

**Maintaining Enjoyment of Life in the Process of Living with High
Cholesterol: A Grounded Theory Study.**

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ATTESTATION OF AUTHORSHIP

I hereby declare that this is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person or material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

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Valerie R Reade-Raethel

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ABSTRACT

Hypercholesterolaemia (high cholesterol) is a risk factor for atherosclerosis, a major contributor to cardiovascular disease. Much has been written on managing high cholesterol levels including the use of drug therapy and recommendations about beneficial lifestyle changes relating to nutrition and exercise in particular. Despite this, and the need for patients to engage in self management of a condition which may impact invisibly on their health, little is known about how people living with this risk factor actually manage.

The purpose of this grounded theory study is to investigate people's process of living with high cholesterol. Eight participants with self reported high cholesterol levels were interviewed and their data analysed using the process of constant comparative analysis, open coding, selective coding and theoretical coding. A substantive theory in the area of patient self-management of high cholesterol levels was generated through the use of this approach. The theory developed was the basic social process of Maintaining Enjoyment of Life, with two supporting categories, Accepting and Getting On With It.

Maintaining Enjoyment of Life was central to the participants' process of living with high cholesterol and the recommended health directives. The identification of this basic social process adds to our understanding of the influences on individuals' motivation for behaviour change and adherence to lifestyle changes. The findings of this study provide understanding that issues relating to behaviour change and adherence are not so much about denying that anything is wrong or not taking personal responsibility, but more about trying to hold on to something important, around which the participants' lives revolve. This is Maintaining Enjoyment of Life. By focussing on this basic social process, which is grounded in the participants' data, health professionals could work

more effectively towards empowering patients to identify their own individualised strategies for self-management of high cholesterol. In addition, health directives could focus more on process rather than on do(s) and don't(s).

CHAPTER ONE: INTRODUCTION

Introduction to the Chapter

This thesis is a grounded theory study on the process of living with hypercholesterolaemia (high serum cholesterol levels). Chapter One outlines the context of the thesis, including the significance of hypercholesterolaemia and the background of the researcher. The chapter also contains an overview of the thesis including its aim and purpose, and its structure.

Hypercholesterolaemia has been studied extensively in medical science because of its contribution to cardiovascular disease. The literature, which will be discussed in Chapter Two, includes the aetiology, risks, drug therapy, research and recommendations for lifestyle modification. However, literature is sparse on the experience and perspective of the very people who live with the condition in the context of the advice and directives provided by health professionals. The directives involve recommendations for lifestyle modifications to control hypercholesterolaemia. Health professionals hope that patients will comply with these recommendations. Tensions arise when they do not appear to adhere to treatment or directives because health professionals view such behaviour as affecting on outcome negatively. As a nurse working with people who have hypercholesterolaemia, I shared this view at the beginning of this study.

The tension mentioned above precipitated my interest in discovering the actual processes and interactions experienced by people who live with hypercholesterolaemia. I was interested in understanding the different aspects of their behaviour, including those which we as health professionals consider non-adherent.

Significance of the Issue

Hypercholesterolaemia has been widely studied over the last four decades and the risks for cardiovascular disease associated with hypercholesterolaemia are well established. They will be discussed in greater detail in Chapter Two.

Hypercholesterolaemia is a significant risk factor for mortality from coronary artery disease (CAD) in men and women, although the risk for women is higher for post-menopausal than for pre-menopausal women (McCance & Huether, 1998; Thelan, Urden, Lough & Stacy, 1998). Mortality was found to increase with age for men (Rubin et al, 1990). Although pre-menopausal women are known to have a lower risk for CAD, younger women (less than 50 years of age) with acute myocardial infarction (heart attack) were found to have a higher mortality rate than men of the same age (Vaccarino, Parsons, Every, Barron, & Krumholz, 1999).

Cholesterol reduction has been found to be beneficial. For instance, in a meta analysis of all randomised controlled trials of two years' duration (n=35), it was found that for every 10% of cholesterol level reduction, CAD mortality was reduced by 13% ($P<.002$) and total mortality by 10% ($P<.03$) (Gould, Rossouw, Santanello, Heyse, & Furberg, 1995).

Knowledge of these benefits has resulted in a number of strategies aimed at helping people reduce their cholesterol levels. These include detection, evaluation of risk for CAD and treatment of hypercholesterolaemia.

Detection includes blood tests for fasting lipid profiles where a fasting blood sample is obtained and screened for levels of total cholesterol (TC), low density lipoproteins (LDL), triglycerides and high density lipoproteins (HDL). This will be

discussed in further detail in Chapter Two. Risk is evaluated in relation to other risk factors such as family history, smoking, weight, sedentary lifestyle and co-existence of other conditions such as diabetes and hypertension. Treatment involves lifestyle modification as well as pharmacological therapy if cholesterol cannot be lowered sufficiently through lifestyle modification. Lifestyle modification targets diet, exercise and weight control. Changes are achieved through health education and patient self-management of the condition.

In my role as a coronary-care and intensive-care nurse in a level-two hospital in New Zealand for thirteen years, I actively participated in cardiac rehabilitation within the unit. Part of my role involved providing cardiac patients with information aimed at reducing cardiovascular risk. Education on cholesterol self-management is a significant component of cardiovascular risk reduction.

Quantitative studies have shown that health education is effective in the short term (Okayama, Chiba, & Ueshima, 2004) but the processes by which people actually engage with the recommendations over time is unclear. It may be that more understanding of the processes from the patients' own perspectives will facilitate both my work and the work of others with patients who have hypercholesterolaemia.

Adherence to medical directives and treatment is known to be limited (Bergman & Berterö, 2001; Kravitz et al, 1993; Kyngas & Lahdenpera, 1999; Price, 1993). Bergman and Berterö have identified “characteristics, prerequisites and difficulties” (p. 740), including adherence, in living with CAD, and they call for increased knowledge in patients.

It is recognised that nurses play an important role in supporting patients and that physicians and nurses have a responsibility to work together with patients to enable them

to implement lifestyle modifications and achievable self-management, hence the promotion of patient-centred care (Bergman & Berterö, 2001). Nurses, including this researcher, work according to the philosophy of delivering patient-centred care to achieve better outcomes. Teutsch (2003) offers a definition of patient-centred care derived from the Cochrane Collaboration and states this as, “a philosophy of shared decision-making with the patient or a consultation focussed on the patient in a holistic manner, incorporating patient preferences and social contexts (rather than limiting focus to a disease or body part)” (p. 1121).

As I prepared to focus my studies on hypercholesterolaemia, it became clear that more understanding of the patients’ own process might shed light on their patterns of behaviour. This would then guide health professionals in making health strategies relevant to individuals. This realisation led to the selection of grounded theory, a qualitative research methodology which focuses on discovering people’s social processes from their own perspectives, as the appropriate methodology to learn more about how best to prevent and treat hypercholesterolaemia.

Aim and Purpose

The aim of this study is to develop a substantive theory explaining people’s process of living with hypercholesterolaemia by using grounded theory. The purpose of the study is to understand the process which shapes the behaviour of people living with this risk factor. Because self-management and adherence to health directives is an important part of the success of cholesterol control, understanding this process and behaviour will be of value in formulating patient-centred strategies for managing hyperchoelsterolaemia. The term “high cholesterol” is often used to refer to

“hypercholesterolaemia” in this thesis because this is the term used by the participants to refer to their condition. “High cholesterol” is commonly used as well by lay people and is the term I use when working with patients.

Structure of the Thesis

This chapter gives an overview of the context of this thesis. The following chapters present the background and research process undertaken for this study. Chapter Two discusses the background of the study in further detail. The condition of high cholesterol is explained and this is followed by a discussion of cardiovascular disease and cholesterol management. Communication and its importance to a collaborative relationship between patients and health providers are also examined.

Chapter Three presents the methodology of grounded theory, the methods guided by this methodology and research process of this study. Also covered within this chapter is how rigour was undertaken and maintained. This chapter concludes with an overview of the findings chapters.

Chapters Four, Five and Six present the findings of this study. Chapter Four explains the first category, Accepting, and its properties. Chapter Five discusses the second category, Getting On With It, and its properties. Finally Chapter Six examines the basic social process and central category of Maintaining Enjoyment of Life around which the first two categories and their properties revolve.

Chapter Seven, the last chapter of this thesis, discusses the main points in the findings of this study in association with other studies and theoretical models. The implications, recommendations, limitations and strengths of the study are presented next.

Conclusion

Chapter One presented a brief overview of the condition of high cholesterol. The aim and purpose of the study were referred to. Finally, the structure of the thesis was presented to introduce the reader to the research process that explored living with high cholesterol. This study generated a substantive theory which describes the basic social process which the participants undertook to live with and manage their condition. To familiarise the reader with high cholesterol and its ramifications, a more detailed discussion of high cholesterol and cardiovascular disease is offered in the next chapter.

CHAPTER TWO: BACKGROUND

Introduction

Chapter Two discusses the issue of high cholesterol and its link to cardiovascular disease. High cholesterol, if left unmanaged, is a significant factor for cardiovascular disease (Grundy, 1997c; McCance & Huether, 1998; Thelan et al, 1998), and is a major cause of morbidity and mortality in New Zealand. Issues related to this are discussed, in this chapter, in sections which define and describe high cholesterol and cardiovascular disease. Following this the significance and physical impact of high cholesterol as well as population demographics relating to cardiovascular disease are described. The recommended management of cardiovascular risk factors is presented in order to enhance understanding of the lifestyle changes patients with high cholesterol are advised to engage in, by health professionals. This is followed by a discussion on communication between health professionals and patients. Finally, the focus of enquiry will be presented. This section begins with a discussion on the definition and description of high cholesterol.

Definition and Description of High Cholesterol

High cholesterol is a risk factor for cardiovascular disease, where lipids or fats are present in higher than recommended plasma concentrations (McCance & Huether, 1998; Thelan et al, 1998). Cholesterol is a lipid (fat-like substance) which is present in cell membranes. It is a precursor of essential substances such as bile acids and steroid hormones. Cholesterol is produced in the liver by a series of chemical reactions along with other lipoproteins such as very low density lipoproteins (VLDLs) which consist

mainly of triglycerides and protein; low-density lipoproteins (LDLs) which are cholesterol and protein; and high-density lipoproteins (HDL) which are mostly phospholipids and protein. Lipoprotein is a collective term for lipids, phospholipids, cholesterol and triglycerides which are bound to carrier protein for transport in the blood (McCance & Huether, 1998; Porth & Kunert, 2002).

There are two types of lipoproteins: low-density lipoprotein (LDL - often called the “bad” cholesterol) and high-density lipoprotein (HDL - also referred to as “good” cholesterol). LDL is the lipoprotein which contains cholesterol and is associated with an increased risk of cardiovascular disease. HDL, on the other hand, is the “good” lipoprotein which protects against cardiovascular disease (McCance & Huether, 1998; Porth & Kunert, 2002; Thelan et al, 1998).

Blood screening for high cholesterol looks at total cholesterol (TC), triglycerides, LDL, HDL and the ratio of total cholesterol and HDL. High levels of LDL (low density lipoproteins – the “bad” cholesterol) and low levels of HDL (high density lipoproteins – the “good” cholesterol) indicate a high risk of CVD. According to the New Zealand Guidelines Group (NZGG) (2003) the Framingham Heart Study found the TC:HDL ratio to be an even better predictor of cardiovascular risk than either the TC (total cholesterol), LDL, HDL or triglycerides assessed individually. The NZGG (2003) goals for lowering cholesterol are: “total cholesterol < 4mmol / l; LDL cholesterol < 2.5mmol / l” (p. 58).

The risk from high cholesterol can be reduced by early dietary intervention (Hager, 1996; McCance & Huether, 1998) and exercise (Hager, 1996; NZGG, 2003). This risk emphasizes the importance of developing effective strategies for achieving the changes conducive to minimising atherosclerosis and its progression to CVD. Atherosclerosis and cardiovascular disease are discussed further in the next section.

High cholesterol is a risk factor for atherosclerosis, a major contributor to coronary artery and cerebrovascular diseases, collectively termed cardiovascular disease (CVD) (Hay, 2002; McCance & Huether, 1998; NZGG, 2003). Atherosclerosis is a condition where there is thickening and hardening of the arterial walls due to soft deposits of fat and fibrin in vessel walls, which harden over time (McCance & Huether, 1998). This causes narrowing of the artery walls which then intrude into the lumen (cavity inside a tube / blood vessel). Over time this narrowing can cause complete occlusion of the vessels by a roaming blood clot or spasm of the artery, thus contributing to cardiovascular disease (Marieb, 2001). The definition and description of cardiovascular disease is presented next.

Cardiovascular Disease

Cardiovascular disease is any condition involving the heart and blood vessels (NZGG, 2002b) where cardiovascular function is altered by atherosclerosis and arteriosclerosis (McCance & Huether, 1998). Arteriosclerosis is also the result of abnormal thickening and hardening of the arterial walls but is not linked to high cholesterol. The Evidence-Based Best Practice Guidelines set out by the NZGG (2003) classify angina, myocardial infarction, coronary death, ischaemic stroke, transient ischemic attack and peripheral vascular disease under CVD.

There are major risk factors for cardiovascular disease. The NZGG (2003) lists these as: “personal history of cardiovascular disease, age, sex, smoking, lipids (cholesterol), blood pressure, diabetes, atrial fibrillation, obesity, physical inactivity, a family history of coronary heart disease and socioeconomic position” (p. 1).

In addition to the factors listed above, Porth and Kunert (2002) list “homocysteine, serum lipoprotein (a), C-reactive protein (CRP) and infectious agents”(p. 435) as other possible causes of atherosclerosis. A brief explanation of homocysteine is offered in the next section because it was mentioned by one of the participants as part of their self-monitoring strategy.

Homocysteine is the product of the metabolism of dietary methionine, which is an amino acid present in animal protein. Plasma levels of homocysteine are increased by inadequate levels of folate, vitamin B6, vitamin B12 and riboflavin, as well as “genetic defects in homocysteine metabolism, renal impairment, malignancies, increasing age, male sex and menopause” (p. 436). There is growing evidence that increased plasma levels of homocysteine greater than 15µmol/L is a risk factor for atherosclerosis (Porth & Kunert, 2002).

As mentioned earlier, cardiovascular disease encompasses coronary artery disease and cerebrovascular disease. These are discussed in further detail in the next section, commencing with coronary artery disease.

Coronary Artery Disease

Coronary artery disease (CAD) is any vascular condition which narrows or occludes the coronary arteries (McCance & Huether, 1998). As a result of the narrowing or occlusion, CAD diminishes blood supply to the myocardium (heart muscle) to the point that the myocardium is deprived of blood circulation, causing ischaemia.

Ischaemia is a state where cells are temporarily deprived of blood supply. The cells remain alive but their function is impaired. A continued state of ischaemia can lead to total occlusion of the artery, resulting in death of the myocardial tissue (infarction).

Myocardial infarction is commonly known as a “heart attack” (McCance & Huether, 1998).

Ischaemia and infarction due to atherosclerosis can also occur in the brain. This is termed cerebrovascular disease and is presented next.

Cerebrovascular Disease

Cerebrovascular disease is any abnormality of the brain caused by a disease process. There are two types of cerebrovascular disease: ischaemia with or without infarction and haemorrhage.

The first type of cerebrovascular disease (ischaemia with or without infarction) is the result of atherosclerosis, where strokes (thrombotic stroke) occur when clots (thrombi) occlude the arteries supplying the brain. Again, as in CAD, the depleted blood circulation leads to ischaemia which can progress to infarction. This results in death of brain tissue (McCance & Huether, 1998).

Because atherosclerosis is the result of fat and fibrin deposits in vessel walls, there is a direct relationship between high cholesterol and atherosclerosis which links it to cardiovascular disease. This link between high cholesterol and cardiovascular disease is explored further in the following sections.

Link Between High Cholesterol and Cardiovascular Disease

The strong link between high cholesterol and CVD is well documented (McCance & Huether, 1998; Porth & Kunert, 2002; Simoons & Saelman, 1994; Thelan et al., 1998; Scandinavian Simvastatin Survival Study (4S) Group, 1994). There is a strong push by the medical profession, the NZ Guidelines Group (NZGG) (2003) and, on an

international basis, the National Cholesterol Education Program (NCEP) (Allison, Squires, Johnson & Gau, 1999), based in the United States, to treat high cholesterol.

According to the NZGG (2003) evidence from studies demonstrate a higher cardiovascular risk with high cholesterol levels. This has serious implications for those at risk. The significance of the issue of high cholesterol and cardiovascular disease and demographics of cardiovascular disease (who and how seriously it affects), are presented in the next section.

*Significance of the Issue of High Cholesterol and Cardiovascular Disease and
Demographics of Cardiovascular Disease*

According to the NZGG (2003), CVD is the leading cause of death in New Zealand. Cardiovascular disease accounts for 40% of all deaths.

