UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCE

School of Nursing and Midwifery

Engaging Families with a Premature Family History of Heart Disease: A Primary Prevention Study for Coronary Heart Disease

by

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ABSTRACT

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Engaging Families with a Premature Family History of Heart Disease; Primary Prevention for Coronary Heart Disease

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This thesis focuses upon a preventative approach for people with a familial history of premature coronary heart disease. The research study had two aims; firstly to understand the experience of individuals when their parent or sibling had been diagnosed with heart disease; secondly to develop and evaluate a primary prevention health promotion programme for these people. The thesis provides unique insight into their personal experiences of living with this familial diagnosis and gives details of how this population can be identified and involved successfully in a health promotion programme.

The study was conducted in a district general hospital; 28 people were recruited of whom 20 participants completed the two year study. Narrative interviews were conducted at the beginning and end of the study, providing insight into people's personal experience. Salutogenesis is the theoretical framework in which the narratives are discussed; from these health resources are identified which can enhance people's progress and maintenance for a healthy lifestyle.

The health promotion programme has established, developed and evaluated a nurse-led and doctor supported primary prevention strategy. Education and support was provided in the programme for individuals and families. The participants' physical and behavioural changes were reviewed six monthly, for two years. People are aware of risk factors associated with heart disease, but still seek professional support and advice in relation to their own lifestyle and behaviour. Individual lifestyle changes were achieved by most participants, which translated into significant findings for blood pressure and alcohol consumption; positive changes were seen in physical activity, smoking, diet and psychosocial stress. There were no improvements in lipid profiles.

The need for a preventative approach in health care, which includes primordial and primary prevention for heart disease, is discussed. The issues in this thesis are reflective upon current government focus to develop preventative health services which actively engage with people as integral to this process. The thesis discusses coronary heart disease, the roles of prevention and health promotion, and identifies health resources for people at high-risk of future cardiovascular problems.

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To all of you, "Thank you!"

ABBREVIATIONS

BFH	British Family Heart study
BHF	British Heart Foundation
BMI	body mass index
BP	blood pressure
CAC	coronary artery calcium
CAD	coronary artery disease
CHD	coronary heart disease
CVD	cardiovascular disease
DH	Department of Health
DM	diabetes mellitus
ECG	electrocardiogram
GP	General Practitioner
GRR	general resistance resources
HEART UK	Hyperlipidaemia, Education and Atherosclerosis Research Trust UK
HDL	high density lipoprotein
LDL	low density lipoprotein
LREC	local research ethics committee
MI	myocardial infarction
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
OXCHECK	Oxford and Collaborators Health Check Trial
PFH	premature family history
RCT	randomised controlled trial
R & D	Research and Development
SOC	sense of coherence
SPSS	statistical package for the social sciences
UK	United Kingdom
USA	United States of America

CHAPTER ONE

Introduction to the Study and Thesis

1.1 Chapter introduction

This first chapter serves to introduce the study and the thesis. The personal background describes how my interest in heart disease has developed over the years as my work in cardiology has changed. My degree has provided me with a unique opportunity to develop this research study in an area of cardiology that is of great personal interest to me and in which I feel, as a nurse, I can make a valuable contribution. The study synopsis outlines the three phases of the research. An introduction to the thesis is provided with a brief description for each chapter, in order to give a clear overall picture of the thesis as a whole.

1.2 Personal background

This study has developed from a personal wish to improve people's health. I concur with Wanless (2004), when he says that in the National Health Service (NHS) we should not just be concentrating on illness, and the treatment of disease, but upon disease prevention and wellness, so that people have the opportunity to live free from disease and are able to reach their full potential.

Soon after I initially qualified I worked in an acute coronary care unit. We nursed men and women, from their twenties to their nineties, all admitted to the unit with heart problems. Once these people had been diagnosed with heart disease they were given extensive advice, support and guidance on a personal level, along with treatment and medication. I found working on the coronary care unit immensely satisfying as I was able to make a very real contribution to the health and wellbeing of my patients. Clinical research continues to prove the benefit of established acute and long-term treatments, and investigates potential new ones. In addition, the secondary prevention and rehabilitation programmes make a substantial contribution to a person's morbidity and mortality when the patient is able to make and sustain healthy lifestyle behaviour. My work now as a cardiac research sister continues to give me insight and first hand experience into what it actually means for individuals, and their families, when they come to terms with their heart condition and the impact and consequences it has on their daily lives. The focus for the research department's work is on the treatment for those diagnosed with heart disease.

While working on the coronary care unit I completed my BSc (Hons) in Health Promotion. After completing my degree I wanted to continue my academic studies and expand my knowledge about coronary heart disease (CHD), while combining this with my interest in health promotion. The subject matter was easily chosen, heart disease and prevention. Heart disease we are told is 'largely preventable' (Yusuf et al., 2004). If this is the case, then why are we not doing more to prevent it? Through my first degree I had learnt about the issues associated with heart disease in the context of health promotion. In my work I felt frustrated knowing that more could be done to prevent this disease from developing in the first place. Heart disease, although a macro problem, can be considered on a micro level when we identify those at increased risk. Taking into account these issues, a research study was designed which would provide screening and health promotion for people at increased risk of developing heart disease. It was important, and useful, to have a qualitative aspect to the study, where this data would give greater understanding from those involved.

1.3 Study synopsis

When a diagnosis of premature coronary heart disease is made, the first-degree relatives (the person's parent, sibling, or child) of the patient are themselves at increased risk of CHD. This study had two primary aims; firstly to understand the experience of individuals when their parent or sibling is diagnosed with CHD and to investigate how this experience has subsequently influenced their own lifestyle and health behaviour. Secondly, to develop and evaluate a primary prevention health promotion programme for these first-degree relatives. It was a two-year programme of education, lifestyle assessment and support, in order that these people's long term risk of developing heart disease might be reduced.

As a consequence the study endeavoured to answer two questions:

1) "What is it like to be diagnosed with coronary heart disease in a family?"

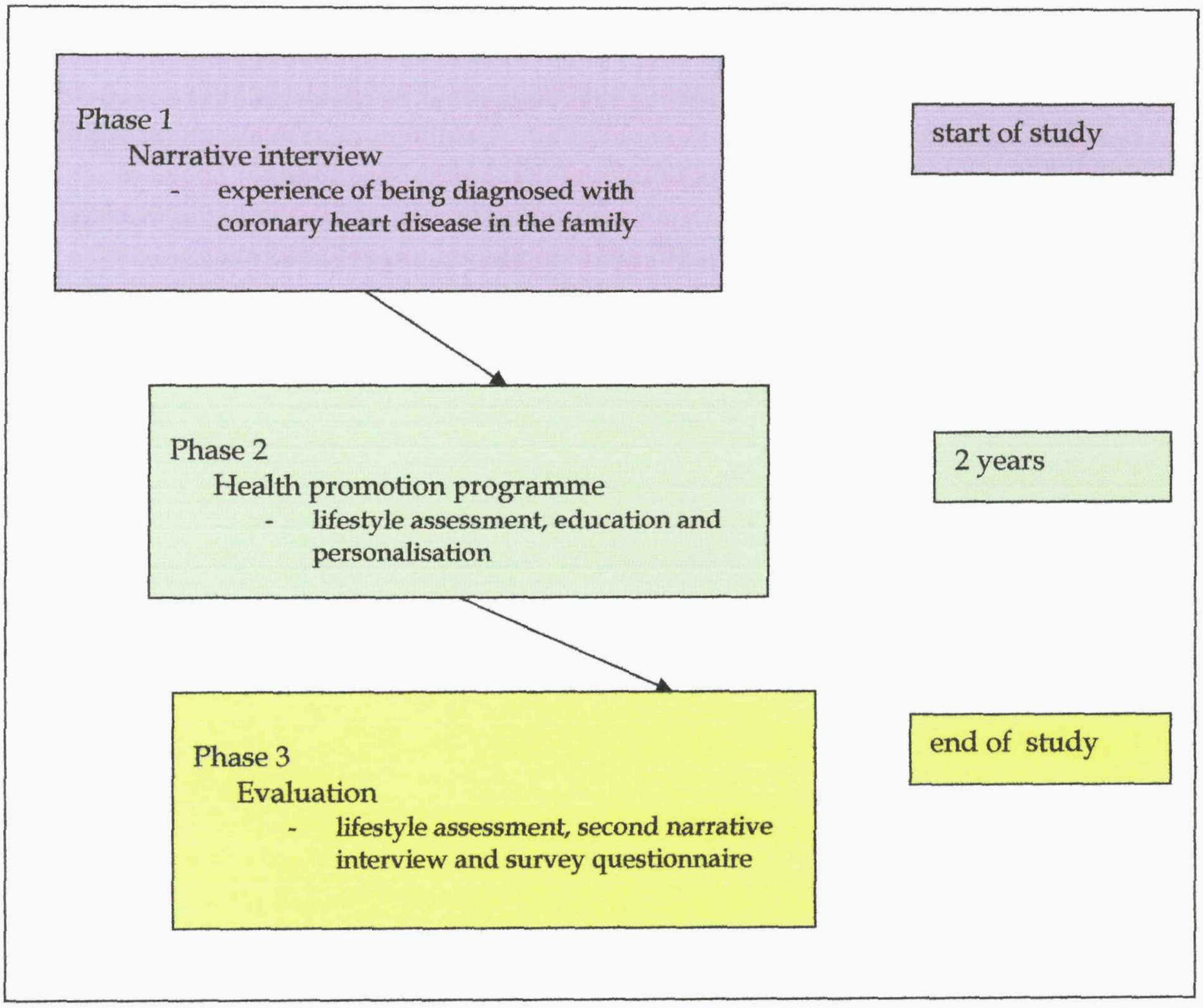
and

2) "Will a two year health promotion programme result in an improved and sustained lifestyle profile?"

The participants in the study are people who had parents or siblings who have been diagnosed with premature CHD. The study participants were firstly invited to relate their experience concerning this legacy of CHD within their family and secondly to participate in a health promotion programme. According to the official guidelines (DH 2000; Wood et al., 2005) the age for men to be classified with premature CHD is 55 years of age or less, and for women it is 65 years of age or less. When a person was diagnosed with premature CHD, they were screened to see if they had adult children over 18 years of age, or siblings, without overt CHD, and it was these adult children and siblings who were invited to participate in the study.

The study was divided into three phases: the initial narrative interview at the start of the study; the lifestyle assessment and health promotion programme; and the final evaluation phase. The duration of the study was two years. Figure 1.1 illustrates these three phases.

FIGURE 1.1 Study phases and outline



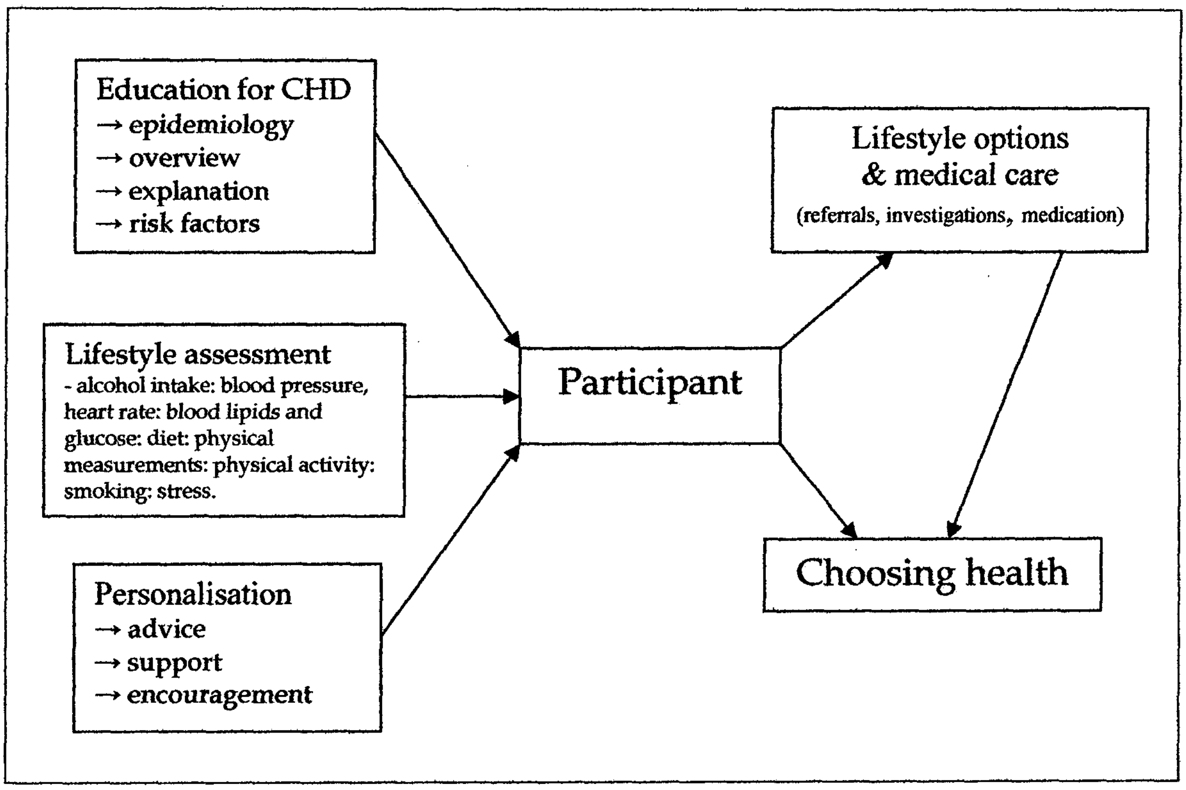
Phase 1 ~ Narrative interview

Two narrative interviews were conducted with each participant in which they were encouraged to tell their own stories. The first interview took place at the beginning of the study before the participant attended the health promotion programme.

Phase 2 ~ The health promotion programme

Participants were asked to attend a minimum of five six-monthly hospital based health promotion clinic appointments, with the researcher, over a two year period. The health promotion programme had three main components: education, lifestyle assessment, and personalisation. The personalisation component was when people were given individual advice, support and encouragement as appropriate to their own personal needs and wishes. With these three components the participant was then in a position to consider their health options and alternatives. Figure 1.2 provides a graphic conceptualisation of the programme. Some participants did not require or wish to make changes to their lifestyle assessment, for those who did make changes support and encouragement was given. While for some, referrals, further investigations, or medication was necessary. Inclusion of family members and partners, to take part in these sessions with the participant, was encouraged.

FIGURE 1.2 The health promotion programme



A comprehensive education folder was developed for use within the programme which provided standardised information. At the end of each consultation, participants were given supporting literature and leaflets, produced and printed by the British Heart Foundation, and their lifestyle assessment sheet to take away. Consultations were usually kept to an hour, unless time constraints and long travel distances made it easier and more practical to have a longer session. Participants were encouraged to return for further visits between their six-monthly appointments if required.

Phase 3 ~ Final evaluation

The final evaluation had three components. Firstly, the personal lifestyle and risk assessment, which measured changes in overall cardiovascular risk and behaviour patterns since the start of the programme. This was followed by the second narrative interview where participants were invited to recount their experiences of the challenges they faced when making possible changes to their behaviour and lifestyle. Finally, a survey questionnaire providing participant feedback and evaluation of the health promotion programme.

1.4 Introduction to the thesis

This next section provides a brief summary for each chapter; it serves as an introduction to the contents and purpose for each chapter individually and for the thesis as a whole.

Chapter 2 ~ Coronary heart disease and social context

This chapter provides an explanation of heart disease, including a description of the pathogenic process while distinguishing between coronary heart disease and cardiovascular disease. It identifies the historical studies which have provided the evidence for the risk factors associated with cardiovascular disease. Social context is discussed by illustrating the extent of the problem both nationally and internationally. The stance of the United Kingdom (UK) Government towards prevention, when the study was initially developed up to the current time of publication, is highlighted. This chapter will clarify the essential aspects of heart disease, providing details of the pertinent contextual issues in relation to the problem.

Chapter 3 ~ Research literature review

The research and literature associated with the aims of this study are identified, explored and discussed. This is divided into four parts, where each part looks at specific aspects of the research: the levels of prevention in heart disease and cardiology; the preventative studies which have been undertaken in the UK in a clinical setting; the research which has identified family history as a risk factor for coronary heart disease and finally, qualitative research which has looked at the experience of people diagnosed with a family history of a chronic disease.

Chapter 4 ~ Study design, method and theory

Details of study design, research methods and ethical considerations are identified and discussed. An overview of data analysis is provided in the chapter. Salutogenesis (Antonovsky 1987), the theoretical framework, is introduced and the relevance of salutogenesis for this study and thesis explained and explored. The transtheoretical model, the stages of change (Prochaska & DiClemente, 1983), is discussed as this was used in association with salutogenesis, in order to promote health behaviour changes.

Chapter 5 ~ Phase 1 ~ exploring the experiences

This is the first of three results chapters, which deal in turn with each of the study's three phases; it is divided into two. Personal and family demographic details of the study participants are provided. Secondly, explanation of the narrative analysis and details of the results from these interviews.

Chapter 6 ~ Phase 2 ~ the health promotion programme

Comprehensive details of the two year health promotion programme are given. The individual risk factors which were assessed during the programme are covered, with a short introduction for each topic. Tables are used to illustrate and summarise the findings from the programme.

Chapter 7 ~ Phase 3 ~ final evaluation

The final results chapter provides details of the second narrative interview, and includes results of the evaluation survey. The chapter provides evidence from participants concerning their experience of being involved in the health promotion programme, and how this has influenced their views about their own health with resultant positive, or negative, changes to their lifestyle behaviour.

Chapter 8 ~ Discussion

This chapter brings together key components from the preceding chapters. The results from the three phases of the study are integrated and discussed in relation to the study aims and within the salutogenesis theoretical framework.

Chapter 9 ~ Conclusions

This final chapter will identify key issues that have been learnt from the research and how these are relevant for nurses and allied health professionals, in the context of these first-degree relatives. Recommendations for how aspects of the study may be used within future health care strategies and initiatives are all identified. How these results may be built upon for future work and further research, is clarified.

1.5 Summary

Through the personal information given regarding my nursing and research interests the focus for this work has been shown, illustrating how the research study grew from my interest in cardiology and health promotion. A concise description of the study has been provided detailing the aims of the research and the phases of the study. An overview of each chapter provides an introduction to the thesis. The next chapter will provide an explanation of coronary heart disease with information regarding associated risk factors. Details of the extent of the disease will be shown which illustrate the importance and relevance for this research within UK health care.

CHAPTER TWO

Coronary Heart Disease and Social Context

2.1 Chapter introduction

This chapter provides an introduction to coronary heart disease (CHD). The first part of the chapter states the extent of the disease, both nationally and internationally; the second part examines the aetiology and pathophysiology of cardiovascular and heart disease, explaining the concept of risk factors and the evidence for these. Next, the current focus of the United Kingdom (UK) Government is discussed, in relation to the need for preventative health care, with reference to the reports and white papers that have been published during the last decade. The aim of this chapter is to provide a comprehensive explanation of CHD and to link this with the requirements of the UK National Health Service (NHS).

2.2 National and international problem

Coronary heart disease is currently the leading cause of death throughout the world (Benjamin et al., 2002; Mackay & Mensah, 2004). This mortality trend is set to continue as it is estimated that from 1990 to 2020, death from CHD worldwide will increase by 100% in men and 80% in women (Benjamin et al., 2002). Currently, 3.8 million men and 3.4 million women, globally, die each year from CHD (Mackay & Mensah, 2004).

In the UK just over 1.3 million people live with angina: 227,000 people have a heart attack each year (Allender et al., 2007), which is the equivalent of one every two minutes, of which approximately 14% will die before they reach hospital (Fox 2005).

The following statistics illustrate the extent of the problem in the UK:

- CHD is the commonest cause of death in the UK
- 1 in 5 men and 1 in 6 women die from CHD
- 1 in 4 men and 1 in 5 women over 75 years of age live with CHD
- CHD is the main cause of premature death accounting for 20% of premature deaths in men and 11% of premature deaths in women (death before the age of 75)
- mortality rates for CHD are falling, but morbidity rates are increasing

- the UK has among the highest death rates from CHD, in comparison to other Western countries (Finland and Ireland are the only countries with higher rates than the UK).

(Allender et al., 2007)

In 2003, CHD cost the UK economy in excess of £7.9 billion a year; this figure includes direct health care costs (45%), informal care (16%) and productivity costs (40%) and represents an overall cost per capita of £133 (Petersen et al., 2005; Allender et al., 2007). The direct health costs for 2003 accounted for £3,500 million (Petersen et al., 2005; Allender et al., 2007). By comparison, in 1999 the direct health cost was only £1,750 million, half the amount (Petersen et al., 2004;). Prevention of CHD is managed mainly within the primary care setting and, for 1999, Petersen et al. (2004), showed that only 0.7% of the cost was spent on prevention, which by 2003, had only risen to 3% (Petersen et al., 2005; Allender et al., 2007).

This introduction has quoted the statistics associated with CHD, illustrating the size of the problem and the need for effective prevention strategies in order to reduce the personal cost for individuals and their families, plus the general burden for society.

2.3 Aetiology of cardiovascular disease

The cardiovascular system is made up of the heart and the blood vessels, including arteries, capillaries and veins. The heart is essentially a four chambered, double pump, where the right side pumps de-oxygenated blood into the lungs and the left side pumps blood to the body. De-oxygenated blood enters the right atrium, blood passes through the tricuspid valve into the lower right ventricle. From the right ventricle it is pumped into the pulmonary circuit, around the lungs. Oxygenated blood returns to the heart into the left atrium, through the mitral valve into the large left ventricle, which then pumps oxygen rich blood into the systemic system.

Cardiovascular disease (CVD) refers to the disease process that occurs in blood vessels, mainly major arteries such as the aorta and femoral; the coronaries, which supply the heart muscle; CVD can also manifest in the medium sized arteries of the cerebrum and kidneys. Table 2.1 illustrates the target artery and its corresponding clinical manifestation.

Table 2.1 Cardiovascular diseases

Target artery	Clinical manifestation
Retinal arteries	Impaired vision
Cerebral and carotid arteries	Stroke and transient ischaemic attacks
Coronary arteries	Coronary heart disease
Renal arteries	Hypertension and renal failure
Mesenteric arteries	Mesenteric ischaemia
Aorta and iliac arteries	Gangrene and intermittent claudication
Femoral arteries	Peripheral vascular disease

Cardiovascular disease is caused by a build up of atherosclerosis: other terms include atheroma, arteriosclerosis, fatty plaque and atherosclerotic lesion. Atherosclerosis is a complex and slow process. It begins with damage to the endothelial lining of the artery wall, which results in the infiltration and proliferation of various cells including foam cells, monocytes and T-lymphocytes beneath the endothelium. Foam cells actively accumulate low density lipoprotein (LDL) cholesterol, and once inside the artery wall the LDL cholesterol begins to accumulate in clumps of fat laden macrophages that begin to become visible in the arteries of many adults by the age of 30 (Berenson et al., 1998; Hansson 2005; McCrindle et al., 2007). Eventually fatty streaks begin to stimulate the migration of cells which generate connective tissue and smooth muscle cells, forming a lesion called a plaque. Over time the plaque will attract deposits of calcium; calcification of the artery is an important marker for the development of atherosclerosis. The arterial wall becomes thickened and loses its elasticity. This lesion, or atheroma plaque, becomes filled with a lipid rich core which is covered by a fibrous cap. The initial damage to the endothelial layer can be caused by toxins such as smoking, by vasospasm and by other haemodynamic stresses such as hypertension (Gudimetla & Kusumoto, 1999; Forester 2002; Goldschmidt et al., 2005).

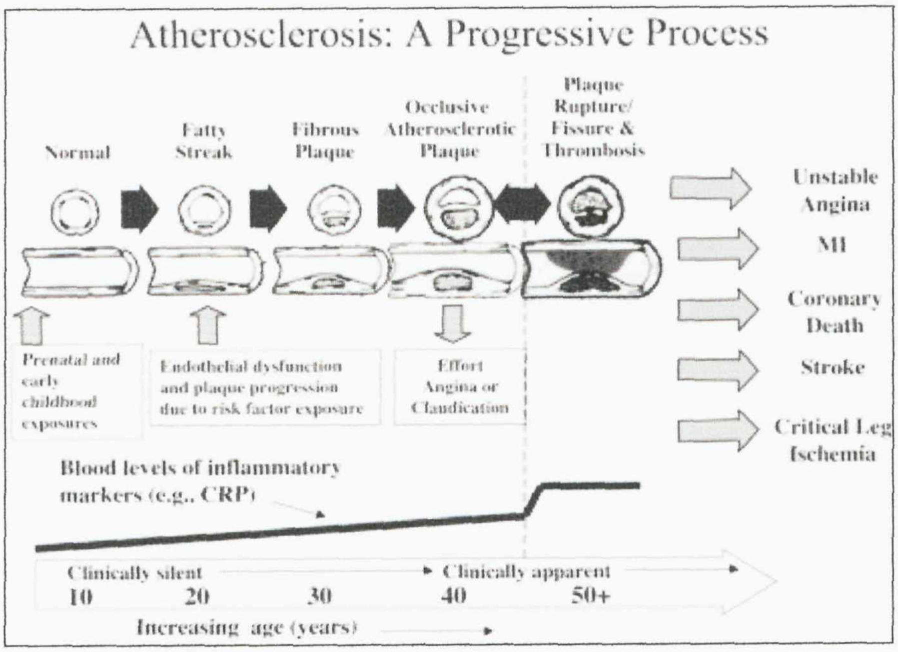
The lesion gradually enlarges over time, as a result of intracellular proliferation, enlargement of the lipid core and uncomplicated plaque rupture. During the early developmental stages the lesion does not usually interfere with blood flow. Blockage within the artery can occur through either gradual enlargement of the plaque resulting in complete stenosis of the artery, or when the fibrous cap becomes dislodged.

When this cap ruptures or is damaged, collagen underneath is exposed, platelet activation is triggered and a clotting cascade starts, resulting in a thrombosis becoming superimposed on top of the lesion. The lesion may become bigger as a result of this uncomplicated plaque rupture, stenosis is increased and the artery becomes narrower but blood flow is maintained. At this stage there are no clinical signs or symptoms manifest for the person.

Alternatively, the thrombosis forms a complete blockage and blood flow is impaired which leads onto ischaemia of the target organ and tissue damage occurs. Signs and symptoms are experienced by the individual. If part of the thrombosis breaks off, emboli may lodge further down the arterial tree resulting in ischaemia which is distal from the main lesion.

Figure 2.1, illustrates the gradual process of atherosclerotic development and thrombosis formation diagrammatically. The way in which the disease progresses over years from 'no symptoms' to symptomatic disease. The lumen becomes narrowed and is positioned eccentrically in the vessel.

Figure 2.1 Schematic diagram of human atherosclerosis



(taken from Greenland et al., 2002, p. 1133 - permission kindly granted from International Journal of Epidemiology; May 16th 2008)

This atherosclerotic process can start as early as childhood (Starty 1989); it is a silent and progressive process. Clinical manifestations occur when the atherosclerosis causes severe ischaemia and, or thrombotic or embolic complications occur (Mancini, 2002). The ischaemic syndromes experienced by the individual may be myocardial infarction, angina pectoris, or sudden cardiac death, if the atherosclerosis is present in the coronary arteries. In conclusion, CVD encompasses the pathogenic atherosclerotic process that occurs in the arteries and which results in a collection of diseases, of which coronary heart disease is one.

2.4 Coronary heart disease

Coronary heart disease occurs as a result of atherosclerosis, which develops in the coronaries, the arteries that supply the myocardium, the heart muscle. Atherosclerotic lesions interfere with blood flow and can reduce the myocardium's blood supply, causing oxygen deficiency leading onto ischaemia and ultimately necrosis of the myocardium. A spectrum of diseases occur, which include:

- angina pectoris
- acute coronary syndromes
- acute myocardial infarction
- chronic heart failure
- ischaemic cardiomyopathy
- proportion of sudden cardiac death

(Walker & Lorimer, 2004)

2.4.1 History of cardiovascular disease

CHD has shown to be on the increase since 1907. Prior to the First World War, the incidence of coronary thrombosis and of myocardial infarction were both recognised, but the disease itself was rare (Morris 1951). As early as 1843 the presence of cholesterol within the atheroma plaques had been identified, and the association of arteriosclerosis within cardiovascular disease has been known since 1906 (Epstein 1995). Up until the 1950's, knowledge with regard to CHD was based only upon clinical studies of those who already had the disease, and not on the causal factors of the disease process itself.

In the United States of America (USA), between 1930 and 1950, there was a steady increase in mortality rates from CHD. By 1949 CHD had become the leading cause of death, accounting for as many as 50% of all deaths in the USA (Kannel 1990). This situation was mirrored in other western countries, where the 1950s international statistics from the World Health Organisation (WHO) showed how the death rates from CHD was increasing; a trend which was to continue in Western Europe and the USA until the 1970s (Epstein 1995).

By the 1940s in the USA, CHD was identified as a major cause of mortality and morbidity. However the causal factors of the disease remained unknown. In 1947 the USA public health service began to lay plans for an epidemiological study of the cardiovascular diseases. The Framingham study was started in the small American community of Framingham, Massachusetts. It was established as a prospective study looking at the epidemiology of hypertension and arteriosclerotic cardiovascular disease. These two 'diseases' were chosen as they were considered to be the most important of the cardiovascular diseases, and the ones about which least was known (Dawber et al., 1951).

The Framingham study became one of the first major studies established to identify the causal relationship between hypertension, atherosclerosis and CHD. Plus as a by-product, the investigators would be able to study the efficiency of diagnostic procedures in either identifying CHD or as indicators for the subsequent development of CHD (Dawber et al., 1951).

> "In short, it was designed to learn which host and environmental factors predispose to cardiovascular disease." (Kannel 1990, p. 206)

2.4.2 The Framingham study

In the late 1940s to early 1950s, Framingham was an industrial and trading centre of 28,000 people, situated twenty-one miles from Boston, rarely used as a commuter town from Boston (Dawber et al., 1951). This formed a homogenous community considered to be reflective upon the larger national population. Initially it was felt that a sample size of 6,000 adults between the ages of 30-59 would be adequate to ensure statistically reliable findings. In 1948, the first 740 volunteers entered the study believing they would only be involved with the study for two decades and by early 1952 the initial examinations where completed (Dawber et al., 1951). Over half a century later, the Framingham study continues, it has now grown into a major prospective trial of over 5,200 people, with original recruits, as well as their off-spring (Sollek 1995).

When the study was initially established it was thought that a single aetiology would be found to be responsible for atherosclerotic disease, however this was not the case. It is now known that CVD is multifactorial, thus giving rise to the 'risk factor' concept, a term first used by the Framingham study in 1961 (Kannel 1990). Through the Framingham study, along with other similar prospective studies which have since been set-up, it has been clearly established that atherosclerosis is a multifactorial pathogenic process, associated with both predisposing risk factors and modifiable risk factors associated with life style choices (Kannel 1990; Yusuf et al., 2004).

Although the Framingham study may have been one of the first studies researching CVD (Dawber et al., 1951; Kannel 1990) there have since been numerous subsequent prospective studies established. Many of these subsequent studies use the research tools and formulae established from Framingham, but if their findings are shown to be similar, then causality and relationship are more strongly supported. All studies will usually reflect some regional influences, whether locally or nationally. Not only has the Framingham study been responsible for establishing risk factors but it has also developed risk functions, which are used to predict coronary heart disease and coronary vascular disease, thus quantifying associated risk factors as well. These provide guidelines for the management of hyperlipidaemia and hypertension, so that treatment can be targeted where appropriate. A derivative of these tables are currently used by the Joint British Societies 2: Guidelines on Prevention of Cardiovascular Disease in Clinical Practice (Wood et al., 2005).

Framingham remains held within its original community setting; however it can still be seen to be reflective and concurrent with other similar studies, and is now the longest operational large-scale prospective study of its kind. It has made an important contribution in the initial identification of associated risk factors for CVD and CHD, upon which much of the work of health promoters is now based. It has also been responsible for developing risk functions and formulae to predict and measure CHD and aid accurate treatment. As a result of its longevity, it has facilitated the long term study of treatments and even witnessed the secular trends and influences of its own initial findings.

2.4.3 Concept of risk factors

The 'risk factors' are the factors that have been found to influence the development of atherosclerosis. From the Framingham study the primary risk factors for CHD have been shown to be hypertension, smoking and hyperlipidaemia (Sollek 1995), and although collectively 246 risk factors have been identified (Kannel 1995), there is no one single factor attributable to the disease. CVD is a multi-factorial disease where risk associated with any single factor is reflective upon the presence of other risk factors present (Kannel 1995).

Other important research being undertaken in the 1950s was that of Morris and his colleagues. In 1953, he was the first to suggest that physical activity in work may be associated with both a lower incidence of CHD, coupled with less severe presentation of the disease itself, in middle aged men. Morris was an epidemiologist who studied the records associated with bus drivers (inactive people) and bus conductors (active people), along with telephonists (inactive people) and postmen (active people). They were subsequently able to make the link between physical activity and CHD, but concluded at this time that they needed further evidence to discover whether physical activity outside work would compensate for the lack of physical activity in work (Morris et al., 1953). Since Morris et al's studies further research validated the claim that physical activity does help to protect against CHD, and not just vigorous exercise but even moderate levels of exercise could be protective (Kannel 1990; Morris, et al. 1990).

The risk factors associated with CHD fall into three categories; firstly personal factors, that are inherent within an individual, making them more susceptible, but with which they can have no influence. Secondly, lifestyle behaviours and personal traits which promote atherosclerosis. Thirdly biochemical and physiological factors, some of which can be modified or treated. Table 2.2 lists the risk factors associated with the development of atherosclerosis.

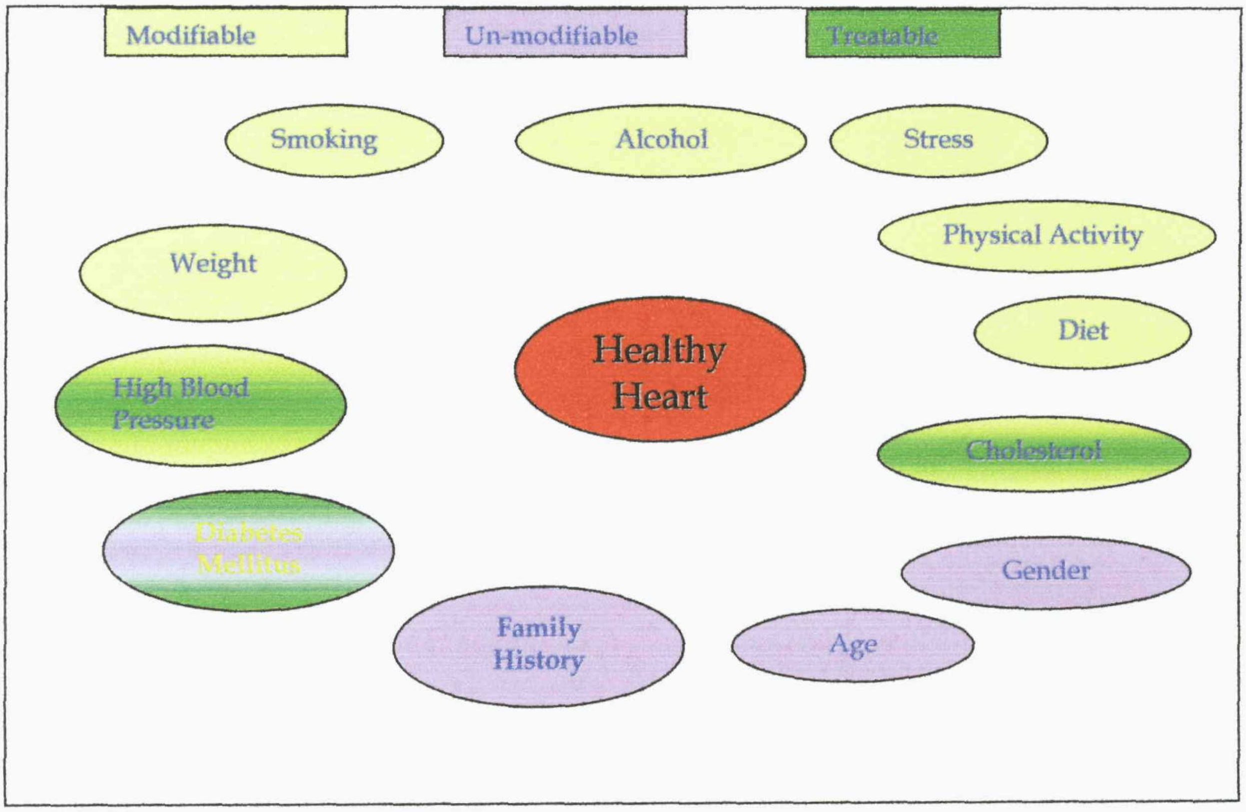
Table 2.2 Risk factors which increase susceptibility to atherosclerosis

Lifestyle	Biochemical	Personal
Smoking	Elevated plasma cholesterol	Age
Poor diet	Hypertension	Gender
Physical inactivity	Thromogenic factors	Family history
Psychosocial stress	Elevated plasma triglycerides	Personal history
Excess alcohol	Diabetes mellitus	Ethnicity
Obesity / increased waist circumference	High plasma LDL-cholesterol	Premature menopause
	Low plasma HDL-cholesterol	

(adapted from Lindsay 2004, p. 32)

Lifestyle factors can be influenced by individual lifestyle behaviour. Biochemical factors are measured and assessed within the medical environment, and these may be modified through behaviour and treated with medication. There is no control over personal factors, and the predisposition increases with advancing age. These three categories can be further sub-divided into modifiable and un-modifiable factors. Figure 2.2 displays the risk factors for heart disease illustrating how some are modifiable, some un-modifiable, while cholesterol and high blood pressure, can be modified through both pharmacological treatment and lifestyle behaviour. However, diabetes mellitus is controlled through treatment and lifestyle, but remains ultimately un-modifiable.

Figure 2.2 Risk factors for coronary heart disease



Novel risk makers are evolving and being investigated; these include elevated total plasma homocysteine levels, atherogenic lipids, including lipoprotein(a) and triglycerides along with abnormalities in haemostatic parameters such as plasma fibrinogen and plasminogen activator inhibitor type 1 (Forrester 2002). Inflammatory markers, such as C-reactive protein and erythrocyte sedimentation ratio, and infections such as 'Chlamydia pneumonia' are also being investigated (Andresdottir et al., 2002; Tonstad et al., 2005). These new markers can help to identify and stratify overall susceptibility and CHD risk, while improvement in these markers can occur through lifestyle modification associated with the principal risk factors (Forrester 2002; Tonstad et al., 2005).

2.4.4 INTERHEART study

The INTERHEART study (Yusuf et al., 2004) identified and verified nine modifiable or treatable risk factors associated with an acute myocardial infarction. The authors concluded that the vast majority, of acute myocardial infarctions could be explained by the presence of nine risk factors, and that:

> "modification of currently known risk factors has the potential to prevent most premature cases of myocardial infarction worldwide."
>
> (Yusuf et al., 2004 p.951)

These nine risk factors were:

1) smoking
2) lipids
3) hypertension
4) diabetes
5) obesity
6) diet
7) physical activity
8) alcohol consumption
9) psychosocial factors

The INTERHEART analysis showed that family history was associated with an odds ratio of 1.55 (99% confidence interval 1.44 - 1.67), where the population attributable rate (PAR) was 9.8% (99% confidence interval 7.6-12.5), after full adjustment for age, sex and geographical region (Yusuf et al., 2004). However, when family history was added into the analysis with the other nine risk factors, the overall PAR increased from 90.4% to 91.4%. Indicating that although family history is an independent risk factor for myocardial infarction, most of the associated burden can be accounted for by the nine risk factors (Yusuf et al., 2004).

The INTERHEART study has provided conclusive evidence concerning the risk factors associated with myocardial infarction and consequently CHD. It has also shown that family history is an associated risk factor, but that most of the risk can be accounted for by nine modifiable risk factors. These nine risk factors are evaluated and measured within the health promotion programme of this thesis, where the aim is to encourage healthy lifestyle behaviour and where necessary advocate pharmaceutical treatment. Motivation is fundamental to the process and in order to evaluate this it is important to look at the person's whole experience associated with CHD, how it has affected them and their family, and their perceptions of their own risk profile. The meaning of health, the promotion of health, and the creation of health within and for a person are the key to this process; salutogenesis provides the conceptual framework upon which this can be analysed, individually and collectively.

2.5 A changing National Health Service

Emphasis in medical and nursing care has never been placed solely on understanding and curing disease, but on relieving suffering and maintaining health, where disease is prevented from occurring in the first place. In the past, mortality in the population has been related to infectious pathogens, resulting in diseases such as cholera and plague. Now the biggest threat to the health of our society is from diseases related to our sedentary lifestyle, high calorie diet and cigarette smoking. Over the last century (20th century) there have been major declines in infectious and nutritional diseases; while continued industrialisation has resulted in an abundance of food, improved transport and many labour saving devices. This has meant that as a global population we are living longer, have a surplus of food, live sedentary lives and have access to mass produced machine made cigarettes; all of which results in excessive risk for CVD (Benjamin et al., 2002; Yusuf & Ounpuu, 2003).

The ethos in today's National Health Service (NHS) reflects a change of health management, individual need and personalised involvement, where health issues are now largely based upon personal choice in relation to lifestyle and behaviour. This is clearly illustrated by the Government white paper, "Our health, our care, our say" (DH 2006a), where one of the foci is upon improving prevention services. Here individuals are involved in this health and well-being process, encouraged to take control and responsibility. Building from the Wanless report where the challenge and aim is about achieving health not just improving health care (Wanless 2002; DH 2006a).

2.6 Government policy

Prevention of CHD and CVD, along with maintenance of health and wellness associated with all cause of mortality and morbidity, is a current priority for the UK government. Over the last decade five key documents have been published which reflect the Government's priorities for the NHS, along with public health policy. Firstly the CHD National Service Framework (NSF) (DH 2000), secondly the Wanless report (Wanless 2002), thirdly 'Choosing Health' (DH 2004a), fourth 'Our health, our care, our say' (DH 2006a) and finally 'our NHS, our future' (DH 2007a). Discussion involving these, and current reports which have lead on from these documents, illustrate how the thesis reflects the contemporary emphasis upon health care within the NHS.

2.6.1 Coronary heart disease national service framework

The CHD NSF published in 2000, issued strategies, guidelines and targets regarding both primary and secondary prevention of CHD. This was in order to meet the targets from 'Our Healthier Nation' (DOH 1998) which stipulated that the death rate from heart disease, stroke and related illnesses amongst people aged under 65 years must be reduced by at least a third by the year 2010 (DOH 1998). This target has now been achieved ahead of schedule, according to the CHD NSF progress report, which states that there has been a 40% reduction in CVD related deaths (DH 2008a).

The CHD NSF delivered a strategy to modernise CHD services in the UK over a ten year period. Chapter two is titled 'Preventing coronary heart disease in high risk patients,' standard three and four is contained within this chapter. Standard three is concerned with identifying those with established CVD, while standard four states that:

> "General practitioners and primary health care team members should identify all people at significant risk of cardiovascular diseases but who have not developed symptoms and offer them appropriate advice and treatment to reduce their risks." (DH 2000, p.14)

It is clearly stated in chapter two of the CHD NSF (DH 2000) that all patients with a family history of premature heart disease are classified as high risk, and should have a full assessment including blood pressure, non-fasting blood lipids, smoking status, physical activity, body mass index and serum glucose. The use of coronary risk prediction chart for estimating the ten year CHD risk is also advocated. The achievement of this is set out in the second step milestones and is milestone number two. For this milestone there must be in place a systematically developed and maintained practice-based register of those at high risk for CHD in order to provide structured care (DH 2000).

The progress report on the CHD NSF (DH 2008a) identifies the significant achievements that have been made since 2000, with emphasis upon the development of services, and treatments for CHD and improvement in the management of arrhythmia services. The importance of secondary prevention is highlighted in the report, with discussion on the publication by the National Institute for Health and Clinical Excellence (NICE) 'MI: secondary prevention' (NICE 2007), and the newly established National Audit of Cardiac Rehabilitation (NACR), which will provide audit data on cardiac rehabilitation services. The work of the cardiac networks is reported, whose work has focused upon sudden cardiac death and the provision of services for those with, or at risk of, inherited cardiac conditions (DH 2008a).

2.6.2 The Wanless report 'Securing Good Health for the Whole Population'

Derek Wanless was originally commissioned in 2001 by the Chancellor to examine future health trends, and identify key factors to determine the funding and resources required for a comprehensive health service based on clinical need up to 2022. The review 'Securing our Future Health: Taking a Long Term View' outlined three scenarios for health care, these scenarios where 'solid progress,' 'slow uptake,' and 'fully engaged.' Each scenario reflected different assumptions concerning the effectiveness of the NHS and the health status of the UK population (Wanless 2002). In 2004 'Securing Good Health for the Whole Population' was published which expanded the fully engaged scenario, and focused on four areas: prevention, determinants of health, whole population cost effectiveness, and health inequalities.

'Securing Good Health for the Whole Population' emphasised the need to develop a NHS which focuses on wellness and health, rather than disease and treatment. Throughout, Wanless asserts the need to engage the public in this whole process of development, that individuals should be involved, that they should be encouraged to take responsibility for both their own and their children's health maintenance. However, the final choices remain with the individual, although Wanless asserts that this should be balanced against the impact that this has upon others.

Regarding disease prevention, the report demonstrates that there are advantages to making behavioural changes early in life. However, health outcomes are not clearly measurable, because there is a time lag between the behavioural change and associated health benefit. This makes scientific methodology difficult to apply because health outcomes are not clearly measurable or quantifiable. A strong recommendation from the report was that continuing research in this area is vital in order to provide an evidence based, cost-effective health strategy (Wanless 2004).

2.6.3 'Choosing Health: making healthy choices easier'

Following Wanless' report, the Government published its first ever public health White Paper 'Choosing Health: Making healthy choices easier' in November 2004. The then prime minister wrote:

> "For each of us, one of the most important things in life is our own and our family's health. I believe that this concern, and the responsibility that we each take for our own health, should be the basis for improving the health of everyone across the nation."
>
> Blair (DH 2004a, p.3)

'Choosing health' aims to inform and encourage individuals to make healthy choices. By focusing at the individual level influence spreads across society. The White Paper stipulates a shared approach to health, with individual choices and co-ordinated action between individuals, industry, the NHS and government, where health promotion and health awareness are key components. The emphasis, as recommended by Wanless (2002) is upon individual choice, as opposed to a paternalist approach. Government and industry provide support for a conducive environment encouraging healthy living, with consideration and emphasis upon:

- helping people to make healthier choices for themselves;
- protecting people's health from the actions of others;
- recognising the particular needs and the importance of emotional and physical development of the young (DH 2004a).

When the NHS was established 50 years ago, the emphasis was on treatment for acute conditions and diseases. In the future the health issues faced by the NHS will be chronic conditions, and illnesses which will be related to our lifestyle, such as obesity and physical inactivity. This White Paper allows for the strategic change of emphasis from a biomedical illness model to a health and wellness model of care.

2.6.4 'Our health, our care, our say: a new direction for community services'

In 2005, the government carried out two major consultation exercises, which involved more than 42,000 people. The 'Your health, your care, your say' listening exercise looked at key areas of health and social care services in the community. As a result of this consultation and a citizen's summit of a thousand people, the 2006 White Paper 'Our health, our care, our say: a new direction for community services' was passed which builds upon the previous 'Our Healthier Nation' (DOH 1998) and 'Choosing Health' (DH 2004a).

The White Paper aims to achieve four main goals:

- Better prevention services with earlier intervention.
- To tackle inequalities and improve access to community services.
- Provide more support for people with long-term needs.
- Give people more choice and a louder voice.

(DH 2006a)

Emphasis upon involving individuals, providing them with choice and respecting autonomy continues.

2.6.5 'our NHS, our future'

In July 2007, Lord Darzi, was requested by the Secretary of State to carry out a wide-ranging review of the NHS (Johnson 2007). October 2007, the interim report 'our NHS, our future' (DH 2007a) was published; this was compiled by Darzi based upon his visits and discussions with NHS staff and the public. The vision of the review is for a world class NHS which is fair, personalised, effective and safe; where the aspirations of patients, staff and public are met. The emphasis for the review is upon delivery of local requirements, meeting the needs of local populations, which is locally accountable. The report recommends that local NHS staff and others, working in partnership across the service, can initiate change and development of services, based upon best evidence, which meet the needs of local communities.

The next stage of the review is that clinical champions are established in every region across the country, to look at eight key issues that affect people at different stages in their lives. These are:

- Maternity and newborn care

- Children's health
- Planned care
- Mental health
- Staying healthy
- Long-term conditions
- Acute care
- End-of-life care (DH 2007a, p.20).

Commissioning services will be key for delivering the recommendations of the review (DH 2007a; DH 2008b), according to the latest report;

> 'World class commissioning will support the shift from treatment and diagnosis to prevention and the promotion of well-being. This is crucial for delivering a fair health service as lifestyle choices are responsible for as much as half of the gap in health outcomes.'
>
> (DH 2008b, p.1).

The focus for 'our NHS, our future,' remains upon the individual and personal choices, in partnership with health professionals, in order to maximise health potential and health care.

2.6.6 European heart health charter

The importance of cardiovascular prevention within the European Union (EU) was acknowledged by the 'European Heart Health Charter' (www.heartcharter.eu), which was launched in July 2007. The aim of the charter is to substantially reduce the burden of CVD in the EU and the WHO European Regions and to reduce inequities and inequalities in disease burden within and between countries (European Heart Health Charter 2007). It calls upon a collaborative approach between politicians, public health organisations and health professionals, so that prevention of CVD becomes a political, organisational and personal priority.

2.7 Current NHS status

There are numerous current government initiatives aimed at reducing risk and increasing emphasis upon healthier lifestyle choices. These include:

- Tobacco, with provision of smoking cessation services throughout the UK.

- Food and health action plan, which has seen a reduction in salt consumption (Wanless et al., 2007)
- Food in schools programme, where free fruit is given to children aged 4 to 6 years.
- 5 a day fruit and vegetables. According to the Food Standards Agency consumers in England, Scotland and Wales (59%, 54% and 50% respectively) claim to consume five or more pieces of fruit and vegetables each day (Food Standards Agency 2008).
- Small change, big difference campaign (DH 2006b). Encouraging people to make small minor changes to their lifestyle, focusing on diet and physical activity.

The importance for focusing upon at integrated approach to risk reduction is recognised in 'Reducing the risk of cardiovascular disease,' an Early Day Motion proposed by Adrian Sanders Member of Parliament (MP), on October 8th 2007. The motion supported the 'Target 1000 – Reducing the Risk,' campaign of the Hyperlipidaemia, Education and Atherosclerosis Research Trust UK (HEART UK), Primary Care Cardiovascular Society, Primary Care Diabetes Society and the National Obesity Forum. The motion called for:

- the Government to deliver a more comprehensive risk assessment programme
- the NHS to offer lifestyle advice and targeted interventions to those identified as having a high risk of CVD
- individuals to take responsibility for their health, by improving their diet, stopping smoking and taking more exercise.

(Sanders 2007)

Central to the recommendations of the Parliamentary motion is health promotion and disease prevention, both of which were acknowledged by Wanless (2002), in his first report. Contrary to this recommendation is the fact that there has been a decrease in the number of public health consultants and registrars, where elsewhere the NHS has increased staffing levels (Wanless et al., 2007). However, the Parliamentary motion does reflect the focus of this thesis.

In 2007 the King's Fund commissioned Wanless to undertake a retrospective review of NHS spending since the publication of the original report in 2003. Key findings from this review, which are relevant to this thesis, are detailed below.

- Prescriptions dispensed between 2002 and 2006 rose by more than a fifth; the majority of these were lipid lowering statin medications. However, the cost of these was lower than expected.
- The health of the population has improved, with a fall in mortality and an increase in life expectancy, both of which are continuations of established long-term trends.
- Information on health promotion expenditure is unavailable.
- Improvements have been seen in some determinants of health, diet, for example. However, obesity rates have increased beyond previous expectation, which will have serious consequences for long-term delivery of care.

(Wanless et al., 2007)

The last 5 years has seen changes to the structure of the NHS and to the delivery of services, resulting in extensive reconfiguration. The King's Fund report has little evidence of changes to prevention services apart from increases in the prescribing of statin medications. Similarly the progress report of the CHD NSF (DH 2008a) makes no reference to primary prevention services and strategies. Despite the emphasis of the CHD NSF 2000, upon the identification of people with premature family history for CHD and their requirement for primary prevention, they remain a neglected group of people which could and should be targeted for prevention (Chow et al., 2007).

Recent reports following the Government's White Papers would indicate that the focus on prevention and health promotion has not met with initial expectations (Wanless et al., 2007; DH 2008a). Where funding which has been "regularly 'raided' "(Wanless et al., 2007, p. 37) from public health and re-directed to reduce hospital deficits or meet productivity targets.

A re-occurring theme in government documents over the last 30 years is that health should be seen as 'everybody's business' (DHSS 1976; DH 2004a). A concern with this approach, as raised in the 1981 report from the Royal College of General Practitioners, is that the tasks of prevention become everybody's business, but the responsibility of no-one (RCGP 1981). By emphasising personal choice, responsibility has devolved to the individual. However with this scenario, the consequences of incorrect choices are still met by the NHS.

Current reports, as discussed, have shown that the NHS remains reactive to the demands and needs of the acutely unwell; arguably it has not received money or services with which to address the shift of focus (Wanless et al., 2007). The core need for acute and emergency services remain central to the NHS. Wanless et al. (2007), conclude that the NHS has remained reactive to short-term problems, and that continued work needs to be made in order to tackle the key determinants of ill health. Even so, substantial funding will be required over the next two decades to supply high-quality health services to the population (Wanless et al., 2007), and commissioning will be key to achieving Darzi's vision for a health care system which is fair, personalised, effective and safe (DH 2008b).

2.8 Focus for this thesis

This thesis reflects the changing focus and needs of the NHS in the twenty-first century. There is extensive literature and research looking at the experience for an individual when they are diagnosed with a major disease. Many diseases run in families; thus when a close relative is diagnosed with a disease, this can be an indicator that other members of the family may be subsequently classified as 'at risk.' There is no evidence of research examining the perspective of these family members; the experience of family members needs to be explored, as this will provide important insight for nurses and allied health professionals into key issues that may influence their lifestyle behaviour.

Salutogenesis is the theoretical framework used to explore and interpret the research findings; literally translated salutogenesis means the 'origins of health.' The concept of salutogenesis was introduced by Professor Antonovsky, who originally wanted to understand people's general attitude to life, and whether this had an influence on their outlook on health. Antonovsky's initial idea was that it was more important to focus on people's resources and capacity to create health than on risks and ill health (Antonovsky 1987). Through the salutogenic theory, the research can be evaluated by looking at the experience of these close family relatives and the outcomes from the health promotion programme.

The transtheoretical model of health behaviour change (Prochaska & Velicer, 1997) is used within the health promotion programme in order to facilitate and identify participants' readiness to change. The transtheoretical model is an approach used in other studies discussed in chapter three (Steptoe et al., 1999; Wood et al., 2004). Through the work of James Prochaska, Carlo DiClemente and John Norcross, the transtheoretical model was developed from theories of psychotherapy and behaviour change in addictive behaviours. From the 1980s they looked at how people change their behaviour, with or without professional support; they integrated over 300 theories of psychotherapy into this model, hence the term transtheoretical (Prochaska et al., 1992; Prochaska & Velicer, 1997). The transtheoretical model was integrated within the health promotion sessions during the clinical encounters so that people could be encouraged and supported to move through the stages of change from pre-contemplation through to action and long-term maintenance.

Salutogenesis and the transtheoretical models are both discussed further and their role within the research and thesis developed in chapters four and eight.

2.9 Summary

Cardiovascular and coronary heart disease have been explained and the risk factors that are associated with the diseases have been discussed. The historical evidence has been charted, from the Framingham study of the 1950s to the INTERHEART study, half a century later. Key government papers have been identified, which illustrate how the emphasis in today's NHS and government is being increasingly placed upon prevention. Finally, an explanation as to why this research is important has been given and how it reflects current government policy. The concept of salutogenesis has been introduced, which will be further developed in subsequent chapters.

The next chapter provides evidence from the literature concerning the key aspects of the thesis, preventative cardiology, primary prevention in a clinical setting, family history for heart disease and the familial experience of living with a diagnosis of chronic illness in the family. The literature will illustrate the research that has already been done in this field and shows the relevance of this study for current clinical practice and effective health promotion.

CHAPTER THREE

Literature Review

3.1 Chapter introduction

The preceding chapter has provided historical details of cardiovascular disease (CVD) and placed into context the extent of the health burden associated with coronary heart disease (CHD). The focus for this thesis is upon prevention of CHD in a clinical setting, and how this can be influenced by personal experience associated with a family history. The chapter is divided into four parts which review the literature associated with the four components of the study focus; preventative cardiology, primary prevention for CHD in the clinical setting, family risk associated with CHD along with the research studies which have specifically recruited this population, and personal experience of CHD families. These four components are associated with the two aims of the study and the study population. They have been refined and focused over the duration of the research. The literature which falls outside these parameters, such as primary prevention studies in the community or workplace, for example, has been excluded.

3.2 Prevention in health care

There are four levels of preventative health care, yet the delineation between these levels can be indistinct resulting in misinterpretation; therefore it is important to include an explanation and brief discussion on these levels of prevention. It is also important to distinguish the different levels when discussing the research which has been undertaken for the prevention of CHD and how this subsequently influences health policy.

Traditionally there have been three levels of prevention within health care. These are illustrated by Tones and Green, (2004) in Table 3.1.

TABLE 3.1 Levels of prevention

- **Primary Prevention:** aims to prevent new cases of a disease from developing by reducing exposure to causal and risk factors
- **Secondary Prevention:** aims to reduce the consequences of disease and increase the chances of cure by early diagnosis and treatment, often as a result of screening procedures.
- **Tertiary Prevention:** aims to halt the progress, or reduce the complications, of established disease by effective treatment and rehabilitation.

Tones & Green, 2004, p.21

In 1993, Beaglehole and colleagues identified a fourth level: primordial prevention. According to Beaglehole et al., (1993), primordial prevention was identified through the epidemiology of cardiovascular disease. They state that CHD only occurs on a large scale if the underlying cause of a diet high in saturated animal fat is present (Beaglehole et al., 1993), for example China and Japan have a low incidence of CHD, despite the presence of other risk factors such as smoking and hypertension. They state that the aim of primordial prevention is:

> "to avoid the emergence and establishment of the social, economic and cultural patterns of living that are known to contribute to an elevated risk of disease." (Beaglehole et al., 1993, p.86)

Primordial prevention aims to prevent the disease from occurring in the first place, the emphasis is upon reducing the occurrence of modifiable risk factors. The primordial risk factors include diet, weight control and physical activity, so that treatable risks such as diabetes mellitus (DM), dyslipidaemia and hypertension do not become prevalent later in life (Benjamin et al., 2002). Primordial prevention is an approach suitable for children and young people and whole populations (Beaglehole et al., 1993; Benjamin et al., 2002; Yusuf and Ounpuu, 2003). An example of legislative primordial prevention is the current United Kingdom (UK) Governments' policy 'Smoke-free Premises, Places and Vehicles' (Health Act 2006).

Primary prevention should be for those who have risk factors, but who have no clinical evidence of the disease. Secondary and tertiary prevention is for those who have a diagnosis of CHD where treatment and rehabilitation occurs in order to stop disease progression and limit the consequences of disease manifestation. People who have had a myocardial infarction clearly receive tertiary prevention, while those who are investigated for cardiac chest pain, then have a confirmed CHD diagnosed will receive secondary prevention; these groups may initially traverse between both secondary and tertiary levels. People who have hypertension and diabetes mellitus, for example, have an underlying disease pathogenesis, but do not have overt CVD or CHD, these people may be categorised into either primary or secondary prevention groups of care and management. Consequently in clinical practice the boundaries between each level merges, hence current literature today talks about preventative cardiology as an all encompassing umbrella phrase.

Secondary and tertiary prevention is guided by the 'Joint British recommendations on prevention of Coronary Heart Disease in Clinical Practice;' which was first published in 1998 (Wood et al., 1998). This report was a collaboration between four groups; the British Cardiac Society, the British Hyperlipidaemia Association and the British Hypertension Society, endorsed by the British Diabetic Association. A collaborative approach between these four bodies was important in order to achieve a unified approach to the prevention of CHD, where previously recommendations and guidance had been provided by separate professional societies. The 1998 report clearly distinguishes between primary and secondary prevention, offering guidelines for each group. The current guidelines published in 2005 are titled 'JBS 2: Joint British Societies' Guidelines on prevention of Cardiovascular Disease in Clinical Practice.' It now encompasses cardiovascular disease, not CHD in isolation; the collaboration has extended and now includes the HEART UK (Hyperlipidaemia, Education and Atherosclerosis Research Trust UK) (formerly the British Hyperlipidaemia Association), Primary Care Cardiovascular Society and the Stroke Association. The guidelines focus upon cardiovascular disease prevention, for those with established CVD and those at high risk of CVD, there is no clear distinction made between the four different levels of prevention. Since the study for this thesis was first established to the current time, the boundaries between these levels are blending.

The current guidelines on prevention (Wood et al., 2005), are principally published to guide medical management in clinical practice; looking at cardiovascular risk and therapeutic treatment according to targets and risk evaluation. They are aimed at people with established CVD and those considered at high risk. The main discussion is upon treatment options, however lifestyle intervention is discussed and encouraged. Risk prediction charts are included, which are used to quantify a persons 10 year risk of developing CVD based on five risk factors: age, smoking habits, sex, systolic blood pressure and ratio of total cholesterol to high density lipoprotein (HDL) cholesterol. They are designed as an aid to guide intervention, especially medication. A high risk population was identified in the 1998 guidelines (Wood et al., 1998) and the current ones (Wood et al., 2005) are people with a premature family history (PFH) of CHD. Screening and identification of these people is encouraged, but their subsequent management is not discussed as a separate issue. However when calculating the total cardiovascular risk for those with a PFH the risk is increased by a factor of 1.3 (Wood et al., 2005). This incremental risk calculation does not take into account other factors associated with a family history, which are identified later in this chapter, and is therefore a conservative evaluation.

The different levels of CHD prevention have been discussed, illustrating how the distinction between each category has recently merged; the JBS 2: guidelines show how emphasis within the medical arena is upon secondary and medical treatment. The role and impact that primordial and primary prevention can have within a population is identified in the next section.

3.2.1 Role of prevention

Two reports that were identified at the start and early stages of the study, were the work of Capewell and colleagues in developing the Impact model, and a report published by the National Heart Forum in 2002, 'Coronary Heart Disease: Estimating the impact of changes in risk factors.'

Death rates from CHD have been falling in the UK since the late 1970s (Petersen et al., 2005). This trend had been visible for sometime, hence the target established by the Governments 'Saving lives: Our Healthier Nation' (DOH 1998), which stipulated that deaths from CVD should be reduced by a third, by 2010 (DOH 1998). In the 1990s Capewell and his colleagues set out to explain this decline in mortality rates, by studying statistics obtained in Scotland between 1975 and 1994. Initial work identified that 40% of this decline was attributable to medical treatments, including medication and interventions, 51% was attributable to measurable risk factors, smoking, cholesterol, fall in blood pressure and changes in deprivation. The final 9% was attributed to 'other' factors which had not been included in the analysis, such as obesity, physical activity and clotting factors (Capewell et al., 1999). The Impact model has subsequently been developed and expanded to other populations, supporting the findings of this initial work (Capewell et al., 2000; Critchley & Capewell, 2002; Unal et al., 2003; Unal et al., 2005; Ford et al., 2007). The Impact model has provided evidence that the decline in mortality is due to reduction in major risk factors, such as smoking, improved diet and physical activity. Concluding that:

> "Approximately half the recent large falls in CHD deaths in England and Wales can be attributed to primary prevention. Much as predicted, primary prevention had a fourfold bigger impact on mortality than did secondary prevention. Comprehensive CHD strategies should focus on primary prevention, particularly tobacco control and healthier diets."
>
> (Unal et al., 2005, p. 5)

The report, 'Coronary Heart Disease: Estimating the impact of changes in risk factors' published by the National Heart Forum in 2002, discusses and illustrates the changes to CHD mortality that could be achieved through risk factor modification. The report illustrates how even modest changes to cholesterol, blood pressure, smoking cessation and physical activity levels can produce substantial reduction in CHD rates over a ten year period. For example if cholesterol in the UK population was reduced to less than 6.5mmol/L this would result in a 11.1% reduction in CHD cases for men, and a 12.6% reduction for women (McPherson et al., 2002). If cholesterol was reduced even further to less than 5.0mmol/L, this would result in a huge 53.4% reduction in CHD cases for men and a 55.5% reduction in women (McPherson et al., 2002).

The Impact model and the National Heart Forum report, may be considered to be directed at population strategies which can reduce CHD mortality and morbidity. However they clearly illustrate the substantial and positive effect that risk factor reduction can achieve. Secondary and tertiary prevention strategies involve individuals, therefore as primary prevention (through risk factor modification), has been shown to be effective, the targeting and engaging of high risk individuals should not be excluded from our nursing and clinical care.

3.3 Primary prevention studies in clinical practice

The literature searches conducted for this review focused on research which has been carried out in the UK. The studies are those which evaluate a primary prevention health promotion initiative looking at multiple risk factors associated with CHD in a clinical setting. Studies associated with familial dyslipidaemia, secondary prevention, sudden cardiac death and pharmacological treatments were discounted. Research which looked at improving a single risk factor, such as physical activity initiatives, smoking cessation, as well as community and workplace projects, were not included. However reference is made to some of this work in the discussion chapter as although these studies are not directly relevant to the thesis, they do have important implications for the larger vision of preventative cardiology.

A systematic literature search was carried out from five databases; the Cochrane Library, British Nursing Index (BNI), Allied & Complementary Medicine (AMED), Cumulated Index for Nursing and Allied Health Literature (CINHAL) and Medlars Online (MEDLINE). All five searches used the same keywords with variation to whether they appeared in the whole text, or were restricted to the title, abstract or as an identified keyword in the document. The key phrases and words used in the literature search were: heart disease, health promotion, family history, premature, patient education, primary prevention, prevention, screening and risk factor. There were five studies identified which meet the criteria discussed above. Table 3.2 summarises the UK primary prevention studies which are discussed in this section.

