

# **A qualitative study of patients' perceptions, interpretations and experiences of fibromyalgia syndrome (FMS)**

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This thesis is submitted as part two of the requirements for the degree of Master of Family Medicine.

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## SUMMARY

This study was conducted to determine patients' perceptions, interpretations and experiences of Fibromyalgia syndrome (FMS). Ten patients with FMS attending Heideveld Community Health Centre (CHC) in Cape Town, were selected for their ability to communicate and were interviewed by means of a tape-recorded semi-structured interview conducted at places preferred by the patients. The interviews were transcribed and analysed by detecting common themes. Six themes emerged namely: *attitudes of patients towards their illness; perceptions and opinions of patients regarding their illness; patients' descriptions of their symptoms; help-seeking behaviour; consequences of having FMS – mainly loss and fears, hopes and expectations*. Another finding was that 5 patients came from *dysfunctional families* where the dysfunction was found to affect the patient's FMS illness.

The interviews brought better understanding of patients' everyday lives and their needs. It became obvious that application of Family Medicine principles to the needs of the patients could improve the quality of care given to them. Also, attention to family functions can help detect patients whose well-being can be improved.

## 1 INTRODUCTION

Fibromyalgia syndrome (FMS) is a chronic diffuse musculoskeletal pain that causes suffering to patients. The following quotations best explain my inspiration to do a study of patients with FMS: Baumann (psychiatrist) (1) "Chronic pain is a distinct but heterogeneous condition. Unlike acute pain, it is not a universal phenomenon, it serves no clear biological purpose and it does not always conform to known pathophysiological principles". McWhinney (2) "Management of chronic disorders call for a careful study of both the patient's personality and the environment". I therefore believed that the biopsychosocial model would best suit the approach to the study. Converse to the reductionistic biomedical model used to understand most of modern medicine, the biopsychosocial was more relevant to my study. In order to understand FMS the biopsychosocial model allowed me to address the humanbeing in his or her illness which is influenced by the complex relationship between the psyche, the biology and the social environment.

FMS is characterised by diffuse musculoskeletal aching and low pain threshold to pressure, nonrestorative sleep, fatigue and morning stiffness usually of three months duration (3,4). The wide spread local tenderness

of FMS is manifested in pain at a minimum of eleven or more anatomically defined tender points (5, 6). **See pictures in appendix 15.1**

FMS tends to affect younger females (5, 6, 7) but may occur in people of all ages including children and the elderly (8). Buskila *et al* (9) reported a 6% prevalence of FMS among schoolchildren studied in Israel. Typically the pain of FMS does not respond to treatment according to the literature and also to my experience.

Doherty and Jones (4) say the principle clinical findings of fibromyalgia are:

- Discordance between symptoms and disability and objective findings;
- No objective weakness, synovitis, or neurological abnormality;
- Multiple hyperalgesic tender sites (axial and upper and lower limbs);
- Pronounced tenderness to rolling of skin fold (midtrapezius);
- Cutaneous hyperemia after palpation of tender sites or rolling of skin folds;
- Negative control (non-tender) sites (such as forehead, distal forearm and lateral fibular head).

## **Background to the Study**

My interest in FMS began in 1994 when I was working as a Senior Medical Officer in the Rheumatology Department of Groote Schuur Hospital in Cape Town. Professor O.L. Meyers who was then the Head of the department had a special interest in FMS and I was able to learn a lot about this illness from him. Many patients were referred to our department with unexplained musculoskeletal pain and most of them were found to have FMS. From the letters of referrals I was struck by how little the referring doctors knew about this disease. When I started working at Heideveld Community Health Centre (CHC) not a single patient at the Centre that I encountered had a diagnosis of FMS. I was able to bring awareness of this easily diagnosed condition to the other healthcare workers. We have since implemented a supportive multidisciplinary management approach and are able to look after our patients at the primary level of care. I see most of these patients and I have acquired considerable experience with this condition since I left Groote Schuur Hospital. I have come to realise for example that FMS is common in lactating mothers. I also find that I am sometimes able to make a spot diagnosis of this illness, by observing what I have coined "a fibromyalgic

look” in a patient and noticing that phrases like “I feel old, doctor” mostly clinche the diagnosis.

As long as FMS is not known by especially first contact doctors, it will continue to be missed. Consequently I have made it my mission to make my colleagues aware of this disease in the hope of saving patients the agony they experience when they are told that there is nothing wrong with them. One of my patients when being told the diagnosis after many years of suffering said ; *“at least I will now fight the devil that I know”*.

## **2. LITERATURE REVIEW**

### **2.1 The Existence of FMS**

FMS is known to be the commonest cause of widespread musculoskeletal pain (3,5,6,7). It accounts for an estimated 2% of patients seen in primary practice, and 5% in a general medical outpatient population (7). According to Wolfe *et al* (5) interest in the long known but generally neglected syndrome was revived in 1977 when Smythe and Moldosky wrote a paper that stimulated some researchers to have a relook at fibrositis. Unfortunately I have been unable to locate this paper. By proposing diagnostic criteria, Smythe and Moldosky further stimulated other investigators and began a cascade of interest that would lead to the publication of more than 60 research papers that led to the clinical recognition of the syndrome. Hensch in 1976 was the first person to suggest fibromyalgia as a better descriptive term for fibrositis (3). In 1986 a consortium of centres interested in FMS began a study of criteria for the diagnosis of the syndrome (5). These diagnostic criteria were published by the American College of Rheumatology (ACR) in 1990 and have a diagnostic sensitivity of 88.4% and specificity of 81.1% (5). A complaint of diffuse pain and a count of eleven or more of the eighteen anatomically

defined tender points makes a diagnosis of FMS. **See appendix 15.2** for the table of the tender points.

Murphy and Mattson (10) say it is estimated that those who consult in general practice 80% have no identifiable pathology, 35% have self-limiting disease and 15% have a disease which require active therapy. Balint (11) on the other hand says many of the health problems in family practice are those which he termed “undifferentiated”. Personally, I have a strong feeling that patients with FMS are lumped in the group of “no identifiable pathology group patients” and “undifferentiated problems group”. For example none of the patients in this study were correctly diagnosed by primary providers before they came to Heideveld CHC . Closer to home I remember how two-and-a-half years ago when I started the course (M.Fam Med, UCT) many of the group members were sceptical about the syndrome, one in fact calling it “an iffy condition” and another calling it “a label for aches and pains”. Today I am glad to say they are “believers” in FMS. Recently a colleague told me she was spotting fibromyalgia for the MCFP (Member of the College of Family Practitioners) examinations! Wider recognition of FMS in South Africa has also been promoted by prominent people in Primary Health like H.P. Meyer who is a professor in Family Medicine at the University of Pretoria. Meyer wrote two excellent, easy to understand and practical articles on FMS which

were published this year (1997) in the South African Family Practice Journals (12,13), a periodical which has widespread readership among primary providers.

I find discussing FMS always raising questions about Chronic Fatigue Syndrome (CFS) for example : "Is there an association between FMS and CFS or are these syndromes different forms of the same disease?". FMS and CFS are syndromes characterised by non-specific symptoms, moreover for both syndromes there is no diagnostic laboratory test that reliably differentiates patients with these syndromes from other patients. Meyer (14) in an article that he wrote about CFS, reported that 92% of patients with CFS fulfilled the criteria of FMS. Meyer (14) also says 35% of the patients with FMS fulfilled criteria for CFS. None of the participants in my study had CFS. The diagnostic criteria of CFS as published by Tally (15) are listed in **appendix 15.3** below.

The precise aetiology of FMS is unknown.

## **2.2 Some hypotheses that have been proposed to explain the low pain threshold characteristic of patients with FMS**

(a) There may be a link with an **antecedent injury** (6,16). The initiating event might lead to alterations within the Central Nervous System that would lead to generalised musculoskeletal pain. This phenomenon is referred to by Wolfe (17) and Culclature *et al* (18) as post-traumatic fibromyalgia.

(b) **Abnormal pain perception** may result from a low regional cerebral blood flow in the hemithalami and caudate nuclei of patients with FMS (19).

(c) **Sexual abuse** has been found to correlate with the number and severity of associated symptoms of FMS (20).

(d) **Stress** also appears to be a factor (21,22). Urrows *et al* (21) investigated the relationship of fibromyalgia tender points to other manifestations of rheumatoid arthritis. They found that the tender point count correlated with the degree of daily stress. Buskila *et al* (23) also say that the fluctuations of FMS symptoms are influenced by the changes in stress levels.

(e) The abnormal **non-restorative sleep pattern** has been found to accompany FMS in some studies (24,25). The FMS patients had more alpha-EEG sleep and less REM and stage 1 sleep (24). The alpha EEG sleep anomaly may reflect a vigilant arousal in the daytime experience of unrefreshing sleep.

(f) **Depression** is another factor associated with FMS (26,27,28). Whether depression is caused by fibromyalgia or *vice versa* is not known.

(g) **Chronic irritable bowel syndrome** (22,29) and **anxiety** (22) have also been implicated as important symptoms of FMS.

### **2.3 The implication of FMS for patients**

FMS is definitely not an innocuous condition. The following examples are some of the studies done that have shown that the severity of symptoms in FMS patients is worse than in rheumatoid arthritis patients. For example patients with FMS exhibit the following:

(a) a higher level of psychological distress (30);

(b) they experience more limitation with regard to activities of daily living (29);

(c) They have greater pain (31). When comparing FMS patients to matched controls, it was found that the muscle function of FMS patients was low and there was also muscle tenderness (32).

## **2.4 FMS in Summary**

At present FMS is regarded as a chronic condition for which there is no cure. Some patients may have to cope with pain of varying degrees of intensity for the rest of their lives, others may go into partial or complete remission of symptoms after a few weeks, months or years. Although patients can usually dress and wash independently, they cannot cope with a job and ordinary household activities (4). In my experience, which confirms reports in the literature, analgesics, non-steroidal anti-inflammatory drugs and local treatments are ineffective (4). Consequently it is important for a physician and patient to work together in order to develop a coping strategy. I find the work done by Granges *et al* (33) particularly encouraging because patients with FMS can be managed at a primary level with good outcome. After the researchers treated FMS patients in a community rheumatology practice with simple interventions, like physical exercise, a good outcome was obtained. After treatment, 47% of patients no longer fulfilled the American College of Rheumatology

(ACR) criteria of FMS (33). Remission was objectively identified in 24,2% of assessed patients. Regular physical exercise, rather than drug or specific physical therapies correlated highly with low FMS scores. At reassessment the patients who still had FMS self-rated their disability as “low” (using a 10cm disability scale). This implied that community FMS has a better prognosis than the literature suggests.