This high mortality is modifiable, when taking into consideration the findings quoted by Grundy (1997c). Grundy (1997c) asserted that cholesterol lowering results in reduced morbidity and mortality from cardiovascular disease in both primary and secondary prevention. In primary prevention (i.e. in patients without clinical atherosclerotic disease), a 20% decrease of cholesterol results in 31% reduction in coronary mortality and 22% reduction in total mortality. Also mentioned was the decrease in the rate of new events, morbidity and mortality as a result of moderate cholesterol lowering, in secondary prevention. No statistics were given.

The population demographics of high cholesterol will be discussed under the headings of gender distribution for 1999 and 2000. Mortality is also presented under the same heading. A short discussion on ethnicity, pertaining to Maori, is also presented.

Gender Distribution

The New Zealand Health Information Service (NZHIS) health statistics show the following distribution for ischaemic heart disease and cerebrovascular disease. These are presented in Table 1 for 1999 and Table 2 for the year 2000. Data is presented for two consecutive years to provide some comparison. The figures presented are part of a comprehensive list of data.

Table 1

Mortality and Demographic Data 1999

Causes of death	Male		Female	
	No.	%	No.	%
Ischaemic heart disease	3646	25.4	2925	21.1
Cerebrovascular disease	1129	7.9	1706	12.3

Source: Mortality and Demographic Data 1999 – numbers and percentages by sex (New Zealand Health Information Service, 2003).

These figures indicate that for the year 1999, ischaemic heart disease accounted for 25.4% of all male deaths and 21.1% of all female deaths.

Cerebrovascular disease accounted for 7.9% of all male deaths and 12.3% of all female deaths.

Table 2

Mortality and Demographic Data 2000

Causes of death	Male		Female	
	No.	%	No.	%
Ischaemic heart disease	3269	23.6	2704	20.9
Cerebrovascular disease	Total 2668	See discussion below		

Source: Mortality and Demographic Data 2000 – numbers and percentages by sex (New Zealand Health Information Service, 2004).

The data listed for 2000 showed a 23.6% mortality for ischaemic heart disease for males and 20.9% mortality for females. The figures for cerebrovascular disease only stated a total mortality of 2668 with no gender breakdown. This was identified as the third leading cause of death.

Ethnicity

An ethnicity comparison for the year 2000 (but not given for 1999) stated that Maori males had an 88.6% higher age-standardised ischaemic heart disease mortality rate than non-Maori. The Maori female age-standardised rate was stated as 121% higher than the non-Maori female rate.

The comparison for cerebrovascular disease stated a 7.1% higher age-standardised cerebrovascular disease mortality rate for Maori males than for non-Maori and a 55.6% higher rate for females. This indicates a health disparity status between Maori and Non-

Maori which needs to be addressed. Management of high cholesterol is, therefore, an important issue for the Maori as well as non-Maori population.

Management

In the literature reviewed, management of high cholesterol is discussed under the management of cardiovascular risk, with lipids being listed as one of the risk factors (Hay, 2002; NZGG, 2002a). The management of high cholesterol targets drug therapy as well as diet, exercise and weight control (Allison, Squires, Johnson & Gau, 1999; Schrott, Brittner, Vittinghoff, Herrington & Hulley, 1997).

High cholesterol has been identified as a modifiable risk factor (Colquhoun, 2000). As a result there has been aggressive targeting of the cholesterol issue in the management of cardiovascular disease, by the development of evidence based guidelines undertaken by professional bodies such as the NZGG, for New Zealand.

The NZGG developed the Evidence Based Best Practice Guideline: The Assessment and Management of Cardiovascular Risk (2003), taking into account the latest evidence. These guidelines are the benchmark for cardiac rehabilitation, management of all CVD risk factors (of which high cholesterol is a part) and public education in NZ. Parts of the guidelines also target cholesterol management. These have been adopted by professional bodies such as the National Heart Foundation, which is actively involved in providing cardiovascular health education to professionals such as general practitioners (GPs) and nurses, as well as to the general public.

The National Heart Foundation of New Zealand is an organisation which identifies itself as “the charity that leads the fight against cardiovascular disease (heart, stroke and blood vessel disease)” (The National Heart Foundation of New Zealand,

2004a, homepage). The foundation maintains a commitment to promoting heart health and reducing morbidity and mortality from heart disease through heart research, heart health promotion and rehabilitation.

The Heart Foundation, with endorsement from the NZGG, has set out guidelines for Cardiac Rehabilitation, which incorporate information about cholesterol, nutrition management (with emphasis on a cardio-protective style of diet), exercise programmes and weight management. The foundation also: “promotes food and exercise programmes in schools, supports medical professionals and work with food manufacturers, to mention a few.....also help people make diet changes and adopt healthy habits, such as quitting smoking” (The National Heart Foundation of New Zealand, 2004a, home page). The Heart Foundation guidelines have been adapted by GPs in the information leaflets: High Blood Cholesterol, 2004 Edition, for patients with high cholesterol. These have been included in Appendix A.

Quite often, at the supermarkets, one comes across food products which have the National Heart Foundation Approved logo tick, to indicate the fulfilment of the low fat, cardio protective quality of that product. Members of the public, myself included, who have an interest in healthful eating and a healthy lifestyle actively seek out these products and look for information regarding these issues. This is the result of much emphasis on public education regarding high cholesterol and ways to manage it.

The NZGG (2003) guidelines on cardiovascular disease, diabetes and stroke are intended for use by health professionals such as GPs, nurse practitioners, practice nurses and dieticians who are involved in clinical management of CVD risk factors. The NZGG also states that the guidelines will be of use not only to people living with diabetes, stroke or heart disease but also to their caregivers and family.

Allison et al. (1999) asserted that appropriate drug therapy was the most important factor in achieving the NCEP (National Cholesterol Education Program) goal for LDL cholesterol level. In addition they also identified exercise, diet and weight loss as important factors in achieving this goal.

Drug Therapy

The Scandinavian Simvastatin Survival Study (4S) (4S study group, 1994) and the Multicentre Anti-Atheroma Study (MAAS) (Simoons & Saelman, 1994) conducted from 1987-1994, both studied the effectiveness of the statin group of (cholesterol lowering) drugs. These are important studies on which drug therapy for high cholesterol is based. This is because the results showed significantly improved morbidity and mortality outcomes for patients with coronary heart disease. The statin group of drugs is one of the group of cholesterol lowering drugs supported by the National Cholesterol Education Program (NCEP) Adult Treatment Panel III (ATP III) (American Medical Association, 2001).

Diet

McCance and Huether (1998) actively present dietary modification strategies, with particular emphasis on a low fat diet, for lowering serum cholesterol levels. This is reinforced by The National Heart Foundation of New Zealand which actively promotes dietary changes in its education programmes. Nutrition and weight management are also main components of lipid lowering management in its cardiac rehabilitation programme (The National Heart Foundation of New Zealand, 2004b).

The NZGG strongly recommends dietary intervention as an essential component of CVD management. Cardio-protective dietary patterns (dietary patterns which assist in lowering CVD morbidity and mortality) are discussed extensively in Chapter Five of the NZGG cardiovascular risk guidelines (2003). The NZGG dietary treatment recommendations are based on evidence from randomised controlled trials that a cardio-protective diet improves lipid profiles. This is supported further by Allison, Squires, Johnson and Gau (1999) who list “exercise, dietary compliance and weight loss” (p. 466) as additional important factors to drug therapy, for achieving the NCEP goal of LDL cholesterol level of 2.59 mmol/l (100mg/dl) or less.

The New Zealand National Heart Foundation dietary recommendations are regarded as key components of a cardio-protective dietary pattern. These features are listed in the Royal New Zealand College of General Practitioners patient information leaflet (Appendix A).

Exercise

Exercise is also considered an important factor, together with diet and weight loss, for the achievement of the NCEP goal for cholesterol levels (Allison et al., 1999). Durstine, Grandjean, Cox and Thompson (2002) concluded, in their study on lipids and exercise, that weekly exercise with energy expenditures of 1200-2200 kcals/week is likely to result in the desired lipid changes.

According to Miller, Balady and Fletcher (1997), epidemiologic studies indicate a twofold risk of developing CAD in people with inactive lifestyles. They too support the findings of favourable lipid profile changes through exercise.

Exercise is actively promoted by the National Heart Foundation of New Zealand in its recommendations for cardiac rehabilitation (The National Heart Foundation of NZ, 2004b). This is reinforced by the NZGG (2002) which recommends 30 minutes of moderate-intensity physical activity on most days of the week for everyone. This may be accrued in bouts of 8-10 minutes for people with time constraints. Physical activity is an essential component of lifestyle counselling for people with increased CVD risk (NZGG, 2002). The term physical activity is used by the NZGG in preference to the term exercise, which is considered more formal, structured and exertional.

Weight Control

Weight control is a valuable adjunct to the methods of cholesterol management (Grundy, 1997b). This is supported by the 1993 National Cholesterol Education Program (NCEP) guidelines which emphasise the importance of diet, weight loss and exercise before placing patients on drug therapy (Kramer, 1995).

Schultheis (1990) discusses the amenability of high cholesterol to dietary and lifestyle changes which includes weight control, lowered intake of fats and cholesterol and increased intake of water-soluble fibre. Also emphasised are the importance of education and supportive counselling in achieving these results.

The link between weight loss and improved lipid profiles is also supported by the NZGG (2003). These guidelines also reinforce other benefits of weight loss such as improved blood pressure; improved “glycemic parameters, insulin sensitivity and co-morbidities associated with type 2 diabetes” (p. 49); it also “delays the transition from IGT (impaired glucose tolerance) to type 2 diabetes and can reduce the need for medications” (p. 49).

In addition to losing weight, maintaining weight loss is just as important to sustaining improved lipid profiles. This can be achieved by a progressive increase of exercise from 3.3 to 5 hours, to 7 to 10 hours of moderate intensity per week in conjunction with low fat and low kilojoule diets (NZGG, 2003). Individuals with high cholesterol are therefore expected to follow guidelines based on research on drug therapy, diet, exercise and weight control, as described above.

The achievement of a healthy lifestyle and successful management of high cholesterol discussed so far require a collaborative relationship between the patients and health professionals. To accomplish this collaboration, open channels of communication between patients and health professionals are important, to assist patients to actively participate in their care and management.

Communication

Communication is integral to health care (Teutsch, 2003). There is increased recognition that improved communication between the health care provider and the patient can result in beneficial health outcome (Barrier, Li & Jensen, 2003; Epstein, Alper & Quill, 2004; Lewin, Skea, Entwistle, Zwarenstein & Dick, 2002; Teutsch, 2003). Effective communication of recommendations on the management of high cholesterol is vital to the successful implementation of these directives.

The paternalistic approach in medicine, with the health professional knowing and deciding what is best and the patient accepting this without question, is no longer considered acceptable. Instead this is being replaced with a greater awareness of consumers' rights and collaborative decision making between the consumer and the health professional (Teutsch, 2003). Epstein et al. (2004) assert that informed patients are

more likely to take active participation in their care, come to better collaboration and decision making, and have better adherence to treatment. Teutsch (2003) supports this and goes further to state that problems with effective health care delivery can be the result of communication difficulties rather than a failure of medical science.

Barrier et al. (2003) and Teutsch, (2003) endorse this perspective in physician and provider-patient relationships. They offer patient-centred care and communication as an alternative to the medical or biomedical model and suggest that this improves patient participation, adherence, outcome and satisfaction.

Medical Model

Simmons, in Glaser (1992a), observed that the medical model pathologises patients. He explains this as a process where “patients” (p. 9) are “diagnosed” (p. 9) as having some “disorder” (p. 9) and then “treated” (p. 9). Simmons posits, from the perspective of a counsellor that the concept of pathologising can be damaging to a therapeutic relationship because of what it can do to the patient’s self concept. Terms such as “resistance”(p. 9) and “denial”(p. 9) were listed as concepts arising out of this phenomenon. Other labels that come to mind from experience are “non-adherent”, “non-compliant”, “afflicted” etc. This labelling can be damaging to the patient-provider relationship, the patient and the therapeutic process (Glaser, 1992b). Barrier et al. (2003) supported this by stating that a biomedical model can impede open communication with patients.

Lewin et al., on conducting a review on interventions for providers to promote a patient-centred approach in clinical consultations, support this observation. They concluded that health care providers appear to focus on diseases and their management

rather than on people, their lives and health problems, and that this can contribute to communication problems.

In order to facilitate communication, a patient-centred approach is increasingly supported by consumers and clinicians (Lewin et al, 2002). To achieve this, Lewin et al. (2002) suggest that people be seen in the context of their physical, emotional, mental and spiritual being and must be recognised as individuals.

My premise is that in order to be able to see people in this complete context, it is essential to learn, from the people concerned, about their process and the issues they live with. This would improve communication and develop a patient-centred approach. In doing so, health professionals would be better equipped to shape effective interactions and treatment strategies for patients with high cholesterol.

Justification

Despite the widespread dissemination of information, there appears to be little known about how people actually live with this process of lifestyle modifications and their success in employing these directives when one gets down to the routine of modifying diet, exercising etc. My searches have not yielded much by way of studies on how people live with the condition of high blood cholesterol. One of the studies identified is a Conceptual Model for Dietary Change to Lower Serum Cholesterol by Janas, Bisogni and Campbell (1993), which provided some insight into the participants' dietary change behaviour. There appears to be little research done on the overall experiences of patients with high cholesterol and issues of living with self management, once they exit the hospital situation or cardiac rehabilitation programmes. Some research

has been directed towards self management of other conditions such as diabetes, which involves living with directives as well as goal setting.

Warren-Bouton, Auslander and Gettinger (1982), conducted a study on a non diabetic group of health care providers attempting to adhere to the diabetic self management lifestyle over a four day period. They reported the lack of success of this group's attempt to adhere to the diabetic self management lifestyle over this period. In a study on self management, Price (1993) also alluded to difficulties with adhering to day-to-day tasks of diabetes management.

Although high cholesterol self management is not as intensive as diabetes, the success of treatment still rests heavily on the patients' adherence to dietary, exercise and medication directives. This raises the question of whether similar difficulties could influence self management of high cholesterol.

According to the NZGG (2003), New Zealand studies show inadequate control of lipids, indicating a gap between "best evidence" (p. ix) and "current practice" (p. ix). With a background in nursing and working with patients who suffer from CVD and the long term effects of these diseases, my involvement in patient education is ongoing. Quite often, some would be seen as non-adhering to directives, which can lead to certain judgemental sentiments from staff members across the disciplines. It has become apparent to me, over the years, that there is more to living with the condition than being given directives and adhering to them.

There appear to be other issues and variables which play a part in that process and these significantly influence the success of any programme which involves living with directives. The process of living with high cholesterol was chosen, therefore, as the topic for this study, to discover the issues that patients and other members of the community

are confronted with, in living with this risk factor. I believe that the participants in this study will contribute insight into peoples' process of living with high cholesterol. It is hoped that this study will assist the process of communication and collaboration in achieving health promoting changes to lifestyle, for those at risk of CVD.

The terminology hypercholesterolaemia will be replaced by the term high cholesterol from this section onwards. The reason for this is that high cholesterol is the term used by the participants in their discussion about their process of living with this risk factor.

Conclusion

This chapter examined the issue of high cholesterol and its link to cardiovascular disease. The definitions of high cholesterol and vascular disease were explored in order to demonstrate the significance and impact of high cholesterol on community health. The success of cholesterol management depends on adherence to key aspects such as drug therapy, diet, exercise and weight control recommended for the control of high cholesterol.

Adherence requires the active participation of the individuals affected, hence the need for a collaborative relationship between the patients and health professionals. This collaboration rests on communication between health professionals and patients. Communication was therefore explored followed by a short discussion on the medical model and its disruption of communication and collaboration.

The focus of enquiry and justification for this study were then presented to demonstrate the necessity for an exploration of the process of living with high

cholesterol. A review on the methodology and methods for exploring this process will be offered in the following chapter.

CHAPTER THREE: METHODOLOGY AND METHODS

Introduction

This chapter presents the methodology and research methods of grounded theory, as applied to this study of living with high cholesterol. Methodology, as described by Crotty (1998), is a strategy, process or design which governs the choice of methods used to achieve a desired outcome. Methodology is underpinned and informed by theoretical perspective (Crotty, 1998). The understanding of the underpinning theoretical perspective guides the researcher in the methods used to collect and analyse data related to the particular study. For this study, the chosen methodology of grounded theory is underpinned by symbolic interactionism (Glaser & Strauss, 1967/1999).

In Chapter Three, the history and philosophical underpinnings of grounded theory will be explained, followed by the justification for the use of this methodology. Following this, the use of grounded theory within this study will be presented. This covers participant selection and sampling, interviewing technique, definitions of terminology, data analysis, constant comparative analysis, rigour and ethics.

Historical Background

Grounded theory is a qualitative research methodology developed in 1967 by Barney Glaser and Anselm Strauss (Cresswell, 1998). It has its beginnings in the social sciences, with symbolic interactionism as its theoretical perspective (Chenitz & Swanson, 1986). Symbolic interactionism has been summarised as the “putting of oneself in the place of the other” (Crotty, 1998, p. 75).