TABLE 3.2 United Kingdom primary prevention studies in clinical practice

Study title and authors	Year of study (publication year)	Research design	Details
OXCHECK OXCHECK Study Group	1989 to 1993 (1995)	Randomised controlled trial. Five urban practices	2,205 men & women recruited to the intervention group, and 1916 people recruited to the control group Intervention group had health checks in 1989/90 & 1992/3. Control group had first health check 1992/3. Aim to determine the effectiveness of health checks performed by nurses in primary care, in reducing risk factors for CVD and cancer. RESULTS: *achieved an overall 12% reduction in coronary* risk, similar in both men & women. After a year cigarette smoking was lower by 1%, weight by 1kg, systolic BP by 7mmHg cholesterol by 0.1mmol/L. Annual rechecks no more effective than a single recheck at 3 years. Health checks occupied significant nursing time.
British Family Heart Study D A Wood, A L Kinmouth, G A Davies, J Yarwood, P N Durrington	1991 - 1994 (1994)	Randomised controlled trial. In 26 general practices, in 13 UK towns	12,472 men aged 40 -59 and their partners (7,460 men & 5,012 women) recruited. Follow-up was one year. Aim to measure the change in CVD risk factors achievable in families over one year by cardiovascular screening and lifestyle intervention in general practice. Intensive family centred nurse led health programme. RESULTS: overall coronary risk score reduced by 16%. Weight, BP and cholesterol concentrations showed greatest reductions
Change of Heart Study S Hilton, S Doherty , E Rink, S Kerry, T Kendrick, A Steptoe	April 1995 to October 1996 (1999)	Cluster randomised controlled trial	*883 men & women were identified for the presence of one* or more modifiable risk factors. Aim to measure the effect of behaviourally oriented counselling in general practice on healthy behaviour and biological risk of CHD RESULTS: brief behavioural counselling led to improvements in healthy behaviour.
EuroAction D A Wood, C Kotseva, C Jennings, EuroAction Study Group	April 2003 to April 2006 (2007)	Cluster randomised controlled trial .Clinical follow-up at 16 weeks and 1 year (hospital arm) and at 1 year only (primary care arm)	Conducted in 8 European countries; 2 general practices and 2 district general hospital recruited from each country. Aim to demonstrate effectiveness of a multidisciplinary approach to preventative cardiology for patients diagnosed with CHD and their families. RESULTS: published one year results from 6 European countries concluded that the EuroAction programme helped coronary patients and their families to achieve a reduction in central obesity, to make healthier food choices and to increase their physical activity levels in comparison with usual care. There was an improvement in blood pressure control (achieved significance) and lipid control (did not achieve significance). (Connolly et al., 2007).
Multiple risk factor interventions for primary prevention of coronary heart disease (Review). S Ebrahim, A Beswick, M Burke, G Davey Smith	2006	Cochrane Review - Meta analysis	39 trials included; studies using counselling or education to modify more than one CVD risk factors in adults.. Objectives to assess the effects of multiple risk factor intervention for reducing CVD risk factors, total mortality and mortality from CHD among adults without clinical evidence of established CVD. RESULTS: The pooled effects suggest multiple risk factor intervention has no effect on mortality. However a small benefit of treatment, 10% reduction in CHD mortality, may have been missed. Risk factor changes were relatively modest and were related to the amount of pharmacological treatment used. Such interventions have limited utility in the general population.

There have been two large randomised controlled studies conducted in the UK which have looked at multiple risk reduction for CHD, through lifestyle and behavioural changes, in a clinical setting. These are the Oxford and Collaborators Health Check Trial (OXCHECK) and British Family Heart (BFH) studies. Prior to the establishment of these studies the need for collecting information from individuals in primary care, to access their cardiovascular risk was highlighted. In 1981 the Royal College of General Practitioners (RCGP) report 'Prevention of Arterial Disease in General Practice' was published (RCGP 1981), this report recommended that the first steps towards a preventative approach should be the measuring and recording of associated risk factors, such as blood pressure, weight, smoking behaviour. In order to test the feasibility of these suggestions, Fullard et al. (1987), established a case controlled trial to see if the provision of health checks improved recording of risk factors, namely blood pressure, weight and smoking. People aged 35 – 64, when visiting the surgery were invited to attend a 20 minute health check with the practice nurse. During the health check if hypertension was detected the general practitioner (GP) in the practice was consulted for consideration of treatment. Improvements in the control practices occurred, but more substantial improvements occurred in those practices offering a separate health check (Fullard et al., 1987). By using an opportunistic approach, recording of risk factor data could be obtained from 90% of the practice in this age range (Fullard et al., 1987). The study focused on the recording of three risk factors for CHD, it does not evaluate any changes to these which may have occurred subsequently in the study population. The key aspects of the study is that it showed that an opportunistic and systematic approach was a valuable way to screen people, using nurse led and doctor supported health checks. This model is one which was subsequently adopted by the OXCHECK and British Family Heart studies, plus this thesis.

3.3.1 OXCHECK and British Family Heart study

The OXCHECK and the British Family Heart (BFH) studies where randomised control trials undertaken in the early 1990s which were designed to measure the impact of a primary prevention strategy for CHD in the UK. These were both nurse-led programmes looking at large sections of the population and concentrating predominantly on measurable risk factors such as smoking cessation, blood pressure, cholesterol and weight reduction; information on self reported exercise, diet and alcohol consumption was also collected. The studies were population based; the

OXCHECK study recruited all individuals aged 35 to 64 years; the British Family Heart study screened men aged 40 to 59 years, their partners were subsequently invited to join the study in conjunction with the men, developing a family centred approach to the strategy. Both studies provided intervention for a year, with additional 3 year follow-up given in the OXCHECK study. The number of visits varied between each study, the OXCHECK follow-up visits were negotiated between the subject and the study nurse according to a protocol for each risk factor; the British Family Heart study the visit regime was stricter as the intervention was more intense, again following a set protocol, one for high overall risk and one for individual risks, resulting in more visits.

The OXCHECK study took place in five urban general practices in Bedfordshire; 2,205 men and women, aged 35 to 64 years, were randomly allocated to an intervention group or a control group. The intervention group received their first health check between 1989 and 1990 and their second health check three years later between 1992 and 1993. The control group did not receive their first health check until 1992 / 1993. The main outcome measures were: serum cholesterol levels, blood pressure, body mass index and smoking cessation, plus self reported dietary fat intake, exercise and alcohol habits (OXCHECK Study Group, 1995).

The larger British Family Heart study involved 26 general practices in thirteen towns across Britain. General practices within each town were paired and randomly allocated to either intervention or external comparison groups. In total 12,472 men aged 40 - 59 years and their partners were identified by household and invited for screening. In the intervention practices, families were further sub-divided into either the screening and intervention group, or the internal comparison group. Families were invited for screening and those in the intervention group received nurse-led lifestyle intervention, which lasted 90 minutes, and were invited back for re-screening one year later, which took place at the same time as the families in the internal and external comparison groups, who were attending for their first screening visit. The overall aim of the trial was to estimate the size of the change in cardiovascular risk factors in men and women that could be achieved in one year, by a practice based strategy, which involved a family centred approach (Wood et al., 1994). The Dundee risk score was used as an outcome measure to quantify the overall risk reduction; this is designed for people aged 35 to 64 years, which excluded some women in the study who were younger than this.

Both studies only resulted in small changes to the risk factors being measured, despite intensive intervention which the intervention groups received. The results of the OXCHECK study showed that mean total cholesterol levels were 3.1% lower in the intervention group which was supported by the self-reported saturated fat intake being significantly lower; blood pressure was lower by 1.9%, although this could have been due to the accommodation effect; body mass index was also down by 1.4%; there were no significant difference between the intervention and control groups in prevalence of smoking and excessive alcohol use (OXCHECK Study Group, 1995).

The conclusion from the study was that there were real benefits to those willing to attend the health checks, and that the benefits were sustained over the three years, but that annual health checks over three years where no more effective in modifying risk factors than health checks over a single year; illustrating that there is no value in subsequent re-screens (OXCHECK Study Group, 1995). This shows that risk reduction is maintained after three years, for those who attended health checks this might lead to a reduction in risk of myocardial infarction by between 5 and 15%. However, these relatively small benefits needed to be balanced against the costs in relation to other priorities, especially in view of the fact that half the nurses' time was spent on recruiting patients into the study and subsequently retaining them (OXCHECK Study Group, 1995). This conclusion was further validated by Field's et al., (1995) cost analysis which showed that recording blood pressure and measuring cholesterol was more cost effective than providing comprehensive screening, especially in older men. They recommended that the most cost effective approach for primary prevention was to target older men and treat where necessary for raised blood pressure and cholesterol; the emphasis being upon pharmacological treatment. Field, at al., (1995) stated that screening and intervention was considerably less cost effective in women. This recommendation was made presumably as women are at less CHD risk than men at the same age; but women were twice as likely to attend the study visits, and showed more lifestyle changes (OXCHECK Study Group, 1995). For lifestyle intervention it could be argued that women are more likely to influence positive lifestyle behaviour within a family; an important consideration where they is family history for heart disease which may be associated with a shared family environment (Bao et al., 1997: Kavanagh et al., 2000).

The British Family Heart study reached 73% of eligible families and maintained contact with 88% men and 85% women over one year (Wood et al., 1994). After a year self reported cigarette smoking was reduced by 4%, weight by 1kg, systolic pressure by 7mmHg, diastolic pressure by 3mmHg and cholesterol concentration by 0.1mmol/L. If these differences were maintained long term this could equate to an overall 12% reduction in coronary risk. However, the researchers concluded that such an intensive strategy could not be justified by these results and that alternative preventive strategies needed to be developed, where these options may include specific targeting of high risk patients, such as those with hypertension, hyperlipidaemia, diabetes and established CHD (Wood et al., 1994). This again is similar to the cost analysis of Field et al., (1995) from the OXCHECK data. These recommendations now reflect the current emphasis of primary prevention as stated in the Joint British Society 2 Guidelines.

The overall results from these two studies showed that the British Family Heart study achieved a 13% reduction in coronary risk for men and a 10% reduction for women; the OXCHECK study achieved a 7% reduction for men and a 13% reduction for women (Wonderling et al., 1996a). When evaluating the results from these studies a cost analysis is important to direct future clinical practice and develop national guidelines. A comparative cost analysis of these studies by Wonderling et al., (1996a) showed that the actual cost for both men and women in the OXCHECK study was £29.27; in the British family heart study it was £66.01 for men and £57.82 for women. (If utilisation of other health service resources is taken into account the costs for women in the British Family Heart study is reduced to £13 (Wonderling et al., (1996b).) Taking the analysis further, for every 1% risk reduction a cost of £4.18 per man, £1.72 per women in the OXCHECK study; £5.08 per man and £5.78 per women in the British family heart study. The cost associated with risk reduction was better for the OXCHECK study rather that the British Family Heart study. Wonderling states that the actual cost effectiveness of these studies needs to be evaluated against life years gained and projected for 10 or more years assuming that the beneficial effect persists. This analysis showed that the more intensive British Family Heart study, although less cost effective, did result in more life years gained. However as Wonderling et al., (1996b) emphasise the analysis only considers the detailed costs associated with the research, and subsequent expenses, such as prescribed medication, it does not include the wider implications, such as the synergistic effect related to other diseases such as stroke and diabetes; the wider implications of health resources; the extended mortality gains set off against the cost incurred for keeping people alive longer. They conclude that larger trials with longer follow up are required to assess long term cost effectiveness (Wonderling et al., 1996b).

Important considerations from these two major UK studies regarding this thesis was firstly that the health promotion strategy used in the studies needed to be reproducible in clinical practice. The health promotion programme developed in the thesis also needed to be replicable in either a secondary or primary care setting, where a senior nurse, with appropriate cardiovascular knowledge could manage the sessions, with medical support where needed. This has meant that specialist investigations such as an electrocardiogram (ECG) and treadmill tests to measure oxygen efficiency, were not used unless clinically recommended. The nurse consultations in the OXCHECK and British Family Heart studies took on average an hour, slightly longer for the initial assessment; again this was the timetable adopted in the thesis. Resulting from the approach of the British Family Heart study, a family centred approach was used in the thesis, where family members were invited and encouraged to attend. Two major differences between the thesis and these studies was that firstly people of all ages were invited to participate, this was important as the atherosclerosis process starts in childhood (Hayman et al., 2007) and influencing behavioural change is often easier when people are younger and less established in their lifestyle practices. Non-probability convenience sampling was used, ensuring that little time was spent on screening, and that equal coverage of people from all social classes (Cruickshank 1994) and ethnic groups was achieved. Minimal time and administration expenditure was spend on retaining participants in the study.

3.3.2 Change of Heart study

A smaller study which took place in general practice during the later part of the 1990s was the Change of Heart study. This was a parallel group randomised controlled study, aiming to identify if behavioural counselling could prove more effective than educational and motivational approaches to cardiovascular risk reduction (Hilton et al., 1999). The study looked at measuring the effect of behaviourally orientated counselling, on the basis of Prochaska and DiClemente's 'Stage of change' model, on health behaviour and biological risk factors (Hilton et al., 1999; Steptoe et al., 1999). Ten practices were randomised as interventional, ten as control practices. All study participants had an assessment at baseline, four and 12 months; those in the intervention group where invited to attend two or three counselling sessions, according to their number of risk factors. Nurses in the intervention practices had attended specialised counselling training, so were able to give individualised enhanced advice; people in the control groups were given encouragement according to the standard practice already used by the nurse. This was a population based recruitment strategy, where people aged between 18 and 69 years could participate, so long as they had one or more of the stipulated risk factors for heart disease.

The participants were recruited through opportunistic screening, computer call-up, self referrals and direct recruitment, at the 20 group general practices in inner city and rural areas. The study was initially designed to recruit 2,000 participants over 12 months; it recruited 883 over an 18 month period. Recruitment was problematic partly due to the fact that many practices had already identified people with multiple risk factors and offered them health checks, and although all staff in the practices were committed to the study, belief in the effectiveness of primary prevention was possibly in doubt (Steptoe et al., 1999). Another problem with the study was retention; 71% of the recruits completed the 4 month assessment only 59% completed the 12 month assessment. On average each practice recruited 44 participants, while about 27 participants in a practice completed the study. The drop out rates were higher, and the recruitment rates lower, in the intervention group; this was felt to be associated with the greater time commitment required for the counselling sessions. Those who did not finish in the study, were younger and more likely to smoke (Steptoe et al., 1999). The time allocated to the sessions were similar to the OXCHECK and British Family Heart studies; sessions were 60 minutes for those with two risk factors, and 40 minutes for those with one.

The study did detect differences in the intervention group for dietary fat intake, regular exercise, number of cigarettes smoked and systolic blood pressure. These occurred at four months and were sustained at 12 months (Hilton et al., 1999). There was no difference between the two groups regarding total cholesterol, weight, diastolic blood pressure and smoking cessation. However, reduction in total serum cholesterol was reported in the control group, although the prescribing of statins had been withheld for the duration of the study (Hilton et al., 1999; Steptoe et al., 1999).

This study illustrates how health checks given by practice nurses, specially trained in the behaviourally orientated counselling can provide greater risk reduction. This thesis has utilised the concept of the stages of change model, recognising the different stages that people go through regarding behavioural changes; starting with precontemplation, progressing to contemplation, preparation, action and finally maintenance. However no specialised training regarding behaviourally counselling had been received, but the underlying principal was utilised. The Change of Heart study also concluded that extended counselling may be required before more substantial reductions emerge (Steptoe et al., 1999); again this is reflected in the thesis where follow-up continues for two years, not one.

3.3.3 Meta-analysis

A meta-analysis looking at multiple risk factors interventions for primary prevention for CHD was initially undertaken by Ebrahim and Davey, published 1997, the updated Cochrane review was published in 2006. The objective of the meta-analysis was to assess the effectiveness of multiple risk factor interventions in reducing cardiovascular risk factors, total mortality, and mortality from CHD among middle-aged adults. Randomised intervention studies using counselling or education to modify multiple risk factors in adults, with or without pharmacological treatments, in the general population, occupational or high risk groups, and which lasted for more than 6 months were selected (Ebrahim and Davey Smith, 1997; Ebrahim and Davey Smith, 1999; Ebrahim et al., 2006). In 1997 they reported on 14 trials which met their selection criteria; by 2006 they where able to include 39 trials in the meta-analysis. The results and conclusions between the two reports remain similar, consequently the recent publication will be quoted. The OXCHECK, British Family Heart and Change of Heart studies were all included in the meta- analysis.

The result of the analysis showed that studies with the highest level of risk factors showed the greatest corresponding reduction in risk, and that those recruiting higher risk patients were more likely to demonstrate beneficial effects. There was a small but significant fall in cholesterol levels (net difference -0.07mmol/L, 95% CI -0.08 to 0.06 mmol/L); which was possibly due to the increased used of statin medication (Ebrahim et al., 2006). Smoking levels showed a net reduction of 24%; blood pressure changes were small (Ebrahim et al., 2006).

The authors raise some interesting issues which have particular relevance to this thesis and will be briefly discussed. Ebrahim et al. (2006), identify the effectiveness of risk reduction in secondary prevention trials, suggesting that the beneficial effects are due to the greater motivation of these people to make and sustain lifestyle changes, because they have had a myocardial infarction. This thesis involves people whose motivation may be greater because they have a first degree relative diagnosed with premature coronary heart disease. The authors go on to suggest that some benefits may not be detectable in the early stages of a study but may emerge over time, this they state is true for pharmacological trials on blood pressure and cholesterol lowering where benefits do not emerge until two to four years (Ebrahim et al., 2006). The follow-up period for the trials in the meta-analysis varied from between six months to six years; for 16 of the trials follow-up was a year, for ten studies duration was between four and six years, while for seven studies duration was only six months. As previously mentioned risk reduction in secondary prevention trials is not seen until two years. When encouraging change in people's behaviour it takes time for them to move through the stages of change as illustrated in Prochaska and DiClemente's model of change, where even once action has been achieved, it is important that relapse does not occur and people revert back to their previous behaviour patterns (Prochaska et al., 1992). Arguably six months, or even a year, is too short a time for people to contemplate, then sustain changes to their lifestyle.

The conclusions reached are firstly, that one-to-one health promotion sessions with people in the general population who are at relatively low risk of CVD is ineffective at reducing clinical events and that targeting high risk individuals may be more effective; secondly that fiscal and legislative changes may be more effective at changing prevalence of CVD in the population; thirdly, it would be unlikely that any further large scale trials such as these would be established; and finally that qualitative research would be useful to gain an understanding of how the participants perceive and respond to lifestyle advice. These conclusions are again relevant to this thesis where people at high risk are being targeted for primary prevention and where two qualitative narratives from each participant are analysised to provide insight into the individuals experience of having a diagnosis of CHD in the family and in order to help evaluate the health promotion programme.

3.3.4 EuroAction study

Recently there has been a European study established - EuroAction (Wood et al., 2004). EuroAction is a cluster randomised controlled trial of a multi-disciplinary preventive cardiology programme for coronary patients, asymptomatic high risk individuals and their families. The aim of EuroAction is to:

> "raise standards of preventive cardiology in Europe by demonstrating that the recommended European and national lifestyle, risk factor and therapeutic goals in cardiovascular disease prevention are achievable and sustainable in everyday clinical practice." (Wood et al., 2004. p. 4)

EuroAction also states that it encompasses a family centred approach involving those with a premature coronary history; the study meets the criteria for a subsequent search for studies in this category. Further details of the EuroAction study are discussed later in this chapter.

The studies discussed in this section illustrate the difficulties for conducting primary prevention for CHD. Namely the extensive cost which is matched against the often minimal positive changes to risk factor modifications. Ebrahim et al., (2006) state that it is unlikely that further large scale randomised controlled trials will be conducted. There remains a need to identify effective strategies for primary prevention, either for individuals who are at high risk, or for the population through legislative and fiscal polices. Where risk factor modification can and does make a real contribution to prevention (McPherson et al., 2002; Unal et al., 2005) but where the effectiveness of a population based approach is only modest (Ebrahim et al., 2006).

3.4 Family history of coronary heart disease

A positive premature family history for CHD is an integral aspect of this thesis. The historical evidence supporting the theory that family history is an independent risk factor for CHD is identified; case-series studies, cohort, angiographic and Doppler studies will be highlighted. The mechanism of family history as a confirmed risk factor is discussed and the few studies which recruit those with a family history are examined. The importance and role for screening this high risk category of people is reviewed at the end.

People with a PFH for CHD were chosen for the research, as this population had been identified in the CHD National Service Framework (NSF) published by the Department of Health (DH) in 2000, and the 1998 "Joint British recommendations on prevention of Coronary Heart Disease in Clinical Practice," (Wood et al., 1998). The CHD NSF (DH 2000) established a framework for unifying the prevention, diagnosis and treatment of CHD in the UK. Standards three and four are concerned with preventing CHD in high risk patients by targeting those with established CVD and those with a significant risk of CVD:

> "General practitioners and primary health care teams should identify all people at significant risk of cardiovascular disease but who have not developed symptoms and offer them appropriate advice and treatment to reduce their risk." (DH 2000, p.4)

The CHD NSF goes on to identify people with a family history of premature heart disease as a population which are at increased risk for CHD and CVD, and consequently requiring a full assessment of their risk factors.

The evidence for family history as an independent risk factor has been established for some time, but routine screening of these people had not previously been undertaken. Today there is no provision for this population within the General Medical Services (GMS) contract; which is arguably why lifestyle advice and support, along with treatment, is not systematically provided. Meanwhile local provision for primary prevention may be funded through various methods, such as the primary care trust, cardiac networks or pharmaceutical companies; supported by individual enthusiasm;

where consequently implementation of a nationally defined systematic strategy is absent.

3.4.1 Historical evidence

The controversy regarding the existence of family history as an independent risk factor for CHD continued until the beginning of the 1990s. Prior to this time the research evidence was disputed and considered to be inconclusive (Rissanen and Nikkila, 1979; Perkins 1986; Goldbourt 1987). In the UK in the 1960s, Slack and Evans studied data from the UK Registrar General's Office and found that first degree relatives of coronary patients had between a 2.5 and 7 fold increase in the risk of coronary death (Slack and Evans, 1966). They observed a 6.4 increase for male relatives of patients who died at ages 35 – 54, declining to 2.3 at ages 55 years and over. For female relatives of patients who died between 35 - 64 years of age, there was a 6.9 fold increase, decreasing to 1.2 at ages of 65 and over (Slack and Evans, 1966). It is of note that these are the ages that are used today to classify a premature family history of CHD for men and women (Wood et al., 1998: DH 2000). The data showed that CHD aggregates in families, but so does the conventional risk factors such as cholesterol, hypertension, smoking and obesity, hence the continued debate about whether family history was an independent risk factor.

In 1976, Colditz and his colleagues collected prospective data from a cohort of 117,156 nurses in the American Nurses' Health Study (Colditz et al., 1986). They were able to provide evidence that there was a positive correlation between parental history of myocardial infarction and risk of coronary heart disease in women. Early in the 1990s, in the UK, Grech and colleagues (Grech et al., 1992) looked at coronary angiogram reports of people with no clinical evidence for CHD, but who were undergoing routine arteriography prior to valve surgery. Of the 387 patients, 27.6% (n=107) had a family history of CHD and of these, 48.6% (n=52) had significant coronary artery disease (CAD), compared with 72.4% (n=280) with no family history, of whom 21.4% (n=60) had significant coronary artery disease. Nearly half of those with a family history of CHD had significant coronary artery disease, while a similar number of people were also found to have coronary artery disease, but these people had no family history. This observational study demonstrated that coronary artery disease was higher for those with a family history and that there was a direct correlation between the number of coronary arteries that were affected in an individual and their number of relatives with overt coronary artery disease, the closest correlation being when father and siblings had CHD (Grech et al., 1992).

The presence of pre-clinical carotid artery atherosclerosis was used to provide evidence of CAD and make another link between family history of CHD and coronary artery disease, for white Americans (Bensen et al., 1999). Similarly, Nasir (2004) used electron beam tomography to detect coronary artery calcium, a marker for atherosclerosis, in 8,549 asymptomatic people with no prior history of CHD. Their results showed that the presence of coronary artery calcium significantly increased with increasing number of risk factors, and was higher for those with a parental history of premature CHD, and higher again for a sibling history of CHD. For those with no family history of CHD, the prevalence of coronary artery calcium was less (Nasir et al., 2004).

> "Those with no family history of CHD, family history of premature CHD in parents and family history in siblings had a prevalence of CAC of 55%, 64% and 78% (P<0.0001) among men and 27%, 36% and 56% (P<0.0001) among women, respectively."
>
> (Nasir et al., 2004, p. 2150)

Another decade on, the results of the Reykjavik study were published, this study, undertaken between 1967 and 1998, was the largest prospective cohort of its kind, collecting data on nearly 20,000 residents in the Reyjavik area of Iceland. The study confirmed that a positive family history gave an independent contribution to the development of CHD. Men with a history of CHD in a first-degree relative were found to have a 75% higher risk than those without a family history, and for women their risk increased by 83% (Andresdottir et al., 2002). This study concluded that 15% of myocardial infarctions and coronary revascularisations were explained by family history and were unrelated to conventional risk factors (Andresdottir et al., 2002).

3.4.2 Family history as a risk factor

Family history is now a well established independent risk factor for CHD, although the size of its effect is still not known (Andresdottir, et al., 2002), nor the mechanism. Today the debate is about the exact mechanisms of how family history affects coronary risk. The association between family history and risk of CHD is not explained by traditional risk factors (Colditz et al., 1986; Grech et al., 1992; Bensen et al., 1999; Andresdottir et al., 2002). However the contribution of new risk markers such as total plasma homocysteine levels, plasma fibrinogen levels, inflammatory markers and infections are yet to be studied (Andresdottir et al., 2002). The Reykjavik study did include some of the newer emerging risk factors and risk markers, such as erythrocyte sedimentation rate (ESR), level of education and physical activity, all of which only explained a small part of the associated risk (Andresdottir et al., 2002).

Research is ongoing to distinguish the effects of sibling and parental history. The details of the family history is important, resulting in altered levels of risk, with the following requiring consideration:

- sibling history, where a sibling history carries a greater risk burden than a parental history (Nasir et al., 2004);
- the number of family members diagnosed with CHD (Grech et al., 1992; Silbergberg et al., 1998);
- whether they are male or female, as the risk is greater for women than men (Pohjola-Sintonen et al., 1998);
- age of onset, where early onset confers greater risk (Pohjola-Sintonen et al., 1998; Silbergberg et al., 1998);
- family history of related disorders, such as diabetes, hypertension, stroke and lipid abnormalities (Jomini et al., 2002).

The size of the effect attributed by a family history is variable in the research. The original work of Slack and Evans, (1966) estimated the risk for women to be 7 times greater than for the general population and for men 6.5 times. Other risk estimates range from 2.2 for men and 5.0 for women (Colditz et al., 1986); while data from the Framingham study gives risk values of 2.0 for men and 1.7 for women (Lloyd-Jones et al., 2004). A UK based study looking at middle-aged men found that their relative risk was increased by 1.73 (Hawe et al., 2003). The current CVD prevention guidelines (Wood et al., 2005) use 1.3 for the calculation of attributed risk associated with a PFH. This is a conservative score, where no details of the family history are used in the risk calculation.

Sibling history may be thought to confer greater risk because parental family history is difficult to accurately obtain, especially when in the past it may have been confounded by the fact that diagnosis for parents was not as accurate as today. It would have been further confounded by them dying at an earlier age from other causes (Pohjola-Sintonen, et al., 1998; Nasir, et al., 2004). The accuracy of family self reported deaths has been questioned (Pohjola-Sintonen et al., 1998; Hawe et al., 2003; Nasir et al., 2004), however a large study in the West of Scotland was able to verify that 90% of the study population (n=2338) accurately reported deaths in their family due to CHD (Watt et al., 2004). It is also true to say that accurate parentage may be questionable, when children can be adopted, have surrogate parents or when precise paternity is uncertain. Parents may be aware of any anomalies, but their offspring may not. The issue of true parentage is an important one, when siblings and children perceive themselves at risk due to their family history.

3.4.3 Genetic link of familial coronary heart disease

The GENECARD Project, designed to look at the prevalence of major CHD risk factors in families with two or more affected siblings, was established in Switzerland (Jomini et al., 2002). The main finding was that hypertension, cigarette smoking, hypercholesterolaemia and obesity were twice as prevalent in this group as in the general population (Jomini et al., 2002). This finding was later echoed by Nasir (2004), who stated that these "individuals may be more susceptible to the deleterious effects of traditional risk factors" (Nasir et al., 2004), thus prevalence is increased (Kavanagh et al., 2000) and clustering of cardiac risk factors occurs (De Sutter et al., 2003). The implication for clinical practice is that these are treatable or modifiable conditions, and that for people who have a positive premature family history for CHD, these conditions and lifestyle behaviours should be treated pro-actively.

Similar findings had previously been found in the Bogalusa Heart study. This study tracked longitudinal changes in cardiovascular risk from childhood to young adulthood in offspring of parents with CHD, between 1973 and 1991. The children were found to be overweight in childhood, with an adverse risk factor profile developing faster into young adulthood, when compared with adolescents with no CHD family history. The prevalence of risk factors was also higher in those with a parental CHD history (Bao et al., 1997). The study concludes that there could be both a genetic as well as an environmental link, and that as being overweight is a modifiable risk factor, this should be targeted.

Collaborative work across Europe is being carried out to identify possible genetic links. The British Heart Foundation (BHF) Family Heart study collected and analysed DNA from siblings in over 2,000 families throughout the UK. They identified a region on Chromosome 2 that seems to be linked to an increased family risk (BHF Family Heart study 2005). Procardis is a study co-ordinated by the Department of Cardiovascular Medicine, the University of Oxford. This is a European, multi-centred study designed to identify susceptibility genes for CHD, in which 2,658 affected sibling pairs have been recruited. The initial results identify a novel replicated locus for myocardial infarction on Chromosome 17, as well as providing consistent results with a CHD susceptibility locus mapping to Chromosome 2 (Farrall et al., 2006).

> "The lack of evidence for other linked loci suggest that the heritable component of coronary artery disease and myocardial infarction may be composed of many genes, with few of them having sufficient effect to permit mapping by genetic linkage even in studies of this size involving thousands of affected sibling pairs."
>
> (Farrall et al., 2006, p.760)

The results from these studies illustrate that there is more than one chromosome involved in the genetic link, and that the multi-factorial risk profile of CHD makes it difficult to identify a single genetic causal link. The mechanism and link for hereditary CHD in families with a positive premature CHD history remains largely unanswered. It is likely to be a combination of four factors; firstly a genetic link, which has yet to be validated and identified (Hawe et al., 2003; BHF Family Heart Study Group, 2005; Farrall et al., 2006). Secondly, the fact that families have a shared environment (Bao et al., 1997; Kavanagh et al., 2000) especially in their younger years. Thirdly, a lifestyle link where individual behaviour patterns are repeated in families through the generations, leading to concordance of risk factors such as obesity and poor diet (Crouch and Gramling, 2005). Finally, there is shared socio-economic status among families (Burke 2003), where CHD prevalence increases in the lower socio-economic groups (McPherson et al., 2002).

3.4.4 Preventative studies for those with a premature family history of heart disease

A systematic literature search was initially carried out at the start of the research, from five databases: British Nursing Index (BNI), Allied & Complementary Medicine (AMED), Cumulated Index for Nursing and Allied Health Literature (CINHAL), and Medlars Online (MEDLINE). The key words used were "family history," "heart disease" and "premature;" the search terms used were kept broad in order to be inclusive and the search was limited to the English language. The databases yielded 198 papers, falling to 126 once duplicates were removed. Nineteen papers were finally selected for further review, one of which was a research study involving a similar population to those recruited as part of this thesis. A second identical search was carried out in June 2007. A further 133 papers were initially identified, falling to 83 once duplicates were removed, then 19 new papers were selected, two of which were prevention studies. Two further databases were included in this search, the Cochrane Library and InterNurse. The Cochrane Library search did not include the keyword "premature." A total of seven papers were identified, all from Clinical Trials, one of which was relevant. The InterNurse search yielded no papers until "family history" and "heart disease" were included in all fields. A potential 356 papers were identified, of which four papers were relevant.

Although limited prevention studies were found, much of the literature found in the searches has been included in this review. Additional papers have been found through extended searches, following internet links and from listed references. Papers which have included participants with a family history of sudden cardiac death, familial hypercholesterolaemia and those which have principally involved pharmacological treatment have all been excluded from the searches.

From the first search, only one paper was identified as a prevention study involving first degree relatives of those with a PFH. This study was undertaken in 2000, by Kavanagh and colleagues, who looked at sons of patients with premature CHD attending the Toronto Rehabilitation Centre. A comprehensive baseline risk assessment was undertaken followed two years later by a postal questionnaire. Although the participants had only one visit to the centre, for 79.2% of the participants, their health awareness had been enhanced by this single visit to a specialist cardiac facility, while 60.3% claimed that their attitude to a healthy lifestyle had changed for the positive (Kavanagh et al., 2000). A change in attitude does not necessarily lead to a change in behaviour. The distinguishing factor of this study is that the research was not conducted in the primary care setting, as is usual for a primary prevention study; here, the participants were seen in a specialist cardiology unit. This is the same approach which was subsequently adopted for this thesis.

Since the start of this thesis, a further four studies have been identified in the literature which have targeted those with a PFH of CHD. Table 3.3 provides details of these five studies. The results from this literature search have been supported by similar findings from a search conducted by the post graduate library.

TABLE 3.3 Familial prevention studies

Study Title and Authors	Year of study (year of publication)	Study Details
Risk Profile and Health Awareness in Male offspring with premature coronary heart disease T Kavanagh, R.Shephard, L Hamm, D Mertens, L Thacker	1993 - 1996 (2000)	571 sons of patients with premature CHD. Single visit to a rehabilitation centre for a comprehensive risk factor evaluation. Follow-up 2 years later with a postal questionnaire. Prevalence of modifiable risk factors, which can be influenced by involvement of family physician. Based in Toronto, Canada. RESULTS: offspring exhibited a substantial prevalence of modifiable risk factors. Family physicians can play an essential role in promoting a healthy lifestyle.
Impact of a community-based multiple risk intervention on cardiovascular risk in black families with a history of premature coronary disease D M Becker, L R Yanek, W R Johnson, D Garrett, T F Moy, S S Reynolds, R S Blumenthal, D Vaidya, L C Becker	not stated (2005)	Black subjects with a family history of premature CHD aged 30 to 59 years recruited, comparing a community-based multiple risk intervention with an enhanced primary care to reduce CHD risk. 364 subjects recruited and monitored for a year. Based in America. RESULTS: the community based care achieved greater reduction in LDL cholesterol and BP. A community based model of care which addressed barriers to prevention may be effective to reduce CHD risk in a high risk black population.
Effect of lifestyle changes on atherogenic lipids and endothelial cell adhesion molecules in young adults with familial premature coronary heart disease S Tonstad, T Sundfor, I Seljeflot	not stated (2005)	172 (men and women) who were untreated first degree relatives aged 18 to 39 years of patients admitted to a Norwegian city hospital. Aim to evaluate the effects of lifestyle modification programme on lipids and novel risk markers. RESULTS: intensive lifestyle advice from a team of dieticians and physicians can reduce atherogenic lipids. Dietary and smoking cessation are feasible in young adults with familial premature CHD.
EuroAction: a demonstration project in preventive cardiology Jennings, C. Wood, D.	April 2003 to April 2006 (2007)	Randomised controlled trial, with 24 cluster hospitals and general practices, based in 8 European countries.
Primary Prevention for coronary heart disease M J Wrigley, T Pakrashi, S Maslin-Prothero, G Watkinson	March 2004 - August 2007 (2006)	28 participants, siblings and offspring of those with premature family history, recruited to a 2 year nurse-led primary prevention health promotion programme. Assessment of modifiable risk factors. Narrative interviews to gain understanding into personal experience of living with heart disease in the family.

The earliest of these subsequent studies were both published in 2005. Firstly, Becker and her colleagues reported on their study, which looked at black people with a family history of premature CHD, but who themselves were without clinical manifestations of the disease. They randomised 168 to an enhanced primary care strategy and 196 people to a specifically designed community-based care programme. Primary risk factors measured over a one year period were blood pressure, low density lipoproteins (LDL) cholesterol and current smoking. Both groups achieved significant improvements in these primary outcomes, however for the community-based care programme, this translated into a significant reduction in global CHD risk, based on the Framingham tables; no global risk reduction was seen in the enhanced primary care strategy (Becker et al., 2005). Although this study was looking specifically at black families and attempting to address the barriers that exist for this specific American population, the design and findings are relevant within the current context. There is a need to establish effective primary prevention policies for people of all ethnic groups. It is also of note that emphasis was placed upon three modifiable and accurately measurable risk factors, two of which are treatable with medication.

A recent Norwegian study randomised 172 participants. The young participants were aged 18 to 39 years, with a premature family history for CHD in a first degree relative, to either an intervention programme, or usual care. The effects of dietary changes and smoking on atherogenic lipids and endothelial cell adhesion molecules were measured (Tonstad et al., 2005). The intensive programme provided by both dieticians and physicians resulted in reduced intake of saturated fat and cholesterol and decreased smoking levels compared with the control group, although no change was noted in body mass index scores over the eight months for either group. The dietary and smoking changes achieved in the intervention group were reflected in improvements in these novel risk markers (Tonstad et al., 2002).

Another study which had a collaborative approach to risk factor reduction is EuroAction. This was a cluster controlled trial, in which hospital and primary care centres were involved across eight European countries. The centres were randomised to either usual care or the intervention programme (Wood et al., 2004; Jennings 2007). One of the objectives of the study was:

> "To demonstrate the process of care and the impact of a hospital-led, preventive cardiology programme for all first-degree relatives of coronary patients with premature disease." (Jennings 2007, p. 41)

The EuroAction study centred on a team approach to the management of these patients and their families, and established a programme of care in order to meet these requirements. Risk tables were used to assess risk and guide treatments for those who did not have an overt diagnosis of CHD, while the recommendations of the 1998 European guidelines (Wood et al., 1998) provided the programmes targets related to lifestyle, risk factors and therapy (Jennings 2007). The focus of the study is upon a family approach (Wood et al., 2004; Jennings 2007), however only the hospital arm recruited patients along with both their partners and first-degree relatives, while the primary care arm only recruited patients and partners (Wood et al., 2004). First-degree relatives recruited onto the programme had to live in the same household as the patient. Otherwise relatives who did not live in the same household were sent a 'Personal Support Pack' (Wood et al., 2004), most of the 'family' recruited into the study were partners and spouses. The full results of the study have not been published; the break-down of the study population will be of note in this context of family. The involvement of first-degree relatives in this family-centred approach and true concept of family is meanwhile questionable within the EuroAction study.

The EuroAction study has many similarities to this thesis: first-degree relatives of patients diagnosed with premature CHD are recruited; there is a hospital based arm of the study; it is nurse-led, by a specialist cardiac nurse; family members are encouraged to participate; participants have their own personal A4 record card; the stages of change model (Prochaska et al., 1992) is utilised; opportunistic screening is used. There are also major differences: it is a randomised controlled trial; follow-up is for one year; there is a multi-disciplinary approach; extensive assessments are made and quantitative research data collected; there is no qualitative data collected; study visits are more frequent.

The fourth study identified in the literature search was 'Primary prevention for coronary heart disease: past evidence and future challenges' (Wrigley et al., 2006). The paper was written as part of this thesis.

Comparisons between these five studies are noteworthy. Firstly three studies are solely hospital based, all of which are single centred studies (Kavanagh et al., 2000; Tonstad et al., 2002; Wrigley et al., 2006); one is based in both the hospital and the community (Wood et al., 2004): one is based in the community (Becker et al., 2005), the traditional setting for primary prevention. Three are randomised studies; one cluster (Wood et al., 2004), two parallel (Tonstad et al., 2002; Becker et al., 2005), so that changes could be measured against a control. The numbers involved in these studies are variable: 571 sons (Kavanagh et al., 2000); 364 siblings (Becker et al., 2005); 150 first-degree relatives (Tonstad et al., 2002) and 28 first-degree relatives (Wrigley et al., 2006). The number of first-degree relatives in EuroAction is unpublished. In comparison to participants in the OXCHECK and British Family Heart primary prevention studies, these recruitment figures are moderate. Further comparisons with the number of people recruited should consider the finer details of the study, so that depth and breadth of information collected may be accurately reflected by the study numbers. Finally, the involvement and role of nurses in all these studies is extensive.

3.4.5 Screening for family history

The assumption associated with health screening is that early detection of those at risk is preferable to treatment after clinical symptoms occur. This can only be true in the context of heart disease if positive changes are made to a person's risk factor profile, either through lifestyle behaviour and /or medication.

Research has shown that for families who have a positive CHD history there is a lack of awareness of the associated risk factors (Langer et al., 1994; Tonstad et al., 2002) or lifestyle changes occurring as a result of a family CVD diagnosis (Kip et al., 2002). However, other studies refute these findings (Hunt et al., 2001; Walter et al., 2004; Walter et al., 2005) where at least perception of familial risk is acknowledged, although transference of this perception of risk to lifestyle modification has not been evaluated.

The support for screening and identification of people with a family history is strong, especially when taking a family history is a traditional tool in clinical medicine (Simon and Rosolova, 2002). Tonstad (2002) in her Norwegian study was able to illustrate that most patients with a premature diagnosis for CHD were willing to contact relatives for screening, where 78% were happy to contact their siblings and 93% agreed to contact their children. Sisters and daughters were more likely to complete the screening details than brothers and sons (Tonstad et al., 2002). The patients in this study (Wrigley et al., 2006) were identified within the hospital; Tonstad (2002) recommends that screening of other family members could be facilitated from this setting, especially where the willingness of the patient to be involved in this process is clearly shown. This is an approach which had already been established for this thesis. The hospital is the ideal setting as it is here that the initial diagnosis is made, the rehabilitation process starts, and through discussion with the Rehabilitation Nurse Specialist, risk factors for both the patient and extended risk to their families can be sensitively introduced. This process is further facilitated if family members are visiting the patient; they can be involved at the outset.

A questionnaire study undertaken by Summerton and Garrood, (1997) identified that Scottish GPs value family medical history, and use it to assist when deciding upon medical investigations and management, especially regarding cholesterol levels (92.1%). Although in practice when it was part of their routine enquiry, only family history for cholesterol and CHD was regularly enquired about, 94.3%; compared with breast cancer, 48.4%, rheumatoid disease 21.3%, colon/rectal cancer 30.7% and thyroid disease 20.8% (Summerton and Garrood, 1997). Opportunistic screening is consequently considered a valuable tool, and one which is used by Scottish GPs in the clinical decision making for CHD. However, it is important to include not just parental history, but sibling history, number of affected relatives and all of their ages (Silberberg et al., 1998).

The EUROASPIRE II survey undertaken between 1999 and 2000, looked at the health records of 8,181 patients with confirmed CHD diagnosis and interviewed 5,556 people, across 15 European countries (De Sutter et al., 2001). The aim of EUROASPIRE II was to determine whether the Joint European Societies' (Wood et al., 1998) recommendations were being undertaken in clinical practice. It followed on from the previous EUROASPIRE I study (EUROASPIRE Study Group 1997). The results of the EUROASPIRE II survey clearly showed that many patients are not making the necessary lifestyle changes. Consequently, there is a high prevalence of unhealthy lifestyles, while pharmacology therapy to achieve lipid and blood pressure targets are under-used (De Sutter et al., 2001). A sub-study was undertaken with 3,322 relatives of

1,289 patients from the EUROASPIRE II survey. This survey showed that family screening was only performed in 11.1% of siblings and that only 50% of these siblings were given some general lifestyle advice regarding CHD risk factors. While for children, only 5.6% were screened, of which 25% were given lifestyle advice. Active medication to control hypertension and improve lipid profiles was rarely prescribed, especially in the offspring group (De Sutter et al., 2003). EUROASPIRE III is due for publication within the next year.

Screening of first degree relatives with a PFH for CHD is recommended by both the CHD NSF (DH, 2000) and JBS 2: guidelines (Wood et al., 2005). Despite these recommendations, screening has been shown to be rarely performed (De Sutter et al., 2003) and the literature search has shown that few studies specifically involve this population in a primary prevention strategy. Consequently, supporting evidence for effective clinical approach and management is absent.

These high-risk people with a PFH are easily identifiable; their susceptibility to CHD is proven and many will already perceive themselves at risk. Screening for these people is straightforward, unlike the expensive and often invasive tests and procedures that are required for cancer screening. Risk factor modification, can through lifestyle changes and pharmacological treatment, improve their life expectancy and morbidity.

3.5 The experience of heart disease

Personal experience of heart disease is a central aspect of the thesis, the literature associated with lay experience of heart and other chronic diseases is discussed.

3.5.1 Literature search

A comprehensive and systematic literature search was undertaken in 2007 looking specifically for qualitative studies where the study population were those who had a family history of heart disease, but whom themselves did not have the clinical manifestations of the disease. A total of nine databases were searched: the Cochrane library, British Nursing Index (BNI), Allied & Complementary Medicine (AMED), Cumulated Index for Nursing and Allied Health Literature (CINHAL), Medlars Online (MEDLINE), InterNurse and PsychInfo. The keywords used were kept broad to ensure full coverage. Abstracts which looked at sudden cardiac death or familial hypercholesterolemia were discounted. Papers were identified which discussed lay perceptions of families living with chronic disease disorders, which included heart disease, and perceptions of family history related specifically to heart disease. Papers which looked at the experiences of spouses and other key people associated with a CHD sufferer were identified. No qualitative papers which looked specifically at first-degree relatives and their experience of living with heart disease in the family were identified. The results from this literature were supported by similar findings from a literature search conducted by the post graduate library.

There are many studies where the focus is on the individual who is experiencing a disease, the biggest is the Dipex website (www.dipex.org) which shows, through videos and narratives the personal experiences of patients who have suffered ill health. Some studies have identified the fact that family lives are also affected (Clark et al., 2004). There are studies which consider the consequences for the spouse (Karner et al., 2003), but there are few studies which focus on how this experience affects the family as a whole (Preston 1997; Astedt-Kurki et al., 2004). Qualitative studies which look at the lived experience for family members when there is a diagnosis of a chronic disease are rare indeed.

3.5.2 Study discussion

The studies identified through the literature search are discussed in the context of the thesis, illustrating how these papers, although not directly targeting families with a premature heart history, do provide some useful insight into family perception of risk. The earliest of these papers was published by Hunt and colleagues in 2000.

Scientific enquiry and investigation has confirmed that a PFH of CHD confers increased risk of developing heart disease for first-degree relatives. Members of a family with heart disease, irrespective of a premature classification, perceive themselves at risk and develop their own lay epidemiology. Perception of risk by unaffected family members is increased by three main factors. Firstly the number of affected members; men need more family members to be affected, for example two close family relatives with a CHD diagnosis, until they perceive a risk, while women perceive a risk with only one affected parent (Hunt et al., 2001). Secondly, personal resemblance to the sufferer; this could be in the form of outward appearance or lifestyle habits (Hunt et al., 2001). If similarities are noted then the perceived risk is increased (Steenkiste et al., 2004), while personal or lifestyle differences reduce the risk (Hunt et al., 2001). People also associated themselves with key individuals outside the family, such as colleagues and close friends, where differences and similarities result in altered levels of perceived risk to themselves (Steenkiste et al., 2004). Finally, the closeness of the person to the event, both in terms of emotional closeness to the sufferer and the extent to which they experience the event with the sufferer, will all affect their perceptions of risk and vulnerability (Walter et al., 2005). This is also true for other chronic diseases such as cancer and diabetes mellitus (Walter et al., 2004).

A sense of personal vulnerability informed by these salient features of their family history develops (Walter et al., 2004; Walter et al., 2005). These people make a genetic link where it is seen as a 'family illness and weakness' associated with their genes (Hunt et al., 2001). This hereditary link is not seen as fatalistic (Hunt et al., 2000). This is important for prevention, as a fatalistic approach would ensure that unhealthy behaviour continues (Walter et al., 2004).

Age of the sufferer is perceived as important, when older sufferers are disregarded by some to confer a family history (Watt et al., 2000), but other studies show that whatever the age of the family member, this increases perceived risk and susceptibility (Hunt, et al., 2001). Disease patterns within the family are of note, especially age, where this can become a milestone (Walter et al., 2004), particularly if more than one family member has been affected at a certain age (Hunt et al., 2001).

Most families show a high level of knowledge regarding the risk factors associated with developing heart disease (Hunt et al., 2001; Walter et al., 2005). They attribute heart disease to these risks (Hunt et al., 2001), especially stress (Hunt et al., 2000). This is important because the multifactorial nature of the disease is acknowledged and this implies that some control over the disease is achievable and consequently, fatalism is prevented. However, the level of risk is changeable over time (Hunt et al., 2001). Families with a CHD history are shown to endorse healthy behaviour, eat a healthy diet, to exercise and they are less likely to smoke (Hunt et al., 2001). Therefore family history does appear to increase adherence to conventional health promotion.

The literature illustrates how important it is to understand a person's perception of their risk; some may perceive risk when there is none (Steenkiste et al., 2004), while others underestimate the level of risk (Hunt et al., 2001). There can be conflict and misunderstanding between lay understanding and medical perspective (Steenkiste et al., 2004: Walter et al., 2004), especially regarding the concept of risk, where doctors measure risk using risk tables and quote percentage possibilities, which has little real meaning to these individuals (Steenkiste et al., 2004), who already have a sense of personal vulnerability (Hunt et al., 2005).

This supports the findings of a systematic review which looked at lay understanding of familial risk of common chronic diseases including coronary artery disease, cancer and diabetes mellitus (Walter et al., 2004). Eleven qualitative studies were included in the final review, from this five main interconnected themes emerged: diseases running in my family, experiencing a relative's illness, personal mental models, personalising vulnerability and control of familial risk. Walter et al., (2004), through this collective analysis, showed that people are aware of the familial link with a chronic disease, which can be affected by both their personal experience of the disease and their own sense of vulnerability. They conclude that in order to enhance the effectiveness of health promotion advice from health professionals, as well as improving communication, it is important to be aware of the differing personal levels of meaning that people ascribe to features of the disease, and the extent of their sense of vulnerability and control, as this will affect a persons attempt to control the perceived risks (Walter et al., 2004: Walter and Emery, 2006).

3.6 Summary

This chapter has reviewed the pertinent clinical and research literature which informs this thesis. It has initially discussed the four levels of preventative health care which guide and facilitate management for CHD; the impact that risk reduction can have upon the UK population has been identified. It has gone on to show how people with a premature family history for CHD have been identified in the UK as a population who should be screened and advised accordingly. The review has highlighted the need for screening, but the lack of follow-up that takes place in clinical practice, while qualitative studies with these people has been shown to be sparse. Prevention studies targeting those with PFH and UK primary prevention studies have been discussed.

This literature review clearly identifies the risk for those with a PFH, the need for adequate nursing and medical follow-up and the difficulties associated with primary prevention, which further highlights the importance of seeking insight from these individuals. All these issues are addressed within this thesis.

The next chapter will explain the research design and data collection methods adopted, which provide the structure for the study. Salutogenesis, the theoretical framework, is discussed, identifying how this will be used within the analytical discussion.

CHAPTER FOUR

Study Design, Theory and Method

4.1 Chapter introduction

This chapter reviews the study design and methodology. The chapter is divided into five sections; the first places the study into its environmental context; the next discusses the study design and choice of research methods; the third section identifies the theoretical framework through which the study results will be informed, and the transtheoretical model, which is used in the health promotion programme. The fourth highlights the research considerations which have been pertinent during the study, followed by issues of scientific rigour and quality; finally, section six places the theory into the context of the research and its three phases.

4.2 Research context

The National Health Service (NHS) Trust where the research took place comprises of two hospitals, which are 11 miles apart. Both hospitals, at the start of the study had an accident and emergency department, intensive care unit, surgical and medical wards. The Trust covers a large and diverse population, with a catchment of around 450,000 people. In cardiology for the year 2004, there were 482 patients discharged with a primary diagnosis of a myocardial infarction. Both hospitals had cardiology out-patients facilities, a coronary care unit and full cardiac rehabilitation services. St Andrew's (pseudonym) had 250 beds, while St Bernard (pseudonym) had 400 beds. At St Bernard's there is a private angiography laboratory which performs diagnostic angiograms, and non-complicated angioplasties. A variety of pacemakers and implantable cardioverter defibrillators are fitted and electrophysiology studies are undertaken in the angiography laboratory. The cardiology department has a dedicated research programme which runs a variety of clinical, device and observational studies.

The design for the research is case study and narrative. The next section will discuss these designs in the context of the research.

4.3 Case studies

> "Case study is a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence."
>
> (Robson 1993 p. 5)

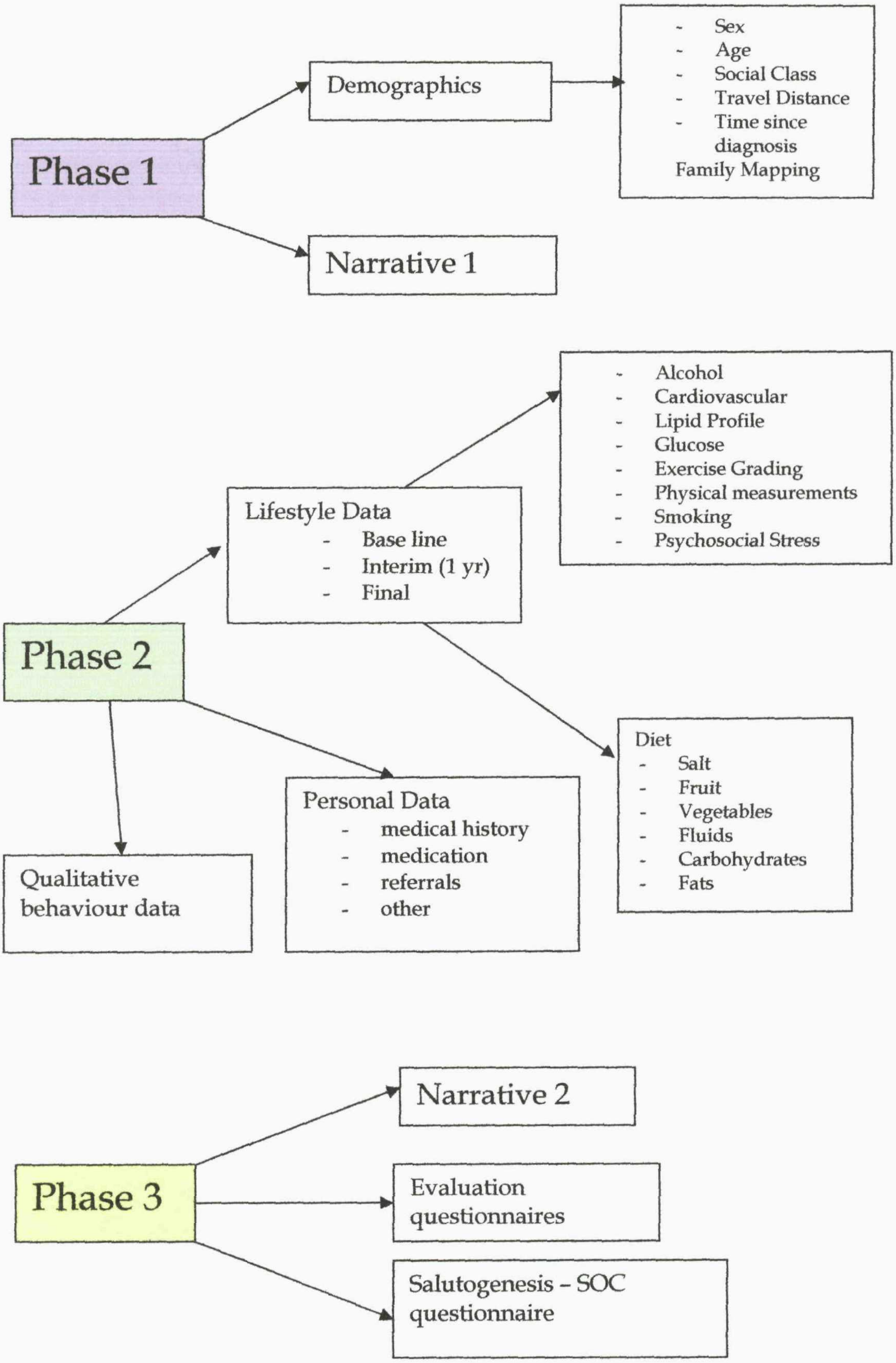
Robson's definition clearly illustrates the centrality and importance of each case or individual who is being studied. It shows the grounded context of the case within their environment and real life time frame. The research strategy enables evaluation and exploration to occur, while ensuring empirical rigour through multi-method data collection methods (Robson 1993).

Case studies are used in medicine as a teaching aid, where single cases are presented or single case reports written, while in the social sciences case studies are used as a research method. Yin (2003) states that there can be confusion between case study teaching and case study research, but that research, unlike teaching, needs to ensure the accurate and true presentation of the empirical data. However, a common concern is that case study research provides little basis for scientific generalization (Yin 2003). This could be true if the research was to extrapolate the findings of a single case to a population sample. Using appropriate analysis the correct conclusions should be drawn, and their worth to a wider population evaluated, where the relevance of the findings are not dependent upon the size of the sample.

A question that arose during the ethical review of this study was why the study was not a randomised control study. Within clinical research, the randomised controlled trial (RCT) is usually considered the gold standard of research in order to test the effectiveness of a health treatment or intervention (Black 1996; Yin 2003); they are viewed as the most scientifically rigorous design, and consequently the most favoured within clinical practice. The primary prevention studies discussed in the previous chapter were all RCTs. A discussion point raised in the meta-analysis of Ebrahim et al. (2006), is concerned with the use and effectiveness of randomised controlled trials for population and social approaches to prevention. This study had no control group against which the intervention, the health promotion programme, could be measured. Tones and Green (2004), assert that the randomised control study should rarely if ever be used to evaluate health promotion, principally because they state that health promotion is about empowerment and must involve the individual as integral to the study where real understanding is being sort. Two further points for consideration are that, firstly, there are multiple variables, such as market forces and advertising, that can impact and influence individuals regarding their lifestyle behaviour. These cannot be controlled and therefore make a control group inappropriate. Secondly, the baseline risk assessment provides a value against which the intervention can have some measurement. In conclusion, if the risk profile improves, it can only be said that the intervention has been a part of this process, and not solely responsible for it. This argument also supports the premise for utilising qualitative data in order to develop greater understanding within the study context.

A variety of data have been collected and analysed in the study: qualitative data from the two narrative interviews, predominantly numerical data from the health promotion programme and quantitative data from the final evaluation questionnaire. The case study approach encompasses all these aspects collectively, both multi-methods and multi-dimensional, where the research process ensures the robustness of the results and conclusions. Figure 4.1 illustrates diagrammatically the data which is collected during the research, at which phase.

FIGURE 4.1 Study data for each phase



4.3.1 Narrative enquiry

A narrative methodology enables the individual to tell their own story in their own words, so that insight can be gained into their unique experience (Labonte et al., 1999). The use of stories and narrative enquiry as a research paradigm has recently gained in popularity and credence within medical and nursing research (Mischler 1995; Fairbairn and Carson, 2002; Priest et al., 2002; Parker and Wiltshire, 2003). Fairbairn and Carson (2002) describe the way in which many of the stories told by nurse researchers are heavily populated by academic language and that for the majority of nurses, who may read such articles, there is little relevance to their day to day practice; there is no empathy with the writing, therefore no change is made to their nursing practice. Wilcock et al. (2003), discuss the use of narrative interviews for the improvement of patient care. They describe the discovery interview process which was used by the coronary heart disease collaboratives and the critical care programme as advised by the NHS Modernisation Agency. The Modernisation Agency advocated the use of discovery interviews, where trained interviewers gather narratives in one-to-one interviews from both carers and patients. The narratives were then read back to a professional team, where the aim was to generate improvement activities that are inspired by hearing these stories (Wilcock et al., 2003). Narratives help to bridge the gap between the academic researcher and the clinical nurse, so that the research has true value and meaning in the clinical environment, and consequently understanding is enhanced and practice is developed.

Narratives and story-telling are terms often used interchangeably. Holloway and Wheeler (2002), explain that narratives can be seen as the account of the person's experience while the story-telling is the approach adopted for relaying to a wider audience or as Parker and Wiltshire (2003) state, the actual data. However when reading the literature, there appears to be no clear distinction in the terminology between narrative and story-telling. This lack of distinction is reflected in the Oxford Dictionary where narrative is defined as 'a spoken or written account of connected events: a story' (Pearsall 2001, p. 1231). Consequently within this thesis, 'narrative' and 'story' will be used interchangeably. 'Narrative enquiry' is the umbrella name used to describe this qualitative paradigm, encompassing narrative and story-telling. Priest et al. (2002), make the clear distinction that 'narrative analysis' can be applied to any textual data, which is collected from interviews, journals, diaries or written accounts.

There are certain characteristics of a story:

1. there is a time sequence, the story has a beginning and an end,
2. there is a narrator and a listener or reader, and
3. it is about individuals.

(Greenhalgh and Hurwitz, 1999)

Most importantly people can identify with a story, since arguably stories are the oldest way of collecting information and people have a natural love for telling their own story, for relaying and for listening to stories. Stories are the natural way in which people communicate, but a story does not merely provide knowledge, it enables the sharing of the experience with the stories' characters (Greenhalgh and Hurwitz, 1999).

4.3.2 The role of stories in health care

Any screening programme needs to be sensitive to the possible impact that the screening process has upon the individual (Marteau and Kinmouth, 2002; Thompson 2002). There is a need to raise awareness within families regarding their future risk (Langer et al., 1994) and to provide education and support. Sensitivity is paramount in order to reduce the possibility of merely adding an 'unhealthy psychological burden' to the vulnerable family (Langer et al., 1994). In the British Family Heart and the Oxford and Collaborators Health Check Trial (OXCHECK) studies, the psychological impact of the health checks were not evaluated. Consequently, in order to guard against an unhealthy psychological burden, it is important that this research study provides qualitative data on the experience of being diagnosed with coronary heart disease (CHD) in the family. It may also help to answer the question raised in the OXCHECK study as to why there was such a poor attendance rate from those at higher risk.

The narratives told by each of the participants at the start of their involvement in the study and at the end provide a personal insight into their own experience both at the initial stages when, for many, the diagnosis is first made of heart disease in the family, and at the end when they can be given an opportunity to tell their own experiences of coming to terms with the diagnosis and consequences. The qualitative aspect of the study is vital in order to provide personal meaning of this health illness continuum. It is integral to the final analysis where effectiveness of the overall health promotion programme is evaluated, using the salutogenic framework where individual meaning to health can be used to reflect overall response to positive lifestyle behavioural change.

4.3.3 Advantages of narrative enquiry

Firstly, narratives enable those at the centre of the research, the participants, to tell their tale, rather than answer a set of predetermined questions. There is an independence of speech which is free from the constraints of structured questioning, and it ensures that control for the information, for the interview process, remains with the participant (Wilcock et al., 2003). Secondly, stories offer a holistic approach to research where interconnected parts can be related back to the whole. The research participant makes their own choice as to where the narrative begins and ends. They give their own picture of events, where the characters in this story are viewed as whole people (Carson and Fairbairn, 2002), and a full account is given, not merely an isolated snapshot (Greenhalgh and Hurwitz, 1999) which has little contextual linkage. Thus rich, meaningful, descriptive data are collected and where the ability to collect data, where both the story and its context are integrally entwined, is a fundamental aim of qualitative research (Holloway and Wheeler, 2002).

Stories can be powerful; Newman (2004) describes the two processes that occur which makes stories powerful. He states that the human brain processes stories better than other forms of input. This returns to man's inbuilt love of stories and the way in which information is processed, where the brain likes to be active and engaged, in order for memory and learning to be enhanced (Buzan and Buzan, 2003; Winston 2003). Secondly, Newman (2004) goes on to explain how the storytellers themselves become important; they are central to the story and therefore the listener or reader has a connection with them. As already stated, this view is echoed by Greenhalgh and Hurwitz, (1999) and Charon (2004) who state that narrative not only allows the narrator to tell their story, but also allows the listener to share that experience, it becomes a 'shared experience.' It is this experience that is at the heart of narrative enquiry and why it is such a powerful qualitative methodology, because it touches the emotions and it is through our own emotions that people truly experience life.

4.3.4 Disadvantages of narrative enquiry

A concern with narrative enquiry is that the apparent simplicity and focus of the story can lead to neglect of other complicated issues and considerations. The listener identifies so strongly with the story that this individual experience can overshadow vast quantities of statistically significant data (Newman 2004). It is important that the researcher does not allow the emotive nature of a single story to cloud logical judgement within a larger picture. Consequently, the context for the setting of the narrative is central to judging the importance and validity of the story, within the current research question. Holloway and Freshwater (2007), would argue that a single 'deviant case' can be included within the analysis, if in the opinion of the researcher it is of relevance and provides insight or understanding. These deviant cases can therefore give a unique perspective on a phenomenon (Holloway and Freshwater, 2007), but if quoted in the results this should be made explicit.

4.4 Theoretical framework

Salutogenesis is used as the theoretical framework, with which the findings and results from the study will be discussed. Salutogenesis comes from Latin where 'salus' means health and well-being, and 'genesis' is the Latin for origins (Antonovsky 1987). Antonovsky became interested in the way in which people where able to maintain good health and lead good lives, having faced extreme situations, such as the concentration camps during the Second World War. Salutogenesis focuses on the causes of health and well-being; it is the opposite of pathogenesis, which studies the causal factors of disease and ill health. Antonovsky defines salutogenesis as the process of movement towards the health end of a health ease/dis-ease continuum (Antonovsky 1987).

In order to explain the concept of salutogenesis as a model for health promotion, Antonovsky (1987; 1990; 1996) uses the metaphor of a river of life. Antonovsky describes a river with a bend, beyond the bend there is turbulence where people are struggling. The health professionals on the shore exert devotion, skill and effort to save those in the river, but no-one is looking upstream to see what or who is pushing these people into the river. According to the biopsychosocial model there are a variety of pathogens, including psychosocial and lifestyle factors, which are responsible for pushing people into the river. The biopsychosocial model assumes that homeostasis is a normal state of affairs, and that people should not get unwell, and should consequently remain safely on the river back (Antonovsky 1990). Antonovsky makes the claim that heterostasis, imbalance and suffering are all inherent in human existence, just as death is (Antonovsky 1990). He says that we are all in the river of life, until we go over the waterfall at the end. The rivers are different for different people, different nations, with different currents and eddies. No-one remains safely on the shore. The salutogenesis mystery is to understand how some people, some of the time, suffer less than others and move towards health (Antonovsky 1990). In this context, the salutogenic questions would therefore be, firstly, how dangerous is our river? Secondly, how well can we swim (Antonovsky 1996)?

Antonovsky (1987; 1990) provides clear examples of the different orientations for the study of health and the study of disease. The questions which Antonovsky asks have been included in this discussion and formulated into a table. The questions highlight key aspects of the paradigms, helping to explain the salutogenic orientation by drawing comparisons with the pathogenic approach. In this way the two ends of the health ease / dis-ease continuum can be illustrated, and explained.

TABLE 4.1 Pathogenic versus salutogenic approaches

The question	Pathogenic orientation	Salutogenic orientation
How are people classified in terms of their health status?	People are classified as either healthy or sick	Total health and total illness are the extreme poles. There are forces pushing us in either direction, we are part healthy and in part sick
What is the focus of attention?	Unhealthy people are seen as patients, who must be categorised with a diagnosis.	There is a concern for all persons located on the health-illness continuum; it confronts the state of their suffering. All aspects of a person's wellbeing are assessed.
What are the important causal factors?	There is a search for the pathogens, (physical, microbiological or psychosocial) associated with the disease, either in individuals or in populations. The emphasis is upon risk factors associated with the diseased state.	We search the person's location on the continuum and get to know 'the story' of the person. So that we can identify the factors which actively promote movement towards the health end of the continuum. The salutary factors.
What are the consequences of stressors?	Stressors are identified as risk factors, as dangerous and damaging.	Stressors may not lead to stress and disease if coped with successfully. Stressors can potentially be pathogenic, they can also be potentially positive and health-promoting.
How is suffering to be treated?	The 'magic bullet' approach, where there are specific treatments for specific diseases.	There is a constant struggle towards the health end of the continuum, which is never completely successful. But the focus is upon the salutary factors which help people to cope and to keep them healthy.

Adapted from Antonovsky 1987 and 1990

The theories of pathogenesis and salutogenesis may be opposite (Lindström & Eriksson, 2005). However they are not mutually exclusive of each other, neither are they contrary to each other. Pathogenesis and salutogenesis are both represented on the health ease / dis-ease continuum, and should be seen as complementary to each other (Antonovsky 1986), so that the relationship between the two paradigms changes depending upon need and where the individual is upon the continuum.