### 3. MOTIVATION FOR THE STUDY

Despite the fact that FMS is the most common cause of diffuse pain in patients it is frequently missed as a diagnosis because doctors lack awareness of its existence. FMS is a relevant condition to research at primary level because:

(a) FMS can be evaluated by means of an easily learnt clinical skill of applying manual pressure to specific points on the body (**See pictures in appendix 15.1**);

(b) FMS can be managed successfully at primary level using the same therapeutic modalities that are employed at tertiary level. These include supportive counselling, physiotherapy, injection of tender points and

simple analgesics. The advantages are obvious : i) cheaper treatment; ii) continuous accessibility of the treating doctor;

(c) As a vocational trainee in Family Medicine and working in a Community Health Centre I am concerned with both the cure and the care of the patients. I, therefore found working in a Primary Health Care setting a golden opportunity for me to do a qualitative research project on FMS. Qualitative research aims to get a full assessment of how patients understand their social and material situation and how they perceive their role within the situation;

(d) The last and very significant motivating factor for me to do the study is my personal interest in rheumatology, particularly FMS. The interest was developed in 1994 when I worked as a Senior House Officer in the Rheumatic diseases Unit of Groote Schuur Hospital, Cape Town.

#### **4. AIM**

The aim of the study is to understand and highlight the suffering of ten patients with FMS. The knowledge about FMS should make it possible for doctors to give better care for patients with FMS.

## 5. OBJECTIVES

(a) To determine ten patients' perceptions, interpretations and experiences of the disease. The method of selection of patients will be discussed under **7.2. of "Study Population"**.

(b) To qualitatively determine the impact of this condition on patients' lives and to learn how they cope with this condition.

## 6. WHAT IS QUALITATIVE RESEARCH?

Qualitative research is a means of engaging and examining the culture and practices of people and their social group from the perspective of those who are being studied. We want to know how our informants see and structure their world in their own words.

According to the Medical Research Council (Cape Town) (34) the qualitative approach is most appropriate when:

- (a) the subject is unfamiliar;
- (b) meaning not frequency is sought;

- (c) for explanatory depth: when you want to relate particular behavior/ practices to the wider social context;
- (d) flexibility of approach is needed to allow for discovery of the unexpected, and in-depth investigation of particular topics;
- (e) for studying selected issues, cases or events in depth and detail;
- (f) for exploratory research, when relevant concepts are unknown or their definitions are unclear.

The Differences between qualitative (naturalist) and quantitative

(positivist ) research methods.

<b>Qualitative</b>	<b>Quantitative</b>
e.g. Social Science	e.g. Medical Science
Holistic	Reductionist / linear
Understanding	Measurement
Public Health	Medical care
Health	Disease
Group / Collective View	Emphasis on the individual
Informant / Community Control	Researchers control
Said to be “soft” science: “subjective”, imprecise	Said to be “hard” science: “objective”, precise

Qualitative and Quantitative methods of research are not mutually exclusive of each other and can be used together to answer some research questions. An example is a paper by Coleman et. al (35) where they used quantitative methods to sample for a qualitative research. Hoffman (36) has also shown that quantitative and qualitative methods can be employed sequentially or simultaneously in a single study.

I chose a qualitative method for my research because I believe it is the best method that will be able to illuminate to us and to help us understand the complex biopsychosocial issues that FMS patients have to deal with because it is able to answer the humanistic “why?” and “how?” questions.

## 7. METHOD

### 7.1 Definition of terms

(a) **Fibromyalgia Syndrome (FMS)** - a chronic illness characterised by widespread pain, fatigue, sleep disturbance and resistance to therapy.

(b) **Tender points** - predictable areas of abnormal tenderness (i.e. lowered threshold of response to pressure at these points) (5, 6). For a tender point to be considered positive, the patient has to state that digital palpation with a pressure of +/- 4 kg/cm<sup>2</sup> at the mentioned anatomical site, is painful (14). This is approximately the pressure required to blanch the blood from a thumb nail.

(c) **Semi-structured Interview** - a loose structure of open questions, which define the area to be explored, at least initially, and from which the

interviewer and interviewee may diverge in order to pursue an idea in more detail (34).

## **7.2 Study population**

Consecutive interviews of ten patients with FMS over a two month period were conducted. All research subjects were patients attending Heideveld Community Health Centre (CHC), Cape Town. I selected patients who were able to give a good account of themselves in terms of their symptoms and were keen to take part in the study. This sampling method of choosing informants who are “richer” than others and therefore more likely to provide insight and understanding for the researcher is discussed in a paper by Marshall (37).

Eight of the interviews were done at the patients' homes mainly over weekends as per appointment. Two patients were interviewed at Heideveld CHC because it was convenient for them to be interviewed there.

### 7.3 Study Design

(a) The study was conducted by means of a confidential questionnaire to establish the demographic characteristics of patients with FMS (**See appendix 15.4**). This information formed part of the field notes recorded during the interviews. The field notes were notes that were written as soon as possible after I left the place of interviewing. The notes described all the issues that the interviewer remembered and thought had a bearing in the interview e.g. description of informant's mood and demeanor, details about the location where the interview took place, about the people around, about smell, sounds etc.

(b) Interview plus tape recording: The interviews were conducted on a one-to-one bases and were semistructured. Some of the items that were explored during the interview sessions are shown in the following interview guide:

1. How long have you been sick?
2. Who have you consulted to help with your sickness?
3. What do they say? Is their treatment / advise helpful?
4. Have you used remedies?
5. What do you think your illness is?

6. Tell me about your family.
7. How is your relationship with your family? How does your illness affect them?
8. Is your family supportive?
9. What about your friends and co-workers - what do they say about your illness?
10. Tell me about symptoms that are caused by the illness.
11. I have had people say your illness is arthritis - what are your thoughts about this?
12. What is arthritis?
13. Tell me about your day / daily routine.
14. Are you managing / coping with daily activities?
15. What do you think makes you or will make you cope?
16. What are your hopes and wishes? Fears? Worries?
17. What are your plans for the future?

An interview guide is a tool for use in semistructured interviews in qualitative research as indicated by Bierman and Muller (38) in their study of determining the legal limitations which influenced the practice of the registered primary health care nurse.

#### **7.4 Pilot Study**

I conducted a pilot interview in September 1996 to resolve technical problems assisted by two experienced qualitative researchers well qualified to conduct such surveys. In order to acquire skill in the conduction of Qualitative Research I attended a one-week course in Qualitative Research offered by the University of the Western Cape Summer School in February 1997.

#### **7.5 Implementation of Study**

I interviewed patients mainly over weekends after making appointments with them to interview them in their homes or other places where they felt comfortable. The interviews were conducted between March 1997 and May 1997. Two interviews were repeated to get more information.

#### **7.6 Limitations of study**

Interviews were often interrupted due to telephone calls, noisy family, unexpected visitors, etc. The presence of other family members within

earshot during the interview inhibited discussion about sensitive issues. Only one interview was performed on 8 patients; sometimes I found, on reviewing the transcripts, that there was additional information which might have been obtained to clarify certain issues. Two patients were interviewed at the Heideveld CHC, rather than at their homes. Therefore, I was unable to assess the potential effects of the home environment on these patients' symptoms.

## **8. ANALYSIS**

1. The analysis was conducted principally on the transcripts of the taped interviews. The information obtained from the questionnaires and field notes was only used when it had a bearing on the interviews.

2. The taped material was transcribed as this is the basic data for analysis (**See Appendix 15.5** for an example of a transcript). Common themes were identified and coded. The transcriptions were duplicated so that two researchers who helped with the pilot study could assist with coding. For the purposes of confidentiality the participants have been given code names in this paper.

## **9. RESOURCES**

No funding from external sources was required. All the costs (for example, transport and typing) were covered by the researcher. A friend had lent me her tape recorder (SANYO mini cassette recorder, model No. M1120).

## 10. ETHICAL AND LEGAL CONSIDERATION

- Informed consent was obtained in writing after explaining the nature and aim of the research.
- Anonymity of participants was ensured.
- Privacy of participants was respected.

## 11. REPORTING OF DATA

The presentation mainly takes the form of quotations from transcripts. Using code names makes it easier for the reader to tell if the data presented is from the same or from different individuals.

### 11.1 A Profile of the Patients Interviewed

*Information on the profile of patients gathered from my field notes, the questionnaires completed by the respondents and the respondents' hospital folders.*

**1. FX:** A sixty year old mother of four adult daughters. She lives with her husband who is a pensioner. FX says she stopped working as a domestic-worker in 1985 because of "*arthritis*". The diagnosis of FMS was made in 1995 at Heideveld Community Hospital when the patient presented with the same complaints that she was previously seen for i.e. "*arthritis*" and insomnia.

Both the patient and her husband are "*Born-again Christians*". FX says she changed from a Muslim to a Christian religion about five years before when her husband was "*saved*" by the Christians. FX says her husband was an alcohol-abuser who subjected her to many years of physical and emotional abuse before he was "*saved*".

The interview took place in FX's one-bedroomed council flat. We were alone in the flat and there were no disturbances.

**2. LK:** A sixty one year old man who shares a house with his wife, two adult sons and their families. LK works as a driver for a Town Council almost a hundred kilometers from his home for the past thirty five years. He travels daily to and from work using public transport and prides himself for being able to wake up at 05H00 every morning in order to make it on time to work!

A diagnosis of FMS was made in January 1997 when LK came to request pain pills for shoulder and arm pains. He said he's been living with aches and pains since he was a youngster.

The interview took place in LK's home - an extended double storey council flat, the only home with a garden (well-tended) in the neighbourhood. LK's wife, daughter-in-law and grandson (a toddler) were present in the same room during the interview. The television was also switched on, but LK's wife was kind enough to turn the volume down. During the interview a church member arrived and the interview had to be interrupted. The family are devout members of the Seventh Day Adventist Church known to South Africans as "*Watch Tower*"

**3. CO:** A forty-four year old single mother of two sons in their early twenties. CO is severely disabled by FMS and is one of very few patients with FMS at our clinic that we had to board from work because of severe symptoms of three years duration. She was also seen twice in the last year by a Rheumatologist from a local tertiary institution who is assisting us with management of problem cases.

CO lives in a council house about half a kilometer from our clinic and preferred to be interviewed at the clinic. The interview conducted in

Afrikaans, took place half an hour before my work started and there were no disturbances. CO is an occasional church attender but her sons are not. CO said her sons are good children and they are supportive.

**4. BH:** A sixty seven year old grandmother of fifteen grandchildren, who lives with her husband who has dementia related to previous heavy alcohol intake and an extended family of some of his children, their spouses and some grandchildren. BH does not know the number of her household members. Despite having FMS, BH is remarkably active and is in fact in charge of everything that is happening in her house. She also seems to have a supportive network of friends.