Symbolic interactionism has its roots in pragmatism (Corbin & Strauss, 1990). Within pragmatism, reality or truth is in a constant state of change (Bowers & Caron, 2000) and linked to outcome (Crotty, 1998). Meaning changes with the situation or process, hence the “understanding of social structure as (an) emergent process” (Bowers & Caron, 2000, p. 286). A person is therefore shaped by the society that he or she belongs to (Crotty, 1998).

Symbolic interactionism was “coined” (p. 1) by Herbert Blumer (Blumer, 1969/1998). Blumer (1969/1998) acknowledges scholars such as “George Herbert Mead, John Dewey, W.I. Thomas, Robert E. Park, William James, Charles Horton Cooley, Florian Znaniecki, James Mark Baldwin, Robert Redfield and Louis Wirth” (p. 1) as having contributed to the “intellectual foundation” of symbolic interactionism. In particular he credits philosopher and social psychologist George Herbert Mead with laying the “foundations of the symbolic interactionist approach” (p. 1).

Blumer (1969/1998) asserts that “human beings act towards things on the basis of the meanings that the things have for them” (p. 2); that meaning is derived from social interaction between people and that these meanings are used, through a process of self interaction and interpretation, to guide action. These three premises form the basis of symbolic interactionism.

Symbolic interactionism focuses on the individual rather than on the system (Bowers, 1988). Analysis therefore begins with the individual, and the resultant theory is then applied to the larger system. Hence symbolic interactionism explains human behaviour and social process. This approach looks at situations from the perspective of the person being studied by taking the role of the other and understanding reality from the perspective of the participant (Chenitz & Swanson, 1986).

By using grounded theory to study the process of living with high cholesterol, the researcher is taking the symbolic interactionist approach, recognising that the participants, all of whom have high cholesterol, will be influenced by their backgrounds. These backgrounds are comprised of family, culture, education, experiences, personality and myriad other variables which constitute society. The variables play an important part in how the participants view their condition, what they do with it and how they live with it.

Justification and Purpose

Grounded theory explains social and psychological phenomena. Its objective is to generate theories that explain human behaviour and the social world. In doing so, it contributes greatly to fields in which little research has been done (Chenitz & Swanson, 1986). This concurs with the objective of this study on the process of living with high cholesterol.

An understanding of the process of living with high cholesterol from the perspective of the participants is important for nursing. Nursing has a vital role in health care that actively adapts to the changing needs of society. Thelan et al (1998) describe four features of contemporary nursing practice. They are, “attention to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation; integration of objective data with knowledge gained from and understanding of the patient’s or group’s subjective experience; application of scientific knowledge to the processes of diagnosis and treatment and provision of a caring relationship that facilitates health and healing” (p. 3).

Of these, three features: “attention to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation; integration of objective data with knowledge gained from and understanding of the patient’s or group’s subjective experience... and provision of a caring relationship that facilitates health and healing” (p. 3), relate to patient-nurse interaction and understanding of a social-psychological process. Nurses provide a caring relationship and facilitate health and healing by paying attention to human experiences and responses, and by understanding the patient’s or group’s perspective.

Although, as discussed in Chapter Two, literature is prolific with studies on the risks, complications and medical management of high cholesterol, information on the patients’ actual experience of living with and managing the condition is sparse. High cholesterol is a risk factor which depends largely on self-management. It necessitates lifestyle modifications relating to diet, exercise and, in some cases, medication, to reduce cardiovascular risk. Understanding patient behaviour in this milieu is therefore essential for formulating health strategies aimed at reducing this risk. This calls for an understanding of a social-psychological and behavioural process, for which grounded theory is the appropriate methodology to give insight into the processes and strategies that would work better for the individual.

The purpose of this study is to generate theory on the substantive area of living with high cholesterol. Although literature is sparse on the process of living with high cholesterol, the prevailing perspectives in literature on high cholesterol as well as on other conditions which involve self-management (such as hypertension) focus on the patients’ adherence to medical directives and their motivation. The next section presents the role of the researcher in the process of generating this substantive theory.

Role of Researcher

The role of the researcher in grounded theory is an active one, through interaction with the participants to discover and understand how their world is “constructed and experienced” (Bowers, 1988, p. 43). In this study, my purpose is to understand the process of living with high cholesterol from the perspective of the participants, through interacting with them and their data and discovering how they construct and experience their world. The researcher has the responsibility to understand the interplay between the participants’ response to the changing conditions and the outcomes of these responses and actions (Corbin & Strauss, 1990). For this reason the researcher cannot remain neutral or detached must be involved in the worlds of the participants (Bowers, 1998). Bowers (1998) also states that ideally the researcher should be able concurrently to stand back and ask “questions about what the subjects take for granted” (p. 43), and see “both worlds simultaneously” (p. 44). These activities allow the researcher to compare both worlds to discover their similarities and differences. This is achieved by employing the technique of constant comparative analysis (Bowers, 1998). This role taken on by the researcher is consistent with the symbolic interactionism perspective of placing oneself in the situation of the other, as discussed by Crotty (1998).

With my background working as a coronary care unit (CCU) nurse and studying the process of living with high cholesterol, it was inevitable that I would go into the study with certain biases. The risk was that these would be carried into my involvement with the participants’ worlds. I felt it would be helpful for me to identify these assumptions prior to the participant interviews. Identification of these assumptions was a way of sensitising me to possible personal biases in the interview and analysis processes. I therefore underwent a presuppositions interview with my supervisor. The assumptions

that I identified as the result of this interview were that there was low compliance to the recommended medical directives for cholesterol management and that this was a problem. This raised the question of why I perceived it to be a problem.

We as health professionals also perhaps ignored the cultural context people live in, which perhaps made compliance to medical directives difficult. It could be that cultural context was a factor in ability to comply. I perceived patients' non-compliance as frustrating for the health professional trying to help with successful management of high cholesterol to lower cardiovascular risk.

There were so many variables affecting compliance. Knowing what they were and how to tackle them would help. I wondered whether support in the community and from within the family was inadequate. There were also financial barriers and motivational difficulties.

I thought that people wanted a magic bullet for the control of high cholesterol. There was an element of denial from the patients. I perceived this in the response of people I knew who appeared to shrug off the reality of having high cholesterol, saying they had to die of something and needed to enjoy life anyway. It was possible both to enjoy life and carry out medical recommendations in relation to diet and exercise.

These presuppositions were put aside and not considered until the completion of the writing up of the findings chapter. The exceptions to this were thoughts about compliance, motivation and magic bullet assumptions which appeared to predominate during the time of data analysis. On going back over the presuppositions interview following the completion of the last findings chapter of this thesis, I re-discovered the aspect of enjoying life at the presuppositions interview. I was thrown into turmoil that I might have inadvertently imposed my presumptions on the data. On reviewing the data

and findings, however, it was clear that enjoying life came out of the participants' interviews. The process of constant comparative analysis of comparing incident to incident and grouping the incidents into categories; generating properties of categories through continued constant comparison; and the integration of the emerging categories and their properties, ensured that the findings remained grounded in the participants' data. Constant comparative analysis will be discussed in greater detail later in this chapter. Although it was apparent from the start of the interview analysis that enjoying life had an important place in the participants' lives, I was surprised at the end to find out how pivotal its position was.

The next stage of preparation for my role was the practice interview. Maryanne (pseudonym), who has high cholesterol, offered to undergo a practice interview, enabling the researcher to check interview techniques and technology with no pressure of a formal interview. The practice interview highlighted technical drawbacks such as the low pick-up range of the tape-recorder that was being used and non-indication when the tape ran out. Fortunately a second tape was available and this captured the last third of the interview. These problems were addressed in subsequent interviews by the researcher utilising more recent technology and having two tape-recorders in operation at the same time. The test interview with Maryanne has been included as interview one, with her permission. The next section provides further detail on the research process.

The Research Process

This section discusses the rigour of the study. This will be followed by auditability of the research process. This section will begin with rigour.

Rigour

In order to establish the trustworthiness of a research study, the integrity of the research process must be maintained. This was done by following the processes discussed by Glaser (1978) and Glaser and Strauss (1967/1999). These are credibility, fit, work and modifiability.

Credibility was maintained by ensuring that the analysis remained grounded in the participants' data, and therefore their reality. This means that the concepts, categories and descriptions emerged out of their data rather than the researcher's preconceived notions or value judgments. One way of ensuring this was taking the theory back to the participants for validation of the process. In this way the participants were able to provide feedback on whether or not the concepts and categories accurately reflected the reality of their experiences which they communicated at the interview. In addition to this, regular feedback was also obtained from the supervisors, member of the critical group and the grounded theory working group, to ensure that the process identified was grounded in the data.

Fit applies to how well the theory fits the participants' perception of their process. According to Glaser (1978), this can only be achieved by emergence of the theory from the data. This means that the concepts and categories should emerge from the data and not be forced by the researcher's presuppositions or bias. Again, remaining grounded and continually going back to the data ensured that fittingness was maintained. Input from the supervisors, the critical group and working group also ensured that the analysis stayed true to "emergent fit" (p. 4).

The categories and their properties in this study emerged out of in-vivo codes which are direct quotes from participants' data. Accepting and Getting On With It were direct in-

vivo codes. “Enjoying” was an in-vivo code and the notion of “enjoying life” was mentioned repeatedly by the participants.

Work means that the theory must be relevant to the area being studied and explain, predict and interpret what is happening in the area being studied. Again, the process and theory must not be forced but should emerge from the data. This is where Glaser (1978) speaks of the development of a Basic Social Process which explains what is happening in the area and how the categories and properties make the theory work. A Basic Social Process also helps to arrive at a core category.

By ensuring that the categories and properties were grounded in the participants’ data, the researcher ensured that the theory generated by this study was allowed to emerge rather than be forced. This means that the theory is relevant to the substantive area being studied and meets the criteria for workability.

Glaser (1978) asserts that theory generation is an ongoing process. Although the basic social process remains, it must adapt to changes and remain relevant as new data appears. This is modifiability and has the ability to “work the data” (Glaser, 1978, p. 5) in a process which requires ongoing modification or adjustment. This ensures the “tractability” (Glaser 1978. p. 5) of the theory, which means that it is easily workable and remains relevant in changing situations.

When I communicated the interim findings of this study with a friend who has high cholesterol (but was not part of this study), he gave feedback that an important part of the process for him was, “Peace of mind – knowing you’ve done all you could do. Functioning in a structure I’ve developed.” This aspect of the process of living with high cholesterol did not feature at all in the data collected up to that point and so had not been

given any consideration. This raised the question of modifiability and tractability of this study. My friend did confirm that the rest of the theory did fit his situation.

On further reflection, I felt that this statement appeared to capture the process of Accepting, Getting On With It, (“knowing you’ve done all you could do. Functioning in a structure I’ve developed”) and Enjoying Quality Of Life by having “peace of mind” through knowing he had done all he could. He further qualified, “if you have peace of mind you can get satisfaction and happiness.” His permission was obtained to include this vignette. Despite the new perspective coming through, the theory and process identified in this study stood up to modifiability and tractability in this situation. The research process has a requirement for maintaining and showing accountability. In qualitative research this is achieved through a process called auditability. The next section demonstrates how auditability was maintained in this study.

Auditability

Auditability is necessary for clear tracking of the research process. This was achieved through field notes written soon after every interview to record impressions that would otherwise have been lost over time (Appendix B) and extensive memoing of ideas and different stages of the process to demonstrate the development of the theory. As part of maintaining an audit trail, transcripts and tapes of the interviews have also been saved in locked storage by the university for a period of ten years. The next section will present the ethical considerations undertaken in this study.

Ethics

Social research involves researchers and participants in a dynamic process based on reciprocal trust and collaboration (Sarantakos, 1994). However, this does potentially expose those involved in the research process to violation of rights and malpractice (such as breach of confidentiality) by the researcher(s). As a result, research is controlled by strict standards and regulations that are legally binding (Sarantakos, 1994). One of the bodies that enforces these guidelines in New Zealand is the Health Research Council (HRC).

With this study being conducted in the health sector and requiring the participation of health-care users, ethical and cultural issues had to be addressed to the satisfaction of ethics committees. In addition, bi-culturalism is an important tenet of health care in New Zealand. An important aspect in this is the Treaty of Waitangi.

The guidelines for Researchers on Health Research Involving Maori (HRC, 2002a) state a commitment to recognition of Article Two and Article Three of the Treaty of Waitangi. The principle of Article Two encompasses the right of iwi and hapu to have an authority over their peoples' participation in research. Similarly, Article Three encompasses an expectation of equivalent health status between Maori and Pakeha and an impartial allocation of the benefits of Crown expenditure. The HRC (2002) affirms a need for collaborative research between Maori communities and non-Maori researchers. These issues were addressed by liaising with the Te Whakaruruhau Maori Health, Lakeland Health. A letter of support (Appendix C) was obtained and enclosed as an appendix to the ethics applications submitted to the Bay of Plenty and Lakeland Health ethics committees.

Recruitment for participants was left open for as long as possible with the hope that a Maori member or members would come forward. Unfortunately no Maori participants volunteered for this study.

Ethical Approval

Ethical approval was obtained prior to commencement of the study and the recruitment of participants. Ethics approval was obtained from the Bay of Plenty Ethics Committee (Appendix D) and the Lakeland Health Ethics Committee (Appendix E). The Auckland University of Technology Ethics Committee (AUTEK) was notified of their approval as required.

The five core principles of the codes of ethics as summarised by Tolich and Davidson (1999) were fulfilled in this study as follows: participation in the study was voluntary. Participants were assured that there would be no repercussions should they wish to withdraw from the study. There was no form of coercion to participate. No payment was offered for participating in the study. A \$20 petrol voucher was given at the end of the interview as a gesture of thanks. Participants did not know of this beforehand. The date, time and location of the interview were decided mutually.

Informed consent was obtained. Each prospective participant was given a notice of invitation (Appendix F), a participant information sheet (Appendix G) and reply to the invitation along with a self-addressed, stamped envelope to respond with if they were interested in participating in the study. This was done through an intermediary, as mentioned in the sampling section, to avoid coercion. I had no idea who the packs were given to. The first contact was made by the prospective participant, in the form of a reply to the invitation. The first two participants volunteered before the commencement of the

study. Both were given the participant information sheet before consent was obtained. An opportunity was given, before obtaining consent, to review the participant information sheet. The option of pulling out of the study should the participant wish to do so was also reiterated. The possibility of a second interview was also reiterated. This ensured that the participant was fully informed about the study before the commencement of the interview. Written and verbal consent was obtained from all participants.

Confidentiality was maintained. Pseudonyms were chosen by the participants before the commencement of the interview to maintain confidentiality. I elected to transcribe the interviews myself, hence limiting breach of confidentiality. Identifying data was kept in locked storage. Apart from this, all participants were referred to by their pseudonyms.

Processes were open and transparent in order to avoid deceit. Data collection was maintained strictly according to stipulations which participants consented to. The questioning and discussion revolved around the process of living with a high cholesterol level. A copy of the transcript of the interview was offered to each participant but was refused. I view member checking (i.e. sharing of the findings with the participants for “work” and “relevance”) as another way of avoiding deceit in that any misrepresentation of data would be identified then. The feedback from all participants was positive. They all affirmed that the findings of this study adequately captured their process: “what you said is exactly what, probably goes through, probably everybody’s mind I think” (Paul). They reported seeing themselves in different aspects of the process as set out in the research findings. For example, Maryanne sees herself as making some sacrifices now in order to enjoy better quality of life later because she needs to be fit and well for the activities that she would like to enjoy when she retires. She added a perspective to quality

of life, “You’re the only one who knows what / how those factors especially, things like the quality of life. No one else can tell you what you value as quality of life.”

It was important to do no harm. Hence, participants were reminded of their rights to not follow a certain line of questioning or to withdraw sensitive information. Provision was made for one free session of counselling for the participants, with a registered counsellor, should it have been required. The availability and terms of service delivery were ascertained beforehand with the counsellor. Payment for these sessions would have been met by the researcher. The need for counselling did not, however, eventuate for any of the participants. The next section presents the research methods.

The Research Method

Grounded theory is the methodology which best fulfils the objective of this study because of the focus on the participants’ experience of the process of living with high cholesterol. As a result the research methods were guided by this methodology and are presented in this section. The methods employed in this research were based on Glaser and Strauss (1967/1999) and Glaser (1978, 1992a & b).

Sampling

The sampling strategy in grounded theory is purposive (Giddings & Wood, 2000) which means that sampling is based on the researcher’s knowledge about the population (Polit & Hungler, 1997). This selection strategy is also based on the knowledge and relationship of the participants with the event or situation under study (Minichiello, Sullivan, Greenwood & Axford, 2004). It was on this basis that the participants for this

study were chosen from a population of people with high serum cholesterol levels. As analysis progressed the researcher decided, in a process called theoretical sampling, what data to collect next and where to collect it from in order to develop the emerging theory in a process called theoretical sampling (Glaser, 1978).

