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**EXPLORING EXPRESSIONS OF
ABANDONMENT AND REJECTION
THAT EMERGED FROM GROUP THERAPY
WITH FIBROMYALGIA PATIENTS**

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University of Cape Town.

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ABSTRACT

Fibromyalgia is a complex syndrome of diffuse pain associated with non-restorative sleep, fatigue, numerous tender points, depression and other conditions that often does not respond well to treatment – posing a dilemma to health professionals.

The aim of this study was to explore expressions of abandonment and rejection that emerged from group therapy with eleven fibromyalgia patients at the former Princess Alice Orthopaedic Hospital, Cape Town. It focused on abandonment/rejection by caregivers during childhood, death as a form of abandonment, abandonment/rejection in adulthood by family, spouse and family-in-law, by friends, colleagues and employers, by government and society, the hospital and doctors, and by fellow group members and the facilitator.

The study is exploratory, interpretative and explanatory in nature with a purposive non-probability sample. The qualitative research method was used to gain insight into the subjective experiences of the lives and illness of the participants. The method of data collection was mainly the tape recorded and transcribed words of the participants over thirty-three group therapy sessions in eleven months and observations by the researcher as full participant observer. The data was sorted and analysed into emerging themes, patterns and categories.

All participants had had repetitive experiences of abandonment/rejection, which they had denied, suppressed and avoided, as it was too painful. Due to a lack of inner and external resources, or any intervention, feelings of abandonment, fear and anger were internalized as an unresolved reservoir of emotional pain. This seemed to have escalated into an eventual expression of physical pain (somatisation). From the findings of this study, there appears to be a relationship between adverse psychosocial factors and stress, particularly experiences of abandonment/rejection and fibromyalgia. However, due to the qualitative nature and small sample, the findings cannot be extrapolated and generalized to the broader population of fibromyalgia patients, and quantitative studies are needed for verification.

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DECLARATION

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**“When people complain about their bodies
it often reflects the state of their minds.”**

- Harold Merskey (cited in Shorter 1992: book review)

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LIST OF ABBREVIATIONS

ACR	American College of Rheumatology
APA	American Psychiatric Association
CFS	Chronic Fatigue Syndrome
DSM-IV	Diagnostic & Statistical Manual of Mental Disorders (4th rev.ed.)
FMS	Fibromyalgia Syndrome
FDR	First Degree Relatives
GP	General Practitioner
GSH	Groote Schuur Hospital
HIV	Human Immunodeficiency Virus
HPA axis	Hypothalamic-pituitary-adrenal axis
IBS	Irritable Bowel Syndrome
MD	Medical doctor
MDD	Major depressive disorder
ME	Myalgic encephalomyelitis
MFP	Myofascial Pain

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND AND CONTEXT OF THE STUDY

“I was totally insecure, because I did not know what I was dealing with. I just had one thing on my mind: pain, pain, pain! The doctors I’ve have lost faith in. I was angry with everybody in the whole world. No-one understands.” - Fibromyalgia patient.

For years fibromyalgia was known as ‘non-articular’ rheumatism. Unfortunately this term has also been a dumping ground for patients who presented with poorly understood complaints relating to severe pain in the musculoskeletal system for which no obvious cause could be found. Over the past twenty years a number of medical publications have appeared describing a syndrome of diffuse pain associated with non-restorative sleep, fatigue, numerous tender points and frequent association with other conditions, amongst others, emotional distress and headache (Lyddell 1997: 554).

Fibromyalgia patients are often symptomatic for years before the diagnosis is made. Pain can be debilitating and many patients respond poorly to various types of treatment. Because of the controversy about fibromyalgia possibly being a psychosomatic illness or a ‘masked’ form of depression, many health professionals are confused and frustrated by this condition. ‘Difficult’ cases were referred to specialists for diagnosis and symptomatic control, such as the arthritis unit at the former Princess Alice Orthopaedic Hospital (PAOH) in Cape Town. Here a dedicated multi-disciplinary team took a special interest in these patients, but even they were at a loss as to what to do with some uncontained fibromyalgia patients who remained symptomatic.

To address this problem fibromyalgia outpatients were invited to participate in a self-help group, facilitated by the researcher (social worker) and an occupational therapist at

PAOH. Both had previously been trained by Kate Lorig¹ from Stanford University, U.S.A. as 'leaders' of a structured six-week self-management programme to assist patients with arthritic diseases to cope with their illness. It is based on behavioural modification with education about their illness, medications, healthy lifestyles and training in problem-solving techniques.

The choice of fibromyalgia as a research topic resulted from an increasing concern by the researcher as the social worker at PAOH to find a solution to the problem of how to assist these patients. It was felt that research could provide valuable insights gained from the patients themselves regarding fibromyalgia and its impact on their lives.

Feedback from the participants of the self-management groups was positive, except that it was too structured and limited by time constraints to meet their emotional needs. The researcher was requested to facilitate an ongoing support group and it was decided to wait until more members could join from a second self-management programme. Ten women requested participation and an eleventh, an inpatient who could benefit, was invited to join, even though he had not done the course. It was thought that the experiences and perspectives of a male patient with an illness that affects predominantly women, would be interesting and add to the group dynamics.

An initial contract for short-term group therapy was extended to thirty-three sessions over eleven months due to the members' evolving needs. **The aims for this group** were to contain and support them, reduce their isolation, depression and anxiety, and enhance their communication and problem-solving skills in order to enable them to firstly, accept their condition positively; secondly, to adjust to their changed circumstances and new limitations; thirdly, to accept responsibility and take control of their lives rather than being helpless victims; fourthly, to cope better with stress and chronic pain; fifthly, to minimize any negative effects on themselves and their families; and sixthly, to find new meaning in life and to set future goals for themselves.

¹ K. Lorig & J.F. Fries 1990. *The Arthritis Helpbook: A Tested Self-Management Program for Coping with Your Arthritis*. 3rd ed. Reading, Massachusetts: Addison-Wesley.

As the group proceeded, common themes and commonalities in their backgrounds emerged. They appeared to be angry, distrustful and harbouring deep emotional pain, which they could not bring themselves to talk about. All complained of being overburdened with problems. They seemed to take on the responsibilities of others in an attempt to be valued and accepted. They resented that, while they were always there for others, they themselves were often unsupported. Consequently, they felt exploited, alone and abandoned. Experiences of abandonment and rejection emerged frequently in many forms and in all facets of their lives and, therefore, became the choice of topic for this study.

To establish if there were similarities between findings in existing research and the emerging themes of abandonment/rejection from the group, an extensive search was conducted on the University of Cape Town's interlibrary network. Various search engines on the Internet and the Medline database of the National Library of Medicine in Washington (that comprehensively covers the medical, biomedical and allied health science research from 1966) were used. Nothing was found linking the keywords of fibromyalgia, abandonment, and rejection, which indicated that the researcher's study would be a new perspective on the subject. Only a few studies showed evidence of adverse psychosocial circumstances of patients, which were thought to be conducive to the development of fibromyalgia. It also became apparent that the search for the etiology (causes) of fibromyalgia was of vital importance. Although this was not the researcher's purpose for conducting this study, it was hoped that her findings would shed some light on the precipitation of fibromyalgia.

1.2 AIM OF THE STUDY

The aim of this study was to explore expressions of abandonment and rejection that emerged from group therapy with fibromyalgia patients. It is emphasized that the purpose of this study is not to prove a point or to generalise the findings to the broader population of fibromyalgia patients, but to gain a better understanding of fibromyalgia by conducting an in-depth study of a limited number of patients. No claim is made by the

researcher to present an explanation for, or even a comprehensive description of the phenomenon of fibromyalgia as a whole.

Although the focus of this study is mainly on experiences of abandonment, the term 'rejection' was often used interchangeably when appropriate or in combination with 'abandonment' because their connotations are closely linked.

1.3 RESEARCH DESIGN

The study is exploratory and interpretative in nature with a purposive non-probability sample since the subjects had already been selected for the purpose of group therapy. The researcher used the qualitative research design since it is ideally suited for group therapy where the facilitator is allowed full participant observation and where the main sources of data come directly from the participants themselves. It allows the use of the participants' own words that is far more effective than an interpretation or insights of an outside observer. The emphasis of qualitative research on how participants themselves perceive events, and how they experience their world provides more insight into feelings of abandonment, which is also a subjective experience. The group sessions were tape recorded and transcribed after termination of the group, and then analysed according to emerging themes.

1.4 OUTLINE OF THE STUDY

Chapter Two will provide a theoretical perspective on fibromyalgia and abandonment in the literature review. Chapter Three will describe the research methodology and key concepts, while Chapter Four will present the findings and analysis of the data, and Chapter Five contains the conclusions and recommendations.

CHAPTER TWO

A LITERATURE REVIEW OF FIBROMYALGIA AND RELATED THEMES OF ABANDONMENT/REJECTION

2.1 INTRODUCTION

The main aim of the literature review was to gain insight into the fibromyalgia syndrome, not only from a medical, but also, and more importantly, from a psychosocial perspective. In reviewing existing research in this field the researcher sought to gain a deeper insight into the various themes of abandonment and rejection and to explore circumstances at the root of such feelings. A considerable number of resources, mostly medical publications and research papers, were consulted and some will be listed in the bibliography for additional reading. No studies were found on the subject of abandonment/rejection and fibromyalgia patients, which explains the oblique manner in which the subject was approached.

It seems that the main aims of scholars were to determine the diagnostic criteria in order to increase or argue against the clinical acceptance of the syndrome, as well as to search for the causes of fibromyalgia and to propose treatment programmes. A much smaller number of research papers by allied professionals in nursing, physio- and occupational therapy concentrated more on understanding the patients and the impact of fibromyalgia on their lives, whereas psychiatry/psychology explored psychiatric disorders and psychosocial factors that could play a contributing role in the development of fibromyalgia or how it is expressed. No articles on fibromyalgia by social workers were found, nor any linked to abandonment or rejection, which account for the fact that the literature is predominantly medically centered.

In reviewing literature, the researcher will, besides providing a general understanding of fibromyalgia, mainly focus on literature that pertains to issues of abandonment/rejection, albeit indirectly, and how the latter may be at the core of fibromyalgia or its expression.

The researcher will not necessarily mention all the studies that relate to a specific topic under that heading due to differing emphases elsewhere.

Being a complex condition, fibromyalgia is commonly misunderstood and remains a source of controversy among physicians and confusion to patients (Freundlich & Leventhal 1993: 247) - although it has been established as a distinctive diagnosis in the World Health Organization's disease classification, ICD-10 (Meyer 1997: 33). Fibromyalgia is a syndrome rather than a specific disease and is defined by a group of symptoms and signs (Goldenberg 1996: 394) that span multiple areas in medicine. It is, therefore, not easy to diagnose.

2.2 HISTORICAL BACKGROUND

Gowers, a British physician first introduced the term "fibrositis" in 1904 for what was thought to be an inflammation ("itis") of muscle fibres and soft tissue. In the absence of pathologic findings of inflammation in muscle or fascia (the surrounding tissue) and an increasing association with depression and stress, the concept of "tension rheumatism" was advanced by Boland in 1947, rather than the existing term "psychogenic rheumatism", due to reluctance to equate the symptoms with hysteria or malingering (Smythe 1989: 3-4). In 1976 Hench suggested "fibromyalgia" as a better descriptive term (cited in Wolfe et al. 1990: 161) as it means, "pain in the muscles, ligaments and tendons - the fibrous tissues in the body" (Fibromyalgia Network pamphlet).

2.3 EPIDEMIOLOGY

Fibromyalgia is a chronic disease with an average symptom duration of 4-7 years at the time of diagnosis, and it is prevalent in all ethnic groups (Meyer 1997: 33). Prevalence studies estimated that between 2.9 - 3.5% of the population (including children) meet the criteria for the diagnosis of fibromyalgia but do not necessarily become patients (Clauw 1995: 844; Lyddell 1997: 555; Boulware et al. cited in Meyer 1997: 32). The most common age presentation is 35-65 years. Ninety percent of sufferers are females and prevalence rates seem not to be affected by race, social class or educational status

(Lyddell 1997: 555). It is the most common cause of widespread pain seen in medical practice, and failure to recognize this disorder often leads to over-investigation and over-treatment of the multiple symptoms of the condition (Meyer 1997: 33).

2.1 CRITERIA FOR THE DIAGNOSIS OF FIBROMYALGIA

The 1990 American College of Rheumatology (ACR) criteria prescribes that diffuse pain must be present in the axial skeleton as well as all four quadrants of the body for more than three months, and eleven out of eighteen tender points must be painful on examination for a diagnosis of fibromyalgia to be made (Wolfe et al. 1990: 171). The most significant finding related to fibromyalgia was the presence of these multiple *tender points* (Meyer 1997: 32), located in tendons, muscles and other structures (Wolfe 1989: 3) as shown in figure 1.

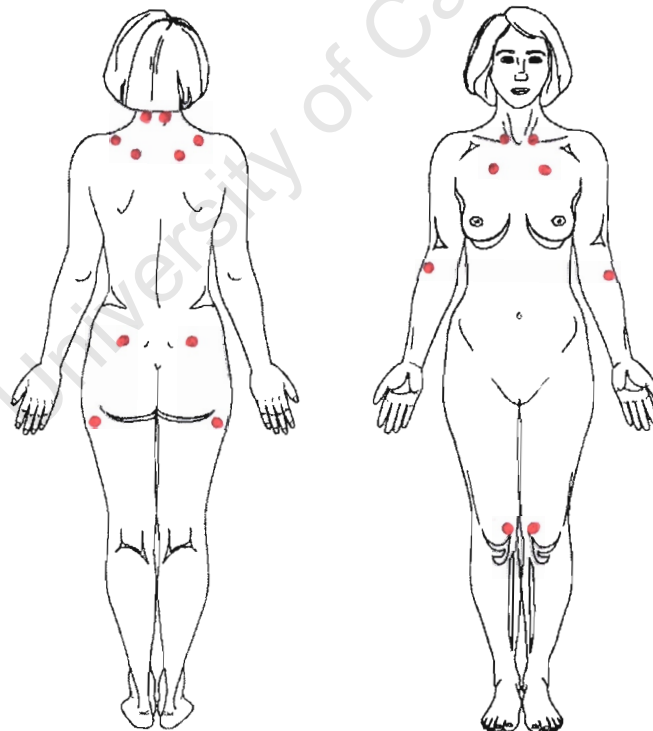


Figure 1
Location of specific tender points in fibromyalgia
(Source: Freundlich & Leventhal 1993: 247)

2.5 CLINICAL FEATURES OF FIBROMYALGIA

Wolfe (1989: 1-7) outlines four categories of features associated with fibromyalgia. These are:

Firstly, core features of generalised pain and widespread tenderness, which are present in all patients. Pain spans all body areas and is most common in the axial skeleton, shoulder and pelvic girdle areas. Pain intensity is found to be more severe than pain resulting from rheumatoid arthritis (RA)² (Wolfe 1989: 2-3). Fibromyalgia pain is relieved or modulated in the presence of warm, dry weather, hot showers/baths, restful sleep and moderate activity associated with stretching exercises, massage and physical therapy. It is aggravated in the presence of cold or humid weather (weather change), non-restorative sleep, physical or mental fatigue, excessive physical activity, anxiety and stress (Hench 1989: 22).

Secondly, characteristic features of fatigue, non-refreshed or disturbed sleep and morning stiffness which are present in more than 75% of patients, but need not be present in the individual patient (Wolfe 1989: 5). Fatigue, rather than pain and stiffness, may be the presenting feature in some patients and can be severe and debilitating, often described as a feeling of “general weakness” (Meyer 1997: 33). There is a strong association between fibromyalgia, *sleep disturbance and morning fatigue* (an indicator of poor quality of sleep). Patients often complain of difficulty in falling asleep, frequent awakening, light sleep and waking tired (Meyer 1997: 33). *Morning stiffness* may also be part of non-refreshed sleep (Wolfe 1989: 5).

Thirdly, common features which occur more than 25% of the time but are not essential to the syndrome. Paresthesias³ and subjective swelling are the most common,

² **Rheumatoid arthritis (RA):** a progressive and incapacitating disease due to chronic inflammation of joints (Cape & Dobson 1974: 28).

³ **Paresthesias:** morbid or abnormal sensations like burning, prickling, itchiness or pins and needles (Dorland 1981: 970).

followed by headache, irritable bowel symptoms (IBS)⁴ and Raynaud's phenomenon⁵. Other common features are "psychological abnormality" (see "The role of psychosocial factors in fibromyalgia") and functional disability (Wolfe 1989: 5).

Functional impairment in fibromyalgia is as severe as that of RA. A study by Cathey et al. in 1988 found that 30% of fibromyalgia patients changed jobs and 17% discontinued work because of their illness. Nine percent considered themselves disabled, but only 6% were receiving disability benefits compared to an earlier study in 1986 by Bengtssen et al. of 24% and 54% experiencing difficulty in performance of all activities of daily living. The reason for apparent decreased function may be because of reduced muscle strength, decreased muscle blood flow or because of pain (cited in Wolfe 1989: 6,7,12).

Fourthly, coexisting rheumatic conditions are often seen in context of fibromyalgia, although it may be "mild," "hard to identify," or "not related causally" (Wolfe 1989: 7). Actually, fibromyalgia without evidence of another medical condition is uncommon. Furthermore, the symptoms of RA, osteoarthritis⁶, tendonitis, cervical and lower back problems intertwine and overlap with those of fibromyalgia (Wolfe 1989: 7). Although fibromyalgia hardly ever evolves into other diseases, it is not uncommon for patients with RA and systemic lupus erythematosus (SLE)⁷ to have associated fibromyalgia symptoms (Middleton et al. cited in Meyer 1997: 35). Fibromyalgia often makes the associated

⁴ **Irritable bowel syndrome** (IBS or spastic colon): A pain disorder of the gastrointestinal tract with no known physiological abnormality, presenting chronic symptoms of intermittent diarrhoea, abdominal pain, constipation, depression, anxiety, fatigue, over-sensitivity and a pre-occupation with bodily functions. Psychological stress (unresolved grief of a parent/spouse or difficulty to adjust after divorce) plays a role in the onset/aggravation of symptoms (Hardin & Stewart cited in Catalano & Hardin 1996: 231-5).

⁵ **Raynaud's phenomenon**: Intermittent bilateral attacks of ischemia [deficiency of blood due to functional/actual obstruction of a blood vessel (Dorland 1981: 681)] of fingers/toes or ears/nose marked by severe pallor, paresthesia and pain. It is brought on characteristically by cold or emotional stimuli and relieved by heat, and is due to an underlying disease or anatomical abnormality (Dorland 1981: 1004).

⁶ **Osteoarthritis**: a degenerative condition attacking the articular cartilage and is aggravated by an impaired blood supply, previous injury or overweight (Cape & Dobson 1974: 28).

⁷ **Systemic lupus erythematosus**: a systemic autoimmune disorder that mainly affects females and can be debilitating or life threatening. It is characterized by widespread inflammation affecting many organ systems of the body, such as the heart, lungs, kidneys and brain. It often causes fatigue, pain, fever, headaches, epilepsy, a typical facial "butterfly rash", oral ulcers, weight loss, alopecia (hair loss) and arthritis (Joshi & Balakrishnan 1999: 227-36).

condition more severe. It is the relative predominance and severity of one or more of the common features and the variable presence of coexisting rheumatic conditions that influences the clinical presentation of the patient and gives the flavour of the syndrome to the individual patient (Wolfe 1989: 1, 7).

Fibromyalgia can be mistaken for a neurological disorder with symptoms such as chronic headaches and pain in the axial skeleton, cognitive complaints such as concentration and short-term memory deficits, and of numbness and paresthesiae [80%] (Meyer 1997: 34). To complicate matters, patients often report gastrointestinal symptoms suggestive of irritable bowel syndrome (IBS) [60%], irritable bladder, urinary frequency and urgency and other genito-urinary conditions, dysmenorrhoea (painful menstruation), migraine headaches, oesophageal dysmotility (dysfunction of peristaltic movement) [70%], restless-legs syndrome and periodic limb-movement disorder (sudden jerking movements at night) [20%] (Meyer 1997: 35).

Patients with fibromyalgia also have a higher incidence of ocular (eye), hearing and vestibular (inner ear) abnormalities causing loudness-intolerance, dizziness and balance problems [40%], as well as echocardiographic evidence of mitral valve prolapse (heart valve collapse) [75%]. ‘Allergic’ symptoms ranging from adverse reactions to drugs and environmental stimuli, rhinitis⁸, nasal congestion and lower respiratory symptoms have also been reported (Clauw 1995: 846).

A number of diseases commonly mimic fibromyalgia and must to be excluded with a limited number of laboratory tests. Some of the listed *differential diagnoses* are anaemia, myofascial pain syndrome⁹, temporomandibular joint dysfunction syndrome¹⁰,

⁸ **Rhinitis:** inflammation of the mucous membrane of the nose (Cape & Dobson 1974: 291).

⁹ **Myofascial pain (MFP):** “essentially single muscle syndromes that may combine to form complex patterns involving many muscles in several regions of the body. The pain referred from myofascial trigger points can be unrelentingly severe. The zone of referred pain is rarely where the trigger point is located and is often also tender” (Simons in Wolfe 1989: 15).

¹⁰ **Temporomandibular joint dysfunction syndrome:** pain emanating from the jaw, head and neck that involves the movement or position of the jaw bone (mandible) (Gevirtz 1996: 205).

nonarticular (soft tissue) rheumatism, polymyalgia¹¹, polymyositis¹², thyroid/parathyroid problems, metabolic myopathy¹³, depression/anxiety, metastatic carcinoma¹⁴, chronic fatigue syndrome, Epstein-Barr virus¹⁵ and Parkinsonism (Hench 1989: 21, 26-28).

Further complicating the diagnosis of fibromyalgia is the considerable overlap with conditions such as myofascial pain syndrome and chronic fatigue syndrome (CFS) also known as myalgic encephalomyelitis ME (Goldenberg cited in Clauw 1995: 843). In a local study 35% of fibromyalgia patients met the criteria for CFS whereas 92% of CFS patients could be diagnosed with fibromyalgia (Meyer 1997: 34). The main difference is that fibromyalgia has widespread pain and tender points, whereas CFS has debilitating fatigue (Goldenberg 1996: 394). For some it seems unlikely that these patients have two separate disease processes. Perhaps the division on the basis of whether or not they have prominent pain is too artificial (Nye 1996: 3). Goldenberg acknowledged that the current syndrome criteria are imperfect and need to be continually revised (1996: 396).

2.6 PROPOSED MODELS FOR UNDERSTANDING FIBROMYALGIA

According to Goldenberg clinicians and patients tend to be split regarding the belief as to whether these conditions are specific diseases or not. In one camp are those who consider that these syndromes must fit the **biomedical cause-effect model**, and should therefore be caused by some physiopathology that must be identified before appropriate treatment can be prescribed. In the other camp are those who believe that fibromyalgia and CFS are non-entities, defined by societal and physician perception of universal psychosocial stress (1996: 396). The term “non-entity” refers to a disease that is “all in

¹¹ **Polymyalgia**: persistent aching pain in the muscles often involving the shoulder or pelvic girdle (Cape & Dobson 1974: 262).

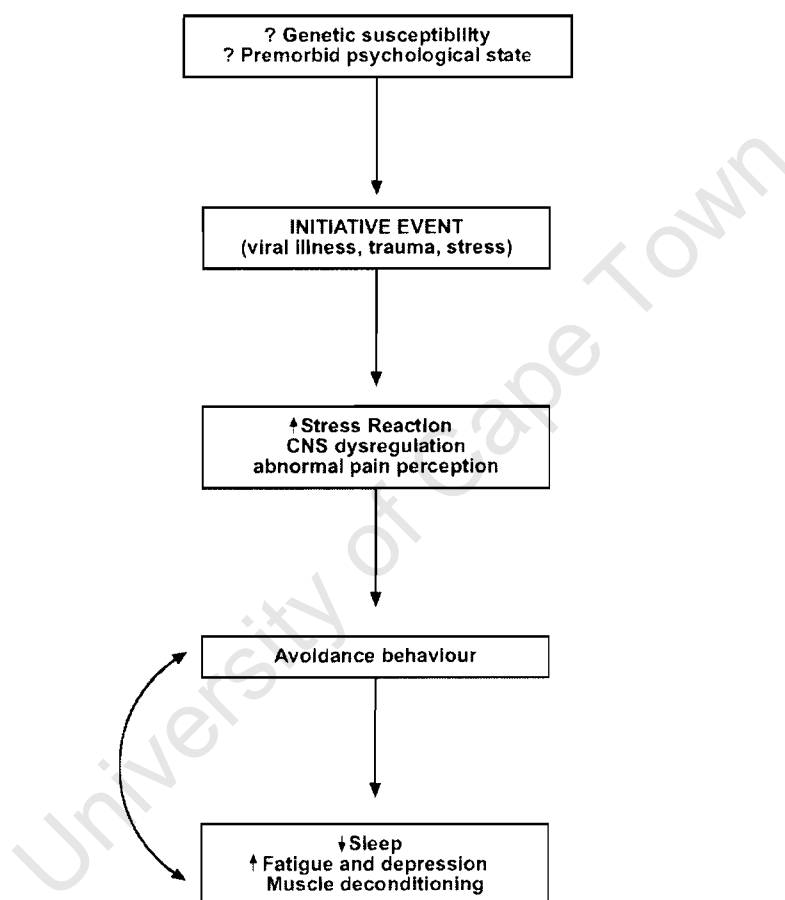
¹² **Polymyositis**: insidious wasting and weakness of muscles (Cape & Dobson 1974: 262).

¹³ **Metabolic myopathy**: muscular dystrophy – a hereditary degenerative disease of muscle wasting and weakness caused by defective metabolism (Cape & Dobson 1974: 209, 218).

¹⁴ **Metastatic carcinoma**: The transfer of cancer from one part of the body to another, through the blood vessels or lymph channels (Cape & Dobson 1974: 209).

¹⁵ **Epstein-Barr virus** causes acute infectious glandular fever (Cape & Dobson 1974: 214).

your head”. It is often described as “a waste-basket diagnosis” – a label for patients whose complaints are imaginary or reflect an emotional response to stress in their lives, which implies that they have no real problem at all (Waddell 1996: 179). Much of the controversy regarding the existence of fibromyalgia and CFS may relate to the failure of the biomedical model to account for such disorders or because these disorders/syndromes do not satisfy the criteria for a ‘medical disease’. It seems unlikely that extensive, costly evaluation would find a cause or suggest a definite treatment and Goldenberg (1996: 396) therefore suggests that chronic pain and fatigue fit best within a **psychosocial framework** – illustrated in Figure 2. (This will be discussed in greater detail on p. 38).



(Goldenberg 1996: 395)

Figure 2
Psychosocial model of fibromyalgia

Goldenberg considers that fibromyalgia is a valid concept that can be distinguished from other causes of chronic pain. Fibromyalgia is not a disease in the classic medical model, but the syndrome overlaps with CFS, IBS, irritable bladder and migraine headache. It is likely that there is no single cause for these syndromes and that they each fit best into a psychosocial rather than biomedical model (Goldenberg 1996: 402).

A model that favours holistic treatment rather than splitting the biophysical from the psychosocial aspects, the **biopsychosocial model** of Engel seems more appropriate for a chronic illness than either of the preceding two. It integrates the biological, psychological and social dimensions of individuals' experience, and each dimension is equally important (cited in McHugh & Vallis 1986: 1). For the researcher, the multi-axial classification assessment format used in psychiatry is a good example to facilitate the biopsychosocial model. This is due to its comprehensive and systematic evaluation, with attention to various mental, personality and physical disorders, psychosocial stressors that significantly contribute to the development or exacerbation of the illness and degree of adaptive functioning that might be overlooked if the focus were on assessing a single presenting problem (Kaplan & Sadock 1991: 223-5).

Dessein & Shipton recommend the biopsychosocial model as being more appropriate in the treatment of rheumatological pain syndromes. In the traditional biomedical model of pain, physical and psychological stressors are considered to be disparate as opposed to mutually reinforcing and similarly causative in pain generation in the biopsychosocial model. The former model has an adverse psychosocial affect in patients occurring as the result of treatment by a physician (iatrogenic effect) (Dessein & Shipton 2000: 95-9).

2.7 THE ROLE OF BIOPHYSICAL FACTORS IN THE ETIOLOGY OF FIBROMYALGIA

The absence of specific structural changes in affected tissues or any widely accepted pathophysiological changes continue to fuel the controversy and frustration as to whether fibromyalgia could be considered a valid entity (Bennett & Goldenberg 1989: ix). No

definitive clinical, biochemical, serological, inflammatory, immunological, or structural pathological findings have been consistently implicated in the fibromyalgia syndrome (Hench 1989: 19). After a century of research it could be concluded that muscle and soft-tissue pathology at the pain sites did not explain fibromyalgia (1996: 403). Although old injuries, spinal stress and poor posture may contribute to pain (Meyer 1997: 24), muscle abnormalities can be attributed to disuse and deconditioning (1996: 397). The tender points are better explained as secondary hyperalgesia [when innocuous stimuli such as light touch may be perceived as painful (Pillemer et al. 1997: 1928)] of peripheral nerve origin - analogous to “phantom limb” pain (Quintner et al. cited in Goldenberg 1996: 397).

More recent research indicates that altered central nervous system mechanisms along with abnormal neuroendocrine function and the consequent central and peripheral processing of pain would be key to a better understanding of fibromyalgia and related syndromes (Goldenberg 1996: 403; Meyer 1997: 25). This may be triggered in a genetically predisposed individual by nonspecific stresses such as physical and psychological trauma, as well as by infection (Meyer 1997: 24).

Evidence of biological abnormalities such as elevated ‘substance P’ in the cerebrospinal fluid and decreased serotonin levels (both neurotransmitters) could be responsible for widespread pain and tenderness, cognitive impairment, fatigue, deficient deep restorative sleep (stages three and four non-REM) and possibly also morning stiffness (Bennett & Moldofsky cited in Meyer 1997: 24). Serotonin may then be a key factor as it is an important neurotransmitter in brain centers involved with pain, sleep and mood (Freundlich & Leventhal 1993: 248). The hypothesis that low levels of serotonin may be responsible for fibromyalgia is significant because of associated conditions such as affective disorders, migraine, irritable bowel syndrome and chronic fatigue, which are probably due to the same mechanism (Meyer 1997: 25). In their quest to find the etiology of fibromyalgia, the focus of researchers has now shifted to study these overlapping disorders since there are more similarities than differences in the potential

pathophysiology, demographics, natural history and therapy of these syndromes (Goldenberg 1996: 397).

Neurohormonal dysregulation is also associated with abnormal regional blood flow to areas of the brain that regulate pain perception. Further abnormalities of neuroendocrine functions were found in an **abnormal hypothalamic-pituitary-adrenal axis** (HPA axis) (Mountz et al. cited in Goldenberg 1996: 398). Dessein & Shipton pointed out that fibromyalgia and other rheumatic diseases are hypoactive stress system (HPA axis and the sympathetic nervous system) disorders. The under-secretion of the hormone, cortisol (for example) can result in poor pain tolerance and cognition, depressed mood and inflammation (2000: 93-9).

Despite the identification of objective hormonal, biochemical and neurotransmitter abnormalities, a subgroup of scientists conversely argued that the neuroendocrinological aberrations could just as well be a consequence of **stress** resulting from chronic pain (Clauw 1995: 848; Hendriksson cited in McDermid 1996: 141). Other investigators thought of fibromyalgia as a psychological disorder or, perhaps a local myofascial pain syndrome. "This disarray in construct has led to a blurring of the margins of the disorder and to the consequent idea that fibromyalgia means something different to every observer". (Wolfe et al. 1990: 161) The proliferation of terminology was the result of disease labels, which stemmed from internal medicine, neurology, rheumatology (and psychiatry) for the condition of patients who exhibited the same kind of symptoms (Shorter 1992: 311-2). Terminology changes within each discipline over time resulted in much conceptual confusion.

2.8 THE ROLE OF PSYCHOSOCIAL FACTORS IN FIBROMYALGIA

2.8.1 Introduction

The search for underlying psychological mechanisms in fibromyalgia has been inconclusive and not without controversy (Meyer 1997: 37). Because no specific

pathophysiological mechanisms have been found to cause fibromyalgia, the syndrome has sometimes been understood as primarily psychological in origin – especially since patients with fibromyalgia seem to have a high incidence of psychiatric disorders (Meyer 1997: 34-7). Because patients were formerly diagnosed as having “psychogenic rheumatism” (Smythe 1989: 3-4) and “psychological abnormalities” are described as one of the common clinical features in fibromyalgia (see p. 9), further studies were prompted. The relationship between mind and body is important in the etiology of fibromyalgia and it is essential to understand this interplay at the level of its effect on altered physiology (Meyer 1997: 24). A small number of scholars explored whether personality type as an underlying factor predispose some individuals to fibromyalgia.

2.8.2 The fibromyalgia personality profile

In 1982 Blumer & Heilbronn proposed that the presentation of chronic pain in the absence of an identifiable organic pathology is a variant of ‘depressive disease,’ the pain-prone disorder. The clinical features of the **pain-prone disorder** are:

Firstly, somatic complaints: continuous pain of obscure origin, hypochondriacal preoccupation and a desire for surgery;

Secondly, ‘solid citizen’ style: denial of conflicts, idealization of self and family relations, and pre-pain ergomania (need to work continuously);

Thirdly, depression: post-pain anergia (lack of energy), anhedonia [(loss of interest in and withdrawal from all regular and pleasurable activities (Kaplan & Sadock 1991: 217)], insomnia, depressive mood and despair; and

Fourthly, social history: family and personal history of depression and alcoholism, past abuse by spouse and relatives with chronic pain or disability (cited in Ahles et al.1987: 105).

The search for a specific fibromyalgia personality profile revealed an overlap with the above-mentioned features. A Swedish study found that depressed fibromyalgia patients had a high need to gain self-esteem through competence and others' approval combined with a low basic sense of self-esteem. They exhibited a lower self-assertiveness and less emotional candour (Johnson et al. 1997: 578). Along with Bossevain & McCain's study, they reported that patients set high standards and were demanding of themselves and of others. The latter added that they were often very effective in their chosen field of activity and had unusual loyalty from employers and family (cited in Meyer 1997: 34).

2.8.3 Psychopathology and fibromyalgia

At least seven studies during the 1980's found evidence of "**psychological abnormality**" in fibromyalgia patients. Three studies using the Minnesota Multiphasic Personality Inventory test (MMPI) (Payne et al. (1982); Ahles et al. (1984) and Wolfe et al. (1984) indicated "serious psychological abnormality" in at least 25% of patients - mostly with hypochondriases, hysteria¹⁶ and depression¹⁷ (Wolfe 1989: 6). Ahles et al. found a high incidence of traumatic life events and noted three subgroups in fibromyalgia patients: 31% to be "psychologically disturbed"; 33% had a typical chronic pain profile and 36% were normal (Ahles 1984: 1101-5). Two studies by Hawley & Wolfe found higher anxiety and depression levels in fibromyalgia patients than those with RA, osteoarthritis, or lower back pain (cited in Wolfe 1989: 6). Both Hudson et al. (1985: 443-5) and Goldenberg (1989: 109) found high rates, and a high familial prevalence, of major affective disorder in patients with fibromyalgia. Gruber et al. expressed concern that depression seen in fibromyalgia is often underrecognised, undertreated and more refractory to treatment than uncomplicated depression (1996: 365). Meyer pointed out that despite the increased prevalence of depression in fibromyalgia patients, the majority is not depressed (1996: 34).

¹⁶ **Hysteria** is an older term for somatisation disorder, which along with hypochondriases, pain disorder and others, is classified according to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as somatoform disorders (Kaplan & Sadock 1991: 416). (See Appendix 1.)

¹⁷ Numerous studies focused on **depression**. According to Dessein & Shipton depression is the most common emotional disturbance in chronic pain and adversely affect morbidity (2002: 95).

An ensuing debate focused on the interpretation of results of studies and whether the “abnormalities” were the cause or effect of fibromyalgia. Owing to the differences in definition of abnormality and psychological test instruments employed, it is almost impossible to come to an accurate statement of the prevalence or severity of psychological abnormality (Wolfe 1989: 6). The inconsistencies of reports and discrepancies between results are probably due to differences in population size, methodology, patient selection criteria and varying duration of disease (Goldenberg 1989: 107).

A critical assessment of the MMPI-test by Pincus et al. indicated criterion contamination and that fibromyalgia symptoms rather than psychological disease could be responsible for most of the abnormalities. The test measured pain-related emotional distress, cognitive state and the behavioural disruption of daily living in individuals with pain disorders (cited in Wolfe 1989: 6). Goldenberg contends that variable results from numerous studies may reflect not only that criteria for diagnosis of these disorders are imperfect, but also that there is an absence of a test for depression that adequately controls for an associated medical condition. Questions about fatigue, sleep disturbances, loss of appetite and headache to indicate depression, as well as concepts like ‘masked depression’ or ‘pain-prone disorder’ as manifestations of depression are totally based on the use of somatic complaints (1989: 110). Similar problems of symptom overlap were encountered in studies to determine whether fibromyalgia is a manifestation of somatisation disorder¹⁸ (Dunne & Dunne 1995: 195). Goldenberg concluded that one could no longer simply accept the dogma that patients with fibromyalgia as a group are psychologically disturbed (1989: 112).

¹⁸ **Somatisation disorder:** a chronic syndrome of multiple somatic symptoms that cannot be explained medically and is associated with psychosocial distress and medical helpseeking. A history of several years’ duration and onset before age 30 is required for diagnosis. Prevalence is among the poor with low educational and occupational status. Somatisation disorder also occurs in 10-20% of first-degree female relatives. First-degree male relatives are prone to alcoholism, drug abuse and antisocial personality disorder. Patients have a history of unstable homes, physical abuse, anxiety, depression and interpersonal problems. Commonly associated with antisocial and histrionic personality disorders and substance abuse (Kaplan & Sadock 1991: 416-7).

A review of research studies indicated four hypotheses regarding the relationship between fibromyalgia and psychopathology:

Firstly, psychopathology is neither the cause for, nor the result of fibromyalgia.

Ahles et al. argued that their high psychological abnormality finding did not necessarily move fibromyalgia as a medical condition to a psychological disorder, but, rather, described another dimension of a common and complex disorder of unknown etiology. (Ahles 1984: 1101-5). Payne et al. interpreted these abnormalities as not the result of chronic pain and disability, but that fibromyalgia patients may be a heterogeneous population with a variety of psychopathologic signs (1982: 216).

Secondly, psychopathology is an effect of chronic and painful fibromyalgia.

Clark et al. speculated that referral bias could be responsible for inflated psychological abnormalities as subjects were selected from specialist tertiary care hospitals, and there is a linear association of psychological symptoms with duration and intensity of utilization of health care (cited in Goldenberg 1989: 107). They then studied patients from a general medical clinic who fulfilled the fibromyalgia criteria but did not seek medical attention for their symptoms. Conversely, they concluded that psychological disturbance was not an inherent part of the fibromyalgia and did not perpetuate fibromyalgia symptoms. Any chronic or severe pain and disability may result in the development of emotional abnormalities. The constant uncertainty about the nature or even existence of a disease could be expected to worsen this problem (Clark et al. 1985: 136).

Yunus et al. also argued that the psychiatric abnormalities were more likely to be related to fibromyalgia itself, but that psychological factors may influence the degree of pain and perhaps the referral pattern. Fibromyalgia presents with multidimensional problems, with psychosocial factors important in some patients. Recognition of this subgroup is important for appropriate management, incorporating psychosocial counseling (1991: 19-20).

Previously it was thought that fibromyalgia patients did not meet the DSM-criteria (see footnote 16) for diagnosis for either a psychosomatic or somatoform disorder and that when present, anxiety and depression were more likely to be the result than the cause of fibromyalgia (Goldenberg 1989; Yunus 1991; Dunne 1995 cited in Nye 1996: 1).

Higher anxiety and depression levels in fibromyalgia patients than patients with RA, osteoarthritis, or lower back pain in two studies by Hawley & Wolfe (cited in Wolfe 1989: 6) also suggested that depression is a result of psychological stress imposed by fibromyalgia (cited in Dunne & Dunne 1995: 194).

Freundlich & Leventhal reasoned that it is not uncommon for fibromyalgia patients to develop a reactive depression to this chronic, poorly understood and disabling condition. Although nocturnal antidepressants have been used effectively in this syndrome, the doses employed to improve the quality of sleep are generally nontherapeutic for major depression (1993: 248).

The hypothesis that fibromyalgia causes major depressive disorder simply because it is a chronic, painful and disabling illness, seems unlikely to Hudson & Pope. It also would not explain cases where major depression and comorbid disorders have appeared at least one year prior to the onset of fibromyalgia, or the high rates of major affective disorder in first degree relatives of fibromyalgia patients (Hudson & Pope 1989: 16).

Thirdly, fibromyalgia is an effect of an underlying psychiatric disorder.

The implication that fibromyalgia is caused by psychopathology, such as a major depression disorder, is a version of the classic psychosomatic theory that psychological distress or conflict is expressed indirectly as somatic complaints (Hudson & Pope 1989: 17) or leads to the development of both psychological and physical symptoms (Hudson & Pope 1996: 297).

It might be argued that fibromyalgia is a manifestation of somatisation disorder as patients display high levels of hypochondriasis, preoccupation with bodily functions, multiple visits to physicians ('doctor shopping') and various physical symptoms found in somatisation disorder. Several considerations against this possibility are that studies found low rates of somatisation in patients with fibromyalgia (Hudson & Pope 1989: 18; Dunne & Dunne 1995: 195).

Hudson & Pope argued that only a few patients have a current diagnosis of affective disorder and many never develop affective disorder at all. Nor is there much support for the view that fibromyalgia is a factitious (hysterical) disorder. Fibromyalgia patients display a stereotyped pattern of symptoms that is stable over time, whereas patients with factitious rheumatic symptoms intentionally exhibit non-stereotyped, bizarre, dramatic, vague, environmentally reactive and changeable symptoms - the motivation for which is to assume the sick role (Hudson & Pope 1989: 17).

Ahles et al. also opposed the assumption that fibromyalgia could be a variant of a depressive disease and that it is a 'masked' or somatised form of depression as most studies did not find depression in fibromyalgia patients significantly higher than in rheumatoid arthritis control groups. They argued that depression also tends to be cyclical, whereas fibromyalgia is continuous. If fibromyalgia was a variant of a depressive disease, they questioned why the symptoms of fibromyalgia persisted despite the resolution of depression. They cautioned how data are being interpreted concerning past histories of depression. The latter may predispose an individual to medical or psychiatric problems, rather than the development of pain specifically (1987: 107).

A Canadian study also found no support for the contention that fibromyalgia is a form of somatised depression as there was no evidence of 'masked depression' or significant differences in depression between fibromyalgia and arthritis patients. However, fibromyalgia patients reported significantly more somatic symptoms of obscure origin

and exhibited patterns of more helpseeking behaviour that may reflect a process of somatisation¹⁹ rather than a discrete psychiatric disorder (Kirmayer et al. 1988: 950).

Winfield suggested that fibromyalgia may not be a distinct entity, but “one end of a continuous spectrum” including psychological distress and somatisation disorder (cited in Gelfand 1998: 1139). More recently a German study found that a subgroup of fibromyalgia patients (20%) displayed somatoform disorders and that somatoform disorders play a primary role in fibromyalgia unlike its secondary importance in patients with RA (Dreher et al. 1997: 25).

