured it in. And he said to me "no way can we stitch this now. It had been open for too long. And that is how my stomach healed. I had it repaired a few years ago, where they cut me from hip to hip. They took all the extra skin and everything off. I always say I have an important stomach because it is underlined. And even then the guy said to me "you cannot go home because you need a nurse to look after you". And I said "I have got a nurse! My friend is a full-time sister". Fine. I came home and went straight back to work! And that is how I have been. I have had all these operations and I have gone back. I have not been worried about myself. I have just disregarded it and carried on.

Researcher: Has that been a good thing?

Joyce: Perhaps not. At the moment it is getting to the stage where I cannot do it any more. And this is also making me unhappy. I cannot switch off any more. It is too much. The pain does not go away. It stays there. Before I could actually wipe it out, and four hours later it would be back. But now I cannot wipe it out any more. It is there constantly. Constantly.

Researcher: So you had your back op and that took you out of work. Is that what happened? How did that affect you? Seeing that your work was so important to you beforehand?

Joyce: It was very important. Look, I was relieved, because it was a lot of work. The responsibility was too much, because if I did not work we would not earn any money. So I would work from nine in the morning, until towards the end, nine at night. I would have people phoning me at nine o'clock at night, and sending faxes through. They wanted the work the next morning. And I felt it was getting too much for me, - too much.

Researcher: But the work was too much? Not the pain? It was actually the pressure?

Joyce: No the pressure. Plus that pain, that nagging horrible pain, and then what started happening, I started falling. I would fall and I would have no feeling in my leg. And then I said to Alan "something is not right." I think he started to panic. And then he started to change his job. What he does now, he is a print broker. So he goes to SABC or to wherever, he gets the work from them, but he gets somebody else to do the setting for him, he gets somebody else to do the printing for him and he delivers the whole job. So that is what he has started to do. Eventually I became redundant. Which hurt. I was in a split situation. I did not want to work anymore but I was hurt because I was redundant. And husband lets you know if you are redundant. I was sitting around I had nothing to do so I thought "well, let me learn." And that is how I went into learning. Still not knowing I was going for a back operation. I only knew four months later.

Researcher: So actually stopping work was more because of the pressure than because of the back?

Joyce: The pressure yes, but - No I don't think so, because my legs were collapsing.

Researcher: Oh because of the legs that were collapsing it actually had a big impact?

Joyce: Yes it had a lot to do with it.

Researcher: But it sounds as if you could not have gone back?

Joyce: No. I cannot sit anymore.

Researcher: How did you cope with that?

Joyce: I was in so much pain for that year that it did not worry me.

Researcher: You didn't think about work in other words?

Joyce: I thought about nothing. That is the worst thing you can ever wish to have. That pain. You can't believe it. You lie, but you do not want to move. You are uncomfortable that you just think "tough" and you will lie like that until eventually you have got to move. Then you grit your teeth and you say "come on, you can do it!" And then you go for it. And you just about die. But I find if you take a deep breath, breathe out, then do it, you can do it. All the injections I've had, the stitches taken out, I have concentrated on breathing and I find it is easier to cope with the pain. So with stitches and injections and things that had to be done I have coped by breathing properly.

Researcher: Do you find that most of what you have had to do to adjust, you have had to teach yourself?

Joyce: Yes. There is no help. No help at all.

Researcher: And what is that like, Joyce?

Joyce: Trial and error. Actually you feel pretty good when you find you can do something by doing something. That is another reason why I carried on with this, because my idea was, I could go to people in hospital, tell them about my experience, - not tell them what to do - but tell them how I coped, that maybe they could try it, and it would make it easier for them.

Researcher: So did you find some sort of reason, or some way you could turn to your pain around into something useful?

Joyce: Yes! Something positive! Because you know, you think to yourself "why did God do this to me?" And then you think, there must have been a reason.

Researcher: Did you find a reason Joyce?

Joyce: Not yet. Because I am battling to get through this.

Researcher: But you think you might go and help other people?

Joyce: Maybe He wants to use me somewhere else. I am waiting to see.

I had a near death experience once and that has helped me a lot. And I have spoken to people about it and they sit back and they say "really"? This was after my twins birth the stomach muscle had split. And all the skin was hanging and they had to bind me up and tie me up. I went in and I had the operation, I came out, and my heart stopped. Fortunately the lady next to me heard me stop breathing. She pressed the button and they came running. I tried to tell the doctor that my head was sore, that was the pain that I am scared of. I just said "head" and I remember him shouting "lift the bottom of the bed!" And they lifted the bottom of the bed but I was gone. And I was in this beautiful passage. At the end of the passage was this white light. But it consumed everything. It was all over. It was such a beautiful feeling. Complete peace. Happiness. Tranquillity. Love. And I wanted to get to this light. I was just walking towards it in absolute happiness, no pain, nothing. And I turned back - why I turned back, I do not know! And there was Alan, standing with the three children. By this

time they were about three years old. Because they were babies still. And I looked and I thought "Alan will never cope!" I will have to go back!" And I was awake. And with all the pain that I am going through, that I look forward to! Eventually one day.

Researcher: That light, and that peace and that experience.

Joyce: Yes. That experience. Not going through the death. That was very bad. That was unbelievable.

Researcher: What is the impact of that on the pain that you have got now?

Joyce: Nothing. I do not put death and this pain together at all. Death to me is far away in the future.

Researcher: But dealing with, we were just saying that you have found a way of kind of turning the pain around, and you are saying that you felt that there was a purpose, and then you mentioned the near death experience, is that a separate kind of concept?

Joyce: No that is separate. And I do not think that you will control that final pain. If your heart stops, the blood stops going to your head, and you can't tell people, and I know that the headache that you get is unbelievable. That is bad. But I do not associate this with that.

Researcher: What I find very interesting is the fact that you have brought your studying and the fact that you feel you can help other people together.

Joyce: Well with the near death experience, I have told a lot of people about it, and they sit and smile. And it gives them something to look forward to. Thankfully, because everybody is scared of death. I was. As a little girl I used to picture them putting me in the coffin, digging the hole and I would lie awake at night thinking about it. It used to worry me. But that does not worry me any more. All that worries me is that I am not going to be able to help myself.

Researcher: That loss of independence?

Joyce: In the hospital, when the staff used to wash me, they were so rough! It worries me. You can't believe how they treated me, as if I was an absolute burden on them. And that hurt me. Terrible! You cannot believe it!

Researcher: The feeling of being a burden?

Joyce: A burden - terrible! That was in hospital and that wasn't once, that was a couple of times. They were really nasty to me. And that I do not like! I do not like to think about it and that is what makes me so scared!

Researcher: That you will be a burden elsewhere?

Joyce: That I will be a burden and they are going to treat me like that! You know in old age homes, in frail care, you have heard of these people smacking the old people. Do you know it is frightful? Absolutely dreadful! This last time now when I came around, I had tubes in my neck, oxygen, tubes in the arm, they tied my legs to something, I don't know what but it was wonderful it was like a massaging machine. It was a weird thing. Moving up and down my legs. And then I called for the bed pan. And I said "excuse me?" You know there are always people in the ward. Do you know there is no visiting hour? So I would say "excuse me, may I have the bed pan," the smile on my face, you know, if you don't mind? And she said "what?" "Could I have the bed pan?" Then I was cross! As they throw it at you! And I think "I want to get up and hit her! So when I was allowed to get up, I got up! I got up and I walked. Not once did I ever ask for another thing again! I hate asking for things! I hate that rejection

Researcher: That independence is very important to you.

Joyce: Very important!

Researcher: And rejection is what worries you the most.

Joyce: Oh. Bad. Even the sister you know I am on anti-anxiety tablets actually it is a tablet that stops my heart pounding. The adrenalin gland is over active. I think it is from all the stress over the years. It is not a tranquilliser it is a heart blocker. And I said to them in hospital "could you give me my heart blocker?" And she said "you do not need it. It lowers your blood pressure. And I got more anxious. And I could not swallow. And that fear that something was going to stick in my throat! And I moved up, moved up and eventually I was sitting straight up in bed! I was sipping a little bit of water and then they came to me and I said "please, can I have that heart blocker?" And she said "no, it lowers your blood pressure! I am not going to give it to you." So for 24 hours I sat up straight. And eventually I lost it. I said to her "if you do not give it to me, I am going to run out of the hospital, and I am going to go crazy! Give it to me!" And then I thought "you sound like a drug addict" then I said to Alan "bring me one from the house." And he brought one from the house to the hospital, and I swallowed it and within 15 minutes I lay back. I had not slept yet. I had sat up the whole night.

Researcher: So Joyce, it sounds as though people were not taking your experience seriously.

Joyce: No, no maybe because I am always smiling and being nice. I should try and be nasty about it do you know the woman next to me, she yelled and shouted, she even hit the sister! She had six sisters around her! I am not lying. They were around her and they were constantly pampering her! And then she was not half as sore as I was. They would come in to me "how are you?" "Fine. I want to go home". Lipstick. Make up

Researcher: Joyce, it is there anything else you can think about your experience of pain?

Joyce: Well when I went in to have that test, you know, they stick needles into your muscles. And then they measure it on the machine. And she kept on saying "I am sorry" and I looked at her and thought "but you are not sorry, you do not look sorry!" And she kept on. Then she would pull it out and move it, and eventually I said to her "you are not sorry!" And she said "I am!" And I said "you are not! You do not look sorry and you keep on doing that!" I flustered her! But sometimes you have got to

talk. But it is just one terrible thing to live with. I just wish somebody could come and take it away! But they are not going to take it away. I have realised lately that this is a permanent thing. And I do not know what to do about it.

Researcher: Joyce, I really understand you saying that you want someone to take it away, but having realised that this is a permanent thing, how does that affect you?

Joyce: It is depressing.

Researcher: It is depressing? It doesn't help you cope? It makes it worse?

Joyce: No. I am sorry I am realising it. Before I realised it there was always hope. That hope is slowly fading. That is what kills you. Because all along you think "now I am going to be fine!" Now I am going to be hundred percent. At every operation and every opportunity. And every operation the pain comes back. Now it is getting worse. That hope is just going.

Researcher: And your pain is getting worse?

Joyce: Yes. Do you know, that the thought of living with pain for another 20 years is not a good thing. It is scary. It is very very scary. Look, you do have your odd moments when that pain fades a bit. And you do something thinking, forgetting. And then you hurt yourself and you are right back where you started again. Like the kids will run away, and before you think, you run after them. And you think "what are you doing?" And you stop and your neck starts throbbing, and you think "oh no!" And it is not that I wish I was young again, I don't. I did not have a good childhood, I had a very bad childhood. And I do not ever want to be young again. I have been happy as I am now. But...

Researcher: You have been happy as you are now - in spite of the pain?

Joyce: Yes, in spite of the pain.

Researcher: Joyce, how did the pain start?

Joyce: Actually, being a dancer, I have had pain since I was a little girl. I would go on the stage, I would dance. I was under terrible stress because I was expected to win, I would come off, and I would lie on the bed and my mum would massage my back. I practised two hours every day. And I would have to be massaged. That is a lot for a child. I would play hockey, I would come home, I would have to be massaged. But I was always head of that first team - win - you know - I have always set myself terribly high goals. I am slowly finding that I cannot get there anymore. And I have to leave it to the young people to do.

Researcher: Did it just get progressively worse?

Joyce: Yes. I was 16 and I was standing on the stage in the Springs Town Hall. It is not a town hall anymore. It is next to the station. Ready to go on for the final championships and my right leg gave in.

Researcher: Is that so Joyce at that age? What did they say it was?

Joyce: I did not go to the doctor. And I could not get my leg to go. And I remember running around "please Lord!" Because you to know, tap dancing, you need both legs. And I started praying and I said "please God, if you let me win and get this leg going, not win, come first, but just win to get on to the stage, I promise you I will stop dancing," because then I got scared. And I went on. You had to do three dances. The one was very modern, it was exercises, the second one was a dance with a story, and the third one was pure straight tap dancing. And I had done the first two and this one I had to get through. And I won. And I was true and I never danced again. When I was 40 I went back.

Researcher: How old are you now?

Joyce: I will be 58.

Researcher: Never! I thought you were my age.

Joyce: No. Well there you see, people think I'm young.

Researcher: You look a lot younger, you really do.

Joyce: But the pain is now taking its toll. Man. You want to be young. You look in the mirror and you want to see a younger face. You know you are going to get wrinkles, because you will look horrible if you are 70 and you haven't got any wrinkles! But, you do not want to look haggard. The other morning I let out a scream and Alan said "what is the matter?" And I said "who is that? Oh it is me!" When I was 40 I went back and I went right through my dancing teacher's exams. And when I was going to do the final, I had passed all my exams, my mum used to play for me, and she died. So I never did the final exam.

Researcher: So when did your actual chronic pain start? How long have you had it now?

Joyce: Chronic since just before the op.

Researcher: Which was when?

Joyce: When I was 51.

Researcher: So you have lived like this now for?

Joyce: Seven years.

Researcher: That is a long time. So you had back problems, but not problems so severe that it became this ongoing thing?

Joyce: Yes. Yes.

Researcher: So it started before the back op or after?

Joyce: After.

Researcher: So the back op did not really help?

Joyce: Do you know, after five years it was fine. I could have lived a proper life, a normal life,

Researcher: Oh so you took about five years to recover. That was when you had that long fusion.

Joyce: Yes.

Researcher: Why did they do such a long fusion?

Joyce: The whole back was disintegrating.

Researcher: The bones? the discs?

Joyce: The bones.

Researcher: And they don't know why?

Joyce: He just said osteoarthritis.

Researcher: Arthritis?

Joyce: Arthritis yes. Then about six months afterwards I started choking at night. And the neck had actually collapsed. The whole neck had collapsed in like that.

Researcher: I can see that here.

Joyce: That is still fixed. You should have seen it before. It was completely hollow like that. The whole neck caved in, and the fear after the op. I took a capsule, and it stuck. I thought I was going to die. Why are we so scared of death? I was beside

myself. I lay in the bed with a bottle of soda water, sipping it trying to dissolve this tablet, because it would not go down.

Researcher: Joyce you were saying?

Joyce: Can a traumatic childhood cause acid to be produced, that could, perhaps, go in to your blood stream, and damage your bones, because surely some chemical is released when you are nervous, because that causes pain in the pit of your stomach, if it can cause an ulcer, why can't it damage your bones?

Researcher: Do you think that is part of your experience?

Joyce: Yes I think so. Definitely. I mean I have spent most of my life being nervous. Scared. Unhappy, upset and pain in the stomach.

Researcher: Did something specific happen Joyce?

Joyce: I had an alcoholic father. And he used to beat my mom too terrible. He abused me, but not fully, sexually. But, he went as far as he could go. And you could not sleep at night because you never knew when he was going to come in your room. And there were nights that he tried to kill my mom. So I remember at the age of ten, sitting up all night checking him out when it was my turn to stay awake. We would take it in turns to stay awake at night.

Researcher: You and your sister?

Joyce: No I never had a sister. My mom and I. The one night she would stay awake, and I would sleep, and then I would stay awake and she would sleep. But the night I had to stay awake it was exam time. I was only 10. And I fell asleep. And he chose that night to try and kill her. And I was just saying the other day, I have just thrown the scissors away that he pushed into her throat. I have kept those scissors all my life. And I am sure that a childhood like that can definitely cause problems in later life.

Researcher: On a physical level as well.

Joyce: On a physical level as well. Oh yes. I mean if you get ulcers from that sort of thing surely, that is acid. So the acid must go somewhere else. So who knows? And they maintain that it causes cancer. Stress. So. It is just a theory of mine.

Researcher: It makes sense though.

Joyce: It is not easy. And of course when I got married - my mom in law - that wonderful lady you cannot believe what she did to us. She used to chase us. Hit us, rip my husband's skin off his arm. That was all stress. She would come and visit us every two weeks. She would check my house to see if it was clean. I had tiny babies. Twins. She would pitch there every second Sunday and check my house to see if it was clean. She would look under the toilets, and all over. She would expect a roast, with salads, and a cake for tea. And then I was a good daughter-in-law. To a certain point. That was all stress. Then it was all those years of working. You had to get this - you had to get a book out. If you did not the client would phone you and start screaming at you on the phone. As a result I never answered the phone. So it leaves you with all this terrible stress. And I am convinced that it has something to do with it. I wish that I could actually find out. Take your blood all the time and check through your stressful life. I am sure they would find acid charging around in your bones. Battery acid. It could happen.

Researcher: And I am sure that it raises your muscle tension.

Joyce: Yes. Your neck is always permanently stiff. It has got to have some thing to do with it.

Researcher: Thank you Joyce:

Second interview with Joyce

Researcher: Joyce you know where we were the first time when I came to see you, the last time we were together, you were talking about your studying, and you said to me you were looking for the Lord's will, and you thought maybe He wanted to use you in some way. Then you told me about a near-death experience. You said "I had a near-

death experience once, that has helped me a lot,” and I think the way I asked the question, I think you thought maybe that I thought your chronic pain was connected with dying.

Joyce: Oh, Okay, no.

Researcher: But, what I wanted to know was how did you relate your near-death experience with chronic pain? Was there a connection, or was it something I just misunderstood?

Joyce: I think it was separate.

Researcher: Was that a separate topic?

Joyce: Yes it was separate. I was scared. The pain that I suffered just before my heart stopped was something that terrified me, and that actually is a big thing in my life, because I'm scared I'm going to go through that again when I die. That bugs me. The actual near-death experience itself when my heart stopped has given me hope for after death.

Researcher: Okay, so that has given you hope after death. What I wanted to know was that feeling of that near-death experience, and that hope that you had – did that have anything to do with the pain that you have got now?

Joyce: No.

Researcher: Okay. That's fine Joyce, because I didn't quite understand (laughter)

Joyce: I was just so scared of that final pain.

Researcher: I just wasn't sure of whether that near-death experience was somehow connected with your coping with pain.

Joyce: No. (laughter)

Researcher: I wasn't sure, when I read the transcript, that's actually what I wanted to know. I thought now "Have I asked the question badly or was there no connection?"

Joyce: Oh ja.

Researcher: Okay.

Joyce: But you know what's so sad, Dr M. from Johannesburg reckons I should never have had the final plate. I should have gone to him in the first place. You know how sad that is? He's the one who did my neck

Researcher: Your most recent op?

Joyce: Yes, and it's fine.

Joyce: And he did that woman in the ward with me. She got up after her op and within two days she was walking around and was fine. I was lying there hoping for death. I was in Intensive Care for three days.

Researcher: So after your op, you felt worse?

Joyce: Oh yes.

Researcher: When did he say this to you Joyce, after the neck op?

Joyce: Yes. I also spoke to the sister, and she said his ops were fine. He gives you lots of morphine. This other doctor wouldn't give me anything for pain.

Researcher: So do you think the pain that you've got now is a result of your op?

Joyce: Oh yes.

Researcher: And do you think if you'd gone to someone else you'd be a lot better?

Joyce: Yes.

Researcher: How does that make you feel?

Joyce: Angry, very angry. But you know Dr B. is so chauvinistic. You know when you go there, he treats you like an instrument. He talks to Alan and says "We'll do this and we'll do that to her and she can..." You know, you don't even exist and there you are suffering all this pain. He says "You know there is a morphine capsule in your back, you shouldn't have all this pain," and there I'm lying just praying for death. Dr H. doesn't do that. He treats you and gives you as much as you need, until the pain subsides. So, if you ever know of somebody who needs an orthopaedic surgeon that's the one.

Is that all me?(looking at the previous transcript.)

Researcher: Yes I actually came to ask you about that near-death experience, but you have given me so much information.

Joyce: I just tried to dig deep

Researcher: You've been fantastic. Is there anything you would like to add.?