BH presented to Heideveld CHC with a history of vague chest pains of short duration and aches and pains of years in November 1996 and a diagnosis of FMS was made. The chest pain was related to tender second costochondral junctions which are two of the eighteen tender points of FMS. Ischaemic heart disease was excluded.

BH's interview took place in a quiet room of her beautiful four bedrooled extended house - a house that BH told me was a cause of her sleepless nights because the family could not keep up with the bond-payments and the bank was threatening to take the house. BH's husband lost his job

due to his dementia two years before and she now had to look after him twenty four hours of the day. BH says her husband never supported her financially even though she had been a housewife throughout her married life. The house could have been the only "*present*" that she got from her husband who used to abuse alcohol, often times abusing BH emotionally and physically and also being unfaithful to her for many years until he got sick. BH is of Moslem religion and says she draws her strength from prayer.

**5. FD:** A twenty-one year old patient who is a sole breadwinner, supporting her sickly mother and two school-going siblings. FD is working for a well-known Food Catering Industry and told me because she is not employed permanently she has not been able to go on holiday because casual employees do not qualify for vacation even though they work six days a week. FD also said she had no time to socialise with friends. FD was seen for the first time a month before being interviewed. She was complaining of upper and lower back pain, fatigue and poor sleep and was requesting "*pills for stress*" because she attributed her symptoms to stress. She in fact had both stress and FMS.

The interview took place on her follow-up visit in hospital as was arranged. FD works late and it was almost impossible to interview her at her home. We did not discuss religion.

**6. GB:** A twenty three year old married mother of two boys aged three and four. Her life was full of mishaps and it was not surprising that we found her to have major depression in addition to fibromyalgia when we first saw her in March of 1997. GB was born to a teenage mother who gave her up for adoption. By the age of seven both her adoptive parents had died and she was then raised by her grandfather who was a pensioner. To escape poverty she left school early and got involved with a man who was involved with drugs. The man has since become her husband and gave up dealing with drugs and became religious again. The family belong to the Muslim faith.

GB says the family is poverty stricken. Her husband is fighting drug addiction and has been unable to keep a job. GB found a job with a security firm two years before but she gave it up because of her aching body. She says the job involved a lot of standing, walking and running around and her feet could not take it. She also blames the stress related to that job to have caused her subsequent two miscarriages. GB says her

body started aching with the first pregnancy and became worse with subsequent pregnancies.

GB has recently re-established a relationship with her biological mother who had since married and now has teenage children with her husband (GB's stepfather). GB and her mother meet secretly because her stepfather and stepsiblings do not approve of her.

The interview was conducted at the clinic as was pre-arranged. GB told me she would be ashamed for me to see her one-roomed rented home and also that she did not want me to be exposed to her high crime ridden neighbourhood.

**7. AD:** A fifty-two year old father of five adult sons (all still at home). AD says he stopped working twenty-five years ago when his General Practitioner told him he had arthritis. He is still angry with that doctor for refusing to board him off work because he told him he could still work because: "*my joints were not yet damaged*". So AD resigned from work, and lost his illness benefits. Since he stopped working as a mechanic/electrician in the "Maintenance department" of a local University, AD has been doing odd jobs (repairing cars and electric

appliances) when his arm and shoulder pains were less. AD's sons are also helping with the finances in the home.

The household comprises of seven adults and four children (all grandchildren) occupying a two-bedroomed council house. The yard is full of cars, which are for repair. Although Mrs. AD was invited by her husband to sit in during the interview, she declined and said she wanted to give us privacy. However, before I left Mrs. AD managed to secure an appointment to see me at our clinic for her failing eyesight.

**8. RS:** A twenty year old single mother of a three year old boy. She left school in standard seven when she fell pregnant with her son. She still wishes to return to school but is unable to because she has to work for her child. Her boyfriend (the father of the child) is unemployed and therefore cannot help with child support. RS also says she has a strained relationship with her boyfriend. RS's mother looks after her son when RS goes to work at a supermarket. She is employed on a part-time basis and works three times a week.

RS is probably the only patient with FMS who we will only see once. She only presented to us after having symptoms for about three years because her neighbour frightened her and told her that some of her

symptoms (chest discomfort that RS always thought was heartburn and fatigue) were probably due to angina. Her neighbour has angina.

RS therefore presented with a request to have her heart checked. When she was told she had FMS and there was nothing wrong with her heart, she told us categorically that she could live with her symptoms because she did not like taking pills or visiting doctors.

RS was interviewed in the living room of her mother's council flat. In the meantime her mother had kept the children (grandchildren) occupied in the backyard.

**9. JS:** A sixty year old who is waiting to be pensioned. Her symptoms of stiffness and pain in the lower body have been attributed by JS for almost two decades to be due to "*arthritis*" in the knees. JS has been widowed for almost the same period. She says a few months after her husband had died she stopped work because she could not manage doing the domestic work with her painful legs. Since she stopped working JS supported her family of two daughters with money that she made by being a day-care mother - looking after small children of working mothers who lived in her neighbourhood. At the time of the interview, JS was looking after a six-month old baby.

During the interview, which took place in JS's council flat, two neighbourhood school children arrived at different times to "offer" to go and buy JS stuff from the shops if she needed any. JS said she did not need anything from the shops but instead asked one of the children to look after the baby whilst she was talking to me. The other child was requested to empty the rubbish bin from the kitchen and to remove the washing from the line - **UBUNTU** in practice! (UBUNTU is a philosophy of humanity embraced by Africans implying that a person is a person because of other people).

JS lives alone as both of her daughters are "*uitgetroud*", as she puts it. She belongs to a church group and says she hosts prayer meetings in her house because she is unable to walk to church.

**10. NY:** A forty-five year old mother of two children who are both doing standard four although in their late teens. According to NY this is so because she says "*abamameli*" meaning the children lack discipline. NY came to see us in November 1996 requesting us to complete a green form for the disability grant. On probing, NY tearfully explained that her employer had fired her because she had failed to wash the windows. NY said she had been able to do all the other housework including ironing a load of washing but she could not wash the windows because she

experienced unbearable pain in her shoulders when lifting her arms. On examination NY had FMS. NY did not want us to contact her employer to explain her sickness because she said she felt extremely let down by her employer and therefore did not want to work for her anymore. She told me her grandmother, her mother, her sister and herself had worked faithfully for the same family through generations. We (at Heideveld CHC) applied for an emergency three-month disability grant whilst NY was looking for another job and we initiated therapy.

The interview took place in NY's two-bedroomed township council house. As I was getting into the house NY's husband was entering another room. We saw each other but NY did not make any effort to introduce us to each other. This made me feel uncomfortable and inhibited me during the interview.

We sat in the living-room dominated by pictures, mostly of children of different ages. One of the children in a picture, I later learned, was NY's employer who was reared by NY's mother.

NY is a Zionist Christian and a regular churchgoer.

**11.2 Analysis of the Transcripts - Six themes listed below emerged and five interviews revealed dysfunctional families (See 11.2)**

1. *Attitudes of patients towards their illness* - these were varied and therefore interesting.
2. *Perceptions and opinions of patients regarding their illness.*
3. *Patients' descriptions of symptoms of their illness* - It was amazing how all the patients described their pains and discomforts in peculiar mechanical and almost symbolic ways.
4. *Helpseeking behaviour.*
5. *Consequences of having FMS - mainly loss.*
6. *Fears, hopes and expectations.*

Five of the interviews revealed dysfunctional families which affected the well-being of the patients **(See Discussion 12.4)**.

### 11.2.1. Attitudes of patients' towards their illness

The attitudes were varied depending on how the patients perceived and experienced their symptoms. It was interesting to note that some of the patients were not affected by the diagnoses given to them by the doctors they had seen before they got the correct diagnosis of FMS. Perhaps this was due to the different labels that they were given by different doctors. CO for example said *"Ek het gesê as daar nie a 'diagnosis' is nie, dan sal daar nie 'n oplossing wees nie...dit was my 'fear'"*. CO basically had lost confidence in doctors. However she ignored the diagnoses of *"verkoue"* and of *"niks makeer met jou nie"* and instead "chose" the diagnosis that would best explain her disabling pains. CO said *"Ek is nie 'n dokter myself nie. As die dokter sê dis... wat?...Rheumatoid? dan vat ek dit so"*.

On the other hand RS did not even want to acknowledge that there was anything wrong with her. She said *"I don't like to be sick"*. Her only agenda of coming to see us was to exclude angina pectoris. Once that was done she told us she was prepared to live with the symptoms and declined to be given a follow-up appointment.

LK was very matter-of-fact about his pain. He said *"I know the pain will never go away. I'll be happy to get relief, that's all...If you've got it (the pain) so long you learn to live with it"*.

There are various factors that influence patients' attitudes towards their illness like religion, having responsibilities and social pressure. Regarding religion FX said: *"The only thing that I do to help myself is pray to the Lord and do exercises"*. LK who is a 'Jehovah's Witness' said: *"In my faith we do a lot of walking, from door to door, so that keeps me active. It helps a lot...this walking. Sometimes you feel tired but you actually feel good because you help people with spiritual matters"*. JS, AD and BH also said that prayer gets them through the days.

Having responsibilities also affected patients' attitudes towards their illness. AD said *"Well ..you've (I've) got a house to see to, you've (I've) got a family...you've (i've) got to keep on going"*. RS said *"I cannot afford to get sick...must work for my son"*. JS said *"even though I feel like a hostage in my house, I must continue looking after my children because I must live, I must eat"*

Society's expectations of some patients affected their attitudes towards their illness. LK said: *"Even at work they take it at my age (sixty one) I am more active than many youngsters"* BH said she was looking after her grandchildren and her demented husband because her children and relatives expected her to do so.

Some patients had learned ways and others had developed habits of minimising or getting around pain, like RS who said: *"If I think about it (the pain) I feel it, like people say - it's all in the mind"*. GB and FD said they requested people to rub their aching body parts to get relief from pain. GB said she was rubbed by her husband mostly at bedtime and FD requested co-workers to rub her upper and lower back intermittently at work. Exercises helped FX, LK and BH.

#### **11.2.2. Patients' perceptions and opinions about their illness and what they (patients) think are causes and/or precipitants of their illness.**

Three of the patients interviewed attributed a cause for their illnesses. GB said *"it started in my first pregnancy ... and with all my pregnancies it was worse"* suggesting that the pregnancies had something to do with the pains. GB felt that whatever illness she had could be detected if she was investigated. She expressed disappointment in the doctors who repeatedly told her that her symptoms were related to stress. She said: *"They say I've got stress ... They did not take blood or anything"*.