Theoretical sampling is a process of data collection where the researcher, having already collected some data, is coding and analysing this, decides both what data is required next and where to collect it (Glaser, 1978). According to Glaser and Strauss (1967/1999) the source of this data can be a group or subgroup used for comparison of data which will produce more properties of the categories and link the categories and their properties to each other. I conducted individual interviews from the subgroup of people with active cardiovascular disease, for theoretical sampling in this study. The criteria for choosing the groups or subgroups are guided by the emerging theory and are those of “theoretical purpose and relevance” (Glaser & Strauss, 1967/1999, p. 48).

Interviews four to seven came under this subgroup, where participants with active cardiovascular disease were interviewed. The data from interviews one to three pointed towards negotiating fat levels and enjoying life as being two possible core categories. The three participants in these first interviews had no history of cardiovascular disease. My questions at this stage were: what is the process for participants with active cardiovascular disease? Would they see and do things differently? If so how?

I therefore set about recruiting participants from the cardiac rehabilitation programme, through an intermediary. This was already in the pipeline so all that was required was a prompt that participants were being sought after.

Responses to my invitation to participate came from four patients, three of whom were interviewed. The fourth person moved to a district outside the jurisdiction of my

ethics approval before I could interview him. These participants came under the subgroup of active cardiovascular disease. The other subgroup was participants without a history of cardiovascular disease.

Another form of theoretical sampling is going outside the group or unit to compare similarities and differences (Glaser & Strauss, 1967/1999). This was not pursued because the purpose of this study is the generation of substantive theory within a specific social group of people, i.e. with the condition of high cholesterol, and not generation of formal theory which cuts across health conditions. In keeping with Glaser (1978), it was unnecessary to go outside the substantive area of high cholesterol for sampling. Glaser (1978) states that going outside a substantive area is mandatory for generating formal theory but debatable for substantive theory because it is ‘dangerous for its undermining effects on relevance’ (p. 51).

Participant Selection

Participation in the study was voluntary. Letters of invitation, with information packs, were given to ex-coronary care unit patients attending the cardiac rehabilitation programme, through an intermediary (Appendix H). Participants also volunteered directly with me prior to ethics approval, on hearing about the study. They too were given the information pack before signing on for the study.

Each pack contained an information sheet about the study (Appendix G), a reply form and a self-addressed, stamped envelope which participants mailed back. Contact was made and an interview date, time and venue were set according to the convenience and preference of the participants. The first, second and eighth participants volunteered directly with me, without going through an intermediary. Two others, participants two

and three, snowballed from participant two. Snowball sampling is an approach where the participants already recruited are asked to refer other possible participants, who met the criteria to be in the study. The first approach to participants who were recruited by this snowballing method was made on my behalf by the participant already in the study, to check that the potential participants were happy to receive the participant information pack.

The total number of participants is eight. Seven of the interviews were transcribed. Interview eight with Fran was carried out to confirm the basic social process. This interview was not transcribed. The data was used in Chapter Six, Maintaining Enjoyment of Life, to support the basic social process. Quotes of the participants are indented, single spaced and identified by the pseudonym followed by the line number(s), in parenthesis. An overview of participants is listed as follows, in Table 3.

Table 3 Overview of Participants

Pseudonym	Age	Gender	Ethnicity	Occupation	Member Checking
Maryanne	50	Female	NZ European	Counsellor	Yes
Alison	50	Female	Other European	Nurse	
Petronella	53	Female	Other European	Housewife / self	Yes
Paul	53	Male	Other European	Doctor	Yes
Les	63	Male	NZ European	Launch Master	
Charlie	79	Male	NZ European	Retired administration manager	Yes
Thomas	46	Male	NZ European	Forecourt attendant	Yes
Fran	48	Female	NZ European	Scientist / quality Co-ordinator	

Data Collection

Three of the interviews took place at a private office in my workplace. The rest of the interviews were carried out at the participants' homes. Leaving the decisions about venue, date and time to the participants enabled them to choose the setting in which they were most at ease, thus facilitating a comfortable interview interaction. The interviews were taped and later transcribed by the researcher.

Interview Technique

The interview method was formal and unstructured, beginning with a general, open question: "Tell me what it's like for you to live with a high cholesterol level." Charmaz (1990) states that questioning in grounded theory starts off generally rather than having a tightly knit framework. Rigid interview formats, following set questions (which may require yes or no answers) with no deviation, limit the amount and type of data that can be collected, hence hindering discovery. They also inhibit the participants from talking freely from their perspective (Strauss & Corbin, 1998).

As the interview progressed, ensuing questions, more specific to the content raised by the participants, were posed. Examples are, "Can you tell me more about..."; "Tell me how your life has changed since then"; "What made the difference?" "You said it was a bit of a bummer, just explain that a bit more." The purpose of this line of questioning was to delve deeper into the issue in order to generate rich, in-depth data.

Throughout the research and writing processes interests, leads and hunches found in the data were followed, then more data was gathered and more questions were asked, to check developing categories as recommended by Charmaz (1990). This process is called theoretical questioning. For example, "not worrying" emerged as a concept which

could have been a cause or strategy of the category of Accepting. At this stage of early data analysis, “not worrying” was discussed in the context of “not finding it a drama”, “not being a struggle” and not worrying enough to change one’s life. My questions of the data were, “was not worrying the participants’ way of ignoring their high cholesterol? Was it a way of not turning one’s life upside down? Was it a strategy? Did not worrying mean that the participants did not care? Did it mean avoiding facing the issue, therefore not accepting? What is going on here?” The issue was raised at subsequent interviews to check out what “not worrying” was about.

The next section presents the process of data analysis. To assist the reader with understanding the terminology used, definitions of terminology are presented first.

Definitions

Category is a conceptual component or feature of a theory which stands by itself (Glaser & Strauss, 1999). It emerges as a concept that fits a pattern when comparing incident to incident during coding (Glaser, 1998). For example, during coding, participants spoke of their discovery of high cholesterol levels, the impact it had on their lives or lack of it, having or not having a background of serious health problems and/or complications, having health issues other than cholesterol to worry about, not worrying about it, facing up to the fact that something is wrong etc. Through much arranging and re-arranging of the codes and memoing, different patterns and possible categories such as “discovering”, “becoming more aware’ and “facing up to it” were identified until, following continued comparative analysis and constant questioning of “what is happening here” the category of “accepting” emerged. This turned out to be the first stage of the process of living with high cholesterol (Appendix I).

In the process of discovering categories during open coding, codes of similar pattern were clustered together to give the researcher an impression of what is happening. This phase generated a list of about fifty four concepts, some of which were viewed as possible categories (Appendix J). The possible categories were noted down as ©. Throughout this process of open coding the data was examined for similarities and differences (constant comparative analysis) and re-clustered into identified categories. At times, new categories were identified during the process of re-clustering. Each category in this study was assigned properties. Properties are defined in the next section.

Properties: Glaser and Strauss (1999) define property as ‘a conceptual aspect or element of a category (p. 36). Strauss and Corbin (1998) describe this further as a characteristic which explains a category and gives it meaning. The properties of the categories in this study are explained using the modified conceptual framework of the six Cs (causes, contexts, contingencies, consequences, covariances and conditions)coding family (Glaser, 1978). The modified framework in this study used the following families: context, cause, cutting point, strategies and consequence. This framework is discussed in greater depth in the following section.

A coding family is a theoretical code or set of theoretical codes which provide a conceptual explanation of how the substantive codes relate to each other in an emergent theory. Substantive codes are the categories and their properties. This framework will be shown in Table 5. The definitions of the terms used in this framework are presented next.

Context is a condition of highest or predominant scope. In this study the participants acted and interacted in the context of “being dealt the card” (of having high cholesterol)

to generate the categories of Accepting and Getting On With It and their properties and the basic social process of Maintaining Enjoyment of Life. It is under context that related categories and properties arise (Glaser, 1992a). A condition is a “category or property that leads to the occurrence of another category or property” (Glaser, 1992a, p. 64). With context being a condition, as defined above, a context generates another category or property.

Cause is also termed causal condition by Glaser (1992a), except that a cause does not have the jurisdiction or scope of a context. A cause is a category or a property which leads to the development of another category or property in relation to the main incident or event (Glaser, 1992). Hence the property of “becoming more aware” in association with having been dealt the cards of having high cholesterol, contributed to the development of the category of *Accepting* and the development of its properties. ‘Becoming more aware’ of high cholesterol and its ramifications following their discovery of having this risk factor caused the participants to Accept what they had been dealt as well as contributing to the cutting point of being/not being evident. By “becoming more aware,” high cholesterol was more evident to the participants so that they could choose their strategies to cope with this.

Cutting point is described as a family which indicates “where the difference occurs which has differential effects” (Glaser, 1978, p. 76). The “differential effects” indicate different or contrasting effects such as interaction with the situation and action taken. The participants had personal limits and tolerance zones which contributed to the point at which the difference occurred and which resulted in actions taken to handle the situation.

Hence the cutting point is the point at which situations shifted, following which different actions/interactions occurred. These actions/interactions were the “differential effects” which occurred as the result of the cutting point. Glaser (1978) lists boundary, critical juncture, turning point and tolerance levels, amongst others, as part of the cutting point family.

This variation of the 6Cs family came about as the result of struggles with a theoretical explanation of the emergent process and theory. The fit of the 6Cs family became evident when I found I had to use different families to explain the findings of this research. Pulling in different families to explain the emerging theory became confusing and cluttered. The 6Cs already had a group of theoretical codes under one umbrella, which suited my findings well, but not all the theoretical codes within this family fitted my data. There were theoretical codes outside of this family which explained the data well so these were included within the modified framework of this family. This meant that some of the existing theoretical codes which did not fit my data had to be excluded.

Strategies are purposeful acts taken to manage a situation or people (Glaser,1978). A strategy has to be a conscious act otherwise is a consequence. Glaser (1978) provides other terms for strategy some of which are tactics, mechanisms, dealing with, handling and ploys.

Consequence is the result or outcome of action(s) taken by the participants; it can also be the result of failure of the participants to take action, in response to a phenomenon (Strauss & Corbin, 1990).

Basic Social Process: The findings of this study culminated in the emergence of a basic social process, which is a type of core category and therefore accounts for most of the differences and alteration of behaviour. As a result, the other categories and their properties all revolve around the core category and / or basic social process. All basic social processes are core categories but not all core categories are basic social processes. This is because a basic social process has two or more emergent stages which makes it “processual” (Glaser, 1978, p. 96).

At the beginning of this analysis, codes were identified during open coding. Codes and concepts identified for different participants during initial analysis, were clustered under common headings and regarded as possible categories, as demonstrated in Appendix K. Constant comparative analysis took place concurrently, throughout analysis. This will be explained further later in this chapter. Memos were recorded to keep track of my thinking and analytical process as well as to record decisions for theoretical sampling. Memos are notes documenting the researcher’s reasoning process during analysis. These show the progression and development of the emerging theory. The memoing process guided further questioning of the data (theoretical questioning) and sampling (theoretical sampling) which took place in the selective coding stage. In theoretical sampling the selection of subsequent participants is guided by the data. The coding process will be explained in further detail later in this section.

At the selective coding stage the codes had all been identified, clustered and re-clustered. Categories had started to emerge from the clusters but there were too many of them. These categories were then subjected to the same clustering process to reduce the list by discovering more general or over-arching categories. For example “discovering”, which was a category in itself, was eventually subsumed under the category of Accepting

as part of the cause of “becoming more aware”, along with acquiring knowledge, having a background of life threatening illness, finding it difficult, finding it a surprise and having a family history. Similarly, “negotiating fat levels” were eventually subsumed under “formulating a strategy”, then later under “learning to live” and eventually under “getting on with it.” The process of living with high cholesterol changed from:

ACCEPTING → LEARNING TO LIVE → CONTINUING TO LIVE → ENJOYING
LIFE

(these were overarching categories) to:

ACCEPTING → GETTING ON WITH IT → MAINTAINING QUALITY OF LIFE

then:

ACCEPTING → GETTING ON WITH IT → ENJOYING QUALITY OF LIFE

and finally to:

ACCEPTING → GETTING ON WITH IT → MAINTAINING ENJOYMENT OF LIFE

The process shown above, although expressed in linear fashion, was in reality not so.

There was continuous interplay and interaction between the categories and their properties. For example, Accepting interacted with Maintaining Enjoyment of Life to assist the participants to Get On With It. Likewise, Getting On With It assisted the participants to Accept, through employing strategies which helped them to Maintain Enjoyment of Life.

To find the basic social process every category was given the position of the central process, to identify the one around which the other two categories revolved.

Accepting and Getting On With It were given the position of the central process and attempts were made to explain the data around each of these categories. This did not

work until Maintaining Enjoyment Of Life was given the central position. The theoretical

explanation of this process fitted and the categories, Accepting and Getting On With It supported this central process well. Maintaining Enjoyment Of Life was identified as the basic social process.

Constant Comparative Analysis

In grounded theory, constant comparative analysis and theoretical sampling take place jointly (Glaser & Strauss, 1967/1999). Constant comparative analysis was undertaken accordingly.

First, relevant incidents to each conceptual category were compared. Here each incident of the data was coded into as many categories as possible. In doing this, new categories emerged, or new codes or concepts that fitted an existing category. For example: “not worrying” was placed under different categories such as enjoying life, realising mortality, discovering and formulating a strategy, to see where it fitted best. As analysis progressed it became apparent that “not worrying” did not mean ignoring or avoiding the issue, but rather a strategy to maintain equilibrium whilst adapting to a change in one’s health situation. It eventually found a place as a strategy in the category of Accepting.

Second, categories and their properties were integrated. This process started out with memos on the comparisons and emerging categories. Comparisons were then made of incident to incident and then progressed to comparisons of incidents to properties. This process, together with joint theoretical sampling, allowed an integrated theory to emerge by itself. For example, “discovering” was clustered with “changing”, “becoming more aware”, “not perceiving high cholesterol as a problem” and “wanting/not wanting to know.” This related to making the discovery as demonstrated in the figure below:

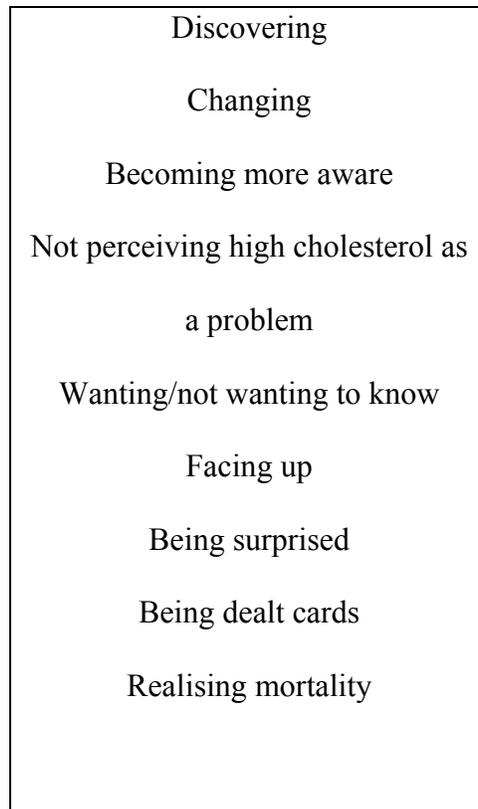


Figure 1. Clustering of codes to find a category.

Changing was then taken out of the cluster because it was identified as being a different process from “discovering”. The concept of “discovering” as a category was played with. Discovering later emerged as a sub-category of the category of Accepting . Discovering again changed to the condition of Accepting and then the cause of Accepting.

‘Discovering’ was finally identified as being part of the cause of ‘becoming more aware’.

Third, the delimitation of theory was a process of determining the boundaries at the theory and category levels to allow the theory to “solidify” (Glaser & Strauss, 1999). p. 110). In this process modifications were made repeatedly, as demonstrated above, to the point where non relevant properties were removed or subsumed under higher level concepts. For example, discovering and acquiring knowledge were integrated under “becoming more aware”. “Becoming more aware” encompassed the different ways of

discovering, acquiring knowledge and information about high cholesterol, as well as a heightened awareness of the impact of a particular situation or circumstance. For example, “becoming more aware” through acquiring knowledge about high cholesterol through different sources increased the participants’ consciousness of the aspects of lifestyle modification, such as exercise, that they had difficulty implementing. This reduced the list of categories to obtain a parsimonious theory with greater scope or relevance to a broader field, as this could apply not only to the condition of high cholesterol but also to other health conditions.

The final stage was writing theory. Data analysis continued through this phase. This involved collating memos relating to each category, further analysis and then presentation of an accurate account of the study “in a form that others going into the same field could use” (Glaser & Strauss, 1999, p. 113). Changes to the theory were made as the writing progressed and gaps were identified. As my understanding of the data changed, concepts which fitted the theory better replaced the existing ones. For instance the category Maintaining Quality Of Life was the basic social process in the first version of the findings chapter. However, Quality of Life did not capture the concept of enjoying and yet enjoying was the principal dimension, from the participants’ perspectives, that their lives revolved around. Enjoying therefore had to be part of the basic social process. On rewriting this chapter, following modifications to the previous chapters, this category was re-worded Maintaining Enjoyment of Life as it best captured the central process around which the other two categories revolved.

The first stage of analysis is the first level of coding. This is called open coding and is discussed next.