Joyce: There's nothing worse than someone saying "There is nothing wrong with you." If your pain could glow and it could shine and they could tell you "Look your pain is so many degrees, or whatever, - now we know how sore you are." But, there's no such thing, especially when a man works with a woman.

Researcher: Really Joyce:

Joyce: Yes, when a man works with a man, he's more sympathetic than when he handles a woman – that I can honestly tell you.

Researcher: Really Joyce:

Joyce: Oh yes. There's that doctor opposite the hospital.

Researcher: Now, you said you were told there's nothing wrong with you.

Joyce: Yes that doctor told me that, - even though I was crawling, battling to get dressed. The nurse had to help me to get my clothes on. I couldn't bend down and within three weeks I was in hospital, and they did eight discs. Now, he either thought that the op was too big for him to handle, or he didn't want to do it because I was a woman.

Researcher: And did that affect you in the long-term?

Joyce: It did, because he wrote a report virtually saying there was nothing wrong with me, and that report, - when I had a car accident – told against me, and I lost thousands of rands because they said at that time, there was nothing wrong with me.

Researcher: So you felt that the doctor's perception carried more weight than your valid complaint?

Joyce: Oh yes it did.

Researcher: And where does that leave you as the patient?

Joyce: First of all you think you're going crazy. You're suffering from all that pain. You can't bend, - you can't do anything, and then he tells you that there's nothing wrong with you. So, your next thought is you are insane. You are going to end up in an asylum. You start panicking and I'm sure a weaker person would have done something stupid.

Researcher: Like what Joyce?

Joyce: Well, if you are suicidal with pain like that, and they tell you there's nothing wrong, nobody can help you, - there's no way out of that pain, you will find a way. You will take a box of painkillers and just end it all – I really feel that. But, some men

aren't sympathetic, but you get some doctors that are very sympathetic. This man wasn't sympathetic. Then you get another doctor who is chauvinistic, who treats you like a piece of machinery. You want to shout "Hey, I'm a person you know. I've got pain, help me." That doctor put a morphine capsule in my back, and decided that's all I needed, and as far as he was concerned, you shouldn't have had pain. There was no way he could actually find out whether you were in pain or not – he just decided.

Researcher: And this is where you would like there to be some kind of a proof, and as I am listening to you, it seems to me that you, as the patient are actually in the position of no power.

Joyce: Yes, you've got no power, and you've got no proof. If you've got a broken arm, you can see that you've got a broken arm. In a lot of cases they actually have to do a CAT scan to see what your problem is, which is very, very expensive. So if you could have a machine that you could walk into and it says "Hey!" (Laughter) "This lady's got pain you know, and it's so many degrees or whatever. She needs an op or she needs a painkiller or she needs morphine, or we'll have to put her down!" (Laughter)

Researcher: So then your actual experience would be seen as valid.

Joyce: Yes.

Researcher: But, as it is now, it isn't.

Joyce: What do you do? He says to you "You've got no pain" And you sit and look at him. Now you think you've become a hypochondriac. But, you realise "I have got pain." "No, you haven't – there's nothing showing up on this X-ray. Lady, do you want to be sick or do you want to be better?" "No, no I want to be better." "Well then, there's nothing wrong with you."

Researcher: And that's what they said to you Joyce?

Joyce: Yes. You go back again and he looks at you as if to say "Oh no, not you again." And you say "I'm sorry, but I can't walk. My legs are giving in. I've got

violent headaches or whatever” – and he says “But, there’s nothing wrong with you.” So what do you do? You go to another doctor and you start all over again. And until they did a CAT scan, did they find out what my problem was.

Researcher: And you want that proof.

Joyce: Yes, you do want that proof to show that you are sick. Nobody else knows that you are sick, but you, yourself know that you are sick. It’s unfair you know.

Researcher: Yes it is unfair.

Joyce: That’s why you find a lot of women want to go to a woman doctor, because they feel that they understand women better, and a lot of them look for a woman doctor. My daughter goes to a gynaecologist in Johannesburg, because she’s a woman.

Researcher: So Joyce, with this pain the hardest thing for you is actually to communicate your experience.

Joyce: Yes, not to the family even, you don’t want to be sick. It’s just to be able to tell the doctor as you know there’s something wrong, and then he doesn’t want to listen to you, and it takes quite a bit of courage to keep on going back, you’re virtually being branded a hypochondriac – that was before the CAT scan. And every time I’ve been to the doctor and I’ve had a CAT scan, I’ve had an operation within 24 hours.

Researcher: Is that so?

Joyce: Yes, so I don’t go for nothing, - I only go when I’ve reached the absolute maximum limit, and I can go no further – and I can’t handle it anymore, I am a burden to everyone. I’m not thinking straight anymore. I can’t act like a normal person. When I can see I am not acting normally, then I’ll go to the doctor. Then to be told there’s nothing wrong with you – whew!

Researcher: I can understand that makes you become very angry, and Joyce do you find that you start to believe that there's nothing wrong with you, or do you rather believe that you are going insane?

Joyce: No, I didn't funnily enough. I knew that there was a problem. I just didn't know how to communicate it to him, and when I saw he was acting the way he was, I knew I must find someone who will understand.

Researcher: So you didn't start to think this was in my mind or in my imagination or I'm going mad.

Joyce: I thought it in the beginning. I thought maybe I was going crazy. When I was in the hospital trying to get out, and I couldn't get dressed, I thought maybe it's me. But, I couldn't put one leg in front of the other, so I knew there was a problem. Then I thought "He's the crazy one, not me." I knew I had to find someone who would understand. Then, Beryl said to me "Go to Doctor (?) in town." His wife had, had a back op. She said I had the same trouble that his wife had, and he sent me to her doctor, who was Dr B.

Researcher: Oh, I see.

Joyce: That's how I got there. I left my own doctor, because every time I went there, he'd give me an injection, and I'd swell up from the cortisone, and because of that report he told me "Lady there is nothing wrong with you. I'll give you another injection. That is all I can do. My hands are tied." So you change doctors and you start feeling like a hypochondriac.

Researcher: And now you look back, and you realise you've actually lost financially, and there's nothing you can do to reverse it?

Joyce: Yes, because if somebody says that you have lied about your condition, aren't you perhaps lying now? You can't claim from insurance. Your honesty is being questioned, and you can see the way he's looking at you. I was treated very badly by the insurance doctor. He really treated me like a pig. He is a pig, but he treated me

like one. Oh, it was terrible. He'd sit me up, and then dig me in the back. He'd examine me, and I'd say "Aah!" He'd say "Sorry" as if he was trying to prove something. "Oh he was a horrible man!" I firmly believe that it was because of that report of Dr Ranker's. It can reduce you to nothing. These doctors can reduce you to absolutely nothing! You've got no integrity. You're a hypochondriac, and you're a darn nuisance, and they just wish you would go away. That's how you feel. So how about a pain machine? (Laughter)

Researcher: One that glows! (Laughter)

Joyce: And when it gets to its highest point it goes "Ping!"

Researcher: Oh Joyce! (laughter)

Joyce: "You've hit the jackpot!" Again not because you want to have the worst pain in the world, because you've got the worst pain in the world! And you want people to know that. And they must treat you and take it away. You don't want to go and live in a home and be pampered.

Researcher: No, you want to be normal.

Joyce: You just want to be corrected, so you can live a normal life.

Researcher: You want that relief.

Joyce: Yes. You know you get these people who love sitting in wheelchairs and just love being wheeled around. They look all sorry for themselves – all right some of them have to, but most people want to exist in the normal way, and when you're treated like that you're not. And there's nothing worse than being branded as a hypochondriac, because then you believe you are, you know. And also you get people who complain of pain for drugs, for tablets, and the doctors are very wary of that, so if you go in there and tell them you've got pain, they're very wary and reluctant to give you a painkiller. I'm very fortunate. I go to Dr N, and I tell him "Look I need so many painkillers, and I may take two a week, and he knows I am not lying".

Researcher: He knows that he can trust you.

Joyce: Yes, and when I go back he can check, and he can see that I do take only two a week. He knows I'm there because of the pain. My mind is working all the time, cancelling out the pain.

Researcher: The pain?

Joyce: Yes.

Researcher: So your mind is cancelling out the pain. How do you do that Joyce?

Joyce: I think of something else – normally I jump in and start learning, or if it is very bad, what I used to do is I'd have a switch inside, which I'd reach into in my mind and switch that pain off.

Researcher: Joyce is there anything else that you wanted to add?

Joyce: I don't think so, but maybe if they know about this...

Researcher: Who?

Joyce: Who you are writing for..

Researcher: The Medical doctors?

Joyce: Yes, maybe if they know and see how the patients feel, it might give them something to think about.

Researcher: Actually Joyce, I really want to write this description, and I said to my supervisor that I want to do it and publish it in areas where there are people who deal with chronic pain. A lot of the literature I've read is not empathetic. People don't understand someone with chronic pain. That is why I came to do this in my research

degree, and I felt that the best way to do it would be to go to people who have chronic pain, and to ask them to describe their experiences, and how they deal with it.

Joyce: Well, doctors have their moments too. He comes to work in the morning in a stinking mood after a fight with his wife. Let's face it, men have their periods too! Now he has to deal with someone like me, who has this horrendous build up of pain for the past six months, and you say to him "Doctor, I could die!" and he says to himself "Oh no not another woman."

Interruption by grandchild.

Joyce: A lot of people can't deal with people with pain, and there are those with pain who come in to the doctor for the drugs. So the doctors are often suspicious. You can't blame them. So, they try you out by telling you there's nothing wrong with you. They think you're out of the Chronic Insanity Home! Laughter. I'm sure in an asylum you don't find people walking around with chronic pain. Then, they (the doctors) are probably just in a bad mood. Then, I look at him and I think to myself "You are human. You are just in a bad mood, but I've waited two months for this appointment, and I don't want to come back. I just want to get better."

Researcher: That's your need – to get better.

Joyce: Yes, you need instant help, so that it's over and done with, because you've built yourself up worrying "what if" – What if I've got bone cancer. You just want him to tell you what's wrong and that it can be fixed - you'll be OK, because you hear of people going in for tests and being told "You've got three months to live." You want to be fixed up.

Researcher: But, I think for you the biggest disappointment for you was you expected to be fixed and you are, in fact, a lot worse.

Joyce: Yes.

Researcher: And now you've heard you could have been better off.

Joyce: But, maybe not, you just need to picture all the screws and the wire and the titanium and all that in my back, and I can't expect to be better. When I walk all that is moving around and your skin is sticking to it. When you think of all these things and you really get down to it, you can't expect too much. You've got to be satisfied with what you've got, and it's no good being sorry for yourself, or taking tablets or anything, just keep going as best you can. If it's really very bad, take a pill, but don't keep on taking pills all the time, or else you're going to have other problems.

Researcher: So, what you are saying is, that you've got to get to the point of accepting where you are, and actually appreciating whatever improvement you've found.

Joyce: Yes exactly. I can now walk without my leg giving in. I've got other problems – where I've got to visit a toilet every twenty minutes (laughter). But, it doesn't matter. It's not cancer. It's not life threatening.

Researcher: Well, Joyce thanks a million for all your help.

Joyce: It's a pleasure.

Researcher: Thank you for letting me come back and talk to you again. As I say, I just wanted to clear up that one thing, because really I was off the track!

Joyce: That was by the by, you know!

Researcher: But I really appreciate your help – thanks a million.

Joyce: It's good talking about it because it brings back all those memories. I want to grab that doctor and throttle him! My hair bristles, you know. I've told everybody "Don't go there." I said to Margaret "Don't go there." But, she did and she came back and told me. She said "You know what? He told me "there's nothing wrong with you." I said to her "I could have told you that." Then you think to yourself "maybe he's trying to make money." Every visit it's money. So six visits that's fine. Then he operates, you know, and that's money too. Who knows?"

Researcher: So, you feel you lose trust in him.

Joyce: There's distrust on both sides - mutual distrust. It shouldn't be like that. A doctor is the type of person that you can go to with your problems. He's supposed to be sympathetic. He's supposed to help you to get better. That's what it's all about. But you know it's also people, because of their attitudes, their cunning, and bluffing that they are sick to get tablets. You can't win. It's a sad society.

Researcher: Thanks so much Joyce.

TRANSCRIPT OF INTERVIEW WITH GERDA

Researcher: Thanks Gerda very much for agreeing to help me. Now, if you could please describe to me in as much detail as possible your experience of chronic pain.

Gerda: That's a pretty tall order! Chronic pain vacillates, but your body and your system and you start to know what you need, and when you need it. The body actually tells you when it needs something, prior to it getting into a really bad state. My own situation has simply been as a result of osteo-arthritis. The osteo-arthritis is pretty extensive. I've since discovered that the osteo-arthritis and discogenic disease goes way back to the early fifties. But, it has increased over the years. X-rays have been taken and results given, but nobody had really picked it up. Going back in retrospect, I can now see where the changes have actually taken place. I can see when the pain has become worse and why, and then with the understanding of why a thing is happening. I'm able to cope more easily with the actual pain. (Researcher: Right.)

Gerda: And that is vitally important. I would have a pain excruciating down the one side of my body. What's causing it? Is it another nipping of a nerve? Why is it causing that pain? Why is it so bad? After the last major back operation in July 1998, I had excruciating pain. I spoke to the neuro-surgeon who did the operation, prior to the operation and examination and the MRI scan. He established that the lower section of my back, the Lumbar area, S1 and L5 and L4 was so bad, the bone had actually become thicker and more dense, and although he went in there to try and remove some of that bone to free the nerves, he was unable to do so. So he told me that at some stage or other, I would have to come back for a nerve block. Not knowing what that meant, I kept it in abeyance. I was fine and came home. The area that he'd operated on L1, 2 and 3 and the fusion there that he did with rods – I think you call them Harrington Rods – (Researcher: Yes, Harrington Rods.)

Gerda: – that went fine, and that part of the spine is stable. L 1, 2 and 3 is stable, but at 3 and 4 there's a shift, and between 4 and 5 there's a shift, with the result that all these nerves are rather clogged up. The osteo-arthritis is increasing, the bone structure is increasing and it's multiplying. The passage is becoming narrower, with the result that the pain is becoming more and more. I was having injections here and I had a nurse giving me the injection and she would go from me to Shirley and say to Shirley

– “Why is Gerda experiencing this pain?” – and Shirley was at a loss to answer it. I went back to Doctor H., my Neuro-surgeon, and I said to him – “Now, Carl, why is this happening?” – He said “Gerda your sensory nerves have been so damaged and so exposed to pain continually that any slight movement is going to send a sensory message to your mind and to your brain, saying it’s bad. Now perhaps you can control that to a degree, but now what is happening is that it’s going to all the other muscles, and the other muscles now go into spasm. When these muscles all go together into spasm, then the pain becomes excruciating.” What do you do? Injections help for about three hours. Painkilling tablets help depending on how you take them, perhaps about four hourly. But I’ve learnt with this situation to be able to know when my body reaches a certain stage, if I don’t take something now, then in an hour’s time I’m going to have so much pain, I’m not going to be able to cope. (Researcher Right.)

Gerda: So knowing that my body tells me beforehand, then I take two painkillers - and nothing major – just two Stillpane tablets, and that eases the spasm. It eases the mind, because the mind now tells the body “it’s okay”. Well, that’s how I see it myself, personally.

Researcher: But you feel there’s something you can do.

Gerda: Yes, I’m involved. I have to be involved with my own pain control, because if I wasn’t involved in my own pain control, then I’m going get out of hand. I’m going to become desperate, and become depressed, and I’m not going to cope. But, I must add at this stage, if it wasn’t for my faith, there would also be a difference. Now, we come to the phenomenological aspect, because my faith in God and my trust in God enables me through his strength, to be able to cope. This becomes an important issue. There are times when the pain does get to you and you become depressed and believe me Christians become as depressed as anyone else. We are normal human beings, but it is by prayer and the continued waiting, together with the medication that I’m able to cope. The pain had however become very bad to the extent that it was actually affecting the osteo-arthritis in the shoulders. The right shoulder, the biceps is off, the Infraspinatus is off and basically how the arm functions is just a miracle in itself. The left- hand side, I had a similar operation. So far the ligament is intact. But the pain is there. Now, because the lower back goes into such tremendous spasm – it basically goes all the way up – and affects the shoulders. The shoulders affect the neck. The

neck affects the head. So it becomes a vicious circle. Now what? At the beginning of this year after the heart operation last year – you know about that? I had a double heart by-pass operation. I'd stayed away from operations – any type of operations. I should have had a shoulder operation done last year, but I didn't want to have it done. I wanted to give my body a chance to recuperate and to recover. It didn't work. I had the heart operation. After the heart operation I veered away from any kind of operation. I didn't want to put my body or my mind through that sort of stress. I've had some pretty nasty experiences with anaesthetics. Then at the beginning of this year, I said to James – "I've got to do something about this." So I phoned Doctor H. and I said to him "Carl, you told me three years ago that I would need a nerve block." He said "Gerda come". They made the appointment. So I went in not quite knowing what the nerve block would entail, simply knowing that it was some form of injection they would give me. I went into the theatre and they did the nerve block. Instead of them giving me just two injections, they gave me four. He went in at two different levels of the back – the lower section of the back and also about L3 and 4. He told me that this should improve the situation, but if it didn't I must come back. I saw him a week later, and actually even my shoulders were pain free at that stage. So in other words, it proved that the lower back spasm was actually aggravating the upper back spasm and the neck. (Researcher: Yes.)

Gerda: It's been marvellous. The muscle spasm is still there. But the actual pain levels have dropped tremendously. It's got to the stage where I have two pain tablets perhaps, twice a day. By and large, one is sufficient.

Researcher: But you still have pain Gerda?

Gerda: Yes, I still have pain.

Researcher: But you don't have the same level of pain?

Gerda: No. The nerve block in itself has helped to control that. I keep up with my physiotherapy, and I keep up with my exercise, because exercise is vital. Keeping the muscles going I think has kept my back pretty stable over the years, and kept me more mobile. If I hadn't had the exercise I could easily have been in a wheelchair. I'm

convinced of that. But by God's grace and by the ability of being able to do the exercise and go for physiotherapy, I'm able to keep up the mobility of my limbs, even though they are pretty bad. Physically, I'm reasonable. I have a fairly strong constitution. The bone structure is causing a lot of muscular pain and this is where I have my major problem. But, I am controlling it. It is under control. I had to go for physiotherapy last week on Monday, and when I saw Shirley she said to me – "Gerda have you still got some of those Voltaren injections?" I said "Yes, I have got them." She said "Your back is in terrible spasm. You may not be feeling it, but it is there. It's in very bad spasm. Please have the injection." So I did. The pain level stays lower from the nerve block, and the discomfort stays the same.

Researcher: What do you mean by the discomfort Gerda?

Gerda: Discomfort in the sense that it affects the muscles when I sit down. I have a sort of burning sensation into my buttocks and into the leg. It's not as painful, but it's really uncomfortable. It makes me get up and walk. I find that after I've walked and done some exercise it's alleviated. So sitting can't go on for long periods. (Researcher Right.) I have to get up and move and in that way the pain again is controlled. There are times when it affects the mind in the sense that I've just had a stroke.

Researcher: How do you mean that you had a stroke?

Gerda: I had a stroke six weeks ago.

Researcher: Is that so?

Gerda: Yes, the stroke occurred quite unexpectedly. I had been having – now in retrospect, in hindsight, I know that I'd been having all the signs leading up to it. But it was only afterwards that I really realised what was happening. I was having sensations of tingling in the face.

Researcher: Did you think it was the pain?

Gerda: I thought it was the neck.

Researcher: Oh I see.

Gerda: Because I'd had the neck fusion, I'd often had this sort of thing in the face, but it's led from the neck muscles, and leading into the base of the skull, with headaches. You know about that. You've treated it. But I thought it was related to that. What I didn't relate to was the fact that I was having dizzy spells. (Researcher Right.)