To summarise the key consequence of the salutogenic orientation, Antonovsky says that:

> "Thinking salutogenically not only opens the way for, but compels us to devote our energies to, the formulation and advance of a theory of coping." (Antonovsky 1987, p.13)

The key components of salutogenesis are that stress is an inevitably part of life, but it is the way in which people cope with this stress that can result in advancement along the health ease / dis-ease continuum. In order to address these issues the sense of coherence concept was developed, so that people's coping mechanism could be understood. The sense of coherence (SOC) is used as a determinant for maintaining position on the continuum and for movement towards the health end (Antonovsky 1987). Antonovsky defines the sense of coherence as:

> 'The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring through dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.'
>
> (Antonovsky 1987, p.19)

These three components are called comprehensibility, manageability and meaningfulness. Comprehensibility is the belief that the challenge is understood, the cognitive component; manageability is the belief that resources to cope are available, the instrumental component; and meaningfulness is the wish to be motivated and to cope, the motivational component (Antonovsky 1996). A person's SOC is measured by the extent to which their life has meaningfulness, manageability and comprehensibility (Antonovsky 1993). In order to maintain their position, or to move towards health, people need general resistance resources, alternatively known as salutary factors. People with a strong SOC have a greater number of salutary factors, which can be genetic, psychosocial, material and biological. For example a strong sense of personal identity, material goods, cultural stability, religious and personal philosophies, are all categorised as salutary factors. These salutary factors help people to perceive their life as consistent, structured and understandable, and many will relate to a sense of wellbeing (Antonovsky 1987).

In order to measure a person's SOC and to test the hypothesis that SOC is causally related to health status, Antonovsky developed the life orientation questionnaire (Antonovsky 1987). There are two versions of this questionnaire, a long version with 29 items, and a short version with 13 items. The life orientation questionnaire has been proved to be a reliable, valid and cross culturally applicable tool for measuring how people manage stressful situations and stay well (Eriksson and Lindström, 2005). The principle is that the stronger a person's SOC, the more successfully they will be at coping with the inevitable, continual stressors in human life (Antonovsky 1990).

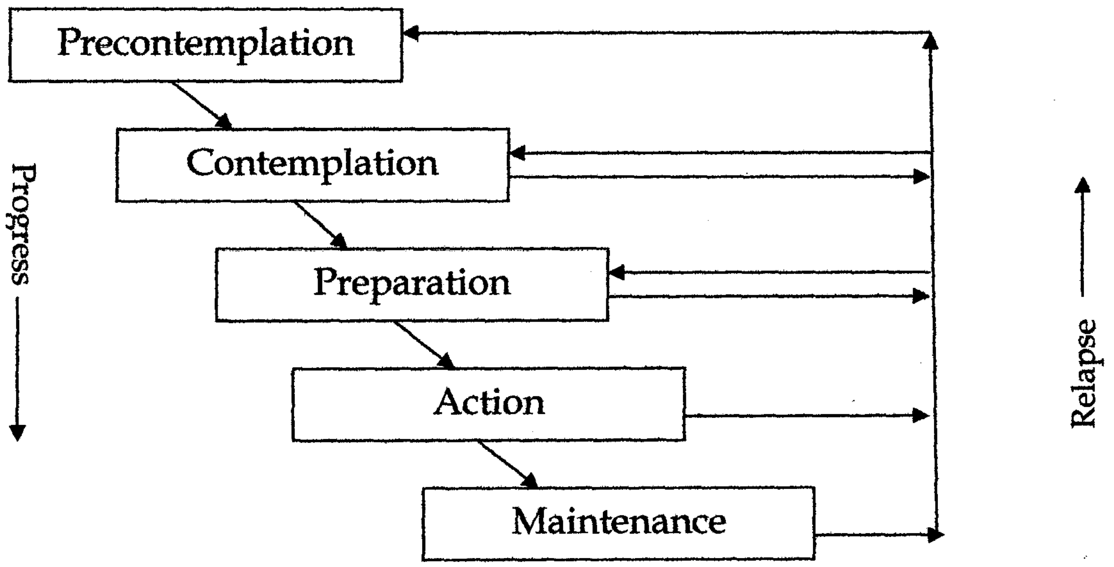
The salutogenic model has been proposed by Antonovsky (1996), as a viable paradigm for health promotion research and practice where the sense of coherence framework is suggested as a theory for taking a salutogenic approach to health promotion (Antonovsky 1996; Eriksson and Lindström, 2006). The use of salutogenesis for assessing health resources has been researched in general practice (Hollnagel et al., 2000) and in health visitors (Cowley and Billings, 1999). The studies identified possible health resources for specific populations which could in theory be used to enhance the clinical exchange between patient and health professional. Consequently, salutogenesis was considered to be an ideal and interesting paradigm to use as the theoretical framework in relation to which data from the research could be interpreted.

As part of the final evaluation, the study participants completed 29 questions of the life orientation questionnaire (see Appendix I). Individual scores were obtained from each participant for meaningfulness, manageability and comprehensibility. These are used as part of the discussion in order to evaluate the extent to which people's sense of coherence influences their orientation towards a healthy lifestyle.

4.5 Transtheoretical model of change

The transtheoretical model, or stages of change model, refined through the work of Prochaska, DiClemente and Norcross (Prochaska et al., 1992), was used in the health promotion programme, to access participant's readiness to change in relation to specific behaviours. The model involves progression through five stages: precontemplation, contemplation, preparation, action and maintenance. People then spiral and recycle through these stages until long-term maintenance is achieved, as illustrated in Figure 4.2. The transtheoretical model represents a temporal dimension which enables the health advisor to understand when particular shifts in attitudes, intentions, and behaviours occur (Prochaska & DiClemente, 1984; Prochaska et al., 1992; Prochaska & Velicer, 1997). The model is designed to embrace and explain the working of a wide range of therapeutic interventions (Rollnick et al., 1999).

FIGURE 4.2 The transtheoretical model of change



(adapted from Rollnick et al., 1999, p19)

Integral to the success of a health promotion strategy is the awareness of which stage people are at. For example, Prochaska et al. (1992), make the point that, if only action-orientated programmes are used, then an initiative is doomed to failure because it must take into account all the stages of change; most importantly pre-contemplation, contemplation and preparation. There is a need to understand what 'change' may mean for a person, such as altering their fundamental belief systems and attitudes, associated with an awareness of the actual process of change. The health professional must also know at which stage a person is, in order that the intervention occurs at the right time.

In order to encourage and support healthy behaviour for individuals, the transtheoretical model of change was used to identify people's readiness to make and sustain lifestyle changes (Prochaska & DiClemente, 1984). The use of this model will be discussed in relation to the health promotion programme.

4.5.1 The stages of change

There are five stages identified in the model, where people traverse between the stages of changes in order that long-term maintenance of the behaviour is achieved (see figure 4.2) . Each of these stages are discussed separately.

- **Pre-contemplation**

This is the stage where there is no intention to change behaviour in the foreseeable future. People who are pre-contemplative do not perceive that they have a problem, or that there is a need for change. It may be at this stage that those who did not complete the health promotion programme where situated, along with those who did not wish to participate in the study. People who are at this stage should not be discounted from inclusion in health promotion initiatives, triggers may occur which move them to the next stage. For example, someone may believe that dietary issues are unimportant, because they are not over-weight; they do not realise that a good diet is fundamental to achieving good healthy until they learn that their cholesterol is raised.

The programme did not focus on a single risk factor, such as improving peoples' physical activity, it encompassed multiple lifestyle issues. The synergistic influence of behaviour was emphasised, explaining how by increasing physical activity, for example, this would result in better weight control, improved lipid profile, reduced blood pressure and stress. People were asked if there was an area in their lifestyle profile which they wanted to change, choice remained their own. However, education was integral, where through greater knowledge, perception and understanding of risk may be achieved, so that people could move onto the next stage.

- **Contemplation**

At this stage people are aware that a problem exists, they are thinking about it, but have not made the commitment to take action (Prochaska et al., 1992). People can remain at this stage for long periods of time, they may know that action is required but are not quite ready. In the clinical sessions it was important that the right questions were asked, and empathy shown, in order to assess the individual's beliefs and attitudes concerning the behaviour and their ability to change. For some it may be that external influences make the change difficult, for example, when discussing dietary changes, it is important to identify who does the shopping and cooking. Communication is important so that barriers to change can be discussed, possible solutions found and alternative suggestions made which are suitable for the individual, ensuring that a salutogenic approach is used.

- **Preparation**

People have the intention to change within the next month, but have not yet taken action; people may be making small changes but have not yet given their full commitment to the behavioural change (Prochaska & Velicer, 1997). People have joined the study, as shown in the narratives, in order to be given greater incentive and encouragement to make changes; many have recognised the need for change and are prepared to make a change, however they may lack direction. The shift in focus may have happened as a result of the diagnosis of their relative, which confirms the outcome and consequences of negative behaviour. People are now in the preparation stage, the health professional can take advantage of this in order to facilitate and support the required action.

For those who have not yet achieved this stage, knowledge, support and empathy remain important during a consultation. The salutogenic approach attempts to understand people's current situation and through enhancement of their SOC aims for possible future changes, or at best stability on the health continuum.

- **Action**

This stage involves behaviour modification, requiring time and energy. People are actively engaged in the behavioural change; they remain at this stage for at least six months before progressing to the maintenance stage. During this time the health professional can provide vital support and praise. As discussed the action itself may not be large, small actions are important, which can be developed so that further progression is made. For example, a participant who gradually reduced the number of cigarettes smoked, until he was able to quit the cigarettes altogether. The action was the change of behaviour associated with the cigarettes, not the quitting. During this stage people are susceptible to the influence of external stimuli, such as the support - or the opportunity to progress through these stages. This is particularly important where there is more than one behavioural change required.

4.6 Research considerations

This section will highlight and discuss the ethical issues that have been considered during the initial planning of the project, during the process of submission and approval, and finally during the actual research.

4.6.1 The review process

The study was submitted to the local research ethics committee (LREC) in February 2002, it was given approval by the committee in April 2002. It was not granted approval from the Trust until July 2002, due to the emergence of the new research and development (R & D) departments. The study was given signed support from the Trust's four consultant cardiologists and the Trust's Data Protection Officer had been informed and written approval provided. Subsequent amendments were made to the protocol, for example in June 2004, the study inclusion criterion was extended to include 'siblings' as well as adult offspring, and in October 2004 the use of the 'perceived stress scale' questionnaire was approved for use. Due to a series of delays, recruitment did not start until March 2004.

When the study was first planned, recruitment focused on adult offspring of those diagnosed with premature overt CHD. Since then, the inclusion criteria changed to encompass all first degree relatives. As already discussed in the literature review, it is both siblings and offspring who are at increased risk of developing cardiovascular disease. Involving older family members provides a richness of family data where different generations are involved in the study and were comparison data for the different age groups can be made.

4.6.2 Screening and sampling

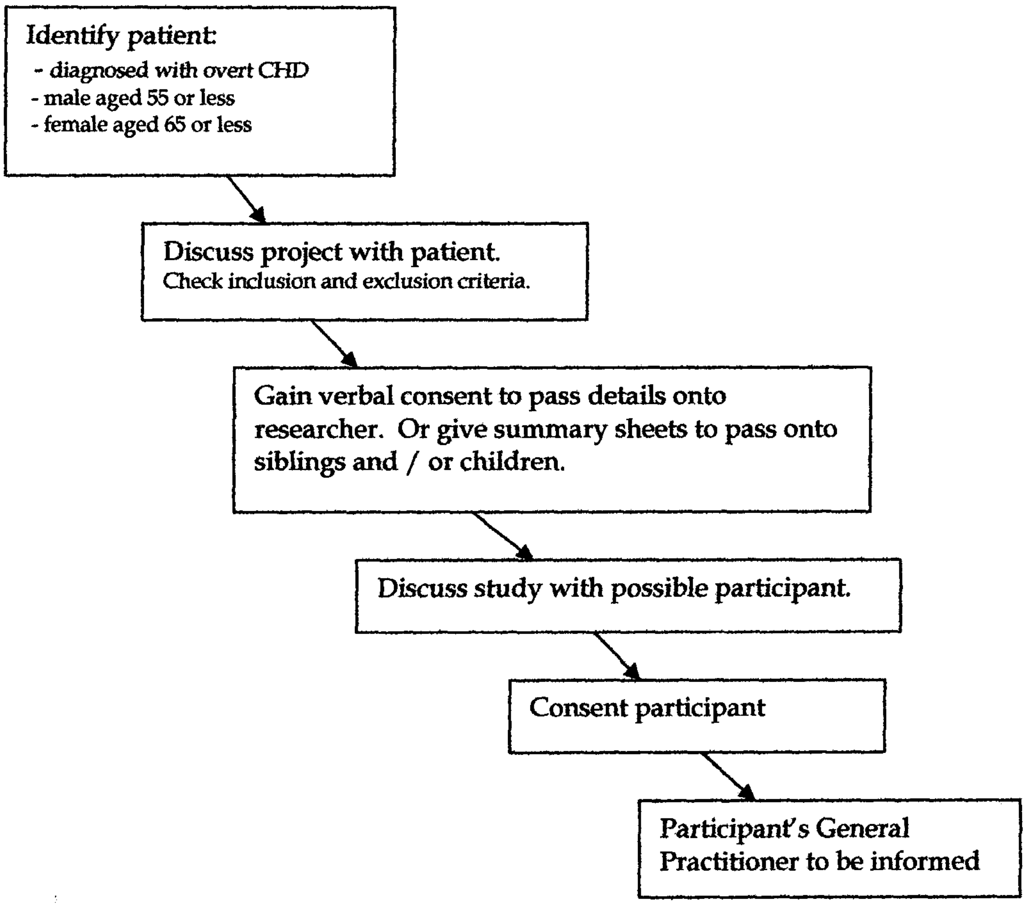
Non-probability convenience sampling was used, where people are directly identified who meet the criteria for the study and who might be interested in participating. Non-probability sampling ensures that all those who meet the study criteria have an equal chance of being recruited, where no pre-judgements are made about the sample (Parahoo 2006), or are required with this study context. An aspect of the study was that as patients were diagnosed, their family could be invited to join a prevention programme, so that both patient and first degree relatives were simultaneously receiving lifestyle assessment and advice. Study participants were identified through the patient coming into the hospital as either an acute in-patient admission or to the out-patient clinic.

The year the study was being designed, 2001, there were 105 men and 41 women identified locally with premature coronary heart disease through the Trust's Cardiac Rehabilitation services. These people had confirmed CHD, having had either a myocardial infarction, percutaneous coronary angioplasty or coronary artery bypass surgery. Thirty participants would represent a sample size of 20% of this population. An additional five recruits would allow for any participants who were lost to follow-up. Consequently, the original aim was to recruit 30 to 35 participants. Recruitment started in March 2004 and ended in August 2005, during this time 28 people where recruited into the study.

4.6.3 Recruitment and enrolment

Each of the four steps involved in the recruitment process will be discussed individually. Figure 4.3 illustrates the steps involved in this whole process of screening and enrolment.

FIGURE 4.3 Study screening and enrolment



- **Step 1 ~ Screening**

In order to enhance recruitment, A5 laminated sheets (see Appendix II) were circulated to key personnel in the Trust with brief details of the study. Presentations of the study to staff members and as part of the cardiac rehabilitation education programme were carried out in order to raise awareness and interest.

Patients who had confirmed premature CHD were identified within the Trust; men aged 55 years or younger, women 65 years or younger. When the study was initially conceived it was assumed that the patients identified would be those presenting with a new diagnosis of heart disease. However, patients were identified through a variety of sources; for example, when they initially present to the coronary care unit, when attending the rehabilitation programme, or when attending an out-patients clinic appointment. As a result of the different methods for identifying patients, the referrals came from both doctors and nurses.

The study was discussed with the patient who had the diagnosis of CHD. They were given the single page information summary sheet (see Appendix III) to pass onto their siblings or children if they felt it was appropriate or it would be of interest to them. Talking with patients about the involvement of their families in this study required sensitivity. Some people may not be aware that heart disease can proliferate in families; if they are parents they may feel guilt or a degree of responsibility about this hereditary link. For others they may simply feel scared, coming to terms with the consequences of the disease. However, some may be pleased to be given an opportunity for their family to be included in a health promotion programme, to be re-assured and advised appropriately. Timing, sympathy and understanding are integral to this screening process.

As well as the anticipated method of recruitment, there was a secondary, unexpected source. These were people who had a history of premature familial CHD, who heard about the study from other sources, such as colleagues and lectures, and expressed an interest to be involved. Consequently they self selected themselves.

- **Step 2 ~ Study criteria**

The following inclusion and exclusion criteria were adopted for the study:

Inclusion criteria:

- The child or sibling of a patient who has been diagnosed with premature CHD.
- Aged 18 years or over.
- Able to give informed consent.
- Able to attend follow-up appointments.

Exclusion criteria:

- Suffering from a terminal illness.
- Known to have overt CHD.
- People without a good command of English.

The first inclusion criterion is inherent to the study itself as this is the population being investigated; this is an adult study, consequently participants must be aged 18 years or over; the requirement for informed consent is mandatory for all research. People with a terminal illness, such as end stage renal failure or terminal cancer, would be inappropriate for a study such as this, those who have overt CHD should be receiving secondary prevention. The last exclusion criterion relates to people who do not have a good command of English. It may be considered to be less than desirable to exclude people just because they cannot speak English well and if this had been a large national study this is likely to be the case. However, this was an unfunded study and the recruitment of participants who could not speak English was not feasible within the study's constraints.

- **Step 3 ~ Enrolment and consent**

The information summary sheet outlined the main details of the study, and was given to those who expressed a preliminary interest in the study. The participant information sheet (see Appendix IV) was more in-depth and followed the sub-headings required by the LREC. Once this had been read and any outstanding questions answered satisfactorily, people were able to make an informed decision regarding participation in the study.

Before commencing the study, participants signed the 'agreement to participate consent form' (see Appendix V). In accordance with the requirements of the International Conference for Harmonisation - Good Clinical Practice (ICH GCP), informed consent must be taken by either the principal investigator, or someone delegated by them to do it, with a sound knowledge of the protocol. The 'post interview consent form' (see Appendix VI), was signed after each interview. This consent forms ensures that participants are happy with the content of their interview and consent to it being used anonymously within the study. Once participants had signed the consent form they were given an identification code. This ensured that information collected and used for the purpose of analysis could be related to individual participants, but in a way that ensured anonymity and confidentiality. Details of their study involvement were documented in their hospital notes; this included patient and GP correspondence, copies of consent forms, a brief synopsis for each visit and lifestyle assessment sheets. If a participant was not already registered at the Trust then a new set of notes was made. No details of their narrative interviews were included in the hospital notes.

- **Step 4 ~ General Practitioner involvement**

A letter was sent to the participant's general practitioner (GP) (see Appendix VII). It was a stipulation of the cardiology consultants, when the study was initially designed, that the GP be involved from the outset. GPs have overall responsibility for the people registered under their care; it is important that they are kept fully informed and involved in the care of their patients. A primary risk assessment, such as the one proposed in the study, would usually occur in the primary care setting under the care of the individual's GP. Consequently it is unusual for primary prevention, such as the health promotion programme, to take place in the secondary care setting of a hospital. However, an approach of this type helps to bridge the gap between primary and secondary care, where the specialist skills available within the dedicated cardiology department can be fully utilised. The initial diagnosis for the parent is made within the hospital, so it would be logical therefore that since the screening process begins in this setting, the continuing prevention strategy can be conducted in the same setting, when the process is similar to that used for secondary prevention. Previous studies have shown the benefits of this approach (Kavanagh et al., 2000; Wood et al., 2004).

In order to ensure that there were no objections, the GP's letter explained the research and asked if they had any objections to their patient being involved in the study. If there were no objections, the GP was requested to take no further action. However, if the GP was unhappy, they had two weeks to reply with their concerns or objections. The letter explained that they would be kept fully informed of the risk factor assessments during the course of the study. None of the GPs expressed concern or objections.

4.7 Scientific rigour

This section will examine the issues of reliability, validity, triangulation and the role of the researcher, that are central to ensuring the quality of the study and data collected.

4.7.1 Issues of reliability

As discussed in the previous section, the issue of reliability had been a major consideration throughout, to ensure that the recruitment process and health promotion programme would be reproducible in other clinical settings. Each stage of the study has been clearly outlined and data for every phase has been systematically and rigorously collected.

This study had many components with data collected from different sources. It was not solely the investigation of a single phenomena, but involved people in a real life setting where evaluation of an intervention was made, and where that intervention would be different for each person. For this study the intervention, the health promotion programme was standardised as much as was possible, but its delivery has been unique to the individual participant in order to meet their own respective requirements and according to their understanding and motivation.

4.7.2 Issues of validity

As with all research data, narrative and story data must be valid in order to have true meaning and worth. Validity in qualitative research is complex (Holloway and Wheeler, 2002). Whittemore et al. (2001), have four primary criteria for qualitative validity; these are credibility, authenticity, criticality and integrity. In applying these criteria to narrative enquiry the issue of credibility and authenticity can be confirmed, because the data collection method used has enabled the participant's experience to be fully heard and by the very nature of the story is consequently a true representation of this personal experience. The participant has chosen for themselves the aspects which they believe are important and pertinent.

The third issue of validity is concerned with criticality. One of the strengths of narratives is that the listener has the opportunity to validate the narrative for themselves. The listener has their own chance to reflect upon the narrative while they are communicating. The process is entirely a personal one and is concerned with whether or not the story has any meaning to them. Thus validity can be measured individually as well as collectively. Integrity should be maintained through the reliability of the data and the quality of the interpretation.

Internal validity is an important consideration where the participants have shown changes to their risk factor profile. The researcher needs to consider whether these changes were the result of their participation in the study or whether they would have occurred through self direction and awareness as a result of their familial diagnosis, or through a screening process under the care of their GP. The collection of data from multiple sources, over a two year period, has helped to identify these patterns of change and confer validity. The majority of the lifestyle assessment data collected from the health promotion programme is clearly and accurately measurable, while some represents self reported information. Information that is self reported can still be validated through triangulation.

4.7.3 Triangulation

According to Foster (1997, p.4) 'triangulation denotes the combination of research strategies to achieve a multidimensional view of the phenomenon of interest.' She goes on to say that it can occur either between methods or within methods. Polgar and Thomas, (2000) liken it to the land surveying terminology, where several reference points are used to get a better 'fix' on the question. Within the study triangulation is used both between methods and within the methods. The combination of the qualitative and quantitative paradigms captures the true bio-psychosocial nature of the participants, while the qualitative data assists in explaining the outcome data obtained from the quantitative measurements. Data are collected from separate sources, and through triangulation, the data from the subjective self reported activities are verified against the objective physiological measurements. For example, if a participant reports that they have reduced their alcohol intake, this should be reflected in their triglyceride measurement; changes in dietary or exercise habits may be reflected in lipid profile, physical measurements or blood pressure. This reflects the synergistic effect of risk factor modifications.

4.7.4 Role of the researcher

This section will discuss the role of the researcher within the study context and the impact that the researcher has upon the study and data collected. These are personal issues relating to myself in the combined role of the researcher and the nurse conducting the clinic sessions. When first planning the study, I had many discussions with the nurse specialists, and met with nurses from primary care. I wanted to ensure that the health promotion programme mirrored what was done for secondary prevention and that it would be complimentary to the work conducted in primary care. I developed the education folder which is used during participant consultations to ensure that information was standardised and reproducible. Participants in the study would be receiving similar information to what they might receive from other health professionals. I have specialised knowledge in the field of primary prevention and risk assessment and it was vital that this was channelled constructively rather than becoming the issue for the outcome of the programme. The study would be unreliable and invalid if success within the programme was as a result of my enthusiasm, skills and expert knowledge.

Qualitative research requires the active involvement of the researcher; they need to invite empathy; they need to appear interested at all times; they need to be trusted by the narrator. Certain skills are needed to encourage the participants in telling their story, such as active listening, asking open questions and awareness of body language. Consequently when I conducted the narrative interviews, I acknowledged that I influenced this experience for the participant, and the story that they told me. This adds to the richness of the data collected and does not detract from the quality, scientific rigour or validity of the research.

4.8 The research process

This section describes the different phases of the research process and gives an overview of analytical methods.

The study is divided into three phases, as previously illustrated in figures 1.1 and 4.1. Phase 1 participants gave their first narrative interview concerning the diagnosis of coronary heart disease within their family. Phase 2, is the two year health promotion programme and phase 3 is the final evaluation of both the participants' lifestyle and a second narrative interview which provides the participants with an opportunity to recount their experiences of the programme and the research during the intervening two years. Each of the study's three phases are discussed individually in relation to the data collection methods and data analysis.

4.8.1 Phase 1 ~ Narrative interviews

Study participants were invited to tell their own story about their personal experience of being diagnosed with CHD in their family; what it was like when their parent or sibling was first diagnosed with CHD, their reaction to the illness, and how it has subsequently impacted upon their own lives. Their views concerning health and illness were sought, along with subsequent issues of motivation and adherence. The interviews did not have a set series of questions; the participants were encouraged to relate the aspects of the whole experience they considered to be important. The focus was on them as the relative, not on the patient who had suffered with CHD. For some people they were discussing a recent event that may have happened only a matter of weeks ago; for others the experience was something they had lived with for many years.

- **Qualitative content analysis**

Content analysis was originally developed in the 1950s and was traditionally used to quantify pre-determined categories in written text and documents such as newspapers and reports, so that actual counts of words and phrases were produced (Cavanagh 1997; Silverman 2001; Priest et al., 2002). This form of analysis was restrictive and was seen as contradictory to the ethos of qualitative research (Grbich 1999), and a simplistic technique of quantitative analysis (Cavanagh 1997). A new form of content analysis developed, qualitative content analysis (Priest et al., 2002). Polit and Beck (2004), define qualitative content analysis as:

> 'the analysis of the content of narrative data to identify prominent themes, and patterns among the themes.'
>
> (Polit and Beck, 2004, p.580)

Priest et al. (2002), state that qualitative content analysis facilitates contextual meaning in text through the development of emergent themes derived from textual data. According to Cavanagh (1997), content analysis is an objective and systematic way in which phrases can be placed into categories where there is a shared meaning within the category. In this way understanding of the phenomena, in relation to the themes identified from the text, can be sought, and significant findings produced. Additional cross referencing within texts and across texts can ensure accuracy and validity of the results, particularly when numerous texts are being studied.

- **Narrative data analysis**

Twenty six interviews were transcribed by an independent transcriber. All transcripts were listened to and checked against the original recordings by the researcher. They were read through initially to provide an overall impression of the main themes and features. Qualitative content analysis was used to identify main themes from each story and cross checked with others in order to identify common elements (Holloway & Freshwater, 2007). The main themes where then identified using mind mapping (Buzan and Buzan, 2003), sub topics from these themes were recorded onto the mind map. The mind map provides a single page illustration of the overall story, its main themes, and sub themes, while illustrating how each are related and interlinked to each other (see Appendix VIII). There was no limit imposed on the number of themes which could be identified, however most narratives yielded between four and six. A report was written giving an overall impression of the whole narrative and main themes. Individual narrative analysis was conducted before the literature relating to family perception of risk had been studied. This was in order to ensure that there was no bias or preconception regarding some of the themes which might be found.

Once all the narratives had been analysed in this way the themes were tabulated against each participant. A spreadsheet was developed to log all the main themes for each participant. At this stage the themes were reassessed and combined. For example, if a theme had been on 'visiting,' and another about 'the hospital,' these were combined into 'hospital experience.' The narratives were re-studied, with reference to the spreadsheet and the themes were further refined.

4.8.2 Phase 2 ~ The health promotion programme

Quantitative data were collected as part of the lifestyle risk assessment. Data were collected from questionnaires, self reported assessments and direct measurements; full details are shown in table 4.2. As part of the health promotion programme, a lifestyle assessment profile (see Appendix IX) was compiled to collect the data relating to the participant's individual risk factor profile assessment for CHD. These are the standard lifestyle assessments that would be made for individuals receiving either secondary prevention or cardiac rehabilitation. These were divided into self reported assessments and measurable factors. The self reported assessments include alcohol intake, diet, levels of physical activity, personal views and issues regarding the stressors in their lives, plus their smoking status and smoking history. Measured assessments were made on blood pressure, lipid profile, fasting glucose, weight, height and waist measurements. An individual questionnaire was used to collect in-depth information relating to dietary aspects and a perceived stress scale was used to provide a measure of a person's stress level.

The diet questionnaire (see Appendix X) was originally developed and expanded from a similar questionnaire which was already in use by secondary prevention clinics. Further questionnaires were considered for data collection on physical activity and smoking, such as those validated from the British Regional Heart Study, but these were rejected, as questionnaires of this length are not usually used to collect this information in clinical practice. An aim of the study was to establish a primary prevention health promotion programme that was similar to care already given for secondary prevention, and which was feasible in clinic practice. Consequently, it was important that the risk assessment data and collection tools were both similar, otherwise reliability is not achieved.

Psychosocial stress is seen as an important risk factor for CHD (Yusuf 2004) but stress is subjective and not easily measurable. A recognised and validated tool was used in order to measure participants' cognitive evaluation of their stress. The 'Perceived Stress Scale' (PSS) devised by Cohen, Kamarck and Merelstein (1983) was used (see Appendix XI).

> "The perceived stress scale measures how predictable, uncontrollable and overloaded respondents find their lives which provides measurements of stress. Because the PSS instrument is a global one and therefore not tied to any specific events, it taps into *peoples* perceptions of ongoing stress and anticipation of future stressors."
>
> (Watkinson 2002,p. 59)

The lifestyle assessment data was collected on a single sheet. The participant held the master copy, their GP had a copy, a copy was filed in their hospital notes, and an anonymised copy used for study data collection. The sheet had a column with the computer read codes so that the information could be easily coded directly onto the GP's computer data systems. This information then provided the GP with the data they were encouraged to collect as part of the general medical services (GMS) contract.

The duration of the health promotion programme was two years. Within secondary prevention studies, which are powered to look at event rates, such as death, myocardial infarction and hospitalisation, it is assumed that no benefit to reduction of coronary events is seen for two years (Goldman et al., 2001). It has also been a criticism of previous primary prevention studies that the follow-up period was short and consequently did not allow for full behavioural changes to occur along with maintenance of risk factor modification (Ebrahim et al., 2006). It seemed appropriate to use this time scale for the duration of the programme.

Each participant had a primary prevention clinic assessment sheet (see Appendix XII) which was completed during each visit. This detailed their medication, medical history, personal details, and referrals, along with details of the visit such as issues discussed, their personal perspective and any agreed action.

- **Statistical analysis**

Data from the health promotion programme was entered using the statistical package for the social sciences (SPSS) version 12.0. Two files were established, one for data from the diet questionnaire, a second for the lifestyle data. Data were analysed at baseline visit 1, half way through the programme at visit 3 and at the end of the programme visit 5, for the cohort of 20 participants. Descriptive statistics for these three periods were used to study the mean, so that an average measurement of the sample could be seen; the standard deviation to see how much variation there was between participants' different scores; range to measure the spread of scores (Harris and Taylor, 2004). A selection of bar charts, line graphs and boxplots were used as appropriate, to provide graphical representation of the data. Some of the graphs were generated from SPSS and some using Microsoft Windows XP Professional, version 2002, excel spreadsheet.

Inferential analysis was done using paired-samples *t*-test, to compare the means from visits 1 and 3, and visits 1 and 5. This is a parametric test based on normal distribution, where data must be measured at least at the interval level and be based upon a normally distributed population (Field 2005). The Kolmogorov-Smirnov test was done in order to test the distribution of the data. Once the distribution had been tested and a normal distribution confirmed the *t* value could be calculated. The dependent means *t*-test was used, because the same participants took part in both conditions of the experiment, the health promotion programme. It was a one-tailed test because the hypothesis had a direction to it; positive changes to the scores were being sought.

SPSS generated the values for these scores. The degrees of freedom (*df*) remained constant for majority of the tests, at n=19, one less than the size of the cohort. The *t*-test was checked against an accredited table, computed by Field (2005, p.755), using SPSS 12. The critical value for a one-tailed *t*-distribution test were $df = 19$, was 1.73, with the significance of $p < 0.05$ (Field 2005, p.755).

Field (2005) states that the *t*-test is simply the ratio of the systematic variation in the experiment to the unsystematic variation. If the experiment produced a change in the sample, then the systematic variation would be greater than the unsystematic variation, and *t* would be greater than 1. However, if the experiment was unsuccessful then *t* would be less than 1. The observed value of *t* is then compared against the maximum expected value for the same degrees of freedom, if the value is greater than the critical value (for this cohort, $df = 19$ and $t \geq 1.73$) then this reflects an effect on the independent variable (Field 2005).

SPSS generates a significance value for a two-tailed test, in order to convert this to a one-tailed test the value was divided by 2 (Field 2005). Statistical significance was set with a probability of 0.05. In order to state the significance of the findings, so that the change in the values was not caused by chance alone, *P* needed to be less than 0.05. The confidence interval was set at 95%, as appropriate for the size of the sample (Harris and Taylor, 2004). The confidence interval gave the true value between which 95% of the population would be likely to lie (Harris and Taylor, 2004).

In order to show how important the effect was in practical terms the size of the effect was calculated using the formula:

$$r = \sqrt{t^2} \; / \; t^2 + df$$

(Field 2005, p.294)

Effect size ranges where:

r = .10 small effect

r = .20 to .50 a medium effect

r = 0.50 a large effect, where the effect accounts for 25% of the variance

(Salkind 2004; Field 2005)

In order to test the correlation between sets of variable, for example alcohol intake with triglycerides, to see if a relationship existed, and whether this was a positive or negative relationship, *Pearson's correlation coefficient, r* was used. The correlation coefficient (r) has to lie between – 1 and + 1, where a coefficient of -1 indicates a perfect negative relationship, + 1, a perfect positive relationship and 0, no relationship (Field 2005). Where size of the effect of the correlation uses the same ranges as quoted above.

4.8.3 Phase 3 ~ Final evaluation

An anonymous participant questionnaire was distributed at the end of the study (see Appendix XIII). On completion they were placed in a sealed enveloped and kept in a separate box. The questionnaires were analysed collectively in batches of ten, ensuring anonymity and confidentiality, and encouraging participants to be honest. Table 4.2 details all the data that were collected over the two year duration of a participant's involvement.

The additional data collected during the study included:

- Screening data
- Individual demographic and geographic details
- Family demographics in relation to cardiovascular disease

TABLE 4.2 Study procedures

	Visit 1a (1 hour)	Visit 1b (1 hour)	Visit 2 (1 hour)	Visit 3 (1 hour)	Visit 4 (1 hour)	Visit 5a (1 hour)	Visit 5b (1 hour)
Personal Details	X						
Informed Consent	X						
Narrative Interview	X						X
Post Interview Consent	X						X
Medical details		X	X	X	X	X	
Alcohol intake		X	X	X	X	X	
Cardiovascular							
Blood pressure		X	X	X	X	X	
Heart rate		X	X	X	X	X	
Cholesterol			If clinically indicated	If clinically indicated	If clinically indicated		
Total cholesterol		X				X	
Low density lipoproteins		X				X	
High density lipoproteins		X				X	
Triglycerides		X				X	
Fasting blood glucose		X	If clinically indicated	If clinically indicated	If clinically indicated	X	
Diet questionnaire		X	X	X	X	X	
Physical activity		X	X	X	X	X	
Physical measurements							
Weight		X	X	X	X	X	
Height		X					
Waist		X	X	X	X	X	
Smoking status & history		X	X	X	X	X	
Psychosocial stress issues		X	X	X	X	X	
Perceived stress scale		X	X	X	X	X	
Issues discussed	X	X	X	X	X	X	
Personal perspective	X	X	X	X	X	X	
Agreed Action Plan (if applicable)		X	X	X	X	X	
Clinic sheet and notes	X	X	X	X	X	X	X
GP update	X	X	X	X	X	X	
Survey questionnaire							X
Sense of coherence questionnaire							X

4.9 Summary

This chapter has discussed the design and methodology of the study. The Trust at which the research was undertaken has been introduced, with details of the study's extensive review process. The use of narrative enquiry and qualitative content analysis has been examined, identifying how and why they were used in the study. Salutogenesis has been introduced, the paradigm that is used as the theoretical framework, and the transtheoretical model, which was used in the health promotion programme. The stages of screening, recruitment and enrolment have been discussed. Issues of validity, reliability and triangulation have been acknowledgement and their importance to achieve scientific rigour. Finally, the research process and data analysis has been detailed for each of the three phases of the study.

The next chapter will provide the results from phase 1 of the study, which will include the demographic details of the participants and their narrative findings, exploring the experience.

CHAPTER FIVE

Phase 1 ~ Exploring the Experiences

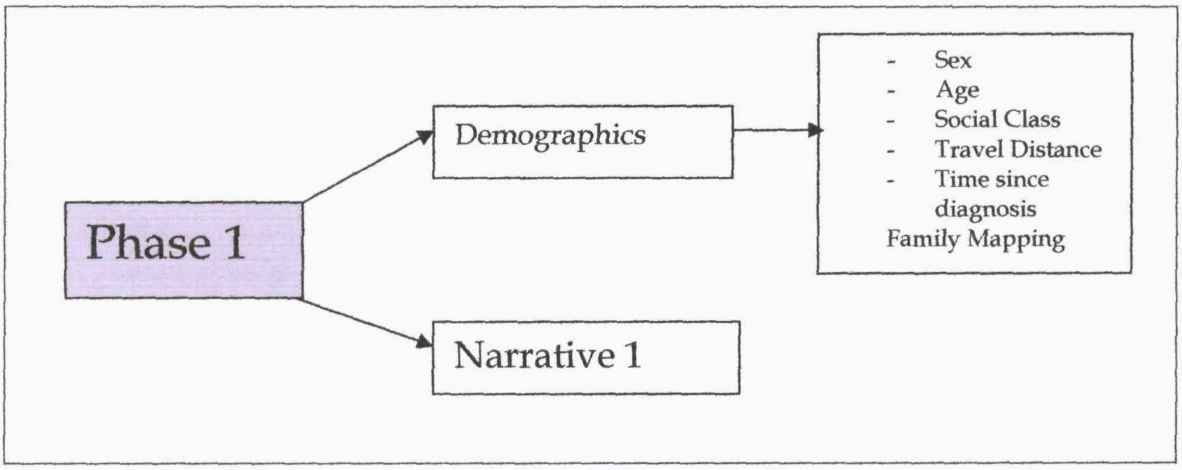
5.1 Chapter introduction

This chapter provides demographic characteristics of the twenty-eight study participants and mapping details of their familial history for cardiovascular disease (CVD). The findings from the phase one narrative interviews are discussed in the second part of the chapter, this addresses the first aim of the study:

' What is it like to be diagnosed with coronary heart disease in the family?'

Figure 5.1 provides complete details of the data that will be reported in the chapter.

FIGURE 5.1 Phase 1 ~ study data analysis



5.2 Study phase 1

Recruitment for the study started at the end of March 2004 and was completed by August 2005. Twenty-eight people gave informed consent for the study, representing fourteen families.

5.3 Screening details

Between March 2004 and August 2005, 46 patients diagnosed with premature coronary heart disease (CHD) were identified within the hospital. The patients were approached regarding the study and 152 participant information sheets were given to their siblings and children. Of these 50 were not eligible, mainly because they lived too far away or already had cardiovascular problems. From the remaining 102 people, 24 consented to participate in the study.

Four people were recruited into the study as a result of learning about the study from indirect sources; at a presentation and through colleagues. These people expressed an interest in the study as they had a premature family history of CHD. They all met the study criteria and were invited to participate in the research.

5.4 Demographic characteristics

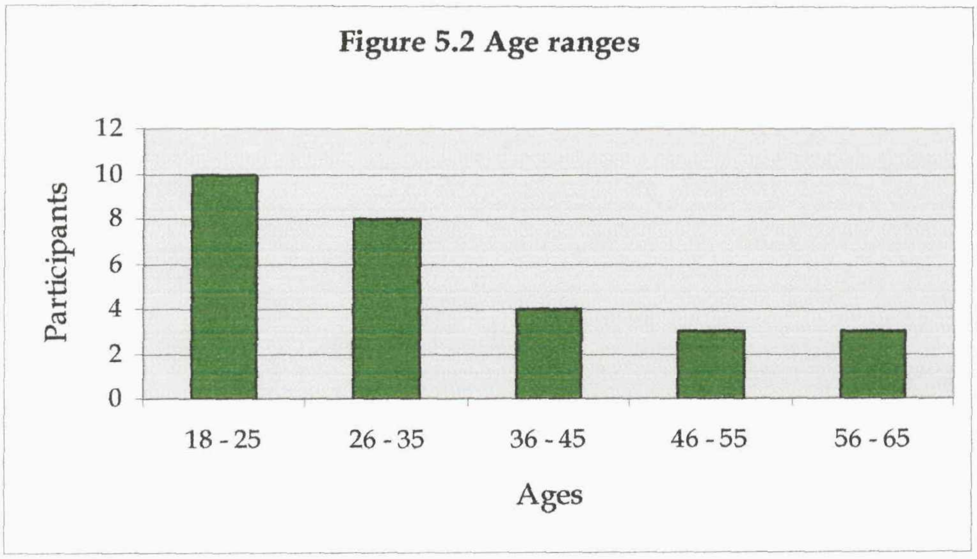
Descriptive statistics are used to illustrate the demographic characteristics of the study population; as the study population is small numerical values have been used rather than percentages. These statistics are based on the original cohort of 28 participants who consented to take part in the study. The demographic characteristics included are gender, family category, age, social class, distance travelled to attend the programme and time since the diagnosis of their parent or sibling with CHD. These characteristics have been chosen to provide background information on the study population and because these aspects are important within secondary prevention and cardiac rehabilitation. The family details give graphical illustration of the familial cardiovascular histories of the participants.

5.4.1 Gender, ethnicity and family category

Within the cohort, 22 were classified as 'children' and 6 were classified as 'siblings'. There were 11 female and 17 male participants; at the start of the study 50% of them were single and 50% married. Twenty-six of the participants were Caucasian and two were mixed Asian and Caucasian ethnicity.

5.4.2 Age of participants

As shown in figure 5.2 the participant ages are spread across the age range: over half (n=18) of the participants are under 35 years.



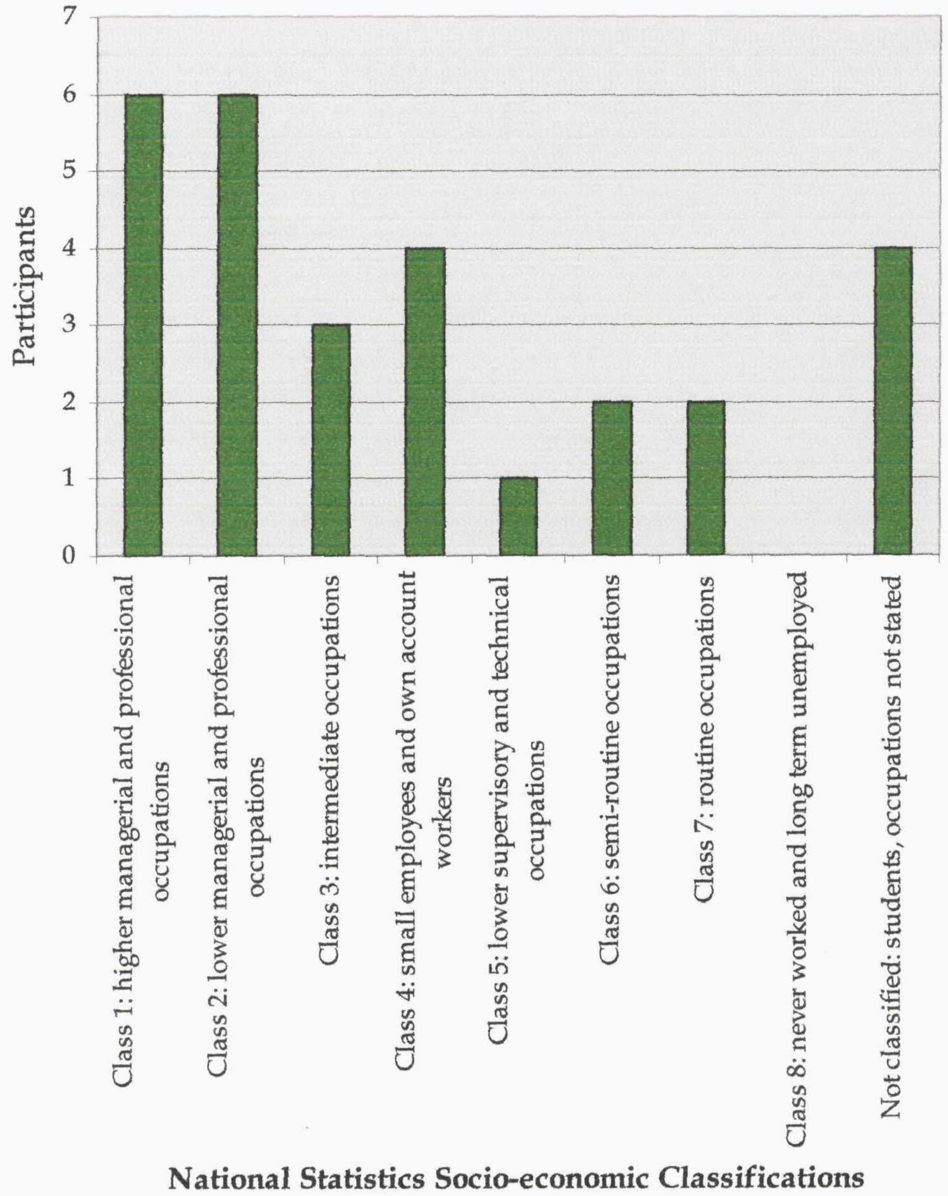
It is of note that the majority of those recruited are under 35 years, whereas neither the OXCHECK or British Family Heart study enrolled people under the age of 35 and 40 years respectively. Nevertheless, the atherosclerosis process starts in childhood (Hayman et al., 2007) and many who are over 18 years of age will already have at least one risk factor for CHD (Bao et al., 1997). When the study was initially reviewed by the local research ethics committee, they were concerned that young adults would not be interested in attending a health promotion programme. The view of the ethics committee is supported by previous cohort studies that have shown that young adults are less likely to participate in health-related studies (Gallagher et al., 2002). However, these results, as illustrated in figure 5.2, show that young people with a premature familial CHD history are interested in a preventative programme.

5.4.3 Social class

Social class, although difficult to adequately define (Critchley & Capewell, 2003), has been included because health promotion initiatives traditionally, do not always adequately target all sections of the population (Davis et al., 1996). This is also true for cardiac rehabilitation, where the research has shown that it is often those in the lower social classes who are considered as being poor attendees (Kelleher et al., 1999), and yet are those who are at increased risk of CHD (Pearson, 1997; Hart et al., 1997). Ensuring that the delivery of health care reaches all sections of society, and striving for social equality, are key issues in the Government's current reform policies for the NHS (Wanless 2004; DH 2005; DH 2007a). Consequently, collecting social class statistics is important.

The National Statistics Socio-economic Classification (NS-SEC) (Office of National Statistics 2005) was used to classify the participants' social class. This version has eight classes and a 'Not classified class,' which categorises students, occupations not stated or where there is inadequate description upon which to make a judgement.

Figure 5.3 Social class

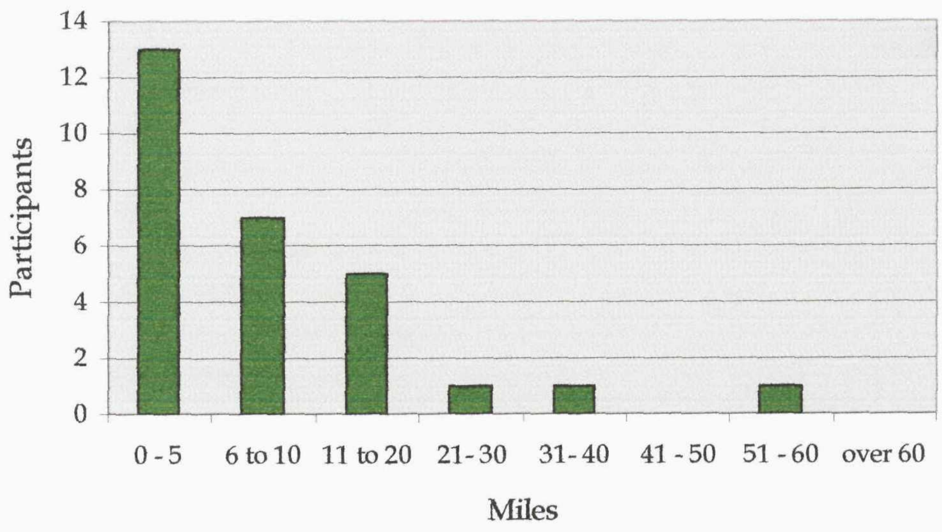


There was a complete spread across the social scale, apart from anyone who was classified as never having worked or long term unemployed. The "not classified" category on the chart represents four participants who were students. The majority of people fell between class 1 and 4. Thus the recruitment process was able to encourage people from all social classes to take part in the study.

5.4.4 Distance travelled

The distance people travel is an important consideration for those attending cardiac rehabilitation, where distance travelled has been shown to be a reason why attendance is variable (Campbell et al., 1994; Ades 1999). However, there are fundamental differences between a rehabilitation programme and this study, where the duration of most rehabilitation programmes is six to eight weeks involving twice weekly sessions. The rehabilitation programme is intensive over a short period of time; this study, on the other hand, asked for a long term commitment with a six month gap between visits.

Figure 5.4 Distance travelled



The majority of the participants do live within five miles of the hospital, and the vast majority live within 20 miles. However it is of note that some are prepared to travel considerable distances to attend the programme.

5.4.5 Time since diagnosis

The timing of the initial discussion concerning the study can be important for many people, when deciding to be involved in a health promotion study. When using Prochaska and DiClemente's (1983;1984), transtheoretical model, an important aspect is where people are within the cycle of change. For some people if the diagnosis is a new one then they may be at a precontemplation stage and they would be unwilling to participate, or they may still be coming to terms with what has happened within their family and it is too early for them to accept the implications of the event within the context of their own lives.

As shown in figure 5.5 for some of these participants the diagnosis for their parent or sibling was a new one, while for others it happened a long time ago, over 14 years. For those who were recruited outside the hospital setting, the original diagnosis was made between 14 and 38 years ago. Yet, even after all that time they were still keen to be involved and included in this study. The five participants for whom the diagnosis was made over 14 years ago were all teenagers at the time their parent was first diagnosed with heart disease.

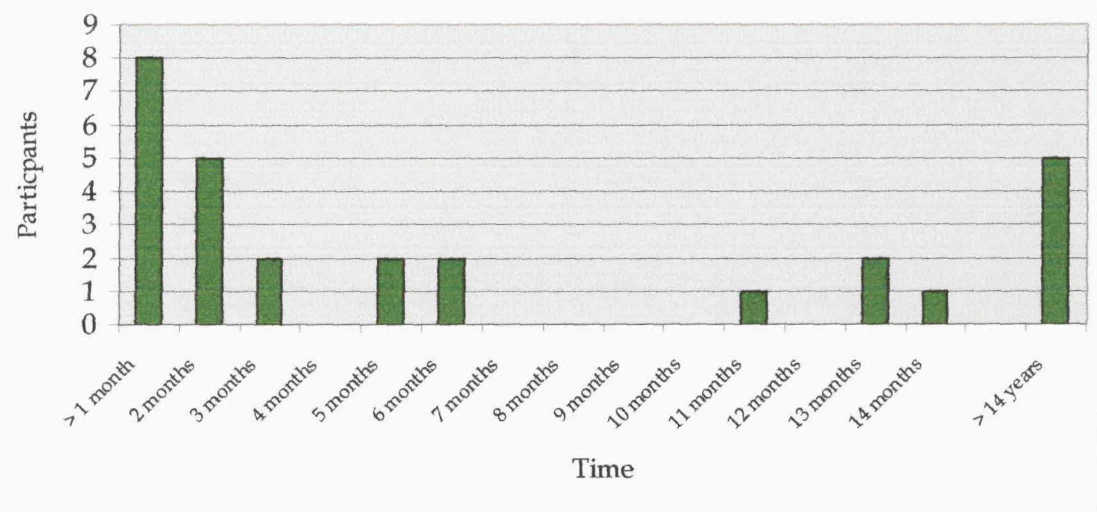


Figure 5.5 Time since diagnosis

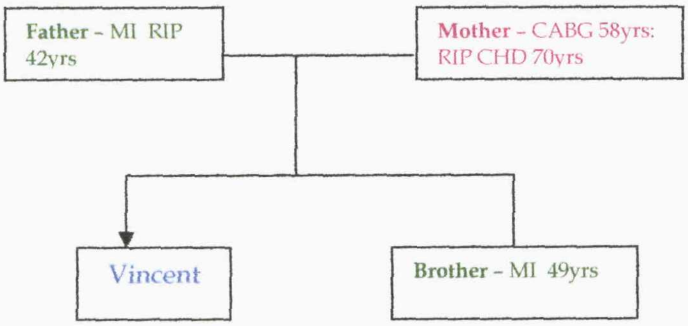
This chart illustrates that for the majority (n=17) they are willing to participate in a health promotion study within 3 months of a diagnosis being made for their parent or sibling. Other people may be interested, even when the initial diagnosis of heart disease in the family was made 38 years ago. There is no right or wrong time for people to be included in a cardiovascular health promotion programme, but that whatever the timing, it has to be right for the individual.

5.5 Family history

The data were collected from the participants, regarding their familial history of cardiovascular disease (CVD). The details were cross referenced with other family members participating in the study. Self reporting, such as this, is the same method used by other studies already discussed (Grech et al., 1992; Andresdottir et al., 2002), and is the same method adopted during clinical assessments.

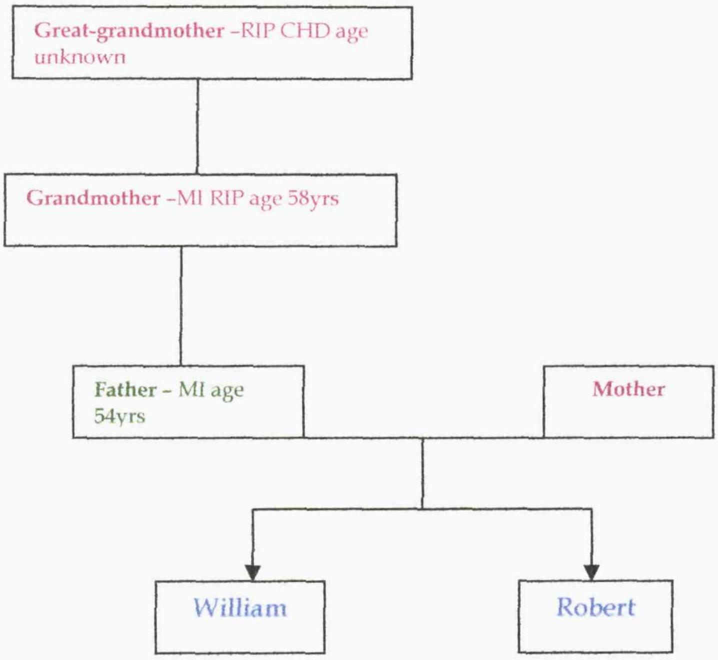
A diagrammatic sample of six family trees have been included. The participants are identified with pseudonyms: these are different to the ones used in the narrative analysis.

FIGURE 5.6 Vincent's family CVD history



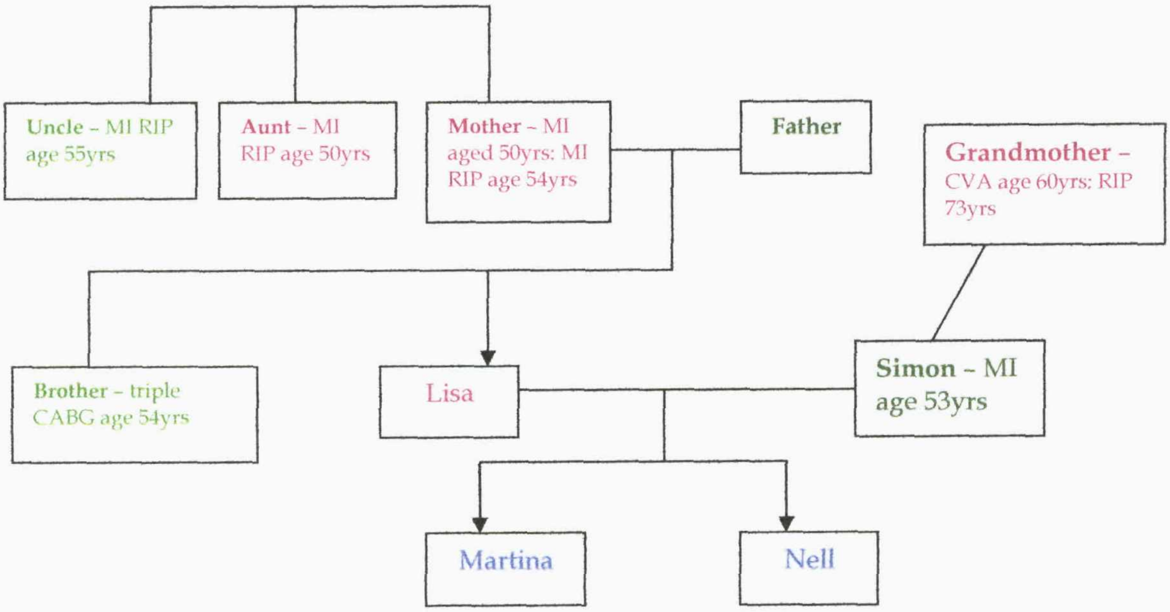
Vincent's family tree illustrates a premature family history for CHD on both sides of his family. His mother had had coronary artery bypass grafts (CABG) at age 58 and subsequently died ('rest in peace' - RIP) from coronary heart disease (CHD) at 70 years. His father died from a myocardial infarction (MI), when he was 42 years. Vincent's brother was admitted to the hospital following a MI.

FIGURE 5.7 William and Robert's family CVD history



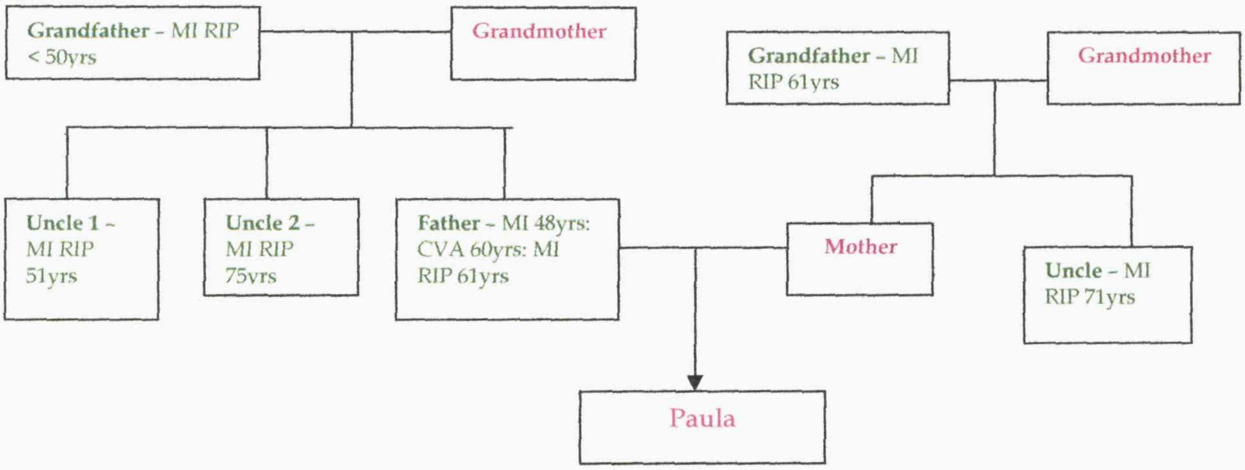
For William and Robert their family history is associated with their father's family line only; manifesting in the females until his father had an MI. Coronary risk is greater if heart disease is present in females rather than males (Pohjola-Sintonen et al., 1998).

FIGURE 5.8 Lisa, Martina and Nell's family CVD history



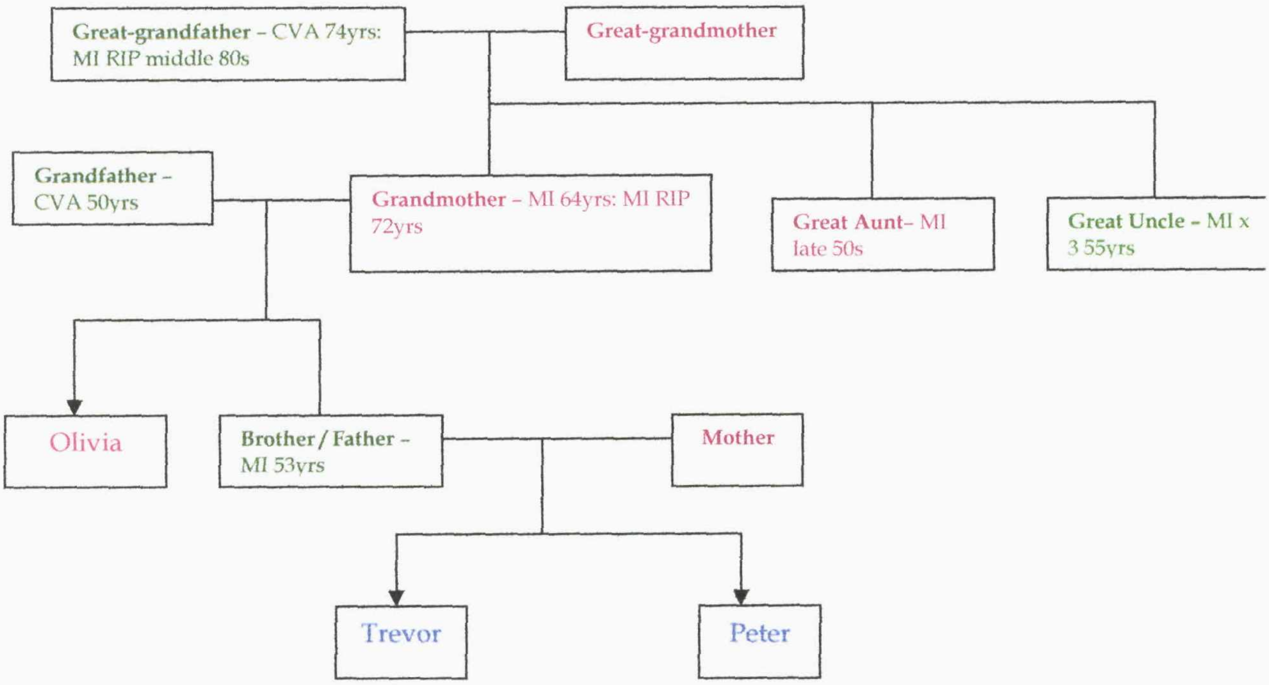
For families such as Lisa's she has lived with her family history since she was a teenager. Her husband, Simon, was admitted to coronary care following a myocardial infarction. Simon's mother had had a cerebrovascular accident (CVA) at the premature age of 60. Lisa and her two daughters, Martina and Nell, joined the study following their father, Simon's, admission with an MI.

FIGURE 5.9 Paula's family CVD history



Paula has evidence of heart disease on both sides of her family, exclusively in the male line, with some classified as premature.

FIGURE 5.10 Olivia, Trevor and Peter's family CVD history



Olivia has evidence of cardiovascular disease in the form of CVA in her father's line and coronary heart disease in her mother's line. Following the admission of her brother with a MI, her nephews Peter and Trevor now have an extensive history of CVD in their father's family.

Taking a family history is a traditional tool used in medicine for evaluating levels of risk. As previously discussed, the EUROASPIRIE II family survey showed that European physicians rarely screen family members of patients with premature CHD (De Sutter et al., 2003). For cardiac conditions such as hypertrophic cardiomyopathy where there is known hereditary link, drawing family details in this way is common practice (Farrer et al., 2005). The debate concerning how familial risk is increased for those with premature CHD continues, but when family histories are diagrammatically mapped in this way, a clear confirmation of the extent of cardiovascular disease that manifests within these families is visibly seen. They show that for the majority of people recruited into the study, the diagnosis of a first degree relative with premature CVD was not an isolated family occurrence.

5.6 Phase 1 ~ Narrative

Twenty-eight people gave their consent for the primary prevention research study. Twenty-six narrative interviews where undertaken, taped and analysed. The main themes from these are discussed in this section. Two transcripts were crossed-checked, by an independent researcher, to ensure that similar themes were being identified.

Participants were given the choice as to where the interview took place, for example in their own home. All participants stated a preference to give the interview at the hospital in a private clinic room. For the interview, a few participants had family members present such as mother, wife or girlfriend. By being in the impersonal clinic environment, professional trust and confidentially were enhanced, and personal vulnerability was protected, resulting in expressive and rich narratives.

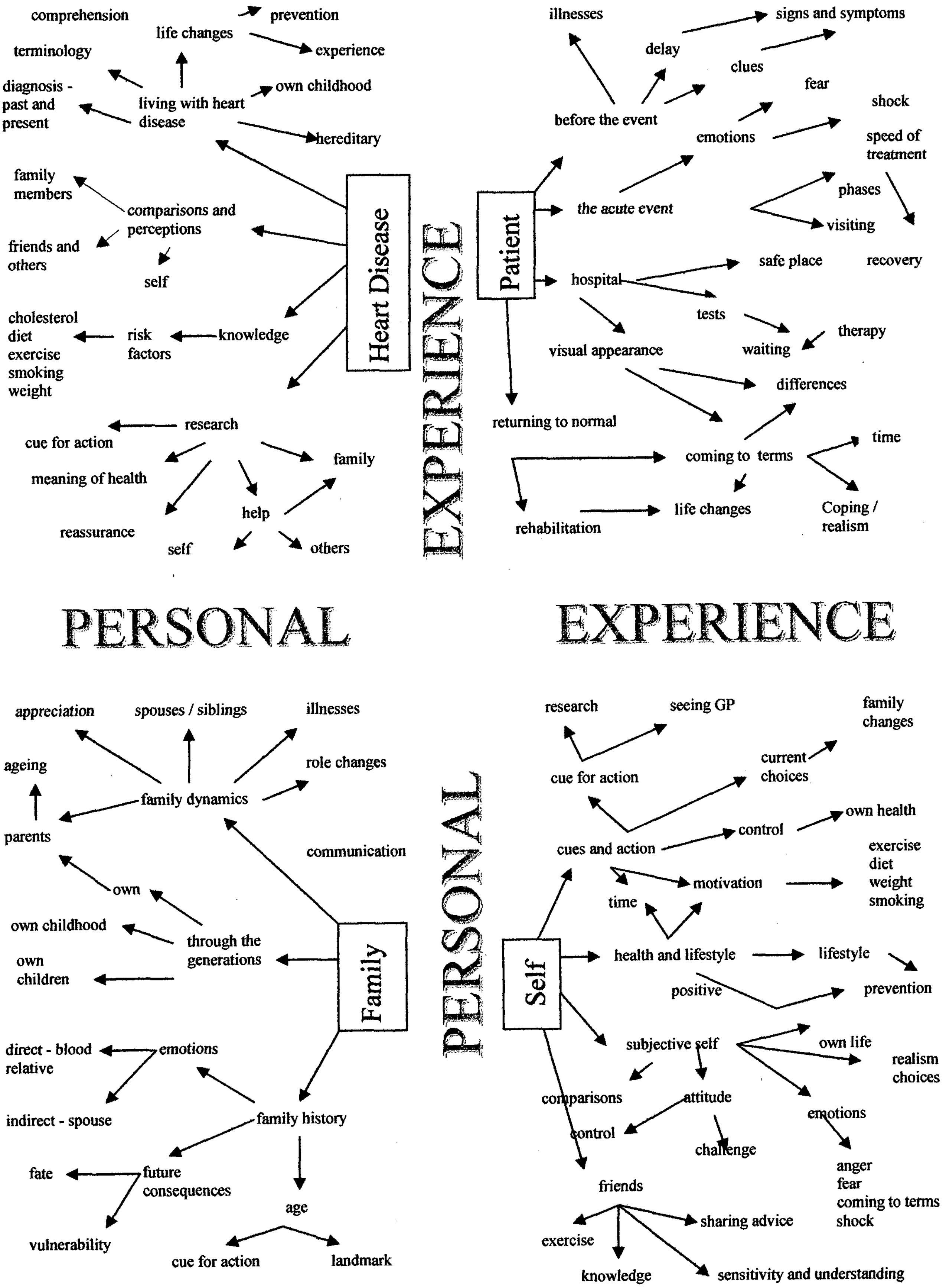
Before starting the interview, participants were asked if they had any questions having read the participant information sheet, and the purpose of the interview was again clarified. It was explained that a small section of their narrative could possibly be used to illustrate the overall findings from this phase of the research, but that the stories would be confidential and that their individual names would not appear. Signed consent was given before the interview commenced. Data from the interviews were coded so that it was not possible to identify individuals by name. These data did not form part of the medical notes and remained confidential to the researcher. The coded tapes were kept securely away from the hospital in a locked filing cabinet and computer data kept on a password protected system.