Two studies, Hudson et al. (1985) and Goldenberg et al. (1989) found high rates of major affective disorder and a high familial prevalence of major affective disorder in patients with fibromyalgia. Major affective disorder occurred one to ten years prior to the onset of fibromyalgia in 64% of their patients (Hudson & Pope 1996: 296). They interpreted that a personal or family history of a major affective disorder may simply predispose some individuals to the development of fibromyalgia. Alternatively, patients destined to develop fibromyalgia have evidence for a predisposition to major depressive disorder before they develop fibromyalgia. There could be a *psychobiological* link between depression and fibromyalgia, but not a causal relationship due to the lack of concordance of onset of depression and fibromyalgia (Goldenberg 1989: 109; Hudson et al. 1985: 443-5).

Fourthly, both psychiatric and fibromyalgia symptoms are caused by a common underlying etiological abnormality²⁰.

¹⁹ **Somatisation** is a process of illness behaviour resulting from social-psychological processes, including increased focus on the body, hypochondriacal worry and attribution of emotional distress to physical causes, which lead to more symptom reporting and helpseeking (Kirmayer 1988: 950-3). The term “somatisation” refers variously to a style of symptom presentation, a tendency to attribute problems to somatic causes, a distinct psychiatric disorder, and a presumed etiology for functional somatic symptoms (Kirmayer 1986: 111).

²⁰ Some cases of fibromyalgia do not share an etiological factor in common with major depressive disorder (MDD). Mufson & Regestein proposed that there may be several forms of fibromyalgia: (1) a form not associated with MDD, (2) a form associated with MDD in which depressive symptoms are caused by fibromyalgia, and (3) a form associated with MDD in which fibromyalgia symptoms are caused by MDD. However, this theory does not account for why most patients with fibromyalgia have experienced other comorbid entities (cited in Hudson & Pope 1996: 298).

Two papers by Hudson & Pope (1989: 15-22; 1996: 296-8) reviewed research findings and found sufficient evidence that fibromyalgia can be associated with psychopathology and specifically major depressive disorder. They hypothesized that if psychopathology is not the cause for fibromyalgia, and vice versa, then the remaining alternative is that both are caused by a common underlying etiological abnormality. At the time there was no direct evidence as to what the postulated etiological abnormality might be. (1994: 843)

They also discovered that fibromyalgia appears to be associated with a cluster of disorders, which includes eleven other disorders: chronic fatigue (particularly CFS), muscle pain or spasm (particularly irritable bowel syndrome, migraine, tension headaches and atypical fascial pain), disorders of mood and anxiety (particularly major depression and panic disorder), as well as attention-deficit-hyperactivity disorder, bulimia nervosa, obsessive-compulsive disorder and post-traumatic stress disorder. These disorders, in turn, are associated with one another, but are not necessarily comorbid with fibromyalgia (Hudson & Pope 1994: 843-8).

Of interest was that the fibromyalgia comorbid disorders (migraine, irritable bowel syndrome, major depression, chronic fatigue syndrome, and panic disorder) began a year before the onset of fibromyalgia in 45% to 67% of the cases. They too were associated with high personal and familial rates of major depression, and responded to antidepressant medication (Hudson et al. 1992: 363).

Hudson & Pope proposed a term “**affective spectrum disorder**” to represent this family of psychiatric and medical disorders that share a common physiological abnormality (Hudson 1992: 366). The term ‘affective’ reflects only that ‘antidepressant’ medications²¹, first used to treat major depression (affective disorders) were effectively used in all of these conditions. It does not mean that they are caused by major depression, or that they are psychogenic disorders. Evidence suggests that they are biological disorders that cause both physical and psychological symptoms (Hudson &

²¹ Serotonin, thought to be linked to depression, anxiety, obsessive-compulsive disorder, social anxiety disorder and post-traumatic stress disorder and a prescription of a mood modifier such as Aropax improves these conditions (SmithKline Beecham Pharmaceuticals 2000 Feb. Advertisement in CME 18(2): 105).

Pope 1996: 299). Some scholars in the field of fibromyalgia in principal accept the spectrum concept, but disagree with its name and the precise list of the disorders within it. Thus the exact composition of these larger families of conditions and the nature of the links within them remain to be elucidated (Hudson & Pope 1996: 299).

This affective spectrum disorder would suggest that it is not useful to continue to focus attention on whether psychological disturbances cause physical illness, or vice versa, but rather consider that both the psychiatric and medical disorders within this family are caused by the same biological abnormality. These disorders should be treated as a cluster and not as discrete entities so that comorbid disorders can be identified in these individuals (Hudson & Pope 1994: 852). This kind of hypothesis is plausible and even probable from examples in the history of medicine, most recently how HIV-infection caused numerous seemingly unrelated conditions (Hudson & Pope 1996: 298).

2.8.4 Somatisation: an expression of intrapsychic, interpersonal and socio-cultural distress

Every physical symptom has some biological, some psychological and often some social component, which needs to be addressed in a balanced and integrated manner without fixation on any one component of the symptom. **Somatic fixation** (one-sided emphasis on the biomedical aspects of a multifaceted problem) occurs not only in hypochondriasis, somatisation disorder and psychosomatic illness²², but in any disease, especially chronic illness, whereby the doctor, patient, or family focus exclusively and inappropriately on the somatic aspects of a complex problem (McDaniel et al. 1990: 248-50).

Western culture and medical practice contribute to the problem by remaining rooted in the notion of a mind-body dichotomy. The physical is viewed as apart from and unrelated to the emotional rather than being integrated. The notion that a physical

²² **Psychosomatic illness:** any illness in which physical symptoms, produced by the action of the unconscious mind, are defined by the individual as evidence of organic disease and for which medical help is sought. Symptoms can either be literally psychogenic (arise in the mind), or be an exaggerated or inappropriate response (illness behaviour) to a physical lesion (Shorter 1992: x).

symptom must have a primarily organic cause or that an emotional feeling is determined primarily by some psychological experience, is still widely accepted (McDaniel et al. 1990: 248-50). Doctors somatise patients' distress when they ignore psychological symptoms in favour of organic pathology so that distress is expressed in somatic terms because such problems are considered more serious and worthy of care. The physical nature of diagnostic procedures and therapeutic interventions maintains a focus on body and encourages somatic attributions of symptoms (Kirmayer 1986: 125).

In spite of relentless social problems or intrapsychic conflict, somatically fixated patients tend not to present with anxiety, depression or trouble coping, but with numerous physical symptoms, such as headaches or fatigue. The body is used as metaphor where symptoms are expressed as part of the helpseeking process (Kirmayer 1986: 120; McDaniel et al. 1990: 248). There is nothing imaginary or simulated about the patients' perception of their illness. The pain or fatigue is very real to them. They cannot simply abolish symptoms, for what they experience is caused by the action of the unconscious mind, over which they have no rational control (Shorter 1992: 226).

Patients with psychosomatic illness tend to lack insight into the role of psychological factors in their illness and see themselves as victims of organic disease. The rejection of psychiatric diagnoses or referral in itself is a characteristic of the illness. They fear that their symptoms will be seen as 'imaginary'. Alternatively, they reject psychological interpretations of physical symptoms with a sense of hopelessness (Shorter 1992: 317, 262). Somatisation adds a focus on the discrepancy between patients' experiences of their problems as somatic, and the belief of health care providers that the problem is psychological or social in nature (Kirmayer 1986: 111).

McDaniel et al. (1990: 253-62) illustrates the vicious cycle where both doctor and patient are locked into a battle over the patient's somatic fixation when a biopsychosocial approach is not used. It begins when a patient seeks help for symptoms from a sympathetic doctor who orders tests and prescribes medication. When the tests come back negative, the physician experiences relief, but the patient is perplexed. With no

biomedical answers, the doctor turns to a psychosocial evaluation upon which the patient becomes angry and denies that the problem is “in my head”. The patient feels misunderstood and requests more tests, leading the doctor to become irritated. The physician may withdraw from the patient and/or refer out to a specialist, or the patient leaves and begins a process of ‘doctor shopping’. Either outcome sets the cycle into motion again as the patient presents the symptoms to a new physician. See Figure 3:

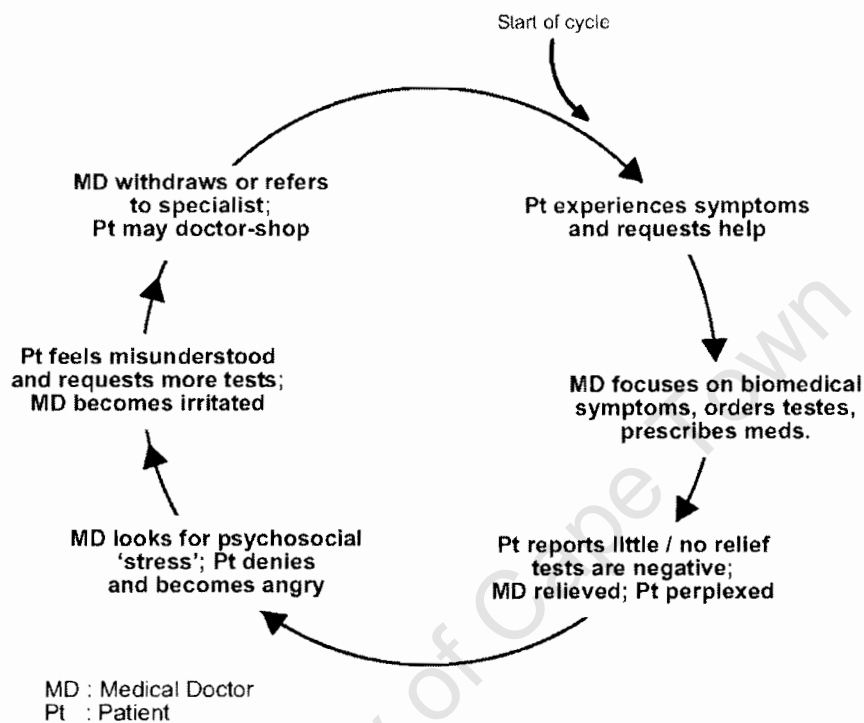


Figure 3
Somatically fixated physician-patient interaction
(McDaniel et al. 1990: 252).

It is not so much the nature of their symptoms but their frequency, severity and persistence that makes somatising patients distinctive (Kirmayer 1986: 111). Some patients who perceive bodily sensations as a threat of illness perceive themselves as highly vulnerable emotionally. This fear of emotional disability prompts them to insist on somatic explanations for all of their distress (Kirmayer 1986: 123).

Kirmayer explains that **somatisation** often results from the inability to express emotion (alexithymia). In social groups that limit or disapprove of the display of certain emotions, individuals may not be able to express or resolve feeling states explicitly. If raised in an environment where families ignore or punish emotional complaints or respond with more attention and nurturance to physical symptoms, children are conditioned to experience any need or problem as physical - reinforcing a somatic style of expression due to its secondary gain (1986: 121-2). They may learn to amplify their bodily symptoms in an attempt to get their needs met. Consequently, they become very sensitive to any physical sensation in their body and equally insensitive to emotional clues (McDaniel et al. 1990: 250).

Somatisation also serves as communication in the family where somatic symptoms are read as messages (Kirmayer 1986: 125). It may serve as an idiom of psychosocial distress through the use of the **body as metaphor**. Illness can be 'read' just like other creative expressions of self, such as art or dreams (Nichter cited in Heurtin-Roberts 1993: 290). Pain has unconscious meanings, which originate in infantile and childhood experiences, such as a punishment for wrongdoing and a way of expiating guilt and of atoning for an innate sense of badness (Kaplan & Sadock 1991: 421). The family process can shape symptom experience and expression without the sufferer's awareness toward a form that maintains the stability and function of the family system (Kirmayer 1986: 125).

Many chronic, severe somatisers tend to have a developmental history of gross neglect and abuse, as well as a family history of relatives using somatisation or pain behaviour as a way of coping or solving problems (Katon cited in McDaniel et al. 1990: 250). It is possible that the patient identifies with and takes on the role of an ambivalent love object who also had pain (Kaplan & Sadock 1991: 421). Pain is a powerful force that often controls the structure, actions and reactions of family members. It can change family roles, realign subsystems within the family or isolate family members from each other and from outside influences (Hudgens 1983: 497). The sick person wields power through justified demands on the time and energies of others (Kirmayer 1986: 125). Some symptoms offer a way to express dissatisfaction obliquely without a direct challenge to

authority, sanction the expression of anger or provide time out and away from difficult circumstances (Kleinman (1986: 152-4).

Heurtin-Roberts's study shows how chronic illness can empower the powerless and become a culturally influenced tool to organise and implement an adaptive response to personal experiences. It offers persons in a severely stressed, constrained and disadvantaged social position one of the few means of controlling their behavioural environment. The sources of patients' distress are often found in the burden or responsibility for holding their family together, for safety and survival in a world of endless work, insufficient resources and threats from crime and drugs. Through illness they can express negative emotion that is otherwise sanctioned by virtue of their ethnicity, gender and social role. Illness also legitimises role or identity change by allowing them to withdraw from active life - to be released from expectations and responsibilities (Heurtin-Roberts 1993: 285-92). Illness is often used to justify dependency or failure in work and marriage (Kleinman 1986: 152-4). Focusing on somatic symptoms may lessen suffering by diverting attention from painful emotional and social circumstances that are perceived as unchangeable (Kirmayer 1986: 122, 125).

Pain offers a means for **manipulation** and gaining advantage in interpersonal relationships, i.e. to ensure devotion of a family member or to stabilise a fragile marriage (Kaplan & Sadock 1991: 510). Pain can be used to punish others, to avoid close relationships or sex, or to control anger (Hudgens 1983: 503). The **sense of entitlement** to care is reflected in interpersonal behaviours by a willingness and skill at soliciting caretaking, as well as by a ready resort to disability, compensation, and litigation to support a sick role. Through 'passive-aggressive' or 'pain games' patients may effect increased attention from relatives or health professionals by splitting or playing off one provider against another. In the short term they are often effective in obtaining additional attention and sustaining the sick role, but over the longer term they contribute to the development of negative feelings and rejection by the provider (Blackwell & Gutmann 1986: 402-3).

Adoption of the **sick role** is invariably associated with some inability to function in a healthy role. This could result from lack of basic intellectual, manual, or social skills to perform adequately, from unrealistic expectations of performance, or from a heightened fear of failure. Adoption of the sick role is facilitated because it reduces or avoids the anxiety associated with the inadequate performance of a healthy role. This avoidance learning becomes self-reinforced not only through the anxiety reduction associated with withdrawal from the healthy role, but also by the negative conditions and secondary inertia that results from the sick role (Blackwell & Gutmann 1986: 403).

To say patients use their illness is not to say that they want that illness any more than they might want diabetes or cancer. However, given that a chronic physical malady exists, it is reasonable to make use of the illness in a way that is culturally allowed and guided. People tend to maximise their options in personal adaptation as best they can, using whatever tools are available to them. They become master strategists to use illness for coping with the problems of everyday life (Heurtin-Roberts 1993: 293).

Patients may be reluctant to manage their pain or loathe relinquishing the sick role due to **secondary gains** and because they would lose what little control they possess over their environment (Heurtin-Roberts 1993: 293). Kirmayer cautions that attempts to redirect their bodily suffering to some other realm would be in conflict with their mode of constructing illness meaning and an imposition of an alien system of values. Reinterpreting somatic distress as psychosocial will prove helpful only if patients have the intrapsychic and social resources to utilise an alternate framework that has beneficial value to them – otherwise it may only disrupt their social order and they may be invalidated and rendered still more powerless (1986: 129). This implicates that the social environment needs manipulation or the illness will not get better. Farmer urged that one should not ignore the “social origins of much - if not most - illness and distress” (cited in Heurtin-Roberts 1993: 293).

Shorter maintains that **psychosomatic illnesses** have always existed, because psychogenesis - the conversion of stress or psychological problems into physical

symptoms - is one of nature's basic mechanisms in mobilizing the body to cope with mental distress (Shorter 1992: x). However, over the past two centuries, the 'shaping' of symptoms resulted in symptoms of psychosomatic illness being passed from the motor side of the nervous system to the sensory side in order to correspond with new medical paradigms of central-nervous disease. Hysterical paralysis of the late eighteenth and nineteenth centuries shifted to quite different symptoms in the twentieth - those of chronic fatigue, pain and allergy sensitivity (Shorter 1992: 2; 267, 311-2).

Sigmund Freud explained the importance of child development in determining the adult personality and that childhood trauma, particularly sexual events and fantasies, was responsible for the symptoms patients exhibited in adult life. Hysterical symptoms as seen in the 1890's were caused by the patient's 'resistance' to unwelcome truths about the past, which had been 'repressed' into the unconscious. The ultimate assignment to psychiatry of somatoform disorders by the end of the 1930's meant that classic hysterical symptoms were no longer medically legitimate. Patients had to instead produce symptoms appropriate for 'real' doctors who claimed to treat real organic illness. This paradigm shift of hysteria to pain resulted from the improvements in medical ability to diagnose disease and disprove symptoms, such as paralyzes (Shorter 1992: 245-53, 315).

In addition to psychogenic pain, fatigue is the other great somatoform symptom of the end of the twentieth century. One might expect that people who are leading frenetic, compartmentalized lives in crowded cities to feel tired and that their "exhausted cerebral centers" would be likely to produce symptoms like fatigue. The cause is likely to be psychogenic, a result of life's stress or depression. Whatever the difficulties patients experience in life, they unconsciously 'choose' fatigue (and pain) as an expression of their distress (Shorter 1992: 267, 300-1).

In terms of symptoms as a means of communicating with others, hysterical paralysis (like anorexia nervosa today) was an emotional response to the overpowering, all-controlling familial intimacy in the nineteenth century. Familial expectations of social roles also helped to shape the nature of symptoms as 'restricted' Victorian women were 'weak' and

produced fainting fits and paralyses. After the 1920's when women became 'strong,' they now could have headaches and tiredness (Shorter 1992: 293-4).

With postmodern time, changes in family and social life resulted in the commitment to the family as an institution, being taken over by the individual's self-actualization or personal growth. The family became remarkably fragile and unstable. Increasing numbers of people living alone are socially isolated. There is a lack of intimacy because of the splintering of social relationships leaving people vulnerable. Ironically, sufferers today are highly symptomatic despite enormous improvements in health care, antibiotic therapy and nutrition. There has been a sharp rise in work absenteeism and disability grants recipients. Higher rates of somatisation and loneliness are linked with feelings of ill health, somatic distress and visits to doctors, and physical disease, especially in patients with interpersonal problems (Shorter 1992: 158, 319-20).

Whereas doctors were seen as demigods until the 1960's, a subculture exists today that is far more skeptical and disrespectful of medical authority. There is often criticism of medical incompetence and indifference and this deep mistrust can lead to 'shopping around' from doctor to doctor. In the absence of folkloric wisdom, alternative forms of cure and outdated practices of 'getting the poisons out of there' are revived. At the end of the twentieth century the authority of the mass media has started to take precedence over medical authority and people have become more 'educated' and 'sophisticated' (Shorter 1992: 270, 299, 315-23).

Today's psychosomatic illness reflects a fixed belief in a given diagnosis. The diagnosis may be changeable, based on a fashion resulting from the rising influence of the media upon public opinion. People are super-sensitive to body signals and more ready to assign these symptoms to a given 'attribution' - a fixed diagnosis of organic disease. Interestingly, the cause of illness has also shifted from internal demons to external toxins, such as yeast infection and food allergies (fixed illness beliefs that spread epidemically) (Shorter 1992: 319, 295, 308). Reputed causes of fibromyalgia or CFS now include environmental toxins ('sick-building', Gulf War syndromes and silicone breast implants)

Lyme disease and food allergies. Conversely, doctors cautioned the media and certain often well meaning patient support groups of perpetuating feelings of helplessness, anger and illness behaviour when claiming a biomedical model for these syndromes (Nicasso cited in Goldenberg 1996: 402). Nonetheless, people are prone to embrace each newly described disease of fashion as the answer to long-standing, multiple, undiagnosed complaints (Shorter 1992: 307).

Shorter explains that the 'discovery' of fibromyalgia came as though heaven-sent to doctors as a diagnostic label for pain patients who displayed an important neurotic component in their illness. From a "grab-bag of scattered bodily pains", fibromyalgia passed to being a specific rheumatic disease despite the absence of a definite organic pathology. Simultaneously, patient support groups and other mechanisms encouraged the spread of a psychic epidemic. Yet, the pattern of insomnia, muscle pain and fatigue exhibited all the distinctive characteristics of somatisation in the twentieth century (Shorter 1992: 312).

Shorter views fibromyalgia and **chronic fatigue syndrome** (Epstein-Barr virus infection and myalgic encephalomyelitis or ME) as different disease labels for "the fashionable illnesses" of our time, "the twentieth-century diseases" (1992: 266). This is similar to Abbey & Garfinkel's theory that fibromyalgia, chronic fatigue syndrome, atypical fascial pain and irritable bowel syndrome represent a "culturally sanctioned form of illness behaviour" (cited in Hudson & Pope 1996: 297). Yet, many rheumatologists continued to believe in the organicity of fibrositis (inflammation of muscle and fibers) despite mainstream medicine shying away. Even sufferers' organizations accepted that fibromyalgia and chronic fatigue were the same disease - except they considered both to be viral in origin, not psychiatric. Despite the conclusion that the two conditions were identical at a National Conference for Persons with Fibromyalgia in Ohio in 1990 (Shorter 1992: 313), it seems that the local rheumatologists only recently began to share this view: "fibromyalgia and CFS are probably different presentations of the same disorder" (Dessein & Shipton 2000: 94).

2.8.5 Probable psychosocial factors predisposing individuals to fibromyalgia

Pillemer et al. explained how **genetic and environmental factors** interact throughout development to shape the phenotype of an individual. Adverse early experiences, including abuse, neglect, or severe childhood illness and associated medical treatment, may influence vulnerability to a variety of physio- and psychopathologies, and possibly to disorders such as fibromyalgia (1997: 1933). However, not everyone with the same predisposing factors develop fibromyalgia. Particular patients may develop somatoform pain disorder rather than other psychiatric disorders because of structural or chemical abnormalities that predispose them to experience pain (Kaplan & Sadock 1991: 421).

A lower pain threshold and other fibromyalgia symptoms are spread across the general population but only some with generalised pain or chronic fatigue become patients (Wolfe et al. 1995: 19-28). A study by Goldenberg found that IBS, premorbid psychiatric illness and psychological distress were the most important determinants of fibromyalgia patients versus nonpatients (those with fibromyalgia symptoms who have not sought medical care), but the best predictor of nonpatients becoming fibromyalgia patients was lifetime psychiatric diagnosis. Whereas both groups had lower pain thresholds and abnormal neuroprocessing of pain, only fibromyalgia patients had diminished pain perception reliability (1996: 401).

The most consistent finding in fibromyalgia family studies, in overlapping symptoms, in neurohormonal research, and in therapeutic trials has been the relationship of fibromyalgia with **stress** and mood disorders. This does not mean, “it’s all in your head”, but rather confirming the mind-body interaction (Goldenberg 1996: 402). Patients note that stress markedly affects their symptoms. It is possible that chronic stress may produce pathophysiologic reactions (Goldenberg 1989: 112). A French study by Genoud et al. found that the onset or exacerbation of fibromyalgia symptoms was temporally related to various life stresses, which ranged from the death of a parent to beginning a low cholesterol diet (cited in Clark et al. 1985: 135).

Croft et al. (cited in Johnson et al. 1997: 578) reported that tenderpoint count correlated with the depressive symptom score and general distress of individuals independently of pain complaints. Urrows et al. found a correlation between the tender point count and degree of daily stress. Buskila et al. noted that fluctuations of fibromyalgia symptoms were influenced by the changes in stress levels (both cited in Namane 1997: 8).

Aaron et al. (1997: 453-460) found that patients with fibromyalgia have more severe **traumas** than nonpatients. Perceived stressful life events and emotional distress, such as death or illness of a family member, caused frequent helpseeking behaviour and more visits to doctors, whereas physical trauma, sexual or physical abuse did not relate to seeking treatment [except in the case of physical assault in adulthood (Walker 1997: 572)]. Emotionally stressful events may enhance the perceived uncontrollability of symptoms and encourage helpseeking – perhaps as a means of modulating distress. Emotional trauma was associated with reports of greater functional disability and fatigue, but they did not find higher levels of pain or lower pain thresholds, as one would have expected.

Stress, as a predisposing factor for fibromyalgia, seems plausible, taking into account that the stress of events such as death, divorce and depression appears to activate the hypothalamus and pituitary, via the limbic system, resulting in the release of endocrine hormones and pituitary peptides, which in turn suppress the immune system. Not only cortisol, but most hormones appear to be implicated in stress reactions. Adrenaline, noradrenaline and serotonin play key roles. Prolonged or excessive stress, or stress in vulnerable individuals, accounts for the maladaptive response, which results in dysfunction or disease. Severe depression and bereavement are associated with reduced natural killer cell activity and raised cortisol levels. Along with gender and chronicity of stress, ageing and certain personality traits also constitute risk factors for developing illness. There is accumulating evidence that social support, religion and exercise protect against the decreased immune function, raised cortisol and depleted serotonin, which occur under stress (Robertson 1998: 46-7).

An **emphatic competence-dependent self-esteem** (Johnson chap. 2 p. 17) is a vulnerability factor, which, in proper genetic and environmental conditions, affects susceptibility to fibromyalgia and depression. This predisposition requires stressful situations as trigger whereas available social support acts as a protective factor. Such an inherent force within an individual to compete and strive to gain self-esteem is likely to result in a more or less continuous “emergency state”, evoked by ego-related concerns about threatening feelings of personal insufficiency and failure (negative self-value). Individuals in this demanding and exhausting, eventually depressive, state would be more prone to somatic diseases than those in a depressive state based on emotional losses and rejections in close relationships, which state is more like apathy. Thus, chronic exposure to demanding situations and threats, congruent with individual dispositions, may lead to a long-term state of arousal, which is both psychologically and physiologically exhausting (Johnson et al. 1997: 578-83).

An Israeli study by Alfici et al. (1989) tested the hypothesis that fibromyalgia is a **variant of a depressive disorder** by examining personal and family history, and the clinical and psychodynamic features of fibromyalgia patients compared to RA patients. They concluded that hypochondriacal complaints are due to the continuous nature of the pain, the ignorance about the pain’s origin and ineffective treatment. They found parental deprivation (broken homes) in 43% of patients with fibromyalgia and construed that this may explain the difficulties in interpersonal relationships experienced by these patients later in life.

Alfici et al. ascertained that the condition was a well-delineated psychiatric ailment in which **childhood deprivation caused depression in later adult life; depression presenting primarily as pain** (cited in Shorter 1992: 313). Thirty percent had had depression in the past and 65% had current depression. A discrepancy of high scores on the Zung self-rating depression scale and a tendency not to reveal depressed affect at the interview, indicated a clear dissociation (Alfici et al. 1989: 159). Pain serves as substitute for depression and that somatic preoccupation protects patients from the depression. Corroborating findings of other scholars, they found 70% of fibromyalgia

patients tended to deny internal and interpersonal conflicts, and maintained the outward appearance of a solid citizen. They displayed greater idealisation of family relationships, specifically with their spouses, and maladaptive responses to loss (Alfici et al. 1989: 160).

Obsessive-compulsive **personality** traits were significant and core ego needs (such as dependence and passivity), ergomaniac behaviour and masochism were noted (Alfici et al. 1989: 158, 160). Their major conflict is between basic ego needs (dependence and passivity) and the needs of the ideal ego (independence and activity). This results in guilt and anxiety, and the patient attempts to cope with the latter by excessive, constant work (ergomania). This pattern indicates reaction formation against the basic needs, and is accompanied by alexithymia. The frustration, resulting from the discrepancy between the ego needs and the ideal ego, and lack of satisfaction of basic needs, lies at the basis of the depression of these individuals. The inability to cope with their frustration leads to further guilt, which finally brings about the breakdown of defense mechanisms and the emergence of depression.

Depressive mood is not apparent among fibromyalgia patients and depression takes the form of a physical symptom - pain. The 'choice' of pain as a symptom appears to be due, at least partially, to the frequent occurrence of chronic pain syndromes among relatives of these patients (38%), who serve as a model or an object for unconscious identification (similar to Kaplan & Sadock statement on p. 27). Therefore, the physical illness (in this case pain) serves to solve the conflict, decrease the anxiety level and satisfy the basic needs. In sharp contrast with the premorbid ergomania, patients now present anergia, anhedonia and insomnia. All of these point to a depressive disorder, although the patients interpret them as a response to pain. The denial of a depressive mood and the fact that the pain serves as a solution to the conflict²³, explain the patient's inability to 'give up' the symptom - thus becoming an invalid (Alfici et al. 1989: 160).

²³ Patients achieve primary gain by keeping internal conflicts outside their awareness. The symptom then has symbolic value in representing the unconscious psychological conflict. Secondary gain results from the tangible advantages and benefits as a result of becoming sick (Kaplan & Sadock 1991: 419).

Inadequate social skills and the **inability to adjust** to change or cope with trauma may further predispose an individual. The hypothesis is that disease occurs when someone is unable to internally regulate distressing feelings, like the helplessness and hopelessness aroused following a disruption in important attachment relationships (Altschuler 1997: 14). Gagiano & Pistorius (1998: 48-9) describe the impediment that persons may experience due to the inability to come to terms with traumatic life events or distressing experiences, some dating from early childhood. It may include abuse, loss or death of important bonding figures, and rejections from a parent, spouse, social group or in the work situation. It may also be a loss that does not objectively appear as such, but is more subtle and on an abstract level (a perceived loss). In order to grow stronger from the experience and develop effective ways of dealing with difficult situations, it is essential that such persons 'work' through the phases of 'bereavement'. These are denial, aggression, introspection and acceptance, forgiveness and peace. Otherwise they do not develop or improve their stress- and conflict management and their coping- and problem-solving skills.

Often a traumatic event causes so much pain that the individual cannot face it and the only way to cope with the trauma is through denial - an effective way of dealing with emotional pain. Yet, a new stressful life event may trigger a 'flood of reality'. Depression and anxiety are often precipitated and maintained by the loss experience. The aggression phase is marked by verbal, physical or passive aggression. Rejection, avoidance, bitterness or hatred is experienced whilst external forces are mostly blamed for problems. During the introspective phase the individual blames him/herself and may experience guilt and depression. It is only when the person progresses through the final phase of acceptance, forgiveness and peace that he/she accepts whatever has happened in the past, forgives whoever is perceived to be the perpetrator and accepts present circumstances. Without inner conflict, turmoil or negative thoughts, the person may be better able to utilize their energy and all skills can be mobilised for effective strategies to deal with more complex situations (Gagiano & Pistorius 1998: 49).

Sometimes adaptation does not occur because of **irrational thought patterns** due to errors of reasoning or perception – often modeled on a key figure in the person's life during an early and sensitive phase of development. Sustained stress leads to psychosomatic symptoms, which later could, if the stress is not handled effectively, lead to actual organic disease. It is vital to unlearn the wrong behaviour and replace it with better-adapted behaviour. Important factors to change behaviour are insight and motivation. Chronic illness, a lack of good support systems and the abuse of alcohol, benzodiazepines and analgesics may inhibit the process of acquiring new behaviour patterns. Many people are scared of change or do not recognise the need for change. This results in poor personality development whereby all stress is handled with defense mechanisms such as denial (or avoidance) (Le Roux 1998: 49-50).

Goldenberg concluded that the stress response system might assist to understand fibromyalgia and the other overlapping disorders. Genetic factors, abuse and chronic psychological distress may provide a premorbid susceptibility to fibromyalgia. Neurohormonal dysregulation may cause abnormal regional blood flow to areas in the brain that regulate pain perception. Multiple external and internal factors may trigger a cascade of psychosocial dysfunction in fibromyalgia (1996: 398). See Figure 2 on p. 12.

2.8.6 Childhood trauma, dysfunctional families, and sexual, physical and emotional victimisation among fibromyalgia patients

Since pain is not only a sensory but also an emotional experience, events during childhood (sexual abuse, family sick role environment, etc.) can modify an individual's interpretation of pain (Bennett cited in Meyer 1997: 24). As found in the case of somatising and somatisation disorder (footnotes 18-19) several studies found that fibromyalgia patients too have a developmental history of dysfunctional families. Hudson et al. (1992: 365) found a higher than expected rate of familial mood disorders, mostly major depression and bipolar disorder [suggestive of a manifestation of a 'familial depressive spectrum disorder' (Katz & Kravitz 1996: 149)], followed by alcohol abuse and migraine in first-degree relatives (FDR) of fibromyalgia patients. Katz & Kravitz

also found that alcoholism and an antisocial personality were more prevalent among the male FDR and depression more among the female FDR. Depression in patients with fibromyalgia was related to a family history of depression or alcoholism in their FDR and not simply a 'reactive' depression secondary to the pain and other symptoms. In contrast, no substance abuse and low levels of alcoholism among patients (lower than the general population) have been reported as unexpected findings (1996: 149). Smythe has also noted an aversion to the use of tranquillizers, drugs and alcohol (1989: 1242).

A British study found that multiple tender points were strongly associated with multiple psychosocial risk factors. These included childhood experiences such as childhood abuse, parental illness, death or disability, together with hospitalisation, institutional care and abuse in fibromyalgia patients themselves (McBeth et al. 1988: 150). A local study at Heideveld primary health care center also showed a high incidence of abuse and dysfunctional families amongst fibromyalgia patients (Namane 1997: 52).

As with other chronic pain disorders (chronic pelvic pain and irritable bowel syndrome) fibromyalgia has also been associated with high incidents of early childhood and adult sexual and physical victimisation or trauma. (Walker et al. 1997: 572). Women with fibromyalgia had higher incidents of sexual abuse (17% vs. 6%) and physical abuse (18% vs. 4%) than women with rheumatic disorders. It seems that a symptom of physical pain may be perceived as a more acceptable complaint by a patient experiencing either subconscious or real psychological distress. It is possible that the psychological stress phenomenon as a result of abuse may in some individuals have an effect upon the expression in and perpetuation of the pain syndrome of fibromyalgia in adult life (Biosset-Pioro et al. 1995: 240).

Taylor et al. who found equally high rates of trauma in fibromyalgia and control groups (65% vs. 52%) concluded that sexual abuse did not appear to be a specific factor in the etiology of fibromyalgia, but could account for more somatic symptoms and severity of pain. Sexual abuse can be one of a constellation of variables (physical abuse, drug and alcohol use in the family and instability of family or relationships) that puts women at

risk for multiple physical ailments (1995: 229). Lifetime victimisation should therefore not be limited to sexual and physical abuse alone, but associated with a more general lifetime history of distressing interpersonal trauma (Walker et al. 1997: 573).

Walker et al. (1997: 574) found higher rates of all forms of victimisation (sexual, physical and emotional) in both adult- and childhood of patients with fibromyalgia compared to those with RA. Higher incidents of childhood physical assault and adult physical and sexual assault were reported. Childhood also had more maltreatment, more emotional, physical and sexual abuse (including more frequent sexual assault with penetration) and more emotional and physical neglect. Fibromyalgia patients reported significantly more parental psychological unavailability or incapacitation by mental disorders or drugs and more unhappiness in childhood. Of significance was finding repeated abuse (abused as child and later re-experienced in a similar form of assault as adults).

Psychiatric symptoms and functional disability correlated highly with childhood maltreatment, which was found to be a general risk factor for later unexplained pain, but particular forms of maltreatment (e.g. sexual abuse) did not have specific effects. However, adult physical abuse and sexual assault (rape) showed a strong and specific relationship with fibromyalgia (Walker 1997: 574).

Trauma severity correlated significantly with measures of physical disability, psychiatric distress, illness adjustment, personality and quality of sleep. There was a greater association between severity of maltreatment and perceived physical disability, dissociation, stress and number of pains (Walker et al. 1997: 575). The presence of a victimisation history seems to be a marker for greater physical limitation and a more limited treatment response – especially since fibromyalgia patients already report higher levels of stress.

The researchers concluded that victimisation, especially in early childhood may have some role in the etiology or maintenance of fibromyalgia. Whether this is mediated by

central nervous system or immune processes remains speculative. They recommended that women who have both victimisation histories and fibromyalgia might need more intensive support and treatment to assist them in their illness adjustment. Future studies of the pathophysiology of fibromyalgia would also benefit from careful attention to the inclusion of psychiatric and psychosocial variables (Walker et al. 1997: 576-7).

The high correlation between victimisation history and the number of medically unexplained physical symptoms suggests that early experiences of victimisation for which there were no timely interventions might be expressed over time through the appearance of medically unexplained physical symptoms. The original trauma might gradually transform into physical symptom manifestations - leading to increased interactions with medical caregivers. Because of the betrayal of trust involved in early childhood maltreatment, for many women this may be an acceptable method of indirectly obtaining care for their traumatic experiences.

Recent studies of other medically unexplained physical symptom syndromes (IBS and chronic pelvic pain) have found similar associations and studies of women with adult trauma have shown increased treatment seeking as well. These findings suggest that the relationship between fibromyalgia and victimisation may actually be a specific example of a larger, more general association between victimisation and somatisation (Walker et al. 1997: 576).

Hudson & Pope pointed out that it is difficult to find a cause-effect correlation between early childhood environment and later medical and psychological effects. Specific negative life experiences are predictive of later poor outcome in particular individuals, but it is the pattern of multiple disadvantages that has the most deleterious effects. It is therefore more important to understand the relationship between fibromyalgia and the overall quality of early family life rather than to focus on associations between fibromyalgia and specific occurrences of physical and sexual abuse (cited in Walker et al. 1997: 577).

2.8.7 A psychodynamic perspective of psychosocial influences on human development

Since this is a limited dissertation and part of a coursework masters degree, human development theories that may apply to this study will not be discussed in detail. However, the theories of Erikson and Wolberg (outlined in Appendices II and III) are briefly referred to as it provides a deeper understanding of the psychosocial dynamics that influence personality, behaviour and adjustment.

Unlike Freud who stresses biological determinants of behaviour, Erikson examines cultural and societal influences on ego development. His major concern is with the growth of the ego; especially with the ways society shapes its development. He believes that personality continues to develop throughout life. In *Childhood and Society* (1950) Erikson postulates eight 'psychosocial' stages of life, each of which constitutes a critical period for social and emotional development. Each stage is characterised by a different psychological 'crisis' where the individual is pressured by internal needs and external demands of society to make a major change in a new direction. Success in each stage depends on the individual's adjustments in the preceding stages and if the crisis remains unresolved, the individual will continue to have difficulties with that issue later in life. (Dacey 1982: 21; Morris 1976: 437-8; Papalia & Olds 1978: 10,106).

Wolberg's theory on personality needs and stresses (Appendix III) elaborates on Erikson's theory by identifying common stresses that affect individuals at different age levels, and pathological syndromes that may develop as a consequence of a collapse in the individual's adaptive capacities. This is most likely when basic needs are not met, and security and self-esteem are shattered, with no hope of immediate reparation. Severe environmental deprivations or environmental difficulties would render individuals with defective personalities incapable of coping - initiating conflict and anxiety. In contrast with Hudson & Pope's reluctance to accept a cause-effect correlation between early childhood environment and later medical and psychological effects, Wolberg established that a combination of physical and psychological symptoms originates from the failure to

solve conflicts. These include mainly the various manifestations of depression/anxiety, psychosomatic disorders, defenses against anxiety, as well as techniques of counteracting or solving the conflictual situation itself, such as, rage reactions, withdrawal or excessive dependency. While symptoms are unique for every individual, definite groupings of symptoms appear with sufficient frequency to constitute familiar syndromes. (Lecture notes, School of Social Development, U.C.T. 2003).

Both theories emphasize the importance of need fulfillment and the successful resolution of conflicts and developmental tasks during crucial periods in human development. A negative outcome has a detrimental impact on individuals and their adjustment in later life. Early childhood experiences are critical and any adverse or traumatic experiences will further impair/damage the developmental process. The following section continues to explore these theoretical perspectives and examines the impact of experiences of abandonment/rejection on the individual.

2.9 ABANDONMENT/REJECTION AND ITS IMPACT ON THE INDIVIDUAL

Bradshaw defines abandonment as not merely physical desertion, but includes various forms of emotional abandonment, including deprivation of physical contact, narcissistic deprivation, fantasy bonding, neglect of developmental dependency needs and family system enmeshment, as well as all forms of abuse (1988a: 41).

2.9.1 Abandonment through the neglect of developmental dependency needs

Since the latter overlaps with all forms of abandonment it will be discussed first. Being dependent and needy, the developmental needs of children must be satisfied by their parents/caregiver. Besides needing security, nutritional food, clothing, shelter and medical care, children need their parents' time and attention, someone to hold and touch them. They need a mutually trusting relationship, predictability and to know that there is someone they can rely on. They need a face to mirror and affirm their feelings, needs and drives. Children need a structure with limits, their own space and be allowed to be

different. Children need direction through advice and acquiring problem-solving techniques (Bradshaw 1988a: 58).

When these needs are neglected children are given the message that their needs are not important, that they do not matter and they lose a sense of their own value. Chronically rejected needs result in a belief that they have no right to depend on anyone and when they do feel needy, they feel shame. Basic needs are often met in abortive ways, such as getting into trouble to get attention (or by being sick). Besides the fact that unmet basic needs may result in an arrested personality at those developmental stages, continual need-deprivation may eventually cause a loss of awareness of those needs and ultimately that they do not even know their needs. Abandonment through the neglect of a child's developmental needs is a major factor in becoming an adult child (an adult with an inner child who feels empty and needy) - often at the core of all compulsive and addictive behaviour or oral fixation (Bradshaw 1988a: 58).

2.9.2 Physical abandonment

Oral fixation is likely, considering that Wolberg (Appendix III) specifically identifies separation from a parent, death of a parent and rejection by a parent as common stresses and sources of conflict during the 'oral stage' of development that may lead to anxiety and psychosomatic disorders, rage or withdrawal.

To be abandoned is to be left alone. Physical absence, or even worse, emotional absence may have a profound effect on a child (Bradshaw 1988a: 42). Prolonged separation from the mother during the first year of life can lead to depression or even paranoia (rejection anxiety) in the adult character (Kaplan & Sadock 1991: 35). An unplanned or unwanted child, or children from dysfunctional marriages will probably have greater issues with periods of separation from a parent (Bradshaw 1988a: 42). Since they had no one to depend on, they may grow up with an excessively needy child within them and exhibit physical and/or emotional clinging behaviour as a defensive strategy (Bradshaw 1988b: 122). They fear the loss of love or even abandonment by their parents if they fail to

control and direct their impulses in conformity with their parents' standards and demands (Kaplan & Sadock 1991: 391).

The presence of both parents are needed, especially the father's, to break the bonding with the mother. Children's egocentric interpretation of events often let them believe that something is wrong with them, or the parents would desire to be with them. Not having their parents' time creates feelings of being worthless - worth less than their time, attention or guidance (Bradshaw 1988a: 42). Children of distant parents enter adulthood longing for closeness, while often afraid to be vulnerable. They search for some 'magic' that will make them like everyone else – loved, accepted and valued. With the mother distant, the child often grows up feeling unnurtured, insufficient and deficient. If the father was distant, a grown daughter often longs for a satisfying love relationship, yet feels hopeless and inadequate (Hillman 1992: 59).