I was having dizzy spells periodically, because I'd lost the hearing in my right ear, unbeknown as to what caused it. So, now you have a situation where your hearing, your ears together with the neck creates a situation where you sometimes have dizzy spells anyway. But now this had become more prolonged. I would find that if I was sitting or standing, I really needed to sit down. I found lying totally down didn't work. I had to lift my head slightly and that would ease it. I'd have this buzzing in the ears – typical stroke patient – but I didn't relate it. Then it would pass off. I went to my sister, and my niece was visiting that day. I'd been having this spell right through the day, but I'd been having these spells for about a week, prior to this day. Then on the Saturday night, I took my niece back to my sister, her brother was picking her up there. I said to my sister "Now I need to get home." I got home and had some tea, and sat down and tried to watch TV, but I couldn't concentrate. Then suddenly there was this buzzing in the ears, and my head was spinning, and I shouted to James "There's something wrong!" Then I had a painful sensation in my left arm, and I thought uh oh, having had the heart operation, this is it – I'm having a heart attack. So I called to James and I said "I'm not feeling well, please come here." He came through to the room and said "What's wrong?" I told him what was happening. So he said "Take a Disprin and phone the doctor." We couldn't raise either doctor. My doctor was away. It was a long weekend. The replacement doctor's rooms were closed. It was a Saturday night. Eventually I said to him "I'm going to go to bed and pray for the best. On Sunday morning I woke up still feeling very, very woozy, so James went to church alone, but when he went to church, I phoned the doctor's rooms again and got hold of the Cellphone number of the doctor. He said "If this carries on come and see me at 4.45pm. James had to go back to Rustenburg, where he was handing over the following day. My daughter took me to the surgery. The doctor took one look at me, examined me and did an ECG. Then he sent me straight back to the car and to Hospital. He put me on oxygen for the night. I saw Dr R. the physician the next

morning. He did extensive tests and he said to me “You know what you’ve had don’t you?” So I said “Not really, but can you explain?” So he said to me “You’ve actually had a stroke, but a very mild one.” – for which I am eternally grateful. I’ve had no visible after-effects, except that I find it hard to concentrate when watching TV, if anything goes in fast movements it worries me. So my time working on the computer is also a little bit limited, but it does pass, and it’s a question of one having to learn to adjust. He put me onto medication, which had tremendous side effects. The medication - I don’t know if you need to know the name – is Azasantin(?) 200mg twice a day, which made me feel terrible. I felt like saying to the doctor “I might as well die, rather than carry on life like this!” I went to see my GP on the Tuesday, and I spelt out the whole scene. She said “No, Mrs Van, we’ve got to try and do something different here.” She took extensive blood tests again and phoned me on the Thursday afternoon. She said “Stop taking the Azasantin. I want you not to take it tonight, tomorrow night, or tomorrow at all, and not on Friday morning. You’ll start on Friday afternoon with a different medication. It should not have these side effects. I’ve not been able to get hold of the physician, but let’s try this.” I’m a different person.

Researcher: Oh, that’s good.

Gerda: So medication has to be monitored. If it’s not monitored by you, then you have got to read the symptoms, so that you can report back to the doctor or physician.

Researcher: Have you always been so in touch with your body Gerda, because as I listen to you and hear you talk about pain, you read your body signs very well.

Gerda: I have to.

Researcher: Is this something you’ve always done, or has the pain made you more aware?

Gerda: I think I’ve become far more aware over the past number of years. I’ve always had back pain. My back operations started basically in 1960. I had another one in 1970, and another one in 1980. From about 1987 onwards I had to learn how to cope

with pain, and friends of mine, who are nursing sisters, ICU sisters, said to me “Learn to monitor your pain. Learn to look at it. See how you can control it.”

Researcher: Yes, you speak a lot about the way you feel you can control it. It’s not something that overwhelms you.

Gerda: No, but it’s only grace that helps that, and my faith.

Researcher: Right. You mention that a lot as well. How does that help with what you experience in that area?

Gerda: My faith - now to some people it may be a strange sort of situation.

Researcher: It doesn’t matter. How is it to you?

Gerda: To me, when I communicate with my God, he’s a father, a knowing father, who understands me. He made me, he created me, so he knows how my body functions. Whatever he’s allowed to happen – notice it’s by allowing only - it’s not that he’s made it like that, or to be like that. (Researcher: Right.) Because nature, and our body life and our way of living, we aggravate situations. We bring things upon ourselves sometimes. Sometimes it’s not us. It’s circumstances, genes or whatever. But, he enables me, when I feeling so totally down in pain, to be able to cry out to him in prayer – not to cry physically with that pain, and yet in that crying out to him through Scripture, he is able to ease my emotion. (Researcher: Right.) And the easing of the emotion, then helps me to stabilise, to a degree together with the medication, physically, the pain level that exists. I have, as a result, a reasonably high tolerance of pain.

Researcher: It’s not something you’re afraid of?

Gerda: No, it’s not something I’m afraid of at all. There was a time when I was afraid of it. There was a time when I was extremely afraid of it, and I would ask for an injection for the pain. But now I am able to, by his help, by prayer, by reading the Scriptures, by singing – believe me, singing and laughing, one is able to reduce that tension, because this is something I feel in myself. If that tension rises high and I put

myself under emotional strain, then the pain is worse. I feel the pain more. It may be there all along, but if I am able to relax my mind, and my emotions, then I'm able to control it more effectively with medication. If I'm not in control, then the pain gets bad. I have found, as a result of the stroke, that if I allow myself to be exposed to any form of tension, it exacerbates the pain. I immediately start losing control. If I get into a stress situation, I try to remove myself from that situation. I will go to my room and start praying and quietening my mind and my spirit. To me, there's a very close correlation between the body, the mind and the spirit. If I am able to control my mind and my spirit, then I'm able, with the help of medication and whatever, to control the pain to a degree. I don't think we can ever take the pain away, but we can control it. It can become a pain that we can put up with. (Researcher: Right). Sometimes you can have difficulty with this, then one goes to the extreme of going and having an injection, or to see the doctor to get something stronger. But, by and large, one is able to control it.

Researcher: What you have said indicates to me that you have reached a point of acceptance.

Gerda: Yes.

Researcher: Although you do a lot, your object is controlling the pain, rather than removing it. Did you find reaching that point of acceptance helped a lot?

Gerda: Yes.

Researcher: Is that how you coped? Or am I reading into it?

Gerda: No, you're correct. I know now - I didn't know but I know now – that there's very little medical science can do to change the situation. I know from reading the x-ray reports, now in retrospect having more understanding of what's going on, that I have a discogenic disease, which is progressive and because it's progressive, it's going to get worse. Unless I learn to accept that and to adapt my lifestyle to it, I'm not going to cope. But God is enabling me to accept that fact, and by his grace to work with it. I know I will need medication. I know I will need help, but I know, up to a

point, I can control that. I think the one thing we all fear, is helplessness. (Researcher: Yes.) If I can feel with my mind and with my soul that I can retain that hope, then I can control – to a large degree – how I allow that pain to affect me, because pain does affect us. It must affect our psyche. It can't do anything else. But with God's grace, I was able to cope with that psyche. Then one can cope with the level of pain that they're at, regardless of what it is. Does that answer your question?

Researcher: Oh, yes that does definitely. Now, when you say it affects your psyche, if you can think back, what are those effects, Gerda? How can you elaborate on that? How you've actually reached a point where you can cope?

Gerda: Yes. That's quite difficult to explain. I think each person is totally different.

Researcher: And in your case?

Gerda: In my case, I think my faith has made all the difference. There are times when I am challenged on that by people.

Researcher: Challenged on what?

Gerda: Challenged on my faith status "Why is it that you believe that your faith is helping you through all this?" And the only thing I can say there is simply that my trust in the Father-God, who created me is such that he enables me to believe and to trust him sufficiently to give me the hope and strength, to overcome the depression. (Researcher: Right.) And if you don't have that hope then one becomes depressed. Then I'm going to be depressed. I have friends, who have very much lower levels of pain control, people who have said to me – "I can't understand how it is that you remain smiling, and that you continue doing what you do in spite of your pain" The only thing I can answer, and this is truthfully – it's not me. It is grace that is given to me that enables me to cope.

Researcher: That's wonderful.

Gerda: One must keep one's eyes outward. To me the most important thing is not to become introspective. The moment I become introspective, I tend to lose hope. If I look out, I can think of a poem I read - Somewhere I saw a person smiling beautifully, and I thought what a wonderful person she must be. Then I looked down and saw that she was crippled. I saw a person walking by singing and she talked to me. I replied and she smiled back at me. As she walked off she said to me it's so wonderful to know that people will talk to you in spite of being blind. You can hear and when one looks at all those things and what I still can do, I have so much to be grateful for. We all have to go one way. The only way we can go to heaven one day is to die. Basically, from the moment we are born we are in the departure lounge of where we are going forth. But what we do in between depends on what we allow him to do with us, and that, phenomenologically, is what touches my body, my mind and my soul, and helps me to cope with the pain. It helps me to have a cheerful outlook on life, and to go about doing what I want to do, and when that comes to an end, well, he will give me the grace to accept that too. But while I can I will, by his grace.

Researcher: What's wonderful to me Gerda, is that you are willing to adapt to the pain, and to change your life accordingly to it. But you are also able to continue with what you can do. I think that's a wonderful asset for you.

Gerda: Yes. This is grace. This is only as we depend on Christ, that he is able, through his Spirit, to enable us to do these things. There are days when I find it difficult. I'll be quite candid about it. It's not always roses and sunshine. There are days when you just feel "Wow, I just wish this would go away." But, in spite of that, when one look out and you see what is going on around you, then you're grateful for what you have.

Researcher: And Gerda the fact that you know - as you say - there are days when you wish it would go away, does the fact that your pain is so chronic, and you don't see a way out of it, does that affect you, or is it something you've come to terms with?

Gerda: It's something I've come to terms with.

Researcher: Does it ever bother you?

Gerda: I think it bothers us all. Being a fiercely independent person, I think that was part of the driving force, that may have taught me to adapt. I had to learn how to cope and do what I wanted to do. I knew I had to work out devices, ways and means of coping and being able to do whatever it was that I wanted to do e.g. Running a home, enjoying a hobby, enjoying my grandchildren, and being able to help others either physically or whatever. Being able to help others has always been very important. The result is that there are days when you feel "I don't know if I'm going to cope." But, in those moments where I feel I could just lie down and die, one looks up and sees God's love, and see his fragrance, and one is encouraged, and one gets up and goes on. I have a friend, who is dying of cancer. I see her agony and her pain. I can do nothing for her. Medical science can do nothing. Who am I to complain? And in that there comes a quiet contentment, and an acceptance of the status quo. Unless one gets to that point, I can understand why some people take a gun and blow their brains out. I can understand that.

Researcher: Yes, it happens.

Gerda: I can understand it. It is purely, purely grace that keeps one sane, because I think in those moments one does become insane, when you do that, if it's a result of pain, that, that happens. The mind just kicks out, and unless the mind is controlled with the grace, it happens. Fortunately, I've never felt that way. I think, possibly it's my faith that has kept me from that aspect. But one does get desperate. One does get desperate if one is lying on that bed day in and day out, and the pain never stops. You get to the stage of saying "Why, God, why?" (Researcher: Yes.) You don't get an answer, except the answer for me is if one looks at the eagle with its nest high up on the mountain, it kicks its chicks out of the nest. Why? To teach them to fly! But, the moment they start tumbling, the mother flies in underneath and picks them up on her wings, and she carries them back to the nest. Tomorrow she kicks them out again, until their wings are strengthened, and they are able to fly on their own. To me my pain has been that kicking out of the nest to strengthen my faithfulness, my trustfulness, and my ability to cope with my situation.

Researcher: So you found a purpose in it?

Gerda: Yes, I think one needs to find a purpose. If one doesn't find a purpose, or cannot see a purpose in one's life, then you're going to get lost. You're not going to cope. And I don't see pain as a punishment. Many people do. Many people see it as a result of sin – Oh you've done something awful in your life. Or they may see it as some sort of punishment for something you've done or your parents have done or whatever. (Researcher: Right.) I don't see it as such. To me, my life is a learning process, a school, preparing me for eternity. What I do with that learning process is vitally important. If I sit in the classroom and I don't pay attention to what the teacher or lecturer is saying to me, I will not absorb what I need to know. And so my prayer has taught me to listen to life, listen to God, listen to people, and to listen to my body. The culmination of that has been a coming together of trust, and not looking for the cause of the problem, but the end result.

Researcher: The outcome?

Gerda: Yes, the outcome. In that way, I think I am able to cope with it all.

Researcher: Gerda, you mentioned there - actually there are two things I wanted to ask you about – you mentioned your family, your grandchildren. How has your pain affected your relationships and the people who are close to you? Has it had an effect?

Gerda: What it has done, it's made me appreciate what I've got. There are times when I've found having the little ones around me too much. Then I need to say to my daughter, "I think you need to take them away for an hour or so." My mind is not coping, and I find myself getting into that tense state. The moment I get into that tense state, I'm now learning – I haven't mastered it completely yet. Researcher Right.

Gerda I'm learning to say to myself – "Okay, relax, let go, move out." Now, that's restrictive.

Researcher: Okay, why?

Gerda: It gets to your psyche, and it says to you, "Why? Why? Why?" Why the pain? Why the tension? Getting you to this state, I find the moment I get tense, - as I said to you just now – then the pain gets worse. It is then that I can feel the pain moving

through. So, I am having to learn to say to the children, “Play over there, Ouma is going to lie down.” Now, for them, this is difficult. They cannot understand why a person who has been playing with them all the time, can no longer do so. (Researcher: Okay.) Tina is five in August, made a statement the other day that made me sit up and take notice – “Ouma hoekom is jy siek?” This is a classic example of a crisis situation happening in the family. It has always been Ma, and Ma has always been there. Now, not only am I having to learn to adjust, they are having to do so as well. (telephone rings.)

Researcher: Now you were saying she was asking you why you were sick, and why you are tired.

Gerda: I’ve just had to sit down with her and say to her “You know I’m getting older, and because we are getting older, our bodies are not able to cope as well as before.” Now for her little mind, this is very difficult to grasp. But she’s getting used to the understanding that I must let Ouma rest. Then she will come and sit next to me, and she will hold my hand, or I’ll hold her hand. I’m able to read to her. Beryl turned two last week, and has more difficulty in understanding the situation. “Why can’t my Ouma pick me up?” And Ouma, literally just cannot pick her up. So, what I’m learning to do is to sit down and say “Climb up onto my lap.”

Researcher: That’s exactly what I’d do.

Gerda: But, it’s not easy. By nature, I’m the sort of person who will grab a child, pick her up, swing her around and play with her. So, it’s learning to adapt to that sphere as well. I’m having to learn to say no. I’m not a person that can easily say no. I’ve always been a very active person, and I’ve had to turn around and say to the Camera Club, “I can’t come tonight, I’m sorry.” I’ve had to say to our Cell Group, “I’m sorry, I can’t make it tonight.” I’ve got to listen to my body’s needs.

Researcher: And not worry about what they think about it?

Gerda Yes, and that’s not easy. It’s not easy because one is, or has a lifestyle of giving, and now you’re having to learn to receive. Now, that hits you somewhere

along the line, emotionally. I think my biggest shock came about with my last back operation in 1998. I was totally helpless, and I had to allow somebody to bath me, to shower me, to wash me. I was unable to wipe myself when sitting on the toilet, because I couldn't reach with my shoulders and with my back. That hits at one's self esteem. It hits at one's ego, and unless one has that relationship with God, you get totally blown over. There were many nights, with James sleeping in the other room, simply because I was disturbing him too much, actually he was disturbing me – when I didn't have a moment's sleep. Beside my bed I would have my Bible and my Hymn Book. Through my tears I would sing through the night, or read through the night, or pray through the night. But by the end, I was able to cope. I would fall asleep in tears, but I would sleep. So, basically, it comes back to that point where unless one has that faith, and again faith is not something that comes from you. It's an experience, a relationship that you can build up. My relationship with God, is much like my relationship with my late father. I thank God everyday for a father like him, because he is a gentle man, a person who used to pick me up and put me on his lap. I could relate really anything to him. Now, my God-Father is the same. I'm able to go to him and talk to him. No one else will understand, but he will understand. He does comfort and he does strengthen me. I think in one's awareness, where one has gone through situations of lungs collapsing, and not knowing, in total delirium of what's going to happen, having a heart attack, which you are unconscious of, having a heart operation, which you're not sure you're going to come out of, and having a stroke and not being sure of what's going to happen, one is so aware of the fact that the person is so alone. (Researcher: Yes.) You may not be lonely in the sense that God is there, and people are around us, but physically you are very alone. And unless you learn to accept that and allow God to walk you through that, no ways are you going to cope with pain, no matter what it is, or no matter how shallow that pain may be. Levels of pain differ, and I think our mental state, our emotional state, and our spiritual state affect – to a large degree – the outcome. That's my personal experience.

Researcher: Gerda, you know you mentioned how alone you are with that kind of experience. Do you find people who don't have chronic pain actually understand?

Gerda: No.

Researcher: Do you feel this is something where you are completely on your own?

Gerda: You're totally on your own. Only a person that has gone through pain –

Researcher: Will really understand?

Gerda: – will really understand, and even then your pain differs, and your understanding differs. I have learnt to say I have empathy. I have an appreciation of - but not to say – I totally understand. No one will totally understand what another is experiencing from the point of view that they're not in your situation. They do not have your psyche. They do not have your emotions. They do not have your body. They are totally unable to have a deep comprehensive understanding. To say you have a total understanding is a no, no. It's just not there, because we are all so different. Also I believe it's the whole situation. I have been taught you can cope. So, you work at it. You don't allow circumstances to get you down. For example, my mother, if I could be like she was, I wouldn't mind, but physically I'm not able to, as we are different. But, it's to learn to accept that, and I think this the most important thing, one has to, as I had to, learn to accept myself – regardless of what everybody thinks or says. That doesn't mean to say I don't take notice of what they think. You know one can think you are cut off from people and that you don't allow people to affect you by their thoughts and their mannerisms, and by their approach to you, but I don't think there is anyone of us who is able to withstand what others around us say and do. We all think about it. But, by grace one is able to take that and hand it to God, and say "Lord, I don't know how to handle this, please help me." In doing that, I find release. Whether anybody else sees that as a psychological "cop out", I don't care. I know it's God's favour, and it's love in me that is creating that sort of situation where I can cast it aside, and in that way, I am able to cope. Is there a God? To me, that's a most important question, and my answer is always this – if there is a God, I'm okay, but you're fine if you don't believe it, and that is the difference. People will say there is no God. These are all facts, cause and effect. It might be. But, to me, God has a purpose in all that I am, all that I do, and in all that I experience, and in that I am able to cope. So, if there is a God I'm happy, because one day I'll be with him, and there will be no more pain. There will be no more heartache. What happens to that person for whom he doesn't exist – well that is their choice. To me, that is the answer, to my

need, and the answer to my pain, and I'm able to cope with it. Are there any other questions?

Researcher: I want to go right back to the beginning. You've spoken a lot about the fact that you've had x-rays. You've been able to see that there are physical signs, and you've spoken about the importance of actually being able to relate your pain to an explanation. Can you elaborate on that Gerda?

Gerda: Yes certainly.

Researcher: If you'd had tests and they showed nothing - well lets not take it that way – the fact that you've got tests to confirm that you have a physical problem, how did that affect you?