The participants were asked to relay their experiences with regard to their relative who had been diagnosed with heart disease, including the factual details and events they felt were relevant and their subsequent thoughts and feelings related to these. No structured format to the interview was used. The narrators were allowed to tell their own story, starting wherever they felt that the story began. Some participants were happy to speak for an hour with minimal prompting, while others were less vocal and consequently needed encouragement. Silences were rarely awkward, providing the narrators with an opportunity to gather their thoughts and assimilate their feelings. At the end of the interview they were asked if there was anything they wanted to amend from their story, and if they were happy with what they had said. No-one amended anything from their narratives and accordingly signed post interview consent was obtained at the end of each interview.

5.7 Narrative analysis

Details of the narrative analysis has been covered in the previous chapter, explaining how the four main themes were identified and their corresponding descriptors. Here figure 5.9 diagrammatically illustrates, using a form of mind mapping, all these four themes, their main descriptors and related sub-themes. This clearly shows how the sub-themes, which were identified in the narratives, contribute to the main themes, and how they have emerged from these. The themes do not appear in isolation, but are interlinked with each other and as a whole. Arguably the arrows could go in both directions as it is a dynamic process and interaction.

FIGURE 5.11 Narrative mind map



Each of the main themes identified from the narratives in relation to these subjects will be discussed. Some of the quotes used fall into more than one category, for example when talking about life style changes, this also illustrates their level of pre-existing knowledge. In the context of this analysis, a linear description is used and examples of the narratives have been used that best illustrate the theme being discussed. The four themes, and their associated descriptors, are summarised in table 5.1. The ordering of these findings is not associated with level of importance, it is the same as the sequence of events that emerged from the narratives.

TABLE 5.1 Narrative themes and descriptors

Themes	Descriptors
Patient	Before the event: clues, or no clues
	The acute event
	Hospital experience
	Visual appearance
	Returning to normal
Self	Subjective self
	Cues and action for risk reduction
	Health and lifestyle
	Friends
Family	Family dynamics
	Family history
	Age
	Through the generations
Heart disease	Living with heart disease
	Comparison and perceptions of risk
	Knowledge

To maintain confidentiality, the participants are identified with pseudonyms. The language of the participants is used in this section of the thesis, and where appropriate the narrator's own words are used in the descriptive account. This is in order to reflect the language used by the narrators and maintain the essence of their stories. Quotes have been used to illustrate key points which are relevant to the participants.

5.7.1 Research limitations

The common denominator among these people is that they all have a family history of premature heart disease in at least one first degree relative. As already illustrated in the demographic section of this chapter, the study participants represent a varied selection of people; they are not homogenous. No specific questions were asked in the interview, so that comparisons between answers can not be drawn and collective conclusions made. This study population, as a result of its own diversity, has produced extensive material upon which these results have been developed; they would not be generalisable to specific intervals as a totality, but should have a degree of relevance to others who have the same common denominator. The themes generated and discussed are those which have been identified from this set of narratives; further interviews may produce additional themes.

5.8 Narrative results

There is a clear structure and sequence of events to the narratives; from symptoms through to diagnosis and acceptance; realism, coming to terms with the event and learning to live with the consequences. For example, Alistair recounted seeing his father in hospital having a heart attack, then realising that they, as a family, needed to do something. He already knew that alcohol, diet and exercise are key components to the change, and that this was a cue for action. He had to take responsibility for his own actions especially because he was newly married and the next generation was on the way. Each of these four themes - patient, self, family and heart disease - will be discussed individually with sub-themes providing the description.

5.9 Patient

All the participants are telling their story about the diagnosis of heart disease, which occurred for their parent or sibling. They recount the story of this event, their thoughts, their feelings and views both now and for the future. Central within their story was the patient. For some the patient, their relative, remains the central subject of their narrative, for others, as discussed later, the main subject within the narrative is themselves.

5.9.1 Before the event: clues or no clues

For some families there were clues that something was wrong with the patient prior to the diagnosis. Sometimes these clues were investigated, but mostly they were ignored or dismissed. For example, for Barbara, 30 years ago when she was a teenager at the time of her mother's diagnosis, medical intervention was limited. Her mother experienced chest pain on exertion for over a year before she sought advice from her doctor who subsequently diagnosed angina pectoris. At this time the only treatment available was relief of symptoms through the action of vasodilators in the form of glyceryl trinitrate tablets (GTN). Glyceryl trinitrate opens the arteries and help to restore blood flow, but does nothing to treat the underlying pathogenesis. A few years later, Barbara came home from holiday expecting her mother to meet her, but she was in hospital following a heart attack, where she stayed for two weeks. Four years later Barbara's mother died from a second heart attack. These events clearly illustrates how thirty years ago an accurate diagnosis was made but little was done for the patient in terms of real treatment or lifestyle advice.

Some people recount how there were clear clues that something was wrong for their relative. For example, it may have been that they were experiencing chest pain, either as a single event some time ago or intermittently, but had either not bothered to consult their doctor about it, or had not attributed much importance to it. At the onset of the event when symptoms manifest, these can be misinterpreted, for example for indigestion, and there is a delay before calling for help. This is especially true if the symptoms are not severe, and if they are not directly associated with the heart. Leo tells how his father had an achy pain in his arm before his heart attack and discounted it as not important. Alternatively Geraldine's mother, having read for herself the symptoms of a heart attack, because her own father had died from one, recognised her husband's symptoms, and called for help, when he would otherwise have remained in denial.

> *He had been outside doing some physical activity, something simple like sweeping. But he was sweating across his body, he sat down and of course he went ashen and started to sweat. He said it was indigestion. And I said to him, "I'm going to call the Doctor." "There's no need" he said. Anyway I called the Doctor.* *Georgina*

For many people there are no clues that something may be wrong with their heart. Many described how well the patient appeared before the heart attack. They describe their shock that one day the patient is fit and well, living a normal life; the next day they are in a coronary care unit. The speed at which a person's condition changed is frightening and adjustment for members of the family takes time.

Annie was enjoying a swim with her mother immediately before her mother had her heart attack. She felt responsible because she had been encouraging her mother to swim, and felt that the physical activity had resulted in her heart attack. After the swim her mother had reported feeling unwell, but not in pain; Annie had consequently attached little importance to these symptoms. The symptoms people describe are important, the association is with the pain, not the feeling unwell, or 'feeling sick.' If someone is in pain it is taken more seriously than if someone is feeling unwell. Even when there were classic symptoms associated with a heart attack, the patient and family still do not recognise what is happening and therefore do not seek immediate help.

> *... he said "Oh I felt a bit funny while I was up there. A bit dizzy." But anyway we just carried on. On the journey he said, "Oh I don't feel well." He said, "I've got pains in the backs of my arms; pain in my jaw; and I feel a bit nauseous and light headed." And I said, "Oh perhaps you have caught something." Anyway we carried on.* *Barbara*

People who had already experienced illness in the family have differing perspectives. Joanne's mother had pain from various medical conditions, on a regular basis. The pain became part of the family's normality. Over time, and as a consequence, the family became desensitised to her suffering; so, although there are clues, they were ignored or misread. While other families may still show adaptation to the regular occurrence of going into hospital, but their unity and support for each other remains intact. They may learn from the experience with one member of the family and are in a better position to help with another; they know what to look out for. Eddie explained how he and his family knew what to expect when his sister was diagnosed with heart disease; in the past their father had been in and out of hospital many times with his angina attacks.

> *Kind of gone through before going into the hospital knowing the tests, knowing he's going to have the angiogram. So it kind of wasn't complete lack of knowledge, we already got some fore knowledge. We knew what to expect regarding everything.* *Eddie*

For them they already had some of the answers and knew what it would mean for the future, although the person was different, they had some insight because the disease was the same.

5.9.2 The acute event

This aspect relates to the events surrounding the actual heart attack; the initial reaction that people feel when they first hear that someone close to them has had a heart attack and how they react to this event.

Numerous participants recalled how shocked they were at their relative's diagnosis. Although people express shock at the event, some also went on to explain that they were not necessarily surprised. They had already thought their relative might be a candidate for, or was susceptible to, heart problems.

> *Umm when I got the phone call – I was just shocked and feeling all numb. Couldn't believe it – my Mum had a heart attack at her age - - .*
>
> *Francis*

This can be intensified if they do not have any previous experience of living with heart disease in the family, or if their parent or sibling has never experienced illness before. For others they can be empathic because it has occurred before. Tension and discordance within the family can result in the acute stages when good communication within the family is vital but can be problematic.

The duration of the hospital admission is important where direct comparisons are made and the length of hospital stay can reflect the degree of severity that is placed upon the heart attack. For example if two family members have been diagnosed with a heart attack and one is kept in for a long time and another relative remains in hospital for a shorter time, the event with the shorter stay was seen as less critical than the one that lasted longer. Severity was measured by different means which consequently affects the emotional impact of the event, and the level of importance to which it was assigned. If an event is seen as critical and severe, this had a greater emotional impact upon the relatives and was seen as more important. For example, Collin and his nephew David both independently describe how the seriousness of the patient's condition was not realised until he had to be transferred to a tertiary centre, and the staff turned away the first ambulance because it did not have a blue light and paramedic crew.

> *So it still really didn't hit you that this is quite serious until you realise that he's got to move for an hour in an ambulance, and they've got to take all the precautions necessary. I think that's probably what made you think, "This is serious!"* Collin

People's initial reaction to the event might depend upon where they themselves were at the time and their own level of involvement, when it first took place or were informed about it. Eddie recounts how his sister had been telephoned at home by her general practitioner (GP), who told her, following the results of a test for a possible diabetic hypo-glycaemia episode, that she had had a heart attack. As Eddie's sister had been given the diagnosis over the telephone, while she was at home, the actually event did not appear so bad. For others the impact of seeing a parent in pain, who was stoical and did not usually admit to pain, remained a vivid memory. Oliver, having been called home by his mother, saw his father in the ambulance.

> *I'd say my dad is a strong man and doesn't suffer pain that easily and to see him like he was in the ambulance. I felt helpless coz there was nothing I could do; I wanted to do something.* Kevin

5.9.3 Hospital experience

Being in hospital was seen as a safe place by those who spoke about it. They were reassured that their parent or sibling was in hospital and being treated.

> *It is a strange place isn't it, if you are not used to it. Yes, it was alright. You could see he was being looked after, that was the main thing. He was better.* Bruce

A couple of people, however, found the hospital an alien place, and they felt uncomfortable in this environment. It can also be difficult to find your way around, and being on one's own intensifies the feeling of isolation especially when concerned for a relative. Harriet described how she was initially worried about coming into the hospital, and had delayed her visit; once in the hospital she did not know where to go and could find no-one to ask for directions; all of which compounded her anxiety.

David's father was transferred to a tertiary centre for percutaneous intervention (PCI); David was relieved that his father had a stent and did not require bypass surgery, and he was positive regarding the success rate told to him about the procedure.

> *The stent, it sounded like a good idea. Rather been relieved that it says 1 in every 250 people die in some way, but that means there are 249 people out there who have had it before him. I was quite reassured, quite confident about it.* *David*

The first 24 hours are crucial when someone has a heart attack, especially if they receive thrombolysis. People talked about this critical time when they were facing up to the shock of the diagnosis. This anxiety was enhanced if their relative had wires and tubes attached to them. Concern may also be felt for other members of the family. Patients were concerned for their spouses and children, sons, whose fathers were critically ill, showed concern for their mothers.

> *Even when I saw Dad in the hospital, when he was tubes everywhere, he was like, 'Make sure mum's alright.' And I was, "Dad don't worry about mum she's going to be alright." And that was all he was worrying about.* *George*

It is of note that, as illustrated by figure 5.9, the hospital experience for many people was not something they talked about in their narratives. The narratives had few details concerning the treatment within the hospital or NHS. Expressions of both negative and positive perspectives of this experience were minimal. There was a single narrative which reflected concern over the initial treatment received by a patient. Ian recalled how 14 years ago, when his father had his heart attack, his father was told after being in hospital for about a week that he was fine, he could go home and return to work. Ian urged his father to use his private medical insurance to get a specialist referral and second opinion, which he duly did. Following the out-patient consultation at a tertiary hospital, he was immediately admitted and within 24 hours had bypass surgery.

> *I was very annoyed that he could just be shoved back out, when in actual fact, they said he could have died at any moment. So I think the two things with that is, hopefully I think a lot of things have got a bit better, since then, but secondly, he was only 42 when that happened.* Ian

5.9.4 Visual Appearance

More important than the hospital experience was the impact of their relatives visual appearance. People sought the reassurance of seeing their parent or sibling for themselves so that they could make their own judgements about the person's condition. Annie described coming into the hospital to see her brother. Annie had no concern about coming into the hospital, but she needed the reassurance of seeing him.

> *As long as I can see him. And I couldn't wait to get to see him; it seemed such a long time waiting to get to actually see him. I came in and saw him in bed, and I thought he didn't look too bad, he was a bit pale, didn't look a very good colour.* Annie

People expected their relative to look unwell, but after the initial acute phase, once the chest pain has gone, patients look remarkably well, which belies the truth and severity of the situation. For those with heart disease there may be little to show how unwell and at risk the person is, or to indicate the severity of the situation. Claire relayed how difficult she found accepting her father's heart attack and subsequent debilitated condition, because, to her, he never looked seriously unwell, even during the acute phase. The difficulty with making the association between disease and current condition was tough because there was no visual or situational reference point. This challenge of coming to terms with the seriousness of the condition was expressed by others. For some, it was not until a later comment was made, or an event happened to the patient, that they realised how seriously unwell their relative was.

> *Again it was just like an unreal experience. Because in some ways you looked at all the other patients and some of them looked ill, but my Dad*

> *didn't. And even he said he didn't feel, you know, as if he should have been there… I mean if you see someone with a broken arm, or a cut on the face or something, you can see something. But with something like a heart attack, because you can't see anything, in some ways it's, it's not that I don't think he had it.* Debbie

Conversely for those who saw their relatives during the acute phase, and witnessed their treatment or saw how unwell they looked, this had an impact upon them both immediately and for the future.

> *And the first few times I saw him I thought, "Cor he looks ill." And he looked like he had aged sort of thing. He looked 5 or 10 years older, and greyer and white faced.* George

Heart disease for many is seen as a temporary illness, something that people recover from. Though people may recover and get over the acute phase of a heart attack, the heart disease remains, it is incurable and they will always be on medication, and many may need to make permanent lifestyle adaptations.

5.9.5 Returning to normal

For both the patient and their families, many were still coming to terms with what has happened. They were shocked initially, and they were still getting over this shock. It was not until people resume the normal pattern and activities of their lives, such as returning to work and resuming leisure activities, that recovery for all is achieved.

> *I still can't believe that he has had a heart attack. Like even when my Nan had her heart attack - we couldn't believe it.* Alistair

Once the patient was home, there was a natural tendency to cosset them. They become the centre of the family's attention, and the family develop a fear of letting go and enabling the patient to return to a normal way of life. The family have learnt that they may be vulnerable, and they have their own internal struggles to overcome. Coming to terms with what has happened is coupled with a need to be realistic about the change of circumstances and situation. For some there is a change of roles, where they are now looking after a parent. Most importantly there is a wish for reassurance, they need to know that all is well with the patient. Many recalled how, especially in the early days following hospital discharge, they would phone frequently, or visit after work to see the person for themselves, seeking visual confirmation and valuing their company.

> *I keep phoning my Mum and checking her everyday now. When I come in from work, or if I got money on my mobile. Or she rings me to let me know that she is ok.* Francis

Post discharge it is common for people to be re-admitted to hospital with re-occurring chest pains. Claire expressed her frustration with her father for returning to hospital with chest pain; this narrative clearly illustrates the misconception that people can have regarding the recovery process after a heart attack.

> *And you know, no one actually told me that he could be rushed into hospital a few weeks later. ... I thought while he was on this medication, he would be fine, and we would not hear any more about it, and he would just go on his rehabilitation, and he would start gaining strength and you know, things would carry on as normal. OK it's a life change for him, but it wouldn't recur. So now I have seen, you know, that something could happen to him again. He could be rushed in. I guess it's one of those things; it seems to be able to strike without anyone knowing at any time.* Claire

For those who have a relative who is readmitted it acts as a reminder of their vulnerability, and the fact that heart disease is not a curable, but a dormant problem. Many families embrace the lifestyle changes that the individual was making, such as dietary changes and increasing physical activity. Although they do the right thing together, relatives sometimes expressed how they struggled with these changes. After they had lived with the diagnosis for some years, the lifestyle behaviour may have become the accepted norm, or they may relapse, especially in relation to dietary and alcohol intake. Occasionally children expressed their frustration with a parent who does not conform to a protective lifestyle. Emma appreciated that it is hard to give up smoking, but was concerned that her mother, along with the rest of her family, did not adhere to advice given and continued to smoke and drink too much alcohol. She was angry that by not making the lifestyle changes, her mother was putting her life at risk.

> *It does make me cross; but unfortunately that whole package of family, my Mum, her sisters, they all smoke too. And I think it is very hard for them to come out of that group situation, you know.* Emma

For some the pattern of life that existed before the heart attack may never be regained, for example, the patient who is no longer able to work, or must work part-time, which results in subtle changes of status within the family. However these changes were accepted as a consequence of the heart attack and adaptations within the family were made to accommodate the changes. George talked about his father whose whole life was literally smoking and work, both of which he had to give up. There can be positive repercussions though, as George explains. George's father needed to have time off work, consequently his mother stopped work for a year, so both his parents were able to enjoy a relaxing time together and had a chance to come to terms with these changes.

5.10 Self

Self is identified as a theme because the narrator is an integral aspect of these events it is also their experience. The objective self can be seen as independent from the narrative, where the narrator plays a small part in the narrative but are not themselves the main subject of the narrative. The subjective self relates to those who are central to this experience, where the events described are in relation to how this has affected them and their lives; they are the main subject of their own narrative. These concepts should not be confused with selfishness.

5.10.1 Subjective Self

Initially people are concerned for the patient, but after the acute event the emphasis can change. For some participants their concern was for other members of the family, especially for mothers where seeing the anxiety of a parent added to their own distress and general concern for the family. The next stage is worry for themselves and finally for their own children and family. For those with an extensive family history there was obvious concern that they might be next, especially if their relative had no discernible lifestyle risk factors that they could have modified for themselves.

This is a very emotional time; some express it in tears, fear or silence. For others there may be a delay, which may be on-going after many weeks or even years. This can also be a learning experience, where people have the opportunity to discover aspects about their own personality and that of others. It can bring families closer together, when people are not taken for granted and individuals become valued. The impact of the event, the diagnosis and general experience is variable, largely dependent upon the final outcome and resolution. For those whose parent had died from heart disease, the impact and influence upon their lives continues over the decades, manifesting in various ways.

Neil's father died when he was a teenager and his death had subsequently shaped Neil's life. This was possibly the first time he had been given the opportunity to share his experiences and thoughts, as he said, not something he usually talks about. As his narrative developed, one could see how Neil had never recovered from the loss of his father, and his father's influence remained. It is his father who had shaped and structured the whole pattern of Neil's life, providing the motivation and driving force for his own achievements, while later giving him the freedom to do whatever he wanted with his life. Not only because of the death, which meant being the eldest of the family, he felt a responsibility for his siblings and mother. Neil's father was successful and provided for his family, consequently Neil wanted to emulate him, to do the best for his own family and to honour the family name.

> *My motivation is, in a strange way, to honour the memory of my father. My Mother is alive, and I want her to be proud of the fact that, OK my Dad isn't here, he can see down and say actually you know, he did alright. But my Dad is my motivation. He still is. I mean he has been dead for 17 years, still makes me very upset to think about it. You know, I still cry like a baby some days about it. Which is ridiculous really, but I have never, I don't know, I've just never really got over it.* *Neil*

Neil described the positive and negative influences his father and his death had had over his life, but the reality of the loss remained.

Some expressed the fear they had for themselves and how they had become watchful, even at a young age, for any signs or symptoms of heart disease. The awareness had been raised and they were sensitive to this.

> *But I have been more aware of what I do eat now, and every little twang I get in my chest I am like 'What's that? What's that?' I think I am quite paranoid about stuff nowadays.* *George*

Generally, throughout the narratives, people showed a high degree of realism. They were realistic regarding what had happened within the family and the reasons for it, the lifestyle issues and family history. They said how they had to get on with life, there was no point in bemoaning the situation. But they also acknowledged the need to do something for themselves, and to be proactive in order to prevent the disease reoccurring for themselves and their own children.

> *I suppose it has made me think a little bit more about me, what I should be doing what I shouldn't be doing, maybe try and get more fit. Yeah, it has made me think of that kind of stuff, a bit more. I mean I have been going down to the gym since then.* *Martin*

5.10.2 Cues and action for risk reduction

This is a three stage phenomenon. First, people describe the cues and triggers they had which had acted as the catalyst for change. The catalyst could be seeing the relative in hospital, fear for their own quality of life, or an isolated remark. The second stage was concerned with action and taking control of the situation. This stage may involve others, such as visiting the GP, or dietary changes where other family members were involved. Thirdly is the change itself.

The diagnosis of a close relative with heart disease often acts as a trigger for people. They have now had direct experience of a relative with heart disease. This is something that does not just affect other people, but can affect themselves and their family with personal repercussions. The initial spur for action could take various forms. It could be a comment made by a doctor or nurse that touched a chord with them.

> *...the cardiac rehab nurse told me, when I came to see my brother, that I had four of the five risk elements, so the only one I don't have was smoking. So that I think probably alerted me as well. That someone actually said it in literally two sentences, you got four of the five risk factors.* *Collin*

Alternatively some explained how they see this as a warning for themselves, their family, as well as the patient. The time has come to make the lifestyle changes in order to improve the status of their health.

Some participants describe the experience of being proactive in seeking professional help and advice from their GP. Those who went to their GP tended to be older. Some had no firm request to make but had either been advised to see their GP or felt it was the sensible thing to do. The care given by the GPs was generally to take a blood pressure and cholesterol reading. Collin described his visit:

> *.., and he said well you have a 17% risk of a heart attack. Now how he got that, I don't know, excluding family history which I thought was the crucial bit. Then he put me on a statin for 2 weeks, and he said he hoped to get it down to 4, and he said that will reduce your risk from 17 to 13%, which I mean I don't really think he is interested. I mean to be truthful: I don't think he is interested.* *Collin*

Despite being given medication, his general feeling was that the GP was not interested, possibly because he spoke about abstract percentages of risk which had little personal relevance or significance. Others described the frustration of seeking medical assistance and receiving none. Fiona had cut out saturated fats from her diet, and then visited her GP:

> *I just wanted some reassurance, I wanted to see you know if my cholesterol was very high, and if it was, I was determined to do something about it.* She goes on to say that the GP said, *"Well it is 5.8: just have Benecol and watch your diet." And that was it. Well I suppose I felt that if she was worried she would have had me back.* *Fiona*

At the time she was reassured by her GP and passively accepted the advice. When Harry, who had Type 1, insulin dependent diabetes visited his GP, the GP decided that now was the time for him to start additional medication. Generally, the experience of visiting the GP seemed to be of little value to most people who were seeking professional advice and guidance from the GP. Others explained how they used the internet to seek knowledge about heart disease, while some learnt from television programmes.

Motivation to make lifestyle changes by family members can be high during the patient's acute and rehabilitation stages. However the motivation and adherence can diminish over time as family life returns to normal. Before joining the study some had already started to make positive lifestyle changes, for example, eating healthier foods, exercising, reducing the number of cigarettes smoked. When making life changes, diet was a key issue for many, while others already knew what needed to be done, and as a family they were making the changes together. Harriet recounts how her siblings and parents, who all live together, had all changed their attitude towards food, and made a conscious effort to eat healthily. Harriet recounts how they as a family had made changes and choices together, and how she was taking responsibility for herself by making positive changes to her lifestyle. For example, she knew that she must increase her level of physical activity, but had not yet achieved this. Harriet's narrative reflects many of the issues discussed in this theme.

> *"Oh it's never going to happen to me, it happens to other people." But when it happens to someone in your family then you start, well I personally, start to think that if it can happen to my Dad then it can happen to me, and what's the point of sobbing at the sides, when if you don't take responsibility for your own self and your own health, then the worse comes? But since it has happened, I have thought about it more and I have thought that my*

> *lifestyle does need to change. But I am at the stage where I need to move on and start taking responsibility for myself a bit more.* Harriet

5.10.3 Health and lifestyle

For many they took their health for granted, that is up until a major life threatening event, or until a trigger occurred which provoked them into action. Although he admitted to taking his health for granted, Bruce had managed to give up smoking as a result of a single comment that touched him, and because of his own, as yet, unborn children, he had looked into the future and acted.

> *I was watching a programme on the TV, on Channel 4, and they announced that it was "Quit Smoking Week." And I was watching it; and one of the doctors said "Every cigarette you smoked takes eleven minutes off your life." And for some reason that just struck with me. And that was probably the main reason why. We had just booked the church to get married next year and obviously you start thinking, and you want to have kids, and you want to spend as long as you can with them, you know.* Bruce

Seeing a close relative, especially a parent newly diagnosed with heart disease, people expressed the realisation that their parents were not invincible, and consequently neither were they. Good health, and how to achieve a healthy lifestyle became pertinent considerations.

> *Well, unfortunately, it* (health) *has been a fairly significant factor because our father died so young at 57. So I have been dealing with the consequences of that, personally, for the last 25 years. So it is never far from my daily thoughts.* Robert

Many people showed a fundamental knowledge of the key risk factors associated with heart disease. For example, Kirsty talked about having the same risks as her mother, she made comparisons between herself and her mother concerning smoking and being overweight. She showed how she knew that weight and exercise were important health issues.

> *To get yourself into shape and to keep healthy; it costs a lot of money. I am sure there are plenty of people that agree as well coz it is like, £50 a month to join a gym. And then all the food, if you like want to get yourself all the 'good to yourself' stuff, you know get into healthy living, it's all that little bit more extra on the top. And I try to put money aside and go out and then I make sure that I buy things that I want, for me.* *Kirsty*

Kirsty is expressing her belief that it was expensive to be healthy, and linking being in-shape and being healthy as synonymous with each other. Kirsty had previously expressed the wish to be healthy, and that this was the time to act. However she had a conflict of interests between enjoying herself and being healthy, coupled with the belief that to be healthy was expensive. Many acknowledged the importance of exercise, and stated that although they may have been sporty and active when younger, other issues, especially work, had impacted upon their lives and finding the time for exercise activities, possibly with the exemption of golf, was difficult.

> *Because I used to be really active and I haven't done anything for a while. Yeah, just sort of like playing football and stuff, which became impossible because of work.* *Martin*

For some there is a conflict of interest, between knowing the right thing to do, and actually being able to, or really wanting to, achieve it. Even for those who have made lifestyle changes in the past, sustainability could be a problem, when the acute event which triggered the change retreats into the past, and relapse can occur. For those for whom the healthier lifestyle had been embraced, they still remained realistic and lapsed on occasions, but usually only special ones.

> *I mean, if we go out for dinner or I have people over, I don't begrudge myself having a pudding or something, because otherwise you would drive yourself mad.* *Fiona*

Improving diet is a key lifestyle change that many had already tried to contend with, a change they maintained. Diet was a major issue as it is an aspect of daily life that is a continual challenge each day. For those who had partners and parents involved with this lifestyle improvement, the change was easier to make and sustain. Kevin's father after his heart attack, was advised to lose weight and cut out cooked breakfasts; he now eats porridge. Kevin told how it was his mother who has provided the impetus for the dietary changes within the whole family. Motivation for change can come from other people, a worried wife for example, a concerned mother, girlfriend or son. There was support within families, where the impact of the behavioural change was felt and shared, as they became aware of the support they could give, coupled with their own need for changes.

5.10.4 Friends

A few participants mentioned the influence and role that friends had in their lives. They talked about the way in which they wanted to involve them, knowing that lifestyle was relevant not just because they had this family history, but because lifestyle influences the health status of others. They either wanted to influence their friends and loved ones to make improvements to their lives, or they wanted to share the experience with them and make positive changes together. This may be in the form of encouraging their friends to stop smoking, going to the gym together or playing sport, or sharing relevant information and knowledge.

> *.. to kind of get some knowledge for myself and to pass on to, you know, my loved ones or whatever and make sure that they are OK.* *Leo*

Geraldine's father died from a heart attack when she was a teenager. She described how she and her mother took the initiative and offer advice to both family and friends.

> *Yeah, so you must always make the most of every moment, definitely. And also take care of people in your own family, or friends or whatever, if you think they are heading in that direction. So for somebody with a very bad lifestyle; I would say something.* *Geraldine*

5.11 Family

The diagnosis of one member of the family with a chronic disease subsequently affects other members. The narratives provided evidence of the consequences of this and how families can be influenced both in the short and long term.

5.11.1 Family dynamics

Through listening to these stories, a clear picture of the extent of family unity emerged. When describing the initial event, the involvement and communication within the family illustrates their closeness or, in some cases, their distance. Families may not express their emotions verbally, but this did not signify lack of closeness. However there could be resentment if things are not shared. Chronic illness can bring families together and provide them with an opportunity to show their feelings.

> *Never really expect your - , you think nothing is ever wrong with your parents do you. Unfortunately as we get older, it is something that you have to take on board – they are not really around forever. So when he's had a bit of a scare like that, it makes you appreciate them more.* Harry

For many children they were concerned for their mothers. This was especially apparent with the sons. George expressed how horrific it must have been for his mother to have witnessed the suffering of his father when he was having his heart attack. He explains how he wanted to be at the hospital to be there for his mother. George's concern for his mother remains.

> *It is worse for the people that are left behind and to think that Mum could be - if Dad had died, Mum would have been - - she could have lived for another 30 years. You know, not having, - - that's the worrying thing really. . . That's sad: it is not nice is it, to be left behind.* George

Family dynamics can be altered by both the event itself and its lasting consequences. Joanne described the changing role of her mother, who had been the main carer for her son since he was young. She recounted the way in which her mother wanted to maintain this role, because it gave her identity and purpose; she wanted her Mum to continue looking after her son so that she could continue her study work. In a separate interview, her sister Kirsty echoed these sentiments, illustrating both the conflict that can occur within the family and her mothers' struggle to keep the peace.

> *She says I'm not looking after him anymore, ten minutes is nothing. I think she realises now that how serious this problem is because she sort of tries to do things right by everyone. She just wants everyone to be happy.* Kirsty

5.11.2 Family history

This theme was notably important for three people whose parents died over 14 years ago when they were still teenagers. For people who also have an extensive family history of heart disease, their awareness can be acute. Often they have lived with this history for a large part of their lives. Barbara, whose mother died when she was only 14, told of her frustration at the lack of information and explanation given to her and her family. She then continued by describing her family history.

> *And then a year after my Mum dies, her sister who was 50 at the time also died of a heart attack. So of course it was even more instilled in me, heart problems, heart problems within the family. Then her brother died of a heart attack 5 years earlier in his mid 50s. So out of my Mum and her two brothers and sister, three died in their early 50s and yet their mother lived until 92!*
> *Yeah, I did think about it over the years. I ought to have may be researched it more. But you try to put it to the back of your mind. It isn't going to affect you. But it is at the back of your mind because you're always — And then when my brother was in, he's 2 years older than me, in his 40s, he started having the angina. That brought it to the fore again.* Barbara

Barbara joined the study after her husband had been admitted to the coronary care unit and the cardiac rehabilitation sister spoke to her husband enquiring if his daughters would be interested in participating in the study. They both did, along with their mother, who had asked to participate. Claire, her daughter commented:

> *I suppose we have always had it in the back of our minds, or certainly I have, that my Mum's family obviously have some heart issues.... it's almost like the unsaid thing.* Claire

Even with an extensive family history there can be denial, while for others it is a family fact that they live with.

> *Throughout my life I have always seen other members of my family, sort of you know, just, you know, out of credits!* John

John explained how before starting the study he researched his own family history, interviewing his parents separately, and then cross referencing the results. He was the only person who questioned the accuracy of the diagnosis, recognising how in the past a diagnosis of a heart attack could be inaccurate. Geraldine also recorded her family history before attending her first study visit:

> *I don't think you really realise until you start to write down, and really analyse what has happened, how serious it is. I mean I know it is quite serious, but until you really start to delve you think, "Oh blimey: most people seemed to have died about aged 50 or 60 from a heart attack; on the male side anyway."* Geraldine

There was an awareness of the hereditary link of heart disease within families. For many, as illustrated by the family trees, this was not a new diagnosis within their family.

> *I mean you know about these things and you don't think it's going to happen, but things do tend to be hereditary in families. Some families have problem with hearts, some families have problems with cancer being hereditary; you know it is just the way of the world isn't it? And as long as we can manage it.* Harry

People did not express anger or resentment about their family history, but demonstrated stoicism and realism, that this was the cards they had been dealt, and that they were going to make the most of life. However they were still going to see what they could do to prevent heart disease from happening to themselves, having already seen what it could do in their families. Eddie had heart problems on both sides of his family and his sister had recently had a heart attack. He knew that heart disease was incurable, but that you can do something for yourself to try to combat it.

> *Gradually he* (his father) *just got worse and worse. More angina attacks, most of the attacks at night. And his diabetes got worse as well. He ended up losing half his leg. He was fine one night, and my Mum woke up the next morning and he was laying dead beside her. I'm aware of it from my mother's side, she'd had problems way back with her heart, twenty years before that. So from what I gather now, yes there is a history of heart disease. Which is fine, 'coz now knowing that it just means you have to fight. Which is why I am prepared to come here and see what happens. I kind of need to know, and if I can do something, to a certain degree, it is up to me whether I do it or not.* *Eddie*

Eddie had a need for knowledge with which he felt empowered to make his own decisions. He was proactive, describing how he and his sister had sought information and done their own research on the internet. The autonomous right to make own choices was important for him, and although his father smoked 20 to 30 cigarettes a day, *(".. but it was his choice, so hey! He still wanted a fag").* Eddie expressed no blame or resentment.

5.11.3 Through the generations

This was not an extensively prevalent theme within the narratives, but a relevant one. The theme relates to how people perceive the risk either through the generations or at specific age points. Firstly it may be that people see the sequence of the heart disease coming down through and across the generations, and they acknowledge that they are likely to be affected by it.

> *Especially like my Nan, now my Dad, the next one in line is me. Because I'm the eldest one.* *Alistair*

For those who were either about to start a family of their own, or who had very young children, they were concerned about their children. They wanted as much information as possible so that they could give their children the best start. This was also reflected in the way in which many parents supported and encouraged their children to participate in the study. Emma, whose own parents struggled to make lifestyle changes, stated how she wanted to break away from the family mould and provide a healthy upbringing for her own children.

Age can be an issue in different ways. Firstly, if a research participant has a younger sibling with a diagnosis of heart disease, this can motivate change. Secondly, the age the person was when they were first diagnosed with heart disease is important; it becomes a milestone for their children who, as that same time approaches, become increasingly worried. They saw it as the time to take action and face up to the challenge of improving their lifestyle. Two sisters Debbie and Claire, in their separate narratives spoke about the same sentiments.

> *I am not looking forward to getting to 53, 'coz it happened to both of them at 53. I think if I ever get to that point I'll think hmmm.. but I think that's just a coincidence.* Debbie

> *You should never be 53 in my family because they were both ill and they were 53. So it's obviously not a good age to be on either side. And I have already – I think both of us, me and my sister, have both thought you know that when we reach 53 —.* Claire

5.12 Heart Disease

The background theme throughout the narratives is the heart disease. This is expressed in various ways. At the start of the narrative they describe the event which happened to their parent or sibling. This is then developed showing how they had come to terms with the diagnosis, how this subsequently affected them and their families and finally what it has meant for the future.

5.12.1 Living with heart disease

Some people recount the reaction that was felt when they were told that a relative had a 'disease' and that the word itself produced strong emotions. It can be the word itself or the connotations that it produces and a subsequent awareness as to what had happened to their relative.

> *I know he did not like the word "heart disease." That really upset him.*
>
> *Annie*

The terminology that was used has an important meaning to people. Annie's father was upset with the phrase 'heart disease,' while Joanne was distressed by the phrase 'heart attack.' The phrases have specific meaning to each individual, where the perception of risk can be linked to the terminology, or label, that is used.

> *.. she said to me "Oh did I have a heart attack?" And I was like, oh I don't know. The words "heart attack" sounds completely different to her being in on the ward or in coronary care, having an angioplasty. And then the actual word 'heart attack' when she said it sounds completely different to, whatever happened.* *Joanne*

There are no outward signs of heart disease; no scars or open ulcers as there can be with peripheral vascular disease: no hair loss following chemotherapy and no paralysis that follows a severe stroke. The consequences of heart disease are internalised; a person has chest pain, they get short of breath, their exercise capacity is limited, they get tired, but their outward general appearance remains largely unchanged. The seriousness of the disease can be reduced in the eyes of the family, due to a lack of obvious signs, although those close acknowledge the symptoms, such as shortness of breath, which may progressively worsen over the years.

The treatment, investigations and procedures all seem to have a direct bearing on the perception of risk. For those who have lived with the diagnosis during subsequent years, the consequences of the disease process have become more prevalent as time passes. Ian's father, ten years after his initial heart attack, was diagnosed with heart failure.

> *It just started getting a little bit worse, a little bit worse, a little bit worse. He was getting a little bit thinner and a little bit thinner. And that was when apparently he had quite bad heart failure. When you look at the fact that he's 56 now, and he looks about 87. He doesn't look a well man.*
>
> *Ian*

Ian expressed his concern for the future, but also for the past, for the loss of quality years that had been denied him with his father, he grieved for the loss of his father who was once healthy and active.

Others saw the diagnosis as a warning sign and were reassured that the patient was doing the right things and were being checked regularly. They were re-assured that they were in safe hands, that people have the knowledge and skills to ensure that all the correct things had happened and will continue to happen. This is a different picture than for those who had a diagnosis twenty or thirty years ago.

> *Now he is being checked regularly and he knows he is in safe hands. 'Coz these people know what they are doing, they are clever nowadays. So it is probably good that he had that; and it was good for me and my brother as well because obviously we are one of a kind, if you like, so we can try, and do this study.* *Leo*

5.12.2 Knowledge

Relatives displayed a high degree of knowledge, both regarding the associated risk factors and how this related to themselves. They talked about the risk factors, how they have been improving their diet, or undertaking more exercise, or trying to lose weight.

> *But I have learnt that it is more as you get older. You have some sort of protection when you are younger. Women, but men not so much. But of course I am a bit more concerned because I am getting to the menopausal stage when you are not protected so much.* *Annie*

They knew about many of the reasons for getting heart disease, but they also wanted to know more in-depth details about the disease itself, the causal influences, how they can establish their own level of risk and how to prevent it. The sources of their current knowledge are varied; school classes, televisions, the internet, books and leaflets. Families share their knowledge, amongst themselves and their friends.

5.12.3 Comparisons and perceptions of risk

People made comparisons, comparing the patient to someone else in the family, to someone they knew who had had a heart attack or to themselves. They looked for and commented on both similarities and differences, where the link was made between the heart attack and the lifestyle risk factors. In this way perception of risk either for themselves or the patient were measured by looking at the risk factors. If they did not have the same risk factors as the patient then their felt that their risk of having a heart attack was reduced. Alternatively risk factors could be traded against each other: 'he smoked, but he was quite thin' or ' diet was good, but she enjoys a drink,' where a positive trait is traded against a negative one.

For others who perceived that there was no risk of a heart attack, the shock of the diagnosis was increased. Fiona illustrated her knowledge of the associated risk factors and her shock at her brother's diagnosis.

> *I was just in total shock, because he was just someone that I didn't think, I just never dreamt it would happen to him. He's not overweight, and he eats a healthy diet: he doesn't smoke or drink; and he is very active. And he was just the last person that I ever thought - -.* *Fiona*

Fiona expressed her fears, she was frightened for herself. This had happened to her brother, who had no known modifiable risk factors, and if it could happen to him, it could happen to her.

People are aware of other family traits and draw comparisons between these, for example poor eye sight. If they and the patient both had poor eyesight, they felt they were likely to have other hereditary traits, for example, heart disease. Comparisons may be drawn between the patient and the participant, where they compare the lifestyle risk factors and personal attributes of their relative to their own lifestyle and to themselves.

> *And I think I have been far worse than her and if she is that young, how young will I be. That is what is scary. I think, now being a mum you know I don't want to sacrifice anything with my son's lifestyle, I want to do whatever is possible.* *Joanne*

Joanne equated the things that she did as a teenager, to her mother's way of life, bringing the consequences of the heart disease back to herself and acknowledging that she could be at risk. The link was made into the next generation, where her son may be her main motivation for any lifestyle changes that she makes.

5.13 Summary

This chapter has descried the results of phase 1 of the study. Demographic details have been provided and an analysis of the individual experience of being diagnosed with heart disease in the family. The narrative analysis have been illustrated with relevant quotes from the participants. The diagrammatic illustrations of their CVD history gives added meaning to these personal narratives concerning the reality of living with a familial history of cardiovascular disease.

The next chapter will provide details of the results from the two year health promotion programme.

CHAPTER SIX

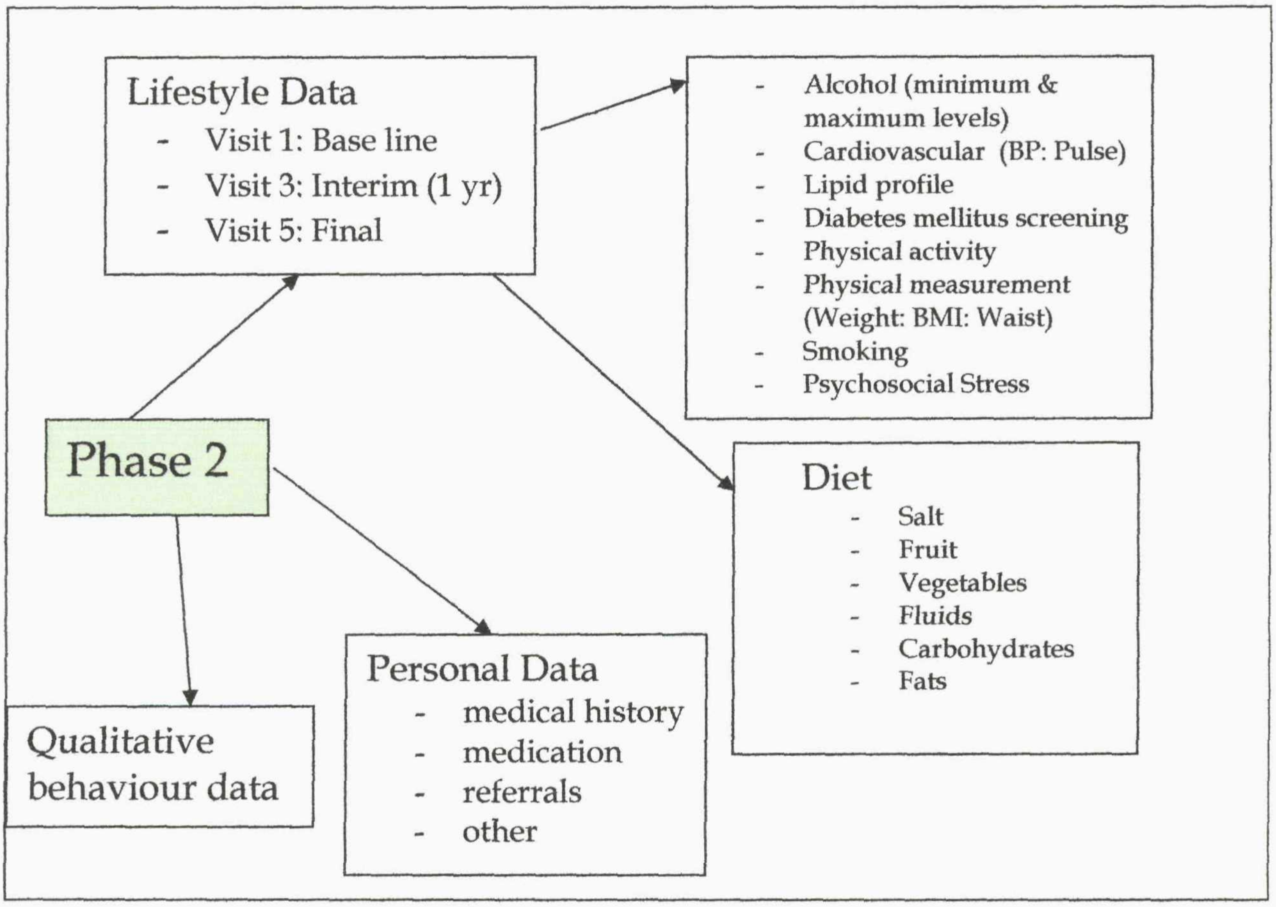
Phase 2 ~ The Health Promotion Programme

6.1 Chapter introduction

This chapter provides details of the health promotion programme, including the assessments and procedures that were conducted during the clinical sessions. Figure 6.1 gives an outline of the data which will be reported in this chapter. Retention of study participants is discussed along with information on those who did not complete the programme. The results from the cardiovascular lifestyle assessment are comprehensively covered, with a short introduction for each of these measurements. Details on data collection tools and statistical analysis are included.

This chapter addresses the second aim of the study: 'Will a two year health promotion programme result in an improved and sustained lifestyle profile?'

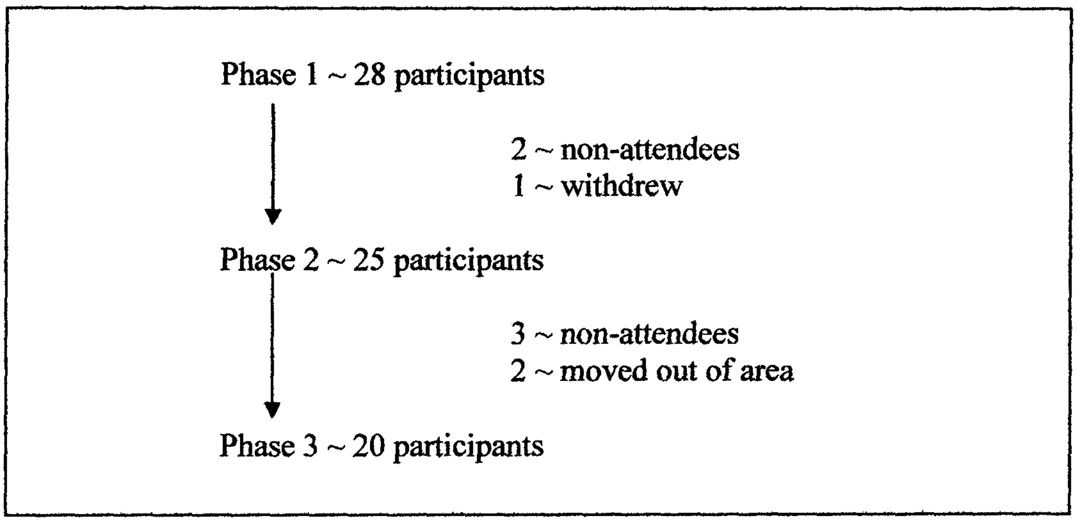
FIGURE 6.1 Phase 2 ~ study data analysis



6.2 Participant retention

Between June 2004 and August 2005, twenty-eight participants consented to participate in the research study. Full details of recruitment and demographics of this original cohort have already been discussed in the preceding chapter five. Table 6.1 provides details of participant retention in each phase of the study.

TABLE 6.1 Study retention



In summary, 28 participants were initially recruited to the study, 20 completed a minimum of two years and all three phases of the study protocol. For the people who completed the programme, according to the evaluation questionnaire, remaining in the study and attending the clinic sessions, had not been perceived as a problem.

The findings from the health promotion programme are based upon these 20 participants who completed the study.

6.3 The health promotion programme

The health promotion programme was designed to take place over two years, constituting five clinic visits every six months. The duration of each clinic visit was an hour and appointments were made at times which were suitable for the participant. Family members and partners were invited to attend the sessions, to participate in the discussion; no physical assessments or measurements were taken on these attendees.

6.3.1 Study duration

Most participants attended the programme for five visits (n=12), six participants requested additional visits. Two participants attended for yearly visits only; this was arranged between the participants and the researcher, because both participants had minimal scope for improvement in their lifestyle profiles and their knowledge regarding coronary heart disease (CHD) was good. Spouses attended the programme with five of the participants, whilst one participant came with her mother. Two of these family members attended for all the visits, two for a couple of visits and two for the initial visit only.

The length of time in the study varied. Ideally all the study visits should have occurred within 24 months; however in reality this proved difficult, and where flexibility in the research was shown, the participants still achieved the five visits. One participant spent a year in Australia: on his return he attended his final two clinical sessions, hence his duration in the study was 36 months.

6.3.2 The health promotion clinic sessions

The sessions were conducted as individual, private consultations with the nurse researcher. Prior to each session, a letter was sent to the participant confirming the date and time, and the diet and stress questionnaires (see Appendix X and XI) were included for completion prior to the visit. If fasting blood samples were required, the participants had the option of receiving the blood request form in the post and attending the hospital phlebotomy service in their own time prior to their appointment. Alternatively the researcher took the blood sample during their visit, and the results were discussed at a later time.

At each visit the medical and personal history was reviewed, and changes to prescribed and non-prescribed medication were noted. The relevant behaviour and physical assessments were done and the lifestyle assessment form (see Appendix IX) completed. This was then discussed with the participant. If there were lifestyle behavioural changes to recommend these were suggested and, if the participant was ready to make the change, further discussion and appropriate recommendations made. For some participants referrals were required. These may have been additional investigations, for example, an electrocardiogram (ECG) or referral to the smoking cessation service. Details of the sessions were written on the assessment form which included a general comment and agreed action. Copies of the form were made; the participant kept the original, one filed in their medical notes, one anonymised and used for study data collection, the fourth sent to their general practitioner (GP) with an accompanying clinic letter. Table 6.2 catalogues the details of the health promotion session.

TABLE 6.2 Health promotion programme

Session time – 1 hour

Aims

- Lifestyle Assessment: to assess individual lifestyle and cardiovascular risk
- Education: to educate regarding heart disease and associated risk factors
- Personalisation: to provide advice, support and encouragement when needed and required

Outcomes

- Choosing Health: through lifestyle options and medical care the health status for individuals can be monitored and may be improved

Time (minutes)	Activity	Resource
2	Welcome	Cardiology out-patient clinic room
2 - 10	Review personal, medical details	General assessment form
1 - 5	Review prescribed and non-prescribed medications	
5 - 10	Blood test (if required)	Phlebotomy form, blood tubes
4	Weight, height (first appointment only) and waist measurements	Scales and tape measure
4 - 8	Review and discuss current stress questionnaires; compare with previous questionnaire	Stress questionnaires
2 - 8	Discuss alcohol intake	
5 - 10	Review and discuss diet questionnaires; note any changes	Diet questionnaires
5 - 10	Discuss physical activity levels	Physical activity score
2 - 10	Access smoking status	Smoking scale
5 - 10	Cardiovascular measurements	Sphygmomanometer
5	Complete lifestyle assessment form Discuss referrals if required	Lifestyle form Referral letter / form
8 - 10	Overview of assessment form, compare with previous forms. Encourage good aspects of assessment form; support and praise any changes. Assess willingness to change, if required.	
10	In-depth discussion on specified topic	Education folder
5 - 10	Advice and support behavioural change	BHF leaflets
5	Conclude	

Post session requirements

- complete medical notes
- referrals, if required
- GP correspondence
- Phone in 5 months to make next appointment

During the first visit the specially compiled education folder was used to explain the aetiology and pathogenesis of heart disease, epidemiology and the general concept of associated risk factors. In subsequent visits, if the participant requested, specific risk factors were covered in depth. Leaflets produced by the British Heart Foundation (BHF) were given as supportive information at the end of the sessions.

6.4 Medical information

In this section, each participant's relevant cardiovascular medical history is detailed including prescribed and non-prescribed medications, illustrating how these changed during the course of the programme. Referrals made during the course of the programme are also included.

6.4.1 Medical history

None of the participants were diagnosed with clinical CHD, either before or during the programme. However, some participants had had cardiovascular or heart problems in the past, as detailed in table 6.3.

TABLE 6.3 Cardiovascular medical history

Cardiovascular	Participant details
Hypertension	2 receiving treatment for: - 2 years - 4 months
Palpitations	2 had been investigated: - age 16 - age 18
Pericarditis	Age 40 (1 participant)
Factor V Leiden	Diagnosed following a pulmonary embolism (1 participant)
Type 1 diabetes mellitus	Diagnosed age 14 years (1 participant)

Other medical history included indigestion, back problems, allergies, gout, migraine, stomach ulcer and asthma. No serious life threatening events occurred to the cohort during the study, although some were investigated, as detailed below, for cardiovascular complaints.

6.4.2 Referrals

Following each visit a clinic letter was sent to the participant's GP by the nurse researcher. Issues of concern were discussed with the consultant cardiologist and if necessary, an additional letter was sent to the GP, or the clinic letter was countersigned by the consultant, endorsing the nurse's letter. At the end of the study, when the final clinic letter was sent to the GPs, a request was made asking for feedback about their views and opinions regarding the study, and the involvement of their patient: none responded.

An electrocardiogram (ECG) was not part of the study procedures, this is a specialist activity and if an ECG was required this was classified as a referral to the cardiology department, where this procedure was carried out. At the start of the programme two participants were referred for an ECG as their family history suggested evidence of sudden cardiac death. Their ECGs were reviewed by a specialist consultant, and evidence of abnormalities on the ECG trace associated with sudden cardiac death excluded.

The majority of the investigations and referrals were carried out within the hospital's own cardiology department. One participant was referred back to his GP for investigation of chest pain. The participant did not live in the catchment area of the hospital, and could not be fully investigated within the hospital. Table 6.4 details the referrals that were made; to whom, the reason for the referral, what was requested, the reason for the referral and the outcome. In total 14 official referrals were made, although discussion concerning all participants remained ongoing between the researcher and consultant cardiologist.

TABLE 6.4 Referrals

To whom	What	Why	Outcome
Consultant	Discussion and letter	Raised cholesterol, glucose and blood pressure	Letter to GP. Anti-hypertensive and statin medication started. Glucose tolerance test performed: nothing abnormal diagnosed (NAD).
Consultant	Discussion and letter	Chest pain	Letter to GP, referral to local hospital for investigation
Consultant	Discussion and letter	Raised cholesterol	To monitor
Endocrinologist	Discussion	Need for further medication	Medication started
Cardiology	Echocardiogram	Shortness of breath, postpartum	NAD
Cardiology	24 hour tape ECG Bloods to check K+	Palpitations	NAD
Cardiology	ECG 24 hour tape	Palpitations	NAD
Cardiology	ECG Bloods to check K+	Arrhythmia	NAD
Cardiology	24 hour BP monitor	Raised blood pressure	NAD
Cardiology	ECG	Family history	NAD
Cardiology	ECG	Family history	NAD
Nurse	Blood test - fasting lipids and thyroid function	Raised cholesterol	Thyroid function NAD, cholesterol to be monitored
Practice Nurse	Dip stix urine	Nocturnal mictuition	NAD
Smoking cessation	Smoking cessation		No change

6.4.3 Medications

At the start of the study two participants were already receiving anti-hypertensive medication. By the end of the programme a further two participants were receiving anti-hypertensive medication . Cholesterol lowering statin medication was taken by one participant at the start, following his brother's recent myocardial infarction (MI). An additional four participants had been prescribed statin medication once they had reached the end of the programme. Six participants were receiving other prescribed medications in relation to their medical histories.

Non-prescribed medications varied; they were mainly vitamins, evening primrose oil, fish oil capsules and glucosomine. Four participants took a selection of these tablets throughout the study. Other 'over the counter' medications taken by participants were analgesics (n=1), medication for hay fever (n=2) and for indigestion (n=2). The remaining 11 participants did, at some time or another, take the vitamin, fish oil, evening primrose oil and glucosomine supplements, but not on a regular basis. One participant took a prophylactic aspirin tablet, but stopped this later in the programme, following advice and discussion.

6.5 Lifestyle and risk factor assessment

The assessment was carried out on nine proven modifiable risk factors (as identified in chapter two) that either increase the risk of developing cardiovascular disease or provide protection against the disease process. The participants lifestyle assessment was divided into nine sections: alcohol consumption, cardiovascular assessment, cholesterol, diabetes screen, diet, physical activity, physical measurements, smoking status, and psychosocial stress.

Following each visit the lifestyle assessments were collated onto data capture spreadsheets (for an example see Appendix XIV). From these sheets the individual improvements made by each participant can be tabulated into a single table identifying positive changes, negative changes, no change and no change required (see Appendix XV). From this sheet two tables were compiled which show the changes made associated with each risk factor (table 6.5) and the collective changes for each participant (table 6.6).

TABLE 6.5 Changes associated with individual risk factors

	Alcohol	Blood pressure	Total cholesterol	Diet	Physical activity	Weight/ Waist	Smoking	Stress
No change required	9	8	0	2	6	4	14	5
No change achieved	2	2	2	0	4	2	1	2
Positive changes	7	9	9	18	9	8	3	9
Negative changes	2	1	9	0	1	6	2	4

From table 6.5 it is evident that smoking was the behaviour which required the least change. Diet was the behaviour which achieved most positive changes, conversely total cholesterol is the measurement which had the most negative changes.

TABLE 6.6 Changes associated with each participant

Participant	No change required	No change achieved	Positive changes	Negative changes
1	3	0	5	0
2	2	1	5	0
3	3	0	4	1
4	3	0	4	1
5	4	1	3	0
6	4	0	3	1
7	3	0	4	1
8	4	0	4	0
9	3	1	2	2
10	1	0	6	1
11	2	2	3	1
12	2	1	2	3
13	0	2	2	4
14	1	2	2	3
15	1	0	7	0
16	2	2	3	1
17	1	2	4	1
18	1	1	4	2
19	2	0	5	1
20	6	0	0	2
TOTALS	48	15	72	25

The participants did not need to make changes in 48 aspects of their lifestyle assessment. After two years in the health promotion programme positive changes had been achieved in 73 lifestyle areas. These changes may, for some people, only have been small, but as recommended by the Government initiative 'Small changes, big difference,' (DH 2006b) which is based upon the research of Professor Khaw (Khaw et al., 2008) these small, but combined, changes can result in substantial long-term health improvements.

The next section will provide an overview of each lifestyle factor, the method of assessment and the statistical results from the participants profile are detailed below. Statistical data are shown for the baseline visit 1, visit 3 after one year and visit 5 at the end of study. The analysis has been conducted for visit five, with an interim analysis at visit 3.

6.6 Alcohol consumption

Epidemiological studies have shown that low to moderate levels of alcohol consumption are protective, where non-drinkers and heavy drinkers have higher all-cause mortality rates. The relationship between alcohol consumption and all-cause mortality is depicted as a J-shaped curve, reflecting the reduced risk of CHD at low and moderate consumption and increased risk of some cancers, cirrhosis and injuries at high levels of consumption (Di Castelnouvo et al., 2002; White et al., 2002). A meta-analysis, looking at the evidence associated with wine and beer intake with vascular risk, showed a 32% risk reduction associated with drinking wine, and a lower, but still significant, risk reduction associated with beer consumption (Di Castelnouvo et al., 2002). The authors (Di Castelnouvo et al., 2002) demonstrated benefit of low alcohol consumption were greater in women than men; this could be explained because consumption was less. This is an important consideration when safe levels of alcohol consumption vary with age and sex (White et al., 2002). In order to maintain the reduced all-cause mortality associated with alcohol, research shows that women should limit their drinking to 1 unit a day up to age 44, 2 units a day up to age 74 and 3 units a day over age 75. Men should drink 1 unit a day up to age 34, 2 units a day up to age 44, 3 units a day up to age 54, 4 units up to age 84 and 5 units over age 85 (White et al., 2002). Despite this recommendation, the British Heart Foundation (BHF) report that alcohol consumption is highest in young people (Allender et al., 2007). This is illustrated in the BHF statistics for 2005 which show that 43% of men and 36% of women, aged 16 to 24, drank more than the United Kingdom (UK) Government's recommended level, and 30% of men and 22% of women in this age group drank heavily on at least one day a week (Allender et al., 2007).

The current UK recommendation for alcohol consumption is 1 - 3 units a day, not exceeding 21 units a week for men and 14 units a week for women (Woods et al., 2005; BHF 2007; DH 2007b), where 1 unit of alcohol is equivalent to a small (125ml) glass of wine, half a pint of normal strength lager, cider or beer or a single pub measure (BHF 2007). The British Heart Foundation state that men should not drink more than 3 - 4 units of alcohol a day and women should not drink more than 2 - 3 units a day. According to the government review, 'The next steps in the National Alcohol Strategy - a summary' (DH 2007b), recommended daily units of alcohol consumption should be published on bottle labels.

The protective effect of alcohol is due to the changes it has upon lipids and haemostatic factors. Alcohol increases high density lipoproteins (HDLs) which helps to remove excess, atherogenic low density lipoproteins (LDLs) from the peripheral cells and return them to the liver for metabolism (Rimm et al., 1999). Alcohol also reduces thrombotic tendency, through reduction of platelet aggregation and reduced fibrinogen level, making the blood less likely to form clots (Rimm et al., 1999).

Excess alcohol results in increased risk of some cancers, including oesophagus, colon, liver and breast cancers, essential hypertension, gastric and duodenal ulcers, haemorrhagic and ischaemic strokes, and injuries, (especially in the young) (White et al., 2002). High levels of alcohol also result in obesity, as it is a source of excess calories, raised triglycerides, sexual impotence, impaired brain and nerve function, permanent liver damage, kidney problems and alcohol intolerance (Cutting 2001). High levels of alcohol intake and binge drinking can cause abnormal heart rhythms and dilated cardiomyopathy (BHF 2007).

- **Measurement and assessment methods**

Alcohol consumption was assessed through participants recall and self reporting, along with discussion with the researcher to ascertain the number of units. The assessment sheet noted the minimum and maximum units consumed and a descriptor, which included information on the type of alcohol, occasions it was consumed and number of days per week.

This method of assessment relied upon accurate recall and honesty from the participant. A high alcohol intake can correlate with a high triglyceride blood sample value, providing a degree of cross referencing. In the statistical analysis there was no correlation found between maximum alcohol intake and triglyceride measurements. However, evidence of reduced triglyceride is seen with lower alcohol consumption in some individual assessments (note the outlier in figure 6.2).

- **Participant details and findings**

Non-drinkers were not encouraged to consume alcohol; this might have been contrary to religious, cultural or personal beliefs and preferences. Moderate drinkers were informed about the benefits of low and moderate alcohol intake, those with high levels of alcohol consumption were advised of the harmful effects of alcohol and suggested they should reduce their levels of consumption. Those who consumed alcohol infrequently, but when they did their intake was excessively high, were educated about the effects of 'binge' drinking.

Seven male participants at the start of the study exceeded the current recommended weekly units of alcohol, whilst none of the females drank more than the recommended weekly quantity. The level of alcohol consumption was varied as shown by the statistics. The analysis show how the range and mean levels of alcohol consumption for the cohort were reduced over the five visits of the programme, and half way through the programme at visit three.

Table 6.7 provides the statistics for the weekly minimum and maximum levels of alcohol consumed by the cohort for visits one, three and five. The boxplot (figure 6.2) graphically illustrates the interquartile ranges and outliers, for visits one, three and five for the minimum level of alcohol intake for the cohort.

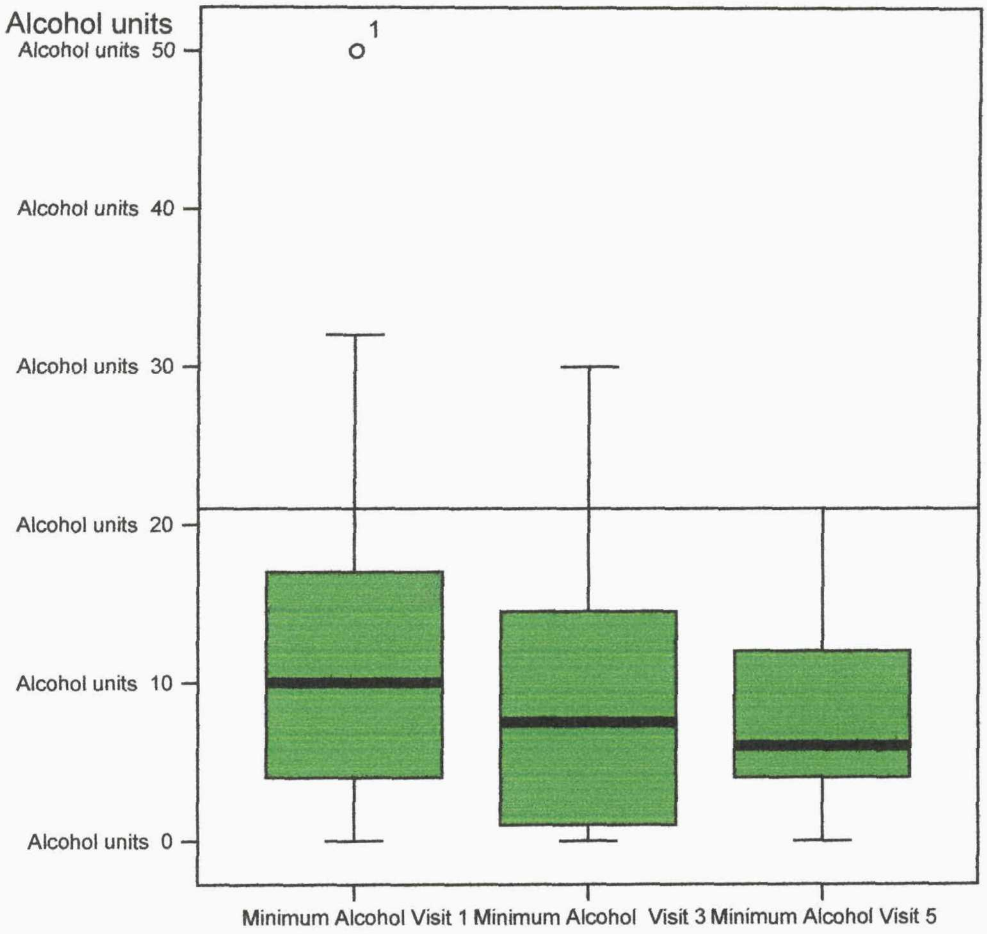
TABLE 6.7 Statistics for minimum and maximum alcohol consumption

		Minimum Alcohol Visit 1	Minimum Alcohol Visit 3	Minimum Alcohol Visit 5	Maxi Alcohol Visit 1	Maxi Alcohol Visit 3	Maxi Alcohol Visit 5
N	Valid	20	20	20	20	20	20
	Missing	0	0	0	0	0	0
Mean		12.90	8.90	7.75	20.95	17.60	17.50
Std. Deviation		12.736	8.239	6.439	17.494	13.481	12.133
Minimum		0	0	0	0	2	0
Maximum		50	30	21	67	60	40

Mean minimum alcohol levels decreased from 12.90 to 8.90 during year one and a further, but smaller decrease to 7.75 for year two. The range for the cohort reduced from 50 units, to 30 units to 21 units. These results are reflected in the decrease in the size of the standard deviation which has reduced from 12.736, to 8.239 to 6.439 respectively.

During the programme there was a steady decrease in the weekly minimum quantity of alcohol consumed. By visit 5 no participants minimum quantity exceeded the recommended level of 21 units.