In Erikson's terms, children's sense of basic trust in their mothers and in the world leads them to a realisation of their own sense of self (Papalia 1978: 106). Abandonment and rejection generates mistrust and a lack of security and confidence in themselves. These children often suffer from 'identity diffusion versus role confusion', characterised by their lack of a sense of self and by not having their 'place' in the world (Kaplan & Sadock 1991: 43). Because identity requires concurrence between their own sense of self and the views that others have of them, those about them confirm their inner being. Love then serves as validation of the person (Dacey 1982: 25-6).

Children need their parents' 'modeling' to develop ego boundaries (internal strength to guard their inner space). When parents are not dependable, do not have strong boundaries, or are not there for their children to identify with, the children will not be able to learn from them or internalise the parent to form a dependable guide inside themselves (Bradshaw 1988a: 43). When children are unable to replace a negative inner parental voice with an inner nurturer, they continue to feel incompetent rather than accepting themselves and to pursue personal and professional goals with confidence and security (Hillman 1992: 67). The lack of faith in themselves may also result from the

ineffective resolution of the conflict between 'trust versus distrust' in the first development stage of Erikson.

2.9.3 Emotional abandonment through deprived narcissism

In their first three years children need 'mirroring and echoing' from their parents to know that they are admired, taken seriously, that they are accepted for who they are and that there is someone there for them. If these 'mirroring' needs (termed narcissistic supplies) are satisfied, children do not have to please the parent and can develop their own needs at their own developmental pace. They can depend on and 'use' their parents because they are separate from them. A parent's independence and good boundaries will allow the child to separate self- and object representation. Being allowed to display ambivalent feelings, children can learn to regard themselves and the caregiver as both 'good' and 'bad', rather than splitting off certain parts as 'good' and splitting them from the 'bad' (Bradshaw 1988a: 44).

Hillman explains that children reared in an accepting, nurturing atmosphere learn to put the 'good' and 'bad' aspects of their parents into one 'package'. The parents can be strict, angry or preoccupied, but they are also supportive, loving and involved. Similarly, these children learn to put the 'good' and 'bad' aspects of themselves into one 'package'. They feel mean, spiteful and hateful, as well as loving, warm and compassionate. The 'bad' within thus becomes tolerable because it is not perceived as negating the 'good', rather it is acknowledged and accepted as part of the human condition. These children become adults who can love themselves, as they were loved by their parents - not only when they are perfect, but all the time (1992: 65).

When parents are needy and never got their own narcissistic supplies met, they are unable to take over the mirroring narcissistic function for the child. Such parents are adult children who are still in search of a parent /object who will be totally available to them. For such parents, the most appropriate objects of narcissistic gratification are their own children since they cannot abandon the parent as his/her own mother did. A child can be

used as an echo, can be controlled and offers full admiration and absorbed attention. By providing in the perceived need of the parent, a child secures love and a sense of being needed and is therefore not abandoned. Paradoxically, the child is now taking care of the parents' needs, rather than the converse. In the attempt not to be abandoned, the child is in fact abandoned. Since the child is there for the parent, there is no one there to mirror the child's feelings and drives, or to nurture the child's needs. Any child growing up in such an environment has been 'morally wounded' by this narcissistic deprivation. Ironically, they often believe that their childhood was happy and protected (Bradshaw 1988a: 45).

Yet, behind this there lurks depression, feelings of emptiness, self-alienation, guilt, shame and a sense that life has no meaning. When children are loved for their achievements and performance rather than for themselves, their true and authentic selves are abandoned. As a result they are often disconnected with their own true feelings, such as anger, jealousy, loneliness, or sadness. Another consequence of emotional abandonment is the loss of a sense of self. When used as another's narcissistic supplies, individuals develop in such a way as to reveal only what is expected of them and ultimately fuses with their own act/performance (Bradshaw 1988a: 45). The true self remains in a state of non-communication (Winnicott's state of unintegration, unconnected and diffuse experiences) and leaves the individual with feelings of emptiness, homelessness and futility. Shame is internalised when one is abandoned. Abandonment is the precise term to describe how one loses one's authentic self and ceases to exist psychologically. Children cannot know who they are without reflective mirrors (cited in Bradshaw 1988a: 45).

Perhaps the most devastating consequence of emotional abandonment is 'bond permanence'. Children who have been denied the experience of connecting with their own emotions are first consciously and then unconsciously (through internal identification with the parent) dependent on their parents. They cannot rely on their own emotions, have no sense of their own real needs and are alienated from themselves. Such individuals cannot separate from their parents and are 'fantasy bonded' with them. They have an illusion of a connection with the parents, but are actually fused and enmeshed in

an entrapment rather than in a relationship (Bradshaw 1988a: 46). Many of these children may never succeed to detach from their parents and struggle to achieve autonomy (Papalia 1978: 165).

Later this fantasy bond will be transferred to other relationships and they remain dependent on affirmation from their partner, children and others. Yet, they never have a real connection or relationship with anyone. There is no real authentic self to relate to. The real parents, who only accepted the child when he/she pleased them, remain as introjected voices. The true self hides from these introjected voices just as the real child did. The 'loneliness of the parental home' is replaced by 'isolation within the self' (Bradshaw 1988a: 46). Kaplan & Sadock (1991: 45) describe it as lacking true intimacy or mutuality reminiscent of the first stage of life. Through the crisis of 'intimacy versus isolation' the person fails to transcend the exclusivity of earlier dependencies and establish mutuality with an extended and more diverse social group.

Many of these individuals often have a sense of grandiosity and cannot live without admiration. If their talents fail them it is catastrophic. They must be perfect or they become severely depressed due to the lost and abandoned child within. They will only be free from depression when the self-esteem is based on the authenticity of their own feelings and not on the possession of certain qualities (lack of a sense of self and identity).

Unfortunately, emotional abandonment becomes multigenerational and a vicious cycle of re-enactment of their abandonment on their own children without them realising it. This is the delusional nature of deprived narcissism. The children may idolise and idealise the parent and continue the delusion of a happy childhood, but when emotionally abandoned people describe their childhood it is always without feeling (Bradshaw 1988a: 47).

2.9.4 Abandonment through sexual, physical and emotional abuse

All forms of child abuse are forms of abandonment, because when children are abused, no one is there for them. Young children believe that they are responsible for the abuse, not only because of egocentrism, but because their survival depends completely upon their parents. They need to maintain the idealization that their parents are not bad or emotionally ill. As a result, they internalise that something is wrong with themselves otherwise they would not be treated like that (Bradshaw 1988a: 47).

According to Miller abused children are alone with their suffering, not only within the family, but also within themselves, as they cannot share their pain with anyone. They cannot create a place in their own soul where they could cry their heart out (cited in Bradshaw 1988b: 113).

Sexual abuse involves more than merely physical sexual abuse. It includes overt sexual abuse in the form of voyeurism and exhibitionism, inappropriate sexual talking and boundary violation with lack of privacy, and emotional sexual abuse where parents use the child inappropriately to meet their emotional needs in a dysfunctional marriage. The child needs a parent, not a spouse (Bradshaw 1988a: 48).

Physical abuse and sexual and physical violence are devastating forms of abandonment. The child is left alone. The child is a victim of his/her parents' shameless needs, and is used and abused. Sexual and physical violence are about the silence of nights spent holding in screams, holding back tears, holding in their very selves (Bradshaw 1988b: 139). The mere threat of violence or the witnessing of violence, such as the mother being battered, is equivalent to the child being battered - a witness to violence is a victim to violence (Bradshaw 1988a: 51). These images are forever etched into their brains. It is detrimental to the child's mental health. Accumulating scientific evidence shows that witnessing violence or being abused physically or verbally literally alters brain development, resulting in a hyperactive emotional system (Wallerstein, Lewis & Blakeslee 2000: 90).

Witnessing violence seems to have a particularly malignant effect on the emotional development of girls as they appear to internalise the father's denigration of women and accept the view that women are inferior, ugly, stupid and deserving suffering. They internalise the image of a man who is overpowering, that they need a strong man 'to hang onto' because "without a man I am nothing" (Wallerstein, Lewis & Blakeslee 2000: 142). Kitahara's study of the perception of parental acceptance and rejection among Swedish university students found a significant relation between various forms of parental rejection in childhood and negative personality assessment of the self as an adult. Females showed more dependence and emotional instability (1987: 223-7).

Ownership of children by parents and the belief that they are willful and need their wills broken, account for the rationale of spanking children. Such parents often expect children to meet their needs for comfort and nurturing. When children fail, they interpret this as rejection and respond with anger and frustration, and deal with the children as if they were much older than they are (Bradshaw 1988a: 51).

Emotional abuse can be overtly cruel through verbal abuse, or as subtle as sanctioning certain emotions as being weak or bad, such as joy, sadness, fear and anger. Many children are made to feel shame for their feelings and become numb. This may lead to repressed feelings that can eventually spill over into rage, paranoia, despair or even suicide (Bradshaw 1988a: 53).

Hillman refers to the continual trauma of being told that one was bad, willful, stupid or crazy and how constantly berated and belittled children would not feel good about, or love themselves. They know only how to attack themselves, constantly criticising, berating, and punishing themselves in mirroring the parent's attitude towards themselves. These children are often constantly on guard with authorities and supersensitive to evidence of their faults, overly fearful and dread that they would be rejected and abandoned when others see how 'bad' they are (Hillman 1992: 65-9). They lack assertiveness and control over their lives. They seem to have failed in achieving a sense of autonomy and experience doubt and a sense of shame (Papalia. 1978: 106).

Several authors, including Wallerstein, Lewis and Blakeslee, concurred that one of the main effects of abandonment/rejection was the fear of further abandonment/rejection (2000: xxxv). Three studies that investigated people with **rejection sensitivity** reported a negative effect on intimate relationships.

Downey & Feldman found evidence that people who are sensitive to social rejection tend to anxiously expect rejection. They readily perceive intentional rejection in the ambiguous behavior of others and overreact to it. This cognitive–affective processing disposition undermines intimate relationships (1996: 1327-43).

A second study confirmed that a self-fulfilling prophecy wherein rejection expectancy lead people to behave in ways that elicit rejection from their partners (Downey et al. 1998: 545-60).

Ironically, chronic needs for acceptance may result in people with low self-esteem seeing signs of rejection where none exist, needlessly weakening attachments. They read too much into problems, seeing them as a sign that their partner's affections and commitment might be waning. They then often derogate their partner and reduce closeness. It seems that the need for acceptance might constrain people's capacity to protect their relationships in the face of difficulties (Murray et al. 2002: 556-73).

2.9.5 Abandonment through enmeshment in the overt and covert needs of the family system

The more dysfunctional a family becomes, the more closed and rigid are the roles it assigns to its members, i.e. to be the hero or rescuer, they have to be strong, never show fear or vulnerability. After years of performing that role individuals do not know who they are any more. In this manner they give up their own reality to take care of the family system. Each form of abandonment diminishes the child's' sense of preciousness and incomparability and unless treated with value and love, it can disappear completely (Bradshaw 1988a: 59).

2.9.6 Abandonment in alcoholic families

Alcoholic families are severely enmeshed. As the alcoholic marriage becomes more entrapped, the children get caught up in the needs of both their parents, as well as the needs of the family system for wholeness and balance. Often a child becomes a parental child, a surrogate spouse, the brother's 'little parent' or mom's scapegoat when she turns her anger or frustration onto the child whereas other children may become lost in the family. In alcoholic families punishment occurs frequently and is usually inconsistent. The discipline is modeled by uncontrolled disciplinarians who are mostly taking out their irritation and rage about their own life on the children. Most of the time it has nothing to do with the children (Bradshaw 1988b: 93).

Because of chronic distress in an alcoholic family, its members often become hypervigilant, anxious and chronically afraid. In such an environment it is impossible for anyone to get his/her basic human needs met. Each person becomes co-dependent. The major consequence of this chronic stress is abandonment. Along with the actual physical abandonment by the alcoholic, the neglect of the child's needs is another form of abandonment. The parents cannot be there for the child because of their own neediness and turmoil. As a result each child turns inward to a fantasy bond of connection with their parents (delusion and denial) and ultimately to self-indulging habits and painkillers (Bradshaw 1988a: 48).

A third form of abandonment comes from abuse since alcoholic families foster every kind of abuse because of the lowered inhibitions from alcohol. Because violence is irrational and impulsive, it is often random and unpredictable. It is this quality of violence that causes 'learned helplessness' in victims when they become passively accepting of their abuse. Their self-worth is diminished. They can no longer choose, think or plan. They do not attempt to free themselves from the battering situation and look for 'morsels and crumbs' of love. Paradoxically, a process of bonding with the offender offers the victim a way to overcome the feeling of helplessness and powerlessness. They literally lose their own reality and become the offender in the

bonding process in order to survive. Children growing up in this environment become 'externalisers' who believe that most of the events that occur in their lives are caused by factors outside their control. They feel the situation is hopeless. Their will has literally become 'disabled'. This all adds up to children who need their parents, but who have been abandoned in their childhood (1988b: 133). According to Papalia (1978: 106) their dependency makes them doubt their ability to be autonomous. If they do not achieve autonomy, their sense of shame may cause a rage turned against the self, as seen in self-destructive behaviour.

Often abandonment sets up compulsivity. The insatiable little child, who never got his/her needs met, is often driven to compulsivity as a result of inner emptiness. These individuals are looking for more and more love, attention, praise, alcohol, money, etc. and constantly seek approval (Bradshaw 1988b: 93-4). An alternative defense is to somatise since feelings cannot be expressed. Victims get sick and therefore can feel as bad as they really feel. With sexual abuse, sickness may appear in the same areas of the body that the original abuse occurred (Bradshaw 1988b: 120). Physically abused individuals have been sick a great deal of their life and have many headaches, stomachaches and backaches. They go to doctors often and are told that no organic cause could be found for their illness (Bradshaw 1988b: 137).

Bradshaw explains that when emotions are inhibited, or when stress becomes overwhelming and chronic, ego defenses come to the defense of the individual in order to maintain a balance. In some cases, early emotional pain was numbed. The inhibiting mechanism (ego defenses) kept them from knowing that the emotional pain is there, but these unresolved emotions need expression. The turmoil in their emotional lives will continue because their original pain is unresolved. The individual may need to give up their delusions and denials about their family and childhood. The wounded child's original pain needs to surface. Contemporary therapy focuses on the inner child where a great deal of 'original pain and grief work' is needed before the inner child can heal (1991: 72-6).

To conclude the literature review, the final section focuses on the prognosis and management of fibromyalgia, followed by a conclusion.

2.10 PROGNOSIS

Longitudinal studies indicated that fibromyalgia does not evolve into another immune or inflammatory disease over time. Most patients continue to be symptomatic, complete remissions are unusual, but gradual modest improvement over time is common (Goldenberg 1996: 401). Even patients who respond to therapy may continue to complain of a lower level of persistent but tolerable pain (Freundlich & Leventhal 1993: 249).

With treatment the majority who were working can return to work, although some may need to change jobs (Nye 1996: 6), whereas the prognosis and ability to return to work is affected adversely by filing for disability benefits (Goldenberg 1996: 401). A small number of patients continue to do poorly despite treatment. The poorest prognoses for pain disorders are patients who become inactive, deconditioned and do not participate in their own rehabilitation or employment (maladaptive pain behaviour) (Meyer 1997: 26), those with preexisting characterological problems or an unrecognised psychiatric component, or an addiction problem (Kaplan & Sadock 1991: 422).

2.11 MANAGEMENT OF FIBROMYALGIA

Fibromyalgia is a complex spectrum of problems with considerable variations from patient to patient, which implies that no single strategy is effective in all patients (Meyer 1997: 25). There is currently no treatment that is consistently successful or continued for any prolonged period of time by individual patients (Fitzcharles & Esdaile 1997: 937). Physicians and patients anecdotally report that simply a diagnosis of fibromyalgia is the most effective therapy in terms of long-range outcome (Goldenberg 1996: 399).

Pharmacological therapy: Getting adequate sleep is essential: Low-dose tricyclic antidepressant medication that improves sleep and pain, increases serotonin levels in the

brain, which are important neurotransmitters in both sleep and in descending pain inhibitory pathways (Meyer 1997: 26). Amitriptyline and Cyclobenzaprine are effective in 33% of fibromyalgia patients, but the dropout rate due to side effects is significant (Lyddell 1997: 555). Prozac has no effect on pain, but is effective for sleep, fatigue and depression in combination with Amitriptyline (Nye 1996: 4, Wilke 1995: 250).

Injection of the tender points: A topical anaesthetic, combined with corticosteroids can offer short-term relief when one region is particularly bothersome (Clauw 1995: 850).

'Alternative' drug and herbal treatments: Fibromyalgia patients are high consumers of alternative treatments and although patients expressed their satisfaction, their effect upon pain and functional impairment were similar to conventional treatments (Fitzcharles & Esdaile (1997: 937).

Physiotherapy is essential in the treatment of fibromyalgia to reduce pain and inflammation, increase mobility and to restore function. Pain management techniques such as massage, electrotherapies and acupuncture assist the process of interrupting the pain pathways or stimulate the release of the body's own neurochemicals and hormones to have pain-relieving, anti-inflammatory, immune-enhancing and beneficial psychological effects. Because emotional and mental stress is often reflected in the neuromusculoskeletal systems and manifest in pain and/or muscle tension, trigger point therapy and relaxation techniques are beneficial (Berger 2000: 101-110).

Exercise²⁴: Lasting improvement in patients seems to be associated with a regular programme of muscle stretching, gentle strengthening and low impact aerobic exercises as part of their lifestyle (Meyer 1997: 25). Unfortunately 50% of patients withdraw in the first few weeks. As with other forms of intervention, the relapse rates are high after cessation (Lyddell 1997: 556).

²⁴ During **exercise** catabolic hormones such as glucagons and cortisol increase while insulin and adrenaline decrease, improving the body's ability to cope with stress. The sense of well-being is augmented with the increase in serotonin, opiates, endorphins and other neurotransmitters (Nowicki 1998: 55).

Literature occasionally calls for *interdisciplinary collaboration in the management* of fibromyalgia patients and refers to close cooperation between physicians, psychologists and physiotherapists (Bradley 1989: 135). The researcher found no articles about social work intervention with fibromyalgia patients, except one suggesting the inclusion of social work and occupational therapy in group programmes. Over the last ten years the focus has shifted to include patient education and reassurance in the initial therapeutic approach (Freundlich & Leventhal 1993: 249) and to include partners/family (Nye 1996: 6).

Behaviour modification was commended since it is based on the assumption that people's perceptions and evaluations of their life events influence their emotional and behavioural reactions to those events. Many patients believe that the pain, disability and other consequences of their disease are uncontrollable and this leads to increased negative affect, pain and sleep disturbance, as well as reduced attempts to engage in activities of daily living or to develop effective coping behaviour (Bradley 1989: 132).

Hypnotherapy and cognitive-behavioural therapy had impressive results. The latter teach patients the skills necessary to manage pain and encourage them to take responsibility, as well as to attribute their coping successes to their own efforts (Bradley 1989: 131-2) – thus decreasing victimisation or 'learned-helplessness' behaviour (Clauw 1995: 849).

A group therapy programme over six-months by allied health professionals (rheumatologists, psychologists, a nurse and an exercise physiologist) found not a 'cure', but a striking improvement (70%) in patients, which many sustained over two years. Its emphasis was on behaviour modification, stress reduction techniques, improved fitness and support to partners. Individual consultations attended to sleep disturbances and management of depression and anxiety. Pain or depression did not predict a poorer outcome. Those who experienced worthwhile improvement came to a better understanding of fibromyalgia and developed effective coping strategies, exercised regularly and changed emotional and behavioural reactions with greater internal locus of control. However, the programme was expensive and time consuming, and a shorter, simpler programme limited

to education, cognitive-behaviour therapy and supervised stretching/aerobic training was recommended (Bennett et al. 1996b: 527).

“A structured six-week self-management programme for coping with arthritic diseases”, developed by Kate Lorig, U.S.A. proved to be popular and effective amongst a small number of South-African patients due to a shortage of trained group leaders.

As a third world country, in South Africa, with considerably less infrastructure, resources or support groups, patients are often entirely dependent on their doctor. In this context, the *integrated biopsychosocial approach* to combat somatic fixation seems crucial as a solution to a vicious cycle of ‘doctor shopping’ (Figure 3 p. 26). With this approach the physician addresses a patient’s complaints with an integrated biomedical and psychosocial evaluation from the beginning and solicits help from family early. McDaniel et al (1990: 253-62) advised the physician to avoid an authoritative position and any implication that a magic treatment exists to relieve patients from their symptoms. If test results remain negative, he will tolerate the uncertainty while the investigation continues. The physician may consult with a colleague/family therapist to share in the evaluation (1990: 254). Meyer emphasizes the importance to accept that total elimination of pain is mostly impossible and that the aim is to improve function and restore the patient to a more functional lifestyle. The patient needs to take an active role in his/her management (1997: 25). McDaniel et al. suggest that they should set limited, concrete goals for treatment and measure outcome by monitoring the patient’s functioning/progress in areas of work, family and personal life rather than only the patient’s symptom picture. As the patient improves the physician is cautious about a cure and predicts typical flare-ups as part of the recovery course to prevent disappointments (1990: 255). It is important to see patients at regular intervals not dictating by symptom occurrence or intensification, as well as to terminate slowly. They need to agree together to make sessions less frequent, but that he still remains available. Visits to other health care providers should be discouraged and the patient may rather bring complaints to them than elsewhere. Multiple work-ups and dispersal of somatic fixated patients tend to reinforce biomedical fixation (McDaniel et al. 1990: 260). The following Figure 4 illustrates this approach.

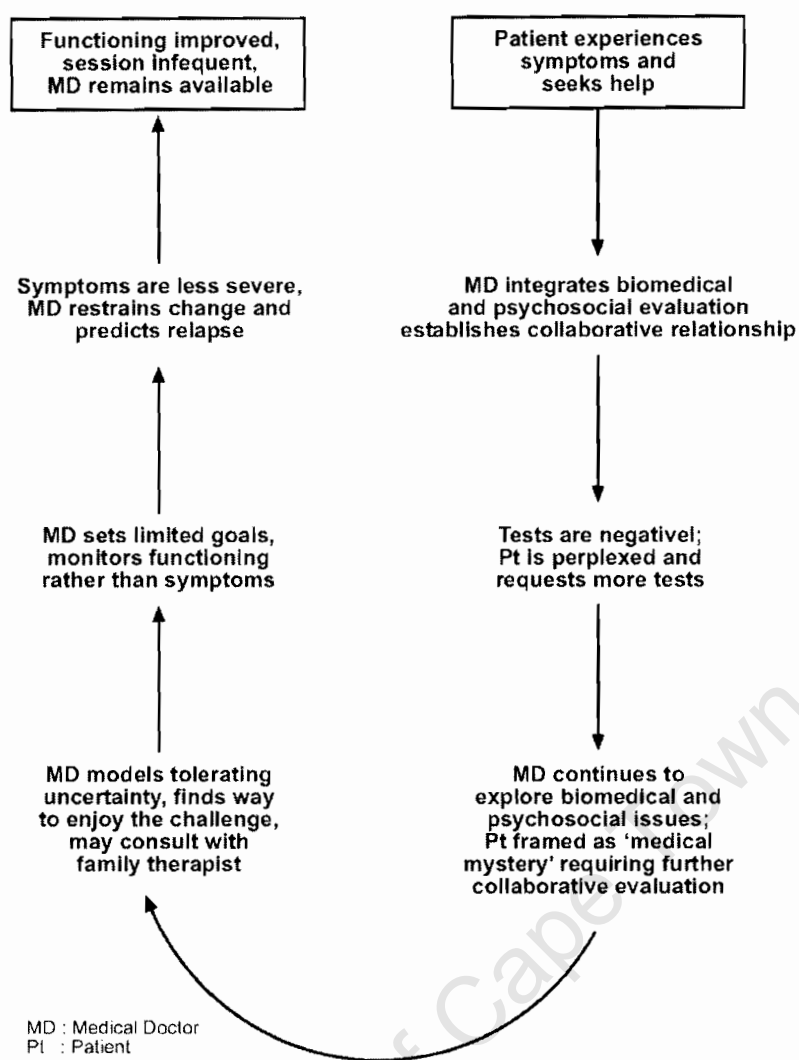


Figure 4
A biopsychosocial approach to somatic fixation
 (McDaniel et al. 1990: 259).

2.9 CONCLUSION

It is clear from the literature review that much controversy and confusion exists regarding fibromyalgia due to varied research findings over the past twenty years. Yet, answers remain elusive about this complex and multifaceted condition. Scholars approach

problems from their own perspectives and theories within their specific disciplines/fields while methodological problems have also been identified.

Most scholars seem to agree that psychiatric symptoms may occur largely as a consequence of the chronic pain, fatigue and sleep disturbance, and that fibromyalgia is not considered to be a reflection of a psychiatric disorder. Others found evidence of a premorbid and familial history of mood disorders or believe that a 'masked' form of depression is at the root of fibromyalgia. A third group considers fibromyalgia as a twentieth-century 'fashionable' illness in reaction to stress and fatigue of modern day lifestyles and a form of somatisation. The hypothesis that fibromyalgia and chronic fatigue syndrome are different presentations of the same disorder, or that they form part of a cluster of disorders is interesting, as it may point to a common physiological abnormality and appropriate treatment. However, it is possible that the criteria to diagnose these disorders are the problem. Spending considerable effort to find the correct 'label' for these conditions may not necessarily be helpful for the patient or medical profession. To the patient, the illness is real and sufficient pathological evidence can explain the symptoms. Considering its diverse symptoms and comorbid disorders, fibromyalgia could be an unbearable condition to endure.

Of specific interest is the most consistent finding in numerous studies of a specific relationship between fibromyalgia, stress and mood disorders. Also significant, are the findings of victimization among fibromyalgia patients, specifically physical abuse in adulthood and all types of abuse and neglect in childhood. There are scholars who believe that sexual, physical and emotional trauma may be important factors in the development and maintenance of this disorder and its associated disability in many patients. More so since trauma severity correlates significantly with physical disability, psychiatric distress, illness adjustment, personality and quality of sleep.

It seems that a significant number of fibromyalgia patients have been exposed to considerable distressing interpersonal trauma. Many come from broken homes, dysfunctional families, or backgrounds with physical and alcohol/drug abuse, antisocial

personality and depression in family members, or a parental physical or mental illness, disability or death. It is important to note that depression in these patients related to the family history of depression and alcoholism rather than being reactive to their chronic pain condition. Another important finding was that they described parental deprivation or unavailability and that many took a parental role to care for family members when they themselves needed care. Reports of unhappiness in childhood, where they felt alone, indicate that their needs were not met. They had been exposed to extreme stress, but no intervention rescued them from the situation.

Of importance is the tendency to dissociate from depression and not to reveal depressed affect, along with denial of internal and interpersonal conflicts and idealization of family relationships. The suppression of and the inability to express emotions may then account for the gradual transformation of original trauma into physical symptom manifestations.

New insights were gained from ego psychology explaining the frustration resulting from the discrepancy between the ego needs and the ideal ego, and lack of satisfaction of basic needs that lies at the basis of the depression of these individuals. Along with their need to gain self-esteem through competence and approval by others (obsessive-compulsive and ergomaniac behaviour), this explains the breakdown of defense mechanisms and emergence of depression (now presented as anergia, anhedonia and insomnia).

Reports of maladaptive responses to loss and stress and the inability to come to terms with traumatic experiences might be linked to findings of a deprived upbringing and a lack of self-assertiveness and coping/social skills. In this context, the assertion that somatisation or the use of the body as metaphor for the expression of emotional distress seems plausible. There appear to be similarities in personality, behaviour and family histories of both somatisers and fibromyalgia patients. Physical complaints then become an acceptable method of indirectly obtaining care for their traumatic experiences and modulating distress. This pattern of helpseeking behaviour becomes self-reinforcing due to somatic fixation by patient and doctors, and to secondary gains.

The theory that prolonged and excessive stress is responsible for neurohormonal dysfunction seems probable – especially since exercise improves both neurohormonal functions and fibromyalgia whilst lessening stress. It is evident from several studies that patients are considerably subjected to psychosocial stressors and are finding it difficult to cope with their fibromyalgia. The recent advance in research, that the stress response system might assist to understand fibromyalgia and the other overlapping disorders, is significant. A possible genetic predisposition, abuse and chronic psychological distress may provide a premorbid susceptibility to fibromyalgia. Neurohormonal aberrations may cause abnormal regional blood flow to areas in the brain that regulate pain perception. Poor sleep, also related to neuroendocrine factors, is likely to be another important interacting factor that would account for morning stiffness, fatigue and cognitive impairment.

There is now acknowledgement that psychosocial factors could be important in the onset, severity, exacerbation and maintenance of many physical or mental conditions, including fibromyalgia. The researcher supports calls for a biopsychosocial and inter-disciplinary approach to manage this multi-factorial condition as conventional treatments alone have proven to be ineffective. There appears to be little evidence of social work involvement in the management or research of fibromyalgia, despite an obvious need. The multiple psychosocial adversities of these patients, as well as the focus on coping- and pain management skills, behaviour modification, inclusion of families and group programmes in treatment regimes, necessitate the skills of social workers.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter provides a brief overview of the focus of the study, definitions of key concepts, research approach and method utilized, sampling techniques, methods of data collection and analysis, and the limitations of the research.

3.2 DEFINITION OF KEY CONCEPTS

Most foreign concepts were explained in footnotes in the text for clarity and convenience.

Abandonment/rejection: The following extracts from various sources indicate the multiple connotations that were ascribed to these concepts in this study. Some antonyms are also provided for a better understanding:

'Abandoned': to be left behind, given up upon, cast aside, deserted, forsaken, neglected or rejected.

Antonym: to be supported, cared and provided for.

Consequent feelings: bereaved, disappointed, disregarded, deprived, lonely, lost, insecure, empty or emotionally detached.

'Rejected': cast aside, unwanted, excluded, denied, discarded or ostracized.

Antonym: to be accepted, understood or acknowledged.

Consequent feelings: unworthy, overlooked, betrayed, criticised, disowned, isolated, alienated.

(Sources: Microsoft Word 2000 Thesaurus; Penguin English Dictionary 1985-1986 and Collins Pocket Reference Thesaurus 1992).

For the purposes of this study, the researcher used a broad, inclusive definition of 'abandonment' and 'rejection' to facilitate the subjective manner in which the group members perceived, interpreted and attached meaning to their experiences of abandonment and rejection, whether it was real, unintended or imagined. Although the main focus of this study was on experiences or feelings of 'abandonment', the latter contains elements of 'rejection' and both concepts were therefore used, sometimes in combination. Depending on the context, both could be construed as an intentional or inadvertent act, an omission or the result of circumstances. Individuals did not need to have been in a relationship where they were then physically abandoned in order to experience such feelings. Exclusion from being part of a group or not being accepted, along with feelings of deprivation and loss are all part of the broader concept of emotional abandonment, even though on their own it might not be seen as abandonment.

Bradshaw's definition, that "abandonment is not merely physical desertion, but includes various forms of emotional abandonment, and is associated with all forms of abuse" (1988a: 41), concurred with the researcher's findings and interpretations regarding this concept. The term 'compounded abandonment' referred to multiple experiences of abandonment.

Attachment: Bowlby's attachment theory explains how infants attach to and then separate from their mothers, experience losses, mourning and depression, and how relationships with the external world affect the development of attachment and security in the young child. Early separation of infants from their mothers has severe negative effects on the children's emotional and intellectual development (Kaplan & Sadock 1991: 29, 847). According to Altschuler, insecure attachment involves mixed emotions of loss, depression and rejection. When facing a threat like illness, unmet dependency needs are easily evoked and people tend to seek out a substitute attachment figure, such as a health professional to feel more secure and relieve their anxieties. On-going access to attachment figures is crucial to enable them to adapt to their changing situation (1997: 15).

Caregivers: include not only parental figures, but can also be a spouse, caring friend, supportive employer, allied health professionals, doctors or the facilitator.

Distress: severe pressure or strain of pain, sorrow, anguish or affliction, exhausted or distressed condition, misfortune or calamity, subject to severe strain, afflicting vex, make anxious or unhappy (Reader's Digest Great Encyclopaedic Dictionary 1964: 258).

'Good' breast / 'bad' breast: Melany Klein emphasizes the biological drives and instincts, which dominate the child's inner world and are inherently directed toward objects. Due to immaturity of the ego and perceptual skills, the infant can only focus attention on part of the object – the first part object being the mother's breast. During the first three months of life, the infant only experiences gratification or deprivation, the latter being regarded as bad. The infant's object world is comprised of gratifying and hostile parts of the real world. The infant is not yet aware of being separate from the object, and there is fusion between the experience of self and the experience of the object. Gratifying experiences reinforce basic trust, but if the experience is frustrating – especially in the first year of life – the person develops a 'paranoid-schizoid position' characterised by isolation and persecutory fears. Splitting occurs when good and bad objects exist with a splitting of love and aggression between them instead of integrating the 'good' and 'bad' object into one whole mental representation (a good and secure whole internal object), which should take place during the 'depressive position phase'. The 'bad breast' refers to the mother object that cannot be trusted, who is unreliable or causes painful and bad experiences (Kaplan & Sadock 1991: 189; U.C.T. Honours lecture notes 1999; Klein 1932).

The inability to tolerate depressive anxieties may result in depressive illness and are thought to influence later object relations. Salzberger-Wittenberg identified several factors, which may contribute to the infant not being able to work through the 'depressive position phase' of development successfully. An early experience of loss, either through death, desertion, or long-term separation may strengthen the infant's feelings of possessing a bad persecuting mother and the omnipotence of its destructiveness ('bad

breast'). Likewise, a sickly or vulnerable mother who is unable to adequately respond to her infant may reinforce the infant's feelings of being damaging and exhausting (1970: 82-4 and U.C.T. Honours lecture notes 1999).

Illness behaviour: describes the ways persons respond to bodily indications and the conditions under which they come to view them as abnormal. It is the manner in which persons monitor their bodies, define and interpret their symptoms, take remedial action, and utilize various sources of help, as well as the more formal health-care system (Mechanic 1986: 101).

Masked depression: somatic symptoms in the complete absence of discernible cognitive or affective symptoms of depression (Lesse cited in Kirmayer 1986: 112).

Negative transference: transference, first described by Freud, refers to the patients' unconscious feelings and behaviour toward the analyst (or any person) that are based on infantile wishes the patient has toward parents/parental figures. Positive transference is when the analyst is seen as a person of exceptional worth, ability and character. Negative transference is when the analyst becomes the embodiment of what the patient experienced or feared from parental figures in the past. It can be expressed and experienced in highly labile and volatile ways. Both positive and negative transference reflect the patient's need to repeat unresolved childhood conflicts (or other traumatic interpersonal experiences that occurred later in life) (Kaplan & Sadock 1991: 573).

Pain: "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage, or both" (International Association for the Study of Pain cited in Gaskin et al. 1992: 711). It is also described as the sensation experienced when the body is injured, or afflicted by certain diseases, suffering, punishment, or distress of body/mind (Reader's Digest Great Encyclopaedic Dictionary 1964: 633).

Separation-individuation: Margaret Mahler who studied early childhood object relations, describes a developmental phase called ‘symbiosis’ during which the infant feels fused with the mother or the mother’s breast. The ‘separation-individuation phase’ begins in the fifth month of life and is completed by age three. The child must separate from the mother, acquire new skills and achieve individuality and attainment of ‘object-constancy’, characterised by the child’s perception of himself as a distinct person, separate from the mother, along with other equally distinct persons. Serious personality defects and mental illness can result from mothers who abruptly disengage themselves from the child leading to the abandonment experience. A child that never has a bond with the mother, is unable to internalise the mother-image as reliable, or who cannot separate and progress beyond the closeness and complete dependence that characterizes the mother-child relationship in the oral phase of development. This child never achieves object constancy. The latter is characterised by a sense of secure identity, which results from a close attachment to the mother during infancy (Kaplan & Sadock 1991: 15, 30, 328; Mahler, Pine & Bergman 1975).

Somatisation: the defensive conversion of psychic derivatives into bodily symptoms or the tendency to react with somatic rather than psychic manifestations. Infantile somatic responses are replaced by thought and affect during development (desomatisation). Regression to earlier somatic forms of response (resomatisation) may result from unresolved conflicts and may play an important role in psychological reactions (Kaplan & Sadock 1991: 184).

3.3 FOCUS OF THE STUDY

The aim of the study is to explore and conceptualize the experiences of abandonment and rejection that emerged from group therapy with fibromyalgia patients - from their own subjective perspective. To this end, although not in this order, this research focuses on the experiences of abandonment/rejection in the context of family (parents, grandparents, siblings, spouses and family-in-law) and how the death of parental figures and loved ones was experienced as a form of abandonment. It further explored abandonment by friends,

colleagues and employers, the government and broader society, doctors and hospitals, fellow group members and the facilitator.

Although the sample in the study is too small to generalise findings, this study poses the research question, at least in this group, of whether there is a connection between the experiences of abandonment/rejection and the development, maintenance and exacerbation of fibromyalgia. It must be emphasized, however, that this must be regarded as a research question, which should be subjected to further testing by future research.

3.4 RESEARCH METHOD

This study is a retrospective study and focuses on a small group of fibromyalgia patients with persistent pain and other symptoms, who repetitively experienced abandonment/rejection. It is primarily explorative, yet also ventures into the interpretative and explanatory fields. It explored the group members' experiences of abandonment and rejection, analysed 'insight-stimulating' examples from group discussions and describes the nature and extent of their abandonment. Babbie points out that explorative studies are valuable in social scientific research, especially for such a relatively new and unstudied subject, where there are persistent phenomena and a desire for better understanding. Explorative studies test the feasibility of undertaking a more careful study. It is often pursued through the use of small group discussions. The chief shortcoming is that it seldom provides satisfactory answers to research questions due a lack of representativeness. It can however, hint at the answers and can give insights into the research methods that could provide definitive answers (1992: 90-1).

Contrary to the positivists who search for potentially 'causal' associations through quantitative methods to make universal, context-free generalizations, naturalists study research subjects holistically and in their own context in order to understand the social and psychological phenomena from the perspective of the subjects themselves. For this reason the researcher prefers the phenomenological approach as strategy or 'tool'.

According to Denzin & Lincoln it aims to understand and interpret the meaning that the subjects give to their everyday lives. The researcher enters the subject's life world and places himself/herself in the shoes of the subject. This is done through naturalistic methods of study, analyses of the conversations and interactions that the researcher has with the subjects (cited in De Vos et al. 1998: 80).

The qualitative research method was selected as most appropriate for this study as it allows in-depth group interviewing, observation, interpretation and utilization of audio material (De Vos et al. 1998: 94). In qualitative research the data is in the form of words, including quotes or descriptions of particular events, which is interpreted by finding out how the people being studied see the world, how they define the situation, or what it means for them (Neuman 2000: 148). The researcher could therefore interpret data from the group therapy sessions by giving them meaning, translating them, or making them understandable. Because qualitative research is flexible and open to unanticipated data and constantly reevaluates the focus early in a study, (Neuman 2000: 149) the researcher was able to gradually narrow the research topic as the theme of abandonment/rejection emerged more clearly from the group discussions.

3.5 STUDY POPULATION AND SAMPLING

The non-probability sampling technique, specifically purposive sampling was used whereby participants were selected in terms of their availability, interest and commitment to participate in a support/therapeutic group. Purposive sampling selects cases with a specific purpose in mind and is often used in exploratory research. The purpose is less to generalise to a larger population than it is to gain a deeper understanding of types. It generates insights, anomalies and paradoxes, which later may be formalized into hypotheses that can be tested by quantitative research (Neuman 2000: 198).

As explained in chapter one, fibromyalgia patients with uncontrolled symptoms were invited to join two consecutively presented "structured six-week self-management programmes to assist patients with arthritic diseases to cope with their illness". They had

been selected from a recent attendance list of outpatients and physiotherapy at the former Princess Alice Orthopaedic Hospital (PAOH). The patients identified a need for an ongoing support group and requested the researcher to facilitate such a group. An invitation letter was sent to thirteen patients. Ten women responded positively and an eleventh inpatient who could benefit, was invited to join, although he had not done the course. He purchased the self-management help book and studied it with some educational input by the occupational therapist. Coincidentally, the gender ratio of the sample reflected the general ratio of fibromyalgia patient population being one male to ten females suffering from fibromyalgia.

The study population was not a selected number of persons who had suffered abandonment. Rather, they consisted of eleven patients who had fibromyalgia in common, and whose ages ranged from thirty-three to fifty seven; an average age of forty-four. Nine were from Cape Town and the so-called 'coloured' population group and two were immigrants from Britain and Hungary respectively. Most had working-class backgrounds with no tertiary education. Four were employed whilst the remainder had all been boarded from work due to fibromyalgia or another illness. Besides fibromyalgia, two had diabetes, one systemic lupus erythematosus, one rheumatoid arthritis, two asthma, one a previous stroke and cancer of the ovaries, one anorexia nervosa, one hypertension and one had had polio. Many had comorbid disorders such as irritable bowel syndrome, depression and musculoskeletal complaints, mostly in the form of backache. Three were receiving disability grants whilst five women did not qualify due to their marital status.

Eight were married, two divorced and one single. Only the latter did not have children. Three raised their children as single mothers. At least eight had received treatment by a psychiatrist or psychologist for what seemed to be depression or anxiety – three concurrent with the group therapy. One of the eight had anorexia nervosa and had attempted suicide several times. Five had been inpatients at a psychiatric clinic. Seven of the group had a history of dysfunctional families in their childhood, two had stressful dysfunctional marriages at the time of the group and five claimed to be happily married.

Gaining entry and building relationships was uncomplicated since the researcher, as social worker already had a natural role in this group and the advantage of previous knowledge and contacts. Trust relationships already existed, although not with some of the members of the second self-management group who the researcher had not previously met. Five of the eleven group members had attended a self-management course that the researcher had co-facilitated the previous year. Whilst awaiting the completion of the second self-management course, five members of the first group intermittently met with the researcher to contain them until the group therapy started. This means that the first group had thirteen group meetings with the facilitator in the preceding nine months. Thus, they had an advantage over the members of the second self-management group who felt like 'stepchildren' joining the 'new family' when the two groups amalgamated with the formation of the therapy group.

Grinnell mentions the disadvantages of a natural role when being too familiar with the scene, which prevents the researcher from observing something that an outsider would have seen as unusual or problematic. Existing relationships may also hinder free disclosure and any splits within the group could cause the full participant observer to be co-opted and biased towards one side (1993: 70).

Since the decision to utilize the group therapy for research was only taken after the first session, group members were approached during the second meeting where the researcher's role was also delineated. They were told that the researcher was keen to learn more about fibromyalgia and considered changing her previously elected research project, as it was located at the hospital where she had formerly worked. It was explained that if they did not want to be part of the research process, the group therapy would not be affected and the researcher would continue with the previous research topic. The group members were informed that the research would be documented as part requirement for a Masters degree and that a copy of the report would be made available to them upon completion of the process. Questions from the group were answered and they were assured that their identity would remain anonymous, as their real names would not be used. The exact topic was still uncertain, but would be something of interest that

would derive from the evolving group discussions. All members seemed excited and pleased to make a contribution as it could enhance the understanding of fibromyalgia and would hopefully improve service delivery to patients in future. They all gave verbal consent for the research and permission that the group discussions could be recorded as from the next session.