Gerda: Now, lets go back. I had, way back in the early sixties, a knee problem. My knee would swell to double its size. I'd go to the doctor. He would look at this knee. He would put on whatever needed – nothing would happen. Eventually, he sent me to an orthopaedic surgeon. The orthopaedic surgeon examined the knee. He examined the x-rays, and he said to me "But there's nothing wrong with this knee." So I said to him "Well please explain the swelling, and the discomfort, and the pain." No, he doesn't know. Eventually they decided to operate. They opened the knee and they found that the cartilage had actually torn, and because of nature, it had healed up from the inside, with the result that the x-rays did not show the cracked cartilage. It did not actually show the abrasions that were moving on the knee-cap, which was causing the pain and the swelling. I think that says something. I was getting quite desperate. I couldn't understand why my knee was doing what it was doing. I couldn't understand why I was having this pain. I couldn't understand what to do about it, or whether there was anything I could do about it.

Researcher: So you felt trapped.

Gerda: Yes, I did feel trapped. I felt that there was no way out. I think this is vitally important, that more needs to be done for the patient to help you understand why things are happening to your body. Then you can cope with it. I found in my own

experience, fortunately I have a very good relationship with my doctor – she knows if I say “Please explain,” then she will take time to explain to me why something is happening, because then she knows then I’ll be coping better. She has now got to the stage where she will prescribe 100 pain tablets at a time, because she knows I’m not going to misuse them. She’s learnt to know me sufficiently well, that I will only take them when I really, really need to do so, and that I will not take them before a certain time again. That’s the relationship.

Researcher: So relationships are very important to you.

Gerda: They are vitally important. Both the healer, and the person being healed, regardless of whether it’s a physician, a doctor, physiotherapist or whatever, there must be some sort of relationship between you.

Researcher: And trust, that what you are saying is valid.

Gerda: Correct. There must be trust. The nurse who came to inject me couldn’t understand why I was having the pain, and was indirectly thinking “Oh she’s really a nut. It’s not as bad as she really makes it out to be.” But she landed in hospital after a car accident, with a broken femur and pain. And she could turn around to me and say “Well now I’ve got some understanding” – trust relationship. The doctor may not really understand why I’m having so much pain, but at least if the doctor confirms, or at least takes the time to talk to me about it, and say to me “Well you can expect such and such” my mind and my body is able to cope more easily with the situation. Now, having said that, I also have to say there are people that if you tell them they probably will freak out, and they will not cope. So there must be an understanding between the physician or the doctor, the healer and the person. The person who is doing the healing work on you, whether it’s a doctor, a psychologist or whatever, if they don’t really fully understand you as a being, and know what you are able to decree or to cope with, they have to learn, and have no need to say “You’ve got cancer” – full stop – they need to break it gently.

Researcher: But it seems to me that the fact that you’ve got confirmation is almost a consolation.

Gerda: Yes, it is, because now I have a better understanding of why I am experiencing it.

Researcher: You feel it's not something wrong with you mind.

Gerda: That is the most important thing. I know it's not my mind. The fact that the nurse was having difficulty in handling my pain, made me wonder – am I being psychosomatic? And that goes way, way back. We've had the knee story in the early sixties.

Researcher: This is what I sensed with you.

Gerda: I said to the doctor "Am I being psychosomatic? Or is there something wrong with my knee?" He answered "You are not being psychosomatic, what it is I don't know, but there is something wrong physically." Having that knowledge, it's helped me to cope. It's helped me to cope throughout my life, no matter what it is – whether it was emotional stress, physical stress or pain, I've been able to cope, knowing God is in control, and because he's in control, I am able to control, and then I am able to cope. But, if I don't have that mechanism, then I'm lost. My mind has to be intact, and I think that's the one thing I pray for everyday, to have a mind that is sane, and that can think and reason. When I see a friend of mine who has Alzheimer's disease and a sister-in-law, my mind just freaks out. I just pray – "Please Lord, don't let that happen to me." Fortunately, they are not aware of what's happening, but I think it must be terrible.

Researcher: My mother's got Alzheimer's.

Gerda: It's really not a nice situation. (Researcher: I know.) When I was having these dizzy spells, I was worried that that's what was going to happen. That's why when the doctor said, "We've got to thin your blood" I allowed him to do it, no matter what. I'm glad there's a medication that doesn't have those side effects. It's important to know that you are in control. For me, that is vital. There was something else you wanted to ask, I can see that.

Researcher: Is there anything else you wanted to say on that line?

Gerda: No not really.

Researcher: Knowing the pain that you have got now as a physical cause, do you find that it impacts on the people around you?

Gerda: Yes it does, very definitely.

Researcher: Does it make it easier for them to understand, or do you think they accepted pain even when you didn't have one?

Gerda: I think what has happened here is that they sometimes feel very helpless, in that they are not able to relieve that pain. They do what they can, but they get to a point where they can't do anymore, and then they become stressed out. So it leads to a point where you indirectly hide a lot of your pain. There are times when you shouldn't have to do so, but it's important that one does it, because once again it's relationships. One learns to read the people closest to you, and the people around you. You go in for an operation and someone says, "Oh no, not again! What's it this time?" To try and remove the barb of that statement is not easy. (Researcher No, it's not easy at all.) It's because they don't understand, and sometimes they think you like having operations. It happens.

Researcher: So, once again, it gets back to the fact - "You've lost your mind!"

Gerda: One has to get back to one's own psyche and say "Is that so?" Is the person correct in making that statement? Or is it my turn, and if it isn't, then hand it over to God, and say "thank you God, help me get through it" If it is then to say "Lord help me not to have it" Okay, then it is relationships. There's an inter-relationship within everybody, not just your physicians, or your healers, but also in those closest to you, even the servant working in your house. You can have extreme pain and suddenly you get ratty, and you say "Get out!" Then you regret it the moment you've said it. Then

one needs to have the grace to say "I'm sorry. I have pain that's why I did it. I'm sorry I shouldn't have done it." That's not always easy, but it can be done.

Researcher: I think what you've brought up for me makes you very honest with yourself, that you are able to say Oh I'm going for another operation. Is it the truth? Don't worry about it. I'm sure of myself – You actually develop more self-confidence. Even as I listen to you speak, and the way that you cope, it seems to me that your own self-confidence has grown a lot, because you know you can handle it.

Gerda: Yes.

Researcher: So, you've actually become stronger.

Gerda: Emotionally, I think I am stronger, but physically I'm not as strong. Spiritually I am stronger and I'm stronger in my mind. There are moments when one needs the physical comfort of another human being. There are times when you want someone just to come and hold your hand – (Researcher: Yes.) – so that you don't feel that aloneness. (Researcher: The isolation.) I know that there are times when the other person gets quite desperate just seeing what you look like when you are in pain. It torments one just to think you are putting someone through all that. But again, it's a growing process. It is a learning process for each one of us. My daughter is finding it the most difficult. (Plane flies overhead, so couldn't hear the tape clearly.) Her mother, who has always been so independent throughout the years, and who has been able to do literally anything and everything, because she puts her mind to it, now suddenly she can't. I think that gets to her, although she will not always admit it. But when she talks, one hears it. One sees it in her eyes. One sees it in her actions. She tries to protect, but she has to be careful, because I need to keep my independence. I think I am like my Mom, in that I knew her limitations. I had to allow her to do what she wanted to do, even though sometimes I knew it wasn't the right thing. I could say to her – "Mom do you...?" - and allow her to do it - but to know I was nearby if she needed me. I think this is the important thing, that a person must be allowed to retain their independence for as long as possible. (Researcher: I think so too.) If one is allowed that independence and self-respect, then you can cope. But, the moment you are relegated to being an invalid in the eyes of other people, it takes away some of

your confidence (?) which is not good, and that makes the person get up tight. I think that possibly, if it wasn't for my faith, which makes me get up each day, I wouldn't cope. God has been good. He has strengthened my faith, and because of that I am able to cope in spite of the pain. I know why I'm like that. I know I have the pain and I know I'm limited. But, I'm not going to let those limitations stop me from enjoying life.

Researcher Gerda, how has the pain affected your work and everyday activities?

Gerda I can't do as much as I used to and I take twice as long to do things, but I don't let that stop me.

Researcher: Do you do everything that you have always done?

Gerda: To do all the things I've always done I've sometimes needed help. I've said to the maid –“ Please take down that big pot, or lift this heavy thing” – or “My daughter put the child on my lap” – simply because I'm not going to stop holding my grandchild on my lap, simply because I can't pick him or her up. I think that's important. I can't hold the little one for as long as I would like to, and I've had to learn to say to my daughter - "Please take the baby, he's getting too heavy." So, one adapts to that.

Researcher: It's a case of adapting again.

Gerda: Yes, where in the past I could make my bed in three minutes flat, now it takes me ten minutes, to use a practical example. Where before I used to be able to work the whole day through, and get so much done, now I find it's a lot less that gets done. But, it's the learning to accept the difference - learning to accept that I'm in the “departure lounge.” Learning to accept that there are stages of approaching the aeroplane taking off. I'm not on the airstrip yet, I'm still in the departure lounge. One is progressing in a direction, and one will get to the point later when you get to the door, where you are approaching the aeroplane, but it's a question of one step at a time.

Researcher: That's really wonderful Gerda. I think you have coped really well. That's one of the reasons why I came to see you!

Gerda: As long as one can be an encouragement to others, that to me is most important. Having meaning in life to me is having meaning for others. If I can give meaning to other people's lives and if I can add purpose to their lives, then there has been a purpose to my life. (Researcher: I agree with you.) I think we all need a purpose, no matter what that purpose is. My daughter sent me a little sentimental thing on the computer the other day. She often does this these days because I think she thinks at times that someone doesn't think about me. It was about setting goals, no matter how long or short term they might be, they are vitally important. Unless we have a goal to reach for, and my goal is basically to reach out to other people. I am a "people person." I love people. I love sharing with them no matter how "down" I may be, by having time to share, to give, to give comfort, to strengthen that adds promise to me. With the heart operation, the second day after the operation, I walked into the ward where another lady was due for an operation. She had lots of marital and domestic problems, and being able to just pray over those things – it drained me, because it was emotional, but with her it worked. That in itself, is what life is all about. It's about being able to share my life, and my faith with others. If I can achieve getting a smile, a light in the eye, an encouragement, then it's been worth it, no matter what comes along. Does that answer your question?

Researcher: Yes, that's great Gerda. Thanks so much. I really appreciate that.

Second interview

Researcher: Gerda, I was talking to my supervisor and I realised there were a few questions I forgot to ask you. One thing was how the chronic pain had affected your occupation.

Gerda: Basically, going back, the chronic pain affected my work in the sense that I was battling to cope.

Researcher: What were you doing Gerda?

Gerda: I was teaching.

Researcher: At a school?

Gerda: Yes, I was Head of the Department of Guidance at a high school. (Researcher: Okay.) I'd moved from Carletonville to Alberton, and I was under tremendous pressure, because the syllabus had changed twice in three years, I had to re-do both syllabuses. The situation arose that I was dealing with staff that I had to train to do the moral preparedness side of it to institute and carry through the counselling in the school. In fact I was counselling parents and children far more than the headmaster was seeing them. That together with all the syllabus work, the training of staff, the preparation of the lessons etc, and I had a hearing disability, My right ear was totally deaf, at that stage, and still is, so I had a stress level which was unbelievable.

Researcher: I can understand that.

Gerda: You teach one hundred Matrics in the hall and you've got to handle them. That together with the neck pain and the back and shoulder pain, it all exacerbated the situation. But again as I stressed last time, faith carried me through. I was able, through prayer, plus the medication, to cope. I did get to the stage where I applied to be boarded.

Researcher: What was that like for you Gerda?

Gerda: It was traumatic in the sense that there wasn't really an understanding. There had been people who were taking this boarding – trying to get out of teaching, who really weren't in any distress.

Researcher: And you didn't really want to get out?

Gerda: No I didn't really want to get out, but I felt I had to, because I felt I wasn't going to be able to bring to my vocation that which I felt should be given to that

particular type of work. (Researcher: Right.) So now one has the situation where I had to see the neurologist, a neurosurgeon, the orthopaedic specialist and the doctor about my general health. I had to go to each of these people and they had to do an evaluation. They then sent the evaluation through to the department. One hears nothing, absolutely nothing from them. I took a full year or more before I heard anything. Then suddenly I got the information a month before school closed, “This December is your last teaching day.” It just blew my mind. I was in the process again of sorting out another new syllabus that had been brought in. My headmaster said to me – “You’re not leaving until that’s done.” So that was the status quo. It meant that I was working till all hours of the night. The only way I could keep myself going was through my prayer-life, and just my normal quiet time. The medication helped to flatten the pain a bit, and I coped. I think I coped reasonably well. (Researcher: I’m sure you did.) In fact when I went back afterwards, I was asked to come back. I said “No ways, I wouldn’t even consider it.” He said “Please” I said “No you’ve got someone in the Department of Guidance, and he said “but he’s not doing what you did.”

Researcher: That’s a certain indication that you did cope.

Gerda: It’s not a case of blowing my own trumpet, it’s purely pointing out the grace of God that enabled me to cope. This is what I would really like you to stress, that there’s no self-edification here. It really is God’s grace that enabled me to manage and to cope. I’m sure others could also find that grace. It was difficult. I’m not denying that for one moment.

Researcher: Did you feel a lot of loss when you did stop work?

Gerda: Initially, yes I did, but I had half prepared myself, knowing that the time would come when I’d have to stop. So, what I did was I got myself involved in Golden Products, purely not from the business point of view, but to have contact with people. (Researcher: To find an alternative.) Yes to find an alternative. I threw myself into my hobbies, one of which is photography. So in that way I made friends outside of school. And I could still continue to be a people person. I’ve kept contact with many of the staff at the school. In fact I’ve kept contact with staff wherever I’ve been,

purely because I am a people person and I need that. And having realised my own need, I try to impress it prior to the cutting off. But, it was a shock.

Researcher: But it was wise though wasn't it?

Gerda: Oh yes, I think we all need to think in terms of retirement, but not just three years before it happens.

Researcher: How old were you Gerda?

Gerda: I was 55 years, turning 56.

Researcher: I think pain affects a lot of people's relationships. (Gerda: Yes it will. It has to.) And in your case you were able to see it coming and you were actually able to do something, and maintain your close relationships.

Gerda: Yes, but it's something you have to work at. Relationships are not something that just happen. Relationship is something like having a treasure chest. If you keep taking the treasures out, there's nothing left. But if you're building a relationship, you keep putting in regardless. If one person breaks it up, then it's destroyed. You both have to work at it. It's not an easy job. But, it's a very rewarding one.

Researcher: And Gerda, in terms of relationships with the family, your children and your husband. Did the pain affect you? Did you find that you could cope?

Gerda: I coped. It affected them more than it affected me.

Researcher: In what way Gerda?

Gerda: In the sense that they became stressed, because they couldn't do anything about it.

Researcher: Okay, but you had their support.

Gerda: I had their support all the way through, and I thank God for that. James, my husband has been an absolute star. During each of these operations, he's literally carried me through. There were times when he couldn't be there. But, latterly, he's always endeavoured to be at home after such an operation. With the back operation he was at home for the initial part, and then a friend of mine came to visit, and she stayed on to look after me when he had to go away. But it was a question of always doing his best to be there. If I had to go in for an operation, it didn't matter what it was - he was there. He waited through the operation with me and after it.

Researcher: It sounds to me as if it's actually brought you closer.

Gerda: Yes it has I think, and it has affected me. James needs to have someone depending on him, and being a very strong personality, he doesn't always experience this. And at these times to him it's precious, in that he is there.

Researcher: That's wonderful Gerda.

Gerda: So that helps. In that way it is good. It does add stress to them though. The result is that it does affect one's relationship with them as well, because you're trying not to show always what you feel and what you're experiencing. That has a detrimental effect in two ways - because you're hiding - or think that you're hiding - but they perhaps are picking up things from you by the way you act or say or do, and then this makes them react, because they don't know what to do.

Researcher: Do you think that they misread?

Gerda: Yes they do (- Researcher: - they take it up the wrong way?) Yes, very often they do. This does happen. There are times when you do not quite know what to make of it. You don't know whether you should just be ugly or whether you should hide it.

Researcher: That is true, and to find that balance of when to reveal how you're feeling, and when to hide it.

Gerda: That does affect relationships. You cannot help it. It's part and parcel of it.

Researcher: But, you can't complain all the time.

Gerda: No, you can't, and the thing is you have to come to a point basically, where you are prepared to be vulnerable. (Researcher: Right.) And if you're an independent spirit, being a vulnerable spirit isn't easy. Vulnerability is something that – if you want to build a relationship – is absolutely vital, because you can't build a relationship without it. Being exposed to all a mother's fears, joys whatever, and again in that respect turning to God, I've been able to get the balance I need in myself. I may not always get the balance in the other person's life, but I get it in mine. Does that answer your question?

Researcher: Yes, I think it does, because something I've been made aware of is this sort of conflict between when to reveal how you're feeling, and when to be quiet, and the effect on your relationships because of the same thing and to what extent to be open. Some people, I find, experience a drifting relationship. But you are obviously one of those people who has been blessed with James, and that's brought you closer.

Gerda: I think if one looks at it, it's something that you yourself choose to do.

Researcher :Yes, you've got to work at it.

Gerda: I think something I've been made aware of over the last number of years particularly, is the fact that one has a choice. (Researcher: Right.) I can choose to be miserable, or I can choose to be cheerful. I can choose to cope, or I can choose to give up, and I must choose to be satisfied with whatever the situation. I think now of this particular friend of mine that I've just got the news about this morning. It must be shattering. She'd been hoping that it was all gone, and now it's come back with a verociousness, that only those who know what cancer is, can know what that feeling is. You are facing death full stop, one way or another, sooner or later. All right we all face it, but coming in that way is, I think, a fear that we cannot comprehend. I know, I couldn't. When I look at her and I look at Mary, I stop complaining about myself. I have much to be thankful for. I have pain, yes, but I still have hope. I listen to my sister-in-law, who has lost my brother, and the hopelessness that is present in her

voice, makes me shudder. How does one enable her to get to that point of acceptance? You can't. You can help to a degree, but it's a choice she has to make. We cannot erase what has happened.

Researcher: It's that acceptance. You keep coming back to that idea of once you have accepted it you can adjust.

Gerda: Once you can accept something you can work it through. If you can't accept it, you can't work it through. She's different. My niece again is retarded, so that is totally different. In her mind she is a child. She can't accept that. She doesn't understand that as an adult I must learn to understand and accept. Even when I don't understand, I can still accept, and then work it through. And this, I think, is vital with chronic pain. If I can understand something of where my pain is coming from, and if I can understand something of what it can do to me and to those around me, then I can work at it through God's grace. Psychologists help up to a point, but can't go beyond that point.

Researcher: But listening to you actually giving people an explanation and a demonstration to the mechanisms is very important, because in many cases chronic pain doesn't make any sense.

Gerda: No, it doesn't make sense.

Researcher: Normal expectations are that the pain gets better, but chronic pain doesn't.

Gerda: No it doesn't, and then you get a letter from a friend who says "but they should be able to do something to contain the pain." Then you sort of smile and you think to yourself "well does that person really know what it's all about?"

Researcher: No they don't.

Gerda: Again it comes back to the acceptance of the pain. There are certain things God changes, and allows us to change, others he doesn't. But, he has a purpose in everything.

Researcher: But, I've found Gerda even the Medical Aid, in treating someone with chronic pain, very often there's a lot of resistance, but you actually find that physiotherapy helps to keep it at bay.

Gerda: It does help to keep the pain at bay, because the moment I become stressed, the muscles tense, and when the muscles tense, it pulls on the nervous system, and then the pain is worse. So if I can go for physiotherapy, at least it eases the pain for that while, for that span of time, and I'm able to cope better.

Researcher: Because you know there is a way out.