CO said she thought her symptoms were precipitated by a fall that occurred three years before her symptoms started. CO expressed her opinion about the aetiology of her illness by saying : *“Die dokter het gesê ek het nie ‘gefracture’ nie maar ek dink my ‘joints were disturbed’ in al twee hande”*. On the other hand FS thought all her symptoms were due to the fact that she had never had a holiday for two years and therefore was stressed. She said : *“my body is tired doctor”*.

AD who once had an X-ray for neck pain and was told that: *“my C5 - C6 is crumbling”* says he always thought he had both joint and muscle pain because he says *“rubbing my muscles aggravates pain”*. LK who’s general practitioner told him his pains were caused by acids accumulating in the joints and that he should avoid eating fatty foods says he ignored this explanation. He says he did not believe the explanation because : *“...there are many other people who eat fatty foods and they do not ache”*. His dietary habits had therefore stayed the same.

NY said she knew she did not have arthritis because *“iminwe yam ayikho ibi goso”* (my fingers do not get deformed).

### 11.2.3. Descriptions of symptoms

Six symptoms were repeatedly mentioned during the interview. The symptoms were pain (in different regions of the body), stiffness, insomnia, difficulty in turning in bed at night, of getting out of bed in the morning and fatigue. The symptoms were experienced differently with varying severity and they were not universally experienced by all the patients.

Regarding pain GB (who was troubled mainly by upper and lower back pains) said: *"When i bend, I can't stand up easily because of the heaviness in my back. It's like iron or...steel and it pulls me down...and it's like my lungs are left hanging ... and at the same time it's like someone is burning you with matchsticks"*. FX also complained of *"pricking pain"* in different parts of the body. BH said the pain in her upper back felt like *"many stab wounds"*. NY complained of *"iinyawo ziya qaqamba kusasa"* (throbbing pains in the feet in the mornings) and *"iingalo ziyasinda"* (heaviness in the arms). It was interesting to note that both men (LK and AD) were not descriptive about their pain.

CO's predominant complaint was stiffness which she experienced throughout the day. She said *"My hele liggaam is stok styf"* and she also said *"my hande is 'tense' "*. FX who on the other hand experienced

stiffness intermittently, said: *"Sometimes I am so stiff I can't bend properly"*. It was surprising to hear RS, who did not want to acknowledge her illness, admit *"I actually feel morbid in the morning!"*. On the other hand it was understandable when RS could not elaborate further because she is the patient who said she does not want to think about her pains. NY is the only patient who said she never experienced stiffness.

Insomnia affected all patients and those who were already put on sleeping tablets said they benefited a lot from them. RS said about her sleep: *"I can't actually fall asleep properly because my body is aching at night"*. CO said *"EK moet die pilletjies (i.e. low dose tricyclics) vat om to slaap"*. GB said: *"I sleep and then I wake up and then I sleep again and so on...because of pain"*.

There is a biological need for people to turn in bed at night when they are sleeping, to avoid developing pressure-sores. Most of us are unaware that we constantly turn in bed at night. However, some patients with FMS are aware. I was amazed at the intensity of the symptom of discomfort when turning in bed at night in some of the patients with FMS. LK said about turning in bed *"it is a struggle"*, BH said *"it is a task"* and AD said *"it is a process"*.

GB and FX said their main problem was the difficulty of getting out of bed in the mornings because their stiffness was at its worst at that time. The other patients did not express this problem .

The only complaint that was expressed by all the participants was that of fatigue. This symptom is, however, not experienced in the same way by the patients. CO is the only patient who said she felt tired all the time. NY experienced fatigue by midday regularly. All the other patients experienced fatigue intermittently and mostly towards the end of the day.

#### **11.2.4. Helpseeking behaviour**

It is not surprising that eight of the patients interviewed had “doctor-shopped” for many years because they were never satisfied with the different explanations given to them. I also worry when we (at our clinic) come up with a new diagnosis which is called FMS. This is tantamount to yet another “new story” for the patients and they might not buy it!

GB, who says the only common diagnosis given to her by different doctors was that of stress, said: “ *I went to different doctors but their medicines did not help*”. LK who never believed he had arthritis said: “*All*

*the time they just treated me for arthritis*". CO who 'chose' the diagnosis of rheumatoid arthritis among many labels she was given, told me : "*daar is nie 'n diagnosis nie*". NY is the only patient who relates being extensively investigated at a local secondary and tertiary institution (including CT of some body parts!) and says "*oogqirha abakhe batsho yintoni*" i.e. "*the doctors never told me what was wrong with me*".

Fear of malignancy is what made FX and NY go and see different doctors. FX says "*They (the doctors) thought it was arthritis and I also thought it was arthritis...one day I thought maybe I've got cancer*". NY was content because the doctors at least told her she did not have cancer. NY was also relieved when an HIV (Human Immunodeficiency Virus) test, which she requested, turned up negative.

Patients' attitudes (whether influenced by their genetic makeup or psychosocial aspects) also determined their helpseeking behaviour. For example RS who said she did not like to be sick and in fact was not acknowledging her symptoms only presented once to a doctor (myself). On the other hand CO was seen numerous times even by us because she seemed to have the highest sensitivity for her symptoms. GB has concomitant depression and this partly explains the numerous visits.

The availability or the lack of time influences helpseeking behaviour. BH, JS have been coming to see us only every three months as per appointments because they had responsibilities to attend to at home. FD came to see us after two years of having symptoms because she could not get time off at work and when she was off duty over weekends our clinic was closed.

#### **11.2.5. Consequences of having FMS - mainly loss**

For all the patients loss of a pain-free body was a common phenomenon. Loss of jobs was the second most common occurrence. FX, AD and JS resigned their jobs because they could not cope. FX and JS had been working as domestic workers and AD was a University Maintenance department labourer. AD was still angry about the loss of his illness benefits resulting from his practitioner's refusal to certify him medically unfit to work. NY, on the other hand, was fired by her employer, who she felt was more like a sister to her because they were literally reared by the same people, their mothers (NY's mother had also worked for the mother of NY's current employer). CO said she detested the loss of independence, because she had to literally rely on her sons with all the tasks she wanted to perform even with self-care. CO said: "...*Ek is nie*

*'independent' nie dokter. Ek kan ook nie 'privacy' kry nie...as ek winkel toe gaan, ek moet my 'boys' saamneem om die goedtjies te dra. Ek kan nie eers 'n pakkie suiker dra nie". JS said : "I feel like a hostage" in her house because she finds it a very painful and daunting task to climb the stairs leading to her upstairs flat.*

It appears as if the only positive thing that some patients experienced because of their illness was support from their families and friends. FD had her employers and co-workers support. Family support was obvious during the home interviews of AD, LK and RS but not NY, who clearly had a poor relationship with her husband and children.

#### **11.2.6. Fears, hopes and expectations of patients**

It is interesting that there was no mention of death during the interviews. However, when analysing the transcripts of the interviews the fear of death emerged in some cases although in an indirect way. For example when NY was asked if she had any wishes she said: *"Ndifuna ukungcwaba umama wam"* meaning "I would like to live long enough to be able to bury my mother". CO and FX expressed the wish to be able to live long enough to see their grandchildren. FX and NY were also fearing

cancer since cancer is known to kill people. NY related the township myth "*iCancer ...Kaloku kuthiwa oogqirha abokuxeleli xa unayo*" meaning "people say when you have cancer the doctors hide the diagnosis from you". I suspect AD was referring to his death when he made the following statement : "*I do not have fears for myself ... maybe for my family*".

There were other fears that came out. CO feared being crippled. She said: "*ek het baie mense gesien wat baie opgetrek is en ek is bang ...my ma was ook 'gecrippled' met arthritis*". NY's other fear was AIDS (Acquired immunodeficiency Syndrome). She told me she had actually requested an HIV test at the secondary hospital she had attended and was relieved when she was told it was negative. Regarding the reason for fear of AIDS NY said: "*kaloku kuthiwa ininzi ebantwaneni besikolo*" meaning "by the way, it is said AIDS is rampant among schoolgoing children". This statement is probably a reflection of the perception of ordinary folk about the HIV status of the community from which NY comes.

Other fears were fears of FMS being a systemic illness. For instance GB said; "*I worry about my lungs and kidneys. Dr I'd like to have X-rays to see what is happening with my lungs and kidneys*" and RS said: "*I was actually fearing a heart problem. I am so young, how could I have a heart problem?*" . JS's fear had to do with the flaws of our present health

delivery system related to the lack of hospital staff. JS said: *"My fear is being turned away from the Day Hospital and not getting my medicine!"*

There are several statements that were uttered by the patients which show that, despite their illness and fears, the patients had hopes and wishes. GB said: *"I do not have plans, I just want to see my children grow. I pray for me and my husband to get well and get work"*. RS said: *"I'd like my child to go to school and make the best of life"*. Interestingly most of the patients who have grown-up children centred their hopes around their grandchildren, presumably because they feel that they had failed their own children. AD said: *"My grandchildren, they are my hopes"*. When CO was asked if she had any hopes she said: *"Ek dink so want ek weet daar is 'n possibility om beter to raak...om eendag my kleinkinders te sorg"*. BH's wish is a secret and before she told me about it she requested me to switch off the tape!

## 12. DISCUSSION

### 12.1 Background of the patients interviewed.

Eight women and two men, whose ages were ranged from 20 to 67 years, were interviewed. There are several possible explanations for the excess of women in this cohort. Firstly, at Heideveld CHC, FMS sufferers are mainly women. Secondly, I know of only twelve male patients with FMS at our clinic (Heideveld) and most of them did not qualify for recruitment to the study because they could not articulate their symptoms explicitly. On the other hand, women seemed to have the ability to bring attention to their suffering very easily. This makes me wonder if this is probably another reason why FMS is diagnosed mostly in women than in men.

Seven individuals were married, all had children and five of them were grandparents. Two individuals were single mothers. The last patient was single but had to care for 2 of her younger siblings, for her sickly mother.

Regarding employment status, three individuals (LK, FD and RS) were employed. Five individuals (AD, JS, FX, CO and GB) had stopped working as a direct result of the symptoms of FMS. The only patient who was a housewife, was BH, who had never worked at all. One patient, NY,

was dismissed from work since her employer was intolerant of her inability to perform certain tasks due to the pain of FMS (washing high windows, hanging up the washing, etc). Although AD and JS could not cope with formal employment, being self-employed enabled them the freedom to work within their pain limits.

## **12.2 Patients' somatic complaints**

In this cohort, the duration of symptoms ranged from approximately 45 years to almost 2 years. I found the women to be more descriptive about their symptoms than men, so it was easier for me to empathise with the women. The women used a lot of symbolism to describe their symptoms. For example, BH said about her upper back pains: "*It is like stab wounds*"; GB said about the heaviness that she experienced at her upper back: " ... *it's like iron or ... steel and it pulls me down...*"; CO said about her stiffness; "*... my hele liggaam is stokstyf*" and FD expressed what she thought was the effect of stress on her body by saying: "*My body is tired, doctor*".