FIGURE 6.2 Boxplot for minimum quantity of weekly alcohol consumption for visits 1, 3 and 5



Mean maximum levels of alcohol consumption reduced from 20.95 at the initial visit to 17.60 at visit 3, to 17.50 at visit 5. The maximum levels show a steady decrease during the 5 visits, from 67 units at visit 1, to 60 units at visit 3, to 40 units at visit 5. The maximum level at visit 5 is reduced but the mean between these two visits only decreased by 0.10.

To test the significance of the finding paired sample t-test was done. A one-sample Kolmogorov-Smirnov test was done which proved a normal distribution. Parametric testing was therefore appropriate and table 6.8 provides details of the paired-samples t-test. On average, the cohort achieved significantly lower levels of minimum alcohol intake during the health promotion programme than at the start of the programme (M=12.90, SE=2.85). This was first seen half way through the programme (M=8.90, SE=1.84) and sustained a year later (M=7.75, SE=1.44, t (19) = 2.15, p = 0.02), with a 95% confidence interval of (0.14 to 10.16), representing a good sized effect r = 0.44.

Maximum levels of alcohol intake at the start of the study (M=20.95, SE=3.91) were reduced at the end of the first year (M=17.60, SE=3.01) and maintained after two years (M=17.50, SE=2.71). This difference was not significant (t (19)=1.54, p=0.07) with a 95% confidence interval of (-1.24 to 8.14); however, it did represent a medium sized effect r=0.33.

Table 6.8 details the results of the data for which parametric *t* - testing was used.

TABLE 6.8 Paired-sample *t*-test results

Paired Samples	Paired Differences			*t*	df	Sig. (1-tailed)
	Mean Difference	95% Confidence Interval of the Difference				
		Lower	Upper			
Minimum alcohol visit 1 Minimum alcohol visit 3	4.00	.13	7.86	2.17	19	0.02
Minimum alcohol visit 1 Minimum alcohol visit 5	5.15	.143	10.16	2.1	19	0.02
Maximum alcohol visit 1 Maximum alcohol visit 3	3.35	-1.41	8.11	1.47	19	0.07
Maximum alcohol visit 1 Maximum alcohol visit 5	3.45	-1.24	8.14	1.54	19	0.07
Systolic BP V1 Systolic BP V3	5.00	-1.02	11.02	1.74	19	0.05
Systolic BP V1 Systolic BP V5	7.45	.99	13.91	2.41	19	0.01
Diastolic BP V1 Diastolic BP V3	3.70	-1.55	8.95	1.48	19	0.08
Diastolic BP V1 Diastolic BP V5	4.00	-.51	8.51	1.85	19	0.04
Male Waist measurement V1 Waist measurement V3	-.11	-2.69	2.45	-.10	12	.46
Male Waist measurement V1 Waist measurement V5	.04	-2.68	2.76	.03	12	.49
Female Waist measurement V1 Waist measurement V3	-.67	-3.03	1.70	-.72	5	.25
Female Waist measurement V1 Waist measurement V5	-.67	-3.53	2.20	-.60	5	.29
Total cholesterol V1 Total cholesterol V5	-.06	-.54	.41	-.29	19	.39
LDL cholesterol V1 LDL cholesterol V5	-.18	-.63	.27	-.84	19	.25
Triglycerides V1 Triglycerides V5	.11	-.29	.51	.58	19	.28
HDL cholesterol V1 HDL cholesterol V5	.08	-.012	.17	1.81	19	.04

6.7 Cardiovascular Measurements

Blood pressure is defined as the force exerted on the wall of a blood vessel by the blood it contains (Marieb 2006). The upper systolic reading represents the maximum force of blood against a vessel wall, following ventricular contraction. The lower diastolic reading is the minimum force of blood against a vessel wall, following closure of the aortic semi-lunar value inside the heart. According to the British Association for Hypertension Guidelines (Williams et al., 2004),the optimal blood pressure should be less than or equal to 120mmHg systolic and 80mmHg diastolic; while normal blood pressure is considered to be 130mmHg systolic with a high normal up to 139 mmHg. The normal diastolic should ideally be less than 85mmHg with a high normal reading of 89mmHg. Hypertension is then graded 1 ,2 and 3 accordingly; grade 1 hypertension 140-159/90-99 mmHg, grade 2 hypertension 160-179/99- 109 mmHg and grade 3 hypertension > 180/110 mmHg.

Hypertension is not a disease, or illness, but without treatment can lead to cardiovascular diseases, including heart failure, angina and left ventricular hypertrophy, cerebral infarction and haemorrhage, plus kidney failure, blindness, and peripheral vascular disease (Kaplan, 1997). The UK figures for 2005 show that 35% of men and 28% of women have hypertension; however only 41% of men and 66% of women were receiving treatment, of which 50% were successful in controlling the high blood pressure (Allender et al., 2007). These figure are an improvement from those published by the BHF (2004) coronary heart disease statistics, which stated that 37% of men and 34% of women had hypertension, with only 20% and 30% respectively receiving treatment (Petersen et al., 2004). For 95% of those diagnosed with hypertension there is no specific underlying cause; the remaining 5% have secondary hypertension which may be caused by renal and endocrine diseases, or through pregnancy, raised intracranial pressure or drug induced (Beevers et al., 2001). The risk of cardiovascular disease doubles for every 10mmHg increase in diastolic blood pressure or every 20mmHg increase in systolic blood pressure (Prospective Studies Collaboration, 2002). Reducing blood pressure reduces cardiovascular risk. Management and treatment for hypertension involves both medication and lifestyle changes.

Heart rate is taken to ensure that the heart is beating regularly and is neither tachycardic (more than 100 beats per minute) or severely bradycardic (less than 40 beats per minute). If these finding were abnormal it might indicate an electrical conduction problem which would require further investigation. Heart rate is measured by feeling a person's pulse. The pulse is felt as a pressure wave of blood as it causes the artery to recoil and expand in concordance with the contraction and relaxation of the heart muscle. Each pulse beat felt represents a cardiac cycle.

- **Measurement and assessment methods**

Blood pressure was measured after the participant had been sitting comfortably for a minimum of 20 minutes. It was measured on the left arm using a calibrated sphygmomanometer. If there was any doubt about the reading this was re-checked either immediately or after a further ten minute rest. All blood pressure and pulse measurements were taken by the researcher; for most of the visits the same machine was used. Heart rate was measured by feeling the peripheral pulse of the radial artery, counted for 60 seconds.

- **Participants measurements and findings**

At the start of the programme two participants were receiving anti-hypertensive medication. For one participant this was new medication which he had difficulty remembering to take daily. At the end of the programme four participants were prescribed anti-hypertensive medication; all were compliant with their treatments.

For one participant her blood pressure readings were consistently high. A clinical diagnosis of hypertension is not made on a single measurement; the patients' blood pressure is monitored over a period of time before a diagnosis is confirmed. The 24 hour blood pressure recording indicated that for the majority of the 24 hours she was normatensive. However, as her blood pressure was measurable at these high levels, it was likely that in the future treatment for hypertension would be required.

6.7.1 Pulse findings

Participant's pulse readings were between the required range of 40 to 80 beats per minute, with a mean value of 66 beats per minute for visits 1, 3 and 5. Those at less than 60 beats per minute would indicate an enhanced level of physical fitness. None of the recordings required intervention or change, so no further statistical analysis is necessary.

6.7.2 Blood pressure findings

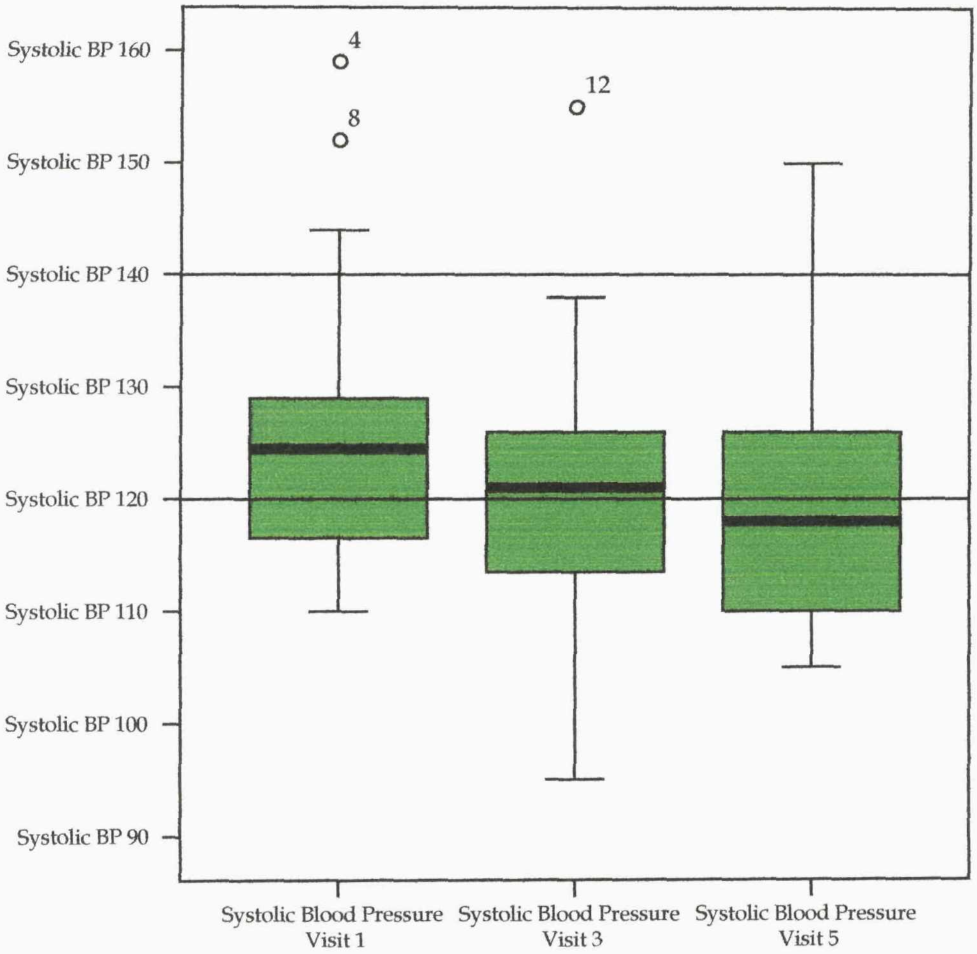
Tables 6.9 tabulate the descriptive statistics for the systolic blood pressure readings for visits 1, 3 and 5.

TABLE 6.9 Descriptive statistics for systolic and diastolic blood pressure recordings

		Systolic Blood Pressure Visit 1	Systolic Blood Pressure Visit 3	Systolic Blood Pressure Visit 5	Diastolic Blood Pressure Visit 1	Diastolic Blood Pressure Visit 3	Diastolic Blood Pressure Visit 5
N	Valid	20	20	20	20	20	20
	Missing	0	0	0	0	0	0
Mean		126.20	121.20	118.75	81.15	77.45	77.15
Std. Deviation		12.862	12.297	10.872	7.278	8.876	7.929
Minimum		110	95	105	70	65	62
Maximum		159	155	150	100	92	94

Figures 6.3 and 6.4 illustrate these findings with the use of boxplots. The outliers for visits 1 and 3 are clearly shown and the reduction of systolic pressure, so that the mean value of the cohort lies below 120mmHg. There is one participant, as discussed above, whose systolic blood pressure remains above the required maximum level of 140 mmHg.

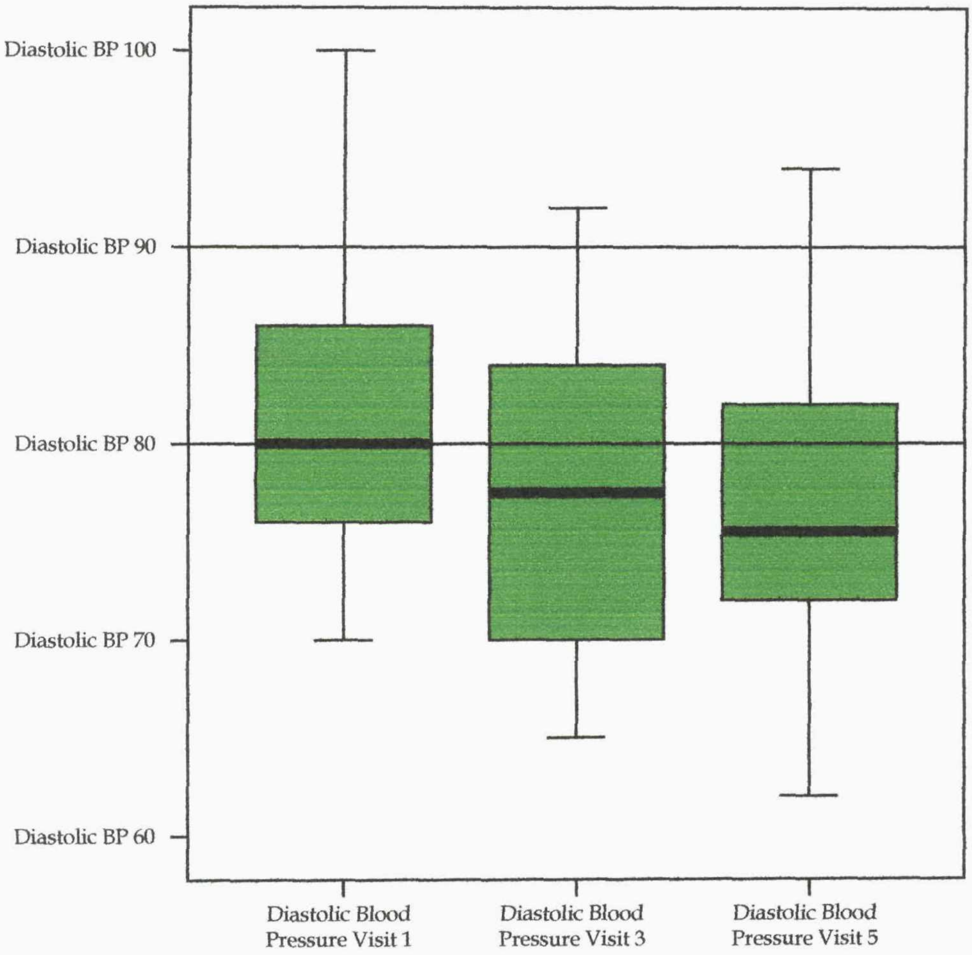
FIGURE 6.3 Boxplot for systolic blood pressure measurements



On average, participants' systolic blood pressure at the start of the study (M = 126.20, SE = 2.88) was reduced by visit 3 (M = 121.20, SE = 2.75), and further reduced after two years (M = 118.75, SE = 2.43). The difference for both of these results is significant, at visit 3 (*t* (19) = 1.74, p = 0.04) with a 95% confidence interval of (-1.02 - 11.02) although representing a medium sized effect *r* = 0.37; at visit 5 the results remain significant (*t* (19) = 2.41, p = 0.01) with a 95% confidence interval of (0.99 - 13.91) and an improved sized effect *r* = 0.48.

Figure 6.4 illustrates the findings from the diastolic blood pressure measurements. There is an overall reduction and improvement in the diastolic measurements for the cohort as illustrated.

FIGURE 6.4 Boxplot for diastolic blood pressure measurements



On average, participants' diastolic blood pressure at the start of the study (M = 81.15, SE = 1.63) was reduced by visit 3 (M = 77.45, SE = 1.98), and further reduced after two years (M = 77.15, SE = 1.77). The results for visit 1 and 3 is not significant (*t* (19) = 1.48, p = 0.07) with a 95% confidence interval of (-1.55 - 8.95) although representing a medium sized effect *r* = 0.32. By the end of the programme the results are significant (*t* (19) = 1.85, p = 0.02) with a 95% confidence interval of (-0.51 - 8.51) and again a medium sized effect *r* = 0.39.

6.8 Lipid Profile and Cholesterol

High concentrations of plasma cholesterol are closely associated with the development of atherosclerosis along with high levels of low density lipoproteins, and low levels of high density lipoproteins, while hypertriglyceridaemia is associated with a high risk of cardiovascular manifestations (Mancini 2002). In the UK, it is estimated that approximately 45% of all CHD cases for men and 47% of all CHD cases for women are attributable to raised cholesterol (McPherson et al., 2002), making it the single most important risk factor for CHD.

The lipid profile gives important information concerning the total plasma cholesterol, level of triglycerides along with high density lipoprotein (HDL) cholesterol and low density lipoprotein (LDL) cholesterol. There is currently controversy regarding the target level for cholesterol measurements. The JBS2: guidelines (Wood et al., 2005) suggest the following figures:

- total cholesterol < 4.0mmol/L
- LDL cholesterol < 2.0mmom/L
- total to HDL cholesterol ratio of ≥ 6.0 (this is identified as a particularly elevated single risk factor requiring CVD prevention (Wood et al., 2005).

However the official target as recommended by the CHD National Service Framework (NSF) (DH 2000) is that:

- total cholesterol < 5.0mmol/L
- LDL cholesterol < 3.0mmom/L.

HDL cholesterol and triglycerides are important, but target figures for these are not given in the guidelines as they are seen as markers for cardiovascular risk (De Backer et al., 2004). For a low cardiovascular risk lipid profile, both total and LDL cholesterol measurements should be low while HDL cholesterol is considered cardioprotective, so should be high.

The CHD NSF (DH 2000) gives clear guidelines on total cholesterol levels for people with a family history of premature CHD. If total cholesterol is less than 5 mmol/L reassurance should be given and the test repeated in five years. If cholesterol is 5 - 7.9 mmol/L and there is no evidence of arterial disease, dietary advice is given and the test repeated in three months; if after three months it is still raised there should be a decision to treat based on cardiovascular risk. If the total cholesterol is over 8mmol/L it should be repeated in a month and if still raised then treatment should be given (DH 2000).

According to the National Heart Forum if everyone reduced their cholesterol level to less than 5.0mmol/L this would result in a 53 - 55% percentage reduction in CHD cases and deaths across the UK population, while a 0.6mmol/L overall reduction would result in a 9.2% reduction in CHD cases for men and a 9.7% reduction for women (McPherson et al., 2002).

- **Measurement and assessment methods**

A fasting lipid blood test, to measure total, LDL and HDL cholesterols and triglyceride were taken from each participant yearly. A vacutainer was used to collect a 8ml venous blood sample; all samples were analysised in the accredited Trusts' laboratory.

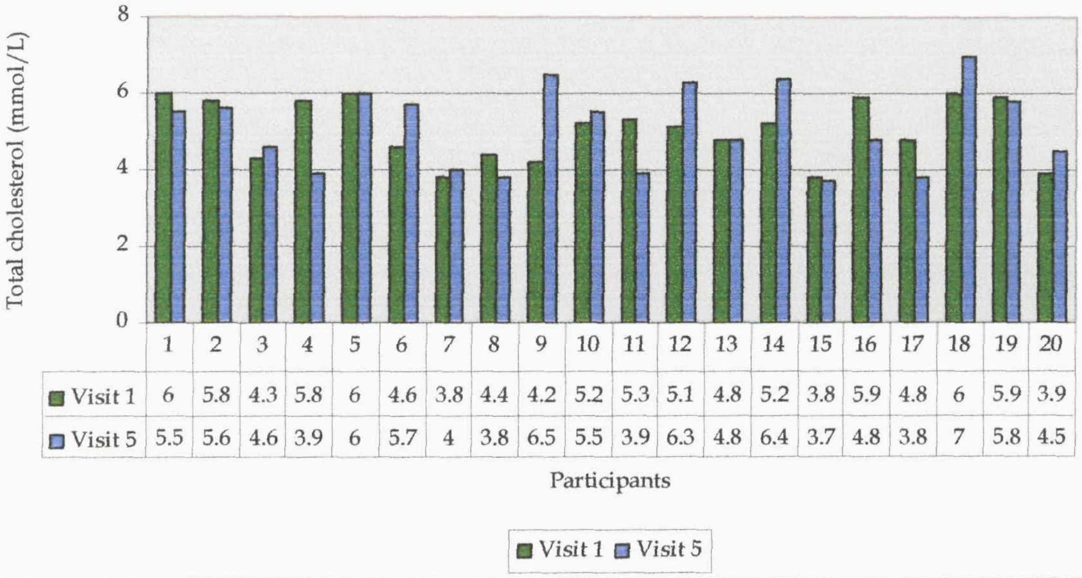
Before the blood sample was taken, participants were advised to eat a light supper, and consume no alcohol, the evening before. A meal high in fat can affect serum lipid levels, and alcohol can affect triglyceride levels. A fasting sample was needed to acquire an accurate lipid profile, but meant that they could consume only water for 12 hours before the blood test.

- **Participants measurements and findings**

Five sets of results are discussed, including total cholesterol, triglyceride, LDL, HDL and total cholesterol to HDL ratio. The graphs which illustrate these results are seen in Appendix XVI.

At the start of the programme, 11 participants total cholesterol value was above the government's recommended value of 5.00mmol/L. During the course of the programme ten participants total cholesterol had shown an improvement, eight participants had worsened and two had remained the same.

Figure 6.5 Total cholesterol measurements



At the start of the programme three participants triglyceride measurement was above the upper limit of normal (2.00mmol/L). At the end of the programme this had been reduced to two participants. During the course of the programme six participants triglycerides had improved, 13 had worsened and one had remained the same.

At the start of the programme seven participants LDL cholesterol was above the upper limit of normal (3.40mmol/L); for one participant the high triglyceride made it impossible to obtain a LDL cholesterol. By the end of the programme there were nine participants whose LDL cholesterol was above the upper limit of normal. During the course of the programme 13 participants LDL cholesterol had increased, six had decreased, and one had remained unchanged.

At the start of the programme all the female participants (n=7) had a HDL cholesterol reading above the lower limit of normal (1.30mmol/L). At the end of the programme this had reduced to four female participants. At the start of the programme, 12 of the male participants had a HDL cholesterol reading above the lower limit of normal (1.00mmol/L). By the end of the programme this had reduced to 11 participants. During the course of the programme three participants increased their HDL cholesterol, 16 decreased their value and one remained unchanged.

During the course of the programme, seven participants improved their cholesterol ratio, while for 13 participants their total cholesterol to HDL ratio worsened. At the start of the study none had a ratio of equal to or above 6.0, at the end of the programme three participants had a ratio ≥ 6.0.

The statistical details of these results are summarized in table 6.11. None of these results are statistically significant as detailed in table 6.8; note that the effect upon the variable for HDL decrease and ratio increase is in the wrong direction, where the *t*-test appears significant.

TABLE 6.10 Descriptive statistics for cholesterol measurements

		N	Mean	Std. Deviation	Minimum	Maximum
Total Cholesterol	**V1**	20	5.04	0.79	3.8	6.0
	V5	20	5.10	1.05	3.7	7.0
Triglycerides	**V1**	20	1.59	0.97	0.49	4.92
	V5	20	1.48	1.04	0.47	4.23
LDL cholesterol	**V1**	19	3.00	0.67	1.93	3.95
	V5	20	3.16	0.95	1.93	4.89
HDL cholesterol	**V1**	20	1.37	0.20	0.85	1.77
	V5	20	1.29	0.28	0.79	1.99
Cholesterol ratio	**V1**	20	3.71	0.62	2.5	5.0
	V5	20	4.13	1.25	2.4	6.6

6.9 Diabetes mellitus screen

The World Health Organisation (WHO) define diabetes mellitus as a chronic disease which occurs when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin it produces, which leads to an increased concentration of glucose in the blood (WHO 2006). Type 1 (characterised by a lack of insulin production) and type 2 diabetes mellitus are associated with an increased cardiovascular risk (Wood et al., 2005). Type 2 diabetes mellitus, caused by the body's ineffective use of insulin (WHO 2006), is a major public health problem world-wide (Rayner et al., 2001: Mackay & Mensah, 2004; Petersen et al., 2004); in the UK the number of people with type 2 diabetes mellitus is 1.4 million, yet studies have shown that there are one million people who do not know they have it, and by 2010 it is estimated that there will be 3 million people with diabetes in the UK (Rayner et al., 2001; Barnett & O'Gara, 2003).

Diabetes mellitus is a debilitating disease because of its long term vascular complications, which are divided into two areas, macro-vascular and micro-vascular disease (Barnett & O'Gara, 2003). When diagnosed, more than 25% of people will already have evidence of cardiovascular disease (Rayner et al., 2001); consequently diabetes is treated as a cardiovascular disease. For those with diabetes mellitus, their CHD risk is double that of the general population (Barnett & O'Gara, 2003). Early detection of diabetes mellitus is vital, especially in a vulnerable population, and prevention by adopting a healthy lifestyle is integral (Gimenez-Perez et al., 2000), having the potential to prevent at least two thirds of the cases of type 2 diabetes (Rayner et al, 2001).

- **Measurement and assessment methods**

To detect and diagnosis diabetes mellitus a fasting blood glucose test is done. A normal glucose reading should be less than 6.0mmol/L (Jarvis & Rubin, 2003). All participants had a fasting blood glucose test at the beginning and end of the programme. The 3ml sample of venous blood was collected in the required vacutainer and analysised in the Trusts' accredited laboratory. No food or drink was allowed 12 hours before the test.

- **Participants measurements and findings**

The results show that 18 participants all had their results less than 6.0mmol/L; one person had type 1 diabetes mellitus; one participant's blood glucose was raised at the start of the programme, 6.4mmol/L and reduced to 6.1mmol/L by visit 5. This had been closely monitored during the programme and investigated with a glucose tolerance test. The participant was given dietary advice to reduce intake of refined sugars. Monitoring for the future for this participant would be necessary, but no further medical management or intervention was required by the end of the programme.

6.10 Diet

Diet plays a substantial role in the risk associated with CHD and (Krombout et al., 2002; Yancy et al., 2003; Chahoud et al., 2004), adherence to a healthy diet can significantly improve cardiovascular risk (Lichtenstein et al., 2006). Some of the recommendations for a healthy diet include the following:

- eat oily fish at least once a week
- limit salt consumption
- eat five portions of fruit and vegetables daily

(Krombout et al., 2002; BHF 2003; De Backer et al., 2003; Lichtenstein et al., 2006)

- **Measurement and assessment methods**

A comprehensive diet questionnaire was developed for the study, building upon the diet questionnaire which was already in use within the Trust for the secondary prevention clinics. A substantial amount of the data was collated onto spreadsheets and divided into categories which comprised the following; general information, fruit and vegetables, dairy products, sugars and fat, proteins and carbohydrates. Only a limited amount of this data will be reported.

- **Participants measurements and findings**

The questionnaire was completed at each visit and details discussed with reference to previous questionnaires. Emphasis was given to eating at least 5 portions of fruit and vegetables daily, and to restricting animal fats, sweets, chocolates, processed foods and cakes, in the diet. Recommendations were made regarding eating food at home and away from home, as take-aways or in restaurants, so that a consistently healthy diet could be achieved.

- **General overview**

None of the participants were vegetarians or vegans. Two had special dietary requirements; one had an intolerance to dairy produce and one had type 1 diabetes mellitus. Four had food allergies, including allergies to stoned fruit and nuts, prawns and wheat. At the start of the programme, five participants did not make a conscious effort to eat healthily; at the end of the programme 19 participants made a conscious effort to ensure that their diet was healthy. At the start of the programme, 16 people thought their diet was already healthy, but by the end of the programme this had increased to 18 people.

Eighteen participants said they had a say in the food shopping, although this activity was done by their partners (n=7), their mothers (n=3), themselves (n=6), or was a shared activity done by both themselves and their partners (n=4). Similarly eighteen participants said that they had a say in the cooking, although again this activity was shared. At the start of the programme, 13 people said they enjoyed cooking and 17 were happy to try out new recipes; by the end of the programme this had increased to 15 and 19 respectively. It is important when discussing diet that those responsible for the food shopping are involved, and that people are prepared to try out new recipes in order to change dietary habits.

The Department of Health (DH) 2005 publication 'Choosing a Better Diet: A food and health action plan,' set out six dietary objectives for England relating to consumption of fruit and vegetables, fibre, salt, saturated fat and sugar. These dietary factors are discussed in relation to this cohort, for charts related to these findings see Appendix XVII.

- **Fruit and Vegetables**

Vegetable and salad consumption did increase during the two years; everyone ate vegetables at least 2 to 3 times a week, and seven people ate them daily. Salad consumption over the weekly period did not change. Fresh fruit consumption increased overall with 12 people having fruit daily. One participant was unable to eat fruit as it caused acute indigestion.

- **Dairy**

Dairy consumption in the form of butter, cream and cheese was limited. Cream was consumed weekly by two people at the start and end of the programme. Spread was used instead of butter, although the use of spread decreased as alternatives were used. Cheese was consumed either weekly (n=8) or 2 to 3 times a week (n=9).

- **Fish**

Fish was consumed at least weekly by most people (n=17), however no changes were recorded during the programme.

- **Confectionary, chocolates, cakes and biscuits**

During the programme confectionary consumption (which was low at the start) and chocolate, along with biscuits and cake consumption, were all decreased.

- **Milk and fluids**

Consumption of milk and fluids varied little over the two years. One person used full-fat milk, most (n=12) used semi-skimmed or skimmed milk (n=6). The type of fluid which was most regularly drank during the day was water (n=15).

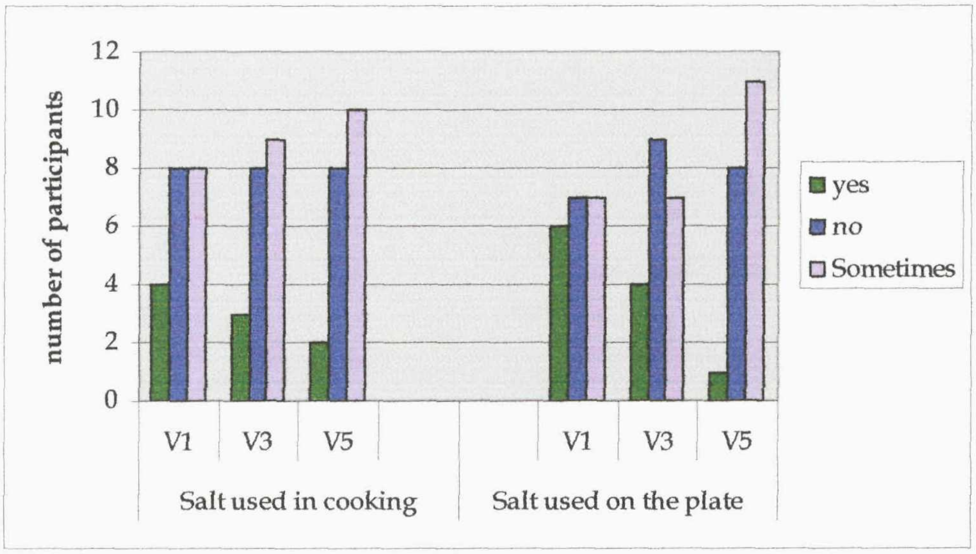
- **Fibre**

There was a reduction in white bread used and an increase in wholemeal bread.

- **Salt**

There were changes in the use of salt. People were encouraged not to add salt to the food on their plate; if required they were advised to add it in their cooking, where less salt is used and required to enhance flavours. The use of alternatives such as herbs and spices were encouraged as flavour enhancers. Figure 6.6 illustrates the change of salt usage. Many people still used salt occasionally on specific items, such as chips. Small changes were seen in the use of ready made meals and take-aways, which can both be high in processed sugars and salt.

FIGURE 6.6 Use of salt



Dietary changes are difficult to accurately quantify when people make small incremental changes over time. For example, eating an extra portion of fruit; experimenting with different vegetables, and adding vegetables to dishes such as casseroles so that they are integrated with the cooking rather than a separate item;

having one biscuit instead of three; using balsamic vinegar instead of mayonnaise; using wholemeal bread not white. The written assessment reports showed that 18 people made positive changes to their diet, two people already had excellent dietary habits which required no change.

6.11 Physical activity

For people who engage in sports and exercise regimes, the reduction of CHD risk is between 30 and 80% (Morris et al., 1980; Myers 2003). The British Regional Heart Study showed that men who were moderately to vigorously active had a 50% reduction in the risk of heart attack compared with men who were inactive (Shaper & Wannamethee, 1991). The Government recommendations for physical activity levels are to undertake a minimum of 30 minutes of at least moderate intensity activity (such as brisk walking, cycling or climbing the stairs) on at least five days a week (DH 2004b). The emphasis was on encouraging physical activity not attending formalised exercise sessions (Wrigley & Pakrashi, 2006). Currently in the UK only 37% of men and 24% of women are sufficiently active to gain any health benefits from their physical activity (DH 2004b), while 30% of the British adult population are classified as inactive, where they undertake less than one episode of 30 minute activity once a week (Petersen et al., 2004).

- **Measurement and assessment methods**

The current grading used in primary care to access and measure physical activity was inadequate for the purpose of the research study as it only provides five grades for exercise and does not take into account work and daytime activity levels. A physical activity score was developed which categorised peoples' ability to be physically active and provides two measures for their physical activity, work/daytime activity and leisure activities. There are seven grades for each measure which are based on duration and frequency (see Appendix XVIII). These scores provide a measure for a person's weekly physical activity levels, scoring between zero and 14.

Participants were asked about both their day time and leisure activities; these were documented and scored using the physical activity score. Participants who were inactive at work or generally during the day were encouraged to undertake physical activity in their leisure time. For those who were active during the day or with their work, they were encouraged regarding cardiovascular exercise. The emphasis was upon increasing physical activity, not attending exercise classes, and that the activity needed to be enjoyable in order to be sustainable. For example, one participant took up jive dancing classes with her husband.

- **Participants measurements and findings**

On average during the course of the programme participants increased their overall physical activity; after the first visit (M= 6.05, SE=0.41) there was an initial decrease (M=5.95, SE=0.46) which had improved by the end of the programme (M=6.80, SE=0.36). The boxplot graph diagrammatically illustrates these finding and table 6.11 tabulates the descriptive statistical details.

FIGURE 6.7 Boxplot of physical activity scores

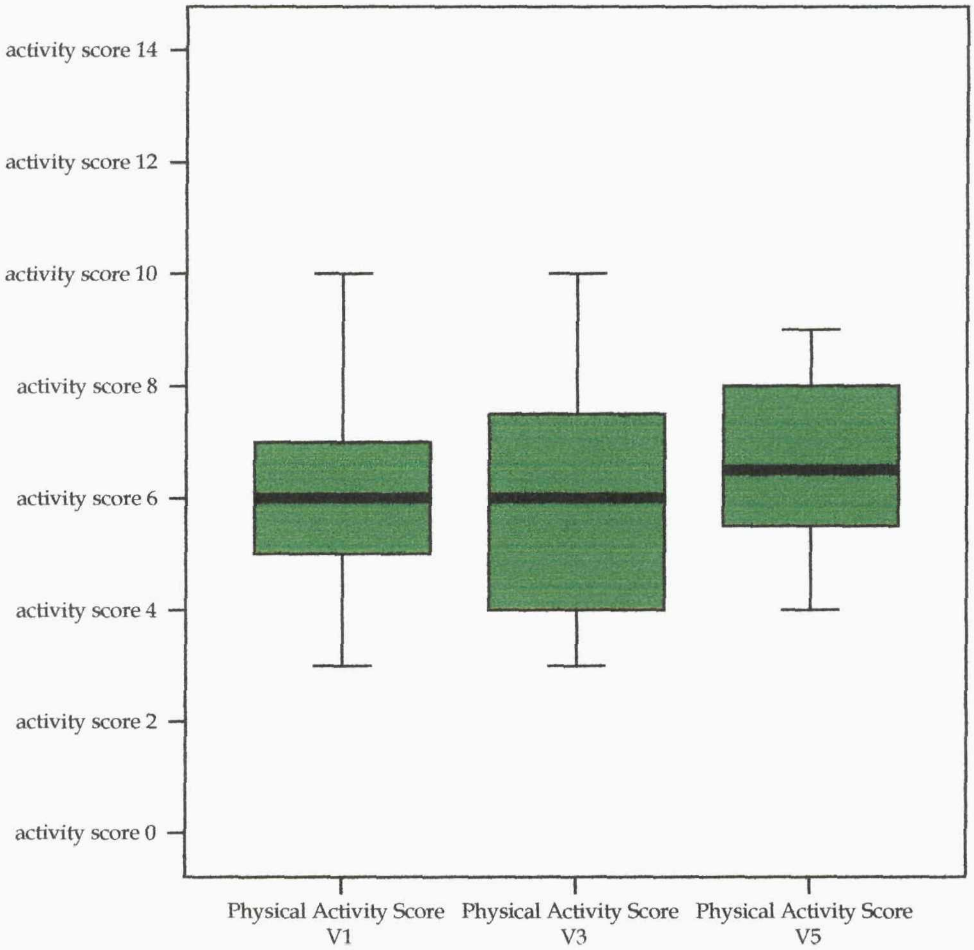


TABLE 6.11 Descriptive statistics for physical activity scores

		Physical Activity Score V1	Physical Activity Score V2	Physical Activity Score V3	Physical Activity Score V4	Physical Activity Score V5
N	Valid	20	18	20	18	20
	Missing	0	2	0	2	0
Mean		6.05	5.39	5.95	6.11	6.80
Std. Deviation		1.849	1.819	2.064	2.026	1.609
Minimum		3	2	3	2	4
Maximum		10	9	10	11	9

6.12 Physical Measurements

In the UK, 44% of men and 35% of women are classified as overweight, having body mass index (BMI) of 25 - 30kg/m^2; an additional 23% of men and 24% of women are obese, with a BMI greater than 30kg/m^2 (Allender et al., 2007). The World Health Organisation (WHO) reports that the incidence of people being classified as overweight and obese is a growing concern throughout the world; they classify obesity as one of the top ten risk factors contributing towards the global burden of disease (WHO 2002). Obesity is an important risk factor for CHD as it adversely affects cardiac function (Klein et al., 2004) and may predispose a person to developing insulin resistance (Bull 2004). In the UK, 6% of all deaths are attributed to obesity and obesity shortens life by an average of nine years (National Audit Office 2001).

Clinically there are two main methods used to measure obesity; these are BMI and waist circumference. The BMI is a globally accepted measure of weight in relation to height which provides a crude indication of body fat (Eckel et al., 2004). A person with a BMI of 25 or over, is classified as overweight and a BMI of 30 or over, is classified as obese; unfortunately BMI does not distinguish fat mass from lean mass (Bull 2004). Waist circumference provides a measurement of a person's central obesity and abdominal adiposity; it is increasingly being used to assess a persons risk of CVD (Dagenais et al., 2004). For men their waist measurement should not be above 102cm and for women 88cm is the maximum (De Backer et al., 2003: Dagenais et al., 2004). UK data for 2003, showed that 33% of men and 30% of women had central obesity (Allender et al., 2007). It has been shown that weight, obesity and central obesity all increase with age (Petersen et al., 2004). Thus it is important that age is taken into consideration for people to ensure that the correct weight is maintained throughout their life span.

- **Measurement and assessment methods**

Waist circumference was measured using a standard measuring tape, the same tape measure was used throughout the programme. During the procedure participants stood upright, looked straight ahead, breathed gently in and out in order to ensure that their muscles were not contracted. The measurement was taken midway between the lower rib margin and the iliac crest, approximately 2.5 cm above the umbilicus.

Height measurement was done at the first visit only, with the same scales used for all participants. Participants removed their shoes and were asked to stretch upwards to their maximum position. Weight was measured on calibrated scales with shoes and outer clothes removed. The same weighing scales were used throughout the programme and all measurements were rounded up to the nearest half kilogram.

- **Participants measurements and findings**

The statistical findings for the waist measurements only have been discussed; the details of BMI scores would show similar results. The results show that one female had a waist measurement above the recommended level of 88cm at 89cm and that all measurements remained stable throughout. One participant was excluded from later analysis due to pregnancy and subsequent child birth. Male waist measurements show greater variability, as illustrated in the minimum and maximum scores. It is of note that there is evidence of reduction as shown in table 6.13 which tabulates the statistical figures for waist measurement during the programme.

TABLE 6.12 Descriptive statistics for waist measurements

			Visit 1	Visit 2	Visit 3
male	N	Valid	13	13	13
		Missing	0	0	0
	Mean		102.54	102.65	102.65
	Std. Deviation		11.631	9.877	10.149
	Minimum		84	88	84
	Maximum		127	119	118
female	N	Valid	6	6	6
		Missing	0	0	0
	Mean		79.5	80.17	80.17
	Std. Deviation		8.689	7.360	7.223
	Minimum		67	68	71
	Maximum		89	89	89

On average for the male participants the mean remained constant throughout the programme (visit 1 M= 102.54, visit 3 M=102.65, visit 5 M=102.50); it is of note that as a cohort the mean measurement was 0.5cm above the recommended levels. The maximum range was reduced from 127 to 118; there was some evidence of waist circumference reduction for those who showed signs of central obesity. However the results are not statistically significant as $t = < 1.73$, $p = >0.05$ and a 95% confidence interval has zero (as shown in table 6.8).

On average for the female participants the mean remained constant throughout the programme (visit 1 M= 79.50, visit 3 M=80.17, visit 5 M=80.17); these figures are within the recommended measurements for waist circumference. Maintenance was encouraged and no further action required.

6.13 Smoking status

The figures for 2005 show that 25% of men and 23% of women smoke (Allender et al., 2007); half of these people will eventually die from their smoking where one in four will be due to CHD (Petersen et al., 2004). The risks from smoking are much higher in those who start before the age of 16, and female smokers have a greater risk for a myocardial infarction than male smokers (Mackay and Mensah, 2004).

Smoking has declined over the last 60 years; the first national smoking survey undertaken in 1948 showed that 82% of men and about 45% of women smoked

(Allender et al., 2007). The 1970s saw a major decline in the smoking rates and a narrowing of the prevalence gap between men and women. Since the early 1990s the smoking prevalence has levelled off and remained relatively stable at just above the current figures (Allender et al., 2007). In 2004/2005 1.4 million hospital admissions were related to smoking, and smoking contributed to 18% of all deaths in 2004 (Wanless et al., 2007).

The INTERHEART study showed that cigarette smoking and abnormal lipid profile were the two strongest predictors for a myocardial infarction (MI) (Yusuf et al., 2004). There was also a strong relationship between the numbers smoked and risk of an MI, following a graded incremental increase (Yusuf et al., 2004). INTERHEART did demonstrate that a reduction in the number of cigarettes smoked did confer cardiovascular benefit for people who are unable to quit (Yusuf et al., 2004).

- **Measurement and assessment methods**

The official classification used by primary care for cigarette smoking is graded into 5 categories. However for the purpose of this study, this was felt to be insufficient, so further categories were added which provided greater scope for accurate measurement of the participants smoking status. Table 6.13 identifies both the primary care categories along with the additional ones developed for the study.

TABLE 6.13 Smoking categories used for the study and in primary care

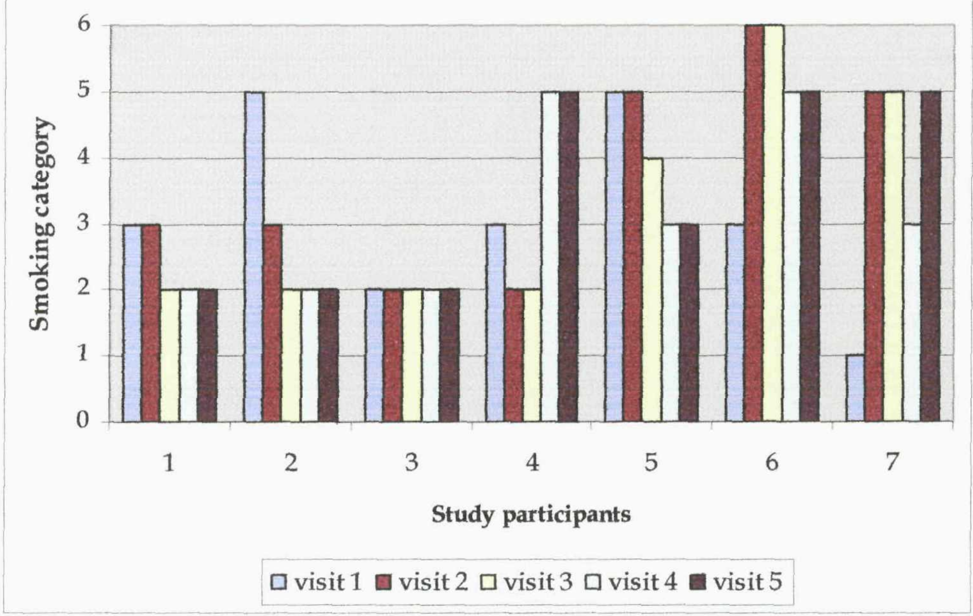
Score	Study Category	Primary Care Category
0	Never smoked	never smoked ~ someone who has given up over 15 years ago would also be included here
1	Non smoker ~ smoked in the past, more that 15 years ago	
2	Ex-smoker ~ smoked in the past, 1 to 15 years ago	ex-smoker ~ having given up between 1 and 15 years ago
3	Trying to quit ~ stopped within the last year	current ex-smoker ~ between 3 and 12 months
		attempting to quit ~ less than 3 months, or still smoking but reduced quantity
4	Social smoker ~ less than 3 a day, not every day	smoker
5	Smoker ~ up to 20 a day	
6	Heavy smoker ~ more than 20 a day	

For those who smoked, the detrimental effects of smoking was explained. If they did not wish to consider quitting, they were encouraged to reduce the number of cigarettes smoked. The health advantages of quitting was discussed so that participants could move from a pre-contemplation stage to a preparation stage, according to the transtheoretical stages of change model. For those who wanted to quit, referral to a smoking cessation service was suggested; one participant was referred to the smoking cessation service.

- **Participants' measurements and findings**

Self reporting by the participants was used to assess smoking status. Thirteen participants were classified as 'never smoked' at the start of the study, and their smoking status remained the same at the end of the programme. The smoking categories of each of the seven male participants who are classified either 2 or above, are shown in figure 6.8. Their smoking category for each visit is shown. It is unfeasible to do a statistical analysis on these seven, so individual details are shown.

Figure 6.8 Individual smoking status



Two participants (numbers 1 and 3) had already quit smoking within the previous year after a relative had been diagnosed with heart disease, but before starting the programme, neither of them resumed smoking. Two participants (numbers 2 and 5) gave up smoking altogether; a staged approach was used to gradually reduce the number of cigarettes; neither wished to be referred to the smoking cessation service. For three participants their smoking states worsened (numbers 4 , 6 and 7), two had attempted to quit within the preceding 12 months and one had quit 15 years ago. All three wanted to quit again during the programme, but found it difficult. The difficulties faced by these participants is reflected in their stress scores.

6.14 Psychosocial factors

Data from the INTERHEART study confirmed the association of psychosocial factors with heart disease, however the extent of this influence varies between the genders, social class and countries worldwide. The population attribute risk was 32.5% with an odds ratio of 2.67 (Yusuf et al., 2005). Marmot and Hemingway (1999), define a psychosocial factor as a measurement that potentially relates psychological phenomena to the social environment and to pathophysiological changes. They go on to state that psychosocial factors may affect health in three ways, firstly by adverse health related behaviours, secondly by direct acute and chronic pathophysiological changes and thirdly, access to and content of medical care.

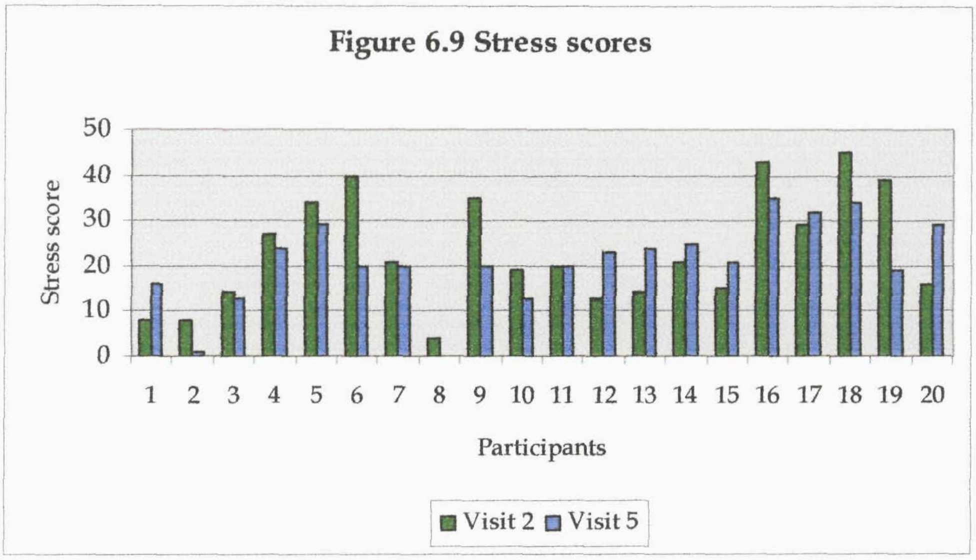
- **Measurement and assessment methods**

Psychosocial stress levels were assessed using a validated measure, 'the perceived stress scale' (Cohen et al., 1983). The questionnaire was not used within the programme until after the research study had started, consequently data is not available for visit 1. Data for visit 2 and 5 was used in the results and analysis and is therefore inaccurate because it is does not represent the start of the programme.

For people who experienced increased or high levels of stress during the programme the importance of stress management was discussed. Practical advice and suggestions were made, for example one participant attended a stress management course, and two male participants subsequently attended monthly reflexology sessions.

- **Participants measurements and findings**

Individual participants' scores for visits 2 and 5 are shown in figure 6.9.



On average, as illustrated in table 6.14, participants reported a reduction in their levels of stress from visit 2 (M=23.25)through to visit 5 (M=20.90).

TABLE 6.14 Participant stress scores for visit 2 and visit 5

		Stress Score Visit 2	Stress Score Visit 5
N	Valid	20	20
	Missing	0	0
Mean		23.25	20.90
Std. Deviation		12.489	9.330
Minimum		4	0
Maximum		45	35

6.15 Cardiovascular risk scores

Cardiovascular risk scores are used extensively in primary care for primary prevention of heart disease. They are advocated by the JBS2: guidelines (Wood et al., 2005) and used in previous studies such as the British Family Heart study (Wood et al., 1994). The risk scores are calculated using gender, age, total and HDL cholesterols, systolic and diastolic blood pressure, smoking status. They also take into account family history, south Asian origin and left ventricle hypertrophy. However they are not useable for those with Type 1 diabetes mellitus, or people less than 35 years. Table 6.16 tabulates the pre and post study risk scores for the ten participants who were aged above 35 years. The scores have been calculated using the BHF CD-ROM, JBS 2, cardiovascular risk assessor (VO1.06). The scores provide a measure of the results from the health promotion programme as they affect individual risk profile.

TABLE 6.15 Cardiovascular pre and post study scores

Participant	Pre study		Post study	
	relative risk score	absolute CVD risk	relative risk score	absolute CVD risk
1	45	8%	52	8%
2*	72	20%	43	5%
3	53	9%	59	11%
4*	48	23%	43	17%
5	74	2%	93	5%
6	50	3%	66	9%
7	48	4%	59	6%
8*	50	10%	43	7%
9	47	10%	80	22%
10	43	2%	44	3%
* on cholesterol lowering, statin, medication				

The principle purpose of these scores are as an aid to making clinical decisions regarding antihypertensive, lipid-lowering and anti-platelet medication and lifestyle advice. Changes that occur to a person's risk profile regarding these treatments and smoking status are shown by the relative risk score. Where the absolute CVD risk is ≥20% over 10 years, they are defined as high risk requiring lifestyle intervention and, where appropriate drug therapies, in order to achieve the targets set by the JBS 2: guidelines (Wood et al., 2005).

6.16 Summary

The health promotion programme has been detailed, the lifestyle assessments that were conducted and details of the clinical sessions have been identified. The nine main modifiable risk factors associated with coronary heart disease, which were targeted as part of the health promotion programme, have been individually discussed. The findings and results, from the 20 participants who completed the programme have been illustrated with graphs and statistics. Paired t-test has been used to prove the significance of these findings. Table 6.16 provides a statistical summary of the findings from the health promotion programme.

TABLE 6.16 Summary of statistical results for the health promotion programme

Lifestyle factor		Findings
Alcohol	Minimum levels	Mean levels decreased from 12.90 to 7.75 units
	Maximum levels	Mean levels decreased from 20.95 to 17.60
Cardiovascular	Blood pressure	Systolic blood pressure mean levels reduced from 126.20 to 118.75
		Diastolic blood pressure mean levels reduced from 81.15 to 77.15
	Pulse	No change required or made
Lipid Profile	Total cholesterol	Mean value increased from 5.04 to 5.10
	LDL cholesterol	Mean value increased 3.00 to 3.16
	HDL cholesterol	Mean valued decreased from 1.37 to 1.29
	Triglycerides	Mean value decreased from 1.59 to 1.48
	Ratio	Mean value increased from 3.71 to 4.13
Diabetes Screen		One person identified for monitoring
Diet		Positive changes made by 18 people, 2 required no improvements
Physical activity		Mean values increased from 6.05 to 6.80
Physical measurements	Waist	Mean value increased from 94.20 to 95.08
	BMI	Mean value increased from 26.62 to 26.87
Smoking		2 people quit smoking. 3 people improved their smoking grade. 2 people's smoking habits worsened
Psychosocial Stress		Mean levels decreased from 23.25 to 20.90

The next chapter will provide a personal account from these participants of their evaluation of the health promotion programme, and their views with regard to their health status.

CHAPTER SEVEN

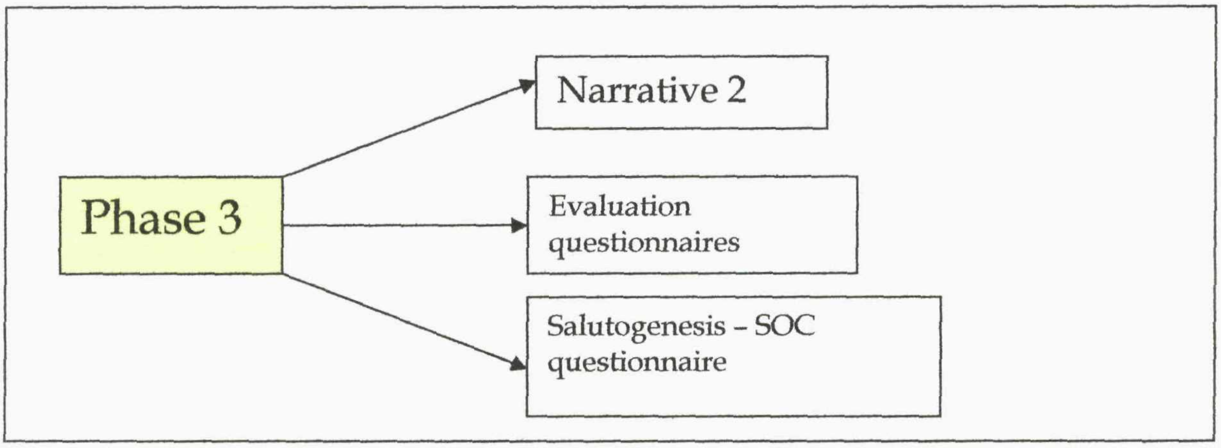
Phase 3 ~ Participant Evaluations

7.1 Chapter introduction

This chapter details the participant's personal evaluation of the health promotion programme and their experiences during the two years of the study. The previous chapter quantified risk factor changes that had occurred during the two years in the health promotion programme. This chapter provides descriptive data from the participants in the form of narrative interviews, in order that a better understanding of this health process may be produced. The survey questionnaire presents evidence concerning the study as a whole.

In phase 3 of the study twenty narrative interviews were conducted and twenty evaluation questionnaires completed. The interviews were conducted at the end of study, during the participants' final visit. Figure 7.1 identifies the data collected during this final stage of the study.

FIGURE 7.1 Phase 3 ~ study data analysis



7.2 Narrative evaluation

No predetermined format or set questions was used for the narratives; participants were asked to recount their experience of being part of this health promotion programme and dialogue developed between the participant and researcher as a natural course of their response. The narratives varied in length from five to fifteen minutes. The twenty narratives were analysed in the same format as had been used for phase 1. Content analysis was used to identify the main themes, which are shown in table 7.1.

The three main themes which have emerged from these narratives are based upon the individual, people who were significant to them and their health. These are all central issues within the study, but it is the participants themselves who bring these issues forward for examination as an integral part of the evaluation process. These three themes are discussed with pertinent quotes from the participants used to illustrate the discussion. Pseudonyms are used to protect the individuals identity.

TABLE 7.1 Narrative themes and descriptors

Themes	Descriptors
Significant People	Influence of others
	Influencing others
	Family
	Relative with heart disease
Self	Subjective self
	Knowledge
	Lifestyle motivation and change
Health	Health and ill health
	Diet and cholesterol
	Other risk factors

In the narrative people gave their views and opinions concerning their involvement in the research study. This set of findings is discussed in conjunction with similar issues raised in the first narrative; these issues are identified later in the chapter.

7.3 Significant people

The sibling or parent who had been diagnosed with heart disease remained central to the participant, along with their spouses or partners, plus friends and colleagues. These people influenced the participant within the study, such as encouraging them to attend the clinic sessions and supporting them while making lifestyle changes. However this relationship was also shown to be reciprocal, where participants were themselves able to positively influence other people's lifestyle behaviour.

7.3.1 Influence of others

Participants reported the positive influence that other people had upon them. The narratives illustrate how key people influence the participants' behaviour, predominantly through support, encouragement and sharing. For some this was in the initial stages when contemplating being part of the research, for others it was subsequently in attending the health promotion programme.

John describes how it was because of his wife that he joined the study initially; due to his family history of heart problems she had always been concerned for him and had seen the study as an opportunity for him to have a lifestyle check. Many spouses, such as John's and Alistair's, were acknowledged as being instrumental in making changes, especially dietary ones.

> *My wife helped a lot. She literally changed what she ate as well, so that made it a bit easier for me. I probably wouldn't have been able to do it on my own, if my wife didn't keep kicking me up the backside.* *Alistair*

Women were acknowledged as being key in influencing the men within the study. For some men this influence might have come from their mother, who ensured that they came for the sessions. Mothers influenced both sons and daughters; those still living at home, those now independent with children of their own. Participants who were encouraged in this way saw this positively.

> *I always tell them I am coming over here and they always make sure that I have done. She's on my case and on my brother's case, all the time really. Which is not a bad thing you know.* *Harry*

Much of the support from spouses and partners was associated with diet and cooking: this is largely dependant on who does the shopping and cooking. From the diet questionnaires it is shown how this is usually done by women, but that men retain influence over this process. Annie comments how it is her husband who does most of the cooking but that she has been able to positively influence his cooking, and they have subsequently both made dietary changes.

> *And my husband's been a great help in cooking all the good food that he cooks. And he tries to listen to my comments and not too much cream and "Ah! No salt in there!"* Annie

Conversely, Harry explains how being independent has made cooking easier, when shopping he decides for himself what to buy and his diet improved because he made his own choices.

7.3.2 Influencing others

Participants tell how they share their knowledge with other people. This process is enhanced when it is done within the family who have encouraged them to attend the study.

> *I told her after my kind of meetings with yourself, "Did you know that and did you know that, and this is not good for you and that's not good for you."* Leo

They also illustrate how this influence is transferred to others, for example, this may be friends or colleagues, where encouragement and support is passed on. It may be concern for others where they now feel greater authority to speak out upon health issues and give advice. Claire explains how she used her knowledge to encourage her husband to stop smoking, as she now felt more confident to talk about the issue. Similarly for Leo:

> *I have tried to speak to people. Actually one of my customers had really high blood pressure. And I told him what my experience is.* Leo

Leo continued by recounting how even though the man was older than himself, which he perceived as a barrier, he was able to encourage him to go for advice and said that his customer was now on medication. Leo explained that prior to being involved in the study he would not have appreciated the importance of high blood pressure, or offered advice in this way. In the same way Annie, shows general concern and awareness for others.

> *Yes I try to tell other people how important it is, but I try to be tactful. Because I can see everyone could benefit from knowing the right way to keep yourself healthy.* Annie

While some want to be able to actively provide support for their families. Two participants spoke of their young children, their concern for the next generation and the need for a healthy upbringing. Emma joined the study because she wanted to learn about heart disease so that she could influence her own family.

> *But one of the issues initially was thinking "Oh if there is this family legacy, would it have been passed down?" We don't know. But I kind of feel like I am doing the best for my children, and you know, my husband.* Emma

Even when family members had been unable to participate in the study, they are shown to be interested. Georgina's brother would have liked to join the study but lived too far away.

> *My brother; I feed back to him and he is always interested to know what is happening, because he is worried that he will follow in my fathers footsteps. Having got past the first threshold at 48, when our father had his first heart attack. He's now not looking forward to 61, which is when my Dad died.*
> Georgina

The analysis of the first interviews had shown how age can be an important milestone for people. This is further illustrated by Georgina who expresses the concerns of her brother who views these ages as landmark events.

7.3.3 Family

Family members are seen as supportive and encouraging, where the participants share details of the health programme with them. This is particularly evident where family members are attending their own study visits; the assessments and visits are compared and discussed, not in a stressful way, as Barbara emphasises, but in a fun way. In this way communication within the family is enhanced. During Claire's first narrative she described the difficulties they had as a family in talking about health issues; this had subsequently improved.

> *As a family we have appreciated it as well, because we were all involved, we were able to talk about it afterwards. Just being able to talk openly about it as a family has been very beneficial.* Claire

Some discuss how their own childhood has influenced their behaviour; they are aware of how their upbringing and family environment may have influenced their lifestyle behaviour negatively. They now acknowledge this influence and do not want it repeated for future generations. Some of these habits are influenced by changes in cooking practice, for example cooking with lard; or may be associated with the fact that knowledge regarding the role and importance of diet remains ongoing. For those whose childhood was affected by post war rationing, there was no differentiation between healthy and unhealthy food.

> *I would just liked to have known from much younger, the healthy ways of eating. I can remember thinking to myself it's not important what you eat, as long as you eat.* Annie

In the past food has had a different emphasis and played a different role.

> *It's survival of the fittest. And food was possibly the only luxury we had, coming from a large family. So you know you fight for it. I think a lot of that really programmed me, in my eating habits.* John

John had previously made the observation regarding his family history, as to whether this was related to genes, or because their lifestyle was poor, or due to other unknown factors. He accepts that there is no answer to his question, and that the mechanism of how family history predisposes people to heart disease continues to be investigated and debated.

Some families had shared commonalities which could be retained even when they were living apart, such as eating similar types of food. When everyone in the family is eating the same type of foods, maintenance of a healthy diet is easier. Both Alistair's grandmother and father had heart attacks, consequently the whole family had altered their diet.

> *Because we eat a lot at each others houses, I just go in there, have my lunch and I haven't got to look at what bread they have. It's always brown bread. So yeah, it does make it easier. And if I go to Mum and Dad's their butters Benecol, so its easier.* *Alistair*

7.3.4 The relative with heart disease

Participants continue to show concern for the relative with heart disease, yet this concern is not necessarily transferred to themselves.

> *I worry about him all the time, but I don't tend to worry about myself because of that too much.* *Harry*

However, susceptibility may be transferred between siblings, for example, Collin eludes to his initial concern when his younger brother was diagnosed with heart disease. It was at this point that Collin realised he was possibly in the same boat; consequently he sort guidance and advice about what he should be doing regarding his own lifestyle. Collin joined the research study, and in addition attended the hospitals' cardiac rehabilitation lectures with his brother and their wives.

The participants appear to be realistic, they accept that there is a diagnosis of heart disease within the family, but this can be seen as a positive influence, ensuring that they try to live a healthy lifestyle, rather than making them unduly worried. Some families are brought closer, and are strengthened by mutual support and help which is given during the difficult times. Meanwhile their relative is a reminder that illness does not just happen to other people, but that illness can, and does happen to loved ones.

> *I think that everyone is set in their own ways, until it directly affects them, then I think that is when they are going to change. Everyone knows smoking is bad for you, eating fatty food is bad for you. But you're not*

> *directly affected by it, I don't think you really pay it much attention, until you realise that it is right in front of you.* *David*

The familial diagnosis continues to act as a re-enforcement, increasing motivation and long term adherence to a healthy lifestyle. Eddie explains how, because he now has greater knowledge and insight into heart disease, he can share information with his sister and understand her issues as well as his own. For some they look for parallels between themselves and their relative, which may be age, appearance or lifestyle.

> *I'm fast approaching 41, when my Dad had his first heart attack.* *Ian*

Ian goes on to draw comparisons between himself and his father, the way in which his father's cholesterol, and his father's blood pressure were all much higher than Ian's own. Ian is reassuring himself that he does not have the same risk factors that his father had and therefore his own risk is reduced. For some whose parents have heart disease, or other severe illness, the parents can inspire their children by the way in which they have faced up to and dealt with the illness. As relative's health improves, this can influence and inspire other family members to improve their own lifestyle in order to enhance their health.

There are key people, such as family members, friends and colleagues who all play a significant and positive role in improving the healthy lifestyle behaviour of these participants. The integral role that these people have for the participants and how they interlink together is shown in the narratives, such as the way in which knowledge is shared and reciprocated between family and friends and how mutual support is given.

7.4 Self

It was a minimum of 2 years since the participants gave their first narrative interview, where for many the main subject of the narratives tended to be the relative diagnosed with heart disease. This second narrative was concerned with the participants current outlook upon the whole process of being involved in the study, with emphasis upon the health promotion programme, what this has meant for themselves and for their families. The interview also examined what their current thoughts and views were concerning heart disease and lifestyle behaviour, how it has effected them and their families, a further two years down the line.

7.4.1 Subjective self

None of the participants express undue worry or anxiety for the future, they were more concerned about being pro-active to prevent heart problems, and taking responsibility for their actions. Through improved awareness and knowledge their worry had lessened. Barbara lived with heart disease in her family since adolescence, even after such a long time since the initial diagnosis, being on the programme has helped Barbara come to terms with many issues. The important issue for Barbara is that she now feels happier and reassured. Her daughter, Debbie, now has heart disease on both sides of the family; during her narrative she explains that although the issue of heart disease is even more pertinent, this makes it more important for her to be healthy now, in order to keep healthy for the future

> *Not to worry about it and think of it negatively. Like OK that has happened what can we now do to prevent it happening again.* *Debbie*

Two participants, who in their first narratives, spoke of the anger they felt regarding the affect heart disease had had upon their family, both of them again spoke about their anger. They explained how in the first interview they had been given the opportunity to acknowledge that this anger existed and to talk about it. As a consequence of both the discussion and the health promotion programme, they had since been able to move on from this and had learnt to be positive for the future.

Age is an issue for some; for those who are young they see the importance of looking after themselves in the future, or for those who feel that they are getting older they realise the need to make changes.

> *Coming here, keeps reminding me that I can't just keep abusing myself on a regular basis, because I am getting older and it is not going to do me any good.* *Neil*

Since starting the health promotion programme some participants had been prescribed anti-hypertensive and statin medications. None of the participants who have been prescribed medications say that this is a problem or concern.

> *So if I have to take a pill or take two pills, or whatever, so I do it at the same time. So it's no problem. As long as the medication is the right medication, then yeah I feel reassured.* *Harry*

They are reassured by their medication. Although this does not exempt them from continuing to take their own responsibility.

> *I think maybe, sometimes, I do take it for granted a little bit. You think "Oh, I'm alright you know, the tablets are there to help." And maybe you would go out and binge drink more, or have some more naughty foods, or something like that. But I can't just live like that. I have got to do it for myself.* *Leo*

Two female participants had General Practitioners (GP) who were reluctant to commence them on statin medication; for which they were both eventually given prescriptions. They describe how they felt thankful to be on medication, but are still careful regarding their diet.

> *I do feel reassured that I'm helping myself to bring my cholesterol down a little even though I eat a fairly good diet.* *Fiona*

Participants who were referred for further investigation rarely raised this in their narratives. Although one person explains how it was reassuring being investigated, something was being done, and she wanted to know the outcome of her investigation. She says how the process itself was more worrying than the outcome. In this situation for her, the focus is on the present, not the future implications.

> *It's always worrying on the day itself, if you don't quite know what's going to happen, and people are going to do things to you, but that's more worrying than actually what they could have found out.* *Debbie*

7.4.2 Knowledge

Knowledge has improved, the first set of narrative analysis showed how general knowledge of the risk factors associated with heart disease was good, where participants illustrated knowledge of the main risk factors. Now their awareness of the issues relating to heart disease has been intensified.