Gerda: I know there's a while anyway that I'm going to be free of pain, at least relatively free of it. And truly as I said to a doctor friend of mine – at least to his wife – “Please just say thank you to Carl again, because that nerve block has alleviated the actual sensory pain to a large degree.” I'm still aching. I still have a lot of discomfort, but the pain level is markedly lower. As a result, I'm able to cope with the other, so medical help and faith – all these things work together. One cannot compartmentalise everything. It's because you're a whole person – body mind and spirit. So if a psychiatrist or psychologist can help me to reason, and I allow God to utilise it together with the medication, then I have a coping mechanism. Any other questions?

Researcher: I think that's it Gerda. Thanks so much!

TRANSCRIPT OF INTERVIEW WITH MOLLY

Researcher: What I would like you to do, is to explain in as much detail as you can your experience of chronic pain.

Molly: Do want me to just give you - to start when I was put on disablement with chronic pain or before that the operations or what do you want me to do?

Researcher: You tell me how you have experienced chronic pain. Start wherever you want to.

Molly: You don't mind if I look at you. I don't like looking at the mike. When I was a teenager my pain in my back actually started. But being a teenager and this was quite a number of years ago - it was put down to growing pains. I never did go to a doctor with it because, you know being a teenager its normal. I just left it and then it got worse and worse but over the years I just left it. About 20 years later my back - I could hardly walk I had such terrible pain in my lower back. Now let me go back - 15 years ago I was about 32, 33 somewhere thereabouts, and I then went to see a doctor and he discovered that I had the tumour on the spine and with the tumour on the spine I'd obviously - they said to me it wasn't new - it hadn't just formed. It had taken years to form. And with the tumour growing there, it had weakened the bone structure. So by the time I went to the doctor for my back it was already messed up quite a bit. The first thing of course was to go in and find out whether the tumour was malignant or not. But when they operated they actually had a problem because of all the scar tissue that had already formed. They actually couldn't get to the tumour with the first operation so they did as much reconstructive surgery of the bone and cut away some scar tissue and everything.

Researcher: What were they trying to do, were they trying to fuse the back or remove the tumour?

Molly: Both. They were trying to remove the tumour. That was the beginning, but then when they opened me up they realised there had to be a fusion but that they'd have to do it at a later stage. The second op they got to the tumour and it wasn't

malignant. But it was like they had to cut part of it away because it was making the bone weaker then they decided the bone was very, very weak. They would have to fuse it and it started off at the S1, L5, L4 but above that the L2, L1, were also shaky, but they started off right at the bottom and did the fusion at the bottom.

After the operation I must admit that the pain was a lot better than it had been before I went. Before the operation - now I'm going back again - I tried different things. I obviously tried physiotherapy. It helped relax the muscles but it didn't help the bone pain. I tried a chiropractor but that made it definitely worse. The chiropractor at that stage - at that stage we didn't know what was wrong with my back - these were all things that I tried - alternatives. I went for acupuncture - the acupuncture didn't seem to do anything. Didn't make it worse didn't make it better. It just didn't seem to help at all. Physiotherapy definitely did help. To a certain degree but not to the degree where it was taking my pain away. I was living day and night with pain. Now after the fusion the pain was definitely better to start with. It wasn't the same kind of throbbing pain that I'd had before the op but - and I was very good after the op. I wore my brace and I didn't sit and - and I really listened and it went very well until I went back to my day-to-day activities. First all I worked in Johannesburg. I would drive myself through.

Researcher: What sort of work were you doing?

Molly: I did training for the bank. I did quite a lot of travelling and as soon as I started getting back in the car - driving through in the traffic - by about lunchtime I could feel my back was really - I could feel the strain on it. I kept on with the physiotherapy all the time. I never let go because I always found that, that helped the pain a little bit.

At this point I was taking painkillers but not on a daily basis. I was just taking them when I really needed them. Then I went in and they decided that the top was really - the vertebrae had also just - the vertebrae had just crumbled so they needed to do another fusion. So what they did - they did a fusion on top of the other fusion. So I had two plates and screws. When I came home after about it must have been about a month - I can't remember - after that op I developed a lot of pain not just pain from

recuperating - in other words from the surgery - I could feel it was in my back too. It never seemed to steady off like it did with the first two operations.

Then the screws in the plates actually came loose. The bone just crumbled around the screws. And the screws came loose. So I had to go in and have all the metal structure taken out of the back and the pain was really bad especially when the screws loosened because every time I would move there would be a problem. But this time I started getting very depressed as well because I thought I'd had these two big back operations and now the third one. I was actually - the pain - nothing had helped. So they went in then and they put in the bigger plate with the screws and everything. When I woke up from that operation and I think this depressed me a lot because I realised the doctors weren't actually listening to me. They were listening to what needed to be said. Because when I woke up I'd kept complaining about pain in the hip. The back was sore where the cut was - that was sore - but I kept complaining about pain in the hip. They kept saying it was referred pain from the back down and at that time I didn't really know a lot about referred pain.

Researcher: Did you feel it was referred pain?

Molly: No. I felt a distinctive pain in the hip.

Researcher: Separate from the back?

Molly: Separate to the back. The back pain was there. I knew what it felt like to have a back operation and wake-up. And to feel that pain - I knew that. But I also had a pain in the hip. Six weeks after the operation they eventually listened to me and they did an x-ray and what had happened when they took the bone out of the hip to do the bone graft they had actually cracked the sacroiliac bone and there was a crack about two inches down, in the joint, but of course, by this time, because it had been left for six weeks it had inflammation, and it had started growing all skew, so there definitely was - I could feel the different pain and I was right.

Researcher: And what did that feel like for you Molly?

Molly: That was the first time now I started thinking “this is definitely - I've done the wrong thing and I should never have let them touch my back.”

Researcher: How did you feel towards them?

Molly: I was cross. I was very cross because I knew I was feeling two separate pains because of the fact I'd had the op before and I knew what that pain was like. I was the one who was experiencing the pain. And for them to just say to me its just referred just leave it. Instead of just - even if I was hallucinating, I feel they should at least have taken the time out to just do tests or something to see if there was something in what I was saying. If there was nothing, if there was no problem you know, they didn't pay for it! I was the one who was losing out. So by now that time the medical profession - I was looking at with - I kind of thought they are not interested in the actual person in listening to them. They put back patients in this step 1, step 2 and 3. You fit into those steps as soon as it is a little bit odd, you don't fit into those steps anymore then you're the one left with it.

But by that time the back - while it had gone higher up it was the whole lumbar region. Then they said to me the only thing they could do for my hip was a whole hip replacement. I refused. I thought I am not - I have let them touch my back I am not going to let them touch my hip. Let me see once my back recuperates what the pain is like. The hip pain has never gone away. To this day I've still got it. And I still blame the medical profession for it, because they didn't listen to me. I feel that as I was paying them, they should at least listen to me.

Researcher: So that leaves you very angry.

Molly: That leaves me very angry. But not as angry as I became after my next a lot of operations!

Researcher: I wanted to ask you something about what you said. Yes you said if you don't fit then you're the one left with it - (Molly yes) - can you elaborate on that?

Molly: Yes what I find is that the neurosurgeons, orthopaedic surgeons - because I had - I don't know about other back patients but I always had a neurosurgeon as well

as an orthopaedic surgeon operating on the same time for me so I have - both were covered. What they would do before you had an operation they would give you a list and it would say, right this is the operation you're going to have and they start on the day before you have the operation, and they give you this long list up until six weeks after the operation. And anything that on say day 3 you get up. If something goes wrong - like for instance - the pain in my hip was so bad and when I got up my leg just crumbled under me - but on day three you should be able to get up. So it was put down that I was weaker, and it was the operation that it made me weaker. It wasn't my back that was weaker. I don't know if you –

Researcher: What did they say was weaker? Was it that you were physically weaker? Did it mean it was you as a person who was weaker?

Molly: Physically as well as mentally “I wasn't putting my all into getting better.”

Researcher: So it almost as if you were blamed for the problem.

Molly: That is right.

Researcher : Rather than that someone said “Look here's a problem”

Molly: That is right. I was not wanting, ja - I was not co-operating with the medical profession. Because I did not fit the steps as they went along.

Researcher: So did you feel quite written off? Or did you feel criticised?

Molly: I felt criticised and I also felt written off. Because the more I'd said - every day when he came in I'd said "no, the back is getting on fine, but my hip is aching and as a result I felt as if I was a child trying to get attention and nobody would listen to me.

Researcher: So your whole experience was that no one would accept what you were saying.

Molly: My whole experience was..., that is right. Then of course as the years went on the plates and screws once again crumbled in the back. They had to take it out so all in all I had at the end of the day four fusions, three laminectomies and a neurolysis. But as this happened, I just totally - after each back operation I went - I didn't just go to one person for an opinion, I went to three people. I made sure I got three opinions every time, and everyone said to me "no they're sorry that it would have to be fixed" Then I started wondering in my own mind although I'd also got three opinions - even when I had my very first back op "did I do the right thing?" Then I started blaming myself, because I kept saying to myself "Molly, if you hadn't let them operate," because I mean I did - I signed for them to operate. If I had not let them operate that very first operation my back, when they went in and did the laminectomy, that pain was a lot better than I was now experiencing, because after the third back op and with each back op the pain got worse. And not the pain of the operation, the surgery as such, but the pain that I had to *live* with after that. I found that a lot of my activities had to be curtailed. For instance I had started losing a lot of feeling in my right leg. And I had to be careful because sometimes when I drive I lose total feeling in the right leg and I have to pull over to the side of the road. I couldn't sit for long periods of time I had to move around. Getting up and down, I was finding difficult. So I could see myself going down, and the pain getting worse with it all the time. But at the same time the doctors were not offering anything new as such to try and help me. They were just saying we have to operate, we need to operate. By this time now I was blaming myself for letting them operate in the first place. Obviously I couldn't leave the mess so I had the operation until the very last operation when the pain was unbearable. I really was having days where I couldn't get to work I couldn't do my job, I was totally useless and they decided to do a neurolysis. So I thought, "well they are trying to fix the nerves let's go in and see what happens." So I had the op. They didn't even try to finish the op. They just sewed me up. When I came around I was told there was too much damage. They could do nothing for it. So now I felt that I had spent the last six or seven odd years with the medical profession, I wake up and they say to me "there's nothing we can do."

At the same time they told me one of the things you are not going to be able to do you are not going to be able to keep up with your job.

Researcher: How did you feel about that?

Molly: Psychologically, it was terrible because you see I felt not only were some of my actions curtailed now, but they were taking my job away. They were taking my livelihood.

Researcher: Where you ready to give it up?

Molly: I wasn't ready to give it up. I fought them on it. I fought them for six months on it they kept saying because - obviously I needed to go to the doctor I had so much pain.

Researcher: Who told you to give up your job?

Molly: The actual neurosurgeon.

Researcher: The neurosurgeon? Not your company?

Molly: No the company were fine. They were quite happy but I would go to work -

Researcher: So did the surgeon feel that your work was making it worse?

Molly: Yes that work was aggravating it. That the back was in such a state that it needed, for instance, if I was up for an hour, walking around that I needed to lie down for a period and I couldn't sit for long periods I couldn't drive around in the car in the traffic and I fought the medical profession on it. I really did. But the pain kept getting worse I was losing something. (Researcher: You were losing something) First of all it wasn't just a job and a way of getting money, I enjoyed it. So it was my career. It was my career. Also I was very worried about if I did give up work what would happen to my brain? I could come and stay at home and everyone thinks when it is wonderful just to stay at home but if you don't keep yourself occupied and get into something I just felt I am going to go downwards. I'm not going to stay steady. And then at that point that was pretty bad because of the pain because at that time I was taking painkillers every day

Researcher: It sounds as though you started to look ahead a lot and wonder what was going to happen to you.

Molly: Also at that time (pause)

Researcher: It also seems as though you look back a lot and wonder if it could have been different.

Molly: That is right. I wondered if it could have been something totally different. I could have carried on with that pain and I was still able to do things whereas now after all the operations - they were supposed to have helped but it was worse. I did put a lot of blame on myself I really went through a bad patch. I didn't only blame the medical profession - really at that stage the medical profession was terrible as far as I was concerned - but I blamed myself a lot. Then after about six months of them telling me I needed to give up my job they then said to me "look it is so bad on your back, the pressure you are putting on your back, we are going to go to your company and approach them. So, you either do it with us, or we do it." Because they felt I was now saying to the medical profession "you've got me this far now you've got to help me!" Something had to happen. They said they were trying to help me and one of the places they could help me, was that I had to stop working.

Researcher: But how did you feel?

Molly: Terrible. I felt as if they had not only taken my back - my back activity - a lot of the usage of my back- they were also now taking my career away, plus my livelihood!

Researcher: So did you feel you had lost control?

Molly: I had lost control. My back had taken over my life. And I couldn't see much out of it at all. (Researcher: Your back had taken over your life) So my back had totally taken over my life, everything. It was keeping me awake at night because of pain. I wasn't enjoying going out any more because wherever I went I would have to

put make-up on my face to greet the band and put a smile on my face and that was another thing - I hated letting people see I was in pain. I really didn't. And by this time I was having a lot of pain.

Also what had happened during the time period of all these operations, after each operation they would obviously give me painkillers and eventually I'm now allergic to 90 percent of the painkillers on the market. I actually can't take painkillers so each time I was actually a little bit worse off. Because now there was another painkiller and another antibiotic for that matter that I couldn't take. So - everything was worsening, nothing was looking brighter.

I then decided I would approach the bank and so with the doctor's letter - obviously they had to give me letters and all the rest of it - not believing, I must be honest, I thought "okay I'll keep the doctors quiet. I'll take their letter. I'll hand it into the bank" - I knew that the bank would send me to their doctor. I mean it's the normal thing. Your employer would send you to their own doctor, for an assessment. I thought, "I'll get away with it that way." Especially with the back. It's not like something you can see. When somebody tells you they've got backache - and this is one of the things I felt. I didn't want to tell anybody - I thought they are going to think "it's in the mind." So that's why whenever anybody asked me how I was doing I would say "fine." "How's your back?" "No fine." And it wasn't. I didn't want them thinking, "oh, it's her back again."

Researcher: As though there is something wrong with your mind.

Molly: Yes it's all in the mind.

So I thought "well their doctor doesn't know me - it'll be all in the mind." And I would keep my doctors quiet that way. Well, it backfired on me because when I did go to the bank's doctor he said to me "look this is between me and himself and the employer" then he said "I'm telling you now you can go back and pack your desk." He did a full neurological examination and he said "no there's too much damage." So as I said it backfired on me and the bank put me on medical disability and I really went through a difficult time.

At the same time the medical profession said, "you must learn to deal with your pain." When I asked "where do I go to be taught how to deal with my pain" there

was no such place. They couldn't help me. I just had to learn to deal with my pain and at first I really was in a terrible - I went down mentally a lot .

Researcher: In what way, Molly?

Molly: I just - I was very depressed. Very, very depressed. Because I just felt all of this had happened now I'm on my own - totally on my own. I have lost the use of my back. I have lost my job. Now I'm relying on a small pension. When I tried to do my arts and crafts and I have pain. I couldn't go to the doctors, they didn't want to see me with my pain after that. The neurosurgeon in fact that told me, "don't even come back for a check up. There's nothing we can do for you."

Researcher: What did that do to you?

Molly: I was so angry I really was. If I could have strangled him I would have. Because I just felt that all along he'd been there, he'd been operating on me, he'd been taking my money, he'd got me to this point in my life where I'm really low, and now he doesn't even want to see me for a check up as such. Obviously, he didn't know what to do with me.

Researcher: Are you saying you've felt betrayed?

Molly: Yes I did. Because now that he didn't know what to do with me, and - it's not just that I'm having a dig at that doctor, because I did try other doctors - it was to the point of fact that he said to me "he doesn't make mistakes." So once again he was putting the fact that the operations hadn't succeeded - it was my fault. And I knew that after the operations I had been very good. I followed instructions, I had done exactly what I had to do. In fact after the one op, I was in hospital for six weeks. So I couldn't have done more.

Researcher: You couldn't have done more.

Molly: I couldn't have messed it up, but I was in such a slump that I actually believed it to a certain extent at first. I felt very depressed. I really did.

Researcher: So you had this terrific loss, and you've felt betrayed and you were feeling depressed and you were told to deal with it.

Molly: To deal with it, and there's no way to go to deal with it. The only relief I was getting, I went for physiotherapy twice a week. And that would help the spasm. But the bone pain stayed there - and again like wintertime I really battle in the wintertime. When it rained I would battle. And when I looked forward to all of these, you know I would say "well I'm looking forward to something" and then the weather gets real bad, and I would fall a lot with this leg that isn't steady - I battle with it. And I would fall and then of course I would hurt my back. Now off to the doctor I would have to go again. And say "please, I need something for pain."

Then, not only that, I had a kidney problem, and with a kidney problem I'm not allowed to take any anti-inflammatories. So that straightaway also took away another thing out that could help me, and it just seemed as if I was going down a path with no help. I couldn't help myself. The medical profession couldn't help me. And I got so low until I went for counselling. And at first I didn't want to.

Researcher: To a psychologist?

Molly: Yes. But at first I didn't want to go. I only saw --, I thought "what is the point?" This is a real thing. But then I started doubting. And I started thinking to myself "now maybe if I go to the psychologist I'll be able to sort this out and I won't have the pain. Maybe it is psychological.

Researcher: May I ask the question? When you went to the psychologist were you looking for relief from the pain, or were you looking for a way to cope?

Molly: I was looking for relief from the pain.

Researcher: You were still looking for relief from the pain, because it sounds as though everything you've done, - the surgery, - was looking for relief from the pain.

Molly: Was to get rid of the pain.

Researcher: And the only thing that did make any contribution was the physiotherapy but that wasn't a solution. And then you started to think maybe this was in your mind.

Molly: This is what I thought. What I thought - if I go to the psychologist, they'll be able to fix the mind, which would take the pain away.

Researcher: Okay. Which would take the pain away.

Molly: No to help me deal with it.

Researcher: Did you again to think it was a mental problem?

Molly: Yes I did. I personally did think it was a mental problem because you couldn't see anything.

Researcher: Because you can't see anything?

Molly: Because I couldn't see anything I just knew that I had this dreadful pain nobody could help me, I thought maybe it was a mental problem. Nobody could help me. I thought, maybe it is psychological.

Researcher: And Molly, the fact that the fact that you had all the tests. And ops done -

Molly: No it made no difference. It made no difference.

Researcher: Didn't make you think it was "real?" You still thought it was psychological?

Molly: No. It made no difference. I still thought it was psychological.

Researcher: And before that - sorry, I'm just asking you for my information - when you first went for the ops and they would do tests and they would operate...?

Molly: I believed then there was a real problem.

Researcher: Then you thought it was a “real” problem and when all that failed you started to think it was “psychological?”

Molly: I started to think it was psychological - something within me. I was weak psychologically. And as a result I was feeling pain that wasn't really there.

Researcher: So then you went for the counselling, thinking that that would fix it?

Molly: So then I went for the counselling thinking that that would fix it. Of course they battled.

Researcher: Who battled?

Molly: The psychologist. For the simple reason, as I said, I was there to take the pain away, not to learn to cope with the pain. So at first we battled until we realised that it was my mind-set, but it took - even with the psychologist sitting me down and explaining to me after having a couple of sessions - explaining to me “Molly, this is real. Have a look at this x-ray. Have a look at this scan. See this is your back. This is what a mess it is in. This is what it should look like. This is what it does look like.” Having the neurological tests of the feeling on the leg and everything. Showing me the arthritis in the bone. I still battled, and you know to this day I still battle. Now and again I still lapse into thinking it is psychological.

But once we'd got that sorted out - and I worked on it - we worked very hard to get me to realise that I had genuine pain. It wasn't psychological. Only now can I sit and think back the reason I did that was because I thought it would be so much easier if I had a mental problem because that I can work on.

Researcher: Okay.

Molly: That I can work on and try and solve and fix. But if it wasn't a mental problem and I had genuine physical problem there is nothing I can do and the doctors were right.