The next step in the research process was a written proposal to the Research Ethics Committee, Faculty of Medicine, University of Cape Town, for permission to study and report findings where hospital patients were used, which was granted.

3.6 METHOD OF DATA COLLECTION

The primary source of data came from the group therapy discussions. To ensure spontaneity and a free flow of information a tape recorder was employed to record the proceedings and to ensure accuracy. The researcher's observations were also recorded on the tape recorder immediately after the group sessions. Additional information obtained from individual interviews, informal conversations and telephonic contacts (captured in process notes), was not related to or for the purpose of research as such, but nevertheless provided insight. Document study was an additional method of data collection, as the researcher had access to the medical folders of patients for additional information regarding their medical history, treatment and response.

A closed therapeutic and supportive group (see aims p. 2) of one-hour duration was conducted fortnightly, but later changed to weekly sessions. A total of thirty-three sessions, which included two social outings, were held over a period of eleven months (from the 23rd of June 1997 until the 12th May 1998). The venue was a comfortable, quiet lounge in the adjacent nurses home of the former PAOH, with easy access to kitchen and toilet facilities. It had a relaxed and homely, rather than a hospital atmosphere, which was conducive to free-flowing communication.

The group sessions were unstructured, following an open non-directive format where members introduced the issues for discussion spontaneously. Abandonment was the most prominent theme, unexpected and although it emerged repetitively during their discussions, it only became the researcher's focus when the tape recordings were analysed after termination of the group. The researcher considered this as research topic, but elected not to pursue themes of abandonment/rejection on a conscious level, as these were not the focus and aims of the group. De Vos et al. warn against the danger of contaminating the research and advise qualitative researchers to become almost invisible and blend in with the setting (1998: 257). Since the researcher did not want to manipulate the group discussion for purposes of the research, no structured questions were asked nor did 'abandonment' or 'rejection' become the focus of a specific discussion or model of group therapy. However, group members were sometimes subtly asked to clarify something in more detail. The last two sessions were used for evaluation and termination of the group and previously absent members were invited to these meetings for closure.

The data in qualitative research is presented in the form of words, quotes from documents and transcripts (De Vos et al. 1998: 243). The 'tools' for data collection in this study were the group 'interviews', tape recorder and notes and unstructured interviews with the group members. The researcher also practiced participant observation. When a social worker acts as both researcher and engaged participant this is referred to as full participant observation. It is used to acquire in-depth knowledge of the subjects within their own context (De Vos et al. 1998: 72). In this study the full participant observation produced an insider perspective of the life and attitudes of the fibromyalgia patients.

In the analysis of conversations and interaction that naturalistic researchers have with their subjects, the strategy of interpretive enquiry is mainly utilized (De Vos et al. 1998: 80). Of importance is the researcher herself as research instrument. Her interpersonal skills and experience as a social worker in hospitals were invaluable. Her understanding of the difficulties that patients experience when they live with a chronic illness and pain,

whilst trying to cope with other life-demands, aided the process of establishing rapport and trust, and gave them the confidence to disclose their problems.

The following two steps in the research process were the literature review and the manual transcription of the taped group conversations to the Microsoft word-processing programme. The latter was only done after termination of the group process. The researcher did not want to interrupt or affect the therapy process of the group by focusing directly on her research interests. The advantage of using a subtle approach was that it reduced contamination of information and researcher bias. It was a laborious task to transcribe the many group sessions from audiotapes – which was done by the researcher herself. The quality of the recorded data was exceptional because a super-sensitive microphone was used. It was beneficial to hear the group conversations again as this aided identification of themes and to notice data that the researcher had ‘missed’ in her capacity as facilitator.

3.7 DATA CAPTURING AND –EDITING PROCESS

The next phase in the data capturing and –editing process was to organise the mass of data emanating from the group sessions into specific areas of focus. The researcher processed data by reducing it to categories and themes with the aid of a manual coding procedure. Selected printed texts were cut and sorted into files with the following categories that were coded as: emotional pain, abandonment/rejection, impact of abandonment, coping with abandonment and the value of the group therapy.

As it became apparent that the study would assume proportions much in excess of the requirements of a coursework dissertation, the researcher decided to narrow the topic to a more limited research question by excluding the categories of emotional pain, impact of abandonment, coping with abandonment and the value of group therapy – which she had previously intended to include in her study. The remaining category, namely experiences of abandonment/rejection, was then organised into a logical sequence and re-entered into the computer in files for each subsection of the current structure. These are

abandonment/rejection by caregivers during childhood, death as a form of abandonment, abandonment/rejection in adulthood by family, spouse and family-in-law, by friends, colleagues and employers, by government and society, the hospital and doctors, and by fellow group members and the facilitator. This reconstruction reflects the advantage of using emergent designs in a phenomenological approach.

3.8 DATA ANALYSIS

Data analysis consisted of three sub-processes formulated by Huberman & Miles. The **first, data reduction**, was applied in the organising of data by selecting a conceptual framework (structuring) and formulating the research question, followed by making summaries, finding themes, clustering and 'stories' to condense the data. Decisions were made about which data to use in direct quotes from the group members (cited in De Vos et al. 1998: 341).

The **second**, refers to the **data display** and the organised, concise assembly of information in the form of text and direct quotes, diagrams or figures to enhance the display. During this phase the researcher continued with coding and the generation of salient themes, patterns and categories as mentioned in the previous section - a complex, yet creative part of analysis (Huberman & Miles cited in De Vos et al. 1998: 341). Because of the mass of data from thirty-three sessions, the analysis was a time-consuming, yet exciting process. Observed patterns and trends in the data were interpreted and explained, e.g. the concepts of compounded abandonment and negative transference that will be discussed in chapter four.

The **third** sub-process of Huberman & Miles, **conclusion drawing and verification** involved the making of interpretations and drawing meaning from the displayed data, mostly through the noting of patterns and themes, clustering, use of metaphors and verifying information (cited in De Vos et al. 1998: 341). The researcher utilized the inductive reasoning mode where theory is built from data (Neuman 2000: 145). She gained insight from the patterns that emerged in the accumulating data and reached

conclusions, which were only probable and, therefore require further research to render findings generalizable.

The next step was a **literature review reduction and control** by interpreting or comparing the results and findings with existing theoretical frameworks or models as identified in the literature review, and by showing whether these were supported or falsified by the new interpretation (De Vos et al. 1998: 48; Mouton 2001: 109).

3.9 LIMITATIONS OF THE STUDY

It was important to the researcher to be aware of possible sources of error during each stage of the research process, and to consider ways to avoid or reduce error, thereby increasing the value of this study.

The primary limitation of this study is related to the inability to generalise due to the research design, small sample and the lack of representation across all population groups and social class. However, this research could provide valuable insights specifically into issues of abandonment and rejection, and into a deeper understanding of the fibromyalgia syndrome itself, namely how patients experience their illness and how service delivery or closures of hospitals affects patients.

Considering that specialist tertiary care hospitals often get referrals that are more severe or complicated than primary health care centers and that there appears to be a correlation between a history of maltreatment, psychological symptoms and debilitating disease, it is possible to ascribe the high incidence of abandonment to selection/sample bias.

Although this study has rich insights and ample data, information on abandonment or rejection may be incomplete since the data captured in this research was only what emerged spontaneously in discussions without the group members knowing the exact topic of research. For example, rejection by peers or rivals at school never emerged from discussions. The researcher did not vigorously pursue or prompt participants for

information on abandonment issues because the focus was on group therapy. Several factors played a role to cause incomplete information from certain participants who did not always get a chance to talk or refrained from sharing intimate experiences, namely: limited time per session and a large therapy group, shyness to talk in groups or when being recorded, lack of trust, painful and sensitive topics, and absenteeism or premature termination. To minimize this error, the number of therapy sessions was increased and shy members were encouraged to participate in discussions.

The advantage of the participants (and initially also the researcher), not knowing the exact topic at the time of the research, was that the focus was then on the group process and on the needs of the patients rather than on research agendas. Consequently discussions were more spontaneous. Errors in data collection were also prevented which means that the gathered information was more reliable. Contamination or manipulation of data was reduced since there were no research expectations- or social desirability effects that subjects needed to fulfill, and evaluation apprehension and demand characteristics were excluded.

Biased interpretation of data and drawing inferences from data that were not supported by the data could be potential errors in interpretive studies. However, the consistent and repetitive emergence of themes of abandonment/rejection over such a long period confirmed the significance of these themes. Besides, the aim of studying such a small sample was to provide some insights and not to prove a point. To ensure internal validity of data, great care was exercised in minimizing incorrect interpretations. Data was scrutinized and the researcher often returned to both the recorded group conversations and transcripts to clarify information or its context. The researcher also had frequent individual contacts with the group members apart from the therapy group sessions, during which she clarified certain issues. Measures taken to minimize errors were to explore all the data, give attention to detail, provide a comprehensive report, and to use direct quotes or participants' own explanations.

It was not possible to reconnect with the group itself after termination and closure of the hospital to verify the researcher's interpretations. However, in the four years subsequent to the group termination, the researcher continued to have mostly informal and sporadic contact with all but one of the group members when they had appointments at GSH. This provided feedback and insight into the effectiveness of the group therapy, the impact of the hospital closure and their adjustment generally. However, since completion of the research process, the main conclusions have been discussed and confirmed with two of the participants who subsequently attended GSH.

A potential error that was carefully contemplated was that possible co-occurrences could be taken as correlations or even as a causal relationship. However, similar findings regarding deprivation and victimization in Israeli and American fibromyalgia patients indicate that this may not be an error.

There appeared to be a paucity of appropriate information on abandonment/rejection as it relates to this specific topic. Since this study had a limited scope of a course work Masters dissertation and did not set out to compare fibromyalgia patients with other individuals who had been abandoned, it was not necessary to search for similar trends of characteristics or histories.

Due to the nature of this type of participation observation studies, the data collection and analysis of data were laborious and time consuming. However, it provided in-depth insider insights and established trust and rapport with the subjects with a concomitant increase in credibility of the findings.

An obstacle in the study was to make sense of a vast amount of complicated, often contradictory medical research studies that did not appear in a logical sequence of events, and to understand medical terms and conditions in order to understand the fibromyalgia syndrome. The inclusion of medical details in the literature review made the research more interesting and complete, but also more complex and too broad for a limited Master's dissertation.

The problems experienced in undertaking this study did not have a serious effect on the quality of the data that was collected. Having mentioned the main limitations, it is felt that they do not detract significantly from the significance of this in-depth study, which is rich in insights.

3.10 ETHICAL CONSIDERATIONS

As previously mentioned, permission for this study was obtained from the Research Ethics Committee, Faculty of Medicine, University of Cape Town.

The researcher was aware of ethical issues throughout the group therapy- and research process as it interplays on all levels and forms part of one's own professional and personal values and principals. Indeed, "ethics begin and end with the researcher" (Neuman 2000: 90).

The research participants gave consent for the research and permission to record the group discussions. Although the researcher was still unsure about the exact topic at the time of the group therapy, this was never a problem to any of the group members. They were fully aware and consented that the researcher would analyse the group discussions in order to identify themes.

Confidentiality and protection of the identities of the group members were important to the researcher; therefore she preferred to do the transcription of the recorded group sessions herself.

It was also important for the researcher to keep the research aspect separate from the group therapy process to avoid interference of the research agendas with the needs of group members.

The following chapter will present, analyse and interpret the findings.

CHAPTER FOUR

AN ANALYSIS OF EXPERIENCES OF ABANDONMENT AND REJECTION IN FIBROMYALGIA PATIENTS

4.1 ORIENTATION AND A BROAD OVERVIEW OF PERTINENT FINDINGS

This chapter tracks the life experiences, which a selected group of fibromyalgia patients perceived as abandonment from their childhood to adulthood. Since group participation was on a voluntary basis, what follows may not be a complete picture of the participants' experiences of abandonment. Group members admitted throughout the group process that intimate disclosures were difficult for them even though they knew it was necessary. For some, these memories were too painful; others had difficulty in trusting fellow group members and the facilitator, and felt vulnerable and afraid to be exposed, judged, or rejected. It is possible that the early termination of group participation for two members offered an escape from mounting pressure to confront certain issues that they felt they could not cope with at that stage in their lives. Yet, although they remained until termination, it appeared that others still had issues that they had not dealt with, nor resolved. However, while it appeared so, it cannot be stated beyond doubt that these issues were necessarily related to abandonment. Nevertheless, thirty-three sessions provided ample opportunity for a clear picture of life experiences of abandonment to emerge from the group process. Besides, the facilitator had also known most participants for several years of individual contacts prior to, during and after the group process. This offered reassurance that no major abandonment issues had been overlooked. As indicated in chapter one, the researcher wishes to reiterate that this study does not set out to prove a point; it is merely a 'window of opportunity' to explore and interpret recurrent themes of abandonment that emerged from group therapy, in order to provide some insights into fibromyalgia.

At the outset it must be stressed that an experience of abandonment may not be an objective fact, but rather a person's subjective definition of her or his life events. For

example, certain actions, or omissions on the part of a person's parents may have been experienced or interpreted as abandonment or rejection. Yet the parents may not have meant to abandon the person, and may not even have been aware of their child's interpretation. Feelings of abandonment were also of a particularly subjective nature when it concerned the group members' interpretation of experiences of being abandoned by hospital staff – particularly doctors - and in the therapy group that came to an end as a result of the closure of Princess Alice Orthopaedic Hospital (PAOH). However, although feelings of abandonment may not necessarily have an objective basis, they are very real to that person, and are likely to have real consequences - psychologically or physically, or both – in terms of their reaction to certain life experiences, and in terms of their behaviour generally.²⁵

Unexpectedly, the most important finding from the group therapy sessions was the repetitive expression of the theme of abandonment, and related themes by each group member throughout the whole group process. In some instances intimations of abandonment were more obvious than in others. It was, for instance, noticed from their yearning for meaningful relationships they had lost or never had. They needed an emotional connection and a sense of belonging and security. All of the group members had experienced abandonment in one form or another by parental figures and/or spouses. The more important the relationship was, the greater their feelings of devastation and their struggle to cope. This was perpetuated by further experiences of abandonment, which emerged in relationships with family members, friends, employers, doctors, physiotherapists, fellow group members and the group facilitator. In addition, they also felt abandoned by the hospital and by the government when PAOH was closed. These divisions should not be seen as exhaustive, nor as separate facets, as the categories clearly interacted and overlapped.

It seems that earlier experiences of abandonment form a frame of reference for further experiences of abandonment; it colours the lens through which such persons view their

²⁵ See W. E. Thomas' discussion of the concept 'definition of the situation' in *The Unadjusted Girl* (1923: 41-43).

world. It must be emphasized that the sense of abandonment is the result of a subjective interpretation of life's events, which can result in **a mindset of abandonment** that influences a person's interpretation of all life experiences. In fact, many of their defenses that were put into play as children became entrenched as their coping style in adulthood.

The relevance of a study of abandonment with fibromyalgia comes to the fore with the realisation that physical pain may very well symbolise the unexpressed emotional pain stemming from numerous experiences of abandonment. As stated in the literature review, no consistent physical pathology has been found to sufficiently explain the symptoms of fibromyalgia or its severity, whereas there is increasing evidence of psychosocial factors that may have a bearing on this syndrome. The mere fact that none of the many forms of treatment could offer lasting relief corresponds with the notion that the underlying causes for the patients' unbearable emotional pain are still unresolved. As discussed in the literature review, scholars acknowledged that they lack effective treatment for this pain disorder and consequently fibromyalgia is shifted from one domain to the other to resolve. Paradoxically, this is a form of abandonment by the very group of doctors who promised understanding and relief! Experiences of abandonment, as the link between physical pain and emotional pain appear to hold tremendous implications for fibromyalgia. In fact, this study poses the research question whether experiences of abandonment may play an important role in the manifestation of fibromyalgia.

This study will illustrate how feelings of abandonment appeared to have led to attitudes and behaviour patterns that could trigger fibromyalgia. Ironically findings will also show that the illness could serve as a coping mechanism for enduring feelings of abandonment, which could perpetuate sick-role behaviour in some patients. By no means does the researcher hereby imply that fibromyalgia has no physical component - rather that it is a multi-faceted pain disorder that requires multi-disciplinary teamwork to assist patients to have meaningful lives despite their fibromyalgia.

There is no doubt that a large number of people have experienced abandonment, yet a very small percentage of such persons in similar circumstances have been diagnosed with fibromyalgia. The assertion by Thomas (1923: 41-43) that if people define things as real, their subjective definitions have real objective consequences, it is felt, applies to the phenomenon of fibromyalgia. The difference between people who develop fibromyalgia and those who do not²⁶, lies in their definition of their particular circumstances and their reaction thereto. According to Graser defining one's situation is more likely to be an unconscious and subjective matter, depending on one's personality, self-image, values, attitudes and emotions. It is also influenced by one's socialization and acquired social skills in resolving termination of relationships and in establishing and maintaining new relationships (1992: 168). Of importance is the accumulated effect and varying degrees of such experiences of abandonment. It appears to reflect an outlook on life that sees oneself as a **victim of circumstances**. Such a 'victim' needs to be rescued and cared for by others. Thus, experiences of abandonment would seem to contribute to a mindset that sets the scene for the development of fibromyalgia in one person and not in the other.

An interesting manner in which experiences of abandonment often surfaced in discussions was when members overreacted to trivial incidents of perceived abandonment. This is probably related to the previously mentioned mindset of abandonment. Group members were not consciously aware that negative transference triggered intense emotions, such as anger, distrust, hurt and resentment. They had difficulty forgiving persons who they believe had abandoned them - in their view unjustly and deliberately. Overcoming this seemed insurmountable and they were left feeling hurt, scarred and helpless. Gradually, through insight development and confrontation in the group, some group members began to understand the link between recent incidents of abandonment and those in their past. They referred to negative transference as "**playing a record that I know**". Figure 5 illustrates how the same issues replayed itself on different levels and remained unresolved. Subsequently, their intense emotions were defused and they could confront the real issue in a more objective manner.

²⁶ Since fibromyalgia symptoms, such as pain and fatigue are spread across the general population but **only some become patients**, this phenomenon was studied and reported on in the literature review (See Kaplan & Sadock; Goldenberg chap. 2 p.33).

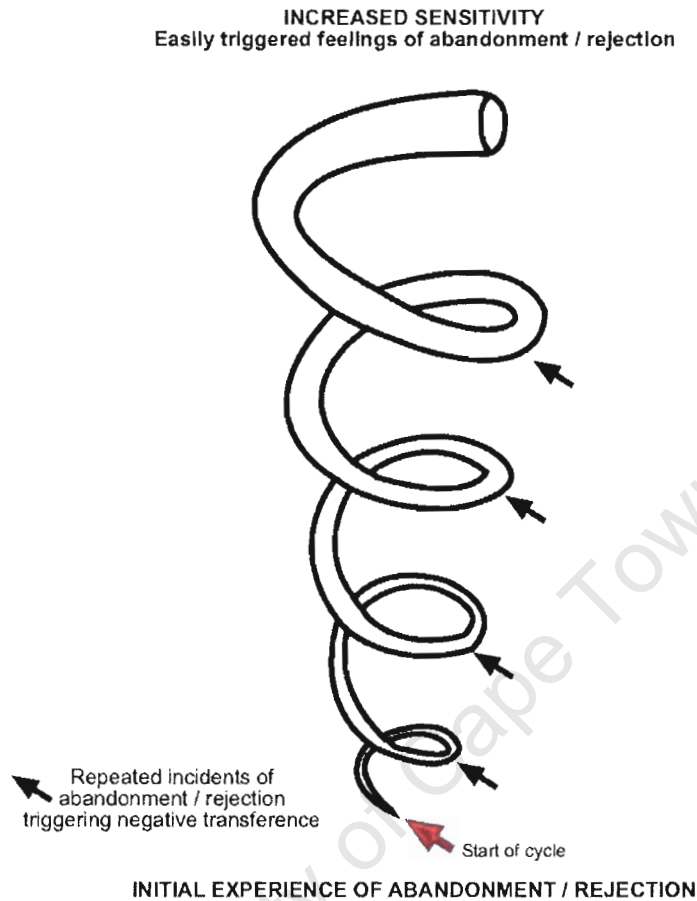


Figure 5
Repetitive experiences of abandonment/rejection and negative transference.

Ironically, this very need also set them up for failure as they held high expectations of significant persons in their lives who, by virtue of their own personality, shortcomings and lack of social skills, were unable to live up to those expectations. Often, just as they thought they had found the right person, history repeated itself when their needs were not met and they were left feeling abandoned and devastated. This fuelled their distrust in people and consequently they would withdraw into themselves, experience more pain and feel even more isolated, unloved and uncontained in a world they perceived as unsafe. As a result, their mindset of abandonment became increasingly more firmly entrenched, and guided their reactions to life experiences.

In the following sections the researcher reviews various scenarios of abandonment that were revealed during group therapy sessions.

4.2 EXPERIENCES OF ABANDONMENT AND REJECTION BY PARENTS AND OTHER PARENTAL FIGURES DURING CHILDHOOD

4.2.1 Childhood experiences of abandonment and rejection

Abandonment by parents and caregivers was commonly experienced during childhood by seven of the eleven members of the fibromyalgia therapy group. Of the remaining four who were contented with their childhood, three experienced intense feelings of abandonment only in adulthood with the death of parents with whom they had had a close relationship.

Most group members who felt abandoned and neglected as children came from **dysfunctional families** with multiple problems such as severe marital conflicts, extra-marital affairs, domestic violence, alcohol abuse, unemployment, homelessness or mental illness. A second factor that seemed to have played a role in abandonment stemmed from **separations** as a result of divorce and inadequate care provided by single mothers, or when they were raised by grand- or adoptive parents and they felt their biological parents had rejected them. They felt emotionally disconnected, unwanted and forsaken by their parents.

The above finding concurs with Bradshaw's assertion that abandonment is not merely physical desertion, but includes various forms of emotional abandonment, and is associated with all forms of abuse (1988a: 41, chap. 2: p. 43). The researcher makes extensive use of the insights of both Bradshaw and Hillman in this section because of Bradshaw's definition of abuse as abandonment. Both explain the impact of abandonment clearly and are appropriate to the researcher's approach, especially since it links up with the psychosocial theories of Erikson and Wolberg. These theories emphasize the importance of need fulfillment and the successful resolution of conflicts and

developmental tasks during crucial stages in human development to avoid the detrimental affect of a negative outcome on individuals and their adjustment in later life.

Wallerstein, Lewis and Blakeslee found that children saw their parents' divorce as the root cause of the trouble that followed in their lives (2000: 92). It disrupted their lives, came suddenly, unexpectedly and was caused voluntarily by the people they loved best and trusted the most (2000: 62). They were often overwhelmed with anxiety as their world had changed overnight into an incomprehensible, unpredictable place in which their central, all-important parent had disappeared and was replaced by sometimes hastily chosen caregivers who themselves had little energy or time left over for them (2000:165). Because children are often not given explanations of the breakup that make sense to them, their anxiety and confusion increase (2000: 92). Consequently, and as part of the long-term effects of divorce, many live with the fear that disaster was always waiting to strike without warning, especially when they were happy (2000: xxxviii) and that they too will be abandoned in their love relationships (2000: xxxv).

A correlation was noted between physical, verbal and emotional abuse, and alcohol abuse in the families of five group members. Being a small sample this conjecture cannot be generalised to all fibromyalgia patients without further investigation. Still, this is in accordance with Bradshaw's finding that alcoholic families foster every kind of abuse because of the lowered inhibitions (1988a: 48). Along with the actual physical abandonment by the alcoholic (because there is no one there for the child), the neglect of the child's needs is also emotional abandonment (1988b: 93). According to Miller these children cannot share their pain with anyone or ventilate their feelings (cited in Bradshaw 1988b: 113). The theme of being alone with their suffering emerged throughout the group process as perceived abandonment.

The researcher learnt from this group of patients that the real harm of emotional abuse is actually not visible in its immediate effect. Instead, it is concealed in an unremitting influence on the lives of the persons, particularly on their personalities. It affects their self-esteem and all their relationships. According to Hillman children who are constantly

berated and belittled by their parents would not feel good about, or love themselves as they have learnt to become self-critical and self-punishing as they mirror the parents' attitude towards themselves. They are on guard with authorities and sensitive to criticism - dreading rejection when others see how 'bad' they are (1992: 65-9). Sensitive group members had taken innocent remarks during the group discussions as personal criticism and were immensely hurt. They considered this as rejection and became withdrawn.

The group members **presented multiple somatic complaints to their doctors and denied depression or anxiety**. They were convinced that their illness was their only problem - deceiving others and themselves that psychosocial factors did not play a significant role in the onset, severity, exacerbation, or maintenance of their pain (Alfieri et al. chap. 2 p. 35; Bradshaw chap. 2. p. 47). Yet, it was quite obvious towards the end of group therapy that they were in denial, as all had unresolved emotional issues and family problems. Childhood traumas were only revealed in the late stages of the group process when a group member triggered unresolved feelings (negative transference) in others upon disclosing that her husband had been abusing her and her young children. Two group members were so emotionally overwhelmed by their suppressed memories that they cried uncontrollably because they relived their own trauma. They identified with the fellow group member's six-year-old daughter who feared her father, but still intervened to break up their fighting, as she wanted to protect her mother. Both group members then admitted that they too came from abusive homes. As children, both these group members had experienced emotional abandonment when their parents had engaged in fighting. Although trigger events like this in the group allowed repressed experiences of abandonment to surface to a conscious level in group therapy, group members still lacked insight into the relationship between their past experiences and their over-reactions to feelings of abandonment or rejection. Whereas there was a strong protective mechanism in place to block their deep emotional pain from their conscious, it seemed to have found a different pathway to surface through somatisation to find its expression in fibromyalgia.

Emotional abandonment is frequently encountered in alcoholic families that are severely enmeshed. Three group members resented being turned into 'little adults' when they had

to become a parental child or surrogate spouse to meet the needs of a dysfunctional or absent parent (Bradshaw chap. 2 p. 52). By not fulfilling their parental role adequately, the parents emotionally abandoned the child to her fate of having to assure a parental role when she was not ready for it. Yet, simultaneously they were also submitted to physical and verbal abuse that often manifested as frequent and usually inconsistent punishment which Bradshaw describes as becoming the parents' scapegoats when they unleash their anger and frustration on the children (Bradshaw 1988b: 93). Although these 'cathartic explosions' seemed 'unfair', group members failed to understand that it had little to do with their own behaviour. They perceived this 'treatment' as rejection.

Physical violence is a devastating form of abandonment. Considering that the mere threat of violence or the witnessing of violence is equivalent to the child being battered, these group members were not only witnesses to violence, but also victims (Bradshaw; Wallerstein, Lewis & Blakeslee chap. 2 p. 49). They lived in fear and uncertainty, never knowing what to expect and this is likely to leave them insecure. Consequently, they feared and avoided confrontations, and would go to great lengths to please others. Although angry with their fathers who abused their mothers, they were unable to express these feelings and remained helpless witnesses, which left them feeling alone, alienated and abandoned. However, in addition to being co-victims of abuse, these children also suffered a further secondary form of abandonment or compounded abandonment, because the remaining parent was not there for them due to their own neediness and turmoil.

This may throw some light on the genesis of fibromyalgia, which might have developed as a result of the inability to express feelings and resolve stressful issues, and the resulting accumulation of intense emotional distress, eventually manifesting in physical pain and helpseeking behaviour.

The 'victim-stance' often observed in this group of fibromyalgia patients may in part stem from 'learned helplessness' in victims of abuse due to the irrational, unpredictable and random violence they had experienced in their childhood. As their self-worth was diminished they passively accepted their abuse and did not attempt to free themselves

from the battering situation, but sought “morsels and crumbs of love” (Bradshaw 1988b: 133). They felt the situation was hopeless and believed that external factors controlled their lives.

Yet again, it needs to be emphasized that a child may perceive the parent’s action as a form of rejection or abandonment, whereas it may not have been the parent’s intention to estrange the child through their choice of parenting methods, albeit as a result of a lack of parenting and communication skills, or by virtue of their own inadequate or pathological personalities. However, the fact remains that the child experienced this as destructive and was left feeling unloved and not accepted. A crucial point is that as long as the child’s needs are unmet, whether it be physical or emotional needs, he or she would feel uncontained, unloved, misunderstood and not valued, and would therefore continue to feel abandoned. It seems then that it is not so much physical desertion that inflicts feelings of abandonment, but rather the unsatisfactory fulfillment of the child’s emotional needs. The problem is that there is often a personality conflict between the parent and child resulting in the unmet needs of the child. If this situation is not halted it could easily be perpetuated as a vicious cycle into the next generation (Bradshaw chap. 2 p. 48). This observation of unmet needs and its tremendous impact on later life concurs with the psychodynamic development theories of Erikson and Wolberg.

4.2.2 Experiences of abandonment by mothers, fathers and grandparents

Abandonment by one’s mother, even if not intended, seemed to have inflicted more emotional ‘damage’ than any other form of abandonment. Seven of the eleven group members perceived such **abandonment by their mothers** which occurred for such reasons as mental illness, finding employment and living in distant cities, being unable to care for their children due to financial need, lack of fixed abode, abusive husbands and alcohol abuse by the husbands, as well as by two mothers themselves. This concurs with previous reports of a traumatic childhood (Walker et al. chap. 2 p. 39).

Three of the seven felt physically abandoned by their mothers, considering that two were raised by their grandparents and another by an adoptive mother. Discovering as adolescents that the people they had bonded with and accepted as parents were not their biological parents came as a shock and triggered an identity crisis for two group members. They felt rejected by their biological parents and deceived by their caregivers. Both left their caregivers to live with their biological parents - with catastrophic results. One was rejected and subjected to severe abuse by her father whilst her mother failed to come to her rescue. The other could not identify and connect with her biological mother because she could not forgive her for “dumping” her as a baby. Though both returned to their caregivers, this relationship was now also contaminated with resentment, guilt and divided loyalties. They felt disillusioned and that they did not fit in anywhere – eventually causing both to leave school prematurely. Despite frequent contacts with their parents, they could never form a meaningful relationship and continued to feel emotionally disconnected. Although they seemed to have intellectual insight into the circumstances that contributed to their mothers abandoning them, they were emotionally unable to understand or accept it, nor to forgive their mothers.

Several group members found that they actually did not know their parents. They could never bridge the gap created by early separation. Four group members experienced emotional detachment from both parents and two others from one parent only. It seems that these children interpreted a physically distant parent as more blatant abandonment than an emotionally distant parent even though both situations constituted unmet needs in the children. One group member only had closer contact with her mother at nineteen but felt that *“this woman was like a stranger to me, although she was my mother”*. Her mother never referred to her as “my daughter”, which made her feel that she did not belong and was not accepted. She found her unpredictable and difficult to communicate with. Gifts to her mother were criticised and never good enough. She desired to be accepted by her mother, but instead felt insecure and inadequate. Considering Hillman’s assertion that children mirror the parent’s attitude (1992: 65-9), it is possible that the mother’s criticism became self-criticism and self-rejection, manifesting in anorexia nervosa and several suicide attempts later by this patient.

Various forms of dysfunction in the mothering of the remaining group members account for their experiences of abandonment. These mothers, overwhelmed in their struggle to cope and without a good support structure, reacted in an inadequate manner to the fathers' desertions and/or pathologies, which revealed that they lacked inner strength, confidence, coping skills, or had dependent personalities.

A group member who came from a dysfunctional family with unemployment and alcohol abuse by parents, marital conflict and violence, was further exposed to abuse and neglect after the parents divorced. The mother and two young children were left with no fixed abode or income and often had to sleep outside. Exposure and malnutrition caused stunted growth and aggravated this child's poor health - thus exacerbating her sense of abandonment, as her mother was unable to take care of her basic needs. In addition, the mother used her as a scapegoat and vented her frustration and anger on this young child. This group member could never understand why her mother had beaten and locked her up unjustly and unnecessarily, and these memories remained vivid and traumatic.

This emphasized a point that a fellow group member had made: "*Physical abuse is one thing; emotional abuse another. The first can heal; the latter stays with you forever.*" She described her mother as a highly critical and domineering person, "*a witch going on a tangent*" who would hit her children with a hot pan. Her mother drank and smoked excessively, and was verbally and physically abusive to them and their father, a fisherman, was often absent from home. Consequently, as the eldest child, this group member endured her mother's wrath more harshly, had to perform household chores and care for younger siblings. She thought her siblings were favourites whereas she was the 'black sheep'. She felt she never got compassion, acceptance, respect, encouragement, and caresses from her mother. Instead the response of her mother hinged around how much her needs were met by the group member – indicative of a narcissistic parent (Hillman 1992: 59). Two other group members, also eldest children, who experienced severe feelings of abandonment, reported the same dynamics – suggesting that eldest children may be at a higher risk if they have narcissistic or abusive parents.

From a young age onwards, the group member described above employed provocative attention-seeking behaviour in order to be noticed. Ironically, this histrionic behaviour often repelled others, exacerbating already existing feelings of rejection. She seemed to be suffering what Hillman refers to as continual trauma of being told that she was “bad, willful, stupid or crazy” (1992: 65). She constantly felt berated and belittled by her mother who told her she would fail in life and become “a prostitute, a drunk, or pregnant teenager”. As a result she felt that nothing she did was right and her attempts to feel loved and trusted were subverted. Continuous criticism has to do with disapproval and not accepting a person unconditionally; factors that collectively evolve into accrued feelings of abandonment. However, what hurt this group member most was that her siblings were forgiven when they turned out to be “*an unmarried mother, an alcoholic, divorcee and a psychotic patient*”. They were still accepted and loved by their mother, whereas she did not “*break those rules*” and yet she was never accepted. Sibling envy emerged as an important factor in perceived abandonment. Several other group members resented the stronger bond their mothers had with their siblings and felt excluded - to them such favouritism meant rejection of themselves.

Two group members had mothers who needed care themselves due to severe mental illness. (Concurs with Walker et al. chap. 2 p. 40). One was merely eight days and the other eight years old when their mothers required long periods of hospitalisation. Altschuler emphasized how these children are often concerned about the parent and can have anxiety, sadness and fear of separation (1997: 99, 104). The mothers and children were taken in and cared for by the maternal grandparents. In fact, three of the four mothers who lived with the grandparents did not meet the children’s’ emotional or financial needs. They felt that they had “*missed out*”, as they had never really had a parent. One asked: “*Who was my mother? My mother was there, but in a way she was not a mother. She was like a sister or something, but not playing her mother's role.*” They felt their mothers had never been there for them - instead had become a liability.

An intriguing role reversal took place where several group members were deprived of nurturing and bonding with their mothers. They took on a parental role, one caring for

her mother and the others for their younger siblings – unconsciously hoping that this would make them indispensable and worthy, and loved by their parents. This fits in with conflict resolution and developmental tasks of the ‘latent’ childhood years (‘industry versus inferiority’) as defined by Erikson. They performed as “good little workers or helpers” because of their need for approval and to form a positive self-concept (Dacey 1982: 24; Papalia & Olds 1978: 228). It further appears that they became fixated at this developmental stage due to the inability to resolve this conflict. This is evident in their ‘solid citizen’ style, ergomania and need to please or help others. In fact, throughout their lives they cared for others, but they always felt that there was no one for them when they needed it - a theme that emerged frequently in group discussions and, it is felt, is closely related to their feelings of abandonment.

In retrospect, they resented the parental role as they had ‘lost out’ on childhood: *“I was a mother when I was six years old. The burden was put on my shoulder because when my mother was in hospital I had to look after my brother. I went through a hard time as a child. I was an adult at six.”* Despite being tireless workers this responsibility was so overwhelming that these children all left home or got married at an early age to escape from enmeshed families.

One tends to view ‘abandonment’ only in terms of ‘desertion’, ‘rejection’ or ‘neglect’, but a broader scope will include parents who failed to be appropriate models – to set a good example. Children need their parents to mirror themselves, in order to learn how to socialise, have good relationships, be a good parent, and successful in their careers and financial affairs. (Bradshaw 1988a: 56) One group member who had been reared by her grandmother, felt that she herself was a good grandmother because that was a role she knew, but she felt she had been a ‘bad’ mother to her own children. *“I don't know how to be a mother. I didn't have a role model of what a mother was supposed to be doing. I tried very hard to be a good mother. I feel I missed out.”*

Not having this interaction with and modeling from parents meant that five of the group members felt that they had been ‘let down’ because the parents had not fulfilled their

roles adequately and had indeed 'abandoned' them in their socialising process. It also affected these children's self-esteem because they internalised the type of parenting they had experienced and copied this behaviour in their 'self-talk'. Hillman refers to an 'inner-caretaker' who is compassionate, supportive and nurturing or a 'inner-critic' who is disparaging and abusive (1992: 69).

The group members were ashamed of parents who had been poor role models, in particular two who had been subjected to neglect and **abandonment by their fathers**, who had also abandoned their other children. One felt her father had double standards. He was a teacher who spent his life uplifting troubled boys in a reformatory, and should have been a loving and responsible father. Instead he was authoritarian, abusive, unreliable with financial support, and neglected his own children, not maintaining contact with his eleven children from four different relationships.

The other group member who had been adopted could not identify with either her adoptive or biological father and felt abandoned by both. She and her adoptive mother had to flee from her abusive and alcoholic adoptive father, leaving their home and belongings behind. In a counter-response she rejected him by disassociation and referred to him as "*Mama's husband*". She was equally disappointed in her biological father when she established contact after she had found out at seventeen that she had been adopted. Not only was he not prepared to be a father to her; he was not a good father to his other children either. She described him as a philanderer who had many children from different women whom he never supported.

This is an example of compounded abandonment that several group members had experienced. In fact, the seven who felt abandoned by their mothers also experienced abandonment by their fathers – some blaming their fathers for their mothers' predicament because they did not fulfill their responsibility as husband and father. They did not have a remaining strong parental figure to compensate for the loss and pain caused by the abandonment by the other parent. In essence, this meant a double rejection that amplified their emotional trauma.

A group member who felt that her father had deserted her numerous times during her childhood illustrated another form of compounded abandonment. Her father had been taken prisoner during the Second World War and upon his release her joy in being reunited as a family was short-lived as he divorced her mother. Whereas the massive abandonment of women and children during the war was the result of external forces, his deliberate desertion was devastating. When her father later divorced a second time, his third marriage reinforced her feelings of abandonment as she had hoped he would return to them. This idealised and unrealistic hope to re-unite with the father she had lost was repeatedly dashed. It appears to be a common fantasy amongst people who have been abandoned and stems from parental deprivation. Wallerstein, Lewis and Blakeslee also found that children hope for many years that their parents will reconcile and some hope that they can bring their parents back together to rescue them (2000: xxx introduction). This also results in a continuous yearning and search to fill their 'emptiness' in their early adult lives. This finding concurs with Bradshaw's views that continually need-deprived children result in adults with an inner-child who feels empty and needy (chap. 2 p. 44).

Two members held their fathers responsible for their mothers' mental breakdown due to abuse and desertion. The group member discussed above had begged her father in vain to return home or at least to visit her mother who remained psychotic despite prolonged hospitalisation, as she believed this would give her mother the will to live. His indifference accentuated her feelings of abandonment. According to Altschuler, if the father is absent, the child has lost two parents and they are pushed into premature independence and placed in a predominantly adult-defined context (1997: 104). She held him accountable for all their suffering as his failure to financially support them had also forced her maternal grandparents to sell their house in order to pay medical bills.

As with their mothers, and even to a greater extent, most group members felt that they did not really know their fathers. Five group members whose fathers remarried never lived with them afterwards. Two only met their fathers for the first time when they were adolescents. Another re-established contact with her father when she was sixteen, whilst two had no further contact with their fathers from the age of five and sixteen respectively.

These fathers did not exist in their lives for long periods. One group member told her teachers that her father was “dead”, indicating that this was how she experienced his ‘disappearance’ from her life. If a father had not maintained contact, it implied rejection to the child. This caused self-doubt, and feelings of worthlessness and abandonment.

Three group members whose fathers divorced their mothers and remarried found reassurances of their fathers’ love confusing and inconsistent. As young children they could not understand the contradiction that their fathers loved them, but left them. They felt that they had been ‘traded in’ for a new family because they had done something wrong. They also felt abandoned because the fathers did not care enough to support them financially. One group member resented the fact that her father took his new wife and children on holiday, but forgot the children from his first marriage who often had to go hungry. They were angry with their fathers, but also experienced guilt, believing that the divorce was their fault (Wallerstein, Lewis and Blakeslee 2000: 63). This resulted in paradoxical and confusing emotions as they hated their fathers, but at the same time loved them. Although they wanted to avoid their fathers, they still needed them. This emotional turmoil ²⁷ became so unsettling that one group member’s holiday with her father had to be terminated through a court order. She perceived this legal intervention as another obstacle separating her from her father.

Two group members felt that they had been unwanted at birth as their fathers wanted a boy and they were girls. Even though their fathers eventually loved them, their rejection remained a deep-seated issue. One was a ‘tomboy’ who did everything with her father – perhaps to ensure his acceptance. She was devastated when he ‘deserted’ her anyway when he left England for contract work in Africa. Her feelings of abandonment were amplified when she also felt excluded from her mother and sister’s alliance - assuming that the ‘fault’ had to be within her as she was ‘clumsy with female tasks’.

²⁷ In retrospect, this patient believed that her emotional pain converted into physical pain and that the ‘aches and pains’ she suffered since adolescence was indeed fibromyalgia, although only diagnosed much later.

The other group member also blamed herself for her father's 'walking out' on them to remarry when she was eight years old. He wanted more children, particularly a son, but her mother refused. She could not bear another painful and life-threatening delivery. The group member felt unwanted as a girl, and that she was not 'good enough' because "*my father was not satisfied with just having me*". This concurs with Bradshaw's statement that "children interpret events egocentrically and may believe there is something wrong with them, or the parents would desire to be with them" (1988a: 42).

The worst case of rejection was seen in a group member whose father denied paternity. She ascribed her two strokes and a nervous breakdown at the age of sixteen, which required hospitalisation for two years, to the continuous abuse and trauma he had subjected her to. She started visiting her biological parents at twelve after she had found out that her 'parents' were actually her grandparents. "*My father threw me out of their home and said I must sleep outside*". Instead of providing for and protecting her, he treated her with contempt, which made her feel unwanted, insignificant and insecure. Even when he later allowed her to live with them, he frequently chased her out to sleep in the vineyards when he was drunk. He was also obstructive and prevented her from forming a close relationship with her mother and siblings.

Although more group members had abusive fathers, they did not elaborate in detail – perhaps blocking it out because it was traumatic. However, one group member remembered the anguish, which she, as a five year old, and her younger brother suffered when they were abandoned and locked up in a house for three days by her father. Her mother had been hospitalised as a result of her father's beatings, and he had 'disappeared' in fear of being arrested. This was experienced as an extreme form of abandonment as she thought they were going to die and that they were forgotten, unimportant and deserted.

This group member could never understand why her father had abandoned her after her parents had divorced. Her attempts to re-establish contact had been foiled by her grandfather unbeknown to her. Only as an adult, after her father's death, did she discover

that his letters, gifts and whereabouts had been deliberately withheld from her whereas her sister had secretly corresponded with him. Her maternal grandfather had prohibited all contact with her father as a condition for taking them in under his roof. She felt betrayed and deceived by her grandfather, as she had incorrectly believed that her father, a white man, was embarrassed with her being coloured and “*did not want anything to do*” with her. This is a good example of perceived abandonment, which was not intended, but which, nevertheless, had the same negative consequences. It also seems that, in this instance, a ‘bad’ father would have been better than no father at all. What group members resented most was that they were often not given a choice and autocratic decisions had been made that impacted negatively on their destiny.