None of the the patients who were interviewed had concurrent illnesses except for GB, who was found to have concomitant major depression.

Although all the participants had initially presented with different complaints according to their hospital records, it was only when they were qualitatively interviewed that I realised that the patients experienced common symptoms of pain, fatigue, poor sleep, stiffness, difficulty turning in bed at night and difficulty getting out of bed in the morning. NY and LK used expressions which suggested that they were experiencing leg cramps and paraesthesiae.

There are several reports of hypotheses that have been proposed to explain the low threshold for pain in patients with FMS (**See section 2.2**). CO gave a history of a fall that precipitated her pains. This phenomenon of post-traumatic FMS has been discussed in the literature (6,7,16,17,18). CO is the only patient receiving a disability grant recommended by the visiting Consultant Rheumatologist of Heideveld CHC. She is the patient who was the most severely disabled by the illness. White *et al* (7), confirmed that post-traumatic FMS is the most disabling form of the illness.

Anch *et al* (24) and Carette *et al* (25) had studied EEG sleep patterns of patients with FMS and had found them to be abnormal. These researchers proposed that this non-restorative sleep pattern was a cause

of FMS. All our patients had poor sleep and, in fact, all had been prescribed low-dose tricyclic compounds to improve their sleep pattern.

FD suffered from stress and Urrows *et al* (21) had found that the tender point count correlated with the degree of daily stress. CO was suffering from concomitant depression and depression has been found to be associated with FMS in several studies (26-28).

All the patients in this cohort complained of fatigue, but to varying degrees. CO complained of fatigue most of every day, while RS said she experienced this symptom intermittently. None of the patients interviewed had criteria to suggest Chronic Fatigue Syndrome (CFS) (15) **[See Appendix 15.4].**

The difficulty with turning in bed expressed by 3 patients as being “a task”, “a process” and “a struggle” is probably related to the stiffness, a common symptom in patients with FMS (3,4,28).

None of the patients interviewed had irritable bowel syndrome, another symptom that is described in FMS (22,28,29).

### 12.3 Support structures for the patients

Religion seemed to play a major role in sustaining the patients in this cohort. AD said: *"I think religion keeps me going despite the pain"*. LK said: *"I am a Jehovah's witness. In my faith we do a lot of walking, we preach from door to door, so this keeps me active"*. GB said: *"I want to be able to work for my children. I hope God helps me"*. FX said: *"I did exercises and I prayed to the Lord"*.

Family, was a support structure for some participants. The two male patients seemed to have the best family support structures. This was observed during my visit to their homes for the interviews. There were other statements made by the patients which suggested family support. For example, GB said: *"My husband wrings the washing for me and hangs it"*; CO said: *"Ja, een ding dokter ek kan sê baie dankie vir die Here dat ek het sulke kinders .... hulle is supportive"*.

In one instance (FD), writing a letter explaining the nature of the patient's illness to the employers proved to be extremely useful in improving her work environment. The patient was now allowed to take regular breaks during work and her co-workers administered massage to the tender areas.

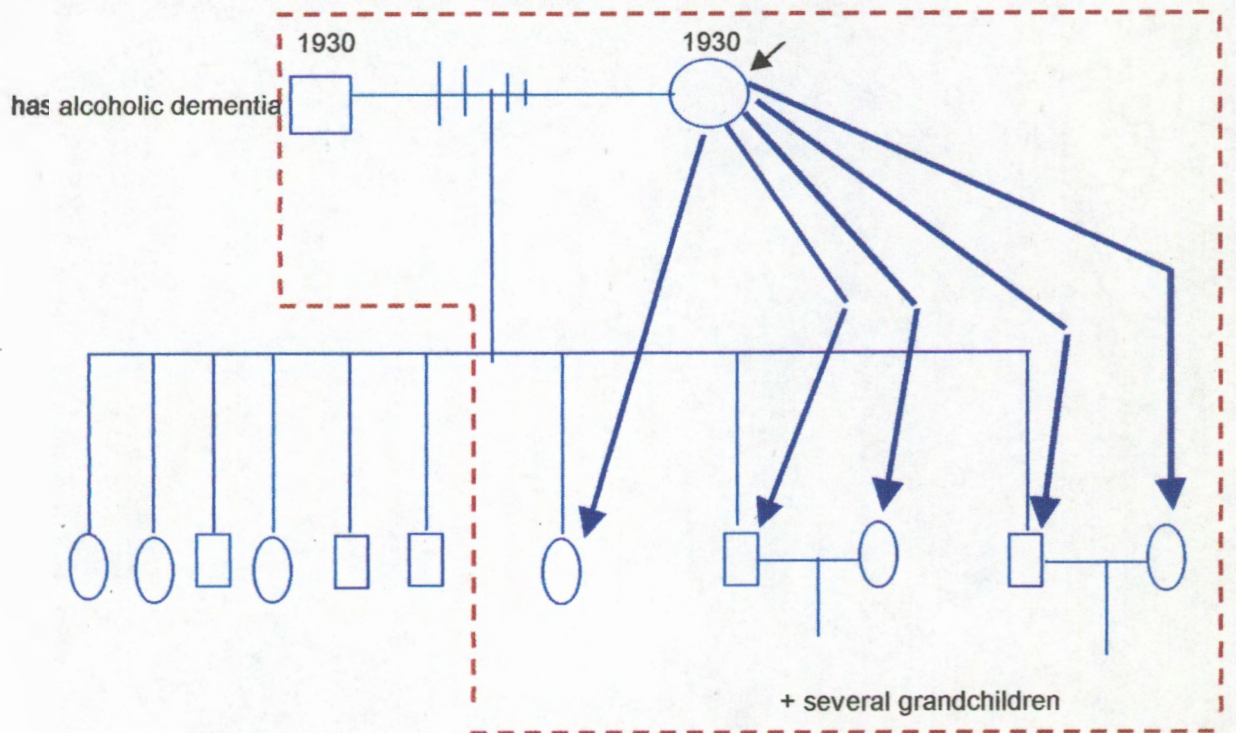
#### **12.4 Dysfunctional families detected during study**

Some form of abuse emerged in four cases (BH, NY, FD and GB). Boisset-Piero *et al* (41) did a study of sexual and physical abuse in women with FMS. Their results raised the possibility that physical, drug and sexual abuse may have an effect upon the expression and perpetuation of FMS in adult life. In the case of CO, it was strange to find that her 2 sons aged in their early twenties, had to be available to her at all times, so that they were unable to leave the home for their own needs.

These dysfunctional family interactions are illustrated in the genograms which follow.

**12.4.1 Genograms for the five dysfunctional families (See Appendix 15.6 for meanings of symbols)**

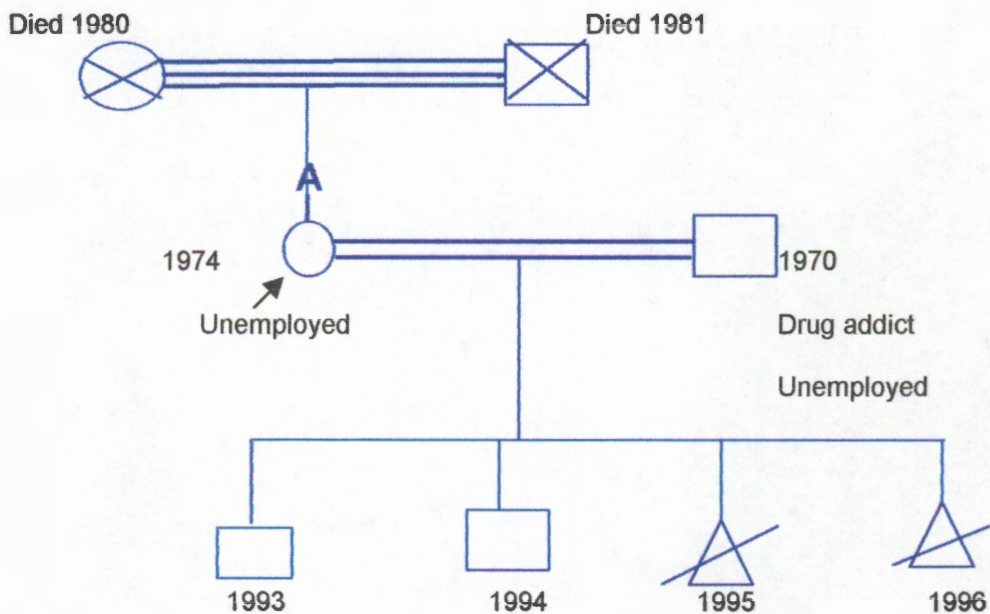
a) **BH:** A woman who has been abused physically and emotionally by her husband for many years, now has guilt feelings for detesting to look after her husband who is now demented. She has intense resentment and anger for her husband. BH also feels burdened by the task of looking after her grandchildren. I feel we may need to talk about these issues and work through these emotions. BH does not want her feelings to be disclosed to her family because she feels her family will lose respect for her if they knew about this.



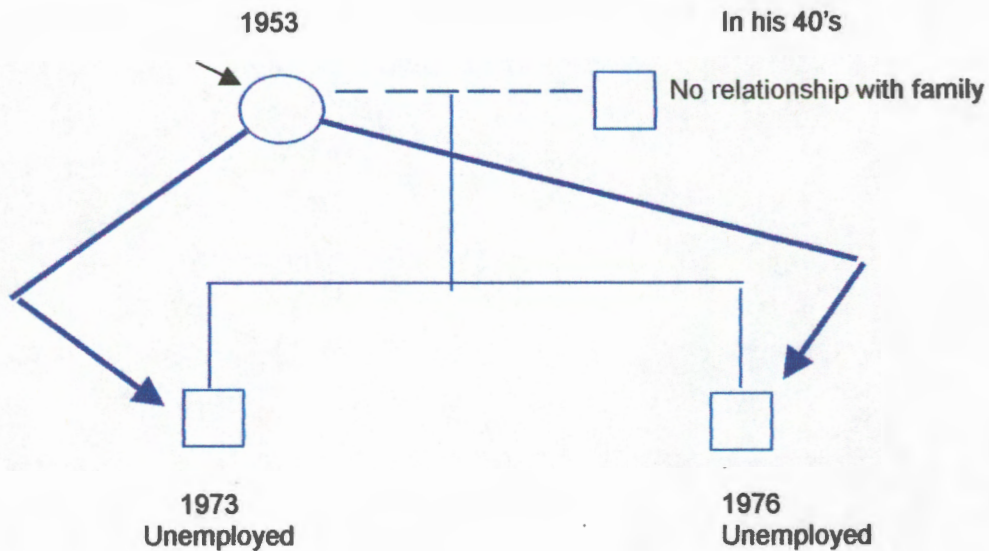
b) **GB:** She has a very sad past and she is also suffering from major depression. She is already receiving counselling and she has been started on antidepressant medication.