Researcher: - and then?

Molly: And that's why I was so - I was actually grasping to the fact that it would be mental.

Researcher: Because then if it was, you could get relief again.

Molly: Yes I could get relief again and the pain would go. So it was very hard -- I tell you it was about two years that I went through this utter turmoil, even to the point of fact that - you're going to think I'm mad now.

Researcher: No I promise you I won't.

Molly: I even went to a - no not a psychic somebody who - and I don't believe in this at all. I really don't believe. But I was so desperate looking for someone to tell me I was a - what is the word when you keep going to the doctor for nothing?

Researcher: A hypochondriac?

Molly: A hypochondriac. I really tried this. I'd - everyone I went to, I wanted them to tell me I was a hypochondriac, for the simple fact that then I had hope. I thought I could go to Tara. I even had it in my mind that I would go to Tara, and I would heal and come out after that, and my back would be better. So now when I sit back and think of it I can see it. I grasped at it I really did. And the doctors had a hard time. My GP - I felt sorry for my GP because he had a hard time. And the more he would explain to me that "Molly it is not a psychological" I just put up a block. I really did. I put up a block and I wouldn't let myself think otherwise.

Researcher: And were you still going for therapy over those two years?

Molly: Yes. Then with the therapy and working through it and (tape ends) doing meditation and working on myself spiritually as well - I realised, I came to the realisation that no I do have a physical problem. But I every now and again do tend to

go to the position where I believe that my mental my mind - every now and then I slip backwards and I have to - have a real battle with myself because I ignore my back. If I take painkiller when my back starts I'm able to control the pain. If I don't it gets into such a bad spasm that by that time it's terrible and I then had to go to the doctor to have any injection.

Researcher: And what do they give you?

Molly: Pethidine. (Morphine.) and that's another thing. I became totally - I couldn't go to the doctor and ask for a Pethidine injection, because I felt like the drug addict. I really did. I felt like " here's another thing that my back had done. I was now - and the medical profession- that I was now a drug addict." The only thing that would take the pain away was to have a pethidene injection, sleep for two days I and then I'd wake up and then my back by could start over again and start doing things.

Researcher: So for you a very important step was to come to accept that this was a physical problem -

Molly: That is right.

Researcher: And to learn then to-

Molly: I had to learn to deal with it.

Researcher: And to take your pain pill when it started.

Molly: To rest up.

Researcher: To control it?

Molly: To control it. To rest up you know. Obviously if I go and walk around the mall all day, tonight I'm going to have pain. So I had to learn to change my lifestyle. I had to learn that I can't drive far distances. They were right in saying I shouldn't drive on the highway. I saw that. But of course it also - and pain took a lot of away from me all

because now I couldn't help somebody. I couldn't drive where I wanted to go. I couldn't do what I wanted to do. The pain got in the way. So I then began to really dislike like my pain. It was very hard to learn to deal with it.

Now for instance - the unfortunate thing is when they did this operation now for my bladder they had to put the modulator in right next to the spine instead of in the stomach because my back is in such a mess they couldn't turn me over on the theatre table . And just this past Friday he had said to me when I came out of hospital, "you are going to have pain like you have with a back op. You have got to treat it as if you have had a back op. Another back op." This straight away upsets me because I had said I would never have - and after the tenth back operation, I said I would never have another back op. Now I've got a doctor telling me I've got to treat - I've got to act as if I've had another back op, so we are right back to square one. So that upset me. But with the machine working so well so wonderfully for my bladder - you know it's worth it but I still am in a terrible amount of pain. A friend of mine said you've got to go to the doctor, so I phoned the specialist and said "I'm in pain". He said, "then you need to go and have an injection." And I was so upset and I really didn't know what was upsetting me. I knew, okay, I had a lot of pain. And I've just recently had the op. And I've been in intensive care so it was quite traumatic. So I went to the doctor and the doctor said to me, "Molly, you know what you are doing. It is your bladder that had the problem. It's your bladder that was fixed. It didn't fix the back." So psychologically I was back to my old thing of thinking that if I get help in one area it would spill over. Somewhere along the line it would help the back. Now I remember the doctor said on Friday, "Molly you are not being fair to yourself," because I was in tears and I wanted to know why. I said that I've had the op it was a success. Why have I got to come for an injection? And with him explaining to me that "you didn't go in for the back, there was no advantage for the back. We worked on something different." That's what got me.

Researcher: Molly, it sounds to me, listening to you, that that actual understanding of the mechanism of the pain and what is being relieved is a very important part of you being able to handle it. Or am I misunderstanding you?

Molly: No that's correct. That's what I'm trying to say.

Researcher: So when they can explain what is going wrong you can accept it but if you don't know -

Molly: If I don't know I feel overwhelmed?

Researcher: You feel overwhelmed?

Molly: Yes. And this straight away I'd start thinking Molly - every time when I have the bad pain - I start saying "is this not you being a hypochondriac?" I have this thing about being a hypochondriac. I really do. It's a big thing in my life. And I go to the doctor and I say, "are you sure? Are you 100 percent sure this is wrong?"

Another thing a little bit off the subject but on the subject, also that I blame the doctor - the medical profession. When I had the last operation the last back operation, I was told at that stage "the back will get so bad that you will end up in a wheelchair. You might lose the functions of your bladder, you might lose the functions of your bowel". When I heard that, I also once again put a block up, and thought "okay, when I'm 80 years old. It will happen." So when six months ago, my bladder gave in, and it became paralysed, when I first went for those tests I knew already that this is what it was but I didn't say anything. When I got the results of the test it was what I knew it would be. The bladder was paralysed. I then once again felt so betrayed because now not only was my job taken away and my livelihood and everything else, and what I could do physically, now I had lost control of the bladder. I now had to have a bag and a catheter. Which put me - I was so depressed. It put me right back down into depression again and it was just - I battled through that still trying to get used to the catheter and the bag and everything until the doctor the urologist said to me that mentally I wasn't coping with it. I would need counselling again. But at the same time he introduced me to the doctor who does these neuro-modulators, and he tested me and said I was a perfect candidate for the machine. So he inserted the machine and as I said it's working 100 percent. So my bladder is working again, so I'm on top of cloud nine with that.

Researcher: Because you've got some relief.

Molly: At least that problem was solved and I don't have to walk around with the catheter bag anymore. I couldn't imagine anything worse. But I blamed the back doctors for that.

Researcher: And Molly being warned that this could go wrong, was that a good thing or a bad thing?

Molly: A bad thing. I think because now - at first it wasn't - now that my bladder went, it's very much real. I kind of now I'm waiting for the next thing to go because they definitely said that the bowel could go - the legs could go.

Researcher: It created more anxiety. So they sort of took away your hope?

Molly: They took away my hope and as I said not worrying about it at first - it didn't worry me. Then the bladder went, then I realised it's a real thing that could happen.

Researcher: So as you said in the beginning you were looking forward and saying "how much worse can this become?"

Molly: Yes. And it can become a lot worse.

Researcher: And it's frightening?

Molly: It is frightening.

Researcher: It hasn't happened.

Molly: No it hasn't happened yet. But I now realise it could happen any day and all through this of course I still live with daily pain. There's never - even as I'm talking to you now I'm in pain. It's different. The intensity of pain. But I have pain all the time. My movements are restricted. I have to have a special bed, a very hard bed. I never get a night's sleep. My back wakes me up. At least two three times at night. Then I've got to walk around a little bit to get relief. To get actual stimulation to my legs again because my legs go totally pins and needles, cramps and I've got to get that

(movement.) So my life really revolves around my chronic pain. And when you take tablets of course you aren't all with it I can't obviously drive a car to go to the shopping centre if I walk around the shopping centre too long the back aches.

Researcher: So you feel that the back controls you?

Molly: I feel that the back controls me. And sometimes when I'm really up I will go ahead and ignore the back. Knowing that tomorrow I'm going to suffer for it if I want to do something now I will go ahead and do it. And rather suffer tomorrow rather than sit back all the time taking things quiet and live my life like that. I've decided that you can't live life just not doing anything. That's not living. So now when I'm able to do something I do it. I grasp it with both hands and go for it, knowing that I'm going to suffer. But luckily now I've found a doctor who is very understanding talks to me a lot about what I'm going through who is there for me, and is sympathetic and listens. Sometimes not necessarily - sometimes I come away from them not having had anything for the pain but just having had someone understand and listen to me because I felt at one stage none of the medical profession would listen to me except the physiotherapist who was with me - I've got the same physiotherapist from before I had the op right up until now. She knows my back, I feel, better than any of the doctors. Because she knew what it was like before I had it. She knows what it's like now. She has also agreed with me that the ops really did more harm.

Researcher: More harm.

Molly: More harm than good.

Researcher: But, Molly, listening to you again, it sounds as though for you to cope you've got to sort of, what's the word, you've got to know how far you can push it and when you've got to back off? Am I right?

Molly: Yes.

Researcher: You saying to me if you do a certain amount you know you have a certain amount of pain. There are times when the best answer for you is actually to lie up and rest.

Molly: Yes.

Researcher: You've got to learn to...

Molly: To learn to control - know how far I can push - my body - my back. I should say my back. I've got to know how far I can push it. They have been times when I, and there are times, I can't say there have been - because there have been and they will continue - that I do overstress my back and then the only thing that helps strangely enough is total bed rest with physiotherapy and I know a lot of people have said now, the medical profession have said that the bed rest doesn't work, but the bed rest does work for me. It really does. I know there's this new thing it's not good to lie up but with my back, at a certain stage, for me to go to bed for a couple of days and total bed rest really does work. But that is when I've pushed myself too far. And then I know I can't go further. And sometimes I end up in hospital with it for four days and where they just treat me, I have physiotherapy, I have painkillers, and I can just lie up and I don't have to do anything, and then I'm back to square one again. I can start all over again. Until I do something really stupid again and push it too far.

But I now and I still believe it - that I should never have had the first back op. Tumour or no tumour. If I had known then what I know now I would never have let them touch my back. I would have rather taken the chance of the tumour being malignant.

Researcher: Really Molly?

Molly: I would rather have taken the chance.

Researcher: But you can only say that now.

Molly: Yes. Then I didn't of course - you know obviously - with hindsight you know - you always know better with hindsight - but that is over now. When I looked at it, obviously the first thing you want to find out - is this tumour malignant?

Researcher: That's life itself.

Molly: That's life itself, but now looking back I've got a lot to live for. I get involved with a lot of things I keep my mind occupied.

Researcher: What sort of things Molly?

Molly: I work at a Bible correspondence school. I mark papers. I do arts and crafts. And I sometimes teach. I sometimes just go to our ladies Bible class every week. I have a prayer meeting in my home once a week as well. I try and do visitation. Sometimes it has to be over the phone. So I try to do visitation, physically or over the phone.

Researcher: So you are very involved in the church?

Molly: Yes. Yes and as I say the arts and crafts I really enjoying doing. Sometimes I'm curtailed in what I can do. With my back. I've battled to sit at the sewing machine but if I do it in small doses - but there are again I'm the sort of person when I start I want to finish it - so I push through and finish it and then for three days I can't move because my back is so sore (laughs). But I have now learnt over the last two years that the sore back that I have afterwards is worth it, because I feel in myself that I have accomplished something. I'm not just useless. I've got the pain but I would have the pain anyway so why not push through it and feel a sense of accomplishment in myself. Also I've tried - I keep up with what's going on with the bank and the work I used to do and everything so that my mind can keep going as well, so I'm not totally out of it and don't know what's happening. And we go from day-to-day. That's another thing I had to learn which I found very hard. I never looked at today. I would look at the future what's going to happen tomorrow, and what's going to happen next. I've had to learn with my back to actually cope from day-to-day, because I don't know, - I could wake up fine in the morning - some mornings I wake up fine - but by that

afternoon I'm in excruciating pain, so by trying to put things far in advance, and all the rest of it - I've had to cancel appointments and cancel certain things which I can't do, which made me very depressed. But I've learnt now "Molly, you have to take it one day at a time, because if you try and cope with the pain for six months you can't. You've got to just try today's pain and get through today and see how it goes." I've learnt that you can't do it all, thinking because if I sit here now and think of the back pain that I've got here now, and that I must endure this for the next 20 years, it puts me in such a depressed mood. It really does, because I think, "Molly, don't worry about it. Get through today. You never know what's going to happen tomorrow."

Researcher: So if you think it therefore 20 years you can't -

Molly: I can't cope. I can't look ahead and think ooh...

Researcher: There's no way out?

Molly: Yes. I keep - although I've said I'll never have another back op, you obviously - as soon as I see an article or I hear about someone doing anything - last year - I tried going back for acupuncture he said to me he could hardly get the needle in through the scar tissue at all.

(Molly began shifting on the couch)

Researcher: Molly do you need a break?

Molly: No I'm fine. He said to me he was wasting my money after about six treatments. He said its just not working. I had reflexology.

Researcher: Did he feel it was not working or did you feel it was not working?

Molly: No it really wasn't I just felt - I thought to give it a fair try. There was my physio. The day I go for the physiotherapy, that night I'm sore, and I hurt, but the next day it's better. So I thought - I thought this is what might happen - that is certain - I've

had reflexology because I find although it doesn't help the bone pain, once again it does help me relax, and if I can relax, it takes as certain percentage of the pain away.

Researcher: Any relief is...

Molly: Any relief is better than none.

Researcher: Is a - what's the word I want - is a positive thing?

Molly: Yes. So I look for ways that would just give me relief in different ways and then you add all of that up and at the end of the day you've got an amount of relief, whereas if I had just left it I wouldn't have had that relief. The pain would be just that much worse.

Researcher: Molly, do correct me if I'm wrong. It seems to me that to cope with the pain for you, the first step is, that you had to accept it, and accept this as a reality, and now, as I listened to what you've just said, you are talking about relief, but you are not talking any more about being cured.

Molly: No.

Researcher: You are talking about what I can do to relieve it, and I have still got some pain, so it sounds to me as if a very important thing -

Molly: Was the change in mind-set that I had.

Researcher: Of stopping looking for the cure, and actually saying it would be there and what relief I can get is a bonus. Is that how you see it?

Molly: Yes, that's how I see it. At first I just fought it all the time thinking that I wanted it cured. Totally cured. And I had to come to the realisation that "Molly, no matter what you do, it is done. It cannot be cured. And you've now got to look for ways to help yourself to deal with it more."

Researcher: And now the fact that you know that there are some things that do relieve the pain how does that help you? Or doesn't it help you? The fact that, you, for example, go to reflexology, and for physiotherapy, and you know you get some relief what does that do to you emotionally?

Molly: It helps me a lot. To know that there is something that is still there that I can grasp that I can hold on to - because I know that if I go for the physiotherapy - I will get a little bit of relief. If I go for the reflexology, I will relax a little bit. It definitely does work. Things like that and that's why I, I've tried everything I've tried the pain machine. I have tried that - similar to this modulator that they've got in my bladder now. I've tried one for the pain in the back. They tried me on one of those for six weeks.

Researcher: Similar to those nerve stimulators?

Molly: Unfortunately it did nothing.

Researcher: For the back, or for the bladder?

Molly: For the back, because I've tried one for the back as well. It didn't help - it didn't help relieve the pain at all. I was then told that the reason for that was because of the dense scar tissue. The scar tissue was just too bad so the current couldn't get through. And that's why it couldn't really help the pain. But I'm always on the look out and I speak to people who might have something because you never know someone out there might know of something that can help but I never - I no longer think of it as a cure. I think of it as something that can help me with the pain. But not, I know now that I have a very real problem and it's not going to go away. But when somebody comes up with something, I try it the next thing I'm going to try - a friend of mine is using these, I don't know what you call it, they are like little rods -

Researcher: Magnets?

Molly: Magnets yes. I'm going to try that now.

Researcher: They are used by one of those doctors who work with Professor S.

Molly: Yes I went to that pain clinic as well. Yes I left that out. I was very disillusioned. Because I went to the pain clinic, first of all for the reason that I didn't want to take strong pain killers. Which was fine, they took me off the pain killers. But then they gave me so many uppers and downers, there were sleeping tablets to make you sleep, muscle relaxants to make the muscles relax, but then in the morning when you wake up you must take an antidepressant because of the muscle relaxant had made you depressed then you needed something to get your muscles going. It was about 20 different tablets you were taking and I didn't know where I was. I was really drugged. I said no. This wasn't for me. I just couldn't handle all those tablets. I never felt as if I was in control when I was on them. I didn't like that loss of control. It was all very well getting rid of one pain tablet, but to replace it with all these different tablets, I didn't see the use in that. I really couldn't see where he was coming from.

Researcher: And Molly with your relationships and your personal life, how has your pain affected those relationships?

Molly: It has definitely affected my relationships in that I don't always feel as if I - I don't want to say good enough that's not the word I'm looking for - I must be a pain to be around, if that makes sense. I just feel like - it's like - and people now, they mock me about it. (I'm fine with it.) But if somebody asks me how I am, I will never say "I'm in pain to day" Never!

Researcher: Why?

Molly: I get the feeling that people must think, "Oh, here she goes again. She is in pain again. She is never not in pain."

Researcher: And you feel that is not acceptable?

Molly: I feel that is not acceptable. I think they must get tired of it. Even with my family, I think surely they must get absolutely sick and tired of hearing me. Saying I've got pain, my back hurts. As a result when my back really is sore I try to hide it

from people. It is only in my eyes that you can see when I've got really bad pain. But I don't like saying to people "no, you know, I've got pain today." And in a way that's also bad, because people have said to me "we know you are lying, we know you've got pain." Most people will say to me now "I'm not going to ask you how you are. I can see how you are." And it's become acceptable. I'm getting a little bit used to that now, I'm - there are certain people who I know I can say to "no look, I'm having a rough day." But I won't just say it to everyone. I would rather say "No, I'm fine, it's no problem." I just feel as if I'm a weakened person if I admit to the pain all the time. I feel as if I'm weak mentally if I admit to the pain.

But it takes over your whole life as I said. It takes over relationships with your family, you know quite often I'll be invited out and I go. And I'm battling halfway through the thing, and I really am, and I go to the toilet and I cry in the toilet. And I think "oh I can't wait to get home so I can take a pain tablet, and lie down". But I never go to someone and to say "listen, I need to go home." I try to hide it all the time.

Researcher: That is difficult.

Molly: Maybe in a way, when I look at it, it's because I still have that block, where, I don't want to have the pain. Not that I'm saying anybody wants to have pain. But I think I have a real problem with admitting that I have pain constantly.

Researcher: And with other people there

Molly: With other people there. Yes. And you don't want to dampen the day. Everyone's having a good time you know, the whole family is around, and you are all having lunch, you don't want to dampen the day for everyone. You want to be lively and part of it, to be able to do things. It's difficult sometimes. It really is.

Researcher: It comes back to what you said, you don't want to feel you are a burden.

Molly: Yes. It took a long time for me to be able to ask people for help. Even just to get to the doctors. I would, no matter how bad I was I would drive myself to the doctors. And I would end up on the pavement sometimes. I just didn't know where I

was driving because of the pain. But I'm getting better. I really am, I'm getting better. But it took me a long time to reach that point.

Researcher: So you think that is one of the things you've had to learn, to need help and to ask for help.

Molly: To admit to someone that you need help by asking them to do something for you. It's very hard. But I'm getting better, I really am. And strangely enough -

Researcher: Do you live on your own?

Molly: Yes. And strangely enough, I have found the people I have asked - I have never had a problem. They have never minded. It's been, you know, fine with them. It didn't worry them at all. So I think that has helped me as well. By starting off slowly, and only asking in real necessities and circumstances and that, but now that I'm doing it I feel more at ease. Asking for help. Because I'm learning that people don't mind. When they say "If I can help in anyway just phone" they really do mean it.

Researcher: So Molly do you think part of the problem is that one assumes that people are going to be critical and judgmental, but in fact they are not?