Open Coding

Open coding was a process where the data was fractured and incidences or codes were generated from the broken down data. They initially took the form of unsystematic impressions (Glaser, 1978). The transcribed data was coded line by line and incident by incident (see Table 4).

Table 4

Example of Open Coding

Transcript	Codes	Notes/Memos
38. PC: I suppose it was a bit of a		
39. surprise I didn't really think,	Being surprised	
40. because I'm not overweight or	Not overweight	
41. anything like that I didn't kind		
42. of think that I would have a	Not expecting high	This is all part of the
	cholesterol	discovery process.
43. cholesterol lev ah problem		Possible category – Discovering? Elements of surprise, unexpectedness. Making a connection between high cholesterol and being overweight - Making assumption.

The transcripts and codes were colour coded. The codes (with line numbers beside them) were then cut up and clustered into as many categories as possible and re-clustered as the process emerged. The colour coding and line numbers assisted with identifying the

source of the code during the analytical process. This also proved helpful when shifting the code around to find the category in which the code fitted the best, during the re-clustering process. As coding progressed with subsequent interviews, new categories emerged or new codes were discovered, which matched existing categories.

The question asked of the data was constantly “what is going on here?” and “What is this an incident of?”

When no new concepts were revealed in the data, coding then progressed to the next stage. This is the selective coding phase and is discussed next.

Selective Coding

This is the stage where open coding ceased and the researcher decides to selectively code for a core variable out of a possible few core variables. This then also guided the next phase of data collection including theoretical sampling which took place with interview four. Details of the selective coding stage have been discussed under basic social process in page 47. Having identified the basic social process as discussed in page 47, refinement of the process continued, e.g. assigning and re-assigning the properties of the categories to ensure that the categories stayed grounded in the participants’ data.

The final stage of coding was theoretical coding. This is discussed in the following section.

Theoretical Coding

Theoretical coding is the conceptualising stage which explains the relationship of the substantive codes to each other and shows their integration into a theory (Glaser, 1978). Glaser (1978) lists 18 coding families. The family identified as providing the best

explanation for the process identified in this study is a variation (described previously) of the six Cs: context, cause, cutting point, strategy and consequence. The coding process occurred concurrently with constant comparative analysis which was vital for emergence of the theory.

Overview of the Findings

The process of living with high cholesterol, identified from the participants' data, yielded a basic social process of Maintaining Enjoyment Of Life, supported by two categories, Accepting and Getting On With It. There is a continuous interplay between these categories as they relate to each other in the basic social process of Maintaining Enjoyment of Life.

Each category will be discussed separately in the following three chapters. The fourth findings chapter will draw the three supporting categories together with the core category, to explain the participant's process of living with high cholesterol. The findings chapters include Chapter Four, Accepting; Chapter Five, Getting On With It and Chapter Six, Maintaining Enjoyment of Life. Table 5 provides an overview of the structure of the findings chapters.

Table 5

Structure of the Findings Chapters

Basic Social Process: Maintaining Enjoyment Of Life		
PROPERTIES	ACCEPTING	GETTING ON WITH IT
Context	Being dealt the cards	
Cause	Becoming more aware	Enjoying life
Cutting point	Being / not being evident	Being / not being in control
Strategies	1. Not worrying 2. Dealing with what is evident 3. Being philosophical	1. Balancing risk 2. Negotiating
Consequence	Doing your best	

Conclusion

This chapter presented the historical background of grounded theory, the methodology, justification and purpose, role of researcher and the research process of the study. Under the research process rigour, auditability and the ethics process and tenets were presented. The research methods covered sampling, participant selection, interview technique, data collection and analysis. The definitions of category; properties; the theoretical codes of context, cause, cutting point, strategies and consequence; and the basic social process were presented. Finally, the structure and overview of the study was presented. The next chapter presents the first of the three findings chapters, Accepting, in Chapter Four.

CHAPTER FOUR: ACCEPTING

Introduction

Chapter Four is the first of three chapters presenting the findings of this study. It examines findings relating to the first stage of the process of living with high cholesterol. This stage is the category of Accepting, which is explained using the theoretical codes of the 6 Cs family which are: context, cause, cutting point, strategies and consequence (consequence is not dealt with in this chapter). The concepts relating to these codes are called properties; hence we have the category of *Accepting* and its properties. This framework will be used to explain all the categories identified in this study. This discussion will begin with the theoretical code of context which explains the property, being dealt the cards.

Context: Being Dealt the Cards

Being dealt the cards emerged out of a statement by one of the participants, “that’s sort of like the cards you get dealt and, you have to play with them sort of...there’s not much that you can do about it” (Paul: 219-223). High cholesterol was therefore something the participants had no say over. Just as in a card game, where one has to play with the cards one is dealt, the participants had to live with the card of high cholesterol. This concept of having to live with high cholesterol was compared to a dog with fleas.

It’s like a dog with fleas, you’ve got to learn to live with it...I can’t do much about it (Charlie: 946-949).

The participants played with the card of having high cholesterol by accepting the hand they had been dealt and learning to live with it, so that they could get on with life.

this is life as we know it...get on with it (Alison: 290-291).

The best thing you can do is.....accept the fact that it's happened, get on with it
(Thomas: 954-961).

This statement also provided the basis for the first two categories of the process of living with high cholesterol: Accepting and Getting On With It.

The participants identified two aspects of being dealt the cards of high cholesterol. They were unpredictability and being philosophical.

The unpredictability was the not knowing what was going to come their way, just as in a card game where one does not know which card is going to turn up next. Although having high cholesterol was not a surprise for some of the participants who had a family history of high cholesterol and cardiovascular disease, others were surprised by it. This was because they had no family history. They also did not consider themselves predisposed to high cholesterol because of never having had a weight problem and generally perceiving their dietary preferences and patterns as healthy in comparison to others.

I suppose it was a bit of a surprise I didn't really think, because I'm not overweight or anything like that I didn't kind of think that I would have a cholesterol..problem (Petronella: 38-43).

I don't cook chips and fried food and you know I mean...I've never been a...take away person.... rather give me a salad than offer me a, a [*fast food brand*] I mean it really for me it's...knowing what it is that I never really thought that it would be an issue for me (Petronella: 162-167).

Regardless of whether or not there was a family history and whether or not having high cholesterol was a surprise, it was still unpredictable just as in a deck of cards where

there were certain combinations, but what was dealt was unpredictable. The participants' response to this unpredictability was to be philosophical about it.

Being philosophical was also expressed as being fatalistic. Hence, being philosophical and being fatalistic have the same significance in this study.

Because the participants had no say in which card or cards they were going to be dealt they were philosophical about it.

I feel quite fatalistic about, whatever...will be will be and ...if that was what I got...I would have to accept it (Alison: 323-327).

It's just sort of, maybe I'm a bit sort of fatalistic or something but...I just sort of think well that's, you know that's how things are (Paul: 89-93).

In being philosophical the participants accepted the card of high cholesterol that they had been dealt.

I'm very philosophical about that things happen...the best thing you can do is...accept the fact that it's happened, get on with it (Thomas: 954-961).

In Accepting these cards, they played with them by getting on with life, hence the emergence of the second category of Getting On With It.

Being dealt the cards was a constant presence in the background. It was an attribute which underlay the strategies taken by the participants in managing and responding to the category of Accepting. The next section covers the cause of Accepting.

Cause: Becoming More Aware

Becoming more aware included the participants' discovery of high cholesterol as well as their gaining more knowledge about high cholesterol and about themselves while

living with the recommendations for managing high cholesterol. For some of the participants the discovery of high cholesterol was the result of a routine medical check-up initiated by their general practitioner (GP). One participant made a connection between her weight problem and high cholesterol, from literature available at the time. She actively advocated for herself and suggested a cholesterol check to the GP. Others made the discovery as the result of an admission to hospital for a cardiovascular event such as a heart attack or during consultation for cardiac surgery.

As discussed under context, this discovery process was a surprise for some because they did not consider themselves at risk for high cholesterol, not having had a family history and not ever having had weight problems. For others, the discovery was no surprise because of their family history, weight problem or just an expectation that cholesterol could be an issue based on their lifestyle, such as diet.

The response of some of the participants to this discovery was “not finding it a drama”, thinking that it would have been better “not to have known about it”, not “think(ing) about it”, not “worry(ing)” about it and “not making it a problem.” Although stating that the high cholesterol was not an issue, the participants still indicated an acceptance that changes had to be made to their lifestyle, thus indicating a covert acceptance of their situation. Others accepted that their situation required drastic changes (such as diet and exercise) to their lifestyle and launched into these changes readily and with positive results. One participant observed, as part of his discovery that, “foods that are, theoretically good for you, are also more expensive” (Thomas: 42-45).

Through it all, regardless of how actively or readily they accepted having high cholesterol, the participants got on with living with it. There were aspects of living with it that they struggled with, such as exercise for some and diet for others. These struggles

and lack of success contributed to the participants not only becoming more aware of having high cholesterol, but also to becoming more aware of the aspects in their lives which needed to be addressed, such as diet and exercise.

I had always thought it was doing the exercise that would be the hardest thing for me and I've discovered it not it's changing my eating patterns that's much harder (Maryanne: 90-95)

I need to do more exercise...to get motivated to do it in some way (Petronella: 349-356).

Some of the participants had standards and expectations of themselves and not being able to live up to these contributed to their becoming more aware of these aspects of their lives and their struggles with them, but continuing to Accept the reality of having to live with high cholesterol, nonetheless.

I'm not a stupid woman and yet still I find it really too hard to comply with what seems on paper such a simple thing, to do (Maryanne: 258-261).

As part of becoming more aware as a result of discovering their high cholesterol, the participants acquired knowledge about the condition through various sources such as the internet; books, magazines and literature; the cardiac rehabilitation programme; as part of their job; their doctor; and friends and family with high cholesterol or cardiovascular problems. This contributed towards becoming more aware of cholesterol in their daily living.

Int: Where did you get that information from?

Thomas: Either on, on the net, I got a lot of it from the hospital here...through their rehab programme...and ah, it's general knowledge talking to other people picking it up, and you just get an idea you get a feel for what's good and what's bad (713-725).

when I first learnt of it I was living in XX at the time, and the doctor there said I think you can control it with diet and gave me...a list of things I shouldn't eat (Les: 273-279).

On acquiring knowledge about high cholesterol the participants became more aware of, “what your body’s doing and what, you are doing, and putting into it” (Thomas: 179-182). As this statement indicates, this awareness related to what cholesterol did to the body and what a person could do in terms of counteracting this process or contributing to it. This awareness was associated with issues of cardiovascular and cholesterol management and control, for example changes of habits such as smoking, diet, exercise, medication and stress.

I gave up smoking at the beginning of the year after the heart attack I haven’t smoked since January, I’ve changed my diet completely I exercise now by, cycling and walking, and, where I normally, used to drive, I walk to the shops, I walk, jump on the bike and I go for a ride round the lake or something like that take the dog for a run (Thomas: 476-494).

I’ve gone for years the only medication I took was a couple of nurofen for a headache. And now, I’ve got daily medication, and that’s gonna continue, right the way through (Thomas: 521-528).

I think it all blows into this, high cholesterol and, hypertension and all those kind of things if you, if you’re tense all the time and irritable and, um, a bit stressed out, I think it, all adds to the problem (Paul: 583-589).

With becoming more aware of the different aspects of living with high cholesterol and Accepting the cards that they had been dealt, the participants expressed personal limits and tolerance zones which influenced their health philosophy and outcome. These limits and tolerance zones are identified as belonging to the cutting point family as defined by Glaser (1998), with being / not being evident established as the cutting point for Accepting. This is the point which determined how actively the participants engaged in lifestyle changes in their process of living with high cholesterol. This will be discussed in further detail in the following section.

Cutting Point: Being/Not Being Evident

Being/not being evident referred to high cholesterol being or not being evident in the participants' lives. This occurred through having or not having obvious physical problems related to high cholesterol. It also referred to a participant's understanding of the reason for these problems and/or the potential for developing cardiovascular disease as a result of having high cholesterol. In general, the participants who suffered from active cardiovascular disease mentioned being more active in their lifestyle changes to keep their cholesterol under control. In this situation, cholesterol was evident in their lives and served as the cutting point of being evident, to influence their lifestyle choices.

The heart, problems that I had.. has to be cholesterol related to the blockages...have to be cholesterol related and...so, now that they've been done I sort of feel that I'm a lot fitter and a lot better and able to enjoy what I have got and even my doctor's told me that I'm a model patient...because I'm, sort of exercising and doing all the right things now...(Les: 777-791).

This perspective did not apply in all instances. In one instance a participant expressed uncertainty in his understanding of his current health status in relation to his high cholesterol, despite having had heart surgery.

Having high cholesterol doesn't, worry me because it's only what the doctor tells me. Unless I can see some physical evidence there that...this is happening because of the high cholesterol, it doesn't I know nothing about it I mean if it happens it happens (Charlie: 522-533).

Another facet of being/not being evident was that, particularly for the participants without cholesterol related conditions or complications, other health issues which were more obvious gained their attention and action more readily than the cholesterol issue because of the impact on their enjoyment and quality of life. Some of these actions such as diet, exercise and weight control did, however, concur with the recommended lifestyle

changes for cholesterol control so that the benefits achieved related to high cholesterol as well.

I feel like I need to be fit. And, 'cos um, I think if you're not fit you get old before your time sort of thing...And there's a lot of, you know physical activity that you want to do that you can't if you're not fit, I sort of try and keep myself fit and also to, give my heart a good workout. And that's...to also keep my weight down...if I don't, run I sort of, put on weight pretty quickly (Paul: 123-138).

I'm trying to cope with a few things at the same time, trying to eliminate my headaches and this nasal drip, so in the last, three months, I've really watched what I've eaten and I've really been trying to keep note (Petronella: 647-653).

I haven't had a headache, now going on three weeks which, up until, three months ago I've been having, ten days every ten days sometimes every week sometimes every two weeks, I don't know if it's that but I'm just at the moment trying to see, I'm not eating a lot of sugar, I'm not eating chocolate I don't drink tea or coffee I'm not having any alcohol (Petronella: 655-666).

Another aspect of cutting point was that it was not linear. It existed in frequent interplay between the changing situations and perspectives of everyday life, so that having high cholesterol went back and forth to being/not being evident in the participants' daily lives. For example, Les demonstrated an interplay of this cutting point in his process of living with high cholesterol and active cardiovascular disease.

My doctor's told me that I'm a model patient because...I'm sort of exercising and doing all the right things (785-790).

On the other hand he states, "spoiling myself once a week once a month I feel I'm not doing a lot of damage to my...system" (334-337). This interaction influenced his lifestyle (choices and strategies) where he, on the whole, kept up the lifestyle which earned him the praise of being 'a model patient' but would at times let go and allow himself a treat because of his enjoyment of food because, "I...live to eat rather than eat to live and I enjoy my foods" (550-552).

As a result of the interaction between the cutting point of being/not being evident the participants, through becoming more aware, developed strategies which related to the side of the cutting point which was more active in their lives at the time. Because of the non-linear aspect of this process the choices and strategies quite often reflected both sides of the cutting point (i.e. being as well as not being evident) as demonstrated above. Strategies pertaining to the category of Accepting will be covered in the next section.

Strategy

The participants in this study employed strategies to manage their high cholesterol. These strategies were taken in the context of having been dealt the card of having high cholesterol. Being dealt this card took them through the process of discovering and acquiring knowledge which helped them to become more aware of high cholesterol in their lives. This caused them to accept the cards they had been dealt. They also had personal limits and tolerance zones which revolved around enjoyment of life and acted as the cutting point which influenced the strategies they took to manage the category of Accepting. The first strategy, not worrying, will be discussed next.

Not Worrying

Not worrying was a mechanism associated, firstly, with not worrying about something that might not be a problem in the long term. This was seen as worrying needlessly and not worth the major change of lifestyle, when there was a possibility that a problem other than high cholesterol could just as well turn out to be the cause of one's mortality. This applied particularly when high cholesterol was on the "not being evident" side of the cutting point.

I don't feel like, spoiling my life and changing everything for the sake of something that, may not be a problem in the long term (Petronella: 1467-1471).

That's a little bit que sera what ever will be will be. I could get run over by a bus (Alison: 315-316).

Secondly, not worrying was associated with avoiding stress. Worrying was regarded as contributing to stress and further health problems, so not worrying was a means of alleviating or avoiding them

I'm not going to give myself hypertension worrying about, my cholesterol (Alison: 87-89).

If I sit and worry about it all the time, it'll probably make it worse...I'm sure it's stress that has some kind of an influence (Paul: 648-652).

The perspective of worry and stress contributing to further problems applied to all participants regardless of whether or not having high cholesterol was evident.

Not worrying was also discussed in connection with a shortened lifespan. There were participants from both sides of the cutting point of being / not being evident, to whom a shortened lifespan was not a worry as long as they were able to enjoy life. For example, a participant who had no history of cardiovascular involvement, expressed this view, "I hope you don't have to come and, cry over my box (laughing). But if you have to, I would have had a lot of fun...that doesn't worry me enough to...feel I've got to try and change my life" (Petronella: 1224-1234).