GB's husband is a drug-addict who agrees that he has a problem and in fact has attended drug-rehabilitation twice in the past two years without success. The last issue is GB's desire to be accepted by her step-father and stepsisters. She is meeting her mother secretly at the moment.

I must say GB's problems are overwhelming and I am in fact consulting colleagues to ask for advice on how to continue helping her.

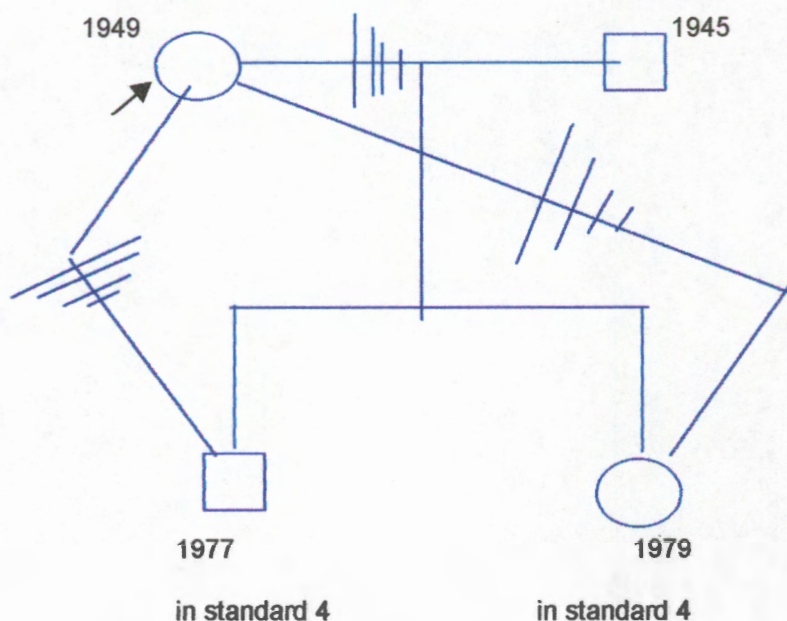


c) **CO:** is a patient who I used to regard as being top of the list of my "heart-sink patients". I had declared her to be somatically-fixated. Listening to CO's story has "converted" me and I have come to appreciate her suffering. I have also become aware of how her illness and its demands dominate her family life. Her sons appear to be a major source of her emotional and social support. I believe CO's sons need caring as well, and I hope to be able to attend to this. I feel like McDaniel *et al* (30) , who say by addressing the needs and stresses of the family as well as the patients, the physician can help promote the healthiest functioning of all concerned.

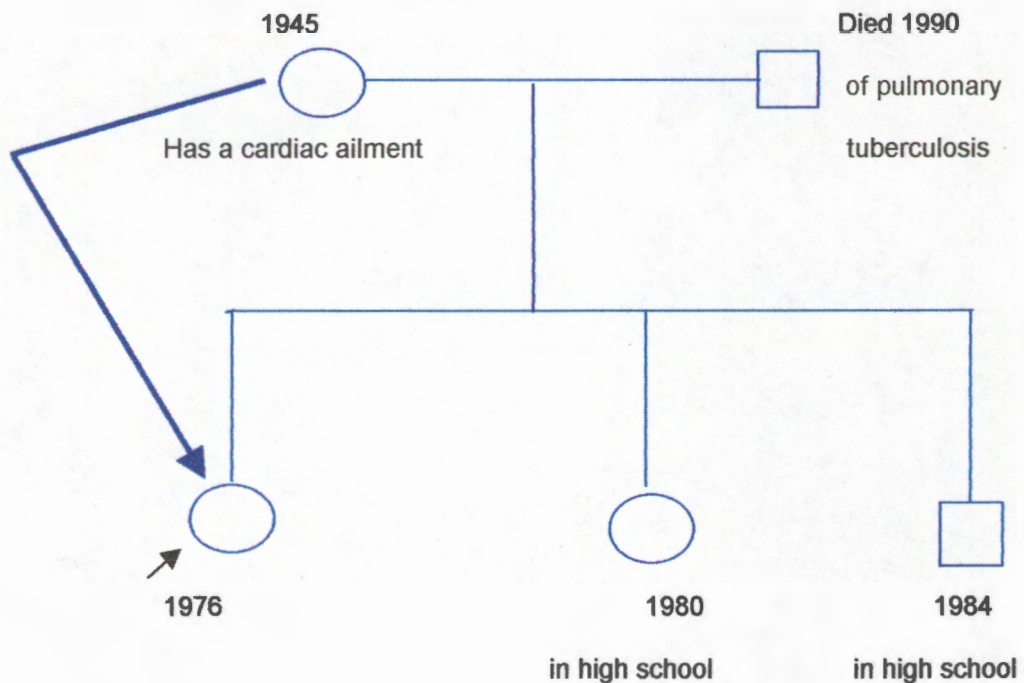


d) **NY:** Has clearly a dysfunctional family from what she said about them in the interview. I also noticed how she did not relate with her husband when I went to her house for the interview.

Another cue is the fact that NY said she could live with the pains after she was reassured by the hospital doctors that she did not have AIDS (and Cancer). Probably there is infidelity in the marriage as well. This is an issue that I wish to raise when NY comes for her follow up visit.



e) **FD:** She struck me as being a lonely figure with too many demands on her. FD is a “parentified” child who has a demanding job and too many responsibilities at home. She is thus stressed and socially isolated. I have written to her employers to explain her illness and FD subsequently told me that her employers are supportive and they, in fact, allow her to get breaks in order for a colleague to rub her back. We have agreed to call a Family conference to address the stresses that FD experiences at home. However, FD feels she has to talk to her mother (for whom she has great respect) first. She will contact me and tell me about her decision.



## **12.5 Patients' expressed needs**

Most of the patients' expressed humble needs: LK expressed the appreciation to be listened to; RS wanted a cardiac condition to be excluded and was otherwise content with her life; NY requested a temporary disability grant while she was looking for another job; FD requested a letter to her employers explaining her illness; JS needed to be guaranteed that she would receive her monthly medication from our CHC. CO was the only patient who needed numerous visits to the clinic for pain control. It was only after I read a paper by White *et al* (7) that I appreciated how post-traumatic FMS that CO was suffering from was disabling. White *et al* (7) say patients who have "reactive fibromyalgia", that is, FMS following trauma, surgery or a medical illness may have an especially poor outcome with one study documenting loss of employment in 70% and disability compensation in 34%.

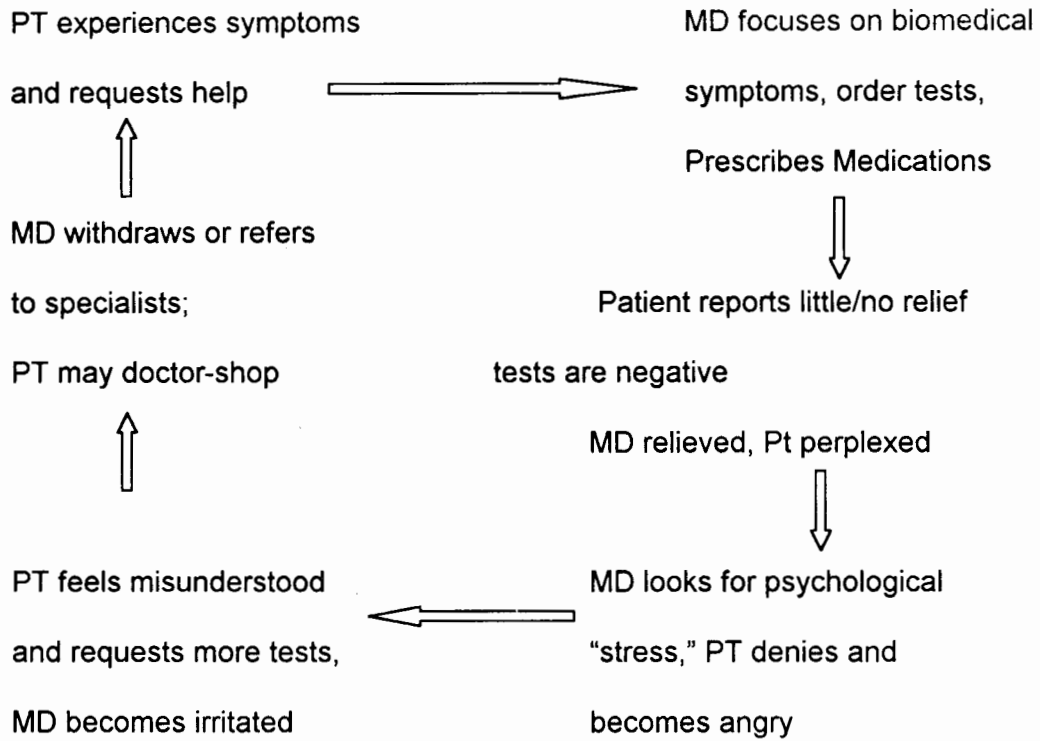
Some of the patients (FD, GB and CO) also expressed appreciation of involvement of their families. The usefulness of applying the principles of family orientated primary care in caring for patients with chronic illnesses is explained in a textbook written by McDaniel *et al* (39).

## **12.6 Other Interesting Findings**

### **12.6.1 Doctor-Patient emotions**

Balint (11) correctly says by far the most frequently used drug in general practice is the doctor himself. Patients with FMS - like any other patients with symptoms that cannot be explained to them, tend to doctorshop. Clearly, for this practice to stop amongst FMS patients the doctors have to be able to diagnose FMS with confidence. This can be achieved by educational exposure. I intend to share the findings of this study with colleagues at the Continuing Medical Education (CME) meetings in the Western Cape, and through a Family Medicine publication. Buskila *et al* (23) did a study in Israel which showed that family members were unfamiliar with the diagnostic criteria of FMS and that educational exposure improved their awareness and knowledge of this syndrome.

For myself, the process of interviewing my patients and listening to their stories about the suffering that they go through on a daily basis has engaged me as their doctor. I have come to realise that in most cases I, the doctor, had been the one who was somatically fixated. McDaniel *et al* (40) have, in their book, an illustration of a somatically fixated physician-patient interaction, to which I find myself relating closely, in retrospect.



PT = Patient

MD = Medical doctor

For me this self-awareness has led to my growth which I hope will benefit my present and future patients.