Molly; Yes, but in fact they probably won't

Researcher: But you don't really know that.

Molly: No. No you don't.

Researcher: So you tend not to test it?

Molly: Because you are frightened of being rejected and if that happens I know for a fact that I'll go right back to being in a state of depression. So it's like slow steps, baby steps to tread out. The last six months I've really had to rely on people a lot. To the point of fact where, when I was having the bladder problems, I came out of hospital and I was just so sick, there was no way I could stay on my own, I was able to pick up

the phone and ask a friend of mine “please come and get me, I need to stay with you.” And I stayed there for a week.

Researcher: That is great.

Molly: So, that I was able to do that, now I would not have done that, two or three years ago. Never. But I've got to the stage now, where I now realise for my own good people do mean that they are there for me. And so far I haven't come across anybody who has been offish or anything like that or said “no, I can't help” type of thing. (End of tape.)

Second interview with Molly

Researcher: All right, Molly, when we were at the end of the last tape, we were talking about the effect of pain on relationships with other people and you were telling me how willing people were to help you, that there are a lot of people who have never had a problem, but that one is reluctant to ask for help. Then you started to tell me about the support group that you joined and that and at that point the tape ran out.

Molly: Okay. About the support group. The support group was actually set up by the doctor, the neurosurgeon, who did my last operation. And with it being a support group, we didn't have a psychologist or anyone who knew anything. It was just a bunch of ladies who had all had back operations and were now battling with pain. So what he did was, he asked us, he gave, could he give us names and he would give our names to people and we ended up with the support group. There were about six ladies from all over. We all found we had similar problems when we spoke, the main thing being you now had permanent pain which was affecting your life, but where did you go for help? Because here we were trying to help each other but none of us was qualified to help each other. We could say to her “oh persevere, I had the pain yesterday and it'll be better tomorrow” but we did not have professional help. So we were not getting what we really needed. But we tried amongst ourselves to keep our spirits up and give each other ideas on what we could do. If one found a good acupuncturist they would tell us, and all of this.

The only thing that happened, in this, and what I've found, is that some of the people in the group lived for *now*. They weren't, they didn't have an idea of eternity

and when this life comes to an end there is another life. They didn't have Christianity in their lives as such. And so the pain became all engulfing because they had nothing left. They had absolutely nothing. All they had to look forward to was daily pain. They felt they were being like - and I also feel this at times - although people are so nice, and have offered and will do things if you phone in, you do feel as if you are a nuisance. You feel as if you don't want to go to a party, because you're fine for the first hour or so and after that you've got pain and what have you, and we all had this problem. At the end of the day also in that group which I found very hard, two of the ladies committed suicide. One tried to commit suicide. But didn't succeed. As a result of the group actually - I still speak to the one lady who was the one who tried to commit suicide. Her and I still speak to each other. But it was very - it made me realise that although I've got pain now, it's not the end of everything. I've got the pain, I've just got to persevere and get through this lifetime. But I do believe in an after life. I do believe in Christ and God and I do believe that my pain will eventually be taken away. (Researcher. So you've got hope?) So I've got hope. Whereas I've found the other people actually - and this is where it was frightening- because when I looked at my life, I realised as well that without God in my life and although I've got my friends and my family around me I didn't actually have hope because I knew my back was actually not going to get better. The pain was not actually going to go away and every now and again I do go into a state of depression, just feeling that from day to day I go on, the back gets worse what do I do? It's like that especially now, as I say just having had this op now I'm stuck. I really am.

There's nothing the doctor can do for me except to say to me you must just have something for pain, rest up and take it easy. But it is very difficult when you've got to live your whole life like that. You feel isolated, useless, you don't want to be around people, because you don't want to tell them you've got pain, and as I said I'm now very wary of support groups because of what happened. I was very close, especially to the one lady. I was very close to her. And she actually on the night she committed suicide she sent her husband - she lived in Bryanston- she sent her husband here, with a pack of books for me and some tapes, and a letter. And when I read the letter, I somehow knew that she was going to do something. But she had tried many times, and had never got it right. And I phoned and her husband said to me that she was sleeping and I said to him "Are you sure she's all right?" And he said "Ja, she's fine she is sleeping." But what she had done is, she had arranged it so that he thought

she was just sleeping, he was going away early the next morning. He left to go down to Durban, and she had actually passed away in the night. So they didn't even know until the maid came in. I was very close to her because we spoke, she would phone me every day, every day on a daily basis. And our problems were more or less the same, - the only difference being that financially she was very well off. And had everything and it just shows that you can have lots of money that it cannot buy your health. It cannot take the pain away. The pain is there and no matter where you are on the scale, whether you're wealthy, whether you're not wealthy, whether you're on the street or what ever, pain is pain, and everybody feels pain. So that was what - I just automatically didn't want to talk to many people after that. Because I thought it was doing us more harm. As I said I still speak to the one lady because she's kept up and on friendly terms we really do she's been battling very much with the pain to point of fact when she doesn't drive well or do anything. She's got a full-time maid, she's got a cook, and everything. And I think that is one of the reasons why you actually go down. I'm not trying to point a finger. But when you have to do things for yourself, you have to get up and you have to cook otherwise you go hungry. But if you've got a full-time maid, and a full-time cook doing everything for you, you don't try and put in an effort. There are days when I can't do anything. I really can't. But then there are the days when I know I can try something today. I can do this or I can do that. And I've learnt to take each day as it comes, and if I'm having a good day I make the most of it, because tomorrow I might have a bad day. And I feel there that I am actually privileged - that I actually have one up on people who had everything done for them. And don't get me wrong, I'm not saying I don't have a lot going for me. I do. But I think you also have to have a bit of reality in your life, you have to do things.

Researcher: You know, is that was one of the things I wanted to ask you about because you mentioned that there are times when you have to take it easy and take your painkillers and so on, or lie down, but then, a little while later you emphasised to me that it is also very important for you to do things. To have a sense of accomplishment. (Molly. Yes). And when I looked at what you said, I wondered if I would be correct in saying that having this pain puts you in a very contradictory kind of situation?

Molly: Yes it does. I think I know what you mean. Where quite often, because there's nothing wrong with my brain - and I think that is what makes pain so difficult - there's absolutely nothing wrong with your brain. Your brain is still active your brain still wants to do things, your brain still wants your body to do things. But your body, because of the pain, just cannot work with your brain. And it is very frustrating. Very very frustrating to have that - because you've actually got a little war going on inside you and sometimes I will push myself when I know I've gone too far. Just for the simple fact where I actually get cross with the pain. I actually get mad at the pain. And I think, "you won't stop me doing what I want to do." And unfortunately, the pain is very real. Just last week I went to the doctor again. And I said "but I can't understand it, my bladder is working, why is my pain, why have I got so much pain?" And he said to me, he said "listen, the bladder has been fixed. Nothing has happened to your pain. You have to realise you do have pain." And I go through spates where I tend to think "Molly, it is in the head you don't have physical pain" so it is a war going on all the time where you have to fight yourself because you've got to - as I said they are some days when I just stay in bed for the day. Have a warm bath and get back into bed because the pain is so bad.

Researcher: And yet it is equally important to do things. (Molly. It is important to do things.) Perhaps the word is more that you live with a lot of conflict?

Molly: Yes. You live with a lot of conflict. You do. You want to do things and you've got to fight and you've got to keep on doing things. I believe. Because the day you stop, when you think, "this pain has just got the most of me. I'm now just going to do nothing" - the pain has won. You can never let that happen. So I am actually glad that sometimes I will force myself to do things. Because that the end of the day I've accomplished something. And you feel good. And this, strangely enough, there's a good pain and a bad pain. That sounds strange.

Researcher: Tell me about it.

Molly: The bad pain is when you've just been in bed all day, the pain is terrible, you feel depressed, you haven't accomplished anything, and you've got all this pain. Good pain is when you've accomplished something that day and you've done something

really worthwhile. It doesn't need to be spring cleaning the whole house or anything. It's just like maybe you've cooked a big meal. And you go to bed and your back is aching, but you know to have accomplished something. So as a result you think, "well okay I've got pain, but I also cooked a big meal today."

Researcher: So it's as if you can retain your sense of worth?

Molly: Yes. You've got to. As I said there's nothing wrong with your brain, and as soon as you start saying, "no, I will not do anything," then you tell your brain that I'm switching off now. And it's a fight. It is not easy. You've got to fight it. And that I believe you do need people around you who also encourage you to do things. I am very lucky I've got friends who at the time when I need to be in bed they will actually say to me "Molly you are going for an injection and you are going to bed." but then there are other times when they say "well why don't you come and spend the day?" And I may be feeling really down and I say "I'm having a pity party." Then I'd go out and spend the day just at a friend's house. Not do anything. I sometimes take my own book with me. Sit and read or something. But I'm out of my house environment, and it's just a difference. So you have to fight it. It is a daily battle. It is a daily conflict in your life. And you've got to learn to live with it. It's very difficult. It really is. Pain is not easy to live with. Because people also don't really realise what you are actually going through at times. And you can't blame them. Myself, I never look ill. I can be in intensive care and I look as rosy as anything. And on the other hand I've got dreadful pain. But people who know me tell me you can see it in my eyes. They tell me you can see the pain in my eyes.

Researcher: And Molly, the fact that there are some people who can recognise it, even if you say is nothing how does that feel for you?

Molly; It gives me a sense of well-being if I can put it like that because I know I've got people around me who will be honest with me, who can be honest with me, because I allow them to be honest. This didn't just happen overnight. I've had to work on it. It doesn't happen. When you have the first back op and the second and the third, and all the rest of it, and the pain started getting worse, you start realising it's tough. It's very tough. To deal with it and work with it. As I said the neurosurgeons and

orthopaedic surgeons sit back and say, “ this is what has happened to you, now you've got to learn to live with it.” They don't realise that 24 hours in the day is a long time when you've got constant pain. It's very easy just to give in to that pain. It is very easy just to feel sorry for yourself, and you cut yourself off from the world. But I've had people, I've been very lucky, that I've had friends, that I've had family and my GP support has been fantastic, because they are right behind me. I can phone and they'll say come in and sometimes I just go in and have a talk and they will make me a cup of tea. I talk to them. I don't necessarily have anything else. But I can do that and I feel much better, and I can come home and cope with it better. So I have been very blessed in having people who encourage me in both ways - when to stop and when to do things, because quite often you can do both of them. You can feel too sorry for yourself for too long a period, or you can try and look at the pain and ignore it. And that doesn't help either. You've got to every now and again admit, “yes I have got pain.”

Researcher: So are you saying both are a way of coping?

Molly: Yes you have got to have a balance.

Researcher: How did you find that balance?

Molly: Through trial and error, and I still have times when I don't have that balance, when I get very depressed. But with talking to people, I did go for counselling and that counselling helped tremendously. In that I could talk about it, and I could see from somebody else's point of view what was happening. That counselling helped because I could hear when they would give me feedback what I was saying and where I was coming from. It also gave me an avenue, because obviously I would have homework, and I would have to work on myself. And to see if I could now do things. I also do believe in, every now and again, and I'm not a writer, I hate writing. I have never been a writer, but what I've found is if sometimes I take a piece of paper and I will write down all my frustrations, exactly how I'm feeling. Then I would throw the piece of paper away. But it gets it off my chest. I haven't had to bother someone else. But it has helped. And that's about the only time that I write.

It's constant, you have to work on yourself. And especially when you are down as I said if you have got a support group where you've got friends and family, and even your doctor, who gives you encouragement, there is that much more that you can do yourself. But I still have my days, trust me when I am in tears, and in pain, and I don't want to know anything and don't want to see people. I am lucky in that way, because I am the type of person I live on my own, and I enjoy my own company I can keep myself busy for days. But I also do go to the point where I feel now I have got to have company, and I have to get out. Then, I am not shy about it. I will pick up the phone and say to someone, I need company. Or I will get in my car and I will go and do something. So that has never put me off. I can go and talk to people, or I can pick up the phone and say I need company. Can I come and have a cup of tea? That helps a lot as well. I don't have to look after the family, I don't have to be there for children. I can go and get into bed so I am lucky in that area. I don't have to cook a big meal every night. And to be quite honest I don't know how people who have to do that cope. And I haven't met anyone yet who has got the problem with constant pain who has to look after children and do school activities, and all that type of thing because I don't know how you would cope with that. I try, sometimes I get involved with my niece's school activities and everything as well, so I can get a balance there as well. I love my arts and crafts. So I keep my mind occupied as well. I won't just read magazines. I will read a book that gets my mind working and I do believe in reading a lot. And having a lot of feedback from my book. I choose the books carefully that I read so that there are times when I need an uplifting book or challenge or whatever and I listen to tapes. I listen a lot to tapes I have people's sending the tapes from all over the world that I listen to. Some relaxing tapes some exercise tapes, some ordinary just gospel tapes I keep myself busy with that, I find it really does relax me. Also too, I'm lucky in that at night when I wake up I can get up and I can make as much noise as I want to in this house because I'm not waking the whole household up. And I do I wake up on an average five to six times at night with the pain as I turn. I don't sleep for longer than an hour at the most. Mostly it is half an hour. And then I wake up. And I have to get out of bed and walk and get the circulation going. Get uncramped and all the rest of it. And I'm lucky because as I said I can put on all the lights and go and make a cup of tea, in the summer time I walk outside I even take her outside (the dog) and go and walk around the garden in the middle of the night so I am lucky in doing that. Whereas, if I was in the family situation that would not be so

easy either, because you would think “no I've got to be still, I've got to lie still, because I'm going to wake the whole household up.” So there are the a lot of things I have got - yes I would love a family, but at the same time there is good in being single as well. But I would love a family. I can't say I wouldn't and everyone I think would say that. But I have learnt to cope with myself, I am happy on my own.

Researcher: When we spoke about the conflict I could see that you felt that conflict with regard to other people. When to tell them that you've got pain and when to ask for help. But it seems as if you have worked that out. It is also part of your way of coping with the pain.

Molly: It is part. It had to be, because when it first happened, I would not tell anyone.

Researcher: Yes. And even now you are not keen on telling everyone.

Molly: Yes. I am not keen on telling everyone and sometimes I will have so much pain that I can feel as sick as can be that I won't say anything. but I am getting better because I really am. Because I know people genuinely - I know people now who genuinely are interested. I also know the people who are asking me just to say hello they are not really asking the “how are you?” I had to learn to know the difference. That's hard.

Researcher. And Molly, in the long run, which is better, to be able tell people you have got pain or do you find it better to sometimes hide it?

Molly; It is better to sometimes hide it.

Researcher: Okay. So you need to do both.

Molly: You need to do both. They are people who are really asking you how you are just as a greeting. They are not asking you how you are because you have got pain. So I have learnt as I said I know the people who are asking me because they really want to know, and the people who are asking just to say “good morning” type of thing. I would hate to become a burden to anyone. And I have actually said to people,

especially my family and my close friends, I have said to them “please will you tell me when I come across as a hypochondriac”. I have actually asked them to do that and I have said that I mean it. I have. I have a friend, I call her a bully, but she bullies me for the right reasons. She will bully me when I just need to stop feeling sorry for myself she will tell me. “Molly, you need to stop feeling sorry for yourself.” I am glad that I have got friends like that. Who see me for what I am and feel comfortable enough to tell me that I have now got to pull myself up. At other times they turn round and tell me to slow down. So it's good - it takes long, it takes quite a while to know who you can trust and who really is not interested. And you will find that a lot of people actually do feel for you. And they are the a lot of people, you do not realise how many people are out there who actually do feel for you. And do realise that you have got this pain. And that you have to live with it on a daily basis. And I thought I - I and really embarrassed and I don't know if I should say this on tape.

Researcher: Shall I switch off?

Molly: I get cards and letters from people and sometimes it's people who I don't even realise, I know them but I am not close to them and I don't even realise the influence that I'm having. And they will write to me and to say what an encouragement I am to them seeing how I deal with my pain and my situation being the way it is.

Researcher; That is wonderful Molly. How do feel about that?

Molly: Look it makes me feel wonderful. It really does. At the same time I tried not to get, how can I put it, too secure in my knowledge that yes I can deal with pain. I've got to realise that “Molly, it's a daily fight, you are going to have to fight it daily. It is not something that you have fought and it's over with.” But it is so encouraging when I get, from people sometimes to either least expect, and I will get a little note saying what you did yesterday - I might have done something like take a plate of eats to the ladies Bible study, and they will say “we can't believe that you, with your pain, brought this.” And it just shows you that just because you have pain, you don't stop your daily life. But it is very encouraging when I get these notes. I do still, I must admit, I feel embarrassed sometimes. Because then I think “Molly, you have to try harder, you have to be even better.” If people are watching you, you also feel as if you

are on an open stage and you have to live up to certain conditions. And at one stage I went to that extreme, where I thought, "now I've got to be fine. People think you are fine, you have to be fine." And it didn't work. You know you can become too cocky with it. And you think you are coping so well, you on your own now, and it doesn't work like that. Each day is a daily fight. It is a new day. But at least I know people are out there and they see things I don't even realise I have done. I really don't realise, I don't even know what I have done. People have said for instance, I have gone out to visit to people, who are ill, and they will say "but what are you doing here?" And I mean why can't I be there? Just because I have got pain doesn't mean that they must come to me. You have to learn to live your life. And there are other people who are far worse off than me and they need encouragement. Just as much as I need encouragement. I find it very therapeutic to be able to help people who are having a difficult time healthwise or what ever, bereavement, because I have been through the a lot of bereavement, and I do, I find it therapeutic to be there for them and to help them with it. Because I can understand what they are going through. And now with pain, I can understand what pain is like. So I can be there, and I want to be there to help them. Because I know I have been there. And it is so different when you talk to somebody who has had pain is opposed to someone who has not had pain and they don't really know what it is all about. They might get a headache once in a while. And they do not realise that it affects your whole life. Everything that you do.

Researcher: So Molly, what you are saying is that the fact that you have had pain has enabled you to better help other people?

Molly: Yes. Yes it has. My life when I left work changed drastically. Here I was going around the country standing up in corporate offices of big corporate clients, giving lectures, speaking about the subject that I knew very well, and I knew I could stand up, because I knew my subject. Now all of a sudden here I was, at home, my brain is not doing this, I am not able to do all of this, and I had to learn a new way of life. I had to learn I could no longer get up and do speeches like that and giving lectures like that, but there were other things that I could do. Going to help people who were bereaved or people in hospital or this type of thing. So I had to learn to change my life. So I was, and I still am -I miss my job. Because it was interesting and exciting. But now, on the other hand, my life is interesting and exciting. In a different

way. That it is interesting and exciting. I can do things now that I wouldn't have been able to do when I was working, because of time constraints.

Researcher: So it is as if the pain situation has created a different set of opportunities?

Molly: That's right. It is different opportunities. Whereas before I would not have had the same empathy with somebody with pain, that I have now I have learned as I have said that I can go to visit people who are sick, and it doesn't bother me. Before it would have got to me. Also even if - I would be busy, I would not have time to go to see them. So - time constraints. Took my time up and I was not able to do a lot of things. So my life has changed. It's like two different lives in a lifetime. It is like the life before pain and the life after pain. It is very different. Very different. But I can now say that I am content with the life, and the things I am able to do now. At first I was not. I really battled. I battled tremendously. But as I got more into it, and more involved, and realised that it was just as rewarding, as what I was doing before, if not more so, I can do something else now. It does not mean that everything was taken away from me. My life is different, but I'm still useful.

Researcher: And that is important.

Molly: That is important. I think that when you let pain get the better of you and that you start feeling useless, which is this one lady that I was close to who committed suicide, that what she felt, she felt she was totally useless to everyone and everything in the world, she was just being a burden and when you let that get the better of you, it is...