The following two examples of **abandonment by their grandparents** revealed the difficulty that group members had to accept what they perceived as unjustified abandonment/rejection. This group member could not understand why she was made the scapegoat when her grandfather had actually been angry with her mother for marrying against his wishes. Since he had ignored their plight for many years before he eventually rescued her from a cycle of abuse, poverty, malnutrition and evictions, she believed it had been a deliberate act of punishment in which she was an innocent victim. She felt abandoned by her grandfather and never even considered that he might have tried to avoid trouble because of racial laws and politics at the time, or wanted to protect them from her abusive father.

Another group member could not forgive her grandfather for his ‘deceitful’ and callous act in forging her mother’s signature in order to give her up for adoption at birth, when her mother had refused. Because the adoption was fraudulent the ‘perfect’ relationship with her adoptive mother was in a sense ‘nullified’. She felt worthless and confused about her identity. Because of her grandfather’s rejection she was deprived of knowing her maternal family. It angered her that he cared for her older brother but had “no room” for her as a second illegitimate grandchild. She too felt that this rejection was unjustified.

A further example of abandonment by their grandparents was noted in a group member who was of the opinion that her maternal grandparents had deceived her by pretending to be her parents. Such betrayal was perceived as a form of abandonment as they had 'let her down' and thrown her life into turmoil (Kaplan & Sadock 1991: 39). Subsequently she also felt deserted when they failed to rescue her from an abusive father whilst living with her parents.

An observation was made that most group members had rigid thinking and egocentric views. They took things very personally and remained subjective, even as adults. Perceived abandonment or rejection was often the result of such errors of reasoning or perception that did not only form the basis of their 'truths' (Le Roux chap. 2 p. 38), but also reinforced such feelings. As children, they could not understand why their caregivers had made certain decisions. They did not, as adults, gain new insight regarding the 'other side of the story' as one would have thought. Culprits remained 'bad' – not a person with 'good' and 'bad' qualities (splitting). Perhaps this is an indication of narcissistic personalities due to arrested development during their childhood. According to Hillman, splitting is often found in children who were not reared in an accepting, nurturing atmosphere (1992: 65).

In four of the five cases where mothers were not capable of rearing their children, it was the maternal grandparents that came to the rescue and became substitute parents for these children; never the fathers or paternal grandparents. Almost half of the group members had a reduced support system since they did not know their paternal families who became distant as a result of the fathers' lack of involvement in the lives of their children. Many of these group members felt that their paternal grandparents had abandoned them when they were in crises, and that they had not cared enough to maintain contact with them.

Three of the four group members who grew up with their maternal grandparents claimed that they had close relationships, especially with their grandmothers. They seemed to be indebted to their rescuers and expressed feelings of guilt for having being an extra burden. However, they admitted that the huge age difference and generation gap, and a

lack of common interests prevented them from confiding in their grandparents about emotional or adolescent issues. This implies that some emotional needs were not met and since they were also not close to their parents they had been deprived of intimacy and a close bond. In actual fact, the three group members who experienced abandonment by both parents also felt abandoned by their grandparents (compounded abandonment).

It was evident that childhood experiences of abandonment/rejection remained painful and unresolved although largely unconscious. As a result any perception of abandonment in adulthood often triggered intense emotions without the realisation that it reflected back to previous experiences. This coincides completely with Erikson's theory. In this light, their negative transference actually reveals the true nature of their unresolved developmental conflicts and tasks.

4.3 EXPERIENCES OF ABANDONMENT AND REJECTION DURING ADULTHOOD

4.3.1 Death of parental figures and loved ones as a form of abandonment

The single most prominent, and certainly the psychologically most devastating experience of abandonment during adulthood occurred as a result of the death of loved ones. Because of its significance, death as a form of abandonment will be discussed first.

One of the principal themes during group discussions was most group members' struggle to accept the death of loved ones. Group members were devastated with prolonged and unresolved grief from the multiple losses they had experienced. The focus here is on the persons' reaction to the loss, which this selected group perceived as abandonment, whereas not all people would feel abandoned. This is not only because of their mindset of abandonment, but also because of negative transference as a result of unresolved issues from past experiences. In addition they had not come to terms with the fact (or perception) that they had been 'abandoned' by their parents/caregivers, and because they had never mourned this loss properly. This is one of the core issues of this group;

namely, a multifaceted and entangled web of unresolved feelings about separation, loss and death, which they interpreted as abandonment.

The impact of death was not necessarily determined by the nature of the relationship with the person, but also by their interpretation of the death and what meaning the person had for them. Contrary to expectation, the deaths of parental figures who had rejected/abandoned them, affected those group members just as traumatically, if not more than the deaths of affectionate parental figures had affected the remaining members. Perhaps it is because death is irrevocable and eradicated all hope of restoring relationships, or because it was experienced as an additional or compounded abandonment. Although two thirds of the group members experienced the deaths of their parents/caregivers as traumatic, it was the death of a mother figure, rather than that of a father figure that was more traumatic and left greater feelings of abandonment, perhaps because their emotional needs were no longer met. However, when the father was the only remaining parent, losing him triggered intense feelings of abandonment. A group member already devastated by her mother's sudden death in Mecca disclosed that "*when my father died the bottom of my world dropped out*".

To more than half of the group members death meant that they had been orphaned after their main parental figures had died and they no longer had a parental 'home' to return to. It implied the loss of a crucial support system. For those who had experienced abandonment by their caregivers, it was a symbolic rather than a real loss. However, all experienced these deaths as abandonment. Some felt vulnerable and insecure, as they had lost their protector, rescuer or guide. Others had lost 'the one magic person' who had nurtured and loved them unconditionally - the person to whom they were important, who believed in and acknowledged them.

Their choice of construct was mostly the positive image of the caregiver, devoid of any faults even if it was the person who had abused or deserted them. Perhaps this image was essential because of their dependence on that person, or, in order to feel good about themselves, they needed to feel good about their parents. However, after the death of 'the

one magic person', this particular group displayed an inability and reluctance to acknowledge both the 'good' and 'bad' attributes of the person. This is unlike the 'normal' phenomenon of re-gaining a balanced view after some time. The over-idealization and unrealistic version of the truth complicated the grief process inducing an aggravated sense of abandonment.

Of interest was that none of the group members had experienced any significant deaths during childhood, but ten had lost primary caregivers such as a parent, adopted mother, grandparents and/or loved ones such as friends, boyfriends, but no spouses during adulthood. Considering that the average age of group members was forty-four, a relative high number of deaths, namely fifty-six (three per group member) were mentioned during group sessions. Little more than half of these evoked feelings related to abandonment and loss, such as being "*robbed*" or deprived and to be left behind in distress and hardship. Over the eleven month period of the group sessions six group members had seventeen deaths, of which seven were experienced as traumatic, amongst other the fathers of two group members as well as two murdered family members of another two. Three of nine women who had children had major difficulties in sustaining pregnancies. This figure seems very high and may indicate some relationship with fibromyalgia. One miscarried twins between her two sons, the second endured four miscarriages in order to have children, whereas the third woman miscarried a twin, lost a child at birth, and her twenty-year-old unofficial 'foster' son was murdered. Two group members were young adults when their boyfriends died in accidents. One was left with a baby of three months and felt that the father had 'deserted' them.

The perception of death as abandonment stems from the enmeshment of various unresolved issues in the minds of group members, as the following will illustrate.

A lack of closure added to unresolved grief and the inability to accept death especially if group members did not "*say goodbye*" or participate in funeral rituals. This was noted in two immigrants who had not seen their families since they were young and two other group members whose mothers had died whilst away on holiday. One died in Mecca on

pilgrimage, where she was buried in an unmarked grave. Apart from intense guilt that haunted the daughter because she had not prayed for her mother before her departure, as their custom requires, she felt bereft of her only true support system. Her intense pain following this loss was evoked by her previous experience of abandonment when her husband had divorced her.

Two group members, who were subjected to abuse and abandonment by both parents in childhood, experienced a second abandonment when their mothers died. They felt they had been 'robbed'. One said: "*I only found my mother as 'mom', three years before she died. We became not like mother and daughter, but like friends. I could confide in her and ask her questions.*" The other looked forward to her mother's retirement plans to live with her, as she saw this as a form of undoing past damage. For the first time she would be important to her mother. But her mother died whilst on holiday prior to moving in. "*I was very angry with her for doing that. How dare she go and die on holiday and on New Years' Eve?*" Dying while away from her caused feelings of further exclusion or separation from her mother and reiterated the same helplessness that she had experienced as a child (victim-stance). This not only triggered old feelings of abandonment, but also compounded its effect. It is postulated that psychological conflicts, personality traits and the inability to internally regulate aroused distressing feelings, like the helplessness and hopelessness following a disruption in important attachment relationships, contribute to the development of disease (Altschuler chap. 2 p. 37). This argument is strengthened by its concurrence with Wolberg's theory (Appendix III).

Some group members admitted that they feared abandonment to such an extent that they were not "*ready to let go*" of loved ones and had tried to "*hold them back for selfish reasons*". One referred to her brother's self-inflicted death through alcohol abuse: "*he wanted to die and I prevented him from doing that.*" Three were in denial when their mothers died and consequently had (along with two others) great difficulty in accepting these deaths, complicating and prolonging the grief process. For years, two could not talk about their mothers without crying and regarded their deaths as something they would never overcome. While they had had good relationships with their mothers, it took

a third group member, who had been abandoned and abused as a child and who only got closer to her mother before her death, *"twenty years to make peace that I haven't got a mother"*. Their perception of death was egocentric and related to feelings of abandonment that remained unresolved. When the deaths became too emotionally intense, they adopted avoidant behaviour patterns in order to cope, further isolating and debilitating themselves, as their fibromyalgia also seemed to become exacerbated at such times. While anniversaries of significant days and festive periods such as Christmas, New Year and Easter were difficult for all, several could not attend church or funerals in fear that they would *"break down" and "go to pieces,"* whereas others cried inconsolably because of memories. Some avoided loved ones' graves, since they would be confronted with the reality of their permanent absence. A nurse who used to be comfortable with death prior to her 'foster' son's murder became distressed when sick and dying persons triggered immense anxiety and unbearable pain, yet failed to understand exactly what she felt or why, other than feeling overwhelmed and 'scared'.

Unresolved issues continued to interplay in and complicate the lives of group members because of negative transference and identification with situations similar to that of their own. These apparently unconnected factors could trigger intense feelings of abandonment in situations where one would not expect these feelings, such as the death of a child. The murder of her 'foster' son was particularly traumatic for the above mentioned group member because his life resembled her own history of abandonment. Although, on an unconscious level, caring for him was a form of undoing the abuse that they had both endured and to compensate for a loveless childhood. Her anger at his alcoholic mother for now wanting to compensate by giving a huge wreath for his grave when she had never considered him when he was alive, reflected her own anger at her mother for waiting too long before reconciling as she had died soon afterwards (negative transference). She was twenty and had to support her young siblings since their father had deserted them at their mother's death. Having sacrificed her tertiary education and young life, she identified with her 'foster' son's life, which had been 'robbed' before he was due to start college.

Similarly, another group member experienced her brother's self-inflicted death through alcohol abuse following his wife's early death, as a desertion and betrayal of her, and his children. Besides identifying with his children, it provoked painful childhood memories as he re-enacted their father's alcohol abuse, unemployment and abandonment of them as young children – *"playing a record that I know"* (negative transference).

Mother-child relationships that were "too close" and co-dependent resulted in exaggerated experiences of abandonment when the mother died. Two group members were devastated and nearly committed suicide because they could not adjust on their own. Neither could accept their mothers' deaths and experienced prolonged grief. One had been adopted and felt unconditionally accepted and loved by her adoptive mother. Their family unit had only consisted of mother and child, whereas the other group member came from an exceptionally large family. She became over-dependent on her mother who had lavished more attention on her than on her siblings because she had been physically disabled since infancy as a result of polio and later became wheelchair-bound.

She had been sheltered from the outside world by her over-protective family, did not have friends, never completed school or pursued a career and became homebound. She got 'stuck' in the 'baby role' and/or 'sick role', which had secondary gains such as being taken care of, getting attention and being able to avoid responsibilities. After her mother's death fibromyalgia enabled her to remain in these roles. Her personality had become fixated, as her emotional development had arrested at early age, which delayed maturity. In her thirties, she was childlike in her dress, manner and emotions. Bradshaw's reference to Freudian thinking that unmet basic needs may result in an arrested personality at those developmental stages (chap. 2 p. 44), seems accurate, considering that she was 'abandoned' at eighteen months for long-term hospitalisation when she had polio ('autonomy versus shame and doubt').

While unintentional, such over-protection and physical and emotional dependence appears to predispose a person to and set the scene for feelings of abandonment and an inability to cope when the caregiver could no longer fulfill this role. In this sense, the

parent abandoned the child by not assisting the child to mature and become independent. When this group member's mother died, she regressed and was admitted to a psychiatric center because she stopped talking. (See Bradshaw chap. 2 p. 48 re. the 'state of noncommunication' and loss of one's authentic self). Life without her mother was too threatening. She felt lost and abandoned, and was angry that her mother "*did not take me with her*". She described death as "*one of the cruelest things that can happen to a person. You think you are given someone for many years and all of a sudden, that someone is taken away from you forever. Life will never be the same for me without her. Since my mom died, to me it's like I don't have a life of my own now. My mom was like my buddy, my friend, my everything.*" She felt her mother's death 'robbed'/deprived her of life. She also clung to the belief that her mother belonged to her and that they should not have been parted. Pistorius attributes poor adaptation to errors of reasoning or perception (chap. 2 p. 37).

This is indicative of the fusion with the mother as object and that she had never progressed to 'separation-individuation' to form her own self. In terms of object relations theory, she resisted change by wanting to stay on the breast of her mother. With the absence of the mother object, the incomplete self that was left behind could not cope on its own, which explains the contemplation of suicide. (See definition of concepts, chapter 3 p. 64-66; Mahler, Pine & Bergman 1975).

In Erikson's terms, she could not achieve autonomy because she never succeeded to detach from the mother to gain independence. She wanted to remain dependent as it reminded of love and nurturing conveyed in the mother's embrace, comfort and warmth during the first year of life. Subsequently, she could not proceed to the next developmental task of explorative behaviour and forming new relationships with peers during the 'initiative versus guilt' stage. Failure to reach autonomy induced a sense of shame where the rage is turned against the self (Papalia 1978: 105-6, 164-5) in the ultimate self-destruction of suicide. Her lack of a sense of self lessened her ability to form her own identity, or to proceed successfully to the next stages of 'identity versus role diffusion' and 'intimacy versus isolation'. She could not overcome these barriers to

grow emotionally (Kaplan & Sadock chap. 2 p. 45) and felt entrapped ('stuck') in her self-absorption, with her inner pain after her mother's death.

Similar to other group members, she struggled with the "*emptiness I have inside - the longing for her*". She was unable to let go of the grief, as that would mean letting go of her mother's memory instead of integrating or adopting aspects of the mother figure to become part of her own personality. Over time, her pain had become unbearable and fibromyalgia was diagnosed. She would sedate herself for days (Bradshaw chap. 2 p.47), remain in bed to escape reality, and avoided the new overwhelming responsibilities of coping on her own and caring for her frail father. Hiding under the blankets symbolised the protection of the womb, and indicated severe regression in order to avoid resolving conflicts. Children who feel inadequate compared with their peers may "go back to the more isolated, less tool-conscious familial rivalry of the oedipal time" (Erikson cited in Papalia 1978: 228) – in other words, they become fixated in earlier development stages prior to 'industry versus inferiority' where productivity becomes important.

Six group members made a correlation between traumatic deaths and the onset or flare-up of their fibromyalgia. Another regarded the emotional pain the same as her physical pain and explained how one "*cannot run away from that pain. I think it's really that pain that sits there. Nobody can do anything about it even if they speak to you, it remains there.*" In the least it seems possible that the pain allegedly caused by fibromyalgia could have been amplified by sublimated emotional distress caused by multiple unresolved deaths and its resulted feelings of abandonment.

A further consequence of death was that many group members had to take on often unwanted, additional responsibilities, such as having to care for a frail father or younger siblings. This amplified existing feelings of abandonment. Many felt over-burdened but did so willingly, although it added to their suffering. One had to work to supplement a meager maintenance grant in order to, besides her own children, also care for her brother's two children after his death. Others resisted additional responsibilities and

found justification in their fibromyalgia. Not accepting death allowed some to remain 'stuck' and not to make a start with their own lives.

While stress aggravated their fibromyalgia symptoms, the converse also seems true in that fibromyalgia helped them to cope with emotional pain (secondary gains). They could mask depression by stating that they were in pain and escape reality or avoid responsibility by taking on the sick role. This also ensured that they received attention and care. (Blackwell & Gutmann chap. 2 p. 29)

The following sections focus on further experiences of abandonment during adulthood that emerged from relationships with family members, friends, employers, doctors, a physiotherapist, fellow group members and the group facilitator.

4.3.2 Abandonment and rejection by parental figures and siblings during adulthood

As adults, four group members tried in vain to establish a relationship with the parents who had abandon them during childhood and felt more rejected. They struggled with feelings of emptiness, inadequacy and that they did not 'belong'. Abandonment or rejection seemed to have caused a lack of a sense of self and a tendency to neglect their own needs in pursuit of approval or acceptance (Bradshaw chap. 2 p. 47).

Several group members experienced feelings of abandonment/rejection as a result of a lack of acceptance, acknowledgment and understanding. One person who felt her **mother** had not accepted her during childhood, continued to experience this as an adult. She lacked confidence and felt insecure, and was frustrated that her mother still saw her as "*a little girl with pigtails*", rather than her eldest daughter, a mature wife and mother. Her mother was demanding, overbearing and emotionally draining; suggesting that the mother's narcissistic needs required priority. In group discussions it emerged that this was one of the most prominent and recurrent themes that most group members

experienced - having to fulfill their parents' needs above their own. This left them feeling frustrated and uncontained.

Five group members felt betrayed, and that they were not as important as their **fathers'** children from subsequent liaisons. They were unable to verbalise feelings of rejection, but felt their fathers had been disloyal, and tended to minimize its impact on their lives. Many group members also perceived personal rejection by a parent in gestures such as money given to, or spent on persons other than themselves or their children. One felt deeply hurt and offended when her father used the money from her study policy for himself and gave her sons only a token amount of R 300, whilst taking his second family on holiday. Unequal financial contributions such as spending R 20 000 on a son's wedding, and not assisting a daughter from a previous relationship in a financial crisis after a divorce, confirmed feelings that they were unimportant and always at "*the short end of the stick*". It was experienced as a denial of their existence and of their worth as persons. They felt 'cheated' and deprived of love and acceptance (recurrent theme of 'being robbed') – perpetuating their mindset of abandonment.

Many group members expressed deep hurt and anger when they experienced rejection that extended to the next generation. The 'innocent' children of group members were sometimes submitted to the same rejection, non-acknowledgment, indifference, or deliberate aloofness that group members experienced from parents, siblings, or in-laws. Again, this portrays their mindset of abandonment through which they even 'filter' what happens to their children.

The impact of such disregard/rejection should not be under-estimated. One group member divulged that she had actually become physically ill (somatisation) after her father had invited her and her children for Christmas and gave presents to his other grandchildren, but not to hers. This tendency to react with somatic manifestations was observed in all group members following severe emotional distress and could support the notion that fibromyalgia manifests as a consequence of repressed emotions, stress, and displaced pain. Illness behaviour can also be perpetuated because of secondary gains,

such as gaining attention and support as illustrated by a group member with a low self-esteem and history of anorexia nervosa and suicide attempts. She felt unsupported and abandoned by her father and that he was unsympathetic, disapproving and judgmental by his perception that her depression and anxiety were "*from the devil*" and that she "*shouldn't give in to it*". She only gained his attention when she was hospitalised as a result of fibromyalgia.

In this small group of eleven there were as many as three group members who had been involved in legal battles about inheritance disputes - in two cases with their fathers and in the other with their in-laws. This did not only reflect the extent to which these families had become disintegrated, but also revealed their battle to be acknowledged, to be seen as legal heirs, which would confirm their value as persons and their rightful place in the family. When others questioned their right to inherit, it was once again experienced as a form of rejection. They felt rejected and not valued or close enough to the deceased to warrant any inheritance. It also reinforced feelings of worthlessness, that is, that they did not exist or have identities.

When a group member's mother died and her father abandoned her younger siblings, they all had to survive on her meagre income as a student nurse. She could not understand how he could forsake his parental and financial responsibilities and ruin her future, because she had to sacrifice a tertiary education. She was shocked at her father's blatant greediness when he contested her mother's will, which resulted in a drawn out court case and a two-year delay in obtaining money for the younger siblings' support. When she won the court case, her father made her life "*such hell*" that she eventually gave him the money to end his harassment. However, he still did not contribute to the maintenance of his younger children. It is feasible that all the stress plus her mother's death contributed to the development of her fibromyalgia three years later. When her father had a stroke years later and no one to care for him, he wanted her to nurse him. Although embittered and astonished that he had the audacity to expect this after he had denied paternity when she was a child and had abused her, she took him into her home - fearing rejection by her family and society if she refused. This situation provoked such emotional trauma - she

had two 'nervous breakdowns, within ten days - that alternative arrangements had to be made for his care. This example typifies this group of fibromyalgia patients who allowed themselves to become overburdened in their pursuit of approval, only to feel unsupported and eventually finding escape through illness. Two other group members also found it difficult to lovingly nurse someone who had abandoned them previously. This can be understood in the light of their insecurity, emotional dependency and their need to be taken care of, rather than taking responsibility for others.

Since they did not successfully resolve the crisis of 'autonomy versus shame and doubt', they continued to have difficulties with dependency. Group members who were emotionally dependent on a 'good parent' were terrified that they would 'go to pieces' if they were to lose this person. Their poorly developed identity and weak sense of self left them vulnerable, uncontained and insecure. In the event of such a loss, they would reach out to the 'bad parent' or any substitute with unrealistic expectations that this person would fulfill their emotional needs – not realising that they were setting themselves up for further disappointment and feelings of abandonment. The disabled group member was frustrated that her father could not fill the emptiness that she felt after her mother's death. Although in her mid thirties, she yearned for intimacy and an emotional connection with her father. *"To me, my father is just a word 'father'. We do not have that bond, that love that I had with my mother. He just provides food and whatever, but he is not really there."* Ironically, it was her aged father who needed care after a heart attack and a leg amputation at the time of the group sessions. Fear of abandonment surfaced as she prepared herself for his death, but instead, he recovered and abandoned her by marrying the woman who had nursed him. She felt even more deserted when she was left alone in their big family house, as her remaining sister had emigrated.

Another common theme of abandonment during adulthood was the disintegration of families when **family members** moved away and became detached or preoccupied with their own lives and new relationships. Several group members had difficulty in adjusting to change and felt more insecure as their strong parental figures became older and frailer

- fearing that they would not be able to cope without this support system, albeit a dysfunctional one.

Relationships between family members were often strained to the extent of breaking contact, or not being on speaking terms for years. Once again, unresolved issues, their history of pain, neglect or rejection led to a mindset of abandonment/rejection that affected their behaviour and relationships. For example, one group member had lent her wedding gown to her half-sister who did not wear nor return it. It later emerged that she had damaged the dress and avoided telling her. This was experienced as disrespectful and a personal rejection - "*a gift thrown back into my face*". Subsequently they stopped communicating. She was unaware that the situation derived from negative transference with her mother who had criticised her gifts and not accepted her.

It seems that people who have experienced abandonment or rejection yearn for an acknowledgement of culpability or an apology to undo some of the damage. The group member, whose **grandfather** forced her mother to give her up for adoption, needed his contrition and acceptance. However, when she met him after many years, he was senile and did not recognize her. It would appear that she experienced this as a further rejection. Discovering that her grandfather had sexually abused two aunts and that her mother's hunchback was the result of his physical abuse did not diminish her conviction that he had rejected her as a person.

Self-blame further intensifies the agony of abandonment, which was illustrated by this group member. She blamed herself for losing her extended family when she re-established contact with her biological mother after her adoptive mother had died. "*I had so many aunties and uncles, but not anymore. I've lost that whole family. Mama's family (adoptive mother) did not want to be involved with me anymore, because I sort of swapped them*". She was devastated by this abandonment at a time she needed them - after her much-loved adoptive mother had died.

Another frequent theme in the group was that of anger at people who had 'discarded' them once they were no longer needed. They felt that they had always been there for others, but when they were in need of care or support, they found themselves alone and abandoned. One group member felt condemned by her sister for remaining in an abusive marriage, whereas she thought that her sister would have been more understanding since her husband had previously been abusive too, especially as she had been supportive to the sister. She resented that her 'calls for help' were disregarded and that she was not getting attention from her sister when she felt sick, but did not look sick (a characteristic of fibromyalgia). However, hospitalisation then provided both attention and a rescue from the abuse, but perpetuated illness behaviour. Not being noticed, or being ignored, stemmed from being one of fourteen children where insufficient individual attention could well have conveyed the message that her needs were unimportant and that they did not really care about her.

Three other group members who also felt 'discarded' were embittered towards their younger **siblings** whom they had not only helped to raise, but also supported financially. They resented the fact that they had been deprived of a tertiary education because they had to work from as young as fourteen years of age. As a result, their younger siblings had had an easier life, more opportunities and obtained good qualifications. What really hurt them most was that their sacrifices were not appreciated and that their siblings had become emotionally detached from them. This reinforced their feelings of rejection.

The emotional pain following rejection by one's siblings was expressed by a group member who was not allowed to visit her brother and sister who had themselves reclassified as 'white'. When she told them: "*a white fowl can also lay a brown egg*" she was accused of being jealous and called "*a bastard*". She felt hurt and rejected because she was visibly 'coloured' and an embarrassment to them. Yet, they owed their tertiary educations and secure professions to her sacrifices. "*They never show any appreciation because I went to work for them. Still, when they have family problems, then it comes back to me. I must bail them out, sort out their problems, and look after their kids,*

whether they are in an asylum or where ever they've landed up". She felt exploited and angry because she was *"always the servant, rescuer and scapegoat"*.

4.3.3 Abandonment and rejection by spouse and family-in-law

Four group members, who had not been subjected to any abandonment during their childhood, experienced abandonment/rejection as adults - three of these by their spouses. (The fourth, a single group member who was disabled, felt abandoned as a result of her mother's death and father's remarriage.) One of the most traumatic forms of abandonment during adulthood was that by a spouse. Seven of the ten group members that had been married, had experiences of **abandonment/rejection by their spouses** in either their current relationship or previously. Three were divorced, of these two remarried and one divorced a second time. At the time of the group sessions, three were unhappy in their marriages and had unsupportive husbands. Three were not involved in a relationship, and five described their spouses as being very supportive and understanding, tolerant of their moods and willing to do household chores that they could no longer do because of their illness.

It was crucial for group members who had had dysfunctional parents or who had been abandoned in childhood to create their own 'happy family' - a form of 'undoing' in order to cope. Some wanted to prove that their marriages would not follow the same route as that of their parents or previous marriages. They needed to be good parents and to have close relationships with their children and spouses. In some cases, when the spouse had failed as the 'one magic person' to fulfill their emotional needs, their children²⁸ assumed this role.

²⁸ A disturbing observation was made, namely that where the next generation was also predisposed to a cycle of abandonment and/or sick role behaviour. Several group members and/or their spouses were themselves dysfunctional parents, or were engrossed in their own struggle and lacked insight into the impact of their behaviour on their children. These children had additional responsibilities because of their parents' illness - often taking on parental roles. They were anxious about their parents' illness(es) and a few complained of similar symptoms - raising fears that fibromyalgia was hereditary. Alternatively, such sickness behaviour could (in part) be a form of learnt behaviour for secondary gain, providing attention for children who felt abandoned. Since this was not the focus of this study no particular examples are discussed, but it could be a subject for further research.

Most group members described their children as more supportive than most other people in their lives. Perhaps such praises were a form of idealising (Alfieri chap. 2 p. 36), given their insecurity and fear of losing their spouses and families. It appeared that they were in denial of any problems – possibly because they felt guilty for being a burden and grateful that their spouses had remained with them, considering their helplessness and need to be taken care of. After all, their biggest fear was to be abandoned. They were anxious that their spouses would become ‘fed up’ with their moods, illness, and inability to perform many of their duties as spouse, parent and housekeeper.

According to Hafstrom & Schram, women seem to have less clear expectations of what their partners should do to help them. They limit their own access to care and paradoxically inhibit their caregiving in the attempt to avoid overburdening their partners. Research highlights this ambivalence with evidence that women increase rather than decrease time spent on household chores when ill (cited in Altschuler 1997: 148). Although several women in the group felt unsupported by their families, their lack of insight in terms of their own needs, inability to express them, together with the fear of being a burden to their families or to be rejected, perpetuated feelings of abandonment.

Another observation of interest was that with the exception of one group member who had a child from a fiancé who had died in a car accident years before her marriage, none believed in living with a partner or having children out of wedlock. They needed emotional security against abandonment in a lawful marriage. The group member who had never been involved in a relationship was not prepared to engage in superficial short-term relationships, as she had major trust and separation-anxiety issues. It had to be perfect and for life, or not at all (indicating the need to replace the fused relationship she had with her mother, as well as her failure to complete developmental tasks regarding gaining trust, autonomy and intimacy).

One woman’s husband was devastated when their first child died at birth. With her second pregnancy she lost one of twins at eighteen weeks and in spite of the risk to her own life and possible deformity of the child, she refused an abortion of the other twin at

six months as urged by her doctor. Keeping the child and accepting him “*with flaws and all*” was her only moral option. “*Nee, never mind of hy gebreklik is, ek sal kan cope*” (*No, never mind if he is disabled, I will be able to cope.*) Her husband could not bear losing her or another child and was so furious with her decision that he stopped talking to her. She felt that he had deserted her at a time when she needed him, and resented that he would not ‘even get her a glass of water’. A suggestion to put the child up for adoption to save their marriage because of the husband’s rejection was equally unacceptable. Because her husband’s behaviour and reaction was reminiscent of that of her father’s harsh rejection (denying paternity) she could not abandon the child like her father had abandoned her. The negative transference exacerbated her feelings of rejection and abandonment.

She thought she had found a husband who would be a good father, only to be confronted with his rejection of her and the child. When he spent more time with his ‘drinking buddies’, she felt deserted. She issued an ultimatum to him shortly after their baby was born, to choose between his family and friends, and gave him a year’s time to find them a home, or otherwise she would divorce him. They were living in one room with her family-in-law and she wanted to raise her child in a positive atmosphere. As a child, her father had thrown her out of the house, to sleep outside when he was drunk. After her mother’s death, he deserted her young siblings without supporting them financially. When her husband did not pay maintenance to her and the child either, following their separation, she laid a non-support charge against him because she did not want her child to go through the same suffering. This example illustrates not only this woman’s abandonment and rejection by her husband, but also how rejection during childhood still impacted on emotions, choices and behaviour (Erikson Chap. 2 p. 42). She described it as hearing the same song over and over again: “*playing a record that I know*” – analogous to the recurrence of her fibromyalgia pain.

Abandonment by their husbands after immigration was particularly traumatic for two women because of their social and psychological isolation (‘intimacy versus isolation’), and their financial and emotional dependency on their spouses. They were reluctant to

separate from them because of the meaning of this liaison - being their last link to their roots and representing their whole family and homeland. "*He formed most of my life, because we left my country when I was sixteen years old. We got married and I combined myself to him, with no family support.*" According to Erikson, to develop successfully, young adults must fuse their identity with another person in a close intimate heterosexual relationship that leads to procreation. The negative outcomes of this period may include isolation and self-absorption (cited in Papalia 1978: 361).

These women were absolutely devastated when their husbands rejected them for other women, especially since both then lost their homes, had not worked for several years, had no income or savings and each had three toddlers to care for. "*My mother and father were already dead. I was living in a country where I did not know anybody and my husband walked out on me and left me with three children. Two weeks later, he told me to get out of the house as he was going to sell it. It was absolute hell*".²⁹ Of interest, the childhood trauma of the latter and another group member who was adopted, was more severe and their fibromyalgia more debilitating. This concurs with Walker et al.'s finding that trauma severity correlated significantly with physical disability, psychiatric distress and illness adjustment (1997: 575; chap. 2 p. 40).

In addition to the two immigrants, another group member was also left stranded with small children and no home or income when her husband deserted her. Their spouses had an indifferent attitude concerning financial contributions towards the upbringing of their children. Inadequate financial support was a common theme often repeated in group discussions. It was not only a form of abandonment but also complicated their adjustment after separation/divorce.

One group member described how a series of incidents constituted compounded abandonment by her ex-husband. She was infuriated that he had let them down three times. He had divorced her, causing her and their young children to lose their home and

²⁹ This group member did not develop fibromyalgia at this stage, but many years later after further experiences of abandonment, whereas the other immigrant believed she had had fibromyalgia since childhood.

income as a result of his imprudent business deals that had ended in insolvency. She did manage to get infrequent and insufficient maintenance with great effort and pleading, which aggravated her sense of abandonment. History was later repeated when her eldest son also lost his investments in a joint project, which his father had mismanaged to the extent that they were once again bankrupted. She identified with the son, took on his pain and made it her own. Like most other group members, she was unable to separate loved ones' experiences from her own, which reinforced her own sense of abandonment.

Several group members complained about the lack of emotional support from their spouses. Many were good providers, but emotionally absent, disconnected and uninvolved. The domestic situations of the following two group members caused them a great deal of emotional anguish, which appeared to have found a pathway to physical distress. One was irritated with her husband and two adolescent sons and for living in a chauvinistic world where a woman is burdened, having to do her own work and run the house, bring up the children, pick up after the husband when "*his lordship does nothing and wants to be served*" and is still critical of her. Another felt she was not getting understanding, empathy or support from her husband and could consequently not show when she was in pain or talk to him for fear of rejection since he "*disapproved of my moaning*". He was very demanding and had a vicious temper. She felt trapped in her second marriage, as she did not have money, a work or a place to go to if she would leave him - reminiscent of the situation she had found herself in as an immigrant after her first husband had deserted her.

One woman feared all her life that her husband might leave her. She endured four miscarriages and eventually gave birth to three sons, but had to spend the full duration of the pregnancies in bed. Taking into account that her father had left her mother because she was not prepared to go through a second difficult birth, one can understand this woman's insecurity and anxiety. They divorced many years later after he had had several affairs, amongst other with her best friend. Since she had been incapacitated for a long time prior to the divorce, from what were most probably severe depression and fibromyalgia, she believed he had rejected her because she was sickly. This

abandonment was particularly devastating because of her negative transference from her mother's life experience to her own, as her father had also deserted her mother when she needed him most and was subsequently institutionalised for a catatonic psychotic disorder, which the group member feared she could be predisposed to. This reflected a negative mindset, causing her to expect the worst. She admitted that she "*was a rotten wife*"; being disinterested in sex. Nonetheless, she not only felt rejected and discarded because she was no longer young, pretty or healthy, but also humiliated and ultimately betrayed and abandoned by her husband and her friend who had been deceitful and disloyal. In her case there was a definite parallel between her marital problems, emotional anguish and the severity of her fibromyalgia.

This, as many of the other examples, portrays a central characteristic that stood out from this group namely, hiding something very emotionally painful, which appears to have found expression in physical pain. They seldom admitted to others, including doctors, that they had other problems, not even depression, yet, they looked miserable. They ascribed their misery to the agony that their physical pain was causing to their lives, which were otherwise "all right" (converting emotional pain into somatic symptoms – often an unconscious process). Alfici et al. (chap. 2 p. 35) came to the same conclusions from a study of fibromyalgia patients in Israel. As seen from the group therapy, it took a great deal of time and trust before they could open up, and even then they were still defensive, if not in denial. These examples reiterate the premise that the presentation of unbearable physical pain and fatigue, i.e. fibromyalgia, is a desperate form of unconscious 'helpseeking behaviour' for overwhelming emotional pain/distress. These persons seem to hope that a caring doctor would offer a cure, or at least some relief through sedation, if not hospitalisation, which would remove them from their stressful environment.

These patients had suffered their emotional pain in silence and breaking their silence left them feeling guilty and disloyal. For instance, the above group member knew her husband had affairs but as her sons did not know, "*I kept quiet. I let it dry, because otherwise he is a very good man.*" This would appear to be denial to enable her to

tolerate the situation, as she was dependent on him and had no family in this country. Again, this portrays how group members often idealised the 'one magic person' despite obvious flaws. This group member was unable to see her ex-husband as other than 'good' despite his infidelity, emotional abuse, disastrous business deals and poor financial child support. Nevertheless, because it served her emotional and practical needs, she endured emotional abuse as it was only hurting her. However, when his flaunting of this woman in front of their friends started to embarrass and hurt their sons, she realised that a divorce was inevitable. She believed he was indebted to her, thus she kept him emotional hostage through guilt and her own helplessness and ill health. They had a co-dependent relationship, albeit dysfunctional, where her role changed to that of a mother figure ensuring that she was irreplaceable.

It was clear from this and similar cases that many group members did not want to take responsibility for themselves, but had expectations that others would take care of them or release them from their burdens. Three group members considered divorce, but losing their home and income were too much to cope with on their own. Besides, their spouses still satisfied some emotional needs. They also needed their practical and financial assistance, because of their ill health and to raise the children. This is exactly where the illness itself became an important manipulative tool to obtain attention, care and assistance. It would (hopefully) create guilt in the spouses, preventing them from abandoning a sick person who depended on them. (Blackwell & Gutmann chap. 2 p. 28). In this sense, the illness trapped both parties in a dysfunctional and co-dependent relationship.

Verbal and emotional abuse by their spouse was experienced by half of the group members at some stage, whereas physical abuse was reported by two group members, one many years previously and another in a current battering situation. This corroborates previous findings of significant high rates of abuse among adult fibromyalgia patients and the notion that the psychological stress phenomenon as a result of abuse may in some individuals have an effect upon the expression in and perpetuation of the pain syndrome of fibromyalgia in adult life (Biosset-Pioro et al. chap. 2 p. 39).

Forward referred to emotional abuse as “an act of emotional violence which can be just as destructive to the victim’s psychological well-being as can physical violence, because it creates the same feelings of violation, fear, helplessness, frustration, and rage. Whereas victims of physical abuse can call the police, there are no laws to protect one from emotional violence” (1991: 78). Disclosures from the group concur with this theory, as stated by one group member: *“I took a lot of hurt. My husband never touched me. He never drank, but emotionally he was abusing me more. Nobody would have ever thought what he could do with his mouth, and that very softly and very gently.”* As this was a pattern, it caused emotional pain, which, as in all the above-mentioned examples, appears to have been modified into physical pain.

A group member who had endured tremendous physical, emotional and verbal abuse kept it secret for five years. She developed fibromyalgia in the fourth year of marital problems, when the abuse - a form of rejection - escalated. This supports the researcher’s notion that unbearable emotional pain stemming from feelings of abandonment/rejection seems to contribute to the development of fibromyalgia. It is also a good example of fibromyalgia that had its onset during adulthood where abandonment/rejection also occurred for the first time during adulthood. It further implies that even if a person had a happy childhood and completed the developmental tasks successfully in the early stages, the trauma of abandonment/rejection in adulthood could severely affect them and their ability to achieve intimacy and ‘generativity’.

Her husband had become increasingly short-tempered, angry and denigrating towards her to the point of being abusive to her and their young children, even when he was not drunk. She often found refuge with a neighbour when he had thrown her out of the house at night. She was once hospitalised for breathing difficulties after a violent episode when he had strangled her. However, in hospital she presented illness rather than marital conflict as the problem (somatisation as helpseeking and an escape - Kirmayer; McDaniel chap. 2 p. 25). She feared that he would either kill or leave her as he became irritated and frustrated with her illness and inability to cope with her work and chores at home. The abuse and ongoing battering caused intense feelings of rejection. She felt unsupported

and deprived of his affection and devotion. She became insecure, disempowered and isolated. Yet, each time when he repented and admitted that he needed her, which made her feel important and valued again, she withdrew a restraining order and stopped divorce proceedings. According to Hillman abused women try hard to please their overcritical mate, but inevitably fail, blame themselves for this failure and feel more inadequate. Concurrently, they accumulate tremendous rage at their spouse for being so denigrating, but cannot affirm themselves. They feel too unworthy, too inadequate, too frightened of punishment and abandonment if they really stood up for themselves (1992: 63-4).

As a result of her disclosures a fellow group member and the only male in the group, confessed that he had been "*a rotten husband and father*" for many years as he had been abusive to his family. This example confirms the findings of Forward regarding 'rejection anxiety' where a possessive husband (as a result of a mindset of abandonment) had become flooded with panic, insecurity, fear and pain that his "one magic person" would leave him (1991: 31). Prior to his illness, he had worked away from home for prolonged periods and became fearful that his wife would leave him. He was jealous and sexually demanding, and misconstrued her occasional refusals as rejection of him as a man. He responded by hitting her and accusing her of having affairs, which was probably projection of guilt for his own infidelity – something she only learnt of later. He had become unpredictable, explosive, and consumed with "*real hatred and anger*" which he took out on his wife and children. When his children "*started to hate*" him and refused to eat at his table he perceived their fear of him as rejection, compounding the perceived rejection by his wife. According to Forward these vengeful assaults, as an attempt to regain control by exorcising his rage, was a futile catharsis. Trying to cause pain to others is unconsciously trying to hand off one's own pain. However, this sort of transfer inevitably fails because the rejection that created the pain in the first place is not eliminated, it is exacerbated (1991: 86). The irony and intrigue of this example lies in the apparent lack of insight about how he was setting up his own rejection through physical, verbal and emotional abuse causing his family to detach themselves. This, in turn, reinforced his own perceived rejection.

He stopped his abuse when his rejection anxiety escalated after his wife and children had sought refuge in a safe house and she filed for a divorce. He realised that he would become an outcast because of his family's condemnation and that he would lose everything. Significantly, he developed fibromyalgia after he had ceased to ventilate his emotional pain by means of aggression. He felt more vulnerable to abandonment since he had been boarded from work due to longstanding diabetes and had become financially and emotionally dependent on his wife. During group sessions, he labeled himself as a "zero-person" when sexual impotence was diagnosed as a result of diabetes. He became severely depressed and was riddled with guilt, shame and regret. He projected his own self-rejection onto his wife, expecting that she would now leave him. He believed he deserved to be abandoned, and that his inability to perform sexually was punishment from God for his past affairs and abuse – perhaps indicative that God had abandoned him too! Not surprisingly, his fibromyalgia flared-up as a result of his definition of his own situation.

This is the only example in this particular group where the response to perceived abandonment/rejection was violent behaviour. This could indicate that certain men tend to react more overtly aggressive, whereas women internalise feelings of abandonment/rejection, which predisposes them to fibromyalgia and/or depression. It could also explain why more women than men suffer from fibromyalgia. The fact that this man developed fibromyalgia soon after aggressive behaviour became an unacceptable coping mechanism for unbearable feelings of abandonment/rejection would appear to substantiate the assumption that the conversion of emotional pain into physical symptoms contributes to the development of fibromyalgia.