> *But this has really driven it home. I knew what I had to do, but this has kind of driven it home, of how important it is to knowing what to do, and actually seeing it through.* David

This is the difference between knowing and understanding, where they can now relate the lifestyle and risk factors to how this affects the heart. Many spoke about knowing how the heart works has enabled them to understand the process of the disease, and the relevance and importance of lifestyle behaviour to this process. The risk factors were no longer seen in isolation but in the context of the problem, and of their health.

Attitude to their own health has changed; the diagnosis of their relative has been a wake up call, where the importance of a healthy lifestyle is clarified. Even for those who are young, they are able to acknowledge the importance of health promoting behaviour starting from a young age, rather than waiting until they are older. Many of the narrators express the reassurance they now feel, they were initially worried about the diagnosis in the family, but now through education and support, they feel in control and empowered. Even those who were already leading a healthy lifestyle, they sought additional reassurance, knowledge and professional advice.

> *So I know that I feel better for it, probably both physically and mentally, because I know that what I am doing is right.* Debbie

Reassurance is a recurring theme where knowledge has lessened their worry, and people are able to respond positively to lifestyle advice. They now know their blood pressure, pulse and cholesterol measurements; they know what aspects of their lifestyle needs to be addressed.

> *I think people sometimes say if you have too much information, it can have a negative effect on it all. It hasn't, because it has reassured me of all the positive things that I am doing.* Emma

Knowledge is also independently sought from a variety of sources; the world wide web, especially the internet site of the British Heart Foundation, from leaflets and newspapers. Eddie explained how he found the internet information overwhelming, but valued the personalisation of the information given to him during the programme and the way in which personal relevance was illustrated The programme had provided an education, on which people can build for the future. Their general outlook has changed, resulting in increased confidence associated with the changed image they have developed for themselves, and the accompanying sense of control.

> *I think I have certainly learnt a lot in the last two year's about myself as a person, and about things I can do to improve my lifestyle.* Claire

7.4.3 Lifestyle, motivation and change

People changed in a variety of ways during the programme. For example, Fiona's major issue were her feelings of stress and anxiety, which she had always found difficult to control. She subsequently attended a stress management course, which had been suggested. After the course she learnt to worry less and to control the stress, she has become philosophical, especially about things beyond her control.

> *Sometimes you just can't change everything, you've just got to get on with it. I feel a much happier person in my head, a little bit, because I feel I have got a bit tougher.* Fiona

This narrative illustrates the realism that many show in learning to accept what cannot be altered in life while trying to change the things they can control and influence. After her first year in the study, Fiona's husband had a non-fatal heart attack, which further increased her anxiety and stress. However, Fiona now considers herself to be a tougher person because of what she has faced and is now happier in herself because she is stronger.

Many are realistic regarding their ability to change further in the future and to adhere to the changes they have already made. They remain conscious of what is required, but appreciate the difficulties of complete adherence. Motivation goes through phases, where sometime, as David explains, he can be highly motivated and exercise regularly, and then less so, if, for example, it is raining.

> *So, you know, I try, I try and keep conscious of what I am doing all the time. But everyone lapses I think; so sometimes it is difficult.* *Harry*

Taking control and being pro-active has brought confidence for the future; uncertainty may remain, but uncertainty is always present in life. For some they are taking responsibility for their own health, their own body.

> *I am not panicking about it, no. It's just that I know what I should do which is good. You can't ask for more than that really, the rest is all down to you.*
> *David*

While some may still need the sessions to act as a reminder, encouraging change and consequently sharing this control. One participant, Neil, explains how thinking about going to the gym or worrying about his waist line does not enter his head. Neil goes on to explain how he is busy and involved in the daily mechanics of his life, he states that he has other issues and priorities in his life, he is not used to putting himself first. What he valued from the programme was:

> *It's an hour devoted to me; which is quite a selfish admission. But no, it's nice just to sit and somebody's actually giving you their full attention. How many times in your life do you actually get the time when somebody sits and is devoted to you?* *Neil*

Through his narrative the complexity of his life is shown which helps to explain why he has had to struggle with some of the lifestyle changes he wished to make. Despite his difficulties in making the changes he has still valued the clinic sessions.

Some state that the lifestyle changes had been easier than they anticipated and that they would be able to adhere to these changes in the future. A few talk about the struggles they have had, for example, stopping smoking cigarettes. At times of stress, either during the working day, or at stressful periods of life, some have shown their need for a cigarette to help them through these occasions. Kevin illustrated how when life's stressors increase, the reliance upon cigarettes increased

> *The smoking at times was hard, because it was a comforter, at bad moments. If I was giving up in a positive frame of mind, when everything else in my life was going well, I found it extremely easy.* *Kevin*

At the start of the programme Ian had stopped smoking for nearly a year. During his first narrative he described the cigarettes as his 'friend.' Since then Ian's life has become more stressful and he has returned to his 'friends' for support.

> *It's [smoking] my crutch at the moment. As you said it's those routines. I don't have a fag till half ten, and almost a bell goes in my head.* *Ian*

For some if it had not been for the health promotion programme they would not have made these positive changes to their lifestyle and behaviour.

> *I'd have waited until something like that happened to me and then I would have probably been forced to make changes. Where as doing something like this sort of gets you to think about it a little more.* *George*

Motivation for change is often precipitated by the diagnosis of their relative where otherwise they would have continued with the same behaviours. ' Life' is another motivator for many to make positive changes to their lifestyle. There is a positive attitude towards life and living, and a wish to maximise the potential for a full and enjoyable life.

7.5 Health

Health has become a pertinent issue, many of the participants have witnessed ill health in a relative which has motivated them to participate in this health promotion study.

Whereas before health would have been taken for granted, or the importance of healthy living would not have been fully appreciated.

7.5.1 Health and ill health

Thinking about their own health and wellbeing, and the importance of lifestyle has continued over the two years of the study. Before the diagnosis of their relative consideration of these issues would not have occurred, but now they are interested in their health. Alistair explains how the measurements taken at his initial assessment shocked him and consequently increased his determination to achieve a healthy lifestyle, and by using the assessment reports he was able to track his progress.

> *I have a lot more interest in it* [health] *than I used to, even since I first started coming. Definitely.* *Alistair*

There is an acknowledgement that if it wasn't for the study this in depth lifestyle assessment would not occur. Some people liken the health promotion sessions to an 'MOT' test, where the 'MOT' test places emphasis on prevention through regular check-ups.

> *It's been nice being part of a programme because actually you're getting a kind of mini MOT, every time you come in.* *Ian*

Coming into the hospital, seeing people who are very sick and those who are older, has also helped to make people appreciate the value of their own health and life.

> *When I come into hospitals, obviously there is more of the older generation and it does make me, - you only get one shot at this, this life. So you know, you should just take care of yourself a bit more.* *Leo*

People may report having more energy, feeling more in control, generally healthier, while for some, there is a sense of achievement and pride. However there remains a need for reassurance for the future. In order to keep a track on themselves, some participants state how they plan to visit their GP or practice nurse for a yearly or two yearly check, while some are now being monitored by their GP regarding their blood pressure or cholesterol.

7.5.2 Diet and cholesterol

Diet has been a major issue for many and for some a revelation.

> *What we should be eating and what we were eating. Two completely different things.* *Bruce*

Ian states that it can be the simple, small changes that have become cumulative and show a big change at the end. Many made a positive, conscious effort to change, such as throwing away the deep fat fryer, not having salt or having one biscuit and no-more. However, following a healthy diet does require more work and as Debbie pointed out it is not a matter of just getting something out of the deep freeze. The main dietary change that people spoke about was eating more fruit and vegetable. To begin with many struggled with the change, but eating fruit and vegetables has now become an integral part of their daily routine, so that future maintenance was not seen as a problem.

The cholesterol measurements and results inspired some to make changes, but it was a risk factor that participants understood little about. Bruce explained how he never knew about the cholesterol, or that is was an issue, and Neil described how he had a cholesterol check when he was 14 years.

> *So I have always thought "Well that's me, fine." Fourteen I was ok, clearly nothing could have changed in 20 years of my life. But, clearly it has.* *Neil*

He had assumed it would remain low, and having seen the changes since then, it has helped to focus him to alter aspects of his lifestyle behaviour. For Collin although health has not been of general interest to him, the emphasis has changed and will not now be taken for granted.

> *Oh I make sure I do things that I should be doing and not forget about it.*
> *Collin*

7.5.3 Other risk factors

Exercise is an important feature for many; they know the importance of being physically active but exercise regimes can come and go, where work, in particular, takes over and time becomes limited.

> *Exercise; comes and goes, depending on what I have to do work wise. I would love to finish work and be at home by five everyday, and go to the gym everyday, but it does not work like that unfortunately.* *Harry*

Some participants had managed to encompass a variety of physical activities and by doing different activities have gained additional benefits, pleasures and a sense of achievement. Some activities have the advantage of being group activities providing an enjoyable sociable aspect to the exercise. Physical activity may have increased, but motivation for this may come from a hobby, rather than a wish to be generally healthier.

> *The outside interest was the motivator. I think to say, I wasn't prepared to go and do it* (the hobby) *unless I thought I was actually reasonably fit to do it in the first place.* *Eddie*

Kevin, who earlier in the study had been attempting to cut down his alcohol, gave up for Lent. He explains how he learnt that by going without alcohol altogether, he realised that he did not need the alcohol to relax and enjoy himself, and that when he resumed drinking he did so at a slower pace. Kevin had also managed to stop smoking.

> *The drink, I'd say I was fond of it and that was the hardest of them all to cut down and then give up.* *Kevin*

The assessments used in the programme provide a clear measurement which participants are able to relate to with regard to their lifestyle and behaviour. Many found the written sheets useful in tracking the changes over the two years, they were also used in discussing issues with other family members.

7.6 The research and health promotion programme

A fourth theme which arose from the narratives was the research study and participation in the health promotion programme. This final section discusses the reasons why people joined the research, and their personal views about the health promotion programme.

Reasons for participating in the study were varied; some appreciate and acknowledge the need for research, the way in which it benefits individuals and the wider population. Some were keen for greater knowledge and understanding, while others wanted support in trying to change and modify their lifestyle in order to reduce their own perceived risks. They were reassured that they would receive advice and an assessment for themselves, many spoke about this as the opportunity they had needed to give them a 'kick start.'

Even for those who lived away from their parents, the influence is evident. George explained how he wanted to do the research for himself, but also to please and to make his father happy. He has the support of his girlfriend, with whom he wanted to share his information.

> *If anything can help me prevent it from happening, but also to please Mum and Dad. And obviously for myself as well. It is hereditary as well. George*

Both Oliver's parents died of heart disease and it is something that has always been at the back of his mind, but brought to the fore again with his brother's heart attack. He was not unduly worried for himself, but pleased to take part in the research.

> *Really, I am here for own peace of mind, so anything you can tell I am keen to know. Oliver*

For many, the clinic sessions were often seen as a reminder to be healthy. They helped keep participants focused, knowing that a session was imminent and that measurements would be taken. Ian explained how the visits gave him an opportunity to discuss other health issues and ask questions which would not have warranted a GP appointment, but were causing concern. The educational aspect was central as it provided a sound knowledge base upon which lifestyle changes could be made, identifying why these changes were beneficial and could enhance long term adherence.

> *The education part of it; sounds a bit daft, but really it has been the most useful thing.* John

Having the same person seeing them was valuable, providing continuity and making the visits personal. Although they were seeing a single person, they knew that there was a specialist team, the cardiology department, to support should the need arise.

> *I felt the best thing about the whole experience, it was the same person throughout. I think it would have been no where near as good, if it was chopped and changed from person to person.* Kevin

The length of time between the visits was for most adequate, they were not seen as a huge burden even for those who had to travel, this did not alter their adherence to the research. For those who worked full-time, the clinic visits were arranged around their commitments and compromises made; the participants appreciated that the clinic times could be flexible to suit the individuals.

Many were ambivalent when the programme finished, whereas others would have liked to continue; the programme had finished but some wanted it to continue so that they could be encouraged to maintain their lifestyle changes, to continue to make further improvements and have their physical measurements monitored.

> *It would be quite good just to check in a couple of years, just to see exactly, - you know your lifestyle whether you are maintaining it.* David

While the two years passed quickly, for many it can still take time to make final adaptations, for example, Annie describes how she had only just achieved giving up cakes and biscuits by her final visit, while others saw the cumulative effects of their changes. People explain how it took time to make a change, contemplate it, understand the necessity, and then proceed to take conscious action regarding their behaviour so that it becomes an integral part of their lifestyle and routine - especially if they are undertaking a variety of lifestyle changes. Ian says how he has made quite a few changes, but that these were small and built up over the time. Debbie, has similar sediments.

> *I think you need a couple of months in between to start changing, because you can't just change overnight. So it gave you a few months to change something and then to start improving on it. So that when you came back in six months time, you know there was quite obviously a difference quite often.*
> *Debbie*

Coming into the hospital was rarely seen as a concern. For many it made the visit seem more important, to be seen in a hospital, and in the cardiology department. One participant, Harry, saw the hospital as a barrier.

> *Some people, I imagine would be put off because it is in a hospital. I would think you would probably get a better response if it was somewhere else not situated in a hospital perhaps. It's just there's a problem with doctors and their equipment, and everything.* *Harry*

Practical issues such as parking could also be a challenge and was mentioned by a few participants; this was not enough to prevent them from attending. Some stated that they enjoyed attending the clinic sessions and being part of a research study, even when coming to the hospital was a difficult experience.

People were positive about their attendance on the programme and the changes they had made. Emma makes the point that those who did not wish to join the study and attend the health promotion programme, this may have been because they would have had to make numerous changes in order to achieve a healthy way of life; a challenge they may have felt unable to contemplate or achieve. Emma was happy to participate in the study and programme because she already felt her lifestyle was quite healthy, she was seeking reassurance and the need for major lifestyle changes were few.

7.7 Evaluation questionnaire

Having completed the narrative analysis, the quantitative data was subsequently examined. The questionnaire has been used to provide statistical information regarding the participants general views concerning their health and their involvement in the programme, while supporting the findings from the narratives. Hence it was important that the questionnaires were analysed after the narratives, in order to provide verification without previous bias, where this triangulation of data supports the overall evaluation.

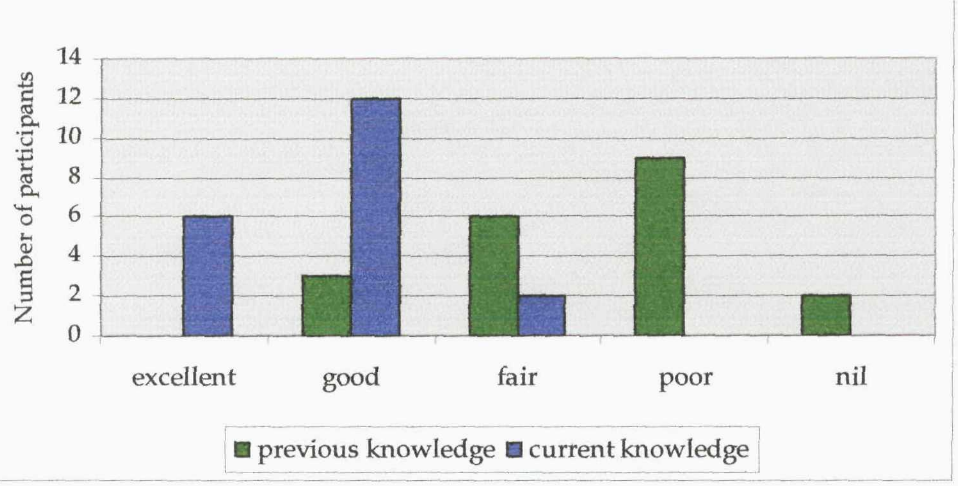
The evaluation questionnaire (see Appendix XIII) were sent with an unmarked envelope to the participants prior to their final clinic visit. It was explained that the questionnaires would be analysed in patches of ten. This process was established so that their identity in connection with the questionnaire would be hidden from the researcher, where the intention was that a truthful and honest evaluation would be provided.

- **Current and previous knowledge**

Nineteen participants said that their knowledge regarding heart disease had improved after completing the programme, for one person there was no change.

Figure 7.2 illustrates how knowledge had changed during the course of the programme.

Figure 7.2 Knowledge regarding heart disease



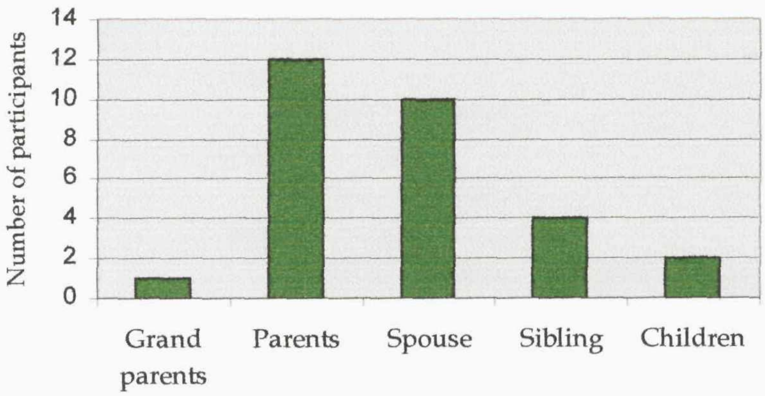
- **Concerns and referrals**

Four participants had concerns at the start of the study, which included concern regarding what they would be asked to do and finding out how unhealthy they were. The results indicated that in reality, none of these concerns were justified. The participants who had a referral as part of the programme all found it useful.

- **Support and health improvements**

Participants felt supported during the programme by the Nurse. For everyone their family was supportive of them, which came from a variety of sources as illustrated in figure 7.3.

Figure 7.3 Family Support during the programme



The support was given in a variety of ways, such as providing encouragement with the lifestyle changes, and encouragement to complete the programme. Family showed an interest in their involvement in the programme, providing an opportunity to talk about the visit and discuss issues which were raised during the sessions. Changes to diet were supported in a practical way, such as by cooking healthy meals. Families showed a personal interest and were able to provide compliments and encouragement.

Seventeen of the participants said that their health had improved as a result of the programme.

- **Clinic appointments**

Eighteen participants did not have any difficulty attending the clinic appointments. For those who did the reasons were due to work commitments and time constraints. Nineteen participants said that the timing of the appointments was just right, for one it was too long. Nineteen participants said that the length of the appointments was just right, for one it was too short.

- **Dislikes and withdrawal**

Nineteen of the participants had no dislikes about the programme, one participant said they disliked fasting for the blood test.

None of the participants had considered withdrawing from the study.

- **Evaluation of the programme**

The most important aspect of the programme was the knowledge and understanding they had gained regarding their heart and heart disease, and how this related to their health and the way in which lifestyle behaviour influences their health.

> *Knowledge how our whole lifestyle can affect our health and lead to heart problems in the future.* *Anonymous*

An important feature of this was diet; the role diet plays in health, the need to be aware of what is eaten and the value of eating the right foods.

What people most valued about the programme, was the opportunity in gave them to have time for themselves, to talk with someone who was interested in them and their health. They valued the relaxed, comfortable and friendly nature of the sessions. They felt reassured; for some they were reassured that what they had previously been doing was correct, for others they felt that now their health had improved and that the knowledge would assist them to maintain their health in the future.

Appendix XIX catalogues the individual responses from these two questions.

7.8 Sense of coherence score

The sense of coherence (SOC) score was the final data collected from the participants; 18 participants completed the SOC 29 item questionnaire. Table 7.2 illustrates the statistical results from the questionnaire. The questionnaire scores can range from 29 to 203, with a high score always expressing a strong SOC (Antonovsky 1993). Antonovsky does not quantify the scores other than high, medium and low; reference is made to army officers who have high SOC scores, mean value 158, and people with a low SOC scoring 80 (Antonovsky 1987).

TABLE 7.2 SOC score results

	SOC
number	18
Mean	144.50
Std. Deviation	17.84
Range	60
Minimum	117
Maximum	177

These results would indicate that the cohort have a medium to strong SOC which demonstrates that their behaviour appears to be positively influenced towards health promoting activities. Studies which show correlation between individual health determinants and SOC scores are discussed by Antonovsky (1993) in order to show feasibility, reliability and validity of the score. For the purpose of the discussion in the next chapter, scores will be discussed in relation to overall findings.

The SOC scores were obtained from all those who completed the study. However, having completed two years in the health promotion programme, this feature alone would illustrate that there are interested in health promoting activities. The five participants who did not complete the study may have shown a lower SOC, especially as they were all still young adults and their SOC was still developing.

It could be that this cohort is biased, as having consented to be in the study they are already interested in their own health. These people have already made sense of their experiences in such a way that their SOC is strong and they want to be enrolled in a health promotion study. This must be true for all people who volunteer to participate in primary prevention studies, where those who participate have some interest in their health behaviour to have given their initial consent.

7.9 Summary

This chapter has provided clear evidence from the study participants concerning their involvement in the health promotion programme and their views about their health in relation to heart disease. By using narrative interviews in depth information has been gathered, which has been supported by the quantitative evaluation questionnaire. The next chapter discusses the findings from the three phases of the study in relation to the salutogenesis framework and transtheoretical model for health promotion.

CHAPTER EIGHT

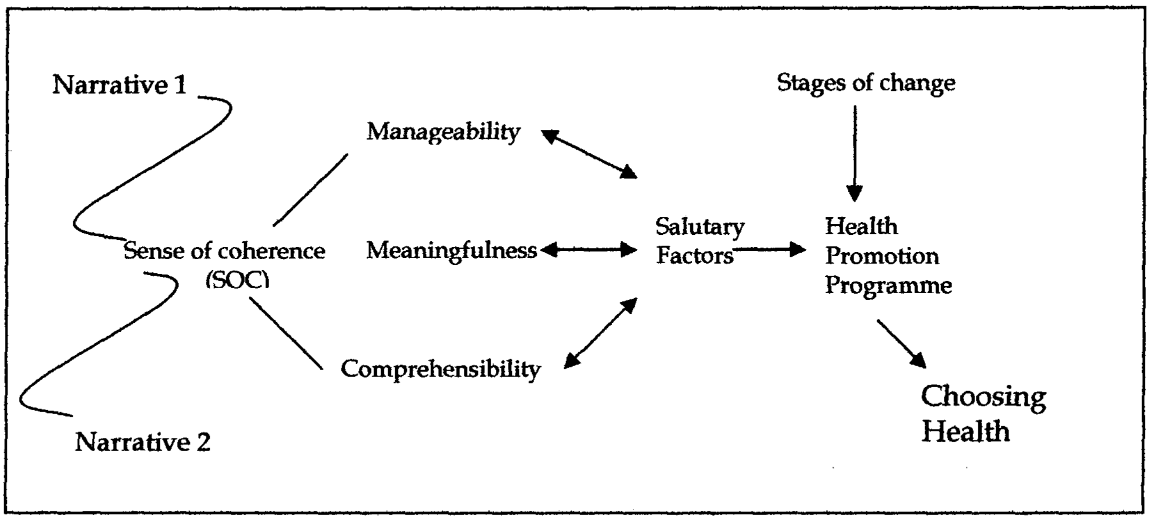
Discussion ~ Developing a Salutogenic Approach

8.1 Chapter introduction

This chapter will discuss the findings and results from the three phases of the study, using the salutogenic framework. The two health promotion models which have been used in this thesis, salutogenesis, and the transtheoretical stages of change, have both been introduced in chapters two and four. Building upon these previous discussions, salutogenesis will be used in order that the research findings can be developed and interpreted within this theoretical framework. Use of the transtheoretical model in the health promotion programme is debated, illustrating how by understanding peoples' cognitive process of change assists the health professional to support people's healthy lifestyle behaviours. These issues are discussed with reference to the original aims of the study, showing how these have been answered and what has been learnt from the research process and the study results, and how this influences issues for heart disease prevention.

Figure 8.1 illustrates how the results were analysed, and where the discussion centring on the health promotion programme is developed from the narrative results.

FIGURE 8.1 Flowchart analysis of study phases linking to salutogenesis



8.2 The salutogenic model

Within the research study, two health promotion models were used in parallel, as a complement to each other; the transtheoretical model (Prochaska & DiClemente, 1984), and salutogenesis (Antonovsky 1987). Salutogenesis enabled a person-centred approach to be used, where knowledge of the participants and an understanding of their life issues were strived for. The narratives at the start of the health promotion programme provided an opportunity for the participants to relay their 'story,' which some found cathartic. This gave a unique opportunity to hear their 'story,' providing insight and some personal knowledge of the participants. This first session with the participant provided the initial framework upon which a salutogenic approach could be used. When behaviour changes were being discussed, the salutogenic approach enabled an understanding of the participants' own circumstances to be appreciated while ascertaining where they may be along the cycle of change, in order to encourage and support the positive change.

According to Antonovsky's (1987) original hypothesis, a person's sense of coherence (SOC) is developed and established over the first three decades of life; childhood, adolescence and young adulthood. Since the original theoretical construction, research has shown that SOC is mainly developed in the first decades of life, but continues to be developed during the whole life span (Antonovsky 1996; Surtees et al., 2003; Eriksson and Lindstöm, 2005). The core components of the sense of coherence are comprehensibility, manageability and meaningfulness. The strength or weakness of these components are influenced by general resistance resources. The general resistance resources are biological, material and psychosocial factors, such as money, knowledge, self esteem, experience, cultural stability, for example. These are the resources which facilitate successful coping with life's inherent stressors (Antonovsky 1987). Antonovsky later describes these general resistance resources as salutary factors, or salutary resources, which can help people cope and are responsible for actively promoting health (1990; 1996).

The three components of the SOC will be discussed individually in the context of the narrative results. In reality, the components do not stand alone, but are 'inextricably intertwined, although they can be distinguished theoretically' (Antonovsky 1987, p. 86). The discussion is in relation to the contextual coronary heart disease (CHD) and health, showing how these influence the SOC and how through understanding and knowledge relating to the salutary resources, this can assist movement along the health ease / dis-ease continuum.

Antonovsky stresses that this is a continuum where people of all ages of all states of health, wellness and ill health, can move towards the health end of the continuum. By placing emphasis upon health, a holistic orientation towards the individual is needed, which is contrary to the medical specialist approach which looks at disease by compartmentalisation, where focus is upon the disease and not the person. Traditionally we study why people become sick and identify causal risk factors associated with the disease, instead Antonovsky argues we should study 'salutary factors.' Identification of salutary factors then has the potential for strengthening a persons' SOC and moving them towards health (Antonovsky 1990: 1996).

8.3 Developing a sense of coherence

When the diagnosis of familial CHD was made, 14 participants were adolescents or young adults whose sense of coherence was still in its major formative stage. For these people the events and diagnosis will have had more profound consequences and influence upon their life and their SOC. Those who were adolescents when their parent was diagnosed with CHD were the four people recruited into the study outside the expected screening process.

For those who have lived with familial diagnosis of heart disease for a longer period of time, the impact upon their own lives can vary. As discussed in chapter five, for those whose parent died, the effect remains with them throughout their lives, which may result in either positive, or negative lifestyle behaviour or may, at a more fundamental level, shape and direct their lives. The progression of heart disease is silent, there are no outward signs until the atherosclerosis is advanced, and results in clinical symptoms. As a consequence of this, people can find it difficult to make the association between health ease and heart disease, because there are no clear and obvious signs of the disease. The perception of risk varies for both the cardiac patient, the individual and the family, dependent upon what had happened to the patient, and the extent to which they had been subsequently affected by the disease process.

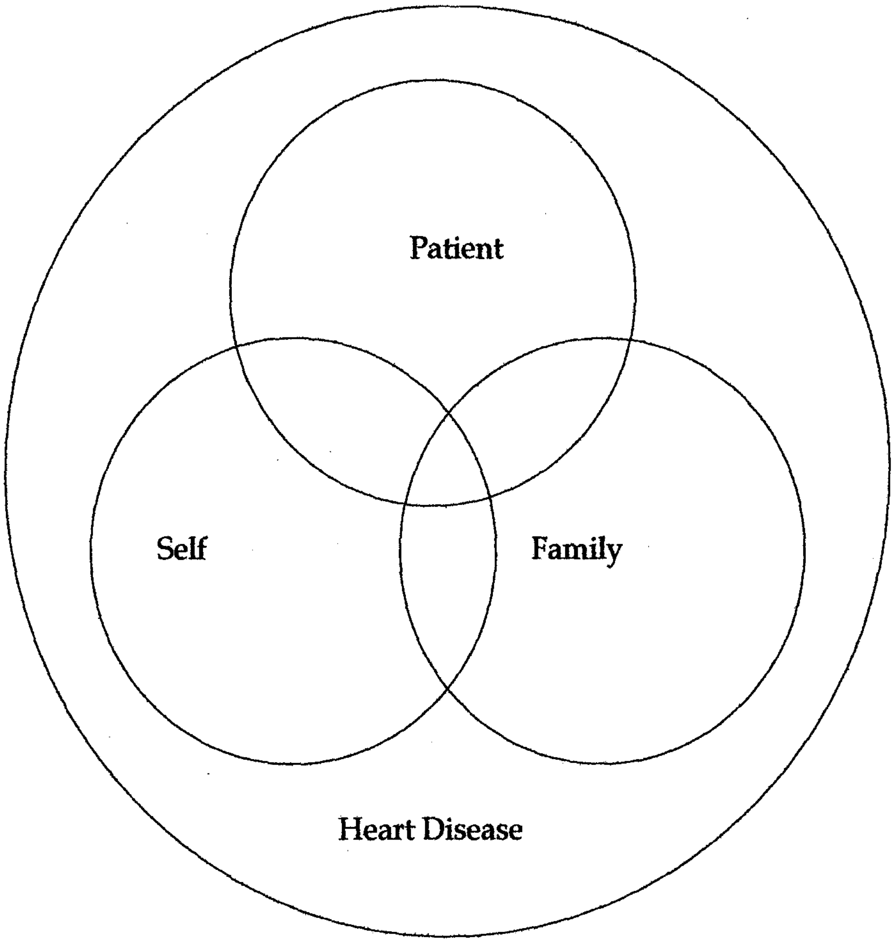
As identified in the findings, people show a fundamental knowledge of key risk factors, such as smoking, poor diet and lack of physical activity, associated with heart disease. As a consequence of their relative's diagnosis, some have already started to make positive lifestyle changes. Antonovsky argues that stressful life events can result in a positive outcome, for example, a person who is made redundant is forced to seek alternative work, which may provide an increased wage, which ultimately improves their salutary factors and increases their sense of coherence (Antonovsky 1987). This argument can also be true in the context of this study population, where exposure of a family relative to CHD can lead to first-degree relatives improving their behaviour and changing their lifestyle. In order to facilitate this process it is helpful to identify the salutary factors which ultimately influence the outcome.

8.4 Family experience of heart disease ~ narrative discussion

The first aim of the study was to explore the experience for people with a family history of premature CHD. It had been assumed at the start of the study that for most people joining the study the diagnosis of heart disease in the family would be new. However, it was discovered that many people already had an extensive history of cardiovascular problems prevalent in the family. Others had lived with this diagnosis in a first-degree relative for many years, the consequences of which had shaped their lives.

From the personal experience of these people and findings from the narratives, four key themes are identified which are encapsulated by family, patient and self within the framework of heart disease. A conceptual model can be drawn linking family, self and patient together, within the context of heart disease. Heart disease is the central component to this experience, but not necessarily the dominant one, where family, self and patient are the themes within which the personal experience is described and made sense of. The model is illustrated in figure 8.2.

FIGURE 8.2 Narrative phase 1: a model for family experience



The three inner circles of the model are the same size. For individual analysis the circle size would vary, depending upon endorsed importance, they would vary in degree of overlap, dependent upon individual variation. Heart disease provides the context, but the extent of influence upon the self, family and patient will vary.

Each of the three components that make up the sense of coherence - manageability, meaningfulness, and comprehensibility - will each be discussed in relation to the findings from the first narrative interviews, showing how these can be seen as salutary factors. Table 8.1 clarifies the definition that Antonovsky gave to these components.

TABLE 8.1 Components of a sense of coherence

Manageability: refers to the resources that someone has at one's disposal in order to meet the demands of the stimuli. These can either be under their own control or controlled by others, such as friends, family, colleagues. The person with a high manageability score will not feel victimised by life's events.

Meaningfulness: is the extent to which life makes sense emotionally. That the problems and demands in life are worthy of commitment and engagement. Where meaning is sought within the challenges.

Comprehensibility: refers to the extent to which one perceives the stimuli that confront one, deriving from the internal and external environments, as making cognitive sense; as information that is ordered consistent and clear. Someone with a high comprehensibility expects that future stimuli will be predictable and that challenges can be coped with.

(adapted from Antonovsky 1987, p. 16 - 19)

Table 8.2 lists the four themes, their descriptions, and the component from the sense of coherence to which they could be applied.

TABLE 8.2 Narrative phase 1 ~ themes, descriptions and sense of coherence

Themes	Descriptions	Sense of coherence component
Patient	Before the event: clues, or no clues	Comprehensibility / Meaningfulness
	The acute event	Comprehensibility
	Hospital experience	Manageability
	Visual appearance	Meaningfulness
	Returning to normal	Manageability
Self	Subjective self	Meaningfulness
	Cues and action for risk reduction	Manageability
	Health and lifestyle	Comprehensibility
	Friends	Manageability
Family	Family dynamics	Manageability / Meaningfulness
	Family history	Comprehensibility
	Age	Meaningfulness
	Through the generations	Manageability
Heart disease	Living with heart disease	Comprehensibility
	Comparison and perceptions of risk	Meaningfulness
	Knowledge	Manageability

Each of the three components will be discussed in relation to the descriptions from the main themes. The subject of this discussion is the study participant.

- **Manageability**

People where reassured when their relative was in hospital, they had faith and trust that the hospital and staff would care for the patient and that the right course of action would occur; the responsibility and management of the patient was transferred to the hospital. The external resources, needed by the individual, to meet the requirements of the ill patient, were met by the hospital. The internal resources they required during this critical time can come from the patient themselves, and be strengthened by family unity, or weakened by family discordance.

Family can be a key resource, where enhanced communication, shifting dynamics and relationships are seen as a positive resource. Acute illnesses can act as a catalyst for enhanced communication through the sharing of the external event and personal emotions. The experience for the individual is usually a unifying one with the patient and other family members. People are more able to manage the situation because they were not doing it alone, the resources required to meet the demands are shared.

If people are involved with the event, either on a practical level, such as when the patient is discharged, or an emotional level, such as providing support for other family members, then the sense of manageability, control and ultimately coping are all enhanced. Manageability and coping can be re-enforced and strengthened through reassurance and truthfulness from the patient and professionals, concerning the health and well-being of the patient. However, if a patient is re-admitted to the hospital or they do not conform to positive lifestyle behaviour, then manageability can be weakened in the short time, as the patient's vulnerability regarding their heart disease is revealed and confirmed.

For the individual with a strong SOC, the adaptations required after a relative's diagnosis of CHD are seen as manageable, as their internal and external resources are utilised. The external resources will come from family, friends and health professionals, as they accept the need to either request help, perhaps in the form of medication, or working together to make lifestyle changes. Friends can be a source of support, and be recipients of advice and encouragement regarding their own lifestyle behaviour.

As people draw upon their own resources, in an attempt to cope with what has happened, they then become the resource for the next generation. Concern for the next generation is transferred into positive action, as parents support and encourage their own children to lead healthier lifestyles, and are themselves motivated. They build upon their knowledge and insight of the disease, the pathogenic and salutogenic factors associated with it.

- **Meaningfulness**

By telling the story people are given an opportunity for the experience to gain additional meaning. Meaning may have already been attributed but the retelling can strengthen this. People spoke of the cathartic experience of being given the opportunity to talk about their experiences, they valued the uninterrupted time given to them to express and share their emotions. For those for whom the experiences were fresh, or even if the initial event with a parent had happened many years before, they saw the interview as a chance to discuss these emotions and feelings which may not previously have been shared.

The meaning that people attribute to the experience will influence their present and future coping strategies. For some, knowledge and insight into heart disease, or what it has meant for a relative can be transferred when a new diagnosis is made. The insight and knowledge helps with their coping and can be built upon, where transferability of knowledge and insight occurs when the disease is the same within the family.

Visual signs are important cues for people, and used to assess risk and seriousness, as heart disease develops there are no clear outward signs of disease progression. Even once the diagnosis of CHD is made, patients can look fit and well. All of which affects the perception of risk and the extent to which people are able to make sense of what has happened. However, when vulnerability is shown - through extreme pain, skin pallor and emergency equipment - the significance of the experience is enhanced and greater meaning attributed. Conversely, when the patient remains 'well,' visual appearance is misleading and it takes longer for relatives to make sense of what has happened, and to come to terms with future implications.

After the acute event, emphasis can change from the patient to the individual, as they seek meaning from the event and emotionally come to terms with what has happened. The closer they are to the patient emotionally, or with regard to their relationship, the more challenging this can be. The younger the person is at this stage, the greater the impact on their final SOC strength or weakness. Key people will contribute by providing practical and emotional support; the extent and influence of their contribution will again affect the person's SOC. Where meaning can enable the process of coping with these extreme events, and coping, as identified in chapter five, can be continual throughout the lifespan if a parent died.

Age becomes relevant, and importance attributed to it, because it is seen as a landmark when the significant event occurred. Significance is then transferred from the patient to the individual, for example if the patient had a myocardial infarction (MI) at age 42 and the individual is now approaching 42 themselves, significance is given to the age. In this way greater meaning than is warranted is imparted, as emotional investment is made, which may produce negative or positive consequences.

Relevance and meaning may also be gained through visual signs associated with the risk factors, such as being over-weight, smoking and poor diet. People make comparisons with themselves, others and the patients, with regard to a common denominator that is CHD. People can struggle to come to terms with the event when it appears meaningless, when they perceive no association with risk factors, or other hereditary traits. The initial shock at the diagnosis is increased and the challenge to accept what has happened greater.

- **Comprehensibility**

When learning about the diagnosis many spoke of their initial shock, but not necessarily surprise, either because of the pre-existing family history or because they associated the risk factors with the disease. As illustrated by the family mapping, heart disease is prevalent in these families and does not occur as an unpredictable, isolated event. The family are able to build upon their previous experiences of relatives with heart disease. In this way comprehensibility is enhanced where there is previous experience on which to develop. For those who have no clues or for whom the diagnosis is new within the family, adaptations must be made which will have future consequences to the strength of their SOC. If they have witnessed the event and been part of it, this may directly lead to a change in their SOC in the short term. Antonovsky (1987) states that following a life threatening event, SOC is reduced, but will recover and can be strengthened. This would be especially true if someone felt helpless and dis-empowered during the acute event.

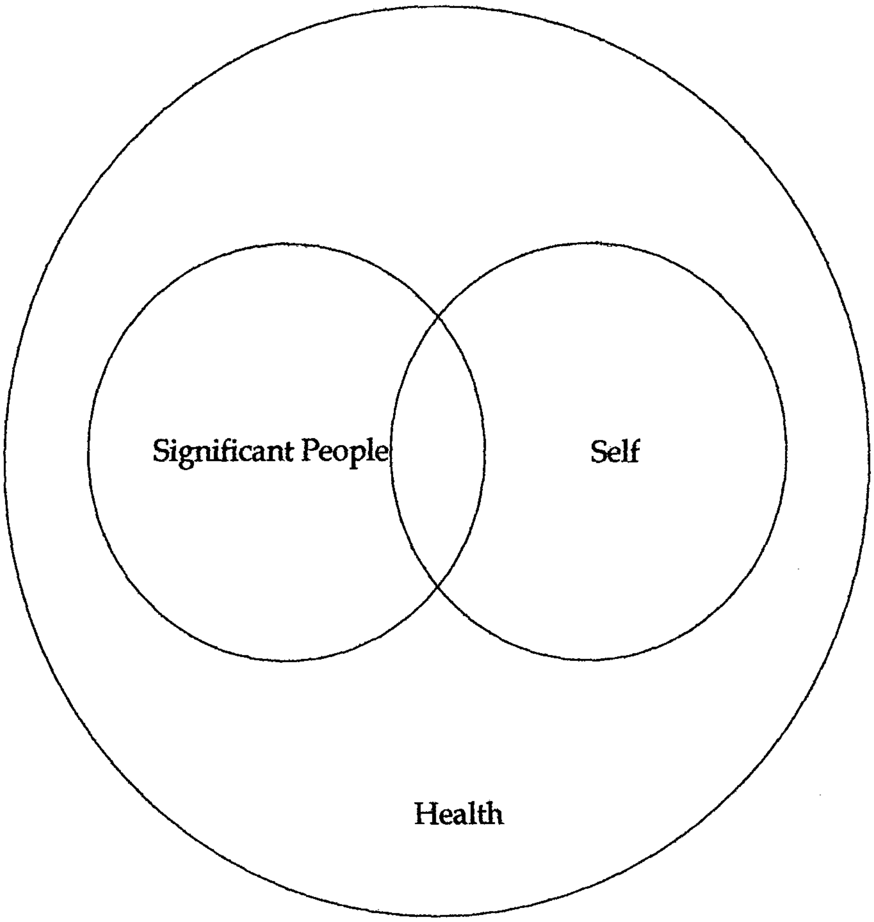
Understanding can be related to language, where the terminology used will produce different reactions. Such as heart 'disease' and heart 'attack.' The association is with the words, which can be at variance when the outward visual signs of CHD are often limited, at least in the early stages. Making sense and finding clarity can consequently be challenging, where people's own internal points of reference are required. This is applicable when people need to learn to live with the consequences of disease, and the changes they make can be a direct consequence of their own perception of risk.

In order to make sense of the situation, people will adopt the healthy lifestyle that is advocated as being protection against heart disease. They have understood the consequences, coping with the event, and meeting the challenge, by acknowledging the importance of their health and making behavioural lifestyle changes. This is in parallel with the meaningfulness of the event and has given additional motivation, especially regarding long term sustainability.

8.5 Phase 3 ~ Study evaluation

A similar model can be drawn to encapsulate the results from the second narrative interview. Where there is a change of emphasis, health becomes the context which surrounds the two themes of self and significant people.

FIGURE 8.3 Narrative phase 3: a model for promoting health



These themes and descriptions can be discussed in relation to the core components of sense of coherence. Table 8.3 lists the themes identified from the narratives and the SOC component attributable to each description.

TABLE 8.3 Narrative phase 3 ~ themes, descriptions and sense of coherence

Themes	Descriptors	Sense of coherence components
Significant People	Influence of others	Manageability
	Influencing others	Meaningfulness
	Family	Manageability
	Relative with heart disease	Comprehensibility
Self	Subjective self	Manageability
	Knowledge	Comprehensibility
	Lifestyle motivation and change	Meaningfulness
Health	Health and ill health	Meaningfulness
	Diet and cholesterol	Manageability
	Other risk factors	Comprehensibility

- **Manageability**

The support of others - whether family, friends or professionals - is integral to people's ability to manage and cope with change. In the study these have been acknowledged as a positive influence; however they could also be a negative influence. When lives are closely intertwined, whether physically and / or emotionally, the influence is greater. Through the involvement of others and working together, the burden and demand is less as the resources are more. Communication, between the individual and their significant others, develops trust and understanding, which strengthens and reinforces their ability to manage and cope with the challenge. This influence can stem from past events, where tangible support was given and meaning enhanced, to the present circumstance where the intrinsic influence remains. This would be especially true for those whose SOC is still developing.

None of the cohort expressed undue worry or anxiety regarding their family history, although anger was felt by some at the start of the study. For those with a strong SOC they would feel that they had the resources available to meet the challenges of coping with heart disease, at either secondary or primary levels. As already shown in the previous chapter, this cohort had on average a strong SOC. For those with low SOC, more support would be needed from external resources to help them meet the requirements that the disease imposes. The demands could either be for themselves or for family members, where the help could be tangible, such as medication, or emotional support either during stressful times, or by encouraging positive lifestyle behaviour. The greater the person's ability to manage the situation, either independently or with assistance, then the negative impact is reduced and a more positive outcome possible.

- **Meaningfulness**

It is a testimony of the importance that people ascribe to something, when they want to reach out and influence others by sharing their knowledge, experiences and insight. Meaning is such that not only does it make sense to them, they speak out with some authority about health issues and give advice.

Health is now seen as an area of life worthy of investment, through meaningfulness they become motivated to make positive changes to their lifestyle. This process can be re-enforced by other people (manageability) and by their own cognitive reasoning (comprehensibility). People are realistic in acknowledging the limitations of the circumstances and their own abilities, but the challenge that is accepted as meaningfulness is clarified; health is no longer taken for granted and the importance of health becomes central. As shown in the narratives, commitment to positive change can be variable as other events influence behaviour and lifestyle, as life's stressors are coped with and levels of ascribed importance vacillate. In the long term, if meaningfulness is realised, then even if there is struggle in order to achieve the change, the commitment to the change is acknowledged as being significant and future adherence increased.

- **Comprehensibility**

The relative with heart disease is a constant reminder to people about the existence of heart problems and consequently the importance of health. Through acknowledging these issues, cognitive sense is achieved where understanding of the implications for the future and present are explicit. This is achieved through knowledge and understanding, where comparisons between themselves and the patient act as negative or positive re-enforcements.

Through the health promotion programme, the narratives show that greater comprehensibility has been achieved as people have been given the opportunity to make sense of what has happened to them and their family and to learn from the experience. They have been given the resources which could help them in the future, either as a result of health promoting lifestyle behaviour or cognitive understanding of the disease and its inherent influence on the family.

8.6 The health promotion programme

The second aim of the research was to see if a two year health promotion programme could result in an improvement in peoples' risk factors associated with CHD. Discussion about the health promotion programme can only occur after the narratives have been discussed because it is the experience of the initial acute event which gives meaning to the health promotion programme, cognitively, emotionally and motivationally. As shown in chapter six, positive lifestyle changes were made, and these translated into key changes for blood pressure, but not for improved cholesterol. Improvements in lipid profile would be required through medication; in this way both pathogenic and salutogenic orientations are seen as complementary.

The results clearly illustrate that positive behaviour changes have been made during the health promotion programme. However, these changes may only be slight, and may arguably not have been as a consequence of the programme. For example, one man bought a dog during the programme, his exercise levels improved, his weight remained stable and his stress levels reduced. Salutogenesis acknowledges the importance of the dog while illustrating to the person how this has positive benefits to health profile. It is the engagement of the person with the health promoting behaviour, from whatever source it may come, that is the role of the health professional / health facilitator. For the individual it is the small incremental changes that occur which can be adhered to in the short term and developed and built upon over their lifetime which will have the greatest long term influence upon their health status. These small changes should not be undervalued in the overall short-term assessment of the health promotion programme.

For some, change in many areas was not required, for others, negative changes were seen over the two year duration, as a possible consequence of other life stressors. For those with a strong SOC these stressors would only impact upon their health determinants in the short time, where coping mechanisms adopted would eventually result in restoration of the their health equilibrium.

8.7 Theory generation

The results from both narratives can be compiled and used to generate theory in relation to the salutary factors which feed into and strengthen the sense of coherence, through seeing an experience as manageable, comprehensible and meaningful. In this way a salutogenic theory can be proposed encompassing the results from the narratives and the health promotion programme.

Major stressors, such as the experience of having a parent or sibling diagnosed with heart disease can and does affect a person's SOC. Health professionals can help to make the experience a meaningful one, where their ability to cope with it is enhanced and their SOC is strengthened and their place along the continuum improves.

If the factors identified from the narrative interviews are seen as salutary factors, contributing, as discussed above, to the components of a sense of coherence, then as health professionals we can assist the family in seeing the event as manageable, meaningful and comprehensible. Consequently their position along the health ease / dis-ease continuum may be maintained or improved.

At the centre of this continuum is the individual, at either end is health ease and heart dis-ease. Interacting with 'self' in order to influence or maintain their place along this continuum is family, the patient, significant people and health professionals. These can now be shown as salutary factors where the link has been made between these and the components of the sense of coherence. Outside these immediate factors could arguably be shown to be the wider determinants of society and legislative policy within which all this is situated. Social factors can and do influence people, whether through social shifts, such as greater intolerance of smoking in public places, to impact through fashion, celebrities, employers, parents and teachers, as well as government policy and legislation.

This continuum model is based upon the results which have been generated from the narrative interviews of this study. Arguably other salutary factors exist, but the evidence for these would need to be confirmed through further research.

Using this continuum in a clinical setting the health professional needs to develop an integrated picture of how these salutary factors interact for the person, and how they can subsequently be used as a resource which will improve their health outcome. Using the transtheoretical model enables an assessment of the person's readiness to change specific behaviours, the salutogenic approach encompasses the factors which will enable, or detract, from the change process and long-term maintenance. Adopting a salutogenic approach to health promotion provides a global orientation, where personal circumstances can be understood and the context for the behaviour. The transtheoretical model directs focus onto specific behavioural issues, where change is advised, being undertaken or for which long term adherence is required. In this way the complimentary aspect of each model is integrated and a personalised assessment achieved.

Knowledge of these salutary factors can be identified during clinic sessions so that individualised care can be provided by the health professional, through personal insight and knowledge. Information regarding each salutary factor can be addressed, where the person is invited to provide details as they feel is appropriate, but which can be developed during subsequent sessions. The health professional has the opportunity to learn the circumstances of the familial diagnosis, extent of family and friend support, the person's existing knowledge of heart disease and the emphasis that they place upon their health and what issues are of personal importance. They may feel it is appropriate to involve key people, such as family members and spouses in future consultations, so that a family-centred approach is used, and the salutary resources are further utilised. The health professional needs to clarify their own role in this relationship, so that trust can be shown and a partnership approach developed. In this way patient centred care is achieved, where salutogenesis provides the basis upon which a personalised approach is developed.

In conclusion, the salutogenic orientation to health promotion ensures that a holistic approach is adopted for individuals, where the role and influence of salutary factors, health promoting resources (Antonovsky 1990), are considered in the assessment. Heart disease, as discussed in chapter two, is not due to single aetiology; it is multifactorial, predominantly brought about by individual behaviour and lifestyle. This makes salutogenesis an ideal theory to use when analysing the personal experiences of people in the context of heart disease. In order to reduce individuals' risk factors, it is necessary to identify the salutary factors which can enhance their sense of coherence, resulting in an improved lifestyle, enabling them to move towards health. Using a salutogenic approach helps to understand the reasons for adverse behaviour, while identifying health resources; in this way the health professional engages with people enabling them to make healthier choices.

8.8 Primordial and primary prevention

In order to unify the issues discussed from the findings of the research it is important to return to the focus of the study; prevention of heart disease. In the context of this thesis 'primary' prevention has been discussed and taken to mean an approach to prevention that happens before clinical manifestations of a disease appear. 'Primary,' according to the Oxford dictionary means 'of chief importance' (Pearsall 2001, p.1471). It is perhaps this definition of primary prevention which should be adopted in clinical practice; an approach to prevention which is of chief importance.

As shown by the Government white papers and reports discussed in chapter two, the current emphasis is on determinants of health and prevention of the causal factors associated with disease and ill health. Central to this preventative approach is the individual, individual choice, and individualised care; partnerships of care between people, health professionals, and government, are nurtured; additional causes of ill-health such as poverty, low income, social inequalities and poor housing, for example, are addressed within the approach. In conclusion, the focus of the National Health Service (NHS) is changing from a pathogenic orientation, which is dominated by the medical model of health, towards a salutogenic orientation, where salutary factors which impact upon people and affect their SOC are being identified and addressed. This change of focus is required in order to meet the medical needs of diseases which are related to lifestyle and personal behaviour.

In chapter three, the medical meaning associated with primordial, primary and secondary prevention strategies, were explained, showing how the distinction between these different levels is blurring, so that preventative cardiology has become the umbrella term. There is a need for greater distinction between primary and secondary prevention. Currently the emphasis for primary prevention appears, in the literature, to be upon pharmaceutical treatment for risk factor modification, such as aspirins, anti-hypertensives and statins; where future emphasis is upon reduction of inflammatory markers (Kuller 2001; Bonow 2002; Hansson 2005). A primordial approach aims to influence the emergence of these risk factors, thus negating the future need for extensive medication and treatments. Primordial prevention focuses upon the risk factors which result in dis-ease, such as poor diet, environmental factors, and social inequalities. It is an approach which focuses upon the fundamental determinants of health.

The discussion in this chapter has shown how salutogenesis can be used to generate a model where focus is upon salutary factors which contribute to health and health maintenance. In order to have the greatest impact regarding health promotion initiatives, it is the younger people who should consequently be involved, where after a life threatening, life changing and SOC altering event, such as the diagnosis of a parent with heart disease, there is an opportunity to strengthen the SOC and encourage positive lifestyle behaviour where emerging life patterns are still being developed. Health professionals can play a direct role in this process, through individualised assessment, policy support and NHS focus.

8.9 Summary

The chapter started with a discussion on salutogenesis and how a sense of coherence can be developed. The core components - manageability, meaningfulness and comprehensibility - were identified and each discussed in relation to the findings from the narrative interviews. A series of models have been shown which illustrate how the themes from the narrative are contextualised within CHD and within health, and how these two models can be combined to make a third. Having discussed the narrative themes within the SOC core components, the resulting salutary factors which influence the health promotion programme are illustrated, the relevance of the third model verified and its application in clinical practice shown.

The two aims of the study have been discussed and analysed in the context of salutogenesis and transtheoretical model of change. By examining the experience of people who have a diagnosis of premature CHD in their family, the exploration has moved on and shown how by using this information, salutary factors can be identified and health outcomes enhanced. Using a salutogenic approach to a health promotion programme, and through generalised knowledge of salutary factors, the outcomes of the programme can be improved. The final chapter will conclude with how these issues can be developed for the future within the NHS.

CHAPTER NINE

Conclusions

9.1 Chapter introduction

This chapter will clarify the salient aspects which have been learned from the research, illustrating how the original aims of the study have been met. The contribution that the research makes in terms of originality and extension to knowledge in this area are highlighted, in order that the future implications of the research, at local and national levels can be explored. The limitations of the study will be discussed, showing how these might have affected reliability and validity of the final outcomes. The conclusions drawn from the thesis are achieved with reference to the aims of the study.

9.2 What has been learnt from the research?

The way in which the relative with the diagnosis of coronary heart disease (CHD), friends, family along with health professionals, can influence the individual along a health ease / dis-ease continuum has been illustrated. The patient / relative with CHD may be seen as a catalyst to the changes, where meaningfulness, comprehensibility and manageability all need to be attributed to the experience in order to enhance their sense of coherence (SOC). The extent of the influence upon a person's sense of coherence will vary. Principally the variance will occur depending on their emotional and physical closeness to the person, their personal involvement during the acute event, seeing the patient in hospital, and the subsequent recovery or demise of the patient.

Family can play a key role in enhancing health status, through encouragement, support and showing personal interest; as a result families are often brought closer together following the diagnosis of CHD through sharing the experience of acute illness. After the acute event family want to support the patient (and each other,) emotionally and physically, where eventually, collective lifestyle changes may be made together. Friends and significant people can also influence this process where knowledge and experiences are exchanged. The individual already has knowledge regarding key lifestyle influences affecting CHD, but the research has shown that health professionals remain an important influence. Through the diagnosis of CHD, these people are more aware of their health, and the need to lead a healthier lifestyle in order to maintain their health and wellbeing for the future. Participants in the study showed realism and acceptance of the diagnosis; heart disease was something they had to live with in the family. This is important as it shows that health professionals should be proactive in engaging with people who have a premature family history of CHD. By engaging with these people health professionals will not be increasing their anxiety, but can help alleviate their worries, by providing education, support and where required medication.

This research has adopted a joint approach of primordial and primary prevention, where participants of all ages can benefit from lifestyle modification which enhances positive behaviour. Most require lifestyle advice and encouragement, while some, in addition, require medication, for example to treat high blood pressure or high cholesterol. If the salutogenic model is used the consideration for the salutary factors which influence a person on their health ease / dis-ease continuum needs to embraced. There is also a subtle change of emphasis away from 'risk factors' to 'salutary factors,' where the positive requirements for a healthy life are re-enforced, rather than negative ones. While accepting that at times life's stressors dominate, so that negative behaviour may prevail as part of the coping mechanism. CHD is a disease related to lifestyle, it is a person's behaviour which influences the pathogenesis of this disease. By encompassing the salutogenic approach these lifestyle issues are embraced and can assist movement towards the health end of this continuum. In order to achieve this, as part of a clinic consultation, it is important to understand peoples' attitude and the reasons why they adopt certain behaviours. It is not sufficient to tell people to quit smoking, without trying to understand why they smoke, and then to address the cause, before looking at the resultant negative behaviour. An approach recommended 25 years ago by the Royal College of General Practitioners:

> "General practitioners may need to ask more about why individual patients began and continue to smoke *(comprehensibility)*, whether and how they themselves have tried to stop, their reasons for failure *(meaningfulness)*, and what support their spouses can give *(manageability)*." (RCGP 1981, p. 8)

This statement, to which has been added the core components of SOC in italics, clearly illustrate a salutogenic approach to a person's smoking, where the persons' circumstances are integral to the consultation. This is an approach which has not been universally adopted under the current general medical services, but which at least was recognised 25 years ago by the RCGP as being as significant to a preventative approach to coronary artery disease.

People of all ages were interested in being involved and showed commitment to a two year programme of health promotion; a programme which used salutogenic and transtheoretical models for health promotion. For some it took two years to make adjustments to their lifestyle, but positive changes to alcohol consumption, diet, weight, psychosocial stress and physical activity can be achieved. Yet these lifestyle changes are not universally reflected in improvement to blood lipids, or translated into reduced risk according to current Joint British Society 2 (JBS 2) cardiovascular risk scores used in clinical practice (Wood et al., 2005). Pharmaceutical treatment for blood pressure control and for improvement in lipid profile, is integral, and necessary as part of the successful medical management of these people.

The diagnosis of CHD in a close family relative and the acute event that preceded it, is a stressful and life changing event. However, as Antonovsky states, stressful events in life do not need to be detrimental to people's health. Stress can result in enhancing and strengthening a person's sense of coherence, in the same way that pathogenic infections can enhance the physical immune system. This event provides a unique opportunity to engage with people giving them an opportunity to share and learn from their experience; to improve their lifestyle and behaviour; ultimately move towards, or maintain their position along the health ease / dis-ease continuum.

9.3 Looking to the future

Three areas for future focus will be discussed which show the importance of clarity towards a preventative approach, where screening can be achieved and small changes result in big differences.

- **Primordial and primary prevention**

Preventative cardiology may be the current term of choice, but it is important that primary prevention should not be forgotten, and that primordial prevention is used to clarify the distinction between these two levels. Primary and primordial prevention should be the approaches of principal and chief importance, where resources are spent on addressing the lifestyle issues and personal behaviour that are the causal factors of disease, so that a pre-morbid state may be achieved.

- **Screening opportunities**

As discussed this population, with a familial history of CHD are easily identifiable. Unlike some screening methods (for example some cancers) there is no expensive screening process or investigation required in order to identify those at cardiovascular risk, enabling a preventative strategy to be adopted with minimal monetary costs. Arguably there is a moral duty to engage with this group. In the past they have been identified as high risk, in the CHD national service framework (NSF) (DH 2000) and current JBS2 guidelines (Wood et al., 2005), at present however, no clear guidelines have been issued which guide clinical practice for these people. This research helps to provide supporting evidence for the need of such guidelines and how these might be of use to individuals and practitioners.

- **Making a difference**

The impact model (Capewell et al., 2000; Critchley & Capewell, 2002; Unal et al., 2003; Unal et al., 2005; Ford et al 2007) has proved that mortality reductions in CHD have been due largely to changes in risk factor modification. The report of the National Heart Forum (McPherson et al., 2002) has illustrated how small changes to risk factors can result in large changes to prevalence in the population. The responsibility for encouraging change should not lie solely with the government, through fiscal and legislative policies; health professionals, should constantly encourage patients towards a healthy lifestyle, where small lifestyle changes can result in substantial differences. Whether healthy lifestyle clinic sessions are established or the encouragement comes as part of ongoing consultations, the role of health professionals in this process is vital and integral.

Primary and primordial prevention remain of principal importance; a salutogenic orientation towards primary and primordial prevention is adopted which embraces a holistic approach, encompassing lifestyle issues, while remaining complimentary to the pathogenic orientation. In this way a real contribution can be made to reduce the incidence of CHD for individuals, in families, and whole populations, where the hereditary link associated with increased familial risk due to repeated behaviour patterns and shared environment, may be broken, and future generations can live free of the cardiovascular legacy.

9.4 Limitations of the research

There are four main limitations to the research which are listed below.

- **Single centred study**

This was a single centred study, established in a district general hospital where the researcher was employed. The hospital had an extensive research programme with practitioners who support the programme, recruitment into research studies was integral to the cardiology department. In other hospitals the process of screening and recruitment would have varied, resulting in different recruitment statistics. Those recruited into the study did represent a diverse population in terms of age, social class and sex, but all who completed the study, were white Caucasians. In conclusion the study sample is reflective of the population within (predominantly) the catchment area of the hospital; it should be acknowledged that a sample population from different regions would reflect regional and locality variations.

- **Small numbers in the programme**

The results of the health promotion programme are based upon the 20 participants who completed the programme. This was a small sample size upon which to make inferences into the wider population quoting statistical significance. However, it is a mixed methods study, which has enabled the in-depth data from multiply sources to provide enhanced meaning and relevance to the findings, supporting the theory that has been suggested and discussed.

- **Hawthorne effect**

The participants knew the health promotion programme was part of a research study, and that an aim of the study was to test the effectiveness of the programme. The wish for a positive outcome for the study, may have influenced (consciously and sub-consciously) their response to the programme. They may also have been subject to recall bias, where inaccurate recall produces inaccurate findings, but a wish to show positive lifestyle changes may have affected their response. In part, however, this can also be true in clinical practice, so is not solely an issue for the research.

- **Research bias**

The study has been designed and conducted by one person. When the researcher is the same person who is conducting the research there can be bias, where a wish for a certain outcome can influence the procedures. The researcher has extensive research experience and the necessity for collecting accurate, reliable data is fundamental. Data collected from the health promotion programme were recorded in hospital notes and sent to the general practitioner (GP). Personal treatment of all cardiology research participants was the same, irrespective of the study. Specialist knowledge or procedures were not part of the study protocol, ensuring that key elements of the programme could be replicated in other clinical settings.

- **Use of the sense of coherence scale questionnaire**

The sense of coherence questionnaire was completed by participants as part of their final visit. As previously discussed Antonovsky (1987) stated that a person's SOC is developed during their first three decades of life. Some studies have shown that SOC can be altered (Eriksson and Lindstöm, 2005; Morrison and Clift, 2005), and since a family diagnosis of CHD can be a major life changing event for a family, this itself could alter a persons SOC. On reflection it would have been valuable to measure the SOC at the start and the end of the study in order to identify changes over the two years, with emphasis upon participants who were under 30 years. During the early stages of the research the potential efficacy of the questionnaire had not been appreciated. It had also been an aim of the study to ensure that the use of questionnaires was limited, so that study procedures were reflective of clinical practice, and the participants did not feel overwhelmed with questionnaires at each study visit.

9.5 Screening the family: implications and challenges

The study has shown that there is potential to engage families in a health promotion programme of this kind. The recruitment and retention figures have illustrated that people of all ages express a desire to be involved in a programme where they have assess to professional assistance and guidance. This population was identified as a high-risk group of people for future manifestation of CHD, but one for which there is a missed opportunity (Chow et al., 2007). It has been demonstrated that people are keen to be involved at different stages in their life, and those who initially refuse the invitation for a consultation should not be excluded for the future, where invitations can be re-issued at later times.

This study population were identified within a hospital setting, predominantly through in-patient admissions when the diagnosis was made. This is an ideal method of screening as it happens at the point of diagnosis. Sensitivity is required when talking with both patients and their relatives, where assumptions regarding paternity should not be made and a need to guard against adding to their worries at this stressful time. As with all screening procedures, once the screening process has started it is important that adequate clinical follow-up for the person is provided.

There are four possible strategies that could be explored with these people. These will be discussed individually.

- **Personalised choice**

People could be given information to highlight the familial risk, with brief details about lifestyle issues, and a recommendation to contact their GP for further assessment and advice. This approach has been established and trialled by a cardiac network. A selection of hospital trusts were involved in the establishment and set-up of the project. Following the positive response and feedback from both the rehabilitation teams and respondents, is now being used within the Trust where this research had been undertaken. This approach, involves minimal work from the hospital, it provides the cardiac rehabilitation team a tangible piece of information to give patients and / or their families. Responsibility for further action remains with the individual; an approach reflected in the Governments' White Paper 'Choosing health' (DH 2005).

- **Primary care**

Would involve referrals made from the hospital to the individual family members' GP. A list of adult children and siblings would be collected from the patient, having explained why the names and details where needed, and ensuring that patients and their relatives give consent to the information being forwarded to the GP. This scenario ensures GPs had relevant information about people registered under their care. However, hospitals making GP referrals about people for whom they have no responsibility of medical care is one fraught with difficulties, such as confidentiality.

This process would generate substantial electronic paperwork, for an exercise which might not produce valid outcomes, for example, if there was no further action taken by the GP, or if the relative did not wish to take further action.

- **Secondary care**

Where family members are seen within the hospital and involved in a joint programme of care within the cardiac rehabilitation programme. EuroAction study, involved the spouses of cardiac patients, and family members if they lived at the same address, in an integrated rehabilitation programme. This programme provided complete risk assessment, lifestyle advice and medication prescribing, from a multi-disciplinary team which included doctors, nurses, dieticians and physiotherapists who took control of the medical care and management of the relatives as well as the patients. This approach may be financially unfeasible; monies for the person's participation in the programme would need to come from the primary care trust (PCT). The PCT would argue that they had not requested this service nor was it essential on clinical grounds.

- **Joint approach**

A less intrusive approach could be one where first-degree family members, irrespective of where their lived, could be invited to attend the cardiac rehabilitation programme (Wrigley and Wilkinson, 2007). The cardiac rehabilitation programme could focus on lifestyle behaviour such as diet, weight, physical activity, smoking and psychosocial stress. Further checks such as lipids and blood pressure could be undertaken, but prescribing for these conditions would remain the responsibility of the GP. The GP would be informed, once permission had been given, when the relative joined the programme, and kept informed if necessary during the programme, and updated at the end. The cardiac rehabilitation programme would be an integrated programme for preventative cardiology where families could participate together. Cardiac rehabilitation programmes take place in a variety of settings, including hospitals and the community. A community cardiac rehabilitation approach would be in line with 'Our health, our care, our say,' Government White Paper which advocates community centred care (DH 2006a).

The role of primary care trusts in these strategies is central, along with motivation from the relative to be pro-active in assessing their lifestyle and cardiovascular salutary factors. These strategies illustrate approaches where the emphasis for responsibility varies between the individual, secondary and primary care, but, where the role of health professionals is central for people's ongoing care and, where necessary, medical management. As shown in the thesis, there is no short term answer or solution, time needs to be invested in these people. The approach of a nurse-led and doctor supported health promotion programme has been shown to be effective in improving lifestyle behaviour. In reality without financial incentive and accountability, for example under the general medical services and CHD NSF, provision of care for these people will not be formalised into daily clinical practice.

9.6 What has this research contributed?

This question addresses the key issues and findings of the research. Key points which answer the question will be selectively identified, illustrating how these have answered the aims of the study.

- The familial experience of being diagnosed with premature CHD has been explored, and key themes identified. By analysing the experiences of these people, salutary factors have been illustrated. Knowledge of these salutary factors may enhance the clinical encounter between health professionals and those at risk.

- This is a high risk group of people who have seldom been the focus for preventative research. The cardiovascular diagnosis is rarely a new one for these people and their families. Irrespective of when the familial diagnosis was made, these people are interested and keen to participate in a health promotion programme.

- Participation in a two year health promotion programme providing education, lifestyle assessment, and practical support, can result in positive changes, leading to healthier lifestyle.