On the other side of the cutting point participants with an extensive history of cardiovascular disease, expressed a similar view:

One way or another I, probably have got a shortened life...it still doesn't worry me (Les: 409-424).

I've reached a good age, and if I go for another few years well that's ah a bonus isn't it. But I've never worried too much about it it's ah, I mean if it's happening it's happening (Charlie: 167-174).

Despite not worrying about a shortened lifespan there were participants from both sides of the cutting point who still expressed a wish to still have the years they could lose if they didn't deal with the problem.

In the meantime I'd rather stay alive (Maryanne: 659-660).

I want to spend a few more years with my wife (Thomas: 457-459).

Nonetheless, they still employed the strategy of not worrying because, "stress leads to more hassles" (Thomas: 948-949) and, "the problem with it only comes if you make it a problem" (Thomas: 1016-1019).

Not worrying was a strategy taken to keep things on an even keel and not create more "hassles" or "problems" (Thomas: 949,1019). Worrying was viewed as unhelpful and pointless because, "it becomes something that I worry about in vain" (Paul: 304-306). Instead, the participants communicated a conscious choice not to worry about their cholesterol, to accept what that they had been dealt and get on with life, thus contributing to the category of Accepting.

If you accept it realise yeah you've got it, and grizzling about it's not gonna help, just...do something about it and just, carry on (Thomas: 1019-1026).

Another strategy for the category of Accepting was dealing with what is evident. This will be discussed in the following section.

Dealing With What is Evident

A second strategy employed by the participants was **dealing with what is evident**. This was a mechanism some participants employed for handling a situation

where they had to cope with more than one issue (such as migraines, nasal drip and weight problems) at once. These were more evident and more aggravating than the cholesterol problem.

I'm trying to cope with a few things at the same time (Petronella: 647-648).

The participants' priority was to resolve these issues which were causing them immediate discomfort and affecting their enjoyment and quality of life more than the high cholesterol did.

I'm trying to eliminate my headaches and this nasal drip (Petronella: 648-650).

If I don't, run I sort of, put on weight pretty quickly (Paul: 136-138).

Despite dealing with what is evident rather than the cholesterol issue, there was still an acceptance of having high cholesterol.

I thought oh well, you know they say it is high so I suppose I'd better do something about it and...cook and eat better than what we had been before (Petronella: 44-48).

The participants still talked in terms of trying to incorporate the lifestyle changes recommended by health professionals, literature and any other source from which their information was derived. It was just the priority that had changed to resolving the issues which caused the more obvious discomfort.

For one participant, staying fit and controlling weight was more of a priority than high cholesterol. He had a regular exercise regime (running) which he maintained to achieve this.

I...do try and keep myself fit and also to, give my heart a good workout. And that's about, to also keep my weight down...if I don't, run I...put on weight pretty quickly (Paul: 131-138).

As a result of dealing with what is evident, the tactic of ‘crossing the bridge when coming to it’ was employed when it came to the issue of high cholesterol.

When the... time comes I’ll cross the bridge (Petronella: 810-811).

This indicated that high cholesterol was currently not a worry but present in the background, whilst they were contending with other problems. By “crossing the bridge” when the time came, the participants accepted that whilst their high cholesterol was not yet an issue it could become a problem later, so they would deal with it then. They elected to deal with what is evident for the time being.

One of the participants summed up this process, “you do your best” (Alison: 14), indicating that despite extenuating factors, as discussed above, they did their best even though dealing with the high cholesterol was not always the priority if another issue was more evident. This revolved around the participants’ enjoyment and quality of life, which will be discussed in more depth in Chapter Six, on the basic social process, *Maintaining Enjoyment Of Life*.

The third and last strategy for the category of Accepting is being philosophical. This is covered in the following section.

Being Philosophical

Being philosophical emerged not only as part of the context of being dealt the cards, but also as a strategy of Accepting. As a strategy, the participants actively used being philosophical as a mechanism of dealing with having high cholesterol.

Being philosophical was also expressed as being fatalistic, with both terms conveying similar concepts. For instance, Alison conveyed her perspective, “I feel quite

fatalistic about, whatever...will be will be and...so, if that was what I got...I would have to accept it" (324-327).

Thomas expressed a similar view, "I'm very philosophical about that things happen...the best thing you can do is just, right OK this's happened accept the fact that it's happened" (954-961). Therefore, both in being fatalistic and being philosophical the participants conveyed the concept that "things happen" and that "whatever will be will be". Just as in being dealt the cards, these events were out of their control, so they had to accept the reality of having high cholesterol and live with it.

The participants, employed being philosophical as a means of maintaining their equilibrium. Doing so helped them avoid worry and stress over having high cholesterol. They used being philosophical as a strategy for staying undisturbed whilst adapting to their health situation and lifestyle changes.

It didn't really faze me particularly other than I thought well I suppose I'd better just be a bit more careful of what...we eat and...I, need to do more exercise (Petronella: 52-58).

Being philosophical related not only to having high cholesterol, but also to the ramifications of cholesterol as well as to the participants' perspective on death. They regarded the issues of morbidity and mortality due to high cholesterol as "que sera" or "whatever will be will be"

There are worse things in, my mind the things actually happening to me (Alison: 315-319).

There are worse things than being dead (Alison: 151).

"Que sera" ("whatever will be will be") indicated a sense of fatalism regarding what the future had in store as long as they could enjoy life, hence being philosophical.

I sort of think we've got to live and enjoy life and, I die a bit earlier because I've got cholesterol um, I've had fun (Petronella: 773-776).

By being philosophical, regardless of the prospect of the “associated risks” (Paul: 186) and the possibility of a “shortened life” (Les: 411) because of high cholesterol, the participants maintained their equilibrium, “to keep things cool” (Alison: 240), in other words, calm and unperturbed and maintain their enjoyment of life.

Conclusion

This chapter described the category of Accepting and its supporting properties, using the theoretical codes of context, cause, cutting point and strategy. Accepting was the first stage of the participants' process of living with high cholesterol. This was made in the context of being dealt the cards of high cholesterol and (for some) its ramifications.

On being dealt the cards of high cholesterol the participants went through a process of discovery and acquiring knowledge which helped them to become more aware of high cholesterol and its impact on their lives. This awareness caused them to accept the reality of high cholesterol in their lives.

In living with this reality, the participants had personal limits and tolerance zones which were influenced by enjoyment of life. These limits and tolerance zones were the cutting point at which the situation shifted to result in action or interaction. The cutting point for this category was identified as being/not being evident, referring to cholesterol being / not being evident in the lives of the participants. Being/not being evident was the point which determined how actively the participants followed the recommended lifestyle changes for controlling high cholesterol. The cutting point was influenced by enjoyment of life and impacted on the strategies developed by the participants to manage this

condition. These strategies were not worrying, dealing with what is evident and being philosophical.

The next stage of this process of living with high cholesterol was Getting On With It. This will be discussed in Chapter Five.

CHAPTER FIVE: GETTING ON WITH IT

Introduction

Chapter Five is the second of three chapters presenting the findings of this study. As with Chapter Four, it sets out those findings that relate to a stage in the process of living with high cholesterol. Chapter Four dealt with what the researcher identified as the first stage or category; Accepting. Chapter Five deals with a second stage of living with high cholesterol; Getting On With It.

As in the previous chapter, the modified 6Cs framework is used to illuminate and explain the category of Getting On With It. Individual properties of Getting On With It, identified here as context: being dealt the cards; cause: enjoying life; cutting point: being/not being in control; strategies: negotiating and balancing risk; and consequence: doing your best, are examined with reference to the perspectives, experiences and actions reported by participants in the study. First, however, this chapter goes on to give a brief definition of Getting On With It.

Definition of Getting On With It

Getting On With It emerged out of a participant's statement, "this is life as we know it and get on with it" (Alison: 290-291). Get on is defined by the Collins Pocket English Dictionary (1981) as to go on or into; to proceed. The participants conveyed this meaning when they discussed Getting On With It in relation to proceeding with life-style modifications recommended for managing high cholesterol.

Things happen, um, the best thing you can do is just, right OK this's happened accept the fact that it's happened, get on with it. You mope or grizzle or groan it's not gonna do anybody any good and you're the only one who's going to be affected by it. So you don't (Thomas: 956-968).

In the category of Getting On With It, the participants learnt to live not only with having high cholesterol but also (for some) learning to live with changes in their health status.

I used to say I was a walking example of a good recovery. I was, and I walked...and I tried the walking group, but this last Christmas or just before the – I ended up by getting angina. I don't know what caused that again but, it did happen. And I've learnt a lot about diet, since then (Charlie: 200-211).

Context: Being Dealt the Cards

Just as in the category of Accepting, the participants continued to live within the context of **being dealt the cards**, in the category of Getting On With It. This context continued to exist as an influencing background throughout the whole process of living with high cholesterol. They got on with life by playing with the cards they had been dealt. The quote, “that’s sort of like the cards you get dealt and, you have to play with them sort of...there’s not much that you can do about it” (Paul: 219-223), not only provided the context for Accepting but also the context for the category of Getting On With It. In the category of Accepting, the participants were dealt the cards of having high cholesterol and were Accepting of it, because it was out of their hands. In the category of Getting On With It, the participants lived within the context of being dealt the same cards and proceeded to play with them. They did this by finding ways of living with the lifestyle changes recommended for managing high cholesterol and, in some cases, the complications that accompanied it, without losing their enjoyment of life. In this process, the stages of Accepting and Getting On With It interacted back and forth with each other as well as with the central process of Maintaining Enjoyment Of Life, within the context of being dealt the cards.

Throughout this interaction, the participants adapted to the unpredictability of the cards they were dealt by continuing to be philosophical about what came their way.

Because having or not having high cholesterol was, initially at least, out of their control, being philosophical about it assisted their acceptance as well as their process of getting on with living with the condition. They Got On With It by formulating strategies which enabled them to live with their high cholesterol, recommended lifestyle changes as well as with changes in their health status, whilst Maintaining Enjoyment Of Life. The categories of Accepting and Getting On With It therefore both revolved around the central process of Maintaining Enjoyment Of Life.

The next property for the category of Getting On With It is enjoying life which is explained by the theoretical code of cause. This is discussed in the next section.

Cause: Enjoying Life

All the participants expressed enjoying life as central to their existence. They lived to enjoy life, so that everything they undertook revolved around maintaining that enjoyment. Enjoyment had different associations, such as food, exercise and social interaction, for the participants. Some expressed enjoyment of life also in terms of having quality of life, both in their current situations as well as in the future.

You've got to enjoy life you've got to be happy (Alison: 152-54).

We're only here for, average of eighty odd years, and the first thirty of that you work like, crazy to get, some pleasure out of life, um, I don't think you realise what you've got until, you have something like this happen and then you realise, y'know, I could die tomorrow I mean this is the, what, second, third, time I've had this, the first time was when I had a car accident and lost my hand. Y'know when you've realised your mortality, then you realise that, enjoyment of life, pleasure, and enjoying yourself with somebody, is yeah very important (Thomas: 616-641).

Without enjoyment of life they described existence as being "pointless" (Paul: 563).

Enjoyment of life therefore had an influence on how successful the participants were in

incorporating the medical directives recommended for the control and management of high cholesterol. Enjoying life was essential to the strategies they undertook to get on with it in their process of living with high cholesterol.

There were aspects of lifestyle changes that the participants enjoyed so that these were relatively easy for them to achieve and get on with. For some, exercise was not an issue because they enjoyed it, so that it easily became a part of their lives.

I find all sorts of interesting thoughts that come in to my mind about it, and it's inextricably linked up with the, weight and diet thing to me, um, much more than it is with exercise, for somehow I've managed to build that, level of exercise and get something that I quite enjoy out of that, but it goes back into very very old, stories of not being able to manage my, not, being in control of what I eat in the sense that I'd like to be (Maryanne: 177-188).

For others diet was relatively easy to manage because of disinclination towards meat, fatty food and eggs.

I hardly make steak at home often when we go out I think ooh I'm going to have a steak you know, and I order it and I think this isn't nearly as nice as I thought it was gonna be. I wish I'd had fish I wish I'd had chicken. So, there's only one place in town that when we do go that I actually do order a steak, because I know that the steak I'm gonna get there is really nice other than that if we go anywhere to eat I I order fish, I I actually, don't order meat stuff. And the ?? have lamb shanks, once or twice, but, it's actually immaterial to me whether I have meat or not (Petronella: 1897-1916).

I hate things like chicken skin. And, actually too much fat can actually make me feel quite nauseated (Alison: 83-85).

Some of the participants found that they lost the enjoyment for such foods as they became better informed about high cholesterol and diet. Their preferences changed, thus shifting their enjoyment over to a more healthful diet.

Before you know I'd buy a huge thing of chips and eat them all up and I'd, still want some more. But now if I have a few I sort of...feel...bilious...you just feel off...I've got more used to not eating rich food (Paul: 453-62).

The participants all reported difficulty in integrating into their lives activities and changes which curtailed their enjoyment of life. Again, these related to diet and exercise.

The dietary changes involved modification of diet, which in turn entailed exclusion of foods they enjoyed. Some of these foods had associations with their childhood and were therefore regarded as treats and comfort foods in adulthood.

well the whole chocolate bread cakes, ice-cream, um, that sort of, that's where a where a um.....as kids we, we grew up where we had, just post war I was born in (year), um, and in New Zealand that meant that, you had milk and cream and custard and sweets and sugar and like wasn't, um, I talked to people who grew up at that stage in Britain where there was rationing well there wasn't rationing here it was a real, um, joy in having all these healthy dairy foods, 'healthy' (with emphasis) dairy foods to live on. So, typical meal at home was to have meat and 3 vegies and you had to eat everything that was on your plate. And that would often be, quite fatty lamb chops and always meat of some sort and...it was all usually fatty sort of meat, mince shepherd's pie, roast mutton...lunch was always bread and butter, you had school milk, and...yeah, breakfast was usually weetbix and, milk but it was full cream milk obviously in those days, got it in the billy at the gate um, and then at dinner if you, ate, everything that was on your plate then you could have pudding, and there was pudding every night, so, and that was with custard or cream or ice-cream and um, and then if you ate all that you were allowed to have a lolly from the lolly jar, so we grew up in a family which had those sorts of and I think that's probably, looking back was very, um, no I mean it was thought of as being healthy and building bonnie plunket babies but, it probably was not at all, it was a very high fat high, animal fat diet. Yeah. Um, and that's what I talk about of bad food I suppose, yeah. 'Cos those are clearly still the things in my life I see as rewards and treats and comfort food (Maryanne: 687-730).

Recommended cooking methods, for example cooking in oil, were also a forfeiture because they reduced the palatability of food. One participant, apparently half joking, suggested that oil is not for human consumption.

Oils are for cars not for eating (Thomas: 421-3).

There were participants who did not enjoy exercise. This was because of a dislike for getting 'hot and sweaty'. They also found exercise boring and disliked non-social

physical activities such as working out in the gym and walking or running on their own. This reflected on their motivation to include exercise in their lives, so they struggled to do so.

To me to just and walk on my own or go and do aerobics or go and stand in the gym and do a treadmill it's so boring I could think of nothing worse (Petronella: 370-374).

I don't like being all hot and sweaty and then I, it's just the way I've always been. (Petronella: 420-423).

Some got around this problem by organising walks in the bush or forest with friends on a regular basis, when it suited them. By doing so, they communicated a greater sense of enjoyment, which they felt was better for them in the long run.

I do yoga, at least once a week for an hour and a half I'm not a sports fanatic by any means. Um, I enjoy walking forest but I can't I'm not very... organised to say I'm going to go 3 times a week for half an hour or an hour, at a time. It's more like a social thing with friends and I think that probably does me, more good eventually, to enjoy the sunshine and just do it when I feel like it (Alison: 89-98).

Others were not as enthusiastic about such pursuits because of "getting hot and sweaty", so that exercise was not as much a part of their lives as they would have liked. Although they made a point of being active in housework and gardening, they felt the need to integrate more "aerobic" type activities in their lives, as they regarded these as not giving them enough of a workout. As a result they considered looking for enjoyable ways to exercise but, at the same time, stated that they were not going to stress out over it.

I need to find something, that I really enjoy doing, that happens to, give me the exercise at the same time, but to go and do the exercise for the sake of doing exercise, I can't motivate myself to do it. Bad good I don't know, its just, I don't, see the point. I can see the, health point of it, but I can't, see the point in myself to actually, go and do it, 'cos it's it's not enjoyable, I don't want to do anything anymore in my life that's not fun (Petronella: 470-484).

For participants in this study, enjoying life and having quality of life included not only enjoyment in terms of having fun and not having to do what they didn't have to do, but also in association with keeping fit, enjoying good health and minimising physical limitations. Fitness, good health and not having physical limitations were regarded as essential to enjoyment of life for some because of the nature of activities they enjoyed, such as outdoor pursuits and sports, for example skiing, hunting, running and walking.