The emotional pain from rejection and abandonment by spouses should not be seen in isolation as it involves a multifaceted and entangled web of emotions, issues and concerns as illustrated by all the above examples. It brings to the fore past experiences, fears, insecurity, anger and resentment and it attacks one's self-esteem and femininity/masculinity. It encompasses the pain of having been disappointed and for having failed, as well as the pain ensuing from betrayal, dishonesty and grief.

Rejection by in-laws also aggravated existing feelings of rejection and abandonment in several group members. They were over-concerned about what others would think of them (rejection anxiety), and felt deeply hurt when their in-laws did not accept or acknowledge them. Four did not feel accepted, no matter how hard they had tried to please their mothers-in-law and sisters-in-law. Two believed that their mothers-in-law were trying to break up their marriages by making them the scapegoat and deliberately turning their husbands and children against them. One felt excluded and jealous of the husband's relationship with his family, since her own family was unsupportive. Instead of communicating her emotional needs, she used her illness to gain their attention (McDaniel chap. 2 p. 25). Another was bitter about broken trust and accused her mother-in-law of maliciously distorting information about her into something negative in order to discredit her. A fourth group member felt exploited when her house was used for late night parties by her sister-in-law so that her children would not be exposed to its consequences. However, the sister-in-law disregarded the group member and her family. When she put an end to these parties her sister-in-law no longer visited. This caused her to feel cast aside (rejected). Another group members' sister-in-law never repaid a large loan and she felt cheated, betrayed and unappreciated.

There was often an overreaction to minor incidents as a result of previous rejection and negative transference – something they were unconscious of and had no insight into. This emerged to be one of the common characteristics of this group of fibromyalgia patients. The overreaction was illustrated by a group member's resentment when her mother-in-law boasted and took credit for her son's graduation, whereas the latter had refused to pay for his training as a teacher. In fact, it was the group member who worked to support her husband while studying, just as she had had to work for her siblings' tertiary education years before and had never been acknowledged for it. It seems that the group members were so preoccupied with unresolved issues from their past that they could not maintain an objective view. As mentioned previously, they filtered life experiences through a mindset of abandonment/rejection.

When they could no longer tolerate the pain caused by rejection and abandonment, these patients coped by withdrawing, disconnecting themselves, avoiding confrontations or rejecting the person in return. It appeared that fibromyalgia patients tended to experience life events in an 'either-or' fashion – not in terms of gradients (a narcissistic trait). In other words, significant persons in their lives either accepted or rejected them. They also had difficulty in asserting themselves or in setting limits and boundaries. Six group members cut all ties with their in-laws for several years – applying a principal of “all or nothing”. One group member mirrored the rejection that her husband, sons and herself had experienced from her in-laws by severing all ties even though they lived in adjoining houses. It angered her that her children were alienated and ‘disowned’ - intensifying her own feelings of rejection.

Because of a mindset of abandonment those individuals who had not experienced love and unconditional acceptance, especially as children, continued to seek external recognition and approval from others, rather than from within themselves (lack of autonomy and a sense of self). When these emotional needs were met, they felt good about themselves, but when love/acceptance was withdrawn or not given, their feelings of worthlessness were validated and their feelings of abandonment/rejection reinforced. These issues were amplified by also having to deal with the crisis of ‘generativity versus stagnation’ of the ‘middle years’. ‘Generativity’ refers to the adults’ ability to look outside themselves and care for others. If not successfully resolved, they would remain self-centered, isolated and experience stagnation. This later develops into despair, since without ‘generativity’ there is no sense of purpose in their life. Failing this developmental task (to be ‘generative’), the obsessive search for intimacy will continue (Kaplan & Sadock 1991: 46). They became more vulnerable and hypersensitive to perceived criticism or rejection and frequently felt victimised. Characteristically, they remained powerless as victims in a situation where they felt that they had no control. Several studies on rejection sensitivity concur with this finding (chap. 2 p. 51).

4.3.4 Abandonment and rejection by friends, colleagues and employers

Group members generally did not seem to have a wide support base. Instead, they were often dependent on one support system, which was mostly a mothering figure, their spouse and children and/or their religion. Any sign that this support system could collapse under pressure left them insecure and anxious. When their support system was lost, they were devastated as there was nothing else to carry them. Some could still cope, but not on days when they did not feel well, had financial or other problems, or experienced abandonment/rejection, which triggered a flood of painful emotions.

As regards to **friends**, all complained that their friends had deserted them since they had become ill and no longer had mutual interests. One group member found that since she had stopped working “*the phone stopped ringing*” and her friends all disappeared (“*verdwyn in die niet*”). She believes that “*always being sick and desperate because of pain*” had caused her to be abandoned by her friends. Another felt deserted by her friends because she could no longer party, dance, ice-skate or go camping due to fibromyalgia. “*I was in a state. I needed counseling. That was a difficult time.*” To have lost her friends in this manner was worse for her than the friends she had lost through death. Because they had become more homebound, they also lost out on making new friends except for fellow patients at the hospital. Sadly, one group member lost four of these new friends within two years when they succumbed to their illnesses.

Many group members had high expectations of friends. Whereas they did not make friends easily, they wanted friendships to last for life. They would rather not have a friend if they could not rely on that person. “*That is one of my problems; when I make friends, I want it to be forever and if I know you're not going to be in my life for long, I won't trust you.*” Trust or rather the lack of trust proved to be a key issue in people with unresolved issues regarding rejection and abandonment. The lack of trust also forms part of the mindset of abandonment. In other words, the distrust after an experience of abandonment reinforces the sense of abandonment and justifies expectations of further abandonment – causing a vicious cycle of abandonment, which feeds on itself. As a

consequence of distrust and fear of further abandonment, many group members had become completely socially isolated (See 'rejection sensitivity', Downey & Feldman chap. 2 p. 51).

Four group members had no friends whatsoever. Two of these were very isolated within their immediate families and one never left home unless it was for hospital or church, whereas the other two had large extended family support. Three had some friends but were not intimate and the remaining four had many friends. Not having any friends was a sensitive issue for one group member because she used to feel very lonely as a child and had only two friends at school. This indicates that a lack of a circle of friends and popularity among peers could cause feelings of inferiority. Such persons felt that they were not good enough and were unloved. This reinforced feelings of detachment and alienation.

Several group members experienced betrayal by their best friends. Two felt ultimately betrayed by their best friends who had had affairs with their husbands. Another felt betrayed by her "best friend" and neighbour of twenty years after their relationship changed when her friend became her boss. She felt that she was still a friend to her boss, but her boss was no longer a friend to her. *"I was the one who was trying to keep everything together. All my life, I'm always the one who tries to have everything going smooth for everybody. And in the meanwhile, nobody a hell cares about what I'm going through. She was a friend of mine. Definitely she is not my friend - that she proved."* She came to realise that she *"never had a friend"* although she was *"a good friend"* for many because their needs were always met, but not hers ('intimacy versus isolation'). She felt disappointed, neglected and forsaken. The significance of such 'betrayal' lies in its amplifying effect on existing feelings of abandonment.

Yet, as observed in this group, incidents related to abandonment/rejection were seldom isolated. The mere emotional over-reaction to minor incidents suggests negative transference and unresolved issues with similar experiences in their past. Tugging on any one of the 'threads' will disturb the whole multifaceted entangled 'web' and trigger

intense reactions. This was well illustrated by this group member who ventilated her anger towards her so-called friend and boss. *"She also betrayed me, just like my husband. She could do it, because she knows me so well."* As with other examples from the group, these emotions were unconscious and it was only through group therapy that unresolved issues were recognized. This group member thought she had *"dealt with all this long ago"*, but learnt that 'the problem' would keep on reappearing, sometimes in different forms, until she had dealt with it and achieved closure. In this case, the group member projected feelings of anger towards her ex-husband onto her boss (neither of which were expressed) because they were both authoritative, powerful, controlling, dominant and self-centered. She felt exploited by both who knew that she would remain quiet, loyal, forgiving and submissive in an attempt to keep the peace and not lose their friendship, her job and income.

Feelings of abandonment also emerged in respect of indifferent and unsupportive **employers and colleagues**. Seven of the eleven group members had been medically boarded from work, although only three as a direct result of fibromyalgia. Being declared medically unfit to work was described as *"a great battle, because we do not look that sick, people actually do not believe we are sick or in pain"*. One took her employer to court in order to be boarded. Another reproached the insurance company she had worked for, that they *"should be kinder to their own employees"*. Most felt that their employers and colleagues did not understand what they were going through, or why they needed to be frequently absent from work in order to attend hospital or physiotherapy. Some felt that their employers and colleagues believed they were pretending or exaggerating the symptoms. Bennett reported similar findings where family, coworkers and friends often harboured suspicions about whether they were truly disabled. They often wondered whether there was a hidden agenda, secondary gain, perhaps escaping stresses of a boring job, receiving attention or getting early pension (1996a: 1627).

Three of the four group members who were still working had difficulty in coping with the demands at their place of work. Two reported reasonable support from work and another excellent support. The latter was employed in a post reserved for the disabled and was

the only group member who enjoyed her work and coped well. Two of the eleven did not disclose their illnesses in fear of rejection (one also underwent regular chemotherapy for cancer and did not even tell her colleagues at the day hospital where she worked as a nurse). Altschuler refers to the secrecy and shame when the sense of shame in being ill means that the battle to manage symptoms has to be kept silent. Value judgments ascribed to the ill contribute to redefining their identity (1997: 5).

In contrast, another group member got angry when colleagues looked at her with pity or “*labeled me as being sick again*”. She wanted acceptance, not to be seen as different. Although she could work, she could not handle people’s reaction to her when she “*shuffled along at work due to pain*” and would rather take sick leave to stay at home. While not all group members felt abandoned/rejected at work, they experienced a lack of support, care and trust from their employers or colleagues, which amplified their isolation and strengthened the mindset of abandonment.

The following section focuses on group members’ perceived abandonment by the government and broader society. It is essential to consider not only their social history, but also the impact of their macro environment – especially as this group of individuals appeared to be particularly vulnerable to external factors as the perceived cause of their misery.

4.3.5 Abandonment and rejection by the government and broader society

Abandonment by the **government** largely concerned issues where human rights and basic human needs were unmet due to unequal resource allocations in the past as a result of racial discrimination. This related to housing, education (including tertiary), healthcare, safety, work and social security for all, as well as an effective infrastructure, such as an efficient public transport system for the disabled.

In some or other way, all group members felt that the government and society had repeatedly abandoned them – many since their childhood. The closure of the hospital,

failure to provide medication and hospital transport were just the latest in a long list of perceived experiences of abandonment by the government. The difference between these persons and the millions of others who had similar experiences of discrimination probably lies in their mindset of abandonment. This mindset causes them to define their experiences as abandonment/rejection. The hospital closure triggered feelings that might not have otherwise surfaced. Group members felt marginalized and discriminated against because they were from a minority group (racially and as the disabled), and perceived themselves as being insignificant to the government and broader society. It also evoked deep-rooted suppressed issues about prejudice and unfairness that 'coloured' group members had experienced during the 'apartheid government' era. Only now, with a predominantly black government, they still felt that as a minority group they were 'forgotten about' and 'left out in the cold'. In other words, they are once again abandoned.

It is not possible to see abandonment in isolation, as it is further compounded by the historical socio-political context in South Africa and specifically its former 'apartheid' laws. With the exception of two white immigrants, British and Hungarian respectively, nine 'coloured' group members were directly or indirectly affected due to 'forced removals' when their family homes in so called 'white areas' were either 'bulldozed' or 'confiscated' during the sixties. Families were separated and neighbourhoods displaced as a result of forced relocation. They had little choice as to where they wanted to live and were removed further away from their place of work. This incurred more expenses for traveling and was time consuming. Worse, it engendered a deep underlying sense of rejection and unworthiness. Over the years living conditions in these allocated areas deteriorated due to over-population, unemployment, poverty, alcohol and drug abuse, crime and gangsterism.

Alternative accommodation was virtually impossible as discriminating laws prohibited them from becoming homeowners until fairly recently. Subsidised city council accommodation had become an 'indefinite wait' for approximately forty three thousand applicants on a more than twelve-year waiting list. Funds were no longer allocated to the

city council for the construction of dwellings and occupants could purchase these homes (P. M. Paulse, Director of Housing, City of Cape Town, letter dated 18 December 1996). Many felt trapped in areas where they did not want to live. Not only were they 'robbed' of their homes, old neighbourhoods, schools and businesses, but also unjustly removed, 'dumped' and then ignored by the authorities. They had lost important ties, a sense of belonging and their identity. They were angry, bitter and helpless, as their basic human rights had been violated. They felt alienated, ostracized, and abandoned by political leaders and the government.

More than half of the group members had already experienced abandonment as a result of insufficient government resources during childhood. They grew up in poor and overcrowded homes where more than one family lived on one property – some in shacks in the backyard with a lack of amenities and privacy. This resulted in premature exposure to sexual activities or inappropriate behaviour such as fights, nudity and drunkenness. As children, two group members had to move frequently when their mothers had been evicted due to rental arrears. They repeatedly changed schools and were often sick due to exposure and inadequate shelter. They felt insecure and a burden to society, yet it was the society and government, sometimes even relatives and neighbours who had ignored their pleas for accommodation, clothes and food.

Coupled with the Group Areas Act, (No. 41 of 1950) was racial intolerance that affected many generations as illustrated by one group member's family history. Her great-grandmother was rejected by her "boere-familie" (Afrikaans farmers) because she had married an Englishman. Her grandmother, who was white, found acceptance in a 'coloured' community, married a 'coloured' man, and was consequently rejected by both her Afrikaans and English white families. When her grandmother's house in a so-called 'white area' was confiscated due to the Group Areas Act, she had to be relocated with her husband and children who were classified as 'coloured'. Paradoxically, being light skinned herself, the group member who had been brought up by her grandmother never felt she belonged in either world and acceptance by others remained an issue throughout her life. This blatant racial discrimination and victimisation due to skin colour left such

emotional scars and bitterness that as an adult, she instigated legal action to reclaim their family home when land redistribution became possible.

Prolonged experiences of discrimination, deprivation and frequent insults on racial grounds had a great impact on expectations that group members had of themselves and others, as well as their attitude to life. It affected their identity, self-esteem and self-acceptance. It can be argued that most citizens in this particular society might have felt some degree of rejection/abandonment, yet not all were adversely affected. However, the members of this particular group did not have the inner resources or the external support systems to help them to cope. Perhaps it is also the combination of the deprivation and injustices that they had experienced in their disadvantaged community, and in their private lives that predisposed them to somatic expression of their emotional distress. They had also become hypersensitive because of the cumulative effect of perceived abandonment/rejection. In fact, they did not even need to be a direct victim to re-experience these emotions, which were often triggered by negative transference when they identified with others, reinforcing their mindset of abandonment.

Group members expressed many grievances about inadequate or non-existing grants for the unemployed, disabled and children, as well as acute shortages in housing and the failure of the legal system allowing fathers to avoid child support. The biggest problem was inadequate or non-existent social security as many failed to meet stringent criteria even if deserving. Legislation that excludes children older than six years of age, even if orphaned, from a meager child grant illustrates this point. Most felt that the government was 'deliberately' making their lives more difficult due to the lack of any financial assistance to the unemployed. In addition, application procedures were complicated, arduous, inconsistent and frequently changed – sometimes resulting in the suspension or termination of grants and lengthy re-application procedures with no guaranteed success and no back pay for the lost months (M. Fransman, Minister of Social Services and Poverty Alleviation, "Our fight to alleviate poverty": a public notice to pensioners/grantees who had applied for pensions/grants between 1 April 1998 and 30 November 2001 and who had not been paid from the application date, Sunday Argus, 28

July 2002). They found this treatment by the government of its citizens shocking. This indifference to their suffering, disrespect, and undignified procedures due to bureaucracy amplified their feelings of insignificance and abandonment/rejection.

An interesting observation was that several group members felt a sense of entitlement – a narcissistic belief that the government ‘owed’ them, either because they had worked hard for the country or because their ‘suffering’ made them eligible for preferential treatment. This was also seen in their expectations of doctors to be rescued, taken care of, and loved, which are, according to Kaplan & Sadock, inherently unrealistic and bound to be inevitably disappointed (1991: 3). It sadly set them up for further disillusionment when they realised that they were not special, or that others, including the government did not care about them. Consequently, it reinforced their existing sense of abandonment and alienation.

Most group members could not break free from their financial struggles, which for many was an extension of childhood suffering. Six of seven group members that were boarded from work due to fibromyalgia or another illness did not qualify for a disability grant because their spouses’ income exceeded a specified minimum despite the fact that they had suffered a loss of income and had dependent children. Four of five group members who had an additional responsibility for children of deceased or dysfunctional family members could also not obtain financial assistance from the government. Two were employed but struggled to cope with work and family demands due to fibromyalgia but felt they would be worse off if they lost this income. Two managed to get disability grants in order to support their families by concealing information of additional incomes. A third who was wheelchair bound only gave up her disability grant when she found employment for the first time in her thirties, after new legislation compelled large companies to employ a percentage of disabled persons.

Further examples of perceived abandonment by the government and society were seen in the indifferent attitude to the difficulties that women and children were experiencing. Female group members expressed that the **legal system** and government had failed

mothers and children in this country by not forcing fathers to pay child support, and its reluctance to provide a supplementary grant for struggling single mothers.

A group member who “*always had to beg for something from the children’s father*” had appealed to the maintenance court for regular and a higher allowance. When an additional fifty Rand per month was granted for all three children, but a petrol allowance, which amounted to more, was revoked, she felt cheated and that the authorities, who were supposed to support and protect her, had done her “*a great injustice*”. Her dependence and helplessness were accentuated instead. It was felt that “*even the law did not stand by a woman in this country*” and that “*women were always at the short end of the stick*”. For this reason, one group member had been a maintenance officer at the Department of Social Services in order to ensure that fathers would fulfill their duty and that children and their caregivers would not have to endure the same hardship she had had as a child.

It was also thought that lawyers were “*very seldom on the side of women*” and would “*often turn on us*”. A divorced mother with three children found that she was not legally protected when she fought against losing her home in the liquidation of her ex-husband’s insolvent business. Her lawyers told her: “*You are becoming too emotional. We do not want to speak to you*”. She felt exploited and that it was futile to pay them a further *thousand* in addition to twenty-five thousand Rand for another attempt to recover the house. She felt dispossessed of her only security and stability. Her bank manager was also unsympathetic as they “*do business and not charity*”. It is often subsequent to periods of such severe stress that group members experienced amplified pain or suffered a relapse of their fibromyalgia. They felt that they lived in an uncaring society where its governing body did not provide adequately for ‘second class’ citizens.

It seemed to the female group members that men have an easier life in a ‘patriarchal chauvinistic’ society that often did not serve the needs of women and children. The male group member concurred and admitted that he had no fear of the police once his wife and

children had obtained a restraining order against him because of his abuse, as *“they could do nothing to me”*.

In analysing the group members' negative feelings towards the government it became clear that they experienced negative transference with the government. It resembled a parental role model that had failed to provide adequately in the basic needs of its dependants, just as many of their parents had failed to provide adequately for them. Interestingly, the group members were ignorant of this parallel process. The previous Apartheid government's exertion of control through unjust laws and excessive force by the military and police were reminiscent of an abusive caregiver. This explains the over-reaction to seemingly minor incidents: it provoked unresolved feelings and amplified their sense of abandonment.

Expectations that the new democratic government would be different were shattered when authorities deliberately closed the only rehabilitation hospital for the disabled in this country; ignoring their pleas and thereby destroying their only support system. They were angry that there was no democracy or transparency, but rather autocratic decisions and orders, which they had to obey. *“They talk about democracy on the one hand and on the other hand they treat you like a lot of cattle and sheep. You can just be shoved and pushed around, and to hell with the rest of you.”* This exclusion also triggered negative transference with previous experiences of abandonment/rejection when they were mistreated and left in ‘the cold’. In terms of object relations theory, the government became the ‘bad’ parental object or symbolising what Klein termed the ‘bad breast’, whereas they remained the disempowered, helpless victims (Klein 1932; see chap. 3 p. 64).

Characteristically, these fibromyalgia patients had difficulties with authority figures such as a dominating parent, spouse or doctor. They either internalised rebellious thoughts or reacted in a passive aggressive manner, often self-destructive in nature and only alienating them further. At times like these, their pain experience was amplified. As mentioned before, their plea to doctors to free them from their pain could well be part of helpseeking behaviour.

Group members believed that the government and society had abandoned them by failing to protect them against crime. Offenders were allowed to 'get away with murder' - just as their caregivers or spouses had not been held accountable for their neglect or abuse (negative transference). Several group members had been directly affected: two had relatives whose murderers had never been convicted, three had been subjected to child abuse, two were abused by their husbands and one had been harassed by her father. Another felt that her grandfather got away with the enforcement of her fraudulent adoption and the physical and sexual abuse of his daughters. One group member had been sexually molested when a hospital technician examined her and the other's daughter had been sexually abused when she was nine years old.

Intense feelings of abandonment/rejection by one's **community** were experienced by this mother in her attempts to unmask the pedophile. She was enraged that no one, including her daughter's psychiatrist and the Muslim Judicial Council, was willing to expose the respected elderly leader and 'ghalifa' (Muslim teacher) in their community who was still teaching young children. She felt disempowered and deserted by her own community, and thought that the men were protecting their own in fear of "*opening a can of worms*" and damaging the 'Muslim image'. To her "*the system falls short in helping victims and only betrays them further*" – like a second 'rape of their rights'. Alone and frustrated in her pursuit for justice, she felt her only remaining option was to distribute flyers to expose and punish this man or to shoot him. Another reason for her intense feelings was because the same community had previously ostracized her when her first husband had made her the scapegoat by spreading false rumours that she had had an affair. In truth, it was his distrust, pathological jealousy and physical abuse that had caused her to seek a divorce. This example also illustrates how a combination of stress and compounded abandonment might have triggered her illness. In a short period of time, she had lost both parents, got divorced a second time, and found out about the daughter's sexual abuse. Fibromyalgia (and systemic lupus erythematosus) were diagnosed within three years.

All group members expressed feelings of **abandonment/rejection by society** because they were chronically ill or disabled. Many times people, including doctors, did not

believe them but thought that they were pretending to be sick. Nye reported in his study that patients often elicit less sympathy and support from family, friends and employers than they deserve because of the lack of physical stigmata signs of disease (1996: 6).

The main issue was that people did not understand their fibromyalgia and how they could literally be paralysed due to pain and fatigue one day, yet on another they appear to be well. They had also become over-sensitive for the slightest criticism of not performing their role as expected – fearing rejection and disapproval. It was construed that society did not care about or accept them when they were sick.

Some felt ignored and invisible when people, including doctors would talk about them in their presence, but as if they could not hear, feel or talk. When shopping, one group member frequently experienced that sales ladies would approach and talk to her sister who had accompanied her, but not to her in the wheel chair. She felt stigmatised because *“people still believes that one is also retarded when you are disabled”*. In fact, this judgment also applies to four group members who ‘deviated’ from societal norms in being overweight. Previous experiences of abandonment or rejection seemed to have made them more susceptible to any criticism or disapproval due to their sensitivity, poor self-esteem and because it reiterates past rejections. These group members expressed deep hurt and anger for rejection by society because they were not young, slim and beautiful. *“People think that when you are fat you are a stupid person also - that your brain is also full of fat. That is how they make you feel. They think because their weight is normal, they can judge you because you are fat. People do not realise how come that person becomes fat and what was the reason.”* They felt degraded as if *“you are not worth anything if you are fat. You get these slim girls and they have birdbrains - and they are acceptable.”*

Radley stated that becoming chronically ill does not remove one from society but, if anything, amplifies one’s position within it (1994: 155). However, most group members often felt rejected and that they did not belong. Although they needed support from others, they resented being labelled or being pitied. They wanted to be treated like

normal human beings and not like 'rejects'. They needed to be accepted for who they were and not seen as disabled or worthless for society. They could sense that they no longer fitted into society since they could no longer make any contributions to society. They were pushed out and condemned. They felt disempowered and marginalized. This finding concurs with Goffman's statement: "... to be labeled chronically ill is to be made exceptional, and, like all marginalized people, to be burdened with the task of continually having to make oneself 'acceptable'" (cited in Radley 1994: 156).

Feeling condemned seems to stem from society's requisite that people have to be interdependent rather than over-dependent or totally self-sufficient as the other extreme. Considering that pain and fatigue have been a method of torture for centuries with the aim to break the human psyche, one should accept that people who have constant pain could have broken psyches. They become insecure, desperate and needy - requiring more care, but this seems to be a threat to society's limited resources. Paradoxically, it is acceptable when society needs people to be inter-dependent or co-dependent for its own existence, but not acceptable when any imbalances occur and people become too needy, disabled or dysfunctional. Becoming 'disabled' to work appears to have triggered previous unresolved developmental tasks of 'industry versus inferiority' and 'autonomy versus shame and doubt'.

Parsons explained how illness is an escape from life's pressures and that the sick role connects with the residue of childhood dependency. Sickness is motivated in ways that are unacceptable to society's world of work and responsibility and why "the sick need to be insulated from the healthy, for their dependency may well be contagious" (cited in Radley 1994: 82).

It is therefore understandable why the closure of the hospital and its diminishing chronic care services were so traumatic for these group members. The hospital, as part of their macro-environment and their main support system, will be the focus in the remaining part of this chapter. Specific attention will be given to their experiences of abandonment/rejection by medical practitioners and as a result of the closure of the

hospital, before analysing how they felt abandoned/rejected by each other and the facilitator as a result of termination of the group.

4.3.6 Abandonment and rejection in the hospital context

4.3.6.1 Abandonment and rejection by medical practitioners and the health care system

A further manifestation of a mindset of abandonment emerged from group discussions through numerous ventilations of the patients' frustrations with doctors and hospitals. Results from an analysis of the group members' comments about their doctors substantiate that past experiences of abandonment/rejection contaminated not only their relationships with doctors, but also affected their expectations. Most prominent was an attitude of distrust, which was reinforced as their reservations were confirmed with each detrimental incident. Group discussions provided many examples where some group members had greatly overreacted to encounters with doctors because it once again triggered negative transference regarding unresolved issues. Of interest was that they were oblivious of past associations with current crises, yet they projected their anger and disappointment onto the current 'culprits'. In both, current and past instances, most felt helpless against a person with authority and power on whom they depended. This explains why it was mainly in respect of male doctors that they experienced negative transference, rather than nursing or paraprofessional female staff that have more caring and less authoritarian and decision-making roles. **Transference** is generally defined by Kaplan & Sadock as the set of expectations, beliefs, and emotional responses that a patient brings into the doctor-patient relationship. They are based not necessarily on who the doctor is or how the doctor acts but, rather, on persistent experiences the patient has had with other important authority figures throughout life. These transference attitudes toward the doctors are apt to be a repetition of the attitudes they had had towards authority figures (1991: 2-3). In the case of the fibromyalgia group members it ranged from basic mistrust to over-idealisation (just as they had exhibited toward the facilitator). In contrast, patients who were not subjected to abandonment/rejection may experience

positive transference and an attitude of basic trust. The difference lies in the history and mindset of abandonment of the group members.

A group member illustrated negative transference when she confronted a doctor about his “*macho, authoritarian attitude*” and reacted either in an attacking or defensive way, or else in an obstructive manner. She had a pattern of antagonism and ‘freaking out’ behaviour with authoritarian male doctors. This is also an example where negative childhood and early adulthood experiences continued to impact on relationships. It emerged that her inability to form any trusting relationships with doctors was negative transference from father who had been very strict, controlling and rigid. She had not spoken to him for many years to avoid painful conflicts and also because he had disappointed her so many times that she mistrusted him. She rebelled by avoiding doctors and staying away from the hospital in a similar response. She told the group: “*I was not aware of it. I could never see it that far back. Maybe I did not want to address the issue in my past. I get angry and aggressive and I want to attack them. So, what I was doing was taking my aggression out on the wrong people and they get cheesed off and put me in a category which is not me.*” (Probably triggering negative counter-transference from doctors as a result of their own past experiences with difficult patients.)

Taking into account that this selected group of individuals had had numerous experiences of abandonment/rejection, it is understandable that some were hypersensitive and distrustful. Because of this mind-set they took matters very personally, felt victimised and suffered prolonged hurt and anger. In their subjective experience, they often assumed that they were unimportant and denied proper care, understanding and respect.

Most group members’ response to the perceived abandonment by medical practitioners can be described as either an ‘acting out’, namely in an aggressive, rebellious, obstructive and most often a passive-aggressive manner, or ‘acting in’ through avoidance, withdrawal, discontinuing attendance to the hospital or their treatment regime and consequently relapsing into pain and depression. Because of a lack of assertiveness and social skills some tended to submit quietly, although they might be complaining to everybody else but

the source of their problem. Since seven of the eleven group members came from homes where they had been physically abused and/or emotionally neglected, it was understandably difficult for them to face confrontations, as many feared conflict. Besides, most group members lacked confidence, felt disempowered and helpless. Their emotional needs had so seldom been met, that they had become out of tune with their emotional needs and feelings and were unable to express these. Nor could they understand the underlying cause for these feelings. They would give a vague indication that they *“did not feel well”* or that something was *“not right”*. Instead, they had learnt to call for help, or draw attention to themselves through illness, thus becoming accustomed to express themselves through physical complaints (somatisation). (Kirmayer chap. 2 p. 25)

Group members had all been suffering from pain, fatigue, stiffness and various other symptoms for many years prior to the eventual diagnosis of fibromyalgia at POAH (Princess Alice Orthopaedic Hospital). Previously they had consulted numerous doctors who did not know what was wrong or *“how to handle”* them. Many were told that there was *“nothing wrong”* with them and were left to feel that *“it’s all in my head”*. One group member disclosed: *“I was totally insecure, because I did not know what I was dealing with. I just had one thing on my mind: pain, pain, pain. The doctors I’ve have lost faith in. I was angry with everybody in the whole world. No-one understands.”* Group members resented the fact that they were not informed sufficiently by medical practitioners about their condition and its effect on them. They also wanted to be better informed about the possible side effects of medications because they had ‘wasted money’ on private doctors for what they thought was another medical condition. They felt these medical practitioners had been unconcerned about their needs and that they were ostracized and *“left outside in the cold to suffer alone”*. As stated before, these reactions are not uncommon to the ordinary person in a similar situation. It was the intensity of the fibromyalgia group members’ feelings and the subjective meaning that they had attached to these experiences that reflected the mindset of abandonment.

Group members also felt frustrated that even the ‘experts’ on fibromyalgia syndrome were at a loss as to what to do and this amplified their own insecurity, anxiety and helplessness. One was amused that her general practitioner often asked her what medication to prescribe, “*as he did not know*”. Another felt rejected by her doctor when she found relief from homeopathic remedies and “*he just gave me a look and said: “Fine, please yourself” as if he didn’t want to see me again after that, because I was now categorized as being somebody that’s mistrusting them. But it’s like they just pump you full of chemicals.*” One other was disappointed with her surgeon who showed no interest in her, as he did not even come to see her in the ward after a spinal operation. It was also thought that private specialists were exploiting them financially. The group was displeased that doctors seldom referred fibromyalgia patients to physio- and occupational therapy even though they had found good relief, support and advice from a multi-disciplinary team approach. Overall, they felt deprived of good care, which added to their skepticism, distrust and lack of confidence in doctors. This exacerbated their sense of abandonment.

This was further exacerbated by what these patients perceived as poor communication, a lack of understanding, disinterest and emotional distancing by certain doctors. At times, the patients found the approach of doctors discouraging. For example, a doctor had casually commented to a group member in a waiting room that “*the Prozac must be working because every time he sees me, I look better. I did not even answer him because I did not feel so good! I’d rather not tell him how I really feel.*” This was a general complaint by fibromyalgia patients as people assumed that “*there was nothing wrong with them*” when they were nicely dressed and looked good, whereas they “*cannot not even lift a foot up a stair*” or “*go to the loo as desperate as I am*”. Although they did not want pity, it hurt them when they were not understood and when others, especially doctors, did not acknowledge their pain. They felt that people did not believe them and thought that they were “*putting it on*” – labeling them as pretenders and hypochondriacs, thus alienating them further (Bennett chap. 4 p. 127).

Several patients complained that it was extremely difficult to communicate with a doctor who was long past his retirement and was hard of hearing. They described him as “*rude and abrupt*”. One got irritated with his “*silly questions*” when he could consult her folder: such as why she was on certain medications, forgetting that he himself had prescribed it, or asking her why she had been boarded as if she was not entitled to it. She was thrown off balance to the extent that she did not bother to tell him how sick she felt and left angry. Another disclosed that she already felt depressed and that “*to be screamed at as if a person is nothing*” made her feel worse. She perceived this as disrespectful and denigrating. A third had changed hospitals in an attempt to avoid this doctor, only to discover that he was also consulting at the other hospital and he still had to see him.

One group member had often complained of a sore shoulder, but felt that the doctor was not taking her complaints seriously and just dismissing it as part of fibromyalgia - sometimes not even examining her. When she later consulted a private surgeon, he was appalled that this had not been attended to, as she needed an operation. They often felt disregarded and dismissed which reinforced their sense of rejection. A group member with marital and sexual problems complained for fourteen months of genital pain and impotence before he was referred to the sex therapy clinic. He became despondent when his appointment was cancelled several times and felt rejected when the referral was then deemed inappropriate due to his longstanding diabetic condition. Not having been assessed in person, he was not advised how to cope with the psychological impact of impotence - exaggerating his fears that his wife would leave him. This amplified his feelings of being a “zero-person”. His fibromyalgia flared up and he became severely depressed and withdrawn. Whereas he had never missed a group meeting, he dropped out of the group and did not even return for the final termination. He was one of four fibromyalgia group members who became angry and disappointed with their doctors and then stayed away from the hospital for a prolonged period. It was seldom a single incident that disillusioned them, as the next example will illustrate.

A group member who had been hospitalised felt terribly exposed and humiliated when a new intern presented her as a *“manic-depressive who did not comply with treatment”* according to her psychiatrist whom he had phoned. This took place in front of fellow patients and the multi-disciplinary team during a ward round. He had not only failed to obtain her permission to consult with her psychiatrist, but also made an inaccurate interpretation of new psychiatric terminology for major depression in order to hide his ignorance from his consultant. After advice from the group, she confronted him, and refused further treatment by him, as she felt betrayed.

Previous adverse reactions to medications had made this patient cautious to combine medication with certain types of anti-depressants. She felt pressurized to take Prozac, an effective treatment for the fatigue symptoms of fibromyalgia, despite questioning its suitability. She felt that the medical registrar *“patronized me as if I had no brain. He came to me, held my hand and told me it was a safe medication and that I could take it.”* When she was adamant that she wanted to verify this with her general practitioner (GP) as this was *“really playing with my life”* he accused her of being *“a negative person and if you’re negative to the medication it won’t work!”* When her GP confirmed that she should not be taking this anti-depressant, she was furious and did not want to see this doctor again. He had been dishonest with her and not taken her seriously enough, making her the culprit whereas the medication was the real problem. Instead of feeling that she was being cared for, she felt unsafe and that her needs had been disregarded. Because of her mindset of abandonment, she experienced this traumatically.

When this member did not attend a couple of sessions, it transpired that she had been admitted to a private psychiatric hospital where she had been in a coma for five days and thereafter received psychiatric treatment following an overdose in a suicide attempt. In retrospect, the good progress made in group- and individual therapy had been diminished by her altercations with the doctors. Ultimately she experienced all the various therapeutic interventions as abandonment, namely by the doctors, group facilitator and group members – at a time she had needed them most.

This example also illustrates another point where group members felt frustrated and helpless when they were blamed for the lack of improvement in their condition, or labeled as 'non-compliant' if side effects caused them to discontinue medication. Alternatively, "*when the medicines they're giving you do not help, they say you are depressed, but you're just in a lot of pain!*" Feeling blamed and misunderstood made them feel that they were not unconditionally accepted. This was probably an accurate assumption on the part of these patients, especially in the light of the type of patients that Kaplan & Sadock listed whom doctors, who have strong unconscious needs to be all-knowing and all-powerful, often dislike. These are patients who appear to repeatedly defeat attempts to help them; who are perceived as uncooperative; who request a second opinion; who fail to recover in response to treatment; who use physical or somatic complaints to mask emotional problems and those in chronic pain since they all represent a professional failure and are, thus, a threat to the doctor's identity and self-esteem. (1991: 3). It seems that these fibromyalgia patients (perhaps because of their chronic pain condition and underlying abandonment issues) represented many of the **characteristics of 'difficult patients'** who evoke negative countertransference in doctors. Kaplan & Sadock describe these, amongst others, as being demanding (e.g., patients who need immediate gratification, do something impulsively and self-destructively, may appear manipulative and attention-seeking, or become angry if their concerns are not taken seriously).

These patients can also be dependent; narcissistic; paranoid/distrustful; or complaining, martyrlike, and passive-aggressive. The latter appear to communicate solely through a litany of complaints and disappointments. They often covertly blame others for all their problems, and make others feel guilty about not caring enough. They are often not able to express feelings of anger directly and thus express them indirectly or passively. They often perceive themselves as being extremely self-sacrificing and as being taken advantage of by others, who are selfish. These patients may unconsciously believe that the only way to be taken seriously or to be cared for or loved is to be sick. This description of characteristics by Kaplan & Sadock (1991: 11-2) seems to also fit the

characteristics that the researcher identified in this particular group of fibromyalgia patients.

Four group members had the belief that they would one day end up in a wheel chair having apparently misconstrued comments by previous doctors. Besides the group member who was wheel chair bound, another had acquired one to ease the pain and discomfort of walking longer distances. This theme, being immobilised³⁰ or 'stuck' (entrapped), emerged often and was interpreted by the researcher as an emotional 'paralysis'. Although one had had a spinal operation, others with backache had been told that an operation was not an option and that they had to lose weight or the pain would worsen. Instead of feeling more motivated and taking more responsibility for their health, they were left with feelings of failure, guilt and helplessness. They felt rejected by their doctors. To them it seemed as if the doctors just shifted the blame or put the onus on them when their treatment did not have the desired effect and they (the doctors) felt helpless. In fear of rejection, one member admitted: *"I used to put my finger down my throat to please them! Then one day I was so sick, I said: 'to hell with them, this is my life. If I have to end up in a wheel chair, so let it be'"*.

Group members had, on several occasions, compared hospital doctors with their GP's (general practitioners). An analysis thereof provided more clarity of how their needs with regards to the doctor-patient relationship could be met to prevent further feelings of abandonment/rejection. Group members described some hospital doctors and private specialists as "condescending, arrogant, dogmatic and dictatorial", whereas their GP was more caring, supportive and understanding - giving them choices and a sense of control. The latter took notice of their complaints and showed concern – even asking the patients to phone him the next day with feedback of her reaction to the medication. His door would always be open for the patients, whereas they could not even get an appointment at the hospital when they really felt sick since doctors were only available on a roster basis

³⁰ **Immobilized** meant that they feared that they would become 'paralysed' by the pain, fatigue and depression. Moore Schaefer (1995: 97-8) refers to the fear of becoming "imprisoned" when they abandon the struggle and experience an all-consuming retreat into illness. They feel depleted of all their resources - financial, physical, psychological and social. (See also Kirmayer chap.2 p. 26).

and these clinics were usually fully booked for months ahead. The relationship with their general practitioner was more intimate as he knew them better and they could trust him. In these cases, the GP fulfilled their need for a positive father- or parental figure and had therapeutic value. In terms of object relations theory the hospital doctor resembled the 'bad breast'. As previously, the majority of group members took on a disempowered, helpless victim stance. Their dilemma was that they could not afford the high fees of GP's and therefore had to rely upon the government hospitals. Yet, according to these patients, hospital doctors did not appear to be really interested in their state of health, as they would merely ask: "*how are you feeling today?*" In contrast, the general practitioner would recapitulate as to how they had been since their last visit. This was of importance as the patients often had no major complaints and looked and felt well on clinic days, but had been quite ill between appointments. If they were told to return in three to six month's time, their mindset of abandonment resurfaced and they felt uncontained, distressed and anxious about how they would be able to cope until the next appointment.

One member illustrated how they were caught up in a double bind, namely that one has to be sick on the day of the appointment in order to get attention or to be taken seriously. She did not want the doctors to always see her as "moaning" and tried to be cheerful. Then when she asked something for pain one doctor said: "*no way, no way, no way!*" "*For heaven's sake, does he know how I feel? Does he know how much I can walk, or stand, or do something? Because he had one look at me, he thinks: 'Oh well, there is a nice fat lady sitting on her bum the whole day and doing nothing. And she does not look in pain. So now she is coming and wasting my time.'*" This desire to be understood and to be accepted seemed to be a common need amongst people who had been deprived of love, concern and acceptance.

Although they held the same expectations for hospital doctors and general practitioners, they concluded that it was largely the hospital system that had failed them, rather than the individual doctor. By this, they meant large, busy clinics and short-term hospitalisation due to the quick turnover, as well as being a tertiary specialist hospital and academic

training institute where doctors have a rotating roster. *"It's because the doctor only sees that patient once and never again, that he has that attitude. But I'm sure if he had to see the same patients over and over, there must be more care and compassion, because now you're not just another number that he has to see. It should not be like that. You are a person."* Yet, in spite of this intellectual insight, most group members still experienced abandonment, as their emotions overruled their logical thinking.

The frequent change of doctors inhibited the building of trusting relationships between doctors and their patients and because *"you have different doctors every time you come, they are not familiar with your case. They have two minutes to assess your file and decide."* Having admitted that they had a problem to adjust to changes, the group found continuous adjustments to new doctors – each with a different approach - extremely taxing. *"You've got to start all over again to break down walls and barriers, build-up trust and confidentiality."* They often felt unable to talk to their doctor due to a lack of privacy, frequent interruptions by nurses and other doctors, or several students present in the room. At times, they felt like objects in attendance for the purpose of student observation and training. They felt rushed because doctors did not have time to listen to them in busy clinics.

Whereas many other patients have better inner resources and support systems, which help them to tolerate and cope with such a system, this group of fibromyalgia patients with their history of repeated rejection and abandonment, and their fear of further abandonment/rejection, found it detrimental. They felt abandoned, and 'robbed' each time when they had lost a 'good' doctor and were devastated because their whole life had been like this. That is, just as they had met someone that they 'connected' with, something happened and they were let down again. Consequently, they withdrew emotionally until they met someone else they could attach to.

The most damaging affect of the hospital system on this group of patients was when the Rheumatology Department had to reduce patient numbers due to severe budget cuts and decided to transfer fibromyalgia patients to local clinics for follow-up. When the doctors

terminated their involvement, these patients felt dismissed and abandoned. To these group members it was not merely a change in policy: it was personal abandonment and betrayal: "*it's just false pretense and nobody actually wants to help us*". In this sense, it also substantiates the fact that these patients did not only have perceptions of abandonment, but that abandonment was frequently real and their feelings were legitimate.

The feelings of abandonment/rejection also derived from differing expectations that the patients and doctors had. The patients did not want to lose this small, specialised hospital's doctors, social worker, physio- and occupational therapists who offered further support, even acupuncture and unlimited access to aqua therapy as these were not available in primary healthcare settings. These were the people who came to their rescue, who understood and believed them, who knew what was wrong with them and how to treat their condition, even if the system or doctors were not perfect. For the patients, the relationship was most important, especially as they had been searching for meaningful relationships for their whole life. It seems impossible for the doctors to meet these expectations, as they viewed their role very differently. This is because, as a specialist unit in a tertiary hospital, they only needed to diagnose and stabilise the patients' condition before discharging them back to the referring clinics/day hospitals or general practitioners. The patients, on the other hand could not accept this approach as they felt they had not been taken into consideration. They wanted the best care to end their unrelenting suffering.