But please, at times, I do start feeling that I am a burden, and that is when I then go to somebody and I can say "listen I need to talk. This is the way I am feeling"

And I never used to talk about my own feelings. Before I had pain. I could speak to people as I said, to big corporate clients, on the subject that was out there. It did not involve me. I'd used to introduce myself, say who I was, what I did at the bank, (tape ends)

What I then learned, when I had pain, I had to learn to speak about intimate things that I had always kept to myself. Even when I was a child I would never talk about myself. I would never run and tell stories and so on, and say this is how I'm

feeling today, or whatever. I was always a very introverted person when it came to talking about myself. I didn't like speaking about myself. I didn't like people to speak about me. I wanted them - that was all private. The pain has taught me - and in a way I think it's good - the pain has also taught me that "Molly, if you want to help people you have to also put yourself out there, you have to lay yourself on the line, you've got to lay yourself bare, as such, and let them see that you do realise what they are going through because this is what you are going through. So you've got to share. What you are doing and how you are working. When you struggle, they shared with you." And it helps a lot. When you can share with people. And as I said to you I can talk - I find that when I talk to somebody - and just this has been very therapeutic for me just this whole little interview that we have had is very therapeutic because you actually talk and you get it all out and it's not all bottled up inside it is not all sunk in there and it is so much easier.

Researcher: I am glad.

Molly: I would never - four or five years - ago, I can now walk into the doctor's room, burst into tears, sit down and have the poor soul look at me, and he doesn't know what to do, - and I will just sit there crying and I can just tell him what is happening to me that day, whereas, I would never have done that before I would never have let people see me cry. I would have waited until I was on my own. But the pain has actually given me, as I said, an- almost like an assurance that you can understand people because you have been through it. You have travelled the road, and that road has opened up doors to you.

Researcher: And I can see that you have learned how to recognise your own feelings and you know how to go and get help. You know who to go to and to see. (Molly. It takes time.) It has taken time, but I think it seems a very important part of the way you have handled things.

Molly: Yes. Yes you've got to, as I said, your life has got to change. You've got to realise that now you need help. So you look for areas, where do I go for that help? What do I need to do? You as I said, you know who you can talk to, you know who you don't talk to. And it's hard, it's a long process and it's a hard process. And every

now and again you fall backwards, but as long as you know where you can get help and say okay this is a new day what am I going to do? But it is a struggle every day, pain that doesn't go away. It's a struggle.

Researcher: On that subject, it seems to me that the fact that this pain doesn't go away makes it a different experience to an acute pain.

Molly: Yes totally different. Before and now I was very lucky, when I was young I wasn't ill at all but when I then started with my kidney problems I would have a kidney infection and it was acute, it was sore, and I could go to the doctor, I would get my antibiotics, it would go away and it was totally different. I knew that within three or four days, I would be fine again. There would be no problem. I now know, sitting here today, that in three or four days I am going to have the pain. It will not go away. But at first you don't realise that, well I didn't. I didn't realise that at first. When I had the constant pain and I kept looking for things that would take it away just as if it had been an acute thing which you can get rid of it's not chronic it's acute you can get rid of it. It took me a long time to realise that "Molly, it's not going to go away. You've got to learn to live with it, and in a way you've got to learn to cope with it." There are days that you don't cope. You've got to learn other coping methods. And then you've got to go and speak to somebody, or sometimes just to sit with somebody and cry. It doesn't necessarily help your pain, but it does in away help your mental pain. Because you realize" look I've still got the pain, but I feel better for having spoken to somebody about it and they have the least understood me." But it is very hard in the beginning when you've got constant pain and you don't know, you don't actually realise, that this is going to go on and on and on. It takes a long while for you to actually start realising that nothing I do, there isn't an op out there, and there isn't a machine out there, there isn't anything out there that can help me.

Researcher: Molly, what is that realisation like? (Molly. Frightening.) That there is nothing out there that can help?

Molly: Frightening, very frightening. For the simple reason that you know you're on your own. As I said, you've got a support group, and you've got friends and family who love you and all the rest of it that at the same time you are on your own with the

pain. You are the only one who knows the kind of pain that you go through.
 (Researcher. So you are isolated). You are isolated. The pain isolates you. It is
 frightening. To know that it is not going to go away.

Researcher: What is frightening about it?

Molly: Because you don't know if you are going to handle it. Tomorrow or today.
 (Researcher so it's the fear of not coping?) So it's the fear of not coping. It's the fear of
 not coping with it, because you can get so low down that and every now and again it
 happens to me I feel that I cannot go on another day. That is when I go and I get help
 somewhere, just to mentally help me. But, sometimes it's even physical help, because
 what the doctor does is, they put me in hospital every now and again, total bed rest,
 knock me out practically, so I mean, I am awake, but only just barely awake for four
 to five days at a time, and that happens about two to three times a year. But then I can
 come out of there. I have got pain, but I can start afresh again.

Researcher: Does the pain lessen, or do you find just having had that break enables
 you to cope?

Molly: Having had that break enables you to cope.

Researcher: So that feeling that this pain is a long term, unbroken thing is what makes
 it is so hard?

Molly: It makes it hard . And when you just see that this is a long road ahead, that I'm
 probably going to live until I'm 96 years old so I've got this pain for another 50 years,
 and I think to myself "I can't cope." You panic, you do, you panic and this is what is
 frightening - you are actually panicking and you think, "no, I can't cope." You take
 your eyes off "Molly, do today what you can do today." And it becomes too much for
 you because I believe in my case mentally I then get so run down that I can't cope. So
 obviously doing that helps me to boost my - obviously the back, the spasm is not so
 bad, the pain isn't as bad as when I went into hospital, it is better, but it's not, it hasn't
 gone, it is still there in a different degree.

Researcher: So it is that chronic nature of pain that is the frightening thing?

Molly: Yes. Very frightening. Because it's very easy, your mind - your mind is a real strong force. As soon as your mind tells you that "no Molly, you're not coping and it's too much for you," then you realise that the mind is taking over and that is when you need to get help as well. Because it does bring you down. I believe it makes the pain worse. I really do. It just makes it less easier to handle.

Researcher: You know, when you spoke about going for counselling. You mentioned that you started working on yourself mentally and spiritually. I wanted to know what you did, I was so sorry I didn't ask you what did you actually do to work on yourself mentally and spiritually?

Molly: Okay.

Researcher: That struck me as a turning point.

Molly: It was. It was a turning point. First of all what I started doing, I started working on my confidence level. Because pain had taken from me, as I said I was doing an important job, I had all of this going for me, and all of a sudden here I was sitting at home with nothing going for me. So I had to start looking for things that could boost my confidence where I knew I could do the job just as well and that there were still things in this world that I could do. I wasn't useless. So number one I had to start looking for things - I had to get involved. Because without getting involved in certain things, you don't know whether you can cope or not. So first of all I've got involved, I've got so bad that I turned nothing down at that stage. I went through as stage where I would do anything. If someone said "would I do this?" I said "yes." I was doing about five different craft things, I actually gave - one of the big things that I did was someone at the Church, that the ladies Bible class actually asked me to speak on my life story and I never believed I could do that. And I said "no, no, no, no." Eventually they said, "no, you will do it." And I did do the talk on my life story, it wasn't just the pain, it was my whole life story, losing my mother early and being with my father, an alcoholic and I was able to stand up there and give this talk without even crying. The whole audience cried, but I didn't cry. But it was things - at first I

really did - I took everything that was going. Until I sorted myself out, but that was the first thing. You've got to learn to say "yes." That is number one. The more you say "no," the deeper you go into yourself. You've got to say "well I'll try this." Even though I've got pain, I'll try and get through this braai or whatever. So I didn't turn down any invitations to begin with.

I started working on myself physically. I now don't. I have put on the weight again, but I managed to lose quite a lot of weight, I'm not one to do much exercise, but I started walking. That helped. The walking helped tremendously because while I walked I could think, on what had gone the day before, on what was going on today. So that thinking process, the walking wasn't just physical, mentally as well I was going through my mind what I could do and what I couldn't. So that was a step.

When I looked better and I could wear clothes that weren't so "Frumpish." I have also started feeling better within myself. I started feeling better in myself because I was accomplishing things, that I had said yes to, that I had started trying.

Spiritually, I started doing my own morning quiet time. I then started getting involved with people who needed things, and I could see that spiritually I had my lows, but if I worked on myself, by every morning having my quiet time, and everything, built myself up, it ended up better. Now as I said, I now have a prayer meeting in my home once a week we have started that and everything, which has helped me a lot. You know, it's not just praying for myself, we actually pray for - people have said to us "please pray for this, please pray for that" but it has helped me a lot to be able to do that. Spiritually I'm just able to do that. Whereas at first I wasn't I had to work through all of that. And it is a hard walk, because every now and again you want to stop, and say, "oh no, I just want to give in." But then I'm right back to square one, and all the hard work that I did to get myself out of that, is lost. That in itself is an impetus to kind of get you to realise "Molly, you cannot lose. It was a hard battle. You can't have done all of that for nothing. You've got to do it. You've got to carry on." That helps.

Researcher: And it involves you again with wider concerns.

Molly: Wider concerns. You are not just worried about your pain. Because sometimes when you see - although you've got the physical pain and it's there, people have so many different types of pain and when you see that, sometimes you come home and

you say “ well, thank you that I've got the kind of pain I have got, because I can cope with it. I've got people who can help me cope with it.” Because when you start looking at other people's problems, a lot of the time our problems are not as bad as we think in our heads. I am not diminishing, trust me, pain is bad, but at the same time you realise you are not the only one. Pain comes in all forms. So a lot of it is, you've got to be able to say, “I will work on it myself.” And when I started off slowly, I then started to pick up things and do things and then afterwards I sifted through what I needed to do and what I could do and dropped what really wasn't - I couldn't keep up with, keep track with, I left that. I now do what I can do. And that helps me to go forward.

Researcher: Another thing that you said earlier, you said, that you believe in Eternal life. And so for you, that kind of spiritual dimension gives you that break (in pain).

Molly: It definitely does. And another thing - now I'm going to sound a bit morbid - I'm going to just move down a bit (changing her position on the couch.)

Researcher: Do you want to stop?

Molly: No I'm fine.

Researcher; I would hate to cause you to become more sore.

Molly; No, I look as though I'm in the Roman times. I look as though I'm in the Roman emperor's time. Now what was I about to say?

Researcher: You were talking about the long term outlook and Eternal life, and that would be a break.

Molly: Yes. I was going to say the one thing I have also come to terms with, having worked through, as I said, it also helped my spiritual life, when I learnt to work with it and to sort myself out and all the rest of it, (Researcher. Do you mean it made you spiritually stronger?) It made me spiritually stronger. To the point where - you now going to - because a lot of people were shocked at me when I said this. I have at

times, when the pain has been real bad, I have actually prayed that God would take my life.

Researcher: I can understand that, Molly.

Molly: And a lot of people have been shocked. They have really been shocked. And I have one day - shame it's a lady, she is old enough to be my mom, she is in the Church, and she calls, we call each other mom and daughter - And she said to me one day - and I didn't realise - I knew I was doing it - she said to me one day she said "you know, Molly, I pray to the Lord that he would rather take you." And I wasn't shocked or anything. I was fine with it. But somebody overheard her and it was "how could you do that?" But to the point where, I don't know if you can call it contented, but I am aware that you have to keep your spiritual life at a good level and you have to keep trying and everything because it could happen. I can't do one thing and then pray for God to take my life, knowing that my life isn't ready to be taken. So in a way that also gives you encouragement. To do your best. So it did actually help in a way. And I don't look at it is being negative.

Researcher: No, it sounds to me as though it is a statement of faith.

Molly: Yes. I don't look at it is being negative at all that a lot of people do. I see it as hope. The other thing I used to always say when my pain - when I first heard the problem, and all the problems and I couldn't cope are used to say "one day I am going to ask all these questions! When I get up there I wanted to know why, why, why?" I now don't. It does not matter. One day when I have gone from this earth, it really doesn't matter why it happened. Who cares? I'll be in a much better place, so what if it happened on this earth? Hopefully it will have helped someone. Hopefully I was able to show someone something. And if I get to heaven - or I should say when I get to heaven, it won't matter. So that has changed - my outlook on that has definitely changed. I do not constantly ask "why me? Why has this got to happen to me? Why did this happen to me? Why did I never find a husband? Why didn't I have children?" And when I stopped asking all those questions and I learnt to be content with what I have got and to make the most of what I have got then I realised it was that much easier to deal with the pain.

But when you are feeling sorry for yourself with other things, with other areas of your life, and you've got to deal with the pain, trust me, it doesn't work. Like every month when I do my budget it doesn't work!

Researcher: So Molly, stopping asking why, comes back to that point of acceptance. When you stopped asking why, it sounds as though that was part of accepting.

Molly: Yes, yet it is. Because you are not out of there constantly thinking "why did it happen? Maybe I could have changed things. Maybe, if I had done this" - because I did do that. A lot of times to do, you tend to be hard on yourself you tend to think "but if I had done this differently things wouldn't be like this I have brought on this pain myself." And when you start doing that, you get into the real circle of feeling sorry for yourself because you blame yourself and your kind of think "well, I was stupid to let him operate." But at the time, thinking back now, now that I have come through working on myself, I now realise that at the time I did the best thing. I did what was best for me. But at first I didn't think that way.

Researcher: One of the things I wanted to ask you - because I could see that you really regretted going for that back operation - the first one - what did you see as the start of your chronic pain? Did you see it as that tumour or did you see it as the back operation?

Molly: I saw it as the back operation

Researcher: I thought so, but it wasn't clear. And you somehow seemed to feel it was your fault.

Molly: Yes. For long time I blamed myself. Because I was the one who ultimately signed on the line for that operation. And when I look back, I'd do, I think, "why did I do it?" But when I think about it too, I didn't do it hastily. I tried everything before hand I went for different opinions, I did the right thing. So now when I look back I can say to myself "Molly, you did what was right. You did what had to be done at that time." But it still does not help every now and again when I have one of my pity parties by keep on saying to myself "well Molly, you did this to yourself."

I don't know why my back was a mess. I don't know why some people are born with mental problems. All people have some problem in their lives and mine is my back. It does not mean I am any worse off than anyone else. I am not. There are things I still can do they are a lot of things in my life that I can still do and still accomplish. And if I look at it like that instead of "why did I'd do it?" then I can get on with my life. But I really did blame myself at first.

Researcher: I really must say Molly, I don't think you had very much option with that first op. And you also don't know whether your actual condition, with that tumour, would not have caused an equally severe problem more quickly. You don't know.

Molly: In hindsight it is very easy to say - you know we can all do that - about anything - in hindsight we can all be fantastic. We can say if I had only done that, it would have stopped this from happening. But at the time I did what seemed to be the right thing. But I still have that little doubt every now and again. It knocks in my brain and tells me that "Molly, it is your fault."

Researcher: Yes I could see that after that op your pain actually got worse.

Molly: Yes.

Researcher: And it seems that with every op you got worse and that seemed to destroy your hope. Is that right?

Molly: It did. It did to the point now if they came and said to me "Molly, we have had a fantastic breakthrough. And this will definitely help your back" but this point I would definitely say "no thank you." I wouldn't trust it. I would want practically 100 percent guarantee, which isn't possible. That that's what it would do. And strangely enough, I'm like that with my back, but not with other things. It's like I was quite content, and quite willing for them to try this machine on me. And I went for the operation without batting an eyelid. And I was not frightened about it or anything. But when it comes to my back, because of every time going in thinking that this is going to be it, and coming out there, and I was a little bit worse, I now have no faith that anything can help it - any operation I should say. I should not say anything, it is any

operation, so I would have to see proof of I'd don't know how many people, who have been in the same position, and see if they have now totally cured them, before I would even dream of first signing for another back op. It is just something I would not do.

Researcher: Molly when you talked about it being difficult to admit that you have pain, but that moment we were speaking about your relationships with friends and so on, what I wanted to know, is it difficult to admit pain to other people, or yourself?

Molly: I think it is difficult to admit to other people, but basically it starts with myself. Because I feel that if I say to myself "yes Molly, you have definitely got pain" I feel a sense of having given in. Having given up. If I say it's physical pain and I say to myself yes Molly it is physical pain, I feel as if "okay Molly, you have given up. You haven't even tried anything yet and you're saying you've got physical pain. Now first try and do x,y,z and if you've still got pain then the pain is there." And that is a constant problem. The neurosurgeon, my GP, now with the urologist they are all having a fight with me about this, is for me to come to the realisation that the pain is very real, it is there, and I am experiencing pain, but I feel I am kind of letting myself down when I just give in to it straight away. I have to first try and fight it.

Researcher: And the only way to can do that is with your mind?

Molly: That's right. Because physically I am not able to.

Researcher: So in a way do you deny the pain (Molly yes) and try to block it out?

Molly: Because if I say I haven't got pain I won't feel it is much. I am not giving into it. Whereas I realise eventually, I have now got to give in to it. And sometimes that is to my own detriment because if I took something when the pain started - I have this constant fight with the doctors. They give me pain tablets. On a regular basis like you would take an antibiotic. And I do not believe in that. I still don't, and I still won't take them, on a regular basis. Now they maintain that my pain would be more constant and it would not have the peaks and the downs and the peaks and the downs if I took my pain tablets regularly as opposed to taking one when my back is so sore that I can't move. I do have that problem. I just can't see that you take pain tablets on a regular

basis. My mind tells me that that is not right. And that goes to an addiction I am afraid of becoming an addict if it goes to that.

Researcher: I know that they do treat chronic pain like that. To try and block it. Have you never just tried it?

Molly: The only time I've tried it is when I'm in the hospital and I have no option because I have a sister forcing it down my throat.

Researcher; And how do you respond?

Molly: Very well. And yet I will come home and I will go back to the same old habit of only when the pain is really bad would I take a tablet. It is the same with sleeping tablets. I told you, I very seldom sleep through the night. And eventually I'm so tired, and the pain has worn me down, I haven't slept, and it is terrible. They wanted to give me sleeping tablets. I will not take their sleeping tablets. They give me scripts and I tear them up - because I don't believe in sleeping tablets. Now they maintain that if I have a good night, I will be better the next day, more able to cope with what I need to do, and then having woken up six times during the night. But then too - and this is not something to do with pain - I think that is also a bit of a fear of my living alone, I don't like being totally out of it. I like to be aware of what is going on around me. So I think if someone does tried to break in whatever that least I am aware of it. So I think that has got a little bit to do with it the sleeping tablet. So I think there is more to that. But I can't come to this where you take pain tablets regularly every six hours and yet I know they have proved it to me, it does work. So! Stubborn! (Laughs.)

Researcher: No Molly, I can understand, you are the one who has got to take the tablets, so you must feel easy with it. You must be comfortable with what you are doing. Is that anything else you wanted to add, Molly?

Molly: Nothing that I can think of at this moment. I have talked myself hoarse. No I think that that is it.

Researcher: Well, Molly, thank you so much. I have really enjoyed talking to you.

Molly: You are welcome. You are welcome.

LETTER OUTLINING THE PURPOSE OF THE RESEARCH

Dear

I am currently completing my Masters degree in research psychology and would appreciate it if you would participate in my research. The topic of my dissertation is the meaning of chronic pain. I wish to provide the description of the experience of chronic pain from the point of view of people who have this condition. I wish to tape record one or more interviews with several people, which you which would then be transcribed and analysed. Results would be used for research purposes only When the results are published, all names will be changed, to ensure confidentiality. If you are willing to participate in the study I would appreciate your written consent. Thank you for your kind assistance.

Yours sincerely,

B. L. Wade

LETTER OF CONSENT SIGNED BY RESEARCH PARTICIPANTS

I _____ agree to participate in the research on chronic pain conducted by Mrs Wade. I give consent for the review of my medical records if necessary, for the tape recording of interviews and the publication of research findings.

Signed

Date