I want to be...fit enough so I can enjoy physical activities, and, um y'know, what whatever if we want to go...skiing or something...you sort of (chuckling) you feel, old and decrepit you can't do it, so you, that's some of the enjoyment you lose out, so ah, whatever, skiing in the snow or water skiing, you know the kids want to go and do something and you wanna go and do it as well but feel ah, not fit enough, you can't do it, so you miss out on it (Paul: 543-559).

As a result, the participants were willing to make sacrifices in order to maintain this quality of life in their current situation as well as into their later years. Consequently, they formulated strategies to achieve and maintain enjoyment of life.

Some days I'll get up, and I'll feel brilliant, and I get up (gestures), and gone y'know not a problem, yet other days I'll get up and I'll feel tired, lethargic, I'm short of breath, um, you just, feel blah and don't want to and they are the days you gotta force yourself...the more you force yourself the fewer and far in between they become (Thomas: 498-512).

I'd rather have those ten or fifteen years, and enjoy them, and, be a little bit fitter a little bit more capable, in that time because, when you finish work, then you can enjoy yourself you can do the tours, and...go around the country, and...I'd rather be able to get out and about, than sitting on the porch in a rocking chair (Thomas: 676-692).

With enjoying life being central to the participants' process of Getting On With It, there were tolerance zones influencing this process. This has been identified as being/not

being in control which will be explained using the theoretical code of cutting point. The cutting point of being/not being in control will be discussed in the following section.

Cutting point: Being/Not Being in Control

Being/not being in control, is another property of Getting On With It. In being/not being in control, the participants chose not to allow cholesterol to rule their lives. There were aspects of their lives that they were able to more easily be in control of, whilst there were others where they more often than not found themselves not so easily in control of, for example diet versus exercise. There were also instances where they found the aspect they were in control of at a certain time shifted to not being in control in a change of circumstances. For example, they may be in control and adhere, to the recommended low fat diet, much of the time, but may also let go from time to time and indulge in food or meals which are not within the cardioprotective recommendations. The participants chose not to stress over it and to make their own choices over the aspects of cholesterol management to undertake in relation to diet, exercise and medication.

We ah, try and, keep, as much as possible off the fatty foods and just not eat too much of fat, or oils or fatty foods and I'm very conscious about reading labels on, ah, on food products nowadays...I always read the label and have a look and, if it's anything over ten grammes of fat then no thanks put it back on the shelf (Les: 1365-1385).

I enjoy going out and...having meals out in restaurants and which we do, not very often but, often enough, and I sort of feel well hey I've gotta treat myself (Les: 321-326).

In relation to medication, some of the participants elected to stay away from cholesterol lowering drugs and control their cholesterol with lifestyle choices such as diet and exercise. They made this decision on the basis of their health background, to avoid the adverse effects of cholesterol lowering drugs. In doing so, they attempted to be in

control of their cholesterol as well as the ongoing progression of the condition by not allowing it to advance to the stage of having to go on medication.

I guess I'm always interested in any new data that is coming through. Um at one time, I spoke to...and he said...if he had...cholesterol as high as that he would give me, um, lipitor or whatever but all those things have quite nasty or can have quite horrible side effects and, I think well, you know, if you can just do it, with your own input and your lifestyle and your lifestyle choices and then convince yourself that that's what you like that's the way to go, not to go for these expensive drugs (Alison: 121-135).

For other participants, taking medication was a means of being in control of their cholesterol. These were participants for whom the cholesterol levels were not as successfully controlled with diet and exercise. Some of these participants had active cardiovascular disease so that their need for more aggressive control was greater. Others had no history of cardiovascular disease. Dietary control for these participants, regardless of whether or not they had cardiovascular problems, was effective only up to a point. They expressed difficulty with the restrictions of a low cholesterol diet because it impinged on their enjoyment of food to the extent that they could not sustain it long term.

I just find it so hard, to bring it down through diet alone...virtually impossible...if I can live on lettuce leaves well yeah sure I could bring it down but, to me that's not...living that's existing (Les: 1223-1231).

This meant that taking the cholesterol-lowering drug enabled the participants to be in control of their cholesterol whilst at the same time maintaining enjoyment of life.

I wasn't over worried about medication ah I just sort of felt that I um I, had to do something and...I knew that...diet alone, was not, bringing my cholesterol down it was keeping it in...under the seven and to the sixes or the high sixes (Les: 214-223).

This situation demonstrated both sides of the cutting point of being / not being in control. On one side of the cutting point, the participants demonstrated not being in control when they were unable to sustain the dietary restrictions required for keeping

their cholesterol levels down, because of its impingement on their enjoyment of food.

This shifted to the other side of the cutting point, being in control, when they went on the cholesterol-lowering medication. This enabled them to have better cholesterol control whilst enjoying what they considered a more normal diet, thereby fulfilling their desire to enjoy life while living with high cholesterol.

This interplay of the cutting point applied also to diet and exercise where participants demonstrated being in control of one aspect and not being in control of the other, depending on which aspect they enjoyed or did not enjoy, respectively. To the participants who enjoyed a more vegetarian, low-fat diet, being in control of the dietary aspect of lifestyle changes recommended to counter cholesterol was relatively easy. However, a recommended adjustment that they did not enjoy (for example exercise) was the area they demonstrated not being in control of. As a result, both sides of this dichotomy were at play at the same time.

Being/not being in control related to making choices as well as to aspects of lifestyle changes which the participants found either relatively easy or more difficult to integrate into their lives. Being/not being in control influenced the level of success they had with the different aspects of lifestyle modifications.

You can make choices you can, decide to, do more exercise and, eat differently...the basic problem that your cholesterol is high is not by choice so that, I mean it's just something that happened so you've gotta try and deal with it, I mean you can ignore it or, or try and do something about it or, but I just don't want to let it become a, a thing that worries me (Paul: 635-646).

There were external variables, in some cases, which assisted the success of some of the participants. They identified these as being observed. Being observed made it easier to choose to follow medical recommendations, for example to say no to food when in the company of others whereas when on their own they would have "a guts out" (Alison: 70-

71). Another example was having a spouse or partner who played an active role in their lifestyle modification. The participants to whom the latter applied talked about their partner's/spouse's role in ensuring that they adhered to the low-fat diet, hence enabling them to be in control of their diet.

I think I've got my wife to ah, take credit there that ah, I can see her looking and saying...you've ah, too much butter (Charlie: 272-277).

Because I'm married I have a partner, I have to think of her as much as I think of myself. And, I know for a fact that if she caught me eating some of the stuff, I shouldn't eat and, I'd get a very good swift kick and, a good y'know, right that's enough of that you don't get anymore (Thomas: 851-863).

The cutting point of being/not being in control revolved around enjoyment of life. The side of the boundary that the participants found themselves on was influenced by the extent to which they were able to enjoy life. In order to achieve this, the participants developed strategies which enabled them to be in control of their cholesterol and their situation as much as possible, hence assisting them to Get On With It. These strategies have been identified as negotiating and balancing risk and will be explored in the next section.

Strategy

Negotiating

Negotiating was the first strategy of Getting On With It. Having been dealt the cards of having high cholesterol, the participants were given directives on lifestyle modification by health professionals. For many, these changes were difficult.

It leaves me in a constant dilemma because I do lots of things that I consider are good for my health, but here's the most important thing probably that I should be doing for my health which is eating sensibly which will help me lose weight which will reduce the risk of cancer which will lower my cholesterol which would, and it seems so difficult (Maryanne: 227-236).

They therefore tried to work out options they thought suited best. In doing so, they negotiated the best deal for themselves.

In your circumstances you've got to do the best for, you, what suits you (Petronella: 1941-1943).

The participants demonstrated different ways of negotiating. They referred to negotiating with regard to fat levels in their food and style of cooking; indulging occasionally in treats and food normally considered off limits for a low cholesterol diet; and living and interacting with others and therefore accommodating others in their process of living with high cholesterol. By negotiating, they demonstrated a process of bargaining or trading-off, to reach an acceptable compromise.

The participants discussed negotiating fat levels by choosing the more healthy option in an unhealthy food range. Other examples of the negotiation strategy were comparing the fat content listed in food labels and making a selection on the basis of the listed fat content.

I really like cheese so I think well, OK, take a strong cheese and don't have as much (Alison: 79-81)

I always like to look at...the fat percentages per, hundred grammes and then I can, confirm that with or, look at that other product and, it gives me a better idea of what's going on (Les: 1395-1402).

Negotiating fat levels involved attention not only to the quantity of fat in food but also the type of fats present in foods, such as the saturated, polyunsaturated and monounsaturated types of fat. As a result, the participants discussed avoiding saturated fats, for example, by changing "from butter to margarine" (Charlie: 95-97). Other methods demonstrated were grilling and removing the fat from meat and cooking in oil

rather than fat. Similarly, takeaways were selected on the basis of the cooking medium, that is, cooked in oil rather than fat.

Gone are the days when you can just...pop down the road get fish and chips or...if we do we've got to watch, what they're cooked in you have to find somebody that does them in..canola oil or, something like that (Thomas: 418-421).

Negotiating also involved allowing oneself to indulge occasionally in a meal without having to pay attention to the fat levels, for example, "bacon and eggs"; "lambs fry and bacon" or "eating out". The participants negotiated by cutting back on something else later, to make up for the indulgence.

You know you're going to go out, this meal's coming, you know it's going to be a nice meal go out, relax enjoy yourself. Coupla days later...you can, work out, OK well I've over indulged in this much so, this week I'll just cut back on something else (Thomas: 984-995).

The last aspect of negotiating involved accommodating others such as a partner or spouse, family and friends. The participants had to learn to live with their high cholesterol and adapt to the changes recommended, whilst also having to consider others in their lives. Accommodating others they lived with had an impact on the types of foods they selected.

My husband was the cook, um, and so I just ate whatever it was that he prepared, and for a while he was very helpful but actually he's a very much a, was a meat eater and fried food and things so, it was harder, in that sense I had to do things separately for myself (Maryanne: 141-148).

They negotiated dietary changes in different ways. There were instances where the family accommodated the changes and the participants were able to select the 'healthy equivalent' of food for the family.

So, for example, when I'm buying things at the supermarket, I think, um... on behalf of my husband as well, when I'm choosing food...I'll choose the healthy...equivalent of whatever I can I hate eggs anyway so eggs are never a problem for me, he loves them so um um we don't eat much, in the ways of eggs (Alison: 52-59).

There were other situations where the participants accommodated the family's preferences more than their own. The consequence of the latter was that the participants communicated not being as successful at negotiating their fat levels down as they thought they should. Overall the participants, regardless of their situation, perceived that they balanced the recommended dietary changes for high cholesterol to the best of their ability, whilst maintaining enjoyment of food.

I'm looking at cooking for him, more than I'm looking at cooking for myself (Petronella: 1616-1681).

We, eat as healthily as I possibly can make it (Petronella: 1865-1867).

Social settings involved a certain measure of negotiating for some of the participants. For example, one participant who preferred water, drank water out of a wine glass to give the impression she was drinking wine or alcohol, to be sociable.

What I do now is...I put water in a wine glass, for, other people not for me...it seems to be a huge problem for other people that you're not drinking wine with them (Petronella: 1326-1334).

Eating out at a restaurant was an easier setting socially, for some, to negotiate fat levels and accommodate others because of the selection offered, for example, having the option of fish instead of meat.

Negotiating was a process which involved constant exercise and dietary transactions as well as accommodating other people, whilst Getting On With It and Maintaining Enjoyment Of Life. The participants got on with it by formulating systems which allowed them to successfully implement the recommended lifestyle changes but at the same time still enjoy life.

The second strategy that participants used for Getting On With It was balancing risk. This will be discussed in the next section.

Balancing risk

Balancing risk is another strategy of Getting On With It. In this strategy the participants used their knowledge of cholesterol and its associated risk factors to work out their risk level for cardiovascular problems. They balanced risk factors such as family history, gender, smoking, the ratio of good to bad cholesterol, diet, exercise, staying safe and self-monitoring.

Having a family history of high cholesterol alerted participants to the fact that they were at greater risk for cardiovascular disease. Some of the participants countered this risk with a reflection on gender where, for the female participants, there was the knowledge that their hormones offered them a certain degree of protection.

As a woman hopefully my hormones will be protecting me to a certain degree (Alison:155-157).

Other factors, such as being non-smokers, having a favourable good to bad cholesterol ratio and having an active exercise regime were also regarded as offering some protection against cardiovascular disease, thereby lowering their risk. In balancing risk based on this knowledge, some of the participants with no history of cardiovascular disease elected to avoid cholesterol-lowering medication for the time being, as long as they were able to control their cholesterol with diet and exercise. The reason for this was that they considered the risk from the side effects of the medication to be higher than the cholesterol risk, in their current situation. For the participants with cardiovascular involvement, balancing risk meant a need for cholesterol-lowering medication as well as other drugs, for survival.

Again, for a participant with cardiovascular problems, balancing risk involved staying safe, particularly because of a recent heart attack. They therefore avoided situations where help was not readily available, by balancing the risk of activities they enjoyed with the risk of an adverse event in inaccessible territory.

My wife and I both like going out in the bush, and, I mean way out in the bush, now if there's a probability of something happening to me because of the levels and because of my heart condition, then I can't afford to be, two days' walk into, the bush where the only way to get there is by helicopter or, two days' walk out, just can't do that anymore...there are areas where we like to travel, where we can't we've got to be basically, within, somebody going, or being able to get help, quickly, and easily (Thomas: 80-104).

A part of balancing risk for some participants was self-monitoring, to assess their risk status. They undertook this in different ways. One was mindful of the increased cardiovascular risk with advancing years, compounded by the cholesterol factor; so he used exercise as a method of self-monitoring.

and that's another thing that the running and the exercise you know, well at least while I'm running I'm thinking at least I'm not getting angina (Paul: 510-514).

He also depended on these indicators as signals that additional measures, such as cholesterol lowering medication, could be required.

Well I think to myself if...it starts getting to that stage maybe the running will, kind of precipitate a, warning, to say hey you know look you're getting to the, limit now, and, maybe if that happened I'd....have to take...some, cholesterol lowering drug...but, I don't think it's high enough for me, to warrant that. So I'll...just keep an eye on it (Paul: 516-528).

Another method of self monitoring demonstrated by another participant was having yearly cholesterol checks, as well as requesting additional tests, such as levels of the amino acid homocysteine (recently linked to cardiovascular risk) in the blood.

I will have my, um, cholesterol checked, perhaps, oh, yearly, and, I have been thinking about asking to have my homocysteine checked (Alison: 231-234).

By employing the strategy of balancing risk, the participants ascertained their status in relation to high cholesterol and cardiovascular risk. In addition, they undertook self-monitoring to give them an indication of their risk status. This influenced the actions they took to incorporate lifestyle changes and medication in Getting On With It, the second stage in their process of living with high cholesterol. Balancing risk was also employed by participants with active cardiovascular disease, to maintain a safety margin in the activities they undertook.

The strategies undertaken by the participants through the categories of Accepting and Getting On With It, in their process of living with high cholesterol, resulted in the outcome of doing your best. Doing your best will be discussed under the theoretical code of consequence, in the following section.

Consequence: Doing Your Best

The strategies undertaken by the participants assisted them to accept and get on with living with high cholesterol. Throughout their process, enjoyment and having quality of life were regarded as essential. As a consequence of this they tried their best to integrate in their lives the lifestyle modifications recommended for cholesterol management. They also did their best to enjoy life whilst integrating these changes.

You do your best (Alison: 14).

The participants demonstrated different ways of **doing your best**. To those with cardiovascular disease, doing your best involved playing “by the rules” as one participant put it. They did this in relation to diet, exercise and medication. The “rules” were the standards recommended by the health profession and health groups for the management of high cholesterol and cardiovascular disease.

I play by the rules I...have reduced the ah, the butter and the margarine, intake (Charlie: 103-107).

I've been doing a lot more exercise (Les: 871-872).

And now I've got daily medication, and that's gonna continue, right the way through (Thomas: 525-528).

Part of “playing by the rules” involved changes in relation to the participants’ dietary preferences, priorities and lifestyle. The participants achieved these changes to different levels. Examples were, changing from butter to margarine, changing the cooking style and changes in their choice of food. Some stated changing the “way I react” (Thomas: 770-772). Others changed their lifestyle to incorporate more exercise in their lives, cutting back on takeaway meals and changing their selection if they did get takeaways. This related closely to strategising in that the strategies undertaken by the participants resulted in their changing, playing by the rules and doing their best in their individual situation.

Doing your best and “playing by the rules” were influenced by the extent to which doing so affected the participants’ enjoyment of life. The participants to whom having high cholesterol was evident, regardless of whether or not they had active cardiovascular disease, played by the rules more stringently than those to whom having high cholesterol was not as evident. This was because enjoyment to the participants (to whom having high cholesterol was evident) encompassed not only good health but also staying fit and minimising physical limitations in the short term as well as long term, to be able to continue the activities they enjoyed. This impacted on their quality of life.

The participants without active cardiovascular disease, to whom having high cholesterol was less evident, still demonstrated doing your best and playing by the rules, albeit to varying degrees. These participants, although employing the tactics of “not

worrying” and “crossing the bridge” when coming to it, did not disregard playing by the rules. They played by the rules, doing their best, as much as they could whilst striving to maintain their equilibrium and enjoyment of life.