When treatment was terminated, the doctors indicated that there was '*nothing more they could do*' to relieve their symptoms and that they '*just had to get on with their lives*' and learn to live with the symptoms. One group member felt that "*he now also thinks like the other doctors before, that 'it's all in your head.'*" She felt betrayed and angry because "*his job is now finished that he has made the diagnosis*" whereas her symptoms were still of the same magnitude. A fellow group member responded that the "*reason for the*

*change in the doctors' attitude was that they have come to realise that **the emotional becomes physical** - if you carry something too long, it becomes physical”.*

She explained that suppressed emotions and unresolved issues of the past, including anger, create such bodily tension that it eventually becomes physical symptoms. “*We have very twisted thinking. Most of us, for the sake of peace keep quiet about things, instead of getting it out. We can't let go so it (the muscle) pulls. The muscles twist³¹; we don't completely think straight (coloured lens through which they view their world). So we tense up. No wonder that our muscles twist into a knot - that is actually the reason for fibromyalgia.” This group member's theory is corroborated by Alfici et al.'s argument that microscopic lesions of the muscle fibers of fibromyalgia patients might result from emotional stress, which produces increased and prolonged muscle tone (1989: 160).*

*“**Something usually triggers a relapse.** Something went wrong somewhere, because you don't relapse for nothing. The relapse shows that there are still other issues deep inside, but sometimes you don't realise (denial/lack of insight).” This view corresponds with the hypothesis that prolonged stress, exacerbated by their experiences of abandonment, had caused an imbalance in the intricate interaction of the physical, psychological and environmental facets of their existence (Goldenberg 1996: 395; chap. 2 p. 38). This supports the researcher's premise that the biopsychosocial, rather than the medical model best elucidates fibromyalgia (Dessein & Shipton 2000: 95-9; chap. 2 p. 13).*

This patient, a ‘healer’ (alternative practitioner) herself had made an accurate analysis. Unbeknown to her, the doctors had just been to an international conference where a paper on fibromyalgia changed their thinking, namely that fibromyalgia was indeed more psychological in origin and that they could do little to alleviate the symptoms with medical treatment alone. Consequently, one questions whether the patients' pathological need for nurturing and care can really be met by the conventional medical treatment approaches.

³¹ **Twisted muscles:** referring to ‘fibrositic nodules’ and ‘ropiness’ of tense muscles near the trigger points (Lyddell 1997: 554).

The group members were left with anxiety about how they would cope, as they did not know whom to turn to with their debilitating pain. They feared isolation and experienced a sense of 'doom' as the doctors had 'failed' them. Consequently such individuals had regressed so gravely that they re-presented in a crisis with unbearable pain perhaps even at a different medical center which led to a form of '**doctor shopping**'. Thus, treatment had to start all over again and the 'progress' that had been made was lost. (See Figure 3 and McDaniel chap. 2 p. 26 re. vicious cycle). The planned restructuring of the health care system with an emphasis on primary health care was riddled with problems because the local infrastructure was inadequate and grossly underfunded. The clinics, being understaffed, were unable to assist all the patients that arrived each day. The doctors and other staff members simply did not have sufficient time and appeared to have been unacquainted with fibromyalgia and its treatment.

The new policy also required patients to collect their medication from **local clinics**. Many group members experienced tremendous difficulties – sometimes leaving them in tears. They had to wait in queues for very long and could frequently not obtain the prescribed medication or the full quantity, which meant they had to return on another day or purchase it from commercial pharmacies at exorbitant prices. Alternatively, they were given ineffective replacements, such as headache tablets (Panado) for depression with suicidal inclinations. The pharmacy was frequently depleted of essential medicines or did not stock certain scheduled medications that were readily available at tertiary hospitals. The inefficient system and threatening closure of Princess Alice Orthopaedic Hospital resembled a devastating further abandonment as illustrated in the following example.

When day hospital staff denied a group member Doxyphine and implied that she had an addiction problem after they had telephoned her doctor for a substitute, she felt highly offended and betrayed by him, as well as humiliated since she used to work at the day hospitals as a nurse. She was determined not to take a poor substitute for Doxyphine, a frequent and effective prescription for fibromyalgia because of its properties for pain relief, but derived from morphine and thus dependency forming because of its mood elevating property. She expected preferential treatment - a form of entitlement and

grandiosity, clinical features of a narcissistic personality³² - as she mistakenly believed that she was his favourite patient and that he was indebted to her having 'used' her on numerous occasions for student practical examinations at medical school. Although she knew it was a policy change, she perceived the directive to collect medication from the day hospital as if "*he now pushed me away,*" (egocentrism) and felt deeply rejected and hurt as the doctor had "*turned against me*".

This incident triggered immense emotions of severe anger and depression. She refused to return to both hospitals and discontinued coming to the group. Consequently, she became totally isolated, depressed and suicidal while her fibromyalgia condition remained debilitating which immobilised her. She blamed the doctor for having deliberately put her through this painful ordeal because his 'attitude' had closed all doors for her - just as her father's rejection of her had inflicted immeasurable hardship and damage to her when she had to sleep outside in the cold as a child. Clearly, this incident triggered negative transference. The self-destructiveness of her 'acting in' behaviour compounded her sense of abandonment. Her unrealistic expectations, inability to confront her doctor to resolve the issue and discontinuation of her treatment and group therapy all contributed to her isolation and ultimate relapse into physical pain and major depression.

It was noted that when this group of patients were dissatisfied with the doctors or hospital system, they had a tendency to withdraw and avoid further contact. They would shop around for another doctor or hospital and only return if they did not find substitute care and their fibromyalgia had become intolerable. This meant that they had access to other sources of medication, albeit not always affordable. Nine of the eleven group members regularly visited their general practitioners as they could not bring all their various physical complaints to the hospital doctor and often felt dissatisfied with the hospital service. Although the different specialising departments in hospitals provided experts in their diverse fields, the needs of these patients did not seem to be served. In fact, the hospital system failed these fibromyalgia patients because their sense of

³² **Narcissism** was not measured with some scale, nor determined by psychometric tests, just a possibility and the researcher's interpretation. Further research is needed for verification.

abandonment/rejection was further compounded by the inadequate treatment that they received in that system. In addition, its very specialised entities have become so compartmentalized that the patient as a person often felt lost in the enormous hospital structure and hierarchy. Group members admitted that they had stopped complaining about certain fibromyalgia symptoms that did not relate to their muscular-skeletal system, and therefore did not belong to the Rheumatology Department. They took these symptoms to other specialised departments or their general practitioners. Consequently, the doctors only had a narrow 'tunnel vision' of their patients' problems and the patients felt 'scattered' and uncontained.

Inefficiencies in the hospital system also exaggerated feelings of abandonment when these patients thought that no one understood or wanted to help them. They felt ignored, insignificant and disrespected when they had wasted their time, effort and money to come all the way to the hospital, but could not use the heated pool due to faulty equipment, or when their appointments were cancelled, but they were not informed. One group member anticipated delays and actually reminded staff telephonically of her appointment to ensure that her folder would be available. Upon arrival, she had to wait hours for a 'missing' folder and when it was eventually found, her doctor had already left. Besides not receiving medical attention, she also could not get her medication without his prescription. Considering that these patients already felt abandoned/rejected at PAOH, a small, but highly efficient hospital with competent and caring staff, one cannot image what impact less functional hospitals or uncaring staff had on these sensitive and fragile patients.

One group member felt terribly rejected at another provincial hospital where she had had a spinal operation. In tears, she recalled how the staff and fellow patients did not accept her: *"They do not have time for private patients. We must go to private hospitals. Everybody judges me because I'm a private patient. They treat me as if I'm somebody above them and all I want to do is be their friend. It's not my fault that I'm a private patient!"* She was made to feel like an unwelcome intruder who did not belong there. She felt discriminated against and very hurt. Although any person might under such circumstance, feel hurt or rejected, it was the frequency of abandonment, the intensity of emotions, and the

interconnection with previous experiences of rejection and abandonment, plus their personality that was conspicuous in this group of fibromyalgia patients.

Abandonment within the hospital context was not only directed at doctors, although they were the largest group of professionals that were singled out by the group. During the time of the group therapy sessions, the members also felt deserted when their **physiotherapist** resigned to have a baby. They were very attached to her, as she had accepted them, gave them extra attention and cheerfully joked with them. She resembled a caring mother figure, reinforced by her nurturing role and physical touching whilst massaging or applying acupuncture. It is possible that some felt rejected or replaced when she left them for a new, 'real' child in her life.

It was only when the new physiotherapist took over that their animosity emerged through objections and complaints, perhaps because she did not 'adopt' them in the same caring manner. When she insisted on appointments and limited their access to aqua therapy, they felt she did not understand their pain, "*had no time for us*" and resented that they had to "*beg for treatment*". They felt rejected and in turn rejected her when seven group members discontinued physiotherapy treatment or came less frequently. This resulted in more absences from the group, as they used to come for both physio- and group therapy on the same days and offered transport to group members who did not have their own vehicles and were often too ill to use public transport.

4.3.6.2 Abandonment and rejection as a result of the closure of the Princess Alice Orthopaedic Hospital

The impact of the hospital's closure is better understood when taking into account that it was originally built in Retreat during 1933 as a home for children with physical disabilities with funds raised by Princess Alice, wife of the Earl of Athlone in England, and a local auxiliary woman's group. It developed into the only orthopaedic hospital of its kind in the Southern Hemisphere that provided reconstructive surgery, including joint replacements, and rehabilitation. The patient population included all ages, from babies to

people in their nineties, the rich and poor, as well as patients with mental retardation or paralysis. It consisted of patients with rheumatic diseases, congenital conditions and cerebral palsy, as well as spinal tuberculosis and other spinal deformities. The purpose of the hospital was to prevent deterioration and maximise independent living – often succeeding in helping bedridden patients to walk again. It had a large outpatient population requiring ongoing physiotherapy, medication and medical care for often painful, crippling conditions. Not only was the hospital built at a strategic and convenient location (next to the bus- and train stations), but also specifically catered for the special needs of the disabled.

PAOH was one of nine hospitals that had to be closed in Cape Town due to a limited health budget and as part of the tertiary health care plan. Groote Schuur and Tygerberg Hospitals would provide specialist services and academic training, whereas primary health care needed to be improved and become more readily available for patients in their local areas. PAOH had to scale down services and relocate to three unoccupied wards at GSH – one serving as a small outpatient department. A sacrifice of quality care and expertise was a detrimental consequence of drastic staff reductions. In reality the closure of PAOH resulted in becoming another acute ward for GSH instead of being a rehabilitation unit. It meant the end of a unique quality service to already marginalized patients with disabilities and chronic conditions.

For a prolonged period, rumours of the closure of PAOH could not be verified to patients until parliament had authorized the process. The group members were disgusted with the management of the hospital when the closure was only publicly announced in a newspaper. Their request for dialogue was ignored and they felt excluded from the decision-making process - implicating that the concerns of the patients of this hospital and the affect of its closure, were not important to those in control of its future. This left them feeling insecure and disempowered. *“They are not even considering us! We are left in a lurch. They decide what’s going to happen.”* Another group member felt that their efforts would be wasted: *“Why bother, we’re being kicked out. We’re not important. We’re not asked. Most of the people are feeling they are (being) let down.”*

“You are just being discarded.” They felt betrayed and abandoned. *“You’re just given a good smack in the face. You already feel so helpless and hopeless and it gets to you. Now the very place and people who understand and care for us, where we can be helped quickly on days when we’re feeling useless, won’t be there for us.”* They felt ‘robbed’ of a good service and resource that catered specially for them.

The hospital closure triggered distrust in and anger with the government for not showing more concern for the disabled or chronically ill. The theme of unmet needs re-emerged during discussions about the move to GSH. It serves to illustrate Erikson’s notion that unresolved conflicts in earlier life-stages are re-experienced in later life when the same situation re-occurs. Their concerns were legitimate as all group members were also patients of GSH and had experienced these as real problems. (In fact, their ‘predictions’ had not only come true, but were much worse than expected since more staff left and conditions had deteriorated due to continuous financial constraints.)

The group members had difficulties with the venue because many disabled patients would not be able to get up a steep hill from the main road or station that is further away. They worried about long distances inside the hospital as the pharmacy and physiotherapy pool are in separate buildings and there were never enough porters and wheel chairs to push them around. Whereas PAOH was small and efficient where patients were assisted quickly, they sometimes had to wait up to six hours at GSH’s pharmacy for medicines. One group member remarked: *“I was crying in the passage because I cannot sit for so long.”* (Medicines were seldom obtainable on the same day, which meant patients had to return and queue for a second time.) It is not uncommon to spend a whole day at the hospital – sometimes from early hours and often without food.

The group members felt ‘robbed’ since they would not receive the same amount of occupational-, physio- and aqua therapy at GSH than at PAOH. (In fact, four years after the move to GSH, physio- and aqua therapies were no longer provided for chronic- or outpatients. Chronic fibromyalgia patients were also the first group of rheumatic diseases

to be discharged from the 'new' Princess Alice unit at GSH when clinic numbers had to be reduced!)

A more direct form of rejection was described by one group member who saw "*GSH as a 'Same Day Service' where you come in now with the ambulance and they chase you out tonight or tomorrow morning.*" Another had felt unwanted and guilty when she was admitted for an operation "*and a girl had to get out of bed so I could go into that bed. She was sitting crying the whole day until the transport arrived!*" A third added: "*that's how bad it is at GSH. You must take your own food, bedding, towel and toilet paper.*" It all signified a lack of care and interest, and in their eyes, such neglect was seen as rejection.

They objected to depersonalised services at GSH where one becomes "*anonymous and just another number*" – especially because of the massive size of GSH where doctors and other staff have less time for the individual in a long queue of patients. One group member had attended physiotherapy for five months and still did not know any of the other patients, in contrast to PAOH where they had all become friends. "*You're just shuttled from one cubicle to the other and nobody says a word to you.*" No one greets another and "*all look like robots*". When smiling and being friendly, a group member "*was looked at as if you're from Mars or Jupiter...it's like: 'What are you smiling about?'*" She felt ridiculed and not accepted - which reflected a pronounced sensitivity for rejection. Consequently, they felt more disregarded and insignificant. On a deeper level, all group members feared emotional detachment in that they would not be able to form meaningful relationships at GSH.

Of particular concern was that fibromyalgia is a relatively uncommon syndrome, which many health professionals may be unfamiliar with. These patients felt deserted by staff at PAOH that had expertise but accepted voluntary retrenchment rather than being transferred to GSH. In addition, all senior managers had accepted packages and left PAOH long before its fate was confirmed – like 'a captain leaving a sinking ship'! Some group members had asked staff to help them with mass action campaigns to keep the

hospital open, to no avail. Yet, once again this group surrendered their own needs and suppressed their annoyance in support of their understanding that the staff was restricted and threatened with legal action should they approach the media. They were unable to express or feel anger at staff members who were 'abandoning' them and were not prepared to take risks, or were only concerned about how the move to GSH would affect them.

Ironically, the group members had compassion and empathy with the staff rather than resenting their passivity, because they knew what it was like to be ignored, betrayed, or deserted. Instead, they viewed the staff also as 'victims' (projective identification) and that they could not be blamed, as they too had no control and were 'just a number'. As pointed out before, a characteristic of these fibromyalgia patients was that they felt rejected and abandoned on behalf of others, such as their spouse, children, fellow patients and, as in this case, the hospital staff.

Their inability to express hostile feelings against the staff for having abandoned them corroborates previous findings where they could also not risk alienating persons who took care of them, such as parents, spouse, doctors and even the group facilitator. This seems to be an inherent characteristic of this group, who, because of their dependence and neediness, could not 'bite the hand that feeds them'. It also indicates that they were still dependent on approval by others and lacked autonomy.

A consequence of their inability to express hostility and anger was that they were left with the unspoken feelings, which evolved into excessive, unresolved feelings that would torment them when any event occurred, reminiscent to past experiences of rejection and abandonment. These feelings were internalised as an unresolved reservoir of anger and, as such, were converted into emotional pain. Along with compounded experiences of abandonment, this emotional pain could escalate into an eventual expression in somatisation (e.g. fibromyalgia), or aggravate their physical pain. According to Erikson, "a deep rage is aroused comparable to that of an animal driven into a corner" when individuals are unable to resolve the crises of the developmental stages (cited in Dacey

1982: 21). Instead of 'acting out' in violence, this particular group of patients internalised it.

Instead of feeling supported and protected by the staff, the latter's helplessness and immobilised position amplified the patients' insecurity and anxiety. It also **triggered memories and pain of previous abandonment (negative transference)**. The same scenario was observed where some group members identified, empathized and sided with their mothers who had been equally helpless against their abusive fathers. Paradoxically, the mother/staff had failed to rescue and protect them, but they could never express resentment. They accepted their fate passively, repressing their anger: *"You just know it's going to change. You know it's going to be bad, like the educational system. And it still happens! Wrong or right."*

The main consequence of their inability to express their feelings was that they became emotionally 'stuck' (entrapped) since nothing was resolved. The theme of being **immobilised** resurfaced in the group as the closure of the hospital became imminent. It emerged in their helplessness regarding management and authorities to prevent the closure. In addition, the nonattendance of six group members after the announcement also immobilised the whole group and caused its eventual collapse.

Group members were acutely aware of and frustrated by their own dependence on the hospital. Their inability to afford 'quality private care' reinforced feelings of failure, worthlessness and amplified their sense of abandonment. In addition, they felt 'paralysed', that is, they felt disempowered and surrendered passively. A group member who considered going to the newspapers in order to get more exposure and support to prevent the hospital's closure, expressed that: *"it was time that they consider us. We've been silent for too long. South African people have been too subdued, too submissive and they've been taking handouts, whatever is dished out. They did not backchat. They never argue – it's a natural thing: 'Ja en Amen'."*

In an emotional session, the group explored the reason for their distress about the hospital's closure and discovered answers in the **meaning and symbolism** that the hospital represented. Several group members explained that PAOH had been like a home for them. Becoming homeless meant a loss of security and anxiety about their uncertain future. Some felt uprooted, similar to when they had been forced out of District Six (negative transference). Distrust exacerbated their feelings of insecurity in their new 'custodial care' (GSH), whereas at PAOH they had felt like a family where patients and staff all knew each well. A unique bond with fellow patients had existed as they got to know each other intimately over the years. It provided a sense of belonging. They felt accepted and loved. *"What is nice about here is at least you get attention (feeling important). Everybody greets you in the corridor"* and *"even the cleaner asks you how you are"*.

Long-term patients experienced the closure more traumatically, as portrayed by a member who had attended the hospital for thirty-three years since she was eighteen months old. She explained that it meant more for her than losing a home. *"They are like a mother and they nurture you. They did exactly what my mother was doing. They were there for me. They cared for me. I would come to them when things were not going right."* In this sense, the hospital symbolised mothering and nurturing. Her mentioning that *"outside it's not like it's inside here"* revealed that she felt warmth and protection like a baby in its mother's womb.

In fact, this group member was troubled with recurrent dreams of her mother being alive and dying again, waking her with feelings of devastation and fear. She felt her life was taken away twice; first, when her mother had died as her mother was her *"whole life"*, and now again with the hospital's closure – probably because her whole life centered around the hospital and her illness – forming part of her identity. The closure triggered unresolved feelings about death and other losses in several group members (negative transference). They felt 'robbed' of a loving home and family. As a result, they experienced feelings of loss and grief in different intensities, depending on the extent of their attachment to the hospital, staff and fellow patients. Besides feeling abandoned,

they also felt 'orphaned' and angered because *"where death is inevitable, this kind of change was made without really focusing on the needs of patients and the quality of service."* To them it was like a deliberate killing of 'the good parent' by the authorities.

When a group member's physiotherapist left PAOH, she followed her to GSH to continue with her physiotherapy in an attempt to maintain a form of control. *"When people started moving away I felt I must get away. I am tired of people leaving my life, so I made a move before they did."* She could no longer bear the intense emotional pain stemming from **compounded experiences of abandonment, loss and grief**, with many staff members leaving. Nor could she bear to witness the hospital's deterioration and slow 'death'. It was as if the hospital was losing its limbs through a series of amputations. She detached herself from the hospital but because of her neediness and dependence had to reattach herself to a surrogate figure (the physiotherapist), as she could not bear to be abandoned.

The above example illustrates a reversed form of rejection (rejecting your rejector first) in order to cope with or avoid feelings of abandonment, which was also seen as a coping style in five other group members. Four broke contact with the hospital and stayed away from group therapy when they heard the hospital was closing. In terms of object relations theory, what seemed to have taken place was that the 'good breast' that had nurtured them, had become a 'bad breast' in abandoning them. They could not return for nurturing to the place that hurt them and in which they had lost trust. *"No matter how much pain you have, you try to stay away from the hospital."* (In fact, over the next two years, all but one returned.) It seemed that their isolation amplified and sustained their feelings of abandonment, leading to the 'flaring up' of their fibromyalgia.

At least half of the group members became more depressed and almost 'immobilised' (unable to help themselves). This perpetuated the 'vicious cycle', where they needed to be rescued when they would re-present in a crisis for 'help', had to build up new relationships, only to be 'disappointed' once again and then to withdraw. From the researcher's observations, it appears that many of the group members displayed

narcissistic personality traits and that they were fixated in an oral stage of development – an area that needs further research (see Bradshaw, Wolberg chap. 2 p. 44). Their continuous need for nurturing and compounded experiences of abandonment set a circular process in motion that feeds on itself. This repetitive obstructive and destructive pattern also emerged in other settings or relationships and is not exclusive to doctors and hospitals. See Figure 6:

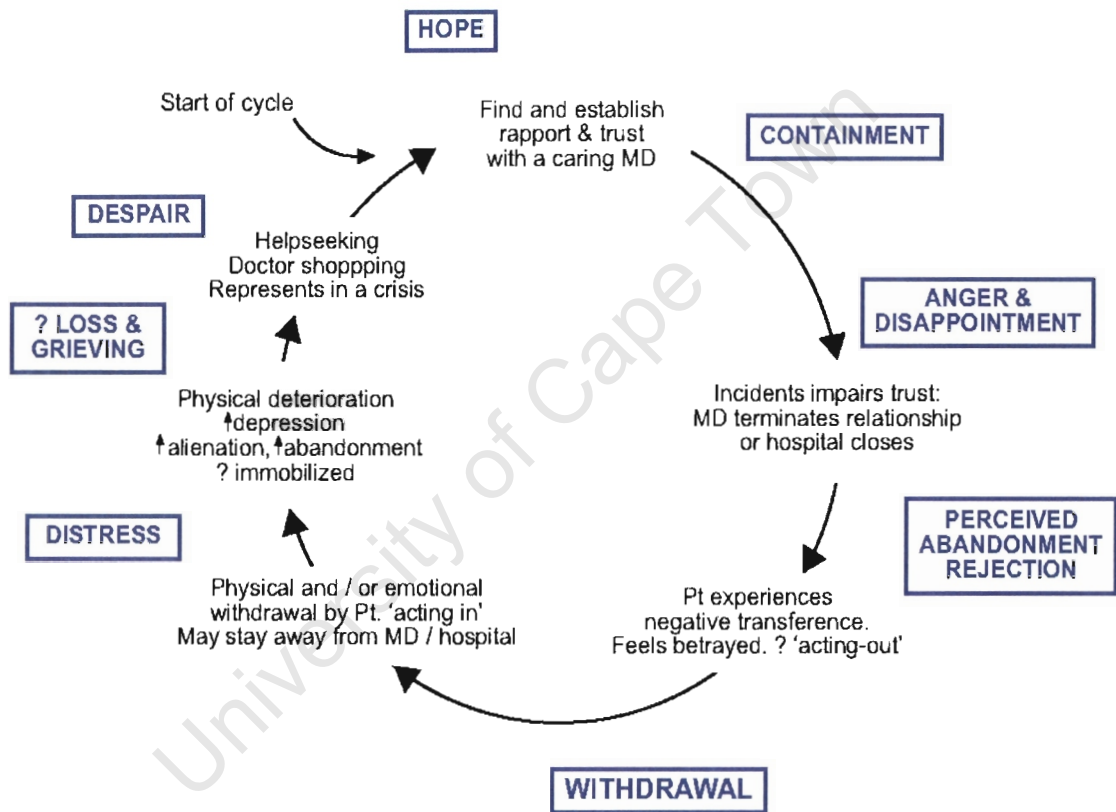


Figure 6
The cycle of abandonment/rejection within the hospital and other contexts.

4.3.6.3 Abandonment and rejection in context of the group

The final section of abandonment/rejection in the hospital context focuses on experiences of abandonment/rejection with regard to fellow group members and the group facilitator.

4.3.6.3.1 Abandonment and rejection by fellow group members:

The first manifestation of a mindset of abandonment was shown in the group's prolonged testing phase and group members' reluctance to trust others or expose their vulnerabilities. This was unexpected in the light of the fact that many already knew each other prior to the start of the therapeutic group sessions from the outpatient clinic, physiotherapy or the self-help groups that they had attended. They were delighted that they had found others with the same condition and problems, and often referred to their strong bond, yet they were still unable to open up about important issues that troubled them. It also appeared that because of a history of abandonment they were insecure and needed to feel safe before revealing sensitive emotional issues. In addition, because of previous experiences of loss, disillusionment and betrayal, they could not bear to make new alliances only to lose them again.

It was only by the thirteenth session that one group member could reveal that she was "a battered woman", because she was fearful of rejection. *"I did not want to open it to the group, because I feel ashamed - because I'm smiling and talking about other things (pretending), but in the meantime I got beaten up by my husband."* The group responded with unconditional acceptance and supported her in her decision to divorce him and to obtain a restraining order for protection. Yet, when she later decided to remain with her husband, she could not tell the group in fear of being judged just like her sister had judged her when she had previously withdrawn divorce proceedings. She interpreted awkwardness in the group as rejection, and subsequently became more withdrawn, which amplified her isolation. This is another example of how one can set oneself up for abandonment because of a mindset of anticipating rejection, the impact of negative transference from past experiences, sensitivity for criticism and the subsequent failure to communicate or confront issues.

Not only did group members take a long time before they could open up, but four admitted that there were things that they had not spoken about. The words of one reflected the fears of others: *"if I would come out with my problems and flaws or*

whatever, many people would take off, not wanting to do anything with me because I am no good. I sit here and everything seems fine, when in fact it is not. And it's just to get it out; to talk about it." Their dilemma was that they had to keep up their pretences because of their fear of rejection. However, this in itself prevented them from forming close attachments. They remained emotionally disconnected. Instead of sharing their fears and emotional pain which would allow connecting with others and experiencing their acceptance, they could not work through their emotional issues and therefore could not experience healing. This is where the use of sedatives, especially Doxyphine with its uplifting properties, helped to ease the pain of psychological isolation – albeit temporary.

Another group member admitted that he had tested the waters for several months before he could muster the courage *"to let the cat out of the bag"*. By waiting, he felt safer as more trust and affection had developed between group members. Yet, at the same time self-revelation became more difficult because of pressure that he would be rejected if group members found out that he had abused his wife and children – especially since he had taken on the role of a moral-keeper in the group. He was extremely anxious in awaiting the group's response and feared that they *"would jump on me and hit me since many people have turned against me"* (negative transference and a mindset of rejection).

Three women were sympathetic and reassured him that he was still accepted, and was not the only one with 'flaws' as they themselves had often been provocative to their husbands. Their minimizing the seriousness of his actions and eagerness to forgive him may mirror their own desire to be accepted despite their wrongdoing. This indicates a typical characteristic of abandoned or abused persons: they are forgiving and fearful to take a stand against others in case they are rejected or receive the brunt of the person's anger.

On the other hand, this group member perceived indirect rejection through meta-communication by two group members who disapproved of wives *"who make martyrs out of themselves"* when nursing their ill husbands who had previously abused them: *"This is the time to leave him, honestly. After the way he has treated you, and now you have to care for him! You must be out of your bloody mind! I will never do it."* This

remark highlighted his greatest fear, namely that his wife would desert him since he had become sickly and dependent on her. His rejection-anxiety escalated and he felt more insecure, exposed and vulnerable after the disclosure. Subsequently, he presented gifts to everyone – a common gesture to gain acceptance. When several fellow group members were suddenly absent from the group, he took it personally, assuming that they felt uncomfortable and did not want to be in his presence. He became noticeably withdrawn. In addition, whereas he had never missed a session, he then withdrew from the group therapy, became severely depressed and his fibromyalgia flared up.

The testing phase was prolonged because of the group members' dilemma. On the one hand, it was so difficult to trust others that they could not open up their emotional issues, and on the other, they lacked insight into deep-seated unresolved issues. It was easier to blame others or ventilate common external factors such as frustrations at others who did not understand their illness, or their anger at doctors and the hospital system. However, as mentioned by Le Roux (chap. 2 p. 38) working on their own issues required acceptance of responsibility, insight and willingness to change – a characteristic that seemed lacking in many group members.

Initially the group was elated at their '**newly found family**' that had developed a strong bond, which was highly noticeable: they sought each other's company and had tea together at the hospital's tuck shop. Four had formed a lift club, some visited each other at home and others had become close friends, phoning one another when they experienced a crisis and needed support. After periods of separation, group members spontaneously greeted each other with a hug or kiss.

Group members gradually became disillusioned with their 'newly found family' who, they thought, understood what they were going through, not realising that their expectations were unrealistic and that this 'family', like real families had its flaws and could not be ideal. Similar to their own families, there were members who felt that their needs were overlooked by the group (negative transference). They became increasingly frustrated with members who dwelled on unimportant issues or were pre-occupied with

their own. Once again, they felt that the ‘family’ was not really there for them. Only here it was less effective to use their illness to gain attention. Consequently, they were left with two options: to engage in therapy by confronting their emotional issues, thereby hopefully gaining others’ empathy, or to distance themselves from the group.

Two group members could not bear to expose themselves and terminated group therapy early. A third left prematurely when she felt criticised and unsupported after ventilating her frustrations, which annoyed the group and disturbed one member to such an extent that she walked out. Others abandoned their attempts to speak out when group members responded inappropriately or seemed apathetic or uninterested. Consequently, one felt that the group had failed her and that it was not safe to open up. *“I’ve wasted my time. They did not really get what I was trying to tell them. Everyone is sitting with his own thoughts.”* Perhaps each was so self-centered and pre-occupied with their own problems that they found it difficult to focus on the ‘pain’ of others.

A group member was intensely angered and hurt by what she perceived as insensitivity and a lack of understanding from the male group member. He had expected that she should turn to her family for emotional support and assistance, whereas this was not a feasible option for her. However, the real issue was that she had projected her anger with her family for ‘abandoning’ her, onto him because he had unknowingly triggered this negative transference. Although the group members provided practical advice when she considered divorcing her abusive husband, she also felt abandoned by them. In retrospect, they realised that she *“wanted sympathy, not advice”*. Another concluded that they themselves were often to be blamed for feeling abandoned because they did not convey their emotional needs, but expected others to read their minds.

The absence of members created a sense of the group not being complete. Perhaps this indicates that they did not feel whole within themselves and that the group relieved inner feelings of emptiness. A group member expressed this in a metaphor: *“We are a jigsaw puzzle - each of us is a piece on our own, to fit in somewhere. When one piece is missing, you actually feel the gap, because the picture is not complete. You do belong. You are*

needed. You do feel you are part of the group." Abandoned/rejected persons seem to search for love and acceptance all their lives because they have never felt that they belonged or been important.

It is, therefore, understandable that these group members were anxious when absenteeism threatened the existence of the group. They immediately phoned or visited absent members, fearing that they would drop out and tried to lure them back. 'Weak excuses' for absences annoyed them since they themselves had been making sacrifices to attend meetings. Along with feeling deserted, they also felt personal rejection and abandonment if their attempts to re-establish contact had been ignored. Later when the group declined, they were disappointed and angered because members did not even make apologies: *"they should at least just tell us if they are okay. How important are we for them if they do not bother about us or that we care about them?"*

The 'dependence' of members on the group and on the hospital was often observed. It was not necessarily a negative factor since the group, as a 'family', required a mutual nurturing process for self-preservation, which indicated a symbiotic or co-dependent relationship. From an Eriksonian perspective, the therapy group came as a solution to the crisis of 'intimacy versus isolation', as well as the next stage of 'generativity versus stagnation'. It provided intimacy and they felt they had a contribution to make. Previously they had felt misunderstood and isolated with their fibromyalgia condition. According to Kaplan & Sadock (1991: 45-6), the failure to find true intimacy in meaningful relationships often leads to becoming self-absorbed in the next stage when life seems worthless and one is unable to guide or establish the oncoming generation. In order to make up for the lack of intimacy such person often pamper themselves as if they are children and become preoccupied with themselves (and their illness or pain).

Members who did not need the group or who became estranged threatened its cohesiveness. Most members who were over-dependent on the group attended it to its termination and probably experienced more feelings of abandonment, whereas most individuals who were more independent terminated prematurely, albeit for various

reasons. Because of the impending closure of PAOH and consequent termination of the group, some withdrew before they could be abandoned.

One group member experienced ambivalence about the group due to a conflict of 'dependence versus independence'. *"I have many friends. I've got lots of different interests. I shouldn't need these people. This is like just one thing in my life. If I do not come on a Monday morning, I'll find plenty more to do, but this is the one thing I actually want to hold onto. I do not want to stop getting together."* She found a sense of belonging, support and value in the group, but often had a 'flight' reaction to avoid certain issues. She feared being dependent or needy. It was important for her to be strong and self-reliant. This stemmed from childhood, as her mother had never met her dependency needs and her father with whom she had bonded, had 'abandoned' her when he left to work in Africa (ineffective resolution of the crisis of 'autonomy versus doubt and shame'). She withheld herself because dependence or attachment triggered fear that she might be abandoned again. She admitted that she had felt this all her life and in various groups, which meant that she had never felt connected or accepted in any group (lack of true intimacy). When she chose to leave, she not only intensified her self-imposed isolation, but also experienced guilt towards the other group members for abandoning them.

Whereas the first two members resigned at the twelfth and twentieth meetings, a sudden collapse of the group occurred when a further four discontinued attendance by the twenty-fourth meeting after the hospital's closure was confirmed. Two of these were dependent on the other two for transport to the hospital and they felt that they had been let down. The remaining five group members felt deserted and betrayed by those who had left prematurely. Their attendance waned further and prompted a **premature termination of the group**. Plans to recruit more members at GSH in order to offer an ongoing support group for fibromyalgia patients were then abandoned. There was a noticeable decline in attendance in the last third of the group therapy period. It seemed that the imminent termination of the group (triggered by the hospital's impending closure) played a direct role. The month's suspension of sessions over the festive season and the Muslim fast, precipitated the group's collapse, as members were hesitant to re-

attach knowing that they would soon be ‘abandoned’ – especially because termination of a ‘support’ group for people with fibromyalgia in itself implied abandonment.

As the threat of the hospital’s closure became real, a greater dependency developed amongst five group members. The fear that their newly found ‘family’ was disintegrating raised intense insecurity and anxiety, which caused ‘clinging’ behaviour - to protect themselves. *“We seemed to be hanging onto each other more and more. We want to be with each other more and more and we look out more for each other.”*

According to Bradshaw, the more individuals have been abandoned, the more they tend to cling to and idealise their families or parents, even though paradoxical. This ‘fantasy bond’ is created as an ‘illusion of connectedness’ with a major caretaker whenever emotional needs are not adequately met and enables them to survive (1988b: 10). When children have no one to depend on, their developmental dependency needs are neglected and they grow up with an excessively needy child within them. Clinging is a defensive strategy to avoid abandonment (1988b: 122).

Three group members over-reacted to the lack of commitment and responsibility of the absentees, because a parallel process of disintegration was taking place within their own families and the group (projective identification). For them, the termination of the group and closure of the hospital meant an additional loss of individual relationships and important support systems, which left them particularly anxious and vulnerable. They feared that they too would ‘disintegrate’ if they did not have the support of the group in coping with their problems. The male member was anxious that he would revert to abusing his family since the group had helped defusing his anger and frustration - amplifying his sense of abandonment.

While **separation-anxiety** is a normal phenomenon in the termination of relationships, several group members experienced this intensely because it compounded their perception of being abandoned/rejected. They did not want to break off their ‘connection’ with the group and expressed fear of the unknown, isolation and loneliness.

One middle aged group member who tried to persuade another of the same age not to leave the group, illustrated her separation-anxiety and neediness, perhaps as a result of her deprivation of good mothering: *"I need you. I need you to be my mother and tell me: 'Look here, you've been there before, you've come out of there.'"* The other group member represented a strong, positive mother figure who had confronted the group about their negativity and acceptance of a sick role. Despite their conflicts, they could not relinquish her as she had a positive influence and projected strength and hope. It seemed that several group members would, because of their dependence and deprivation, accept a less than ideal caregiver than none at all. They feared that the group would disintegrate when she left, just as some of their families had when their mothers had deserted them.

Of interest in this study was that more than half of the group members abandoned the group before the group could 'abandon' them. The prospect of termination created such separation-anxiety that they avoided 'goodbyes' because it stirred unresolved issues that they could not cope with. Although this premature termination from group therapy was not an official resignation, it meant that they were not 'victims' of circumstances, but that it was their choice and that they had retained a sense of control. It created a time window during which they could get on with their lives before they would be completely on their own, thus still having the group as a safety net to fall back onto, if they should fail. More frequently, absences also helped remaining members to detach themselves from the 'family' they had become so fond of. This lessened the pain of experiencing the decline of the group, the demise of the hospital, and the devastation of the final 'goodbye'.

Just as the hospital's closure was seen as a death, the group's termination also symbolised death and triggered unresolved issues and thoughts of death and previous losses. *"It's something that's dying forever."* Because these parallel processes were playing off at the same time, group members were more devastated by the loss. They expressed sadness and mourned the loss of a wonderful kinship and 'family', regretting that once again they would be isolated and 'struggling' on their own.

It was difficult for several members to attend/return to the group for the final session since many had a pattern of avoiding issues, which would then remain unresolved. They were challenged by the facilitator to view this as an opportunity for self-growth in order to get closure. At the last session group members sought reassurances from each other that they "*were obviously not going to abandon one another when the group terminated*" as they would "*still need each other's support*". Even two members who had discontinued group sessions tried to convince the group that they had not 'abandoned' or 'deserted' them. The choice of words confirmed the researcher's assumption that this particular group of individuals had unresolved issues regarding abandonment/rejection.

An analysis of the group members' adjustment after termination reveals that three members who had stayed away without apologies (avoidance) seemed to have deteriorated in terms of depression, isolation and their fibromyalgia. The life of a fourth member remained chaotic and dysfunctional despite her decision "*to get on with my own life and get off my crutch - not lean too much on support*". Conversely, the group members who had persevered until the group's termination and worked through unresolved issues showed evidence of more positive growth and outcome. Whereas group therapy had made their lives more bearable, the group members had to continue coping with fibromyalgia on their own. Medication remained an integral part of their pain management. Whereas they might have stayed away from a particular doctor or hospital, they would go to great lengths to obtain their medication.

Another interesting observation was that all members invested in substitute support networks to bridge the termination process and lessen the impact of abandonment. These included their general practitioners, other hospitals, physiotherapists, psychiatrists or psychologists and even another support group and a sport club. Although some had felt abandoned by the facilitator, they found reassurance in knowing that she would still be available if they had any problems.

4.3.6.3.2 Abandonment and rejection by the group facilitator:

Previous experiences of abandonment left group members insecure, anxious and distrustful of whether the facilitator would not also tire of them and she was asked whether she would be able to “*cope with us some more*”. It was as if they almost expected abandonment because they were undeserving of such loyalty. Questioning whether they would be tolerated may also indicate that they feared rejection once a defect in their makeup was detected. This may relate back to a childhood perception that their parental figure had left them because they were ‘bad’ or had done something wrong.

Some, fearing abandonment/rejection, wanted reassurance that the group would continue beyond short-term therapy similar to Alcoholics Anonymous meetings. Since fibromyalgia was a lifelong problem, they felt that they required continuous support: “*it must not be a support for six weeks and then throw me away*”. They also believed that “*nobody must be kicked out from the group*” - when the facilitator suggested that members who were not utilizing the group experience should make place for other fibromyalgia patients who were eager to join the group. This confrontation created such rejection-anxiety that they started to reveal personal details that they had never shared with others.

Their disbelief that someone could be reliable and be genuinely concerned about them placed an added onus on the facilitator not to disappoint them from the onset of the group sessions. This was also seen in their interaction with doctors and other caregivers, which made those people aware of a greater demand on them and higher expectations of such relationships. The facilitator was asked whether she found the meetings beneficial and gained something meaningful from the group members in return. This demonstrated a need to be of more significant value. Also noted was a longing for more than just a professional relationship that would end when the group terminated.

Of significance was that group members were largely unable to express negative feelings such as frustration or anger at the facilitator, which lessened the opportunity to become

empowered and more assertive as regard to their needs. Instead, they reacted with avoidance or passive aggressiveness as seen in absences from meeting after something had vexed them. Because of their dependence on this one person, they could not risk contaminating the relationship out of fear that it would lead to their rejection and isolation. This relates directly to their history of abandonment and consequent rejection-anxiety. To complicate matters more, they not only identified with the **facilitator as a role model**, but she also represented a surrogate parent for the group. They were idealistic and protective of the facilitator - similar to previous findings regarding their primary caregiver (despite apparent abandonment or abuse in some cases). Availability, reliability, consistency and trust formed part of being a positive role model that was required by this group to undo the damage of 'bad' parenting and to avoid feelings of abandonment by the facilitator.

It became apparent that the relationship between the facilitator and the group members was of greater importance than the actual contents of group discussions. As a result of their history of abandonment, it was crucial for members that the facilitator was sincere, reliable, trustworthy and consistent. They were hypersensitive to abandonment/rejection and needed to feel unconditionally accepted and loved. Whereas with doctors they had to be sick in order to be seen (see somatic fixation, Kirmayer chap. 2 p. 25), the group provided the ideal space to be themselves without any pretence. They did not need to present pain in order to get attention. Neither were they rejected because they were not feeling well. This fulfilled their need to be accepted, to belong and to be part of a group. However, just as they were initially delighted with their 'newly found family', but later disillusioned, their high expectations of the facilitator also set the scene for possible disappointment and feelings of abandonment – particularly because it was a large group that only had one facilitator.

As a result of unexpected regular attendance³³ at meetings (because of their neediness) and the consequent large group it was not possible to give everyone equal time, attention

³³ To ensure a viable therapy group, it was started with a larger number of patients because **attendance** by outpatients in hospitals is notoriously poor.

and support – especially when group members broke down and cried. The group often ran out of time when members still wanted to ventilate or participate in discussions. Some waited for weeks before they found the moment to open up. Although the facilitator tried to be neutral, some members had to be hushed up more often than others because of inconsiderate, insensitive or inappropriate responses. Although not meant as such, it seemed that both dominant and reticent members experienced this as rejection because of their hypersensitivity.