- Salutogenesis can be used as an approach to health promotion, and as a theoretical framework within which the findings of the qualitative and quantitative preventative research can be analysed.

- Strategies for screening and identification of these people has been illustrated. Possible approaches have been discussed which consider ways in which these people can subsequently be involved for future care and management.

- Smoking and physical assessment activity scores have been developed which, as a standard data collection tool, can ensure parity of audit data collected in clinical practice.

- This varied population was interested in increasing their knowledge about CHD and in improving their lifestyle profile, though positive behavioural changes and with pharmaceutical medication for blood pressure and cholesterol control.

In conclusion, this research has many aspects which are original and which can contribute to our understanding of what it means to have a familial diagnosis of CHD. By using a salutogenic approach, it has been illustrated how insight into the personal experience makes an important contribution for developing future primordial and primary prevention strategies for this group. Salutogenesis can be used to improve our understanding of these issues by identifying salutary factors, which enable people to cope with stressors associated with CHD. Treating people in a salutogenic orientation ensures that respect and autonomy are given while encouraging and supporting positive healthy lifestyle choices.

9.7 Future Research

There are three avenues along which future research could progress. Firstly, the identification of salutary factors and testing their usefulness in clinical practice. The salutary factors in figure 8.5 are those which were identified from the narrative themes. Having recognised these salutary factors the way in which these can be integrated effectively in clinical encounters could be studied, so that their value as health resources in influencing the health outcome can be quantified. Further research narratives from this familial CHD population may also identify additional salutary factors.

Effective screening and engagement is an essential first step in developing a preventative approach for these people. Different strategies have been suggested; evaluation of these strategies along with exploration of other possible approaches would be needed in order to identify effective screening which is suitable and meets the needs of local populations and circumstances. Having identified and engaged with these people the establishment of a health promotion programme is required, where collation and analysis of their lifestyle assessment data and medical management would be essential in the evaluation process. There are no short-term solutions, as illustrated some people need time to make adjustments to their cognitive evaluation of a problem, so that sustained positive behaviour can occur. Research in the future will need to develop long-term strategies, ensuring that health determinants and outcomes can be accurately measured and assessed, for example the Biobank study, which is currently in its recruitment phase.

Biobank, is a United Kingdom (UK) prospective epidemiological study aiming to recruit 500,000 healthy people, and follow their health progress over many years. The study is researching the impact on health of lifestyle, environment and genes. Where through personal follow-up and communication, along with medical and health-related records, the identification of those who later develop disability and life threatening conditions can be studied. The study aims to identify factors which are related to lifestyle, environment, genes and 'luck,' so that future preventative strategies may be identified. In addition it is looking at linking to other research, so that a collective approach to learning and theory generation may be shared and embraced (Biobank UK 2006).

This thesis has shown that people are interested in participating in a health promotion programme, and can make positive lifestyle changes. The challenge for the future will be how best to channel this into a productive programme of care. Research and initiatives could be established which build upon the recommendations made above, regarding the screening and involvement of family members in a community cardiac rehabilitation programme, or health promotion clinics in primary care.

9.8 Reflexivity

The joint role of researcher and clinician can produce bias when there is personal investment in the research. However, as a researcher involved in varied cardiology studies, the essential requirement to collect accurate data which reflects the reality of the participant's circumstances and clinical encounter, and the need to limit research bias, is a fundamental principal and practice. It is the research process, that leads onto the journey of exploration and discovery that is, I believe, the exciting part of research. If you try to influence this process then your own predetermined conceptions are all that you will end up with. If you are not true to the research, then you are being false to yourself and your initial point of enquiry, to those who agreed to participate - because they also believed in the research – and to the conclusions and recommendations that you develop.

In my opinion and experience, research is exciting, even with the constraints of today's research governance. Research needs to have some flexibility because it is a dynamic process. Changes are made to the original protocol, but not the original research questions; this allows for a natural evolutionary process to occur as time, understanding and recognition of the salient features which are integral to the study and reflective upon it, develop and grow.

It has been an advantage to be both researcher and clinical nurse. A relationship between me and the participants was developed, where mutual trust and respect enhanced the dialogue during the health promotion programme and the narrative interviews; this type of positive relationship is natural between patient and health professional. I have been entrenched within the research, from conception, to implementation, to analysis and finally theory generation. Complete knowledge of the study and those involved has enabled me to produce accurate and truthful findings based on this wealth of experience and complete involvement. It is impossible to completely remove all bias when the researcher is also the nurse practitioner; the role of facilitator remains entrenched within the whole process. It is my belief that this does not affect the validity of the qualitative findings, because theory is being generated not tested. However the results of the health promotion programme which is testing the value and worth of the approach may be influenced by my own expert knowledge, enthusiasm and personality. I have, however, attempted wherever possible to minimise this influence. For example the education folder which I compiled could be reproduced and used by other nurses conducting these health promotion sessions, and the leaflets given were validated ones from the British Heart Foundation.

The research needed to be reproducible in other clinical settings and therefore keeping specialist knowledge and personal enthusiasm to a minimum was essential. Nevertheless it was not always easy to achieve where my own personal interests came through, for example with regard to cooking and physical activity. These are inescapable facts of all clinical encounters and are reflective upon the real world clinical setting where similar individual bias from the health professional will exist. Arguably all health professionals have their own set of hidden skills and talents which they bring to a clinical encounter, along with their hidden prejudices and insecurities. My own skills are that I believe myself to be a good and empathetic listener, and am genuinely interested and care about the welfare of my patients and research participants. My insecurities are based around my lack of knowledge outside cardiology, but if someone asks me something I do not know, I say so and find the answer. My own role of nurse and researcher are well-established in my routine practice that I rarely question these roles. This is primarily because the well-being of patients is a paramount consideration at all times beyond the research, and I view myself principally as a nurse rather than a researcher, in the context of the clinical encounters for this thesis and my daily work.

The research has been informed by the participants' narratives, it was their stories and their perspective of their personal experiences which have formed the focus of the research; it has been my role, as researcher, to facilitate the telling of these stories and the sharing of these experiences without undue influence.

9.9 Research dissemination

The research has been presented at conferences and study days, a list of which appears in Appendix XX, and two publications written (see Appendix XXI and Appendix XXII). An invitation had been issued to be involved in a project which aimed to raise awareness for people with a premature CHD family history. A post card was designed to be given to first-degree relatives (see Appendix XXIII) and building upon the interest generated during the screening phase of the study, our cardiac rehabilitation team took part in this pilot project, and have continued to distribute the post cards following positive results.

9.10 Summary

This final chapter has shown how the original aims of the study have been answered and what has been learnt from the research. Issues regarding screening strategies for first-degree relatives of those diagnosed with premature heart disease have been discussed and recommendations made for future research which can validate these recommendations.

The original contribution that this thesis makes to knowledge in the field of primordial and primary prevention for coronary heart disease has been discussed. Through exploring the experiences of first-degree relatives salutary factors have been identified which could be used to enhance health outcomes as part of a health promotion programme.

APPENDIX I

ORIENTATION TO LIFE QUESTIONNAIRE

Salutogenesis: Orientation to Life Questionnaire

By: Aaron Antonovsky

Here is a series of 29 questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number which best express your answer, the numbers are 1 to 7. If the statement nearest to 1 best expresses your answer, please circle at this end, or if the stament nearer to 7 is true, please circle at this end of the scale instead. Please give only one answer to each questions.

1) When you talk to people, do you have the feeling that they don't understand you?
Never 1 2 3 4 5 6 7 Always have this feeling

2) In the past, when you had to do something which depended upon cooperation with others, did you have the feeling that it:
Surely wouldn't get done 1 2 3 4 5 6 7 Surely would get done

3) Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?
You feel that they're strangers 1 2 3 4 5 6 7 You know them very well

4) Do have the feeling that you don't really care about what goes on around you?
Very seldom or never 1 2 3 4 5 6 7 Very often

5) Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?
Never happened 1 2 3 4 5 6 7 Always happened

6) Has it happened that people whom you counted on disappointed you?
Never happened 1 2 3 4 5 6 7 Always happened

7) Life is: Full of interest 1 2 3 4 5 6 7 Completely routine

8) Until now your life has had:
No clear goals or purpose at all 1 2 3 4 5 6 7 Very clear goals and purpose

9) Do you have the feeling that you're being treated unfairly?
Very often 1 2 3 4 5 6 7 Very seldom or never

10) In the past ten years your life has been:
Full of changes without your knowing what will happen next
1 2 3 4 5 6 7 Completely consistent and clear

11) Most of the things you do in the future will probably be:
Completely fascinating 1 2 3 4 5 6 7 Deadly boring

12) Do you have the feeling that you are in an unfamiliar situation and don't know what to do?
Very often 1 2 3 4 5 6 7 Very seldom or never

13) What best describes how you see life:
One can always find a solution to painful things in life 1 2 3 4 5 6 7
There is no solution to painful things in life

14) When you think about your life, you very often:
Feel how good it is to be alive 1 2 3 4 5 6 7 Ask yourself why you exist at all

15) When you face a difficult problem, the choice of a solution is:
Always confusing and hard to find 1 2 3 4 5 6 7 Always completely clear

16) Doing the things you do every day is:
A source of deep pleasure and satisfaction 1 2 3 4 5 6 7 A source of pain and boredom

17) Your life in the future will probably be:
Full of changes without your knowing what will happen next 1 2 3 4 5 6 7
Completely consistent and clear

18) When something unpleasant happened in the past your tendency was:
"to stress yourself out" about it 1 2 3 4 5 6 7 to say " ok that's that, I have to live with it " and go on

19) Do you have very mixed-up feelings and ideas?
Very often 1 2 3 4 5 6 7 Very seldom or never

20) When you do something that gives you a good feeling:
it's certain that you'll go on feeling good 1 2 3 4 5 6 7
it's certain that something will happen to spoil the feeling

21) Does it happen that you have feelings inside you would rather not feel?
Very often 1 2 3 4 5 6 7 Very seldom or never

22) You anticipate that your personal life in the future will be:
Totally without meaning or purpose 1 2 3 4 5 6 7 Full of meaning and purpose

23) Do you think that there will always be people whom you'll be able to count on in the future?
You're certain there will be 1 2 3 4 5 6 7 You doubt there will be

24) Does it happen that you have the feeling that you don't know exactly what's about to happen?
Very often 1 2 3 4 5 6 7 Very seldom or never

25) Many people - even those with a strong character - sometimes feel like losers in certain situations. How often have you felt this way in the past?
Never 1 2 3 4 5 6 7 Very often

26) When something happened, have you generally found that:
You overestimated or underestimated its importance 1 2 3 4 5 6 7
You saw things in the right proportion

27) When you think of the difficulties you are likely to face in important aspects of your life, do you have the feeling that:
You will always succeed in overcoming the difficulties 1 2 3 4 5 6 7
You won't succeed in overcoming the difficulties

28) How often do you have the feeling that there's little meaning in the things you do in your daily life?
Very often 1 2 3 4 5 6 7 Very seldom or never

29) How often do you have feelings that you're not sure you can keep under control?
Very often 1 2 3 4 5 6 7 Very seldom or never

Thank you!

APPENDIX II

A5 RECRUITMENT LAMINATE SHEETS

Outline of the Project

Informal Interviews

- one at the very beginning of the project and a second at the very end of the project. The aim of the interviews is to explore the experience for the individual when their sibling or parent is diagnosed with CHD and what it means to them.

Primary prevention risk factor clinic

- Participants will be asked to attend a minimum of 5 six monthly hospital based clinic appointments.
- Sessions will involve education and risk assessment
- A full biopsychosocial assessment will be made. Should they have modifiable risk factors that they wish and need to modify further appointments can be made as required to provide support and assistance.
- If referrals to other health care professionals are required these will be made accordingly.
- Partners / husbands / wives will be included in these sessions if requested by the participant. Inclusion of family members is encouraged.

Summary

The study will involve adult offspring and siblings of patients newly diagnosed with premature coronary heart disease. These adult children and siblings now have a family history of heart disease placing them at increased risk of developing heart disease themselves. The study programme will involve education, risk assessment and support for the participants while endeavouring to reduce their overall risk for developing heart disease.

The study will also explore the experience for these individuals of being diagnosed as having coronary heart disease in their family, how they come to terms with this diagnosis and what it has meant to them and their families.

Martha J Wrigley

Primary Prevention for Coronary Heart Disease:

Developing and evaluating a primary prevention health promotion programme for adult offspring and siblings of those with overt coronary heart disease.

Step 1 ~ Identify patient:

- diagnosed with overt CHD
  - → STEMI
  - → confirmed angiography
  - → PCI or bypass surgery
- male aged 55 or less
- female aged 65 or less

Step 2 ~ Discuss project with patient

- check Inclusion & Exclusion criteria

Step 3 ~ Gain verbal consent to pass details onto Martha

- (she will then discuss project further with patient and send a Summary Information Sheet to them for them to forward to their brothers or sisters or children)

Inclusion Criteria

- ➢ The sibling, or child, of a patient who has been diagnosed with premature heart disease
- ➢ Age 18 years or more
- ➢ Able to give informed consent
- ➢ Able to attend follow-up appointments
- ➢ Subjects with a good command of English

Exclusion Criteria

- ➢ Terminal illness
- ➢ Known to have overt CHD

APPENDIX III

INFORMATION SUMMARY SHEET

Information Summary Sheet

Primary Prevention of Coronary Heart Disease: Developing and evaluating a primary prevention health promotion programme for adult offspring and siblings of those with overt coronary heart disease.

This sheet contains information about a research project which is being undertaken at ********** NHS Hospital Trust by Martha J Wrigley, Cardiac Research Sister. This sheet has been designed to give you a brief overview of the project. If you would like more information or an informal discussion please contact Martha at ******* Hospital on **** ******.

One of your parents or siblings has recently been diagnosed with heart disease or had a heart attack. If it is your father or brother and he is less than 55 years old or your mother or sister and she is less than 65 years old, this is then classified as premature. As your parent or sibling has premature heart disease, research has shown, that you are now at increased risk of developing heart disease.

Heart disease affects 25% of the population in the UK and is a major cause of death and illness. As it is so widespread and because you are at increased risk from heart disease yourself, it is thus important that you are informed of what heart disease actually is, and how you can best reduce the risk or prevent it from affecting your own life.

This project will involve you in an active programme of education and support which aims to reduce your chances of developing heart disease. The effectiveness of this strategy will then be evaluated and forms the basis of the research.

There are "risk factors" that are associated with people developing heart disease. Some risk factors we have control over and can do something about. These include such things as diet, smoking, and exercise. Unfortunately there are also risk factors over which we have no control. These include such aspects as age, gender and family history. The more risk factors a person has, the greater their chances are of developing heart disease.

The main purpose of this study is to produce a health promotion strategy for those at risk of developing coronary heart disease. Through a programme of identification and education the aim is to help people understand heart disease and its associated risk factors while supporting them to make any appropriate lifestyle changes that they might wish to make.

A secondary aspect of this study is to attempt to understand the experience that an individual goes through when their parent or sibling is first diagnosed with heart disease and the challenges that they themselves face when making possible changes to their lifestyle.

If you decide to take part in this study you will be involved in the project for a minimum of two years.

You will be involved in a "risk factor prevention programme." This will involve an initial session of explanation and assessment, where a full screening will be carried out to assess your risk factors for heart disease. Physiological measurements will be done, such as your blood pressure, weight and height, plus a blood test. Other factors such as smoking, diet, alcohol intake, work and leisure activities will all be discussed. Once this assessment has been done it will be discussed with you and explained in full. This will form part of your medical notes, and any areas of concern (such as raised blood pressure) will be reported to your own GP. Your GP will be informed of your involvement in this study ensuring, that as your primary physician, he is happy for you to participate. He will be informed of the details of your risk factor assessment.

If you feel you would like to make any changes to your current lifestyle the research nurse will be available to assist you in this process. **You are under no obligation to make any changes to your lifestyle if you do not want to.** For those who do want to make changes, follow-up appointments will be made as required. For those who do not need to make any changes, or who prefer not to at present, a six month follow-up will be arranged, with subsequent six monthly follow-ups, where again a full risk factor assessment will be made and discussed. This will take place in the hospital.

The secondary aspect of the study will involve two informal interviews. The first interview will take place before any risk factor assessment is made, the second will take place at the end of the study. Each session will last about an hour. The aim of the informal interview is to explore the experience for you when your parent or sibling was first diagnosed with heart disease and what it has subsequently meant to you. These two informal interviews will be taped, but the tapes will be anonymous and only the researcher will have access to this information.

There are no lifestyle restrictions. If lifestyle changes are suggested, then it is up to each individual to decide to make these changes. If you do not wish to alter your lifestyle, you are under no obligation to do so. However if you do, then full support will be given, which may involve referral to other health professionals or specialist clinics.

In summary, you will be asked to attend four six monthly follow-up appointments, give two private and confidential informal interviews, plus complete an evaluation questionnaire.

Many thanks for reading this information sheet.

APPENDIX IV

PARTICIPANT INFORMATION SHEET

Participant Information Sheet

Primary Prevention of Coronary Heart Disease:
Developing and evaluating a primary prevention health promotion programme for adult offspring and siblings of those with overt premature coronary heart disease.

You are being invited to take part in a research project being undertaken by Martha J Wrigley, the Cardiac Research Sister at ******** Hospital. This study forms the basis for her Doctoral thesis (PhD), which she is undertaking at the University of ********.

This project will involve you in an active programme of education and support which aims to reduce your chances of developing heart disease. The effectiveness of this strategy will be evaluated and forms the basis of the research. Before you decide to take part in this study it is important for you to understand why this research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with friends, relatives, and your GP or nurse if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Coronary heart disease (CHD) is the disease process that leads to the formation of fatty deposits, or atherosclerosis, in the arteries which supply blood to the heart muscle. When the circumference of these arteries becomes narrowed, due to these fatty deposits, the blood supply to the heart muscle is reduced. A person is then at risk of developing angina or of having a heart attack.

There are "risk factors" that are associated with people developing heart disease. Some risk factors we have control over, these are termed "modifiable risk factors," and include such aspects as diet, smoking, and exercise. Unfortunately there are also "un-modifiable risk factors" over which we have no control. These include such aspects as age, gender, diabetes and family history. The more risk factors a person has, the greater their chances are of developing heart disease.

Heart disease affects 25% of the population in the United Kingdom and is a major cause of death and disease. Therefore it is important that everyone is aware of the risk factors that are associated with its development. Especially when so many people in this country suffer the physical pain and limitations that heart disease causes in the day-to-day lives of both their own and their families.

The main purpose of this study is to produce a health promotion strategy for those at increased risk of developing coronary heart disease. By identifying people who have un-modifiable risk factors for heart disease we aim to look at the risk factors over which they do have control and by, if necessary, adjusting these aspects of their lifestyle. We can then reduce their chances of developing heart disease in later life, or at least reduce its severity. Through a programme of identification and education we aim to help them understand heart disease and its associated risk factors while supporting them to make any appropriate lifestyle changes that might be required and desired.

A second aspect of this study is to attempt to understand the experience that an individual goes through when their parent, or brother or sister, is first diagnosed with heart disease and the challenges that they themselves face when making possible changes to their behaviour and lifestyle.

Why have I been chosen?
You have been chosen because your parent or brother or sister has been diagnosed with premature heart disease.

Premature heart disease means that either your father or brother, mother or sister has been diagnosed with heart disease and they are below the age of 55 or 65 respectively. As one of your parents or siblings has premature heart disease this puts you at a greater risk from developing heart disease. Thus it is important that you are made aware of the disease and the risk factors associated with its development.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign an agreement to participate. If you decide to take part you are still free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

What will happen to me if I take part?
If you decide to take part in this study you will be involved in the study for a minimum of two years.

You will be involved in a "risk factor prevention programme." This will involve an initial session of explanation and assessment, where a full screening will be carried out to assess your risk factors for heart disease. Physiological measurements, will be done as required, such as your blood pressure, weight and height, plus a blood test. Other factors such as smoking, diet, alcohol intake, work and leisure activities will all be discussed. Once a risk factor profile has been drawn up this will be discussed with you and explained in full. This will form part of your medical notes, and any areas of concern will be reported to your own doctor.

If you feel you would like to make any changes to your current lifestyle the research nurse will be available to assist you in this process. **You are under no obligation to make any changes to your lifestyle if you do not want to.** For those who do wish to make changes, follow-up appointments will be made as required. For those who do not need to make any changes, or who prefer not to at present, a six month follow-up will be arranged, with subsequent six monthly follow-ups, where again a full risk factor assessment will be made and discussed. This will take place in the hospital. Other family members such as your husband / wife / boyfriend or girlfriend are invited to attend these appointments with you.

A second aspect of the study will involve two informal interviews. The first interview will take place before any risk factor assessment is made, the second will take place at the end of the study. Each session will last about an hour. The aim of the informal interview is to explore the experience for you when your parent or sibling was first diagnosed with heart disease and what this has subsequently meant to you. The discussion may take place in your own home or in the hospital. Whichever setting is most convenient and comfortable for you.

These two informal interviews will be taped, but the tapes will be anonymous and only the researcher will have access to this information. You will be asked to sign a second consent form after this discussion to ensure that you are still happy for that information to be used.

What do I have to do?
There are no lifestyle restrictions. If lifestyle changes are suggested, then it is up to each individual to decide to make these changes. If you do not wish to alter your lifestyle, you are under no obligation to do so. However if you do, then full support will be given, which may involve referral to other health professionals or specialist clinics.

You are only requested to attend four six monthly follow-up appointments, give two private and confidential informal interviews, plus complete an evaluative questionnaire at the end.

What is it that is being tested?
The process of identification, education and support as a strategy for preventing heart disease is being tested and studied. It is also the intention of the research to develop greater understanding of this whole process as it is experienced by the individual.

Are there any possible disadvantages or risks from taking part?
The main concern we have for those willing to take part in the study is the stress and worry that coming to terms with a diagnosis of heart disease in the family may have upon them. Which is why we feel it is important that people are informed about the problem and that they are given support and advice in coming to terms with this. This is also why the interviews are an significant part of the study as this give us valuable insight into the individuals own experience.
A small risk is the blood test which can carry a minimal risk of bruising.

What are the possible benefits of taking part?
The main benefit is that the individual will have greater understanding of heart disease, its development, risk factors and implications. They will also receive a full screening with regard to their risk factor profile. If there are any modifications that should be made to their risk factor profile assistance and support can be given to achieve this.

It is hoped that the study will help those taking part in it. However this cannot be guaranteed. The information we get from this study may help us to understand the individual's perspective of the condition and assist us in developing an effective strategy to decrease peoples chances of developing heart disease or reduce its severity.

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of this research will be kept strictly confidential. The details of your risk factor profile will form part of your medical

notes and your GP will be informed of your participation in the study, ensuring that as your primary physician, he is happy for you to participate. Some correspondence may be required between the researcher and other health care professionals, but this will be of a medical and confidential nature only. Within the research study itself you will not be named and no information will be recognizable as yours.

The data collected from your informal interviews will be completely confidential between you and the researcher, your name will not appear on this information.

What will happen to the results of the research study?

The study is part of a PhD thesis and will written up under strict academic criteria, and marked accordingly by the University of ********. Individuals will not be identifiable in the study. A copy of the final thesis will be available from the University library. The findings of the study will be reported in an appropriate nursing or medical journal.

Who is organising and funding the research?

This is an academic study and no funding apart from tuition fees is being sought. All other expenses incurred are being met by the researcher herself. A few hours each week is being made available to the researcher so that she can undertake this study along with her usual activities.

Who has reviewed the study?

The study has been approved by Dr *** ****** plus the other Consultant Cardiologists at ********** NHS Trust, and reviewed by the trust's own ethics review board. The study has been also been reviewed by the University of ******* and by the *** *** *** Research Ethics Committee.

Contact for further information?

Martha J Wrigley Cardiac Research Sister, ****** Hospital – **** *****

Many thanks for reading this information sheet.

If you would like further information or a discussion before reaching a decision please do not hesitate to contact me. A group discussion can be arranged between yourself and any other family members if this would be helpful. If you decide to take part in this study you will be given a copy of this information sheet to keep and a copy of your signed consent form.

APPENDIX V

AGREEMENT TO PARTICIPATE CONSENT FORM

Primary Prevention for Coronary Heart Disease Research Study

Researcher - Martha J Wrigley

Ethics Study Number: PRO/21/02

Agreement to Participate - Consent Form

Please initial each box

1. I have been given a Participant Information Sheet, and all relevant issues have been discussed with me. ☐
2. I have been given an opportunity to discuss the study and ask any questions. ☐
3. I understand that I will be asked to give two informal interviews with the researcher for which I will give additional consent once they have been conducted. ☐
4. I understand that I will be asked to attend confidential consultations to evaluate and assess my risk factors for heart disease. However I am under no obligation to make lifestyle changes. ☐
5. I understand that my GP will be informed of my participation in this study and that only information regarding my risk factors for heart disease will be forwarded to him/her. All other information collected will be strictly confidential between myself and the researcher. ☐
6. I understand that I will be asked to complete a confidential questionnaire at the end of the study. ☐
7. I understand that I am free to withdraw from the study at any time, without giving a reason, and without affecting my future medical treatment. ☐

I agree to take part in this study.

Signature of participant..Date..

Name (block letters)..

Researcher

I have explained the study to the participant and he/she has indicated their acceptance to take part.

Signature of Researcher...Date..

Name (block letters)..

---

1 for the participant: 1 for the Researcher: 1 to be kept with hospital notes: 1 for the hospital research review board

APPENDIX VI

POST INTERVIEW CONSENT FORM

Primary Prevention for Coronary Heart Disease Research Study

Researcher - Martha J Wrigley
Ethics Study Number: PRO/21/02

Post Interview Consent Form

Please initial each box

1. I am aware that this discussion has been taped, that the tape is anonymous and that only the researcher has access to this information. ☐

2. I agree to the content of this discussion being used within this research study. ☐

3. I understand that I am free to withdraw from the study at any time, without giving a reason, and without affecting my future medical treatment. ☐

I agree to take part in this study.

Signature of participant..Date..

Name (block letters)...

Researcher

I have explained the study to the participant and he/she has indicated their acceptance to take part.

Signature of Researcher..Date...

Name (block letters)...

1 for the participant: 1 for the Researcher: 1 to be kept with hospital notes: 1 for the hospital research review board

APPENDIX VII

GENERAL PRACTITIONER LETTER

Primary Prevention of Coronary Heart Disease:
Developing and evaluating a primary prevention health promotion programme for adult offspring and siblings of those with overt premature coronary heart disease.

Date

Dear Dr ....

Re: ***Name of participant. Date of Birth***
Address

I am writing to inform you that your patient *name of participant*, would like to participate in a research study being undertaken by myself at ********* NHS Trust (ref:PRO/21/02). This study forms the basis for my Doctoral thesis which I am undertaking at the University of **** and for which Dr * **** (Consultant Cardiologist) is my clinical supervisor.

One aspect of the study is to produce a health promotion strategy for those at increased risk of developing coronary heart disease (CHD). By identifying within the hospital those whose parent or sibling has been diagnosed with premature CHD, I hope to develop a programme of education and support which enables these people to understand CHD plus its associated risk factors and if necessary and desired to make appropriate lifestyle changes.

A second aspect of the study is to attempt to understand the experience that an individual goes through when their parent or sibling is diagnosed with heart disease and the challenges that they themselves face when making possible changes to their behaviour and lifestyle. This will involve the participant giving two informal interviews, one at the beginning of the study and one at the end where additional consent will be given each time. This will provide qualitative data for the research.

We would like *Mr/Mrs/Miss (name)* to attend the hospital for a comprehensive assessment of their risk factors with regard CHD. This assessment will be carried out by myself and will include fasting lipids and glucose, blood pressure, weight as well as smoking status, diet and exercise regimes. This will all be explained and discussed with them. *Mr/Mrs/Miss (name)* knows that I will be keeping you informed of this assessment, and should any referrals be required or desired these can be made in the same way as for the secondary prevention clinics, for example referral to the smoking cessation service. *Mr/Mrs/Miss (name)* will attend for follow-up appointments every six months for two years, unless more frequent appointments are requested or deemed useful.

We are aware that this type of assessment is usually carried out in the primary care setting, and as you are *Mr/Mrs/Miss (name)* primary physician we want to ensure that you are happy for them to participate in this study. If you feel that this is inappropriate please reply within two weeks of the date of this letter. If I do not hear from you I will assume that you are happy for *Mr/Mrs/Miss (name)* to participate and I will keep you fully informed of *his/her* details and progress.

I have enclosed a Summary Sheet of the study for your information. If you require any further information please do not hesitate to contact me.

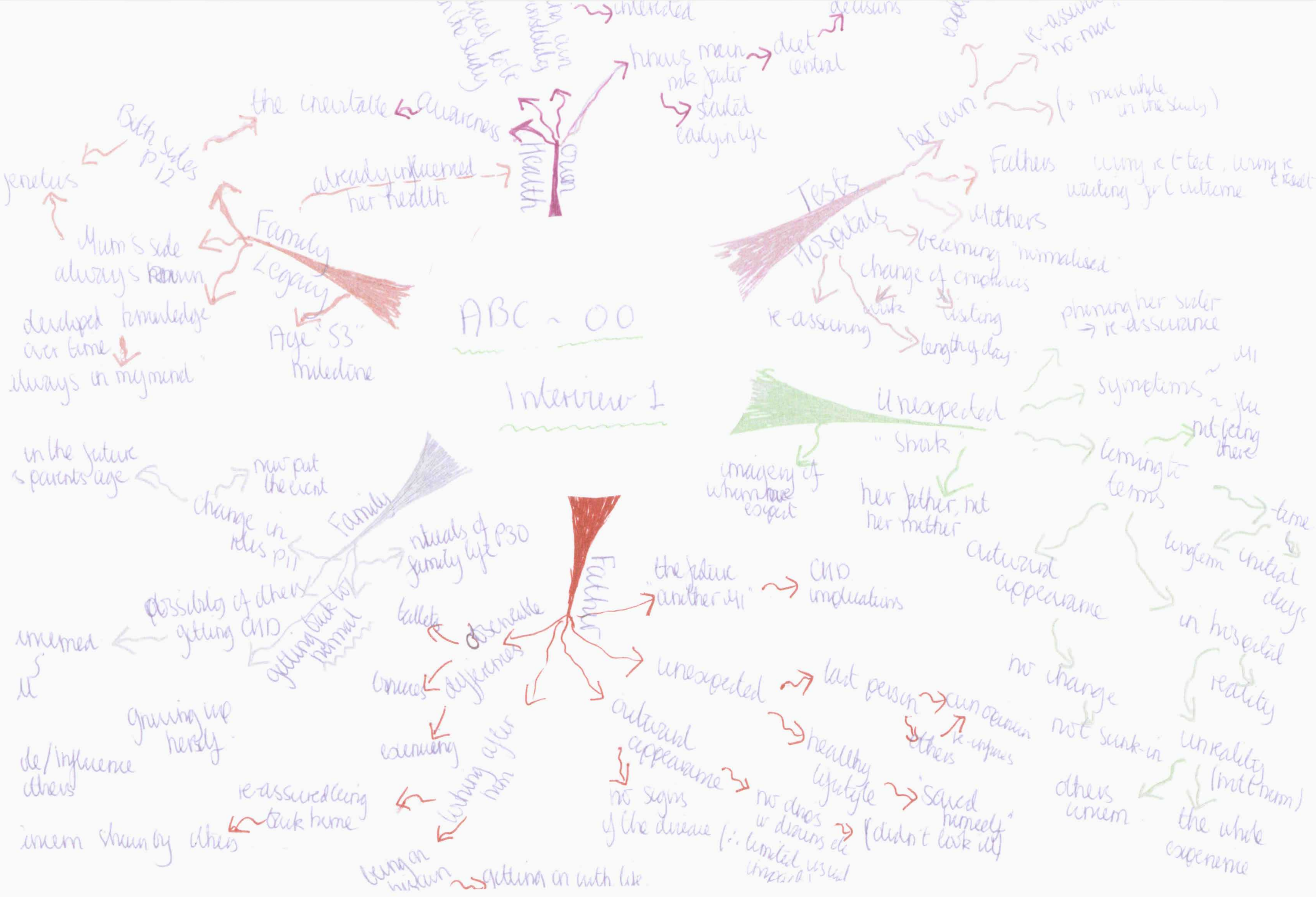
With thanks for your consideration.

Yours sincerely

Martha J Wrigley RN BSc(Hons) PGDip SRM
Cardiac Research Sister

APPENDIX VIII

MIND MAP NARRATIVE ANALYSIS


ABC ~ 00
Interview 1
Family Legacy
Mum's side always ~~known~~ known
developed knowledge over time
always in my mind
genetics
Both sides p12
the inevitable
Age "53" milestone
already influenced her health
Own Health
awareness
placed tole in the study
own vulnerability
understated
knows main risk factor
started early in life
diet central
decisions
Tests Hospitals
her own
Fathers
Mothers
(+ more while in the study)
re-assuring "no more"
worry re (-test, worry re result
waiting for the outcome
becoming "normalised"
change of emotions
re-assuring
work
visiting
lengthy days
phoning her sister → re-assurance
Unexpected
"Shock"
imagery of whom we expect
her father, not her mother
symptoms ~ MI ~ flu
not feeling there
coming to terms
outward appearance
no change
not sink-in
others unaware
-time
longterm
initial days
in hospital
reality
unreality (initial)
the whole experience
Father
the future "another MI"
CHD implications
unexpected
last person
uncommon
others
re-infarcts
healthy lifestyle
"saved himself"
outward appearance
no signs of the disease
no drugs or diuretics etc (∴ limited visual impact)
(didn't look ill)
dosenable
tablets
differences
worries
caring
looking after him
being on his own
getting on with life
re-assured leaving back home
Family
change in roles p11
now put the event
in the future ≤ parents' age
rituals of family life p30
possibility of others getting CHD
getting back to normal
unnamed
MI
growing up herself
de/influence others
unaware shown by others

APPENDIX IX

LIFESTYLE ASSESSMENT PROFILE

Primary Prevention Study

Lifestyle Assessment for Coronary Heart Disease

Name:

Date:

Alcohol consumption Men – 21 units in a week Women – 14 units in a week		***GP read code*** *6792* 136
Cardiovascular	Blood Pressure: (less than 140/90, maximum 160/90mmHg) Pulse: (60-80 beats per minute)	246 242
Cholesterol	Total cholesterol: (3.8 - 5.2mmol/l) Triglycerides: (0.80 – 2.00 mmol/l) LDL: (2.30 – 3.40 mmol/l) HDL: (1.00 – 2.00mmol/l men) (1.30 – 2.30 mmol/l women) Ratio:	44P 44P6 44P5
Diabetes Screen	Fasting Blood Glucose: (3.0 – 6.0 mmol/l)	44U
Diet 1/3 – fruit and vegetable 1/3 – carbohydrates – bread, rice, pasta, potatoes 1/3 – equal amounts of protein, dairy, and foods containing sugar & fat		6799
Physical Activity 30 mins moderate activity most days of the week		6798
Physical Measurements	Weight: BMI: (20 – 25 correct weight) Height: Waist: Men – less than 102 cm Women – less than 88cm	22A 22K 229
Smoking status & details		137
Stress		

Comments:

Agreed Action:

Next Appointment Date:……………………….

APPENDIX X

DIET QUESTIONNAIRE

Diet Questionnaire

- Are you a vegetarian? Yes ...... No ...... (please tick)
- Are you a vegan? Yes ...... No ...... (please tick
- Do you have special dietary requirements? Yes ...... No ...... (please tick)
- Do you have any food allergies? Yes ...... No ...... (please tick)
  - If yes, what are they? ....
- Do you make a conscious effort to eat "healthy" food? Yes ...... No ...... (please tick)
- **How often do you eat:**

Poultry (eg chicken, duck, turkey, pheasant ....)

Daily .... 4-6 times a week .... 2–3 times a week ..... weekly .... monthly .... rarely .... never ....

- Which type of poultry do you eat most of? ....

Meat (eg beef, lamb, pork, venison ......)

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- Which type of meat do you eat most of? ....

Fish

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- Which type of fish do you eat most of? ....

Potatoes

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- How do you usually cook your potatoes? ....

Chips

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Fried food

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What type of fat do you use for frying? ....

Cooked Vegetables (as part of a dish or a separate portion)

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- If daily, how many portions do you have? ....

Salad

Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What would a typical salad consist of? ....
- What dressing do you use? ....

Rice
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Pasta
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Pulses – peas, beans, lentils
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Bread
More than twice a day .... Daily .... 4-6 times a week .... 2–3 times a week ....
weekly .... monthly .... rarely .... never ....

- Which type of bread do you eat most of? ....

Breakfast cereal
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- Which type of breakfast cereal do you eat most of? ....

Fresh Fruit
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- If daily, how many portions do you have? ....

Dried Fruit
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Cheese
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What type of cheese do you eat most often? ....

Milk
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What type of milk do you use?
  - Full fat ...... Semi-skimmed ...... Skimmed ......

Dairy Products (Yoghurt, Fromage Frais etc...)
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What product is this and is it low-fat? ....

Cream
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- How do you usually use the cream? ....

Butter
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

Spread
Daily .... 4-6 times a week .... 2–3 times a week .... weekly .... monthly .... rarely .... never ....

- What type of spread do you use most often? ....

Eggs

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ How do you usually cook your eggs? ………………………………………..

Cakes

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

Biscuits

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

Crisps

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

Chocolate

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What type of chocolate do you eat most often? ………………………………

Sweets (eg jellies, boiled sweets, candy, toffees…..)

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

Deserts

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What type of desert do you eat most often? ……………………………….

Eat Out (staff canteen, pub, restaurant, friends house….)

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What would be your preferred menu when eating out?

………………………………………………………………

Take Away Meals

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What would this be? ………………………………………………………..

Snacks

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What snacks do you eat most of? …………………………………………..

Ready-made packet meals

Daily ……… 4-6 times a week ……. 2–3 times a week ……. weekly ……. monthly ……. rarely ……. never …….

- ➢ What pre-packed meals do you eat most of? ………………………………..

- ➢ Do you add salt to your food when cooking?

Yes …… No …… Sometimes …… (please tick)

- Do you add salt to your food on the plate?
  Yes ...... No ...... Sometimes ...... (please tick)
- What is a typical breakfast for you? ....
....
- What is a typical lunch for you? ....
....
- What is a typical dinner for you? ....
....
- How many cups of coffee do you drink each day? ....
- How many cups of tea do you drink each day? ....
- How much water do you drink each day? ....
- What do you drink most of during the day? ....
- How often do you drink alcohol and how many units is this?
  - What alcoholic drink do you drink most of? ....
- How often do you drink fruit juices?
  - What type of fruit drink is this? ....
- How many people eat together in your house? ....
- Who does the main food shopping? ....
- Do you have any say in the food shopping? Yes ...... No ...... (please tick)
- Who does most of the cooking? ....
- Do you have any say in the cooking? Yes ...... No ...... (please tick)
- Do you enjoy cooking? Yes ...... No ...... (please tick)
- Do you or your family try out new recipes? Yes ...... No ...... (please tick)
- Do you think your diet is healthy? Yes ...... No ...... (please tick)
- Other comments ! . ...

APPENDIX XI

PERCEIVED STRESS SCALE

The Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case you will be asked how often you felt, or thought, in a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often

a. In the last month, how often have you been upset because of something that happened unexpectedly? ☐

b. In the last month, how often have you felt that you were unable to control the important things in your life? ☐

c. In the last month, how often have you felt nervous and stressed? ☐

d. In the last month, how often have you dealt with irritating life hassles? ® ☐

e. In the last month how often have you felt that you were effectively coping with important changes that were occurring in your life ? ® ☐

f. In the last month, how often have you felt confident about your ability to handle your personal problems ? ® ☐

g. In the last month, how often have you felt that things were going your way? ® ☐

h. In the last month, how often have you found that you could not cope with all the things that you had to do ? ☐

i. In the last month, how often have you been able to control irritations in your life ? ® ☐

j. In the last month, how often have you felt that you were on top of things? ® ☐

k. In the last month, how often have you been angered by things that were outside of your control? ☐

l. In the last month, how often have you found yourself thinking about things that you have to accomplish ? ☐

m. In the last month, how often have you been able to control the way you spend your time ? ® ☐

n. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? ☐

Adapted from Cohen, S., Kamarck, T., and Mermelstein 1983. From 'A global measure of perceived stress', *Journal of Health and Social Behaviour*, 24. 385-96.

APPENDIX XII

CLINICAL ASSESSMENT SHEET

************ NHS Trust

Primary Prevention Clinic Assessment

Name:………………………………………………………………………… Date of Birth:……………………………………………

Address: ……………………………………………………………………Hospital Number…………………………………………

………

G P Details:

………

Sex ……………………………………………… Ethnicity ……………………………

Date of Assessment: ………………………… Number of previous visits …………

Family Details

Physiological Details

Fasting Glucose: ……………………… Diabetes ………………………………

(details as appropriate HbA1c: duration : control)

Fasting Cholesterol –

TC: …….mmol/l LDL: ……..mmol/l HDL: ……..mmol/l TG: ……..mmol/l

Blood Pressure: ……………………………… Pulse: …………………

Weight ……………………… Height ……………………………… BMI ……………………

Waist / Girth ………………… Hip ………………………………

Early Menopause (under 45) Yes / No

Lifestyle Details

Smoking Status

Alcohol Consumption

Diet

Stress and Sleep

Exercise

Medication Details

Prescribed:

Non-prescribed: (herbal supplements, regular analgesia, vitamins…)

Relevant Medical History

Relevant Personal Details (dependents, marital status, work details, living accommodation)

Issues discussed

Individual's perspective

Other family members present

Referrals

Date for Next Visit

Signature: …………………………………. Date: ……………………

Martha J Wrigley Cardiac Research Sister

APPENDIX XIII

EVALUATION QUESTIONNAIRE

Participant Evaluation

- How do you rate your general knowledge of heart disease now that you have completed this programme?

  Excellent ...... Good ...... Fair ...... Poor ...... Nil ......(please tick)

- Before you started on the programme how would you have rated your knowledge with regard to heart disease?

  Excellent ...... Good ...... Fair ...... Poor ...... Nil ......(please tick)

- Were you concerned about starting the programme?

  Yes .... No .... (please tick)

  - If "yes" what were you concerned about?

    ....

  - Where your concerns justified?

    Yes .... No .... (please tick)

- Have you been referred as part of this programme, to anyone else for assistance or advice?

  Yes .... No .... (please tick)

  - How useful was this referral for you?

    Very useful ...... Useful ...... Not useful ......(please tick)

- Did you feel supported during this programme?

  Yes .... No .... (please tick)

- Who gave you the most support? ....

- Where your family supportive?

  Yes .... No .... (please tick)

  - If "yes," which members of your family were the most supportive?

    ....

  - How was this support given?

    ....

- Do you feel that your overall health has improved as a result of this programme?
  Yes …….. No …….. (please tick)

- Was it difficult to attend the clinic appointments?
  Yes …….. No …….. (please tick)

  - If "yes" why was this?
    ……………………………………………………………………………

- How was the timing between each clinic appointment?
  Too long …… Just right …… Too short ……(please tick)

- Was the length of the appointments:
  Too long …… Just right …… Too short ……(please tick)

- Is there anything you disliked about the programme?
  Yes …….. No …….. (please tick)

  - If "yes," what was this? ……………………………………………………

- Did you ever consider withdrawing from the programme?
  Yes …….. No …….. (please tick)

  - If "yes," why was this? ……………………………………………………
  - If "yes," what made you continue? ……………………………………………

- What is the most important thing you have gained from this programme?
  ……………………………………………………………………………

- What did you like most about the programme? ………………………………………

Many thanks for completing this questionnaire.
In order to maintain anonymity please place the questionnaire in the envelope provided. Once a set of ten are available the envelopes will be opened and the questionnaires analysed.

APPENDIX XIV

DATA CAPTURE SHEET

Risk Factor Assessment			Visit 1	Visit 2	Visit 3	Visit 4	Visit 5
Alcohol		minimum	0	2	8	0	4
		maximum	8	10	10	0	6
Cardiovascular	blood pressure	systolic	115	100	95	100	110
		diastolic	80	75	70	60	74
		pulse	79 regular	86 regular	75 regular	84 regular	75 regular
Cholesterol		Total	6.0	5.5	/	/	6.0
		Trigs	1.34	2.19	/	/	1.09
		LDL	3.65	2.75	/	/	4.07
		HDL	1.77	1.8	/	/	1.46
		Ratio	3.3	3.1	/	/	4.1
Diabetes Screen			4.6	/	/	/	4.6
Diet			Veg 4-6 x wk. Fruit occasional. Wheat intolerance, eats daily, but can be made to feel sluggish. Protein varied, but insufficient quantity.	Remains the same. Stopped eating prawns.	Trying to increase proteins and reduce carbs (pasta & bread). Now eats breakfast daily, eats little and often during the day.	Very good, well balanced. Eats a little and often. Has made a conscious effort to vary carbs & protein.	Has five portions fruit & veg daily. Fish 2-3 x wk. Varied carbs. Limited sugar & fats.
Physical Activity		Exercise grading	0 : 3	0 : 2	0 : 3	1 : 3	3 : 4
			Yoga 10 – 30 mins daily 10 – 15 mins moderate to light activity	Yoga 2- 3 weekly. Wears a pedometer.	DVD exercise workout, 30 min session. 3-6 x wk. Yoga weekly.	Swimming weekly. Yoga video tape 2-3 x wk. Active day.	Walks 15-60mins daily. Vigorous 1-2 a wk.
Physical Measurement		Weight	62	63	66	70	66
		Height	174	174	174	174	174
		BMI	20.5	20.8	21.8	N/A	21.8
		Waist	74	78	79	N/A	88
Smoking Status			Never : 0	Never: 0	Never: 0	Never: 0	Never: 0
Stress		Score	Not done	34	31	24	29
		Description	Works long hours	Work	Improving	More in control	Different.

APPENDIX XV

CHANGES DURING THE HEALTH PROMOTION PROGRAMME

APPENDIX XV

Changes during the health promotion programme

Participant	Alcohol	Blood pressure	Total cholesterol	Diet	Physical activity	Weight / Waist	Smoking	Stress
1	+1	Ø	+1	+1	+1	+1	Ø	Ø
2	+1	Ø	+1	+1	+1	0	+1	Ø
3	Ø	+1	-1	+1	+1	+1	Ø	Ø
4	Ø	+1	+1	+1	Ø	-1	Ø	+1
5	Ø	Ø	0	+1	+1	Ø	Ø	+1
6	Ø	Ø	-1	+1	Ø	+1	Ø	+1
7	+1	+1	-1	+1	Ø	+1	Ø	Ø
8	Ø	+1	+1	+1	Ø	+1	Ø	Ø
9	Ø	Ø	-1	+1	0	-1	Ø	+1
10	+1	+1	-1	+1	+1	Ø	+1	+1
11	0	Ø	+1	+1	+1	-1	Ø	0
12	Ø	-1	-1	+1	0	+1	Ø	-1
13	-1	0	0	+1	-1	+1	-1	-1
14	0	+1	-1	+1	0	-1	Ø	-1
15	+1	Ø	+1	+1	+1	+1	+1	+1
16	Ø	0	+1	+1	0	-1	Ø	+1
17	-1	+1	+1	+1	+1	0	Ø	0
18	+1	+1	-1	Ø	+1	-1	0	+1
19	+1	+1	+1	+1	Ø	Ø	-1	+1
20	Ø	Ø	-1	Ø	Ø	Ø	Ø	-1

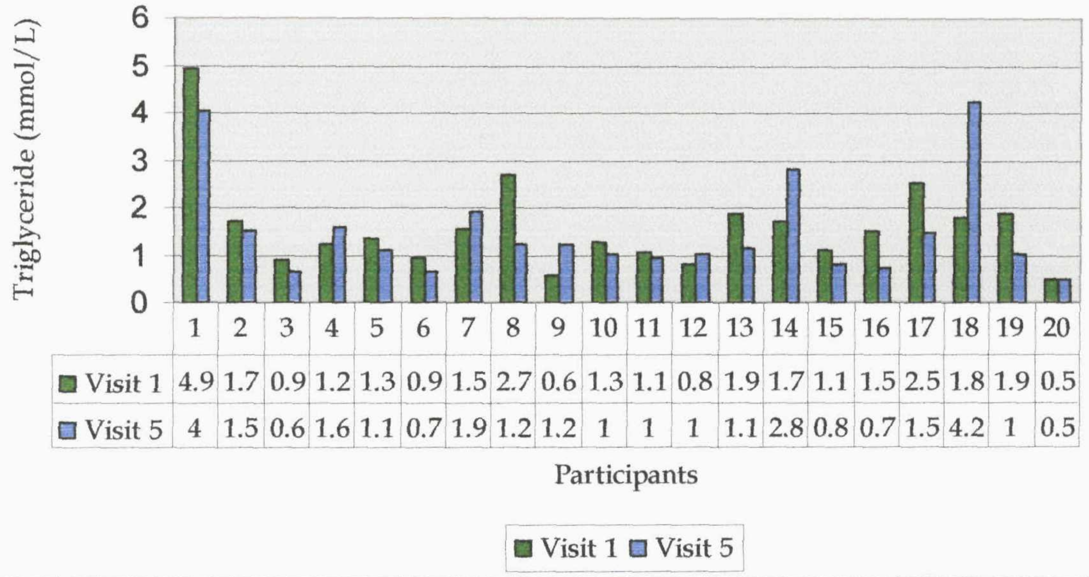
Key:

No change required	Ø
No change achieved	0
Positive changes	+1
Negative changes	-1

APPENDIX XVI

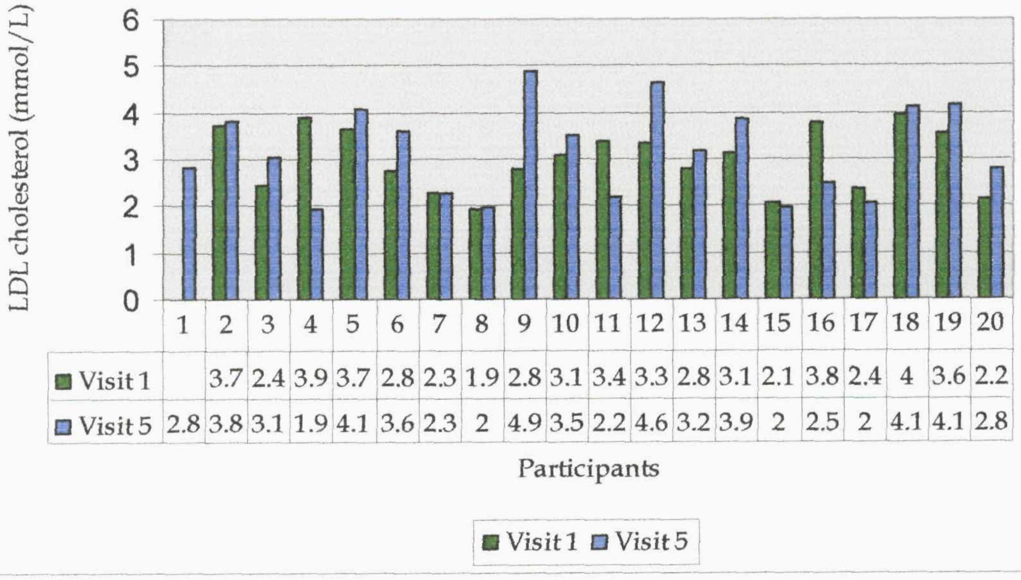
CHOLESTEROL CHARTS

Figure A XVI 6.1 Triglyceride measurements



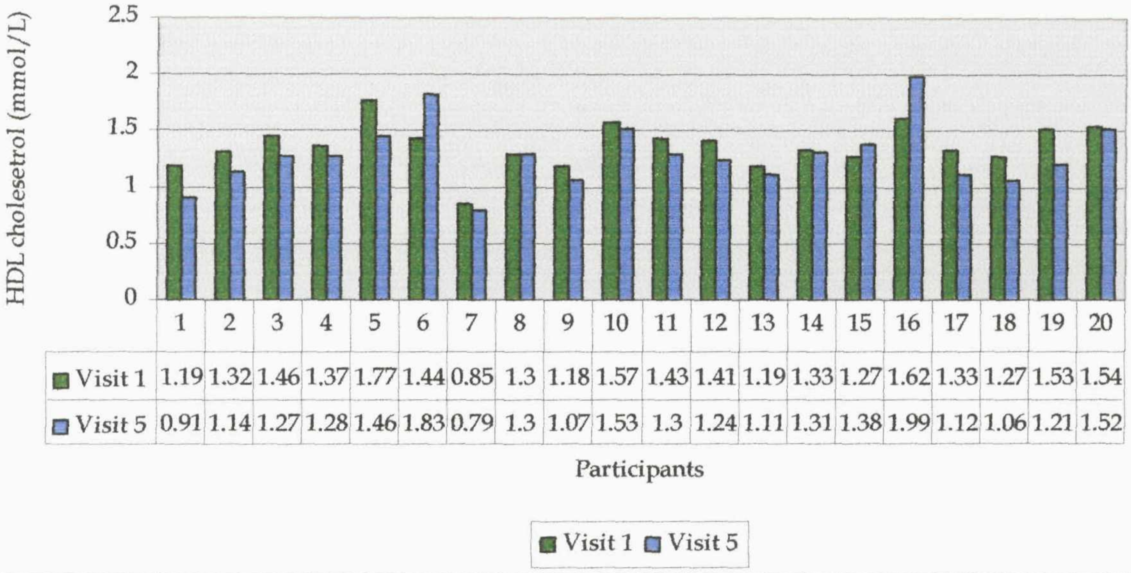
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
🟩 Visit 1	4.9	1.7	0.9	1.2	1.3	0.9	1.5	2.7	0.6	1.3	1.1	0.8	1.9	1.7	1.1	1.5	2.5	1.8	1.9	0.5
🟦 Visit 5	4	1.5	0.6	1.6	1.1	0.7	1.9	1.2	1.2	1	1	1	1.1	2.8	0.8	0.7	1.5	4.2	1	0.5

Figure A XVI 6.2 Low density lipoprotein measurements



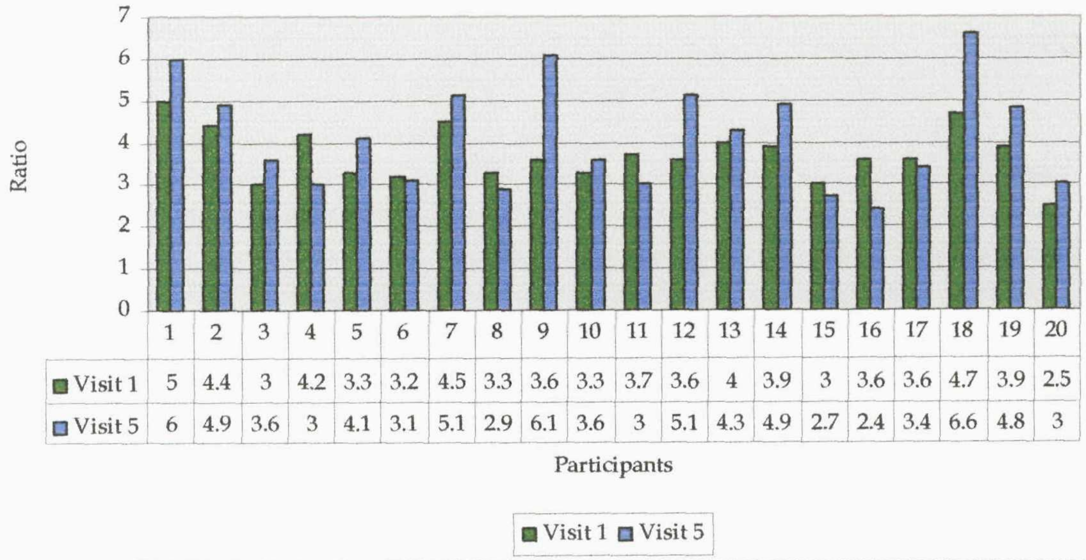
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
🟩 Visit 1		3.7	2.4	3.9	3.7	2.8	2.3	1.9	2.8	3.1	3.4	3.3	2.8	3.1	2.1	3.8	2.4	4	3.6	2.2
🟦 Visit 5	2.8	3.8	3.1	1.9	4.1	3.6	2.3	2	4.9	3.5	2.2	4.6	3.2	3.9	2	2.5	2	4.1	4.1	2.8

Figure A XVI 6.3 High density lipoprotein measurements



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
🟩 Visit 1	1.19	1.32	1.46	1.37	1.77	1.44	0.85	1.3	1.18	1.57	1.43	1.41	1.19	1.33	1.27	1.62	1.33	1.27	1.53	1.54
🟦 Visit 5	0.91	1.14	1.27	1.28	1.46	1.83	0.79	1.3	1.07	1.53	1.3	1.24	1.11	1.31	1.38	1.99	1.12	1.06	1.21	1.52

Figure A XVI 6.4 Total cholesterol to high density lipoprotein ratio



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
🟩 Visit 1	5	4.4	3	4.2	3.3	3.2	4.5	3.3	3.6	3.3	3.7	3.6	4	3.9	3	3.6	3.6	4.7	3.9	2.5
🟦 Visit 5	6	4.9	3.6	3	4.1	3.1	5.1	2.9	6.1	3.6	3	5.1	4.3	4.9	2.7	2.4	3.4	6.6	4.8	3