There are other important issues that have to do with for example dysfunctional family relationships that were brought out by the interviews of five participants. These issues cannot be ignored as they seem to have direct or indirect influences on the patients' illnesses. I have started working with the patients and involving family members in some cases to address some of the problems. I still have a lot left on my running agenda.

#### **12.6.2      Emerging Issues for the Researcher**

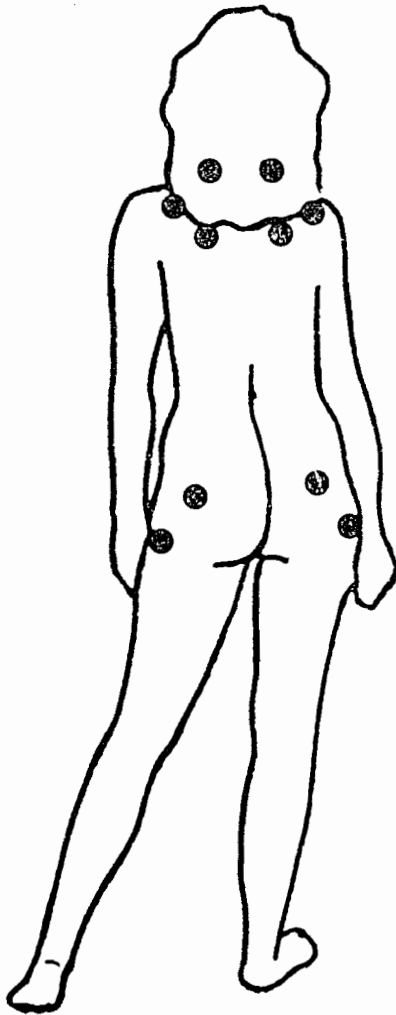
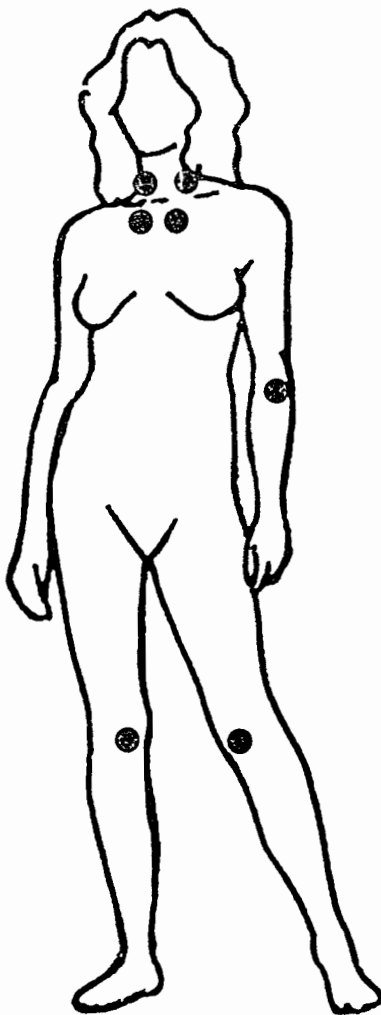
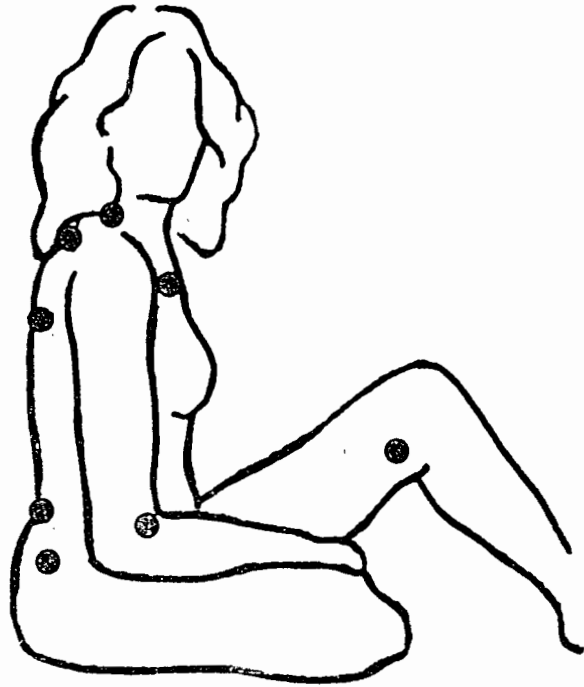
1.      Subsequent to the interviews I have been unable to bring a balance between maintaining a professional distance and nurturing the special and almost intimate patient-doctor relationships that have been most certainly promoted by the interviews. For example, one of the participants' spouses asked for my telephone number and I gave it to her reluctantly. How could I refuse her? After all I had been to her home - to interview her spouse!;
  
2.      Receiving secret information makes me feel like I now have to carry extra baggage! It also bothers me that not being able to refer to this information might affect the longterm management of the patient;

3. I found the feeling of inadequacy that the interviews evoked in me quite enormous. I felt as if I had been doing very little for the patients all along. It felt almost as if I had been cheating my patients by not giving them the opportunity to talk and thereby probably discovering more things about them that I needed to know as their doctor.

### **13. CONCLUSION**

- 1.** This study showed that qualitative research techniques were able to highlight the differences in perceptions, interpretations and experiences of a group of patients with primary FMS.
- 2.** The results showed that the impact of the disease varied among the different patients and ranged from minimal effect on lifestyle to severe disability from the FMS.
- 3.** This qualitative analysis of a small cohort of patients with FMS identified the similar patient characteristics as those described in larger quantitative studies of FMS patients.

APP 14.1 : FMS PICTURES



**App. 14.2 : NINE PAIRED TENDER POINTS OF FMS (refer to appendix 14.1.)**

1. Nuchal muscle insertions to occiput.
2. Midpoint of upper border of trapezius.
3. Inter-transverse process C5/6; C6/7.
4. Scapular spine origin of supraspinatus.
5. Costochondral junction 2nd rib (immediately lateral to CCJ).
6. 2cm below lateral epicondyle of humerus.
7. Origin of gluteal muscles from pelvis.
8. 2cm posterior to greater trochanter.
9. Medial fat pad proximal to joint line of knee.

### **APP. 14.3 : CRITERIA FOR CHRONIC FATIGUE SYNDROME (CFS)**

(15)

Unexplained, persistent or relapsing chronic fatigue lasting six or more consecutive months and that :

- Is of a new onset
- Is not the result of ongoing exertion
- Is not substantially relieved by rest

*and*

- Results in substantial reduction in previous levels of occupational, educational, social or personal activities

*plus*

four or more of the following symptoms occurring concurrently:

- Impairment of short-term memory or concentration
- Sore throat
- Tender cervical or axillary lymphnodes
- Muscle pain or multi-joint pain
- Headaches
- Unrefreshing sleep
- Postexertional malaise

#### APP. 14.4 : QUESTIONNAIRE

Consent to be involved in study. No invasive procedure. Strict confidentiality maintained.

\_\_\_\_\_Signature

1. Study Number
  2. Name
  3. Address
  4. Age
  5. Date of Birth
  6. Date (of presentation)
  7. Sex  
Male  
Female
  8. Marital Status  
Single  
Married  
Divorced  
Separated  
Widowed
  9. Employed  
Yes  
No
  10. Religion  
Moslem  
Hindu  
Christian  
Other
  11. Children  
Yes  
No
  12. Other illness  
Yes  
No
- If Yes, explain \_\_\_\_\_

#### App 14.5: INTERVIEW WITH GB

- Dr : You told me you have been ill for some time. Can you recall for how long....plus or minus?
- GB : It started with my first pregnancy. My boy is four years old now.
- Dr : Mm
- GB : ...and then with all my pregnancies it was worse. It is four years now since I have this pain.
- Dr : Did the pain start before, during or after the pregnancy?
- GB : It started whilst I was pregnant, I thought it was morning sickness..... maybe.
- Dr : So you mean it (the pain) started with the first pregnancy and it has been present all the time but the pain is getting worse during each pregnancy?
- GB : Yes Doctor.
- Dr : How many children do you have?
- GB : I've got two that are alive and then I had two miscarriages. My last miscarriage was five months ago. So I've got two boys.... four and three year olds and two miscarriages.
- Dr : Tell me.... who have you consulted before for your body pains?
- GB : I went to different doctors....but their medicine did not help.
- Dr : What did they (the doctors) say the problem was?
- GB : They said I've got stress. They did not take blood or anything.
- Dr : So, they told you your illness was stress?

GB : Yes.

Dr : Why did you think it was necessary to have blood taken?

GB : Because I am sore and I feel tired (flat voice).

Dr : Any advice that they (the doctors) gave you?

GB : Yes, that I must talk to someone.

Dr : Did you talk to 'someone' or a counsellor perhaps?

GB : No. I (I sensed reluctance to talk so I didn't push for the answer but instead continued with the interview).

Dr : What have you done to help yourself....to ease the pain?  
Any remedies that you used perhaps and so forth?

GB : No.

Dr : No! No remedies?

GB : No.

Dr : OK...What do think is the cause of the pain?

GB : I thought my problem is with my lungs and my kidneys because I am mostly sore and stiff here (showing back of neck, upper back and shoulders) I....

Dr : Mm

GB : I told the doctors my lungs, my kidneys and my joints here (showing upper arms and elbows) are sore.

Dr : Tell me about your family....briefly?  
[I sensed again that patient was reluctant to talk and noticed tears in her eyes. I switched off the tape recorder and did not know what to do next. The silence was awkward and so I held the patient's hand. I was now thinking of stopping the interview but then the participant started crying and talking! She told me she has had 'bad luck' since she was a baby. Her mother gave her away because she was the product of

a rape. Her foster parents were 'good' but they both died 'quickly'. She was then raised by her grandfather - 'foster grandfather' she called him.

Grandfather was a pensioner and there was no money and so she left school early. She has re-established contact with her biological mother but they meet secretly because her stepfather and three step sisters don't want her. Her husband is supportive but he is a drug addict and cannot keep a regular job. The patient is also not employed. GB appeared calm after this talk so I asked for permission to tape the rest of the interview].

- Dr : Have you spoken to your mother about the pains?
- GB : Yes. In fact she would like you to explain to her what is wrong with me. She said I must give you her number (telephone number). My mother has had diabetes and a stroke and she is worried about me.
- Dr : Mm
- GB : My aunt has also high blood (ie hypertension) and so my mother is worried.
- Dr : OK. I'll take her number and I'll phone her. She appears to be caring for you.....and supportive.
- GB : Yes.
- Dr : What about your husband?
- GB : He's waiting outside. We came together this morning. He rubs my back with strong 'salf' (methylsalicylate ointment) that you gave me.
- Dr : That's very nice. I'll talk to your husband before you leave.....Tell me about your symptoms? I'd like to know how you function from morning to evening.... in spite of your pains.
- GB : I've got difficulty getting out of bed and dressing up because I'm very sore and stiff in the mornings.