This was observed when the facilitator intervened when a member had monopolized the session after the festive period when meetings had been suspended for a month, and several group members also needed to talk after this difficult time. Some were dismayed and criticised her after a catharsis about her chaotic life and the lack of family support during which she made denigrating remarks about her children. Her rampant behaviour caused one member to leave the room as she had sounded just like the latter's verbally abusive husband. It can be inferred that she not only experienced this as rejection by the facilitator and fellow group members, but also left her feeling excluded and that there was favouritism towards certain members. Since as a child she had competed with her siblings for love and attention from her mother without success, **the re-emergence of sibling rivalry** with fellow members hurt her deeply and she felt extremely rejected; thus "*playing a record that I know*" (negative transference). This compounded rejection amplified existing feelings of inadequacy and insignificance. Evidently, any incident experienced by the group members that corroborated their feelings, justified their beliefs and strengthened their mindset of abandonment.

When this group member subsequently stayed away from the sessions for legitimate reasons and the facilitator failed to phone her, she felt "bad" because she thought that the facilitator did not care about her. In a paradox she revealed the core issue: "*It's not that I want to feel important or anything, but...*" However, due to her deprived childhood, this was exactly what she desperately needed. She wanted the facilitator to reach out to her, to rescue her, to show that she cared for her. Yet, none of her negative attention-seeking behaviour styles elicited the desired effect. Her withdrawal into

rebellious, passive aggressiveness left her more isolated. Asserting her needs in what she called her “*fishwife*”-style also pushed people further away, as did her retaliation in being obstructive when she undermined the facilitator and jeopardized the group. Since two group members had relied on her for transport, their additional absence precipitated the collapse of the group. Perhaps this was intended to hurt the facilitator just as she was hurting because of the rejection/abandonment that she had experienced. It was also a form of testing the facilitator. When the facilitator did not want to play into her negative attention-seeking/manipulative behaviour or engage in a power struggle between them, she felt the facilitator had failed her and perceived this as rejection. Underneath these surface manifestations, she probably felt the fear that she would never get what she needed from others and, thus, had to act in such an inappropriate manner.

She later admitted that she had been angry and had “*sulked for a while*” but decided: “*I’m not going to wallow in the misery that Ria (the facilitator) did not phone me. She has a life to get on with, let me get on with mine. I think, that made me a little more positive and get off my crutch - not lean too much on support.*” This excerpt and disclosures from other group members reveal that these patients relied a great deal more on the facilitator, doctors and family than one realises. They concealed their devastation by staying away (avoidance) from the person they perceived to have abandoned/rejected them. Rather than expressing their feelings and needs, they withdrew and internalised their pain – which is exactly what they had done all their lives.

Another way in which abandonment was experienced derived from a member who confronted the facilitator with having betrayed her trust. She felt exposed and let down when the facilitator’s attempts to protect her from her abusive husband had inadvertently let a colleague infer that she had marital problems. Subsequently, she felt insecure and abandoned because previously she had unburdened her problems to the facilitator. Of importance is that she had found it very difficult to break the silence of the abuse due to fear of rejection and judgment by others. However, she became empowered when she was able to assert herself against a powerful figure like the facilitator. In addition, she

realised that revealing a secret could actually free her from her fear and isolation, as people seemed to support, rather than ostracize her.

Perceived abandonment/rejection by the facilitator, rather than having negative ramifications for certain members, actually provided opportunity for positive growth because of the therapeutic context of the group, although they did not realise it at the time. Instead of remaining victims, these members started to take responsibility for themselves and asserted their needs. A group member who rebelled ('acted out') against the facilitator achieved a symbolic triumph over her domineering mother. By leaving the 'child-role' behind, she matured into an assertive and more responsible person.

Whereas it is normal to experience some form of separation-anxiety in any group, persons who had a history of abandonment seem to have more acute feelings of despair, anxiety and abandonment because it echoed previous experiences. It was, therefore, crucial that the group meetings were not postponed for trivial reasons, even at a time when the facilitator had flu – especially since they themselves often endured pain and discomfort to be at meetings. When they decided to suspend meetings for five weeks over the festive season and Ramadan, the facilitator continued to be available for individual support. Just by knowing that the facilitator had an open door policy provided some containment for their separation-anxiety. Because the facilitator was conscious of their insecurity and neediness, as well as the anguish they went through, she was often left with feelings of concern and guilt. This was exactly what their spouses or main caregivers also experienced and it may be indicative of manipulation to prevent others from abandoning them too.

All members found the festive period particularly trying, stressful and depressing as it reminded them of loved ones who were absent in their lives – some, despite spending these days with their families! Because this period is usually a time when families come together, their own emptiness and loneliness were accentuated – reminding them of their abandonment and alienation. Five who had anniversaries of the deaths of loved ones over the festive period felt vulnerable and nervous about coping without group support.

For example, acute separation-anxiety was observed when one member inquired about the availability of the facilitator over this period. Upon exploring the grounds for her anxiety she disclosed for the first time that her 'foster' son had been murdered eight months previously and that she was scared of being on her own over Christmas, New Year and the anniversary of his death. *"I do not have anybody as I'm not close to my family anymore."* Yet, she would be with her husband and son. She feared that the absence of a 'life-line' with the facilitator would deprive her of strength and support. However, the facilitator could not meet such unrealistic expectations. Consequently, she not only felt abandoned by the facilitator, but it also resonated with the abandonment that she was experiencing by her siblings' detachment and disinterest in her life. It also reminded her of how deserted she felt as a child when her mother had not rescued her from her abusive father. It is in this same sense that she perceived that the facilitator was abandoning her at a time when she needed her and consequently suffered unnecessary pain.

Another member, who had had intensive individual counselling from the researcher over a period of five years prior to group therapy, experienced severe separation-anxiety as termination approached. She was particularly vulnerable because her whole support network was disintegrating. She felt that the facilitator was abandoning her at a critical time. Not only had she lost her mother, but also the hospital that felt like 'home' to her was closing down. She was the only family member remaining in the large house of her parents and fourteen siblings, as her sister was emigrating and her frail father had remarried after he recovered from a near fatal illness. Yet, she was the dependent one because of her existence in a wheel chair.

As discussed previously she had not reached emotional maturity or independence, because of her disability and over-protection as a child. Her inability to achieve separation-individuation from her mother explains why she had a history of successive attachments to caring healthcare professionals. Each time these relationships were terminated she was devastated and relived feelings of abandonment and unresolved grief for her mother's death. The facilitator had become a surrogate mother figure to her because of her dependency needs, and the mere thought of separation induced great

anxiety. *"I just hope by that time, I do not need you anymore"*. She felt uncontained and required constant reassurance: *"if you should disappear out of my life, will I be able to go on and cope?"* To her losing the facilitator would be like another death. This clinging to the facilitator was much like an umbilical cord that could not be cut. She dreaded having to *"to start all over again with someone new"* and resisted change or taking responsibility. Although she proceeded to become more mature and independent as a result of therapy and employment - for the first time at age thirty-five - she still felt unable to leave the safety of the 'nest', albeit to another safe place until she had gained confidence.

A direct consequence of the hospital closure was that the therapeutic goals of the group were thwarted and this exacerbated the abandonment experienced by the group members. Since they seldom expressed negative feelings with respect to the facilitator, the researcher could only infer what they might have felt, but never uttered it. Some idealised the facilitator and, as in the case with their own parents, struggled to integrate the good and bad in one person (splitting), and consequently had unrealistic expectations. Whereas she had been a positive role model and caring 'mother' figure, this probably started to change for some when they realised that the group would not go on indefinitely and that the facilitator would also 'abandon' them. Three group members were unable to form a positive bond with the facilitator because they had never had a positive relationship with their own mothers. This probably relates back to abandonment in the first year of life that causes an ongoing conflict with issues of 'trust versus mistrust'.

It can be inferred that members also resented the fact that the facilitator had accepted the hospital's closure passively rather than assisting them in taking protest action. In this sense, she would then have failed as a 'good' mother just as their parents/caregivers had since she was supposed to take care of their needs and protect them - thereby becoming a 'bad' mother, or symbolising the 'bad breast'. By 'forcing' them to confront troublesome issues in their own lives and listening to the harrowing accounts of other members, the facilitator seemed to deliberately inflict more pain that re-opened old wounds – perhaps contributing to the premature departure of two group members. A few others perceived it as abandonment when the facilitator did not attempt to lure absent members back to

meetings and omitted to invite one who had only attended seven of thirty-three sessions, to the final two termination sessions. Although this was not deliberate abandoning, it disturbed the facilitator, who, in a sense, was also drawn into the group process as a role player. Instead of helping the group members, she too compounded their abandonment. This left her with feelings of guilt and concern. It is possible that members, who stayed away from the group, were in a sense rejecting the facilitator before she could reject them. Ironically, this left some feeling more abandoned and alienated.

However, the fact that circumstances had caused the group to terminate, did not lessen the impact of the pain it caused. Nor did availability of the facilitator on an individual basis after termination offer reassurance - comparable to the situation where the parents of a few members had had to work in distant cities when they (as children) nevertheless felt deserted. They had not only lost the person, but were also 'robbed' of containment, care, support, motivation and pleasure that they had derived from the relationship.

In order to cope with their separation-anxiety, some group members needed to keep a connection of some kind with the facilitator, such as a group photograph, photocopies of inspiring stories and access to tape recordings of missed group sessions. This is referred to as the 'transitional object' by Winnicott (cited in Kaplan & Sadock 1991: 108). It represented something, a part of the facilitator, that they could still hold onto for the purpose of anxiety reduction when they moved away from the secure base of an attachment figure (Ainsworth cited in Kaplan & Sadock 1991: 108). Another member who identified with the facilitator took notes at the termination session with the intention to become a surrogate therapist and pass on the 'good work'. The thought of detaching from her was overwhelming: "*I will not be separated from you Ria, because I'm not going to break away. I'm going to be an extension there.*" In this manner, the facilitator will live on inside her (internalising). However, as others were, she was still in denial, as she had not accepted the finality of the termination.

Several members were fearful and uncertain about the future without the safety of their newly found 'family' (group) and their surrogate 'parent' (the facilitator). They felt

exposed and vulnerable outside the safety of the 'womb'. Although grateful for the group experience and having a sense of achievement, they felt 'dumped'. Only this time, there was no safety net, which had been provided by PAOH, to catch them.

The abandonment by the group and by the facilitator was the last in a series of abandonment experiences. Figure 7 illustrates the concept of compounded abandonment and rejection. It is symbolic of a basket of fruit that the individual is carrying and each experience adds to the unresolved issues. It serves not only to illustrate the compounded experiences of abandonment/rejection, but also how the history of abandonment/rejection contaminates current relationships because of the mindset of abandonment.

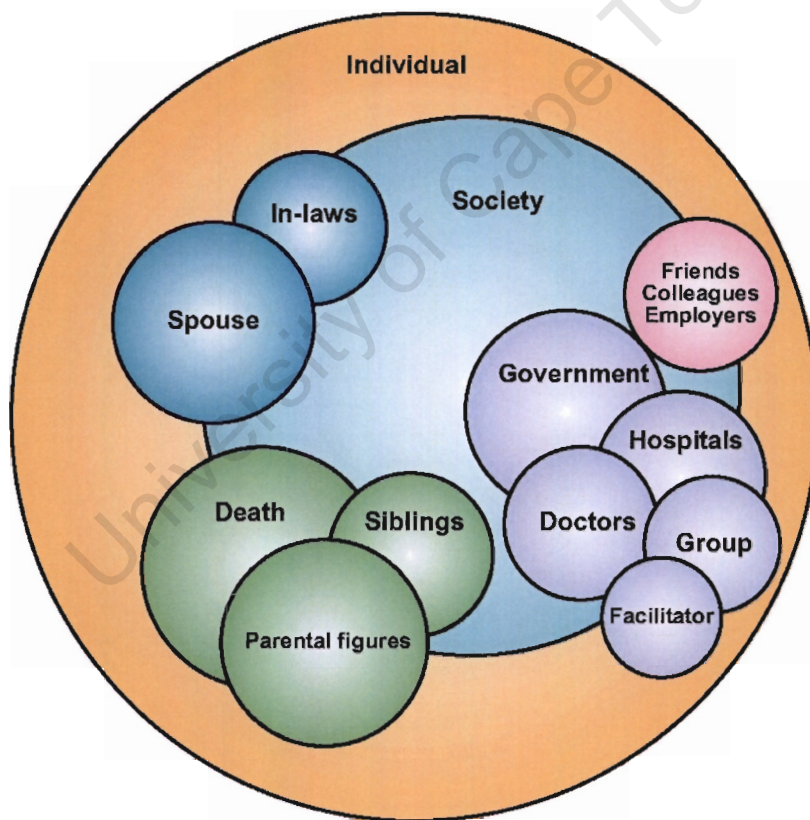


Figure 7
The concept of compounded abandonment and rejection

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSION

The aim of this study was to explore expressions of abandonment/rejection that emerged from group therapy with fibromyalgia patients. It poses the research question whether experiences of abandonment may play an important role in the manifestation of fibromyalgia. From the findings, a definite relationship between abandonment/rejection and fibromyalgia emerged. However, since this study was qualitative in nature and used a small sample, findings cannot be extrapolated and generalised to the broader population of fibromyalgia patients. Although this is the first study that focuses on abandonment and rejection and fibromyalgia to the researcher's knowledge, American and Israeli studies identified similar childhood deprivation, traumas, psychosocial circumstances and characteristic features in their fibromyalgia patients. The probability that abandonment or rejection issues may apply to the wider population of fibromyalgia patients needs further investigation.

This study was more complicated than expected due to fibromyalgia being a controversial, complex and multi-faceted disorder. The most important finding in this study was the repetitive, consistent expression of the theme of abandonment and related themes by each group member throughout the whole group process. Whereas their physical pain related to fibromyalgia, their predominant emotional pain is best described as feelings of abandonment/rejection. Much like an 'umbrella' term, abandonment and rejection encompass many emotions and cannot be isolated completely from other interacting issues. Abandonment/rejection was both at the root of, and the link between painful experiences/traumas described in the preceding literature review and analysis of the findings in this study. Experiences of abandonment/rejection were, besides fibromyalgia, the common factor between eleven diverse individuals.

Abandonment/rejection was not merely a reaction to the closure of the hospital. It seems rather that the closure triggered, perpetuated and amplified deep-seated emotions that might not have otherwise surfaced. More important, finding and then losing a hospital that felt like home, a group which became like their 'family' and a facilitator that represented a mother figure, accentuated their deprivation, emptiness and lack of attachments – thus pushing sub-conscious and previously denied emotions to the surface during the group sessions.

The sense of abandonment resulted from subjective interpretations of real or perceived abandonment/rejection, which seemed to form a mindset of abandonment through which all life's events were filtered. Distrust proved to be a key issue in individuals with unresolved issues regarding rejection/abandonment. Feelings of inadequacy or worthlessness were validated with each experience that left them more vulnerable and hypersensitive for perceived criticism or rejection. Because of rejection-anxiety some group members could not make close attachments or had become isolated in an attempt to protect themselves from further hurt.

Abandonment triggered an intricate range of intense, overwhelming emotions as it linked with unconscious memories of previous experiences of perceived abandonment. Because of accumulated experiences and unresolved issues, minor incidents triggered exaggerated feelings of abandonment. Seemingly unrelated, insignificant issues were in fact subconsciously interconnected and easily triggered. Numerous incidents of negative transference indicated that 'the problem' would keep on to represent itself, sometimes in different forms, until they had resolved it. However, they were completely oblivious of past associations with the current crisis and projected their anger and disappointment onto the current 'culprit' in an excessive manner. Of particular interest was negative transference with paternalistic or autocratic male doctors that reenacted their helplessness against a person with authority and power, on whom they had depended as children.

Termination of the group and closure of the hospital evoked unresolved feelings about death. The group members had been devastated by the deaths of parental figures, which

they interpreted as a form of abandonment due to dependency issues. Since death also provoked unresolved feelings of abandonment, they suffered prolonged grief. There seems to be a correlation between traumatic deaths and the onset or exacerbation of their fibromyalgia. Physical pain appears to have been amplified by sublimated emotional distress.

In certain instances, some set themselves up for failure as they held unrealistic expectations of significant persons in their lives who, by virtue of their own personalities, shortcomings and lack of social skills, were unable to live up to expectations. Many ruined relationships by their inability to clarify misconceptions, confront issues and by their failure to communicate their needs in an attempt to restore or strengthen these relationships. As long as there was unsatisfactory fulfillment of their needs, they felt uncontained, unloved, misunderstood and not valued. This appeared to have exacerbated the persons' fibromyalgia. In cases where their developmental dependency needs had been neglected they remained excessively needy and dependent, even fixated in an oral stage – especially when separation from or rejection by the mother occurred during the oral stage of development. Since their sense of significance and self-worth depended on others' approval, many often sacrificed their own needs to please others and feared to take a stand against others in case they were rejected or received the brunt of the person's anger. They either internalised rebellious thoughts or reacted in a passive-aggressive manner; often self-destructive in nature that only alienated them further. These fibromyalgia patients generally exhibited a lack of social skills in dealing with relationship problems and perceived abandonment/rejection. This lack seems related to a deprived childhood and dysfunctional families where parental figures were not positive role models.

Concurrent with other findings, group members clearly tended to deny problems and rather blame others or fibromyalgia for their misery, as well as exhibiting a tendency to idealise their spouses and family. The latter seems to stem from their dependency and fear of abandonment as they needed the 'illusion of connectedness' to survive. Most seemed to have a poor or inappropriate support base, for instance, being emotionally

dependent on their children or having an over-protective family. For self-preservation, many engaged in a mutual nurturing relationship – often a symbiotic or co-dependent relationship.

Group members showed a lack of insight in underlying dynamics or self-destructive behaviour, although this might be part of denial and avoidance of unconscious conflicts and suppressed pain. They seemed to have rigid thinking and egocentric views. Surprisingly, as adults they were unable to correct errors of reasoning or perception that perpetuated perceived abandonment. Consequently, they were unable to accept what had happened to them and remained resentful. Conversely, it indicates that emotions override reasoning.

All had suffered their emotional pain in silence – keeping their ‘abandonment’, abuse and dysfunctional families a secret. It took many months of group therapy before they overcame distrust and shame to reveal these. They had denied, suppressed and avoided their feelings because they were too painful and overwhelming. Since they never had an outlet or intervention, feelings of abandonment, fear and anger were internalised as an unresolved reservoir of emotional pain. Along with compounded experiences of abandonment/rejection, this emotional pain seemed to have escalated into an eventual expression in physical pain (somatisation).

Most citizens in this particular society might have felt some degree of abandonment or rejection, yet not all were as adversely affected. This concurs with research findings among individuals in the general population who meet the diagnostic criteria of fibromyalgia, yet they do not become patients. It seems that it is not so much what has happened to them that counts, but their reaction to these experiences and their ability (or inability) to adjust to change or overcome obstacles. All group members had unresolved issues about separation, loss and death. It would appear that the lack of inner resources or external support systems to help them cope could predispose individuals to somatic expression of their emotional distress. The compounded nature of their abandonment,

subsequent stress, personality type and subjective meaning attached to these experiences reflect the mindset of abandonment.

It is postulated that the accumulation of emotional pain from experiences of abandonment/rejection reached a saturation point at some stage and then manifested as physical pain, i.e. fibromyalgia. For some, this saturation point had already been reached in childhood, and others in adulthood – explaining the later onset of fibromyalgia due to its compounded effect. Further research is essential to verify and generalise this finding. It also seemed that the more severe their experiences of abandonment/rejection, the more debilitating their fibromyalgia, unless they had had good substituting caregivers, strong inner resources and social skills. This concurs with findings in the literature review that trauma severity correlated significantly with physical disability, psychiatric distress and illness adjustment.

When important attachment relationships ended, all members were devastated and severe depression surfaced that often caused regression, as they felt helpless, hopeless and lost until they could reattach to a surrogate figure. Some became immobilised and isolated themselves whereas others sought help from doctors to ease their distress. Amplified pain or a relapse of their fibromyalgia was often subsequent to periods of such severe stress. Those group members who had had mentally ill mothers, found it unacceptable to present with depression themselves – probably due to shame and the stigma attached to mental illness. This may explain in part why some scholars did not find a diagnosis of affective disorder prior to/or at the time of diagnosis. Similar to some scholars the researcher believes that the physical pain serves as substitute for depression, and somatic preoccupation protects patients from the overwhelming depression.

Secondary gains can then perpetuate a sick role. Fibromyalgia provides an outlet of personal expression where the body, as idiom of their distress, communicates that they hurt, feel tired or 'disabled'/immobilised. Because of early life experiences they had developed an aversion to destructive ways of coping (e.g. alcohol abuse) and would therefore rather sedate their emotional distress with their medication. Hospitalisation

offered an escape from an emotionally stressful environment to a safe haven where they had no responsibilities and received 'nurturing'.

However, once back to their 'empty' lives full of hardship and suffering in an uncaring society, they felt dissatisfied with their lives and relationships, yet helpless to change it. Most had anger and resentment towards some 'culprit' and could not accept what had happened to them. They felt 'stuck' in often-dysfunctional relationships and unable to take charge of or responsibility for their own lives.

The finding that this sub-group of fibromyalgia patients tended to avoid responsibility seems incongruent with their hard working, solid citizen style as found by other scholars. Actually, it is not a matter of avoiding responsibility or laziness, but rather because they had had an 'overdose' of burdens, some since childhood when they had cared for a sick parent, or financially supported their siblings or raised children as single mothers without adequate support from their ex-husbands. Most felt unappreciated, exploited, isolated in their suffering and uncared for. Their withdrawal into their illness and/or isolation is then understandable as they felt overwhelmed and at the end of their limited resources. Now that they had fibromyalgia, they felt more needy and longed for nurturing and rescuing from their burdens. Previously they had felt abandoned, now they just wanted someone to take care of them.

Besides pre-existing adversities and compounded experiences of abandonment/rejection, the subjects had the added complications of a chronic pain disorder. It compounded an already low self-esteem and caused more insecurity and rejection-anxieties. They feared that their families would disintegrate, or that their spouse would desert them now that they were helpless and could no longer fulfill their roles adequately as spouse, mother or employee.

It is difficult to determine whether personalities were possibly the result of all the above, and not necessarily a pre-morbid characteristic of fibromyalgia patients. Although predominantly dependent, avoidant, histrionic and narcissistic personality traits were

noticed in some members, they presented a diverse group of individuals. It was interesting to note that some of these fibromyalgia patients, perhaps because of their chronic pain condition and underlying abandonment issues, represented many of the characteristics of 'difficult patients' who evoke negative countertransference in doctors.

It seems from both, the literature review and the findings in this study, that a certain subgroup of fibromyalgia patients struggle to cope with life's demands, raising the question whether their, sometimes pathological, needs can really be met by the conventional medical treatment approaches. It was clear from this study that their needs were not adequately met by rotating doctors in an academic specialised hospital, where they felt scattered between numerous specialist departments for different physical ailments, where doctors only had a narrow 'tunnel vision' of their problems. Serious budgetary constraints further exacerbated feelings of having been abandoned by the hospital and government, when they could not obtain physiotherapy, prescribed medicines or were discharged to primary health care clinics that did not have sufficient time or understanding of their complex problem. This further escalated feelings of abandonment that contaminated their relationships with the facilitator whereas the therapeutic aim was to undo the damage of 'bad' parenting. Ironically, the facilitator, doctors and hospital who were previously the 'good breast' that had nurtured them, had become a 'bad breast' in compounding their abandonment.

A number of unexpected findings emerged from this study. There were high rates of an inability to carry pregnancy to full-term, of the deaths of attachment figures and unresolved grief. Also of importance was that the group members might still stay away from a specific doctor or hospital, but would never go without their medication. It was clear that the sedating and mood enhancing properties of some medications caused some patients to become 'dependent' on these. A lack of coordination of services was noted in the costly duplication of services by various general practitioners, different departments in the same hospital and at various other hospitals. Unexpectedly, group members who did not dwell on the past, were the ones who moved on and complained less about their

fibromyalgia. This finding could indicate that psychotherapy may be less effective than self-help groups for certain patients.

Fibromyalgia is a multi-factorial syndrome that still evades full understanding. This qualitative study provided a unique window of opportunity to gain deeper insight into minds and experiences of eleven fibromyalgia patients. The researcher believes that it is not beneficial to continue an academic debate about the etiology of fibromyalgia, nor to label or avoid these patients. Fibromyalgia seems to lie on the border between psychiatry and medicine and is probably best described as a pain disorder associated with both psychological (and social) factors and a general medical condition (see Appendix 1). Although symptoms are affected by psychosocial factors, the physical pathology that was triggered is real and remains chronic. It seems likely that several, rather than a single factor, are responsible in the pathogenesis of fibromyalgia and its comorbid disorders, which would include neuroendocrine aberrations, the stress system, non-restorative sleep, genetic and other factors.

This study adds its voice to other scholars who have identified psychosocial factors that seem to play a part in the development, perpetuation and aggravation of fibromyalgia. The difference is that feelings of abandonment/rejection link and include all the emotions associated with the adverse psychosocial circumstances or traumatic experiences that fibromyalgia patients seem to have in common. From the findings in this study, as well as a literature study, it seems that there is a significant relationship between experiences of abandonment/rejection and fibromyalgia. It is postulated that experiences of abandonment/rejection may be at the very root of fibromyalgia. Since this was a small study, further research is now needed to determine if this applies to the wider population of fibromyalgia patients.

A link between physical pain and emotional pain has immense implications for the treatment of fibromyalgia since it implies that psychosocial factors, behaviour patterns, attitude, etc., can contribute to the development of the disease. This is rendered more plausible by the fact that other medical conditions are also associated with stress and

psychosocial factors, such as breast cancer after the death of partners and heart attacks in persons with 'A'-type personalities. It is even more probable considering Wolberg's findings that definite groupings of symptoms/syndromes (i.e. anxiety and psychosomatic disorders) appear when adaptation collapses.

Erikson and Wolberg's development theories corroborate many findings of this study and strengthen the argument in favour of a link between experiences of abandonment and rejection, trauma and dysfunctional families, and the development of fibromyalgia. These theories also provide deeper insight of why abandonment/rejection, as a stressor (or trigger when it re-occurs) had such severe impact on these individuals. It is clear that when developmental needs were vitiated, they could not sufficiently resolve their developmental tasks and its conflicts. Negative transference was often indicative of these unresolved conflicts. Consequently they felt 'stuck' or unable to move to next phase - some even regressing to an earlier development stage. Compounded experiences of abandonment and severe psychosocial difficulties rendered them incapable of coping with demands. Because of a lack of inner and outer resources they could not adjust. This explains the manifestation of fibromyalgia, as an expression of their inner pain and becoming a coping mechanism as well.

There are tremendous implications for social work and allied professions as this multi-generational cycle of abandonment/rejection needs to be broken if it is at the root of fibromyalgia. Being qualitative in nature, and from a social work perspective, this study may have an important contribution to the treatment of fibromyalgia, as it provides insight into interpersonal and other psychosocial dynamics in fibromyalgia patients, specifically relating to issues of abandonment/rejection. It also has larger relevance and value, not only to the Princess Alice Unit at Groote Schuur hospital, but for all medical, psychiatric and allied health professionals with an interest in any of the comorbid disorders. It may also be of interest for hospital management, politicians and Social Welfare Services that make policies and decisions that affect these patients.

Social workers and allied professionals in the following fields may also find insight from this abandonment/rejection study. This includes: those working with abandoned babies and AIDS-orphans, families (especially divorced, single parent and stepfamilies), foster care and adoption services, survivors of abuse and non-support offices.

5.2 RECOMMENDATIONS

5.2.1 Direct service delivery

- A biopsychosocial approach and a patient-doctor partnership must be implemented where the patient takes an active role. Realistic expectations of their treatment are important and the aim should be to control the pain and symptoms, improve their coping skills and still live an active life. A positive lifestyle, pacing of activities, sufficient sleep and exercise must be encouraged. Fibromyalgia patients need more information and education about their condition, symptoms, medications and especially its side effects to enable them to take more responsibility in managing their condition. Regular contact, slow termination and continued availability is important.
- A secondary health care facility with permanent staff that does not rotate is required to serve as a center for ongoing treatment of fibromyalgia patients who need consistency, familiarity, containment and a stable relationship with their doctor and health care professionals. All complaints must be recognized as part of one condition, rather than compartmentalizing these to various specialised departments in tertiary hospitals. Doctors must avoid a narrow 'tunnel vision' of their patients' problems to prevent them becoming lost in the hospital structure/hierarchy.
- An inpatient treatment programme should be considered for larger hospitals such as GSH, which involves a comprehensive, treatment or pain control programme by multidisciplinary team members, as well as good follow-up after discharge to prevent a relapse.

- Concurrent psychiatric and medical disorders must be diagnosed and treated, whilst addiction to analgesics and hypnotics are managed. The Department of Psychiatry should provide psycho- or group therapy to fibromyalgia patients who are not coping with their illness.
- Multidisciplinary pain units must be more accessible for larger numbers of fibromyalgia patients with a focus on cognitive, behavioural and group therapy, extensive patient education, relaxation techniques and exercise programmes.
- There should be a specific clinic day for fibromyalgia patients at outpatient facilities in order to lessen their isolation, facilitate patient education- and skills training programmes, physiotherapy, as well as consultations with other health care professionals.
- Social skills training, stress management strategies, assertiveness training, problem-resolution skills and interpersonal communication skills must be made available to patients before attempts are made to tamper with or remove the established and ingrained secondary gains of the sick role.
- Employment and further education opportunities ought to be encouraged by referring fibromyalgia patients to the Occupational Therapy Work Assessment Unit, GSH, rather than applying for disability benefits.
- Practicum placement of social work- and occupational therapy students should be extended to offer group therapy or skills training programmes to patients.
- Adequate social work services must be made available to fibromyalgia patients. Individual and/or family therapy are needed for survivors of abuse, patients and families who are struggling to cope, as well as patients requiring support after a traumatic life-event or death of loved ones. Considering that abandonment/rejection occurs mostly

within the family, family or marital therapy is crucial to prevent further disintegration or dysfunction in families.

- More group therapy should be offered to fibromyalgia patients, as it is particularly effective in reducing social isolation, offering peer group support, and confronting patients with underlying issues. It also allows ventilation of frustrations, anger, fears and the grieving of losses. Through gaining confidence, becoming more assertive, setting limits, improving communication skills and taking responsibility, patients become more empowered. It is strongly suggested to have two facilitators for group therapy, in order to reduce the risk of dependence and help contain needy and vulnerable patients.

5.2.2 Management

- More care should be exercised in the closure of health care facilities, as it is not cost-effective to transfer these to other centers and later to build new hospitals. Patients should be actively involved in the transitional and decision processes when health care facilities are to be closed. Governing bodies should not make unilateral decisions based on short-term fiscal aims or budgetary decisions instead of quality health care and patient needs.
- The Department of Health has to increase the health care budget to maintain services, equipment and to employ critically needed staff to ensure that these patients receive adequate treatment. The budget for chronic and pain conditions has to come more in line with those for terminal care patients, especially because of a longer life-expectancy and the possibility to return to employment when more effective, but unaffordable anti-inflammatory or pain medications are made available. Regular physiotherapy, aqua therapy and adequate occupational therapy services must be provided to fibromyalgia patients. These are crucial for both pain- and stress management in fibromyalgia patients and to prevent unnecessarily hospitalisation when patients deteriorate and become immobilised.

- The policy- and decision makers, hospital management and the heads of departments (including nursing and allied health professionals) should all be included in policy making decisions regarding any changes to patient service delivery. What ought to be addressed, is an optimal and effective patient treatment plan for fibromyalgia and other special categories of patients that would be cost-saving in the long-term, rather than merely terminating services and referring patients to primary health care facilities where the same problems, if not worse, exist in terms of constraints of time, patient overload, poor facilities and the containment of costs.
- Multiple attendances at various hospitals and private practices have to be discouraged. The existing regional hospitals' computer system should be modified to identify duplication of services and to 'monitor' medication 'over-use' by the patients.
- It is imperative that larger health care centers employ a holistic, multimodal or integrated approach to pain management, where various allied health professionals could collectively address the patients' biopsychosocial needs. Since drug treatment alone has proven to be ineffective for fibromyalgia patients, coordination of services and proper teamwork are needed, rather than scattered or insufficient services where health care disciplines work in isolation.

5.2.3 Education and training

- It is vital that staff from the tertiary specialist units and primary health care facilities have more interaction, combined meetings and in-service training with the aim to enhance knowledge and skills, share problems and provide support for 'burn-out' or isolated professionals. The policy decision that fibromyalgia patients should be treated at day hospitals or clinics should be reconsidered until the infrastructure and expertise at these primary care facilities exists to provide an adequate service.
- The Rheumatology Department's annual Educational Day at Medical School ought to focus on fibromyalgia where speakers from a multidisciplinary perspective make

contributions regarding a treatment plan for these patients. It is crucial that primary health care staff and private practitioners are included.

- More articles are to be written in journals about fibromyalgia, especially from a social work perspective to improve insight into the needs of these patients.
- Similarly, lectures/workshops for doctors, allied health professions and students could provide new insights and make them more aware of how patients experience doctors and hospitals. Dealing with 'difficult' patients and other topics of interest should also be discussed.

5.2.4 Community resources

- Fibromyalgia patients must be informed about or referred to existing resources such as doctor-patient partnership programmes, self-management programmes and support groups for people with rheumatic diseases.
- Existing resources in the community, such as F.A.M.S.A., the Parent Center, N.I.C.R.O. Support for Women and local church leaders should be used to assist patients/families with issues such as family relationships, parental skills, divorce or death of loved ones.
- More efforts are required from local resources and leaders in the community to improve the patients' quality of life and lessen their isolation. The patients should be encouraged to engage in activities where they can have fun and social contact, such as to join a book club, bird watching group, learn to paint, or exercise together.

5.2.5 Future research opportunities

- Larger sample, quantitative research is needed to explore the relationship between abandonment/rejection, emotional pain and fibromyalgia in the wider population of fibromyalgia patients.
- More qualitative studies are needed with fibromyalgia patients who have unresolved abandonment/rejection issues or complicated grief in terms of its impact on their lives and their subsequent adjustment and ability to cope.
- Further research should be conducted to ascertain whether the onset of fibromyalgia correlates with, or is triggered by traumatic life-events in patients and whether earlier trauma brings on an earlier onset of fibromyalgia.
- There is a need to conduct research that investigates whether personality type plays a role in the adjustment and coping of fibromyalgia patients, and whether certain personality types are more at risk for the development of fibromyalgia if certain life events occur.
- A study of the impact on children growing up with sick parents and how to prevent the perpetuation of a multigenerational cycle of abandonment is urgently needed.
- Frequent studies to ascertain the needs of fibromyalgia patients and to evaluate the effectiveness and impact of service delivery, would be valuable to inform clinicians on appropriate treatment, as well as informing policy makers in terms of adequate service provision.

Appendix I: Pain disorder

Pain disorder (previously called psychogenic pain disorder and somatoform pain disorder), is one of five disorders classified under somatoform disorders in the upgraded DSM-IV. The others are somatisation disorder, conversion disorder [both previously referred to as “hysteria” (Kaplan & Sadock, 1991: 416)], hypochondriases and body dysmorphic disorder. The common feature of somatoform disorders is the presence of physical symptoms that suggests a general medical condition where the physical symptoms are not fully explained by a general medical condition, direct effects of a substance, or another mental disorder. (American Psychiatric Association 1994: 445)

Epidemiology: The peak age of onset is between 40-50 years of age as pain tolerance decrease with age. It is most common among people with blue-collar occupations. First-degree relatives are likely to have the same disorder. Depression and alcohol abuse are common in families of these patients. (Kaplan & Sadock 1991: 421)

Clinical features: Pain must be severe and continuous and of at least 6 months’ duration. Patients often have long histories of medical and surgical care, visiting many doctors and requesting many medications. They are completely preoccupation with their pain, citing it as the source of all their misery. They often deny any emotional dysphoria and frequently have a history of drug abuse or alcoholism. Major depression is present in 25-50% of patients and dysthymia/depressive symptoms in 60-100%. (Kaplan & Sadock 1991: 421)

Diagnostic criteria for pain disorder

- Pain must be the predominant focus of the clinical presentation and of sufficient severity to warrant clinical attention.
- Pain must causes significant distress or impairment in social, occupational, or other important areas of functioning.
- Psychological factors are judged to play a significant role in the onset, severity, exacerbation, or maintenance of the pain.
- Pain is not intentionally produced or feigned.
- Pain is not better accounted for by a mood, anxiety or psychotic disorder. (American Psychiatric Association 1994: 459)

Pain disorder has two subtypes that best characterizes the factors involved in the etiology and maintenance of the pain:

- Pain disorder associated with psychological factors when psychological factors, rather than medical conditions, are judged to have the major role in the onset, severity, exacerbation, or maintenance of the pain.
- Pain disorder associated with both psychological factors and a general medical condition when both have important roles in the onset, severity, exacerbation, or maintenance of the pain.

When pain disorder associated with a general medical condition and psychological factors are judged to play either no role or a minimal role, it is not considered a mental disorder. (American Psychiatric Association 1994: 458)

Pain is specified as acute when the duration is less than 6 months and chronic when 6 months or longer. (American Psychiatric Association 1994: 459)

Appendix II: Erikson's Eight Stages of Human Development

Psychosocial Stages	Age	Successful Resolution of Crisis leads to
<p>Basic Trust versus Mistrust</p> <p>Consistent maternal care versus negligence, irregular satisfaction in needs.</p>	First year	Trust, optimism, warmth.
<p>Autonomy versus Shame, Doubt</p> <p>Assertiveness & physical self-control versus dependency on parents & inability to be assertive.</p>	Second year	Sense of autonomy, pride of accomplishment.
<p>Initiative versus Guilt</p> <p>Exploratory behaviour & self-initiated activities versus fearfulness & self-doubt.</p>	Third to Fifth years	Development of conscience, self-worth, goal definition.
<p>Industry versus Inferiority</p> <p>Co-operation & competition versus fear of failing, & feelings of inadequacy.</p>	Sixth year to Puberty	Competence, mastery of skills, self-confidence.
<p>Identity versus Role Confusion</p> <p>Integration of identity versus role diffusion, lack of positive identity.</p>	Adolescents	Sense of continuity with one's past, present & future, healthy sense of identity.
<p>Intimacy versus Isolation</p> <p>Caring deeply for another person & vulnerability versus shallow interpersonal relationships & fear of commitment.</p>	Early Adulthood	Ability to form stable commitments & close relationships.
<p>Generativity versus Stagnation</p> <p>Need to be needed & desire to contribute versus self-absorption & early invalidism.</p>	Middle Adulthood	Productivity, creative concern for the world & future generations.
<p>Integrity versus Despair</p> <p>Reflection & evaluation versus regret for past life & strong fear of death.</p>	Old Age	Acceptance of mortality & of the human life.

Source: ERIKSON, E., 1964. Insight and Responsibility. In Calhoun, J.F., et al. 1977. Abnormal Psychology: Current Perspectives. (2nd ed.). (p. 47). New York: CRM/Random House.

Appendix III: Wolberg's Personality Needs and Stresses

Age Level	Needs	Common Stresses & Sources of Conflict	Symptoms of Collapse in Adaptation
First year "Oral Stage"	Intense & urgent demand for oral satisfaction, sensory stimulation, love & approval. Strivings for omnipotence.	Interference with nutrition, sucking pleasures, sensory stimulation, love & approval (separation from, rejection by, or death of parent). Blows to omnipotence & narcissism (impact of reality). Trauma of weaning.	Diffuse anxiety reactions. Psychosomatic disorders (anorexia, vomiting, colic, diarrhoea, breathing & circulatory disorders). Rage reactions (screaming, crying). Withdrawal reactions (dullness, apathy, stupor).
Two to three years "Anal Stage"	Investigative & exploratory needs, genital manipulation. Beginning strivings for independence & mastery, aggressive assertiveness. Development of social outlets for aggression. Frustration tolerance.	Habit training (too lax/severe discipline). Interference with independence & mastery (rejection, over-protection). Faulty handling of rage/aggression (severe restrictions or excessive permissiveness). Too great or too little emphasis by parent on rights of other family members. Interference with investigation, exploration & genital manipulation.	<u>Psychoneurotic reactions</u> : anxiety, phobias, compulsions & psychosomatic disorders (gastro-intestinal disorders, feeding difficulties like anorexia, constipation, diarrhoea), speech & bladder disorders. <u>Character disorders</u> : Rage/withdrawal reactions, or excessive dependency.
Three to six years "Phallic Stage"	Need for extra familial group contacts & co-operative play. Keen interest in sex, genital differences & birth processes.	Problems related to entry into nursery/pre-primary school. Interference with interest in sexuality, masturbatory intimidation. Precocious or excessive sexual stimulation.	<u>Psychoneurotic reactions</u> : anxiety states, anxiety hysteria, conversion hysteria, compulsion neurosis & psychosomatic disorders (gastro-intestinal), speech, bladder & skin disorders, or tics. <u>Character disorders</u> (as above). <u>Primary behaviour disorders</u> .
Six to ten years "Latency Stage"	Need for intellectual growth & understanding. Need for further social contacts & for organized team play. Particular needs to belong to a group/club/gang.	Problems related to entry into primary school (improper school, teachers, fear of relinquishing dependency, etc.). Neighbourhood stresses. Exposure to racial/religious prejudices.	Similar symptoms to above. Plus psychosomatic disorders (hearing & visual disorders, muscle spasms, nailbiting & compulsive masturbation) & juvenile schizophrenic.

Age Level	Needs	Common Stresses & Sources of Conflict	Symptoms of Collapse in Adaptation
Ten to fifteen years "Puberty"	Intense sexual feelings & interests - requiring a social outlet (social recreational programmes). Need to practice skills for successful participation in groups.	Conflict between need for and defiance of parents. Conflict in relation to sexual demands and social restrictions, masturbatory conflicts.	As above.
Fifteen to twenty-one years "Adolescence"	Gradual emancipation from parents. Need to make a vocational choice. Growing sense of responsibility. Courtship, marriage.	Conflict between dependence & independence. Continuing sexual conflict.	As above.
Twenty-one to forty years "Adult"	Good sexual, marital, family & work adjustment.	Conflict in relation to economic, sexual & family stresses. Conflict in relation to groups & social relations.	As above plus alcoholism, drug addiction & manic-depressive psychosis.
Forty to sixty-five years "Middle Years"	Acceptance of a slower life pace, physically & competitively. Need for new interests, hobbies, new friends & community activities.	Menopausal & climacteric changes. Conflicts in relation to separation from children, increased leisure time, retirement, unfulfilled ambitions, sexual declination & cessation of child bearing.	As above plus involuntary melancholia.
Sixty-five years on "Old Age"	Acceptance of physical, sexual & memory recession. Need to engage in social activities to cultivate new friends, to develop community interests & hobbies.	Conflicts in relation to loneliness, death of friends/partner, increased leisure time, failing work, physical & sexual activities. Fearful anticipation of death.	As above plus arteriosclerosis & senile psychoses.

Source: WOLBERG, L.R. 1954. The Technique of Psychotherapy. New York: Grune & Stratton.

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ONLINE INFORMATION CAN BE FOUND AT:

Fibromyalgia:

- <http://www.alpha.net/dci/fibro.html>
<http://Prairie.Lakes.com/~roseleaf/>
<http://www.w2.com/fibinfo.html>
<http://www.nlm.nih.gov/medlineplus/fibromyalgia.html>

Erikson's Eight Stages of Human Development:

- <http://psychology.about.com/library/weekly/aa091500b.htm>