APPENDIX XVII

DIET CHARTS

FIGURE A XVII. 6.1 Type of bread

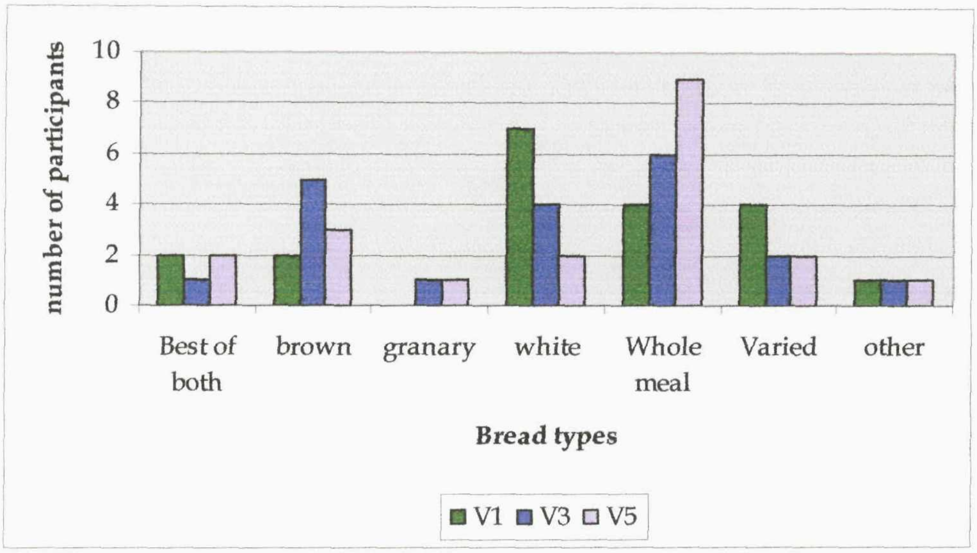


FIGURE A XVII. 6.2 Use of spreads and level of consumption

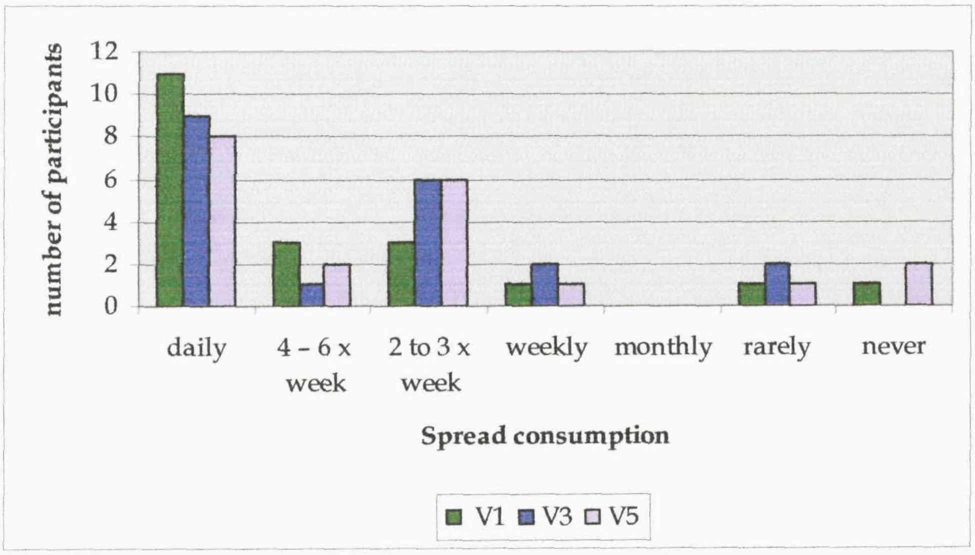


FIGURE A XVII. 6.3 Butter consumption

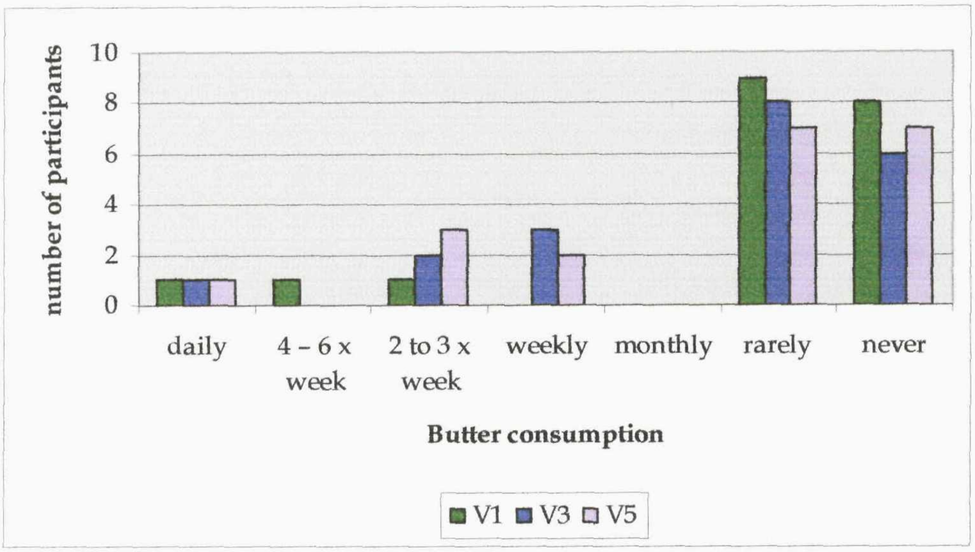


FIGURE A XVII. 6.4 Cream consumption

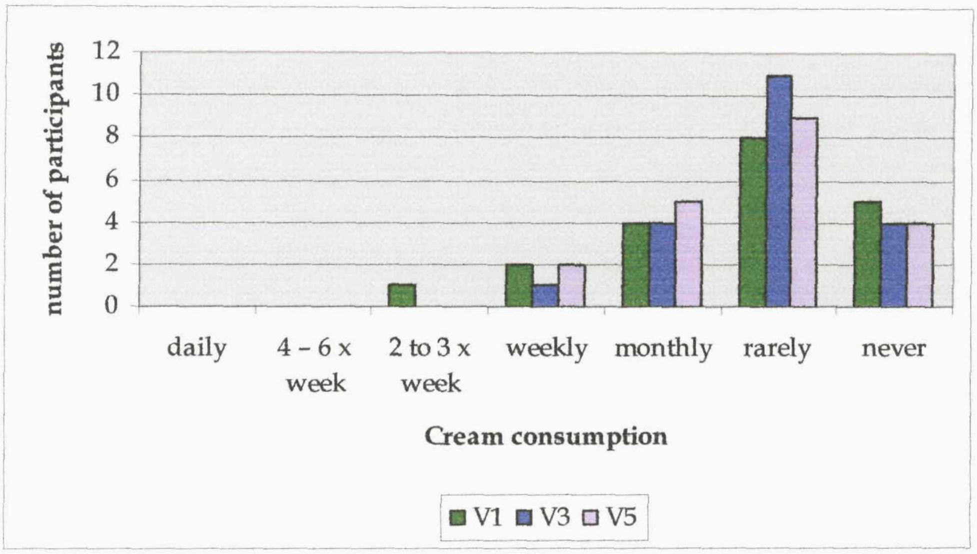


FIGURE A XVII. 6.5 Cheese consumption

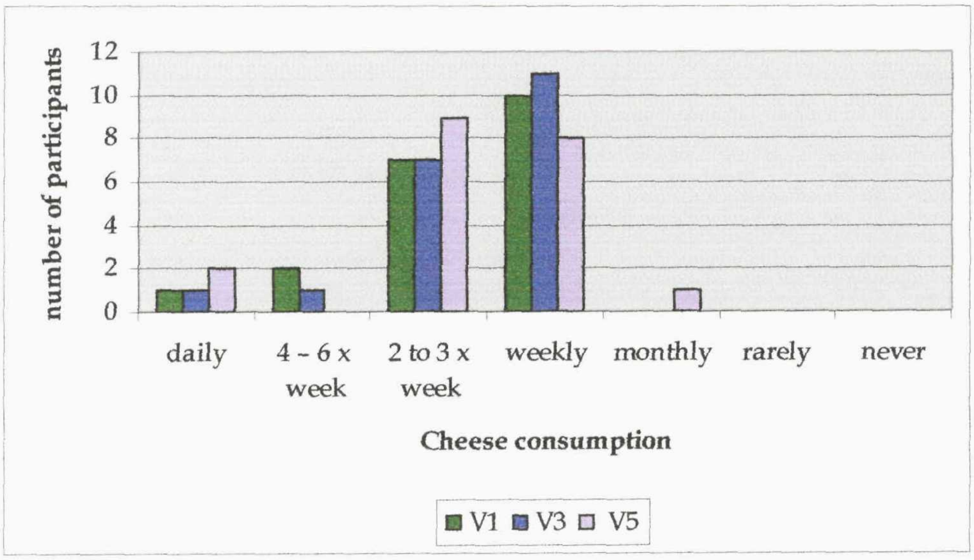


FIGURE A XVII. 6.6 Salad consumption

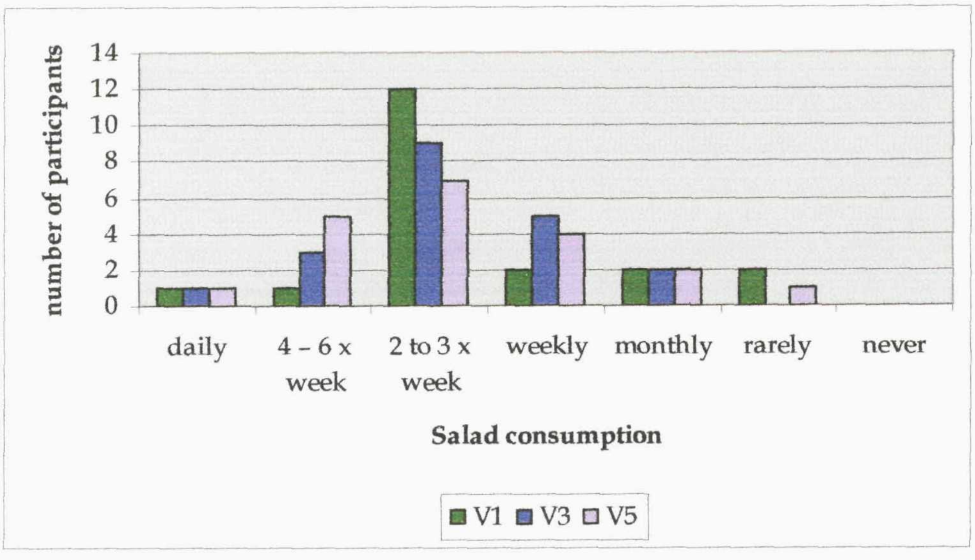


FIGURE A XVII. 6.7 Vegetable consumption

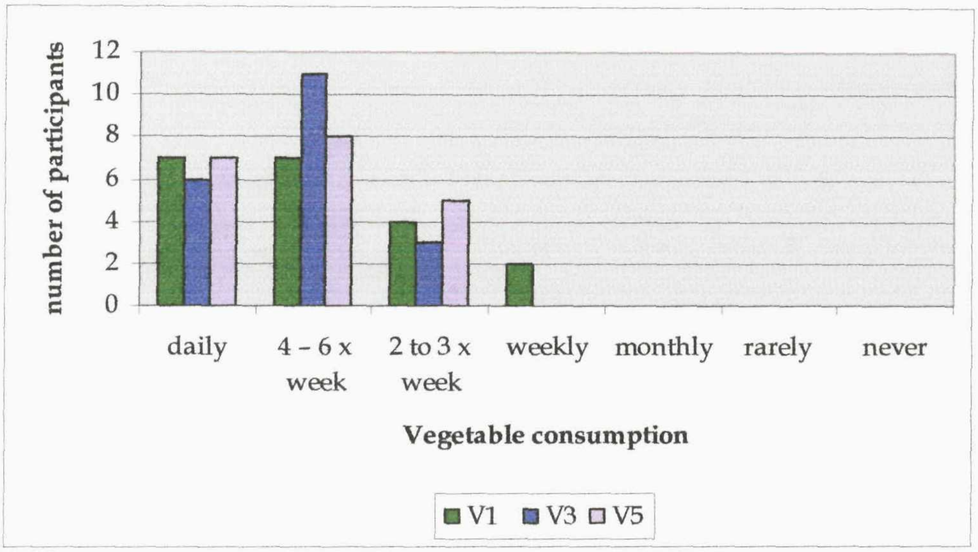


FIGURE A XVII. 6.8 Fruit consumption

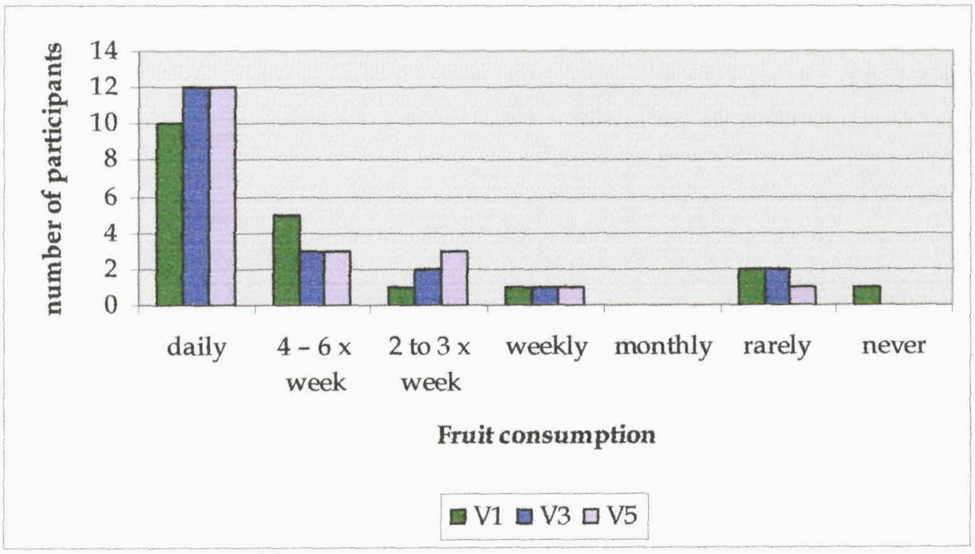


FIGURE A XVII. 6.9 Sweet and confectionary consumption

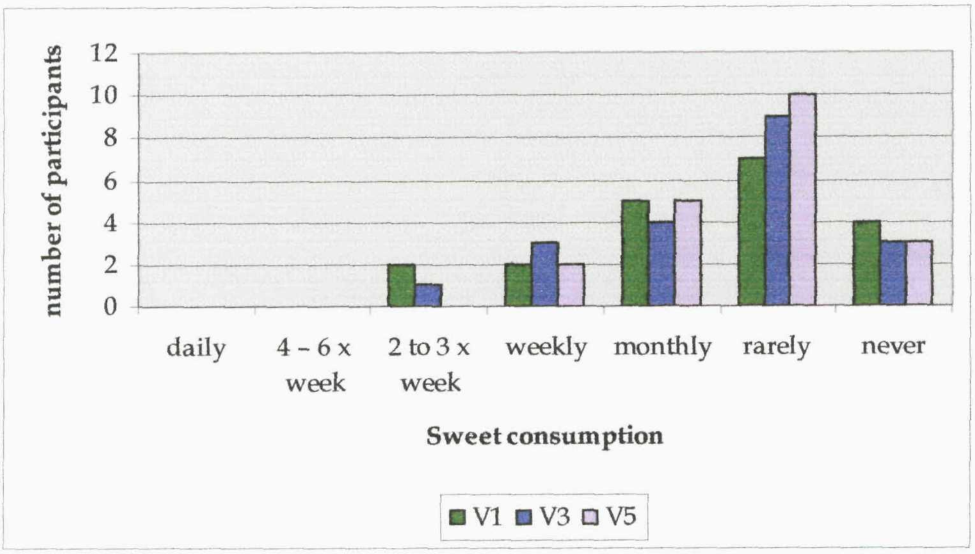


FIGURE A XVII. 6.10 Biscuit consumption

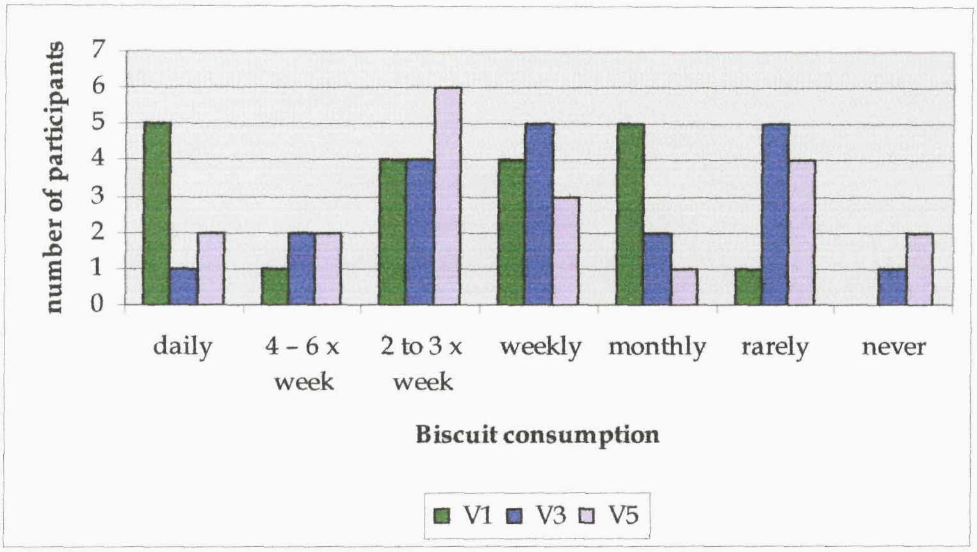


FIGURE A XVII. 6.11 Cake consumption

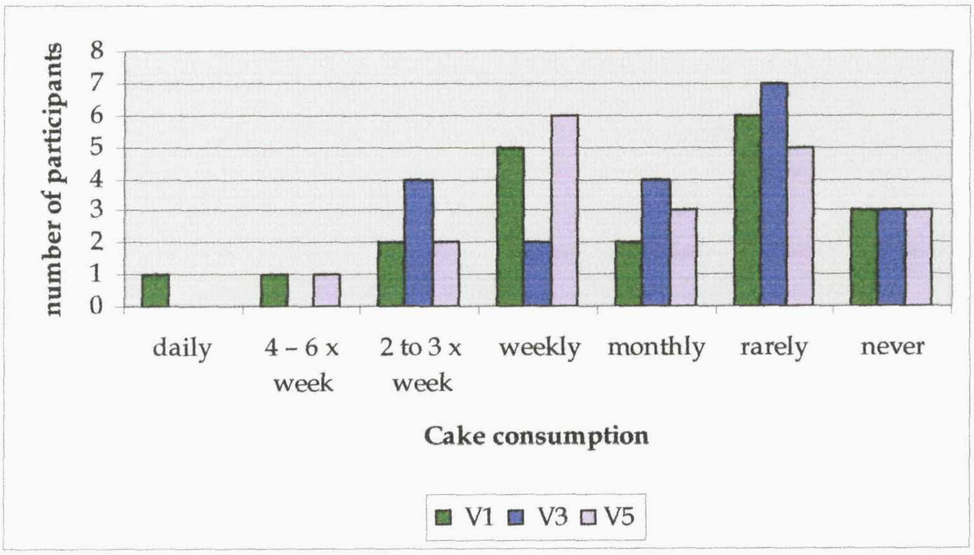


FIGURE A XVII. 6.12 Ready-made meals

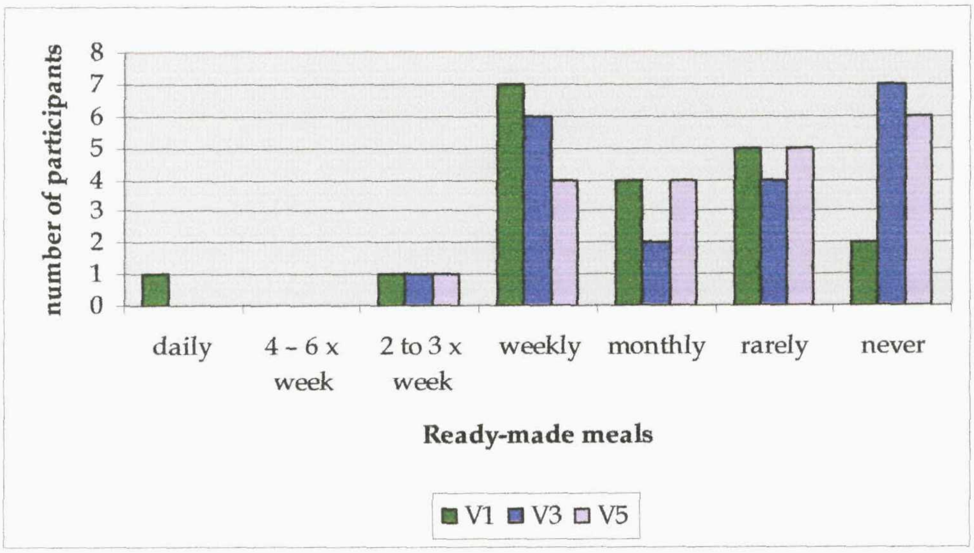


FIGURE A XVII. 6.13 Take-away meals

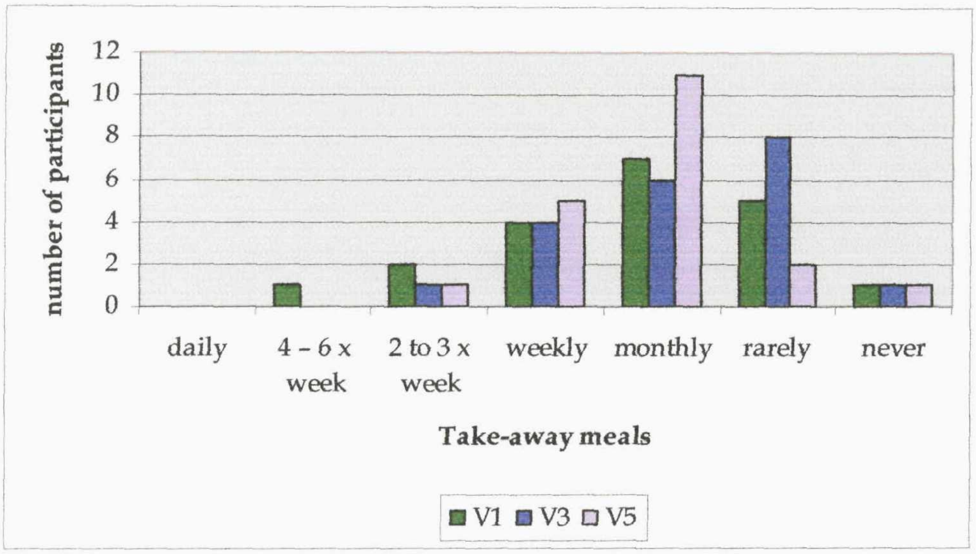


FIGURE A XVII. 6.14 Type of milk

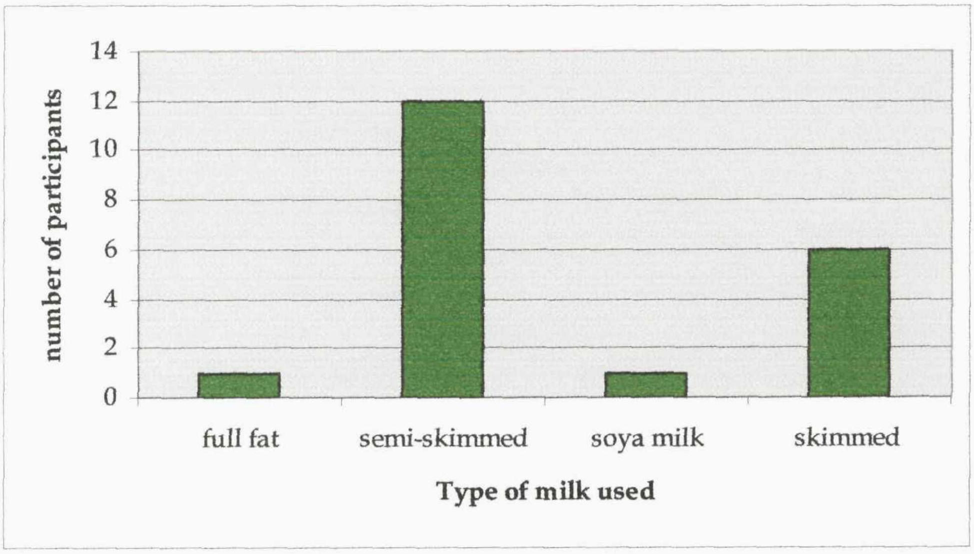
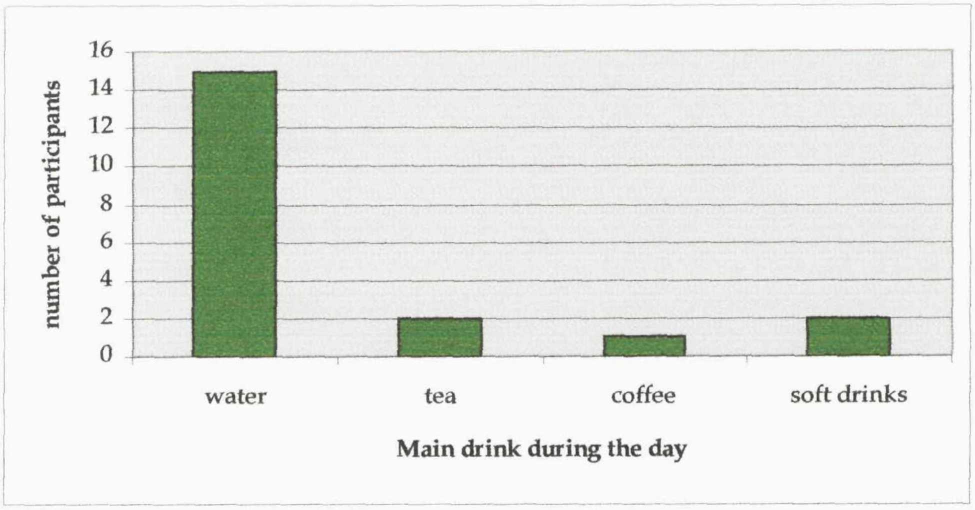


FIGURE A XVII. 6.15 Drink



APPENDIX XVIII

PHYSICAL ACTIVITY SCORES

Physical Activity Score

Alphabetical categories for Ability

2 measures for physical activity

- Work / Day Activity
- Leisure Activity

7 grades for each measure, valued 0 to 6. Based on duration and frequency.

Ability

Category	Descriptor	Explanation
A	Unable to move	Paralysis, bed or chair bound
B (B_T / B_P) (**B_T** - transient **B_P** - permanent)	Limited mobility: Disease limited – Physically limited -	 CCF, COPD, emphysema Injury, lumbago, CVA, PVD, false limb
C	Extreme age	Dependent upon the individual
D	No limitations	

Work / Day Activities

Grade	Descriptor	Examples
0	Inactive ~ sits 90+% of the working day	Telephonist, office worker, taxi driver, writer
1	Mainly inactive ~ sits 60 - 90% of the working day	Receptionist, student, seamstress, accountant
2	Moderately active ~ sits 30 – 60% of the working day	Laboratory technician, journalist
3	Active ~ sits 10 – 30% of the working day	Teacher, camera person
4	Rarely sits ~ gently active most of the time	Nurse, usherette, supervisor, sales assistant
5	Walks, uses arms for light lifting and carrying	Waitress, chef, housework, gardening, shop assistant, electrician
6	Walks, uses arms for heavy lifting and carrying; strenuous prolonged activity	Builder, plumber, removal man, professional athlete

Leisure / Non-work Activities

Grade	Descriptor	Duration
0	Inactive	sedentary, avoids physically activity
1	Gently active	totals 30 mins a day, 1 to 2 x a week
2	Mildly active	30 – 60 mins a day, 1 to 2 x a week
3	Moderately active	totals 30 mins a day, 3 to 4 x a week
4	Active	30 - 60 mins a day, 3 to 4 x a week
5	Very active	30 - 60 mins a day, 5 to 6 x a week
6	Extremely active	Over 60 mins a day, 5 to 6 x a week

APPENDIX XIX

EVALUATION RESULTS

APPENDIX XIX

Results from the evaluation questionnaire: questions 11 and 12.

Question 11: Importance gained from the programme	**Question 12: Most liked about the programme**
Overall knowledge and understanding of health and diet	Research sister's manner. Very helpful and deserves a big raise in salary!!
Information for keeping my heart healthy	Talking to research sister
Diet information, how to improve my overall health	Having the opportunity to talks through things about my health to someone other than family, or GP, and that they listened
More knowledge about heart disease	The reassurance that my diet, exercise etc was correct
Knowledge about heart attacks and they happen	All of it
To monitor my diet	Relaxed interviews
An increased knowledge of my personnel health	Informative chats with research sister
Knowledge of the heart	Helpfulness and knowledge of research sister
General useful information	The fact that it has made me think about my lifestyle
A better understanding of diet and its effects	Open and friendly
Knowledge of how to do the utmost to prevent heart complications	The way it was completed in a relaxed and comfortable manner
A far better understanding of the impact diet has on your health	The personal one-2-one meetings with the same person. For the whole duration of the cardiac research programme
Knowledge how our whole lifestyle can affect our health and lead to heart problems in the future	It was informal, reassuring and interesting
Understanding more about diet and better living	Talking over diagrams on heart disease
Awareness of eating right things	The fact it should help my health long term
The value of eating the right foods	Talking to someone who is interested in all things medical
Continuous reminder to try and stay healthy	Quality of 1 on1 time with research sister
Reassurance that following good diet, exercise etc	Talking to research sister
	Research sister

APPENDIX XX

LIST OF PRESENTATIONS

CONFERENCE PRESENTATIONS

Wrigley, M. J., Maslin-Prothero, S. & Watkinson, G. *Primary Prevention for CHD*. Poster Presentation. The 2006 International Nursing Research Conference, April 21st to 25th 2006.

Wrigley, M. J. *Primary Prevention for CHD: an imperative challenge*. University of Southampton. Faculty of Medicine, Health and Life Science Postgraduate Conference 2006, June 6th 2006.

Wrigley, M. J. & Watkinson, G. *Primary Prevention for Coronary Heart Disease ~ targeting at-risk families*. Southern Central CHD Network Conference 2006, October 20th 2006.

Wrigley, M. J. *Preventative Cardiology ~ the debate for health promotion.* AstraZeneca Nursing Matters IV, March 24th 2007

Wrigley, M. J. *Targeting At-risk Families ~ primary prevention for coronary heart disease.* West Surrey Cardiac Network. Primary Prevention Conference, January 23rd 2008

Pending

Wrigley, M. J. *Engaging families with a premature family history for heart disease.* Ashford & St Peter's Cardiology Study Day, April 25th 2008.

APPENDIX XXI

PUBLICATION ~

'PRIMARY PREVENTION FOR CORONARY HEART DISEASE: PAST EVIDENCE, PRESENT MEASURES AND FUTURE CHALLENGES.'

Primary prevention for CHD: Past evidence, present measures and future challenges

tha Wrigley
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Tapesh
Sian Maslin-
Graham Watkinson

Coronary heart disease (CHD) is the leading cause of death worldwide (Benjamin et al, 2002; Mackay and Mensah, 2004). It is estimated that between 1990 and 2020 the global mortality from CHD will have increased by 100% in men and 80% in women (Benjamin et al, 2002).

Review of UK studies

The following statistics illustrate the importance of CHD in the UK (Petersen et al, 2004). They show that:

- CHD is the leading cause of death in men
- One in five men and one in six women die from CHD
- Around 275,000 people each year have a myocardial infarction, and 30% of them die before they reach hospital
- CHD is the main cause of premature death and is responsible for 22% of premature deaths in men and 13% in women
- CHD mortality is falling, but morbidity rates are increasing
- In 1999, CHD cost the UK economy more than £7 000 million when direct costs, informal care and productivity costs were taken into account. The direct health costs amounted to £1 750 million, 0.7% of which was spent on primary prevention (Petersen et al, 2004).

ABSTRACT

is paper discusses the importance of primary prevention in reducing ronary heart disease. The first part reviews UK studies on primary evention in coronary heart disease (and also looks briefly at the ıro-Action study) and illustrates how past studies have influenced our ırrent approach. The second part considers the government's ırrent policy on CHD prevention and suggests that the future focus r preventative care should be at a more individual level.

EY WORDS
Primary and primordial prevention • Coronary heart disease
Health promotion • Government policy
Premature family history

cepted for publication 14 March 2006

Levels of prevention

This paper focuses on primary prevention for CHD. However, it is important first of all to define the different levels of prevention generally accepted within health care. These are described by Tones and Green (2004,) as primary prevention, secondary prevention and tertiary prevention.

Primary prevention

Primary prevention aims to prevent new cases of a disease from developing by reducing exposure to causal and risk factors.

Secondary prevention

Secondary prevention aims to reduce the consequences of disease and increase the chances of cure by early diagnosis and treatment, often as a result of screening procedures.

Tertiary prevention

Tertiary prevention aims to halt the progress or reduce the complications of established disease by effective treatment and rehabilitation.

Primordial prevention

Beaglehole et al (1993) identified a fourth level of prevention—primordial prevention. They emphasized the findings in epidemiological studies that the incidence of CHD is raised in western countries, where diets are high in saturated animal fat, but not in countries such as China and Japan, despite the presence of other risk factors such as smoking and hypertension. According to Beaglehole et al (1993: 86), primordial prevention aims to

> **avoid the emergence and establishment of the social, economic and cultural patterns of living that are known to contribute to an elevated risk of disease.**

Primordial prevention focuses on modifiable risk factors such as diet, weight control and physical activity, so that treatable risks such as diabetes, dyslipidaemia and hypertension do not become prevalent later in life (Benjamin et al, 2002). It is an approach which is suitable for children and young people (Benjamin et al, 2002; Yusuf and Ounpuu,

03) and for whole populations (Beaglehole et al, 1993; njamin et al, 2002; Yusuf and Ounpuu, 2003). Primordial evention is a novel strategy, which enables us to identify e need for early advocacy regarding lifestyle behaviour at ther a population or individual level. Secondary and terti- y prevention are well established and are seen as integral mponents in the continuing care of people diagnosed ith CHD.

rimary prevention studies

e primary prevention studies discussed in this section are ose which aim to reduce the multiple risk factors associ- ed with CHD in a UK adult population. Some studies look CHD risk factors such as dyslipidaemia, hypertension, d even obesity, in which pharmacological treatment can odify the outcome and overt consequences. Others look risk reduction, where changes to diet, for example, are ade in order to achieve measurable outcomes such as eight reduction and improved lipid profile or self reported etary improvements. Since primordial prevention is a wly defined level of prevention in health care, published ports show no clear delineation between it and primary evention in risk management and reduction. Ebrahim d Davey Smith (1999: 1) state that

> ***primary prevention programmes attempt to reduce*** **mortality and morbidity due to CHD through risk factor modification.**

his definition clearly places the emphasis on risk factor odification, with or without pharmacological treatment, here primary prevention can include the use of medica- on but primordial prevention arguably would not. The rimary prevention studies discussed in this article do not clude those whose aim is to evaluate the efficacy of phar- acological treatment.

XCHXECK and British Family Heart studies

he OXCHECK study (OXCHECK Study Group, 1995) and e British Family Heart (BFH) study (Wood et al, 1994), ere two of the largest randomized control trials (RCT) ndertaken in the 1990s and were designed to measure the npact of a primary prevention strategy on CHD in the UK. oth were nurse-led programmes which examined large mples of the population (11 090 and 12 481 recruits spectively) and assessed the impact of smoking cessation nd reducing blood pressure, cholesterol values and weight. oth studies were based in general practices.

In the OXCHECK study, participants had health checks t different times over a four year period. The 2205 people the main intervention arm had health checks in 1989-90, nd their last follow-up in 1992-93. The control group did ot receive their first health check until 1992-93. In the ore intensive and structured BFH study, the intervention roup was given nurse-led lifestyle advice which lasted 90 inutes, and was invited back for re-screening one year ter. During this year further follow-up visits were allocat- d according to the subjects' initial risk scores. Those in the control group had their first screening visit after a year. The BFH study aimed to estimate how large a reduction in cardiovascular risk factors in men and women could be achieved in one year by a practice-based strategy. The study involved a family-centred approach as it was felt that lifestyle changes would be more likely to occur with the participation and support of the whole household.

Reported results

In the OXCHECK study, there was no change in smoking or alcohol habits, but there were improvements in diet, and consequently reductions in mean cholesterol (3.1%—a difference of 0.19 mmmol/litre) and blood pressure (2.5/1.5 mmHg) which were sustained over the three years. In addition, reductions achieved by year one were sustained but not improved further by year three (OXCHECK Study Group, 1995). The BFH study showed that after one year smoking was reduced by 4%, mean weight by 1 kg, mean blood pressure by 7/3 mmHg and mean cholesterol by 0.1 mmol/litre (Wood et al, 1994). The long-term reductions in coronary risk for men were 7% in the OXCHECK study and 13% in the BFH study; in women the risk reductions were 13% and 10% respectively (Wonderling et al, 1996).

Evaluation

The strategies adopted by these studies proved to be labour-intensive, time-consuming and expensive, and, in addition, there are no data on long-term adherence (more than three years) (Wonderling et al, 1996). Based on the calculations of Wonderling et al (1996), the OXCHECK programme cost £29.27 per participant, while the BFH study cost £66.01 for men and £57.82 for women. The BFH study concluded that such an intensive strategy could not be justified and that alternative preventive strategies were needed, which might include the specific targeting of high-risk patients such as those with hypertension, hyperlipidaemia, diabetes and established CHD (Wood et al, 1994).

Change of Heart study

Another approach to multiple risk reduction for CHD is through behavioural changes. The smaller, Change of Heart study was a RCT which recruited 883 men and women with one or more modifiable risk factors (Hilton et al, 1999; Steptoe et al, 1999). The aim was to measure the effect of behaviourally orientated counselling on health behaviour and biological risk factors (Hilton et al, 1999; Steptoe et al, 1999). The study used the stages of change model developed by Prochaska and DiClemente (1992). Behavioural change involves the progression through five stages: pre-contemplation, contemplation, preparation, action and maintenance. However, people usually cycle and recycle through the middle stages until long-term maintenance is achieved. Participants in the control practices group were given encouragement according to the standard practice already used by the nurse while the nurses in the intervention practices group had attended specialized counselling training, and so were able to give individualized and enhanced advice. The study showed that counselling sessions did result in positive lifestyle changes but these did not equate to biological risk reduction (Hilton et al, 1999; Steptoe et al, 1999).

Community and workplace studies

Community health promotion programmes have also been carried out. These include, Heartbeat Wales and Action Heart, in which local strategies designed to reduce lifestyle risk factors associated with heart disease were developed and evaluated (Tudor-Smith et al, 1998; Baxter et al, 1997). These studies included a control group against which the intervention could be measured. With community studies it is important to show that positive results are derived from the intervention, particularly when drawing conclusions about cost implications and effectiveness and planning future projects. However, this is difficult because contamination of the study population can occur through other sources. For example, when Heartbeat Wales was established, national health awareness campaigns were also in place and may have affected the results (Nutbeam, et al, 1993; Tudor-Smith et al, 1998). There is on-going controversy regarding the effectiveness of these approaches and the validity of positive conclusions reached by the studies (Ebrahim and Davey Smith, 1998; Capewell et al, 1999).

Workplace interventions

Primary prevention health promotion studies in the workplace have also been conducted. These have adopted different research designs: action research, a feasibility study and a randomized control trial (Wilkinson et al, 1997; Fine et al, 2004; Hanlon et al, 1995). The advantage of work-based projects is that they provide access to a diverse cohort and, in particular, to people who may not usually visit a health professional (Fine et al, 2004). Fine et al (2004) aimed to improve CHD risk factors and back pain in workplaces in South Wales which employed fewer than 50 people. This feasibility study did not achieve significant changes in behaviour in the 290 respondents who completed it. However, stress was identified as the major CHD risk reported by participants, and differences between workplace and domestic stress were identified. In addition, the action research of Wilkinson et al (1997) showed that employers need to be encouraged to invest in health promotion which involves a range of staff, not merely those directly affiliated through human resources or occupational health. Staff participation in the whole process of planning, implementing and sustaining effective health polices is integral to its success.

Hanlon et al (1995) conducted single health checks in a Glasgow workplace. The study group showed improvements in self-reported diet and exercise levels and reduced alcohol consumption compared with the control group. The authors stated that the intervention had only a small effect on cholesterol values, where knowledge did little to motivate people further to make lifestyle changes. They concluded that the positive results were small and their value questionable given the effort and time involved. However, Graham (1996) stated that the cholesterol reduction of 2.2% (from a baseline value of 5.88 mmol/litre) seen in the study of Hanlon et al equated to a 9.6% fall in coronary risk, assuming that it could be sustained over time, and that this level of risk reduction provided good value for money when compared with the cost of coronary artery surgery.

Meta-analysis: UK primary prevention studies

The meta-analysis conducted by Ebrahim and Davey Smith, (1999) included studies which showed the following criteria: they had to use a counselling and/or an educational approach, with or without pharmacological interventions, in reducing blood pressure, cholesterol levels, smoking rates, total mortality and CHD mortality. A total of 18 trials met these criteria, 10 of which reported clinical event data (for example, death, myocardial infarction and stroke). Both the OXCHECK and BFH studies were included in the meta-analysis. The main conclusion of Ebrahim and Davey Smith (1999: 5) was that

> **multiple risk factor interventions comprising counselling, education and drug therapies were ineffective in achieving reductions in total cardiovascular disease mortality when used in general or workplace populations of middle-aged men**

EuroAction study

The studies discussed in this section illustrate the difficulties in conducting research into primary prevention for CHD. Ebrahim and Davey Smith, (1999) state that it is unlikely that further large scale RCTs will be conducted. However, the recent EuroAction study (Wood et al, 2004) is a RCT trial of a multidisciplinary, preventive, cardiology programme for CHD patients, asymptomatic high risk individuals and their families. Its aim is to:

> **raise standards of preventive cardiology in Europe by demonstrating that the recommended European and national lifestyle, risk factor and therapeutic goals in cardiovascular disease prevention are achievable and sustainable in everyday clinical practice.**

The study is being conducted in eight European countries, and in six of these, two district general hospitals have been recruited along with general practices. The sample size required is smaller than that in the two larger studies already mentioned, requiring a minimum of 400 subjects (patients or partners or first degree relatives) in both arms of the study. The hospital phase of the study was launched in April 2003. Preliminary results reported by Professor Wood show that nurse-led teams in European general hospitals can help coronary patients and their families to reduce their risk of future cardiovascular events (Wood 2005). Final results from the study will be reported in September 2006.

uestions of time and effectiveness

limitation with many of the research studies is their short uration, particularly as cost-effectiveness needs to be easured over time (Wonderling et al, 1996). The average llow-up for the studies quoted in the meta-analysis was etween one and six years. When making realistic lifestyle ehavioural changes, people do not change immediately; ese changes occur over time, often with a series of relaps- before long-term maintenance is achieved. This conclu- on is echoed by Ebrahim and Davey Smith (1999: 5) who uggest that 'it is possible that benefits cannot be detected in e early stages but emerge over time'. This is especially true r studies which involve young people who have no pre- xisting cardiovascular disease. The motivation to make nd maintain lifestyle behavioural changes is different in eople who have not experienced cardiovascular problems om that in people who have CVD. Primordial and pri- ary prevention have long term goals and objectives which mply cannot be quantified over a relatively short period.

The roles of secondary and tertiary prevention have een well researched and are now an essential aspect of ur modern cardiovascular health management. However, esearch studies have not yet identified a comprehensive pproach to primary CHD prevention which provides onclusive evidence of clinical and cost effectiveness. The nphasis on evidence-based practice has meant that there e no guidelines for primary prevention or structured pro- sion within current practice and health care. Current uidelines focus on secondary and tertiary prevention and eople at high risk, where tables and scores of risk are used direct medical prescribing. Consideration should be iven to including full provision for primordial and primary revention within the general medical contract, with incen- ves to develop a structured approach. Meanwhile, indi- idualized provision for primary prevention remains oppor- unistic and impromptu with generalized advice being iven by practitioners.

urrent strategies

overnment policy

oronary heart disease is one of the UK government's main riorities. The government has published three major docu- ents on CHD since 2000: the *National Service Framework r Coronary Heart Disease, Securing Good Health for the hole Population (Wanless Report)* and *Choosing Health: aking Healthy Choices Easier* (Department of Health DH), 2000; Wanless, 2004; DH, 2004). These three docu- ents illustrate the importance of CHD prevention in the K government's overall treatment strategy and its long rm focus for encouraging healthy lifestyles in both indi- iduals and populations.

ational service framework

he UK's national service framework (NSF) included strate- ies, guidelines and targets for both primary and secondary revention of CHD (DH, 2000). The NSF was needed to eet the targets from *Our Healthier Nation* in which the overnment declared its intention that mortality from heart disease, stroke and related illnesses among people aged under 65 years should to be reduced by at least a third by the year 2010 (DH, 1998). The NSF outlined a strategy for modernizing CHD services in the UK over 10 years.

The Wanless Report

The Wanless Report was commissioned in 2001 to examine future health trends and identify the key factors which determine the resources required for a comprehensive health service based on clinical need. A year later, Derek Wanless expanded the 'fully engaged' scenario of this report. This scenario focussed on public health measures and health inequalities and on how well people become fully engaged with their own health.

Securing Good Health for the Whole Population focused on four areas: prevention of disease, determinants of health, whole population cost effectiveness and health inequalities. The essence of the report is captured in its definition of public health (Wanless, 2004: 3), which it considers to be

> **the science and art of preventing disease, prolonging life and promoting health through the organized efforts and informed choices of society, organizations, public and private, communities and individuals**

The Wanless Report emphasized the value of prevention and the need to develop a NHS which focused on 'wellness' and 'health' rather than 'disease' and 'treatment.' According to Wanless, we should not rely on the science of prevention, there is also an 'art' to preventing disease. Throughout, the report, Wanless stresses the need to engage the public in the health process. People should be encouraged to be accountable for their own health as well as that of their children. Thus, the ultimate responsibility does not reside with government, the final choice is made by the individual. It is the government's role to ensure that everybody is given personalised, high quality information, advice and support to help them make decisions (Wanless, 2004).

Wanless acknowledges that there are difficulties in applying rigorous scientific methodology to the preventive policies of public health and in evaluating their practical implementation. In relation to disease prevention, the report demonstrates that there are advantages in making behavioural changes early in life but that the associated health impact and outcomes are not clearly measurable because there may be an appreciable time lag between the behavioural change and any associated health benefit.

Choosing Health: Making healthy choices easier

In response to the Wanless Report (Wanless, 2004), the government published its white paper, *Choosing Health: Making Healthy Choices Easier*. In the prime minister's own words (DH, 2004:3)

> **Choosing health sets out how we will work to provide more of the opportunities, support and information**

Table 1.
Effects on coronary heart disease in relation to changes in risk factors

Percentage reduction in coronary heart disease cases or deaths

Risk factor	*Target*	*Men*	*Women*
Cholesterol value	All reduced to <5 mmol/l	53.4%	55.5%
	All reduced to <6.5 mmol/l	11.1%	12.6%
Physical activity	All light and sedentary to become moderate	9.6%	10.7%
Blood pressure	All reduce diastolic blood pressure by 5 mmHg	10.6%	8.6%
Smoking	All quit	20%	17%
	Prevalence of 24% by 2010	0.6%	0.5%
Obesity	All have body mass index of 27.5	4.9%	6%
Alcohol	All non-drinkers become 'low' drinkers	4.5%	7.5%
	Everyone to become 'low' drinkers	6.1%	8.1%

Adapted from: Mcpherson, Britton and Causer, 2002

people want to enable them to choose health. It aims to inform and encourage people, as individuals, and to help shape the commercial and cultural environment we live in so that it is easier to choose a healthy lifestyle

The white paper emphasized the sharing of responsibility between individuals, families, industry and the government, so that true, informed choices could be made to improve the population's health. When the NHS was established 50 years ago, the emphasis was on treatment for acute conditions and diseases. In the future, the major health issues faced by the NHS will be chronic conditions and illnesses, many of which, such as obesity and physical inactivity, will be related to our lifestyle. This paper allowed for the strategic change of emphasis from a biomedical illness model to a health and wellness model of care.

Choosing Health places the emphasis on individual choices and coordinated action between individuals, industry, the NHS and government. Health promotion and health awareness are key components. There is considerable emphasis on the importance of support for individuals from childhood through to old age.

National population-based projects to meet current strategies

Current government initiatives to encourage and promote a healthier lifestyle in the general population, rather than targeting individuals, include the following (DH, 2006):

- Tobacco cessation
- Food and Health Action Plan
- The 5 A Day programme
- Food in Schools programme
- Local Exercise Action Pilots (LEAP)
- Healthy Living Centres

These are all national projects. Services include the smoking cessation clinics and the provision of a free piece of fruit in school to children aged between four and six years. In addition, public awareness of the 5 A Day programme, which was launched in March 2003 and aims to increase fruit and vegetable consumption, has been raised through colourful logos and advertising.

Importance of focusing on risk factors

A recent briefing paper from the NHS Health Development Agency discusses the relative contributions that changes in risk factors and treatments make to reducing CHD mortality (Kelly and Capewell, 2004). The paper argues that improvements in CHD mortality are attributable more to reductions in risk factors than to medical treatment. It states that only strategies to reduce risk factors have the potential to halve the death rate from CHD (Kelly and Capewell, 2004).

IMPACT model

Unal et al (2003) developed the IMPACT model which has been used to combine and analyse data on the uptake and effectiveness of cardiovascular treatment and risk factor trends across England and Wales. They showed that between 1981 and 2000 half of the reduction in CHD mortality in Britain resulted from reductions in major risk factors—namely smoking, cholesterol and blood pressure. These researchers also showed that the adverse trends in obesity, decreased physical activity and diabetes caused a total of approximately 8000 additional CHD deaths in the year 2000 (Unal et al, 2003). Their conclusion is that comprehensive CHD strategies should actively focus on primary prevention, especially tobacco control and healthier diets (Unal et al, 2003: Unal et al, 2005).

Risk reductions

The 2002 report from the National Heart Forum discusses how changes in the risk factors for CHD can lead to reduced rates of CHD in the population. These have been examined over time and assume that there is a causal relationship between the risks (McPherson et al, 2002). *Table 1* shows the reductions which might be achieved in 10 years, if these population targets were met. The effect of reductions in alcohol consumption has been included by the authors for comparison. The table clearly shows that the cholesterol concentration is the major determinant of CHD incidence, and illustrates how changes in risk factors can influence CHD levels.

Our health, Our care, Our say

This latest government white paper was published in January 2006. It sets out the government's vision of more effective health and social services outside hospitals (DH, 2006). The focus continues to be on the individual and the maintenance of health within the community setting. Five key areas for change are identified as follows:

- More personalized care

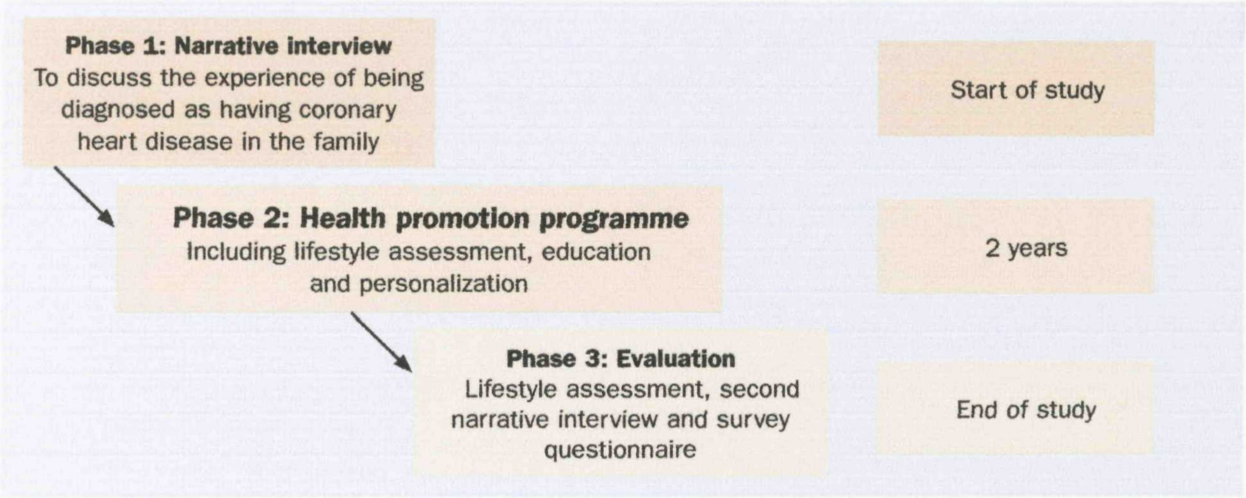

Figure 1. Study phases

- Services brought closer to the people
- Better co-ordination between local councils and the NHS
- Increased choice
- Focus on prevention as much as care.

Money matters

The reports and papers discussed above illustrate the importance the UK government places on the need to maximize the health of the population through encouraging and supporting prevention. Unfortunately, however, this emphasis is not reflected in the levels of funding for primary prevention in the NHS. The latest figures available from the British Heart Foundation are for 1999, when less than 1% of the total CHD cost was spent on primary prevention (Petersen et al, 2004).

Role of the randomized controlled trial in primary prevention

It could be argued that the studies discussed in the first part of this article have been of questionable value in providing sustainable risk factor modification. Wanless (2004) stated that it is difficult to apply the rigorous scientific evaluation used in intervention studies to the area of public health, where it is hard to accurately measure the long term outcomes of health promotion activities. The RCT is considered to be the gold standard of medical evidence-based

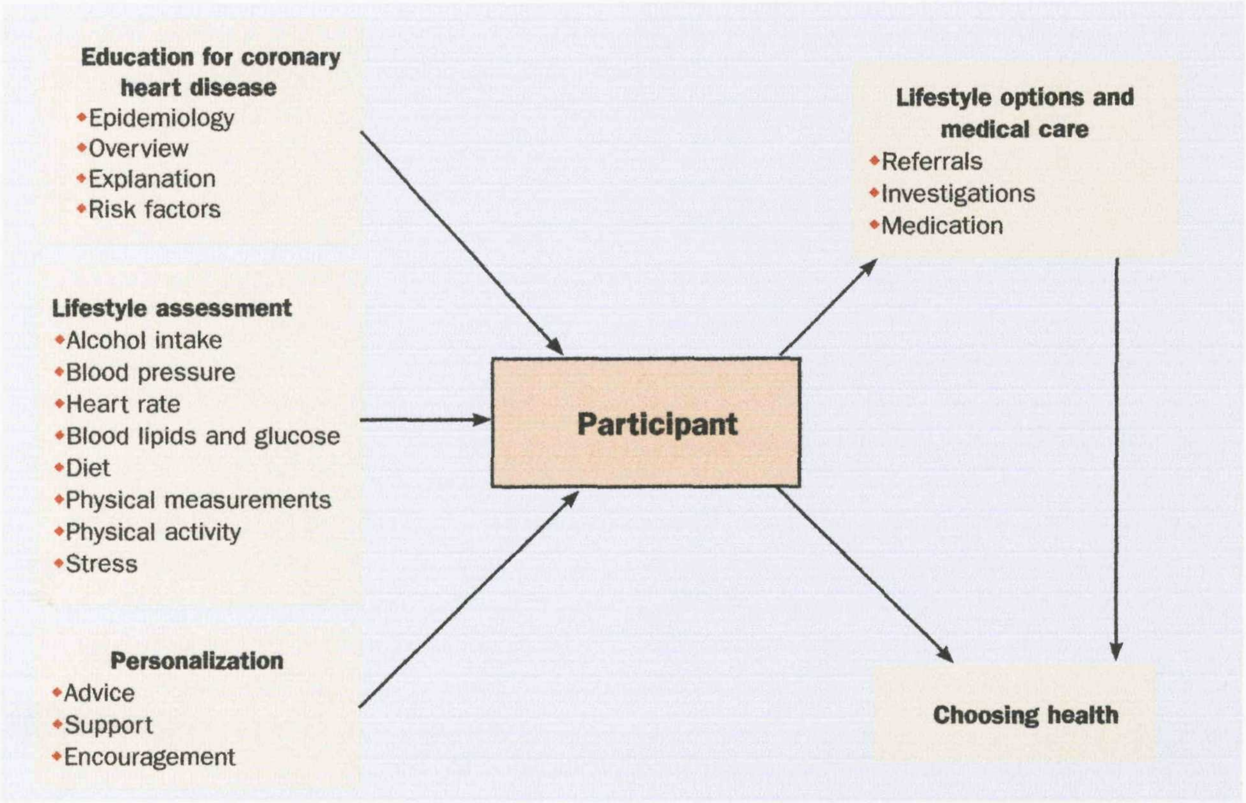

Figure 2. The health promotion programme

Table 2.
Mrs Smith's lifestyle assessment at the first visit and fourth visit

Lifestyle assessment

Factors *(recommended values)*	***Visit 1 (baseline)***	***Visit 4 (month 18)***
Alcohol consumption Women: <14 units per week	10–12 units per week	10–12 units per week
Cardiovascular BP: <140/90 mmHg, maximum 160/90 mmHg Pulse: 60–80 bpm	BP: 159/86 mmHg Pulse: 85 bpm, regular	BP: 124/68mmHg Pulse: 76 bpm, regular
Cholesterol (local reference ranges) Total cholesterol: 3.8–5.2 mmol/litre Triglycerides: 0.8–2 mmol/litre LDL cholesterol: 2.3–3.4 mmol/litre HDL cholesterol women: 1.3–2.3 mmol/litre	Total cholesterol: 5.8 mmol/litre Trigycerides: 1.22 mmol/litre LDL cholesterol: 3.9 mmol/litre HDL cholesterol: 1.37 mmol/litre	Total cholesterol: 3.8 mmol/litre Triglycerides: 1.84 mmol/litre LDL cholesterol: 1.73 mmol/litre HDL cholesterol: 1.27 mmol/litre
Fasting blood glucose: 3–6 mmol/litre	6.4 mmol/litre	6.1 mmol/litre
Diet 1/3 fruit and vegetables 1/3 carbohydrates 1/3 equal amounts of protein, dairy foods, foods containing sugar and fat	Five portions of fruit and vegetables daily. Limited dairy produce and red meat	Overall excellent balance. Limited sugary foods
Physical activity 30 minutes of moderate activity most days of the week	Active daily for a minimum of 30 minutes. Vigorously active twice weekly	Limited at present due to injury
Physical measurements BMI: 20–25 correct weight Waist (women) <88 cm	Weight: 70 kg. BMI: 25 Waist: 88 cm	Weight 71 kg. BMI: 25 Waist: 85 cm
Smoking	Never	Never
Stress	High at persent	Feels more 'laid back'

BP = blood pressure, bpm = beats per minute, LDL= low density lipoprotein, HDL = high density lipoprotein, BMI = body mass index

practice, but is the RCT an appropriate study design for showing the effectiveness of primary prevention strategies? It is expensive and time-consuming, it often includes too few subjects or is undertaken for too short a period, and the inclusion/exclusion criteria can limit its generalisability to a wider population.

A primary prevention strategy in a district general hospital

Earlier parts of this article have described the problems in studying interventions for the primary prevention of CHD. The recently published *Joint British Societies' Guidelines on Prevention of Cardiovascular Disease in Clinical Practice* (British Cardiac Society, British Hypertension Society, Diabetes UK et al, 2005) places renewed emphasis on targeting those at high risk for developing CHD. Those with a family history of premature death or morbidity from CHD are at high risk and should be advised and screened accordingly. However, identifying these people is problematic. The advantage for secondary prevention is that the people who would benefit are clearly identified when they receive their diagnosis of CHD at the hospital. We are currently undertaking an exploratory study to identify those at high risk of CHD and provide primary prevention in a hospital setting.

Two year study

The research project has been established within a district general hospital to determine the feasibility of providing primary prevention for those at high risk of developing CHD. The study provides a two-year programme of education, lifestyle assessment and support, aiming to reduce the overall risk of developing heart disease. (It is acknowledged that the research has similarities to the hospital arm of EuroAction Study, but was established prior to the publica-

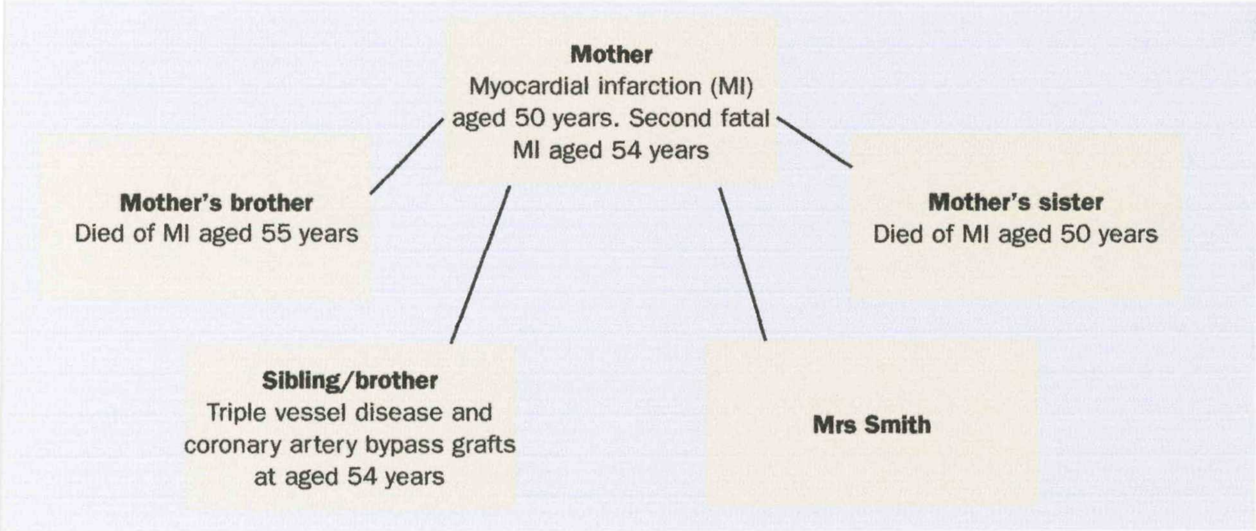

Figure 3. Mrs Smith's family tree for coronary heart disease

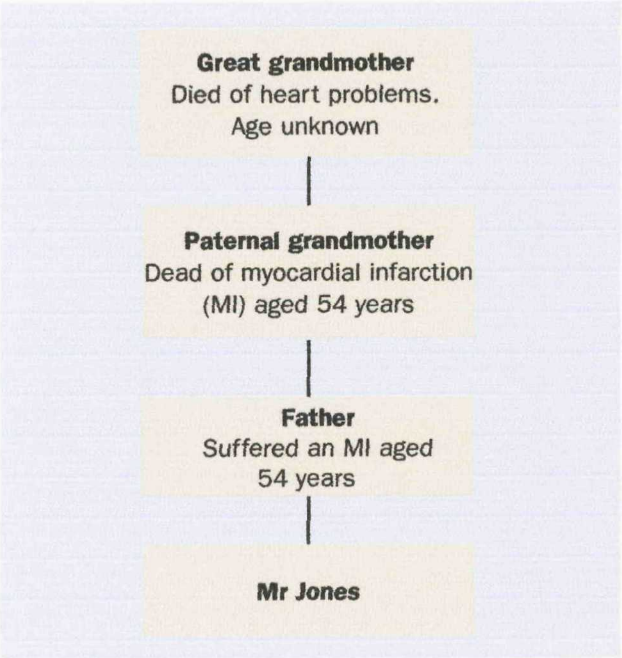

Figure 4. Mr Jones's family tree for coronary heart disease

n of the EuroAction study (Wood DA, Kotseva K, nnings C et al, 2004).

The study was granted approval by the local research eth- committee in July 2002; recruitment did not commence til April 2004. Over a 14 month period, 28 people were cruited and completed phase 1 of the study. This repre- nts 23% of those who were identified and invited to par- ipate. The final study results will be available in 2008.

ho are the subjects?

e study subjects are those who have parents or siblings ho have been diagnosed with premature CHD in our partment. The definition of 'premature' for men is a diag- sis of CHD at 55 years of age or younger; for women the finition is 65 years of age or younger. The study aims to swer two questions:

- What is the experience of being diagnosed with CHD in the family?
- Can a two year health promotion programme result in an improved cardiovascular risk profile?

udy phases

e study is divided into three phases: the initial narrative terview at the start of the study, the lifestyle assessment d health promotion programme, and the final evaluation ase. *Figure 1* illustrates these three phases.

he health promotion programme

articipants are asked to attend a minimum of five, six- onthly hospital-based clinic appointments over two years. isit one would take place right at the beginning, visit two month six, visit three at month twelve, visit four at month 8 and visit five at two years. The clinic is nurse-led and octor supported. The health promotion programme has ree main components:

- Education
- Lifestyle assessment
- Personalization

The personalization component comprises individual dvice, support and encouragement as appropriate to each subject's personal needs and wishes. With these three components the participant is able to consider the health options. *Figure 2* shows this schematically. Participants may not need to consider options for some aspects of their lifestyle assessment, while for others, referrals, further investigations, or medication may be necessary. Inclusion of family members and partners is encouraged. Reproducibility is an important feature of the programme, ensuring that the programme could feasibly be replicated by other practitioners.

Primary prevention in secondary care

Primary prevention studies usually take place in general practice. This approach is unique because it takes place in secondary care, involving the specialist services of the cardiology team. It encompasses both sexes, all ethnic groups and all age ranges. Young people are encouraged to

Table 3.
Mr Jones's lifestyle assessment at the first visit and third visit

Lifestyle assessment

Factors *(recommended values)*	***Visit 1 (baseline)***	***Visit 3 (month 12)***
Alcohol consumption Men: <21 units per week	18–32 units per week	18–32 units per week
Cardiovascular BP: <140/90 mmHg, maximum 160/90 mmHg Pulse: 60–80 bpm	BP: 127/76 mmHg Pulse: 81 bpm, regular	BP: 110/65 mmHg Pulse: 64 bpm, regular
Cholesterol (local reference ranges) Total cholesterol: 3.8–5.2 mmol/litre Triglycerides: 0.8–2 mmol/litre LDL cholesterol: 2.3–3.4 mmol/litre HDL cholesterol Men: 1–2 mmol/litre	Total cholesterol: 5.2 mmol/litre Trigycerides: 1.25 mmol/litre LDL cholesterol: 3.09 mmol/litre HDL cholesterol: 1.57 mmol/litre	Total cholesterol: 5 mmol/litre Triglycerides: 1.58 mmol/litre LDL cholesterol: 2.56 mmol/litre HDL cholesterol: 1.75 mmol/litre
Fasting blood glucose: 3–6 mmol/litre	4.9 mmol/litre	Not required
Diet 1/3 fruit and vegetables 1/3 carbohydrates 1/3 equal amounts of protein, dairy foods, foods containing sugar and fat	Two portions of fruit daily. Mainly white meat Limited vegetables and fish	Increased vegetable consumption and fish. Diet balanced during the week, less so at weekends
Physical activity 30 minutes of moderate activity most days of the week	Active at work. No formal exercise	Active at work. Attends gym two to three times a week
Physical measurements BMI: 20–25 correct weight Waist (men) <102 cm	Weight: 72 kg. BMI: 22 Waist: 84 cm	Weight 75 kg. BMI: 23 Waist: 90 cm
Smoking	In the evening	Ex-smoker (8 months)
Stress	No problems	Moving house at present

BP = blood pressure, bpm = beats per minute, LDL= low density lipoprotein, HDL = high density lipoprotein, BMI = body mass index

take part since atherogenesis begins in childhood (Mancini, 2002) and lifestyle habits can be influenced at an early age, encouraging life time adherence to healthy behaviour.

Case study design

The design of the research is a case study in which both qualitative and quantitative data are collected. The case study approach was chosen as it enables an empirical investigation to be studied within the real life context, where multiple sources of data are collected and where the individual case is studied in its own right (Robson, 1993). The effectiveness of the health promotion programme will be measured by comparing the risk assessment data collected at baseline with the data collected at the final visit. The narrative allows the participants to share their experience of living with CHD in the family and the challenges they face. The narrative interviews will facilitate the analysis of individual data while providing personal insight into their experiences. We give two examples of case studies below.

Case study 1: Mrs Smith

Mrs Smith is 54 years old. She was informed about the study when her own husband was admitted to the hospital with a myocardial infarction (MI). Her family tree (*Figure 3*) illustrates the extent of CHD in Mrs Smith's family. She was 21 years old when her mother died, this was followed a year later by the death of her aunt. Her uncle had died five years earlier. In her narrative Mrs Smith said:

> **and then a year after my mum dies, her sister who was 50 at the time, also died of a heart attack. So of course it was even more instilled in me, heart problems, heart problems within the family. Yeah I did think about it over the years. But you try to put it to the back of your mind. It isn't going to affect you. But**

> **it is at the back of your mind because you're always.... and then when my brother was in his 40s, he started having the angina. That brought it to the fore again.**

When she visited her GP she said:

> **Well I had mentioned it to him, my family history ... but I had this new GP which must have been 5 or 6 years ago; and he didn't seem that concerned about my family history. He said we'll just do your cholesterol and blood pressure. And my cholesterol, I think, was 5.4 and my blood pressure was fine.**

llow-up

e initial lifestyle cardiovascular risk assessment showed at Mrs Smith's lifestyle behaviour, which she had adopted er the subsequent years, was exemplary. She had never noked, nor was she exposed to passive smoking; her diet as good with moderate alcohol consumption; she was ysically active; not overweight. Her blood pressure, cho- sterol and fasting blood sugar values were all high. There ere no changes she could make to her lifestyle that would nprove these, apart from reducing her intake of sugary ods. Two months after this assessment, her GP had com- enced treatment with a statin for cholesterol reduction, lcium channel blocker for her blood pressure and her ood sugar levels were closely monitored. *Table 2* illustrates rs Smiths' lifestyle assessment at visits one and four.

ase Study 2: Mr Jones

r Jones is 28 years old. *Figure 4* illustrates his family his- ry for CHD and *Table 3* shows his lifestyle assessment for sits one and three. During the first year in the study Mr nes managed to stop smoking, he made substantial nprovements to his diet including increasing his con- umption of vegetables and oily fish, and in addition to ese changes he undertakes formal exercise sessions by tending a local gym two to three times a week. His lipid rofile and blood pressure were improved.

onclusions

he question of primordial and primary prevention of HD in the UK is topical and important. The effective- ess of risk factor modification in reducing CHD has een shown by the IMPACT model and has been sup- orted by the National Heart Forum. Although the gov- rnment has declared its strategies for developing a ealth' focused service, funding is an issue. Furthermore, e effectiveness of research studies in which a RCT xperimental design has been used to evaluate primary revention has been disappointing. What is clear from e case studies we describe above is that a family history f CHD can be extensive and may influence behavioural nd treatment outcomes.

The authors believe that there is a need to develop a ersonalized approach to primary prevention research. n approach in which those features which cannot be measured quantitively can still be studied while maintaining scientific rigour. The authors support an approach which places the individual participant, not merely the outcome data collected from them, at the centre of the research. It should be from the participant that we learn, and can consequently evaluate their pathway to a healthier lifestyle over a period of time. It is then possible to develop a range of effective cardiovascular health promotion strategies within the UK.

KEY POINTS

- There are three generally accepted levels of prevention - primary, secondary and tertiary prevention
- There is a fourth level, 'primordial' prevention, which focuses on risk factors which can be modified early, in children and young people, before disease develops
- Primary prevention research studies for reducing cardiovascular risk in individuals have been costly and authors report limited success
- Current government policy focuses on healthy lifestyles for individuals and whole populations
- Lifestyle assessment for high-risk individuals can begin at all ages

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APPENDIX XXII

PUBLICATION ~

'TARGETING AT-RISK FAMILIES FOR CARDIOVASCULAR PRIMARY PREVENTION.'

In their article discussing the opportunity for targeting families with a history of premature coronary heart disease, Chow and colleagues 1 conclude that research is needed to identify barriers and determine the most effective approach. Over the past three years we have undertaken a single centre case study looking at primary prevention for the first degree relatives of patients diagnosed with premature coronary heart disease (CHD) 2. The study was undertaken in a district general hospital, when their relative, sibling or parent, was initially diagnosed with premature CHD on our coronary care unit. The participants were invited to participate in a two year health promotion programme where a nursing assessment of their lifestyle risk factors was evaluated, discussed and they were encouraged and supported to make behavioural changes. The final results are being analysed, so we are unable at present to comment on the outcome of the study; but can reflect upon certain demographics which provide valuable insight regarding the participants who completed the study.

We used purposive sampling and within a year recruited 28 participants, from 14 families; 21 of these completed the study. We invited first degree relatives of any age and gender to participate in the study, excluding those with a diagnosis of cardiovascular disease. The age range of our population varied from 19 to 58 years; 4 of the participants were less than 25 years, while 7 where between 26 and 35 years of age. A third of our participants, 7, lived within 5 miles of the hospital but 8 travelled over ten miles to attend the study. For 13 of our participants their relative had been diagnosed with CHD in the preceding year; however for 8, the diagnosis had been made between one and 14 years previously.

The points of interest arising from this study is that firstly people of all age ranges are interested in participating. It is important that young people are involved in prevention studies, when the atherosclerotic process can start in childhood 3 and influencing behavioural change is often easier when people are younger and less established in their lifestyle practices. We know that attendance at a cardiac rehabilitation programme is influenced by distance, where the distance that patients travel to the classes can affect adherence to the programme 4. Yet here we show that people were willing to travel to receive comprehensive lifestyle assessment and advice. Even those for whom the diagnosis of their relative occurred over a year ago, again they are still willing to attend five visits, in a hospital setting, over a two year period.

Perhaps instead of looking for barriers to prevention we should be encouraged that people of all ages are actively interested and will travel to participate in a health promotion research study. Reflecting upon our own experience with this cohort we can illustrate that the sustained enthusiasm and interest from these people, to receive professional advice, encouragement and support, may not be as problematic at one might assume. We would regard the model of cardiac rehabilitation classes to be suitable for patients to bring their relatives to receive appropriate assessment, advice and support; where integration of primary, secondary and tertiary prevention can occur.

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Competing interests: None declared

APPENDIX XXIII

FAMILIES AT RISK PROJECT POST CARDS

Our family
now has a history of early
heart problems.

TAKE CONTROL

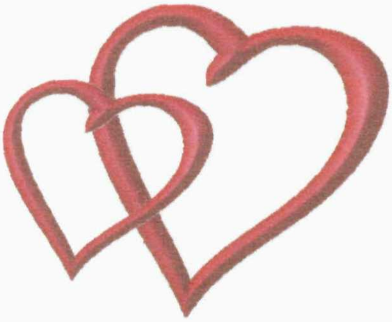
ACT NOW

REDUCE YOUR RISK

NHS

Cardiac Network

A HEALTHY LIFE STYLE HELPS TO KEEP YOUR HEART HEALTHY



What you should do:

- **Inform your doctor** about your family history of premature heart problems
- **Stop Smoking** - your GP will be able to offer you advice and support
- **Stay in Shape** - Be active and keep a healthy body weight
- **Eat and Drink Healthily** – limit alcohol and choose a balanced diet with plenty of fruit and vegetables
- **Take time to relax** and reduce stress

What your GP can do:

- **Life Style Assessment**
- **Blood Pressure Test**
- **Cholesterol Blood Test**
- **Fasting Glucose Test**

Your GP will be able to offer you advice and support to help you to mak changes to your life style and reduce your risk of Coronary Heart Disease

For more information on Coronary Heart Disease contact the British Heart Foundation.
Phone: 020 7935 0185
Website: bhf.org.uk

GLOSSARY OF TERMS

ANGINA PECTORIS: is the pain caused when the heart muscle is deprived of oxygen due to reduced blood flow; the muscle becomes ischaemic, and cardiac chest pain is felt. The pain is transient and is relieved once blood flow is restored.

ATHEROSCLEROSIS: is the disease process which occurs in the arteries. Other terms include atheroma, arteriosclerosis, fatty plaque and atherosclerotic lesion (see page 11).

CORONARY HEART DISEASE: results from atherosclerosis developing in the coronary arteries that supply the heart muscle, and leads onto impaired functioning of the heart muscle (see page 11).

CARDIOVASCULAR: pertaining to the heart and blood vessels (arteries, veins and capillaries) (see page 10).

CARDIOVASCULAR DISEASE: is the disease process that occurs in blood vessels, mainly major arteries such as the aorta and femoral; the coronaries, which supply the heart muscle; cardiovascular disease can also manifest in the medium sized arteries of the cerebrum and kidneys (see page 10). Cardiovascular disease encompasses the pathogenic atherosclerotic process that occurs in the arteries and which results in a collection of diseases, of which coronary heart disease and cardiovascular accident are examples.

CARDIOVASCULAR ACCIDENT: a stroke. Due to haemorrhage or infarction in the cerebral artery.

CHOLESTEROL: cholesterol is essential for life, it is found in the brain, nerves, kidney, cell walls, hormones and the liver, where it is produced. The different types of cholesterol are called 'lipoproteins.' The low density lipoproteins (LDL) infiltrate and contribute to the build-up of atheroma; high density lipoproteins (HDL) scavenge excess LDL from the blood stream; triglycerides are another fat which circulate in the blood stream. These make up a lipid profile.

FIRST-DEGREE RELATIVE: a person's parent, sibling or child.

GENERAL RESISTANCE RESOURCES: these are resources, which according to Aaron Antonovsky, help people move in the direction of positive health (see pages 8 - 12).

MYOCARDIAL INFARCTION: a heart attack. A thrombus or stenosis occurs in a coronary artery, causing a blockage (infarction) so that blood is unable to flow, which results in ischaemia to the distal arteries. Ischaemia of the myocardium (heart muscle), causes necrosis (death) of the surrounding tissue.

PREMATURE FAMILY HISTORY: this is classified as before the age of 55 years for men, and before the age of 65 years for women.

SALUTOGENESIS: the origins of health. Salutogenesis focuses on the factors that enhance health and well-being. It is the opposite of pathogenesis where the emphasis is on the causes of illness and disease. It is a term first used by Aaron Antonovsky.

SALUTARY FACTORS: factors which enhance and promote a strong sense of coherence, thus encourage movement toward the healthy end of a health / dis-ease continuum: health-promoting resources.

SENSE OF COHERENCE: is described as a 'sixth sense' for survival which generates health promoting abilities; it is made up of three core components, comprehensibility, manageability and meaningfulness (definition see page 11).

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