Dr : Mm

GB : Then I move a little and I feel these cramps in my body.

Dr : Yes.

GB : ...and then I've got a burning feeling in my lungs and in my shoulders.

Dr : Mm

GB : Right down (indicating from shoulders to legs). I've got pains.

Dr : Yes, and as the day progresses?

GB : The pain remains strong and during the day when I do my washing i feel it, especially at the back.

Dr : So you cope with your washing. Is it hard doing the washing?

GB : Yeah. My husband wrings the washing for me and hangs it. I struggle to hang the washing.

Dr : Why?

GB : I struggle with washing and hanging.... when I bend I can't stand up easily because of the heaviness in my back.

Dr : Heaviness?

GB : Its like iron or.... steel and it pulls me down from here (shows upper back) .... and its like my lungs are left hanging.

Dr : Yes.

GB : It is how heavy the pain feels.

Dr : Mm

- GB : At the same time the pain is burning like someone is burning you with matchsticks.
- Dr : You mean like fire?
- GB : Yes.
- Dr : And in the evening? You told me last time when I first saw you that you feel tired most of the time. Are you able to prepare meals in the evening?
- GB : I do prepare food but I feel very tired. Sometimes my husband helps.
- Dr : How is your sleep at night?
- GB : I've got difficulty in sleeping.
- Dr : How?
- GB : I sleep and then I wake up and then I sleep again and so on.
- Dr : Why?
- GB : Because of the pain.
- Dr : Some patients with your illness tell me it is difficult to turn in bed. Is it the same for you?
- GB : No. Its only difficult when I've got to get out of bed.
- Dr : Oh. Tell me about your children. Your boys are four and three (years old) they must be at an energetic stage. How do you manage to look after them?
- GB : I do manage with them but when I am too tired I shout at them too much.
- Dr : So you are able to look after them?
- GB : Yeah. I look after them but I get very tired. At night I'm very tired.

Dr : OK. Do you have any friends?

GB : No I don't have friends.

Dr : You told me you lost your last job as 'security' (security officer). When was this and why?

GB : I worked for six months and I was off, then I worked for four months and then I was off again. I could not manage with pain.

Dr : Mm

GB : I stood too much at work and my feet were paining also.

Dr : Mm

GB : I had to walk a lot and I was also getting cramps.

Dr : Mm. So when did you stop working?

GB : Two years now.... or two and a half years.

Dr : Tell me about your hopes... your wishes?

GB : I hope this illness should go away. I want to live a normal life like other people

Dr : Mm

GB : I want to be able to work for my children. I hope God helps me.

Dr : Are you religious?

GB : Yes, I'm Moslem.

Dr : Do you have any fears?

GB : I worry about my lungs and kidneys. Doctor I'd like to have X-ray to see what is happening with my lungs and kidneys.

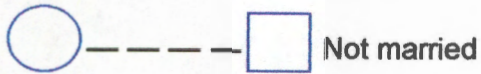
Dr : We will talk about that. Do you have any plans for the future?

GB : I do not have plans, I just want to see my children grow. I pray for me and my husband to get well and get work.

Dr : Thank you.

## APP 14.6. Explanation of Genogram Symbols (42)

Year of birth (19..).



## 15. REFERENCES

1. Bauman S.E. **Chronic pain management and psychiatry.** Continuing Medical Education Journal. 13 (10): 1187-1194, Oct 1995
2. McWhinney J.R. **A textbook of Family Medicine.** Oxford University Press (1<sup>st</sup> Edition). p. 4, 1989
3. Hench P.K. **Nonarticular rheumatism, Twenty-second rheumatism review: Review of the American and English literature for years 1973 and 1974.** Arthritis and Rheumatism (suppl) 19: 1081 - 1089, 1976.
4. Doherty M. and Jones R. **Fibromyalgia Syndrome.** British Medical Journal (SA Edition) 4: 759 - 762, April 1996
5. Wolfe F. *et al* **The American College of Rheumatology 1990 Criteria for the classification fibromyalgia.** Arthritis and Rheumatism: 33 (2): 160 - 171 1990
6. Littlejohn G. **Soft tissue rheumatism today.** Modern Medicine. 19 (7): 106 - 122 Jul 1994
7. White K.P. *et al* **Work Disability evaluation and the fibromyalgia syndrome.** Arthritis Rheum . 24 (6): 371 - 381, Jun 1995.

8. Wolfe F. **Fibromyalgia in the elderly: differential diagnosis and treatment.** *Geriatrics* 43 (6): 57 - 60, 65, 68, Jun 1988
9. Buskila D et al. **Assessment of non-articular tenderness and prevalence of fibromyalgia in children.** *Journal of Rheumatology* 20: 368-370, 1993
10. Murphy and Mattson B. **Qualitative Research in Family Practice: A marriage made in Heaven.** *Family Practice.* 9 (1): 85-91, 1992
11. Balint M. **The Doctor, His Patient and the Illness.** Churchill Livingstone (2<sup>nd</sup> Edition). Ch I: 1-8, 1963
12. Meyer H.P. **Fibromyalgia Syndrome. Part 1: Explaining the general body pains and fatigue of the nineties.** *South African Family Practice* 18 (1): 32-35, Feb/Mar 1997
13. Meyer H.P. **Fibromyalgia Syndrome. Part 11: The Pathophysiology and Management of FMS.** *South African Family Practice* 18 (2): 24-27, April 1997
14. Meyer H.P. **Chronic Fatigue Syndrome: The fibromyalgia approach.** *South African Family Practice* 17 (1): 14 - 21, Jan 1996
15. Tally N. J. **The Tired Listless Patient.** *Therapeutics* 2 (3) : 28 - 33, Jul 1997

16. Lydell C. **Fibromyalgia in the work place.** Rheumatology 8 (1): 2 – 4, 1995
17. Wolfe f. **Post traumatic fibromyalgia: a case report narrated by the patient.** Arthritis Care and Research, 7 (3): 161 - 165, Sep 1994
18. Culclature T.F. *et al* **Post traumatic stress disorders presenting as fibromyalgia.** American Journal of Medicine 94 (5): 548 - 9, May 1993.
19. Moutz J.M. *et al* **Fibromyalgia in women. Abnormalities of regional cerebral blood flow in the thalamus and the caudate nucleus are associated with low pain threshold levels.** Arthritis and Rheumatism, 38 (7): 926 - 938, Jul 1995
20. Tayler M.K. *et al* **The prevalence of sexual abuse in women with fibromyalgia.** Arthritis and Rheumatism 38 (2): 229 - 234, Feb 1995
21. Urrows S. *et al* **Unique clinical and psychological correlates of fibromyalgia tender points and joint tenderness in rheumatoid arthritis.** Arthritis and Rheumatism, 37 (10): 1513 - 1520, Oct 1994
22. Fibromyalgia (fibrositis) syndrome pamphlet. Published by Arthritis Foundation, Roggebaai, south Africa 1995.

23. Buskila D et al. **Awareness of diagnostic and clinical features of fibromyalgia among family physicians.** Family Practice 14 (3): 238-241, 1997
24. Anch A.M. *et al* **Sleep physiology aspects of the fibrositis (fibromyalgia) syndrome.** Canadian Journal of Psychology, 45 (2): 179 – 184, June 1991
25. Carette S. *et al* **Sleep electroencephalography and the clinical response amitriptyline in patients with fibromyalgia.** Arthritis and Rheumatism, 38 (9): 1211 - 1217, Sept 1995
26. Yunus M.B. *et al* **Relationships of clinical features with psychological status in primary fibromyalgia.** Arthritis and Rheumatism, 34 (1): 15 - 21, Jan 1991
27. Goldberg D.L. **Psychological studies in fibrositis.** American Journal of Medicine 81 (3a): 67 - 70, Sept 1986
28. Vitali C. *et al* **Fibromyalgia features in patients with primary Sjogren's syndrome.** Evidence of a relationship with psychological depression. Scandinavian Journal of Rheumatology, 18 (1): 21 - 27, 1989
29. Gaston-Johanson F. *et al* **A comparative of feelings , attitudes and behaviors of patients with fibromyalgia and rheumatoid arthritis.** Social and Medicine 31 (8): 947 – 952, 1990

30. Quimby L.G. *et al* **Fibromyalgia: generalised pain intolerance and manifold symptoms reporting.** Journal of Rheumatology, 15 (8): 1264 - 1270, Aug 1988
31. Robbins J. M. *et al* **Illness, worry and disability.** International Journal of Psychiatry in Medicine. 20 (1): 49 - 63, 1990
32. Jacobson S. and Danneskold-Samsøe **Inter-relationship between clinical parameters and muscle function in patients with primary fibromyalgia.** Clinical and Experimental Rheumatology, 7 (5): 493 - 498, 1989
33. Granges G. *et al* **Fibromyalgia Syndrome: assessment of the severity of the condition 2 years after diagnosis.** Journal of Rheumatology, 21 (3): 523 - 529, Mar 1994
34. Medical Research Council (Cape Town) ; **Qualitative Research Notes 1997**
35. Coleman T. *et al* **Sampling for qualitative research using quantitative methods. 1 Measuring GPs' attitudes towards discussing smoking with patients.** Family Practice 13 (6) : 526 - 530, 1996.
36. Hoffman H.R. **Qualitative Inquiry in Medical Research** J.Clin. Epidemiol 42 (1) : 29 - 36, 1993

37. Marshall M.N. **Sampling for qualitative research.** Family Practice 13(6): 522 - 525, 1996.
38. Bierman J. and Muller M. **The view of Primary Health Care practitioners regarding legal limitations influencing the practice of Primary Health Care nurses in South Africa.** Curationis 17 (3): 29 - 32, 1994
39. McDaniel S. et. al. **The developmental challenges of chronic illness .** The Family-Oriented Primary Case - A Manual for Medical Providers. Springer-Verlag (1<sup>st</sup> Edition). Ch 15: 229-247,1990
40. McDaniel S. et al. **Integrating the Mind-Body-Spirit. A biopsychosocial approach to Somatic Fixation.** The Family Orientated Primary Care - A Manual for Medical Providers : Springer-Verlag (1<sup>st</sup> Edition). Ch 16: 248-262
41. Boisset-Piore MH et al. **Sexual and physical abuse in women with fibromyalgia syndrome.** Arthritis Rheum 38 (12): 235-241, 1995
42. Teichler MJ et al. **Family genogram.** SA Family Practice Manual. A Fraser (Ed). Vol 1-12, 1:13, May 1995
43. McWhinney I.R. **Illness, suffering and Healing.** A Textbook of Family Medicine. Oxford University Press (1<sup>st</sup> Edition). Ch 6: 72-86, 1981