I’m not ignoring it I know it’s there but I’m not going to change my lifestyle because of that...(Petronella: 1136-1139).

Although not as extensive as those undertaken by participants with active cardiovascular involvement, they still achieved changes to their lifestyle. Meanwhile, in being aware of aspects of lifestyle changes they were not as successful at integrating into their lives, this group of participants continued to seek enjoyable means of successfully incorporating the measures required to control their high cholesterol. Their focus was maintaining enjoyment of life whilst doing their best to play by the rules.

Conclusion

In the category of Getting On With It the participants continued to live in the context of being dealt the cards. Whilst living within this context they expressed the importance of enjoyment in their lives. Hence enjoying life was the cause or basis of Getting On With It and influenced every aspect of their process of living with high cholesterol.

Enjoying life affected the participants’ interaction with the cutting point of being / not being in control. This interaction shaped the strategies, of negotiating and balancing risk, which the participants undertook, to manage their high cholesterol as much as they could, according to the guidelines set up by health professional groups.

As a consequence of living within the process described, the participants reported “doing your best” to successfully integrate the lifestyle changes recommended for cholesterol management. They did their best to play by the rules. Regardless of how

stringently they played by the rules, the participants talked about doing their best to incorporate the health directives in their lives, whilst also doing their best to maintain enjoyment of life. Maintaining Enjoyment of Life was the central process around which the categories of Accepting and Getting On With It revolved. This central process has been identified as the basic social process. The basic social process of Maintaining Enjoyment of Life will be presented next, in Chapter Six.

CHAPTER SIX: MAINTAINING ENJOYMENT OF LIFE

Introduction

This chapter presents the basic social process of Maintaining Enjoyment Of Life. An explanation of the basic social process will be presented first. Following this, Maintaining Enjoyment Of Life will be discussed in conjunction with Accepting and Getting On With It and their properties, to demonstrate how each category supports the basic social process.

The Basic Social Process

Maintaining Enjoyment Of Life is the basic social process of living with high cholesterol. A basic social process is a central process which accounts for most of the differences and alteration of behaviour. Because it is a process it must have two or more emergent stages. Accepting and Getting On With It were the stages required to achieve Maintaining Enjoyment Of Life. As a result, the categories of Accepting and Getting On With It and their properties, revolve around the basic social process of Maintaining Enjoyment Of Life.

The participants all discussed the importance of enjoyment in their lives. For some it meant what they did not want to do overall, “I don’t want to do anything anymore in my life that’s not fun” (Petronella: 482-483), and “don’t wanna do anything that I don’t have to do” (Petronella: 485-486). To others it meant what they did want to do overall.

Got to enjoy yourself got to enjoy life you’ve got to be happy (Alison: 152-154).

Others detailed specific elements of enjoying life. These included being physically fit, enjoying good health and minimising physical limitation. I placed enjoyment of life, being in good physical, mental and emotional health and being able to carry that on into latter years, as communicated by the participants, under the collective term of “quality of life”. In this study enjoying life is the overriding element of quality of life. Doing the right things, according to the recommended lifestyle modifications, is secondary.

I’ll be careful but, I’m not going to, change my lifestyle to make it, you know sack-cloth and ashes because it’s going to bring my cholesterol down by two points because, I don’t think it’s worth that (Petronella: 1250-6).

Maintaining Enjoyment Of Life was central to the participants’ process of living with high cholesterol because they considered life without enjoyment pointless. Without being able to maintain enjoyment of life, the participants would have had difficulty accepting their situation and getting on with the lifestyle modifications recommended for the management of high cholesterol. The next section will demonstrate how the category of Accepting and its properties revolve around the basic social process of Maintaining Enjoyment Of Life.

Accepting

Context: Being Dealt the Cards

In the category of Accepting the participants, by being philosophical, chose to take things as they came and not get upset about what they had been dealt.

I sort of tend to take things as they come and...I wasn’t going to get upset about it (Paul: 48-50).

For some, being dealt the card of high cholesterol was no surprise. For others, it was unexpected. Regardless of whether or not it was expected, the participants were philosophical about what they had been dealt. By being philosophical and taking things as they came, they Maintained Enjoyment of Life by avoiding stress from worrying about their condition

I don't want to make life, a real hassle because I'm worried about my cholesterol (Petronella: 1127-1129).

Being dealt the cards remained a constant presence throughout the participants' process of living with high cholesterol. Although high cholesterol was a constant presence in their lives and being dealt these cards was out of their control, the participants endeavoured to Maintain Enjoyment of Life regardless.

Having made their discovery of having been dealt the cards of high cholesterol, the participants acquired information on the condition. This led to their becoming more aware of high cholesterol and their process of living with it.

Cause: Becoming More Aware

On making their discovery and **becoming more aware** of high cholesterol in their lives the participants became more in-tune with their body, the risks of cholesterol and what they did in response to it. Their awareness extended as well to aspects of cholesterol management (such as diet and exercise) that they struggled with. The aspects they had difficulty with were ones which restricted their enjoyment of life. The participants' responses to all this were, "not finding it a drama", not "thinking about it", "not worry(ing) about it" and choosing "not to make it a problem", hence not allowing themselves to become stressed. These responses revolved around Maintaining Enjoyment Of Life. By avoiding stress, as they became more aware of high cholesterol and its

impact on their lives, the participants were able to maintain their equilibrium and retain their enjoyment of life.

Enjoyment of life also had an influence on the personal limits and tolerance zones which influenced the health philosophy of the participants. These limits and tolerances will be discussed in the next section under the theoretical code of cutting point.

Cutting Point: Being/Not Being Evident

The cutting point of being/not being evident was the demarcation point which determined the participants' actions, in relation to integration of the recommended lifestyle changes in their lives. The extent to which high cholesterol was evident in the participants' lives was influenced by enjoyment of life. This was because aspects of the recommended lifestyle modifications, such as diet and exercise, quite often curtailed the participants' enjoyment of life. The loss of enjoyment because of having to do something they did not enjoy (for example, exercise) was the overriding factor to relegate high cholesterol to the background, hence not being evident for that point in time. Because high cholesterol was silent and there were no obvious physical symptoms affecting the quality of life of some of the participants, they were happy to ignore this aspect and get on with dealing with something else instead, such as weight gain or migraines, which were more obvious.

feeling uncomfortable, in my clothing or, seeing a photo that makes me feel fat, so being fat is far more of a driver than, cholesterol...and I think it is affecting my quality of life (Fran).

there are worse things than being dead I really believe that. You know what you've got to enjoy yourself got to enjoy life you've got to be happy (Alison: 151-154).

Paul: I don't really think about it (13).

Paul: I want to be, like fit enough so I can enjoy physical activities, and, um y'know, what whatever if we want to go, I'm trying to think of a...if we want to go skiing or something you know um, you sort of (chuckling) you feel, old and decrepit you can't do it, so you, that's some of the enjoyment you lose out, so ah, whatever, skiing in the snow or water skiing, you know the kids want to go and do something and you wanna go and do it as well but feel ah, not fit enough, you can't do it, so you miss out on it.

Int: So enjoyment of life is important?

Paul: Yeah. I mean otherwise it's pretty pointless I think (543-563).

to go and do exercise for the sake of doing exercise, I can't motivate myself to do it. Bad goo I don't know, it's just, I don't see the point. I can see the health point of it, but I can't see the point in myself to actually, go and do it, 'cos it's..not enjoyable, I don't want to do anything anymore in my life that's not fun.....I'm trying to cope with a few things at the same time, trying to eliminate my headaches and this nasal drip, so in the last, three months, I've really watched what I've eaten (Petronella: 474-486; 647-652).

I just enjoy my food I, today I sort of more..live to eat rather than eat to liveand I enjoy...experimenting with foods (Les: 549-554).

To some participants, high cholesterol was evident in their lives. They were the ones who had cardiovascular disease and regarded high cholesterol as a significant contributing factor to their condition. Some had a health background and dealt with patients who had cardiovascular disease and its complications. The impact of high cholesterol on enjoyment of life was therefore more tangible to these participants. With high cholesterol being more evident in their lives, these participants were more active in modifying their lifestyles to keep their cholesterol under control. This was done to prevent further complications and progression of the condition, which could impinge on their quality of life and therefore restrict their enjoyment.

I feel that I'm a lot fitter and a lot better and able to enjoy what I have got and even my doctor's told me that I'm a model patient...because I'm, sort of exercising and doing all the right things now (Les: 782-90).

To these participants, actively engaging in the recommended lifestyle modifications, even if it involved making sacrifices, meant improving their quality of life, hence maintaining their enjoyment of life in the long term.

High cholesterol was evident and not evident to participants depending on how much their enjoyment of life was affected. Enjoyment of life had an influence on which side of the cutting point of being/not being evident was more active in a participants' life at any given point.

The influence of enjoyment of life on the cutting point also shaped the strategies taken by the participants. The strategies often reflected the side of the cutting point which was more active in the participants' lives at the time.

Strategy

The strategy of **not worrying**, in the category of Accepting, was associated with avoiding stress and the associated problems that the participants perceived as accompanying stress. It also involved not worrying about a shortened lifespan.

Avoiding stress was employed by the participants to not create more "hassles." Some regarded high cholesterol as something that might not be a problem in the long term and so saw no point in, "spoiling my life and changing everything" (Petronella: 1468-1469). Not worrying helped them to maintain the status quo and not upset their lives more than they had to. This helped them to retain their enjoyment of life.

In general, by not worrying and avoiding stress and more problems, and maintaining their status quo as much as they could, the participants held on to the things in their lives that they enjoyed. They were able to Maintain Enjoyment of Life by not making their lives "sackcloth and ashes" for nothing. Some went as far as to state that if

they had to go early because of their high cholesterol, at least they would have had a lot of fun. Having fun and enjoying life was preferable to a longer life of “sackcloth and ashes.”

I hope you don't have to come and, cry over my box. But if you have to, I would have had a lot of fun (Petronella: 1224-1228).

Dealing with what is evident was another strategy employed when there were other issues and health problems which caused the participants greater discomfort and stress, thus affecting their quality and enjoyment of life. Dealing with these issues first was considered more important by the participants, to maintain their enjoyment of life. By choosing to deal with what is evident, their approach to high cholesterol was that they would “cross the bridge” when the time came.

When the...time comes I'll cross the bridge (Petronella: 809-10).

Being philosophical was the last strategy for the category of Accepting. This was associated with Maintaining Enjoyment of Life through maintaining equilibrium and avoiding worry and stress over having high cholesterol. By being philosophical about having been dealt the card of high cholesterol, the participants, rather than worrying and becoming stressed about it, accepted it as, “this is life as we know it” (Alison: 291) “que sera whatever will be will be.” Consequently, they were able to remain undisturbed whilst adapting to their discovery and the recommended lifestyle changes. Regardless of the “associated risks” of high cholesterol, the participants preserved their enjoyment of life by being philosophical about whatever they were dealt.

It's not gonna do any good to get stressed out why bother. Things will happen anyway (Les: 974-977).

They also expressed the perspective that there were worse things in life that could happen, so by being philosophical their situation was regarded as not being so bad. As a result they continued to maintain enjoyment of life. Maintaining Enjoyment Of Life continued as the central process through the next category, Getting On With It. This is presented in the following section.

Getting On With It

Context: Being Dealt the Cards

Being dealt the card of high cholesterol continued to be the context within which the participants got on with living their lives. Getting On With It was the next stage of the participants' process. This was facilitated by being able to Maintain Enjoyment of Life. The participants' acceptance of the cards they had been dealt and the ability to get on with living with them, were influenced by the degree to which they could maintain enjoyment of life. Enjoyment of life enabled the participants to adapt to their changing situations (as in the cards that they were being dealt). Being able to maintain enjoyment of life assisted them to get on with doing whatever it was they had to do whilst living within this context. They communicated the importance of enjoyment in their lives and indicated that enjoyment was the element that made life worthwhile.

Having accepted the cards that they had been dealt, the participants engaged in finding ways to live with these cards. They continued to adapt to the unpredictability of the cards that they were dealt by being philosophical about it. By being philosophical about it and taking things as they came they got on with finding ways of living with the recommended lifestyle changes for the management of high cholesterol. These ways of

living with the lifestyle changes were influenced by enjoying life. This contributed to the identification of enjoying life as the cause for this category.

Cause: Enjoying Life

Enjoying life was important to the participants. They considered life without enjoyment pointless. Consequently, their process for learning to live with high cholesterol revolved around Maintaining Enjoyment Of Life. By holding on to their enjoyment of life the participants were able to get on with living with the condition of high cholesterol. There were aspects of lifestyle modification which the participants enjoyed so that these were easy to get on with and integrate into their lives. Other aspects curtailed their enjoyment of life and were therefore not as easy to get on with. These were the aspects that the participants struggled to incorporate into their daily lives.

I realised I had always thought it was doing the exercise that would be the hardest thing for me and I've discovered it not it's changing my eating patterns that's much harder...um...and so I still, I still go to the gym, I'm actually just starting to do some I've just joined a, outdoor pursuits women's group and went tramping at the weekend, so I'm beginning to pick up some other, of the things that I enjoyed as exercise and in the BUT the cholesterol thing has been..um...I've put on a lot of weight in the last 4 years and, my eating is, totally, not sensible (Maryanne: 90-104).

Getting On With It was influenced by the cutting point where the participants' personal limits and tolerance zones determined the shift in their action and interaction. The cutting point, being / not being in control, will be presented next.

Cutting Point: Being/Not Being in Control

In being/not being in control, the participants chose not to allow high cholesterol to rule their lives. This involved living with lifestyle modifications and was influenced by enjoyment. As discussed earlier, the aspects of lifestyle changes that the participants

found relatively easy to achieve were the ones they enjoyed. The ones they expressed difficulty with were the ones they did not enjoy. Retaining enjoyment gave the participants quality of life, hence the demarcation between one side of the cutting point and the other, where they found it easier to be in control of aspects they enjoyed and not being in control of aspects they did not enjoy.

Another perspective of being/not being in control was decision making by the participants on the direction of cholesterol management, based on their perception of safety and impact on quality of life. For example, some of the participants chose lifestyle changes over medication, to control their cholesterol. They made this decision to avoid the adverse effects of the cholesterol lowering drug, which they considered worse than the high cholesterol itself. For others, taking the cholesterol lowering medication meant that they could stay in control of their high cholesterol, which would otherwise have been very difficult (if not almost impossible) to control just with lifestyle modifications. Either way, the focus was on avoiding an adverse outcome that would affect their quality of life, hence limiting their enjoyment of life.

Maintaining Enjoyment Of Life was therefore central to the personal limits and cutting point which determined how actively the participants engaged in getting on with the recommended lifestyle changes. As a result of this, they developed strategies which assisted them to Accept and Get On With living with their high cholesterol, whilst Maintaining Enjoyment Of Life.

Strategy

The strategy of **negotiating** demonstrated an approach whereby the participants endeavoured to work out the most suitable and enjoyable means of implementing the

lifestyle changes they found difficult. These difficulties related to diet and exercise, as discussed under negotiating in the category of Getting On With It. The strategy of negotiating allowed the participants to Maintain Enjoyment of Life whilst “playing by the rules” as much as they could, in their circumstances.

In the strategy of **balancing risk** the participants endeavoured to Maintain Enjoyment Of Life whilst determining their risk level for cardiovascular problems. On working out their risk level, the participants selected measures which they considered were to their best interests and which best promoted their enjoyment of life, for example, choosing to stay away from cholesterol lowering medication and controlling their cholesterol as much as they could through diet and exercise, to avoid the adverse effects of the medication.

Maintaining Enjoyment Of Life in staying safe whilst balancing risk was a challenge for some of the participants because of the curtailment of some of the activities they enjoyed, because of recent cardiovascular events such as a myocardial infarction. For this reason they felt unsafe to venture into territory where they were out of reach of ready assistance. They still took part in these activities such as boating or going into the bush. However, in the interests of their ongoing physical safety, they stayed within the bounds of being within call for help in the event of a health crisis.

As part of balancing risk the participants undertook self monitoring. Self monitoring was also a means of Maintaining Enjoyment Of Life. By engaging in self monitoring, the participants assessed their risk status regularly to ascertain their cardiovascular risk. They used the indicators of their monitoring measures (such as running and blood tests) to signal impending changes or deterioration of their condition and the need for additional measures, to control their cholesterol and prevent further

complications. In doing so they attempted to Maintain Enjoyment Of Life in the short term and long term. In the short term, they were able to continue in the status quo with peace of mind. In the long term, these indicators signalled a need for additional measures required to maintain their health and quality of life.

The consequence of the participants' process and strategies in living with high cholesterol was doing your best. This will be presented next.

Consequence: Doing Your Best

The participants did their best, under their circumstances, to integrate the recommended lifestyle modifications into their lives and to play by the rules to the best of their ability. Doing their best did not necessarily entail living by the health directives to the letter, but doing their best under their circumstances, individually, whilst at the same time Maintaining Enjoyment Of Life. Although they had to make sacrifices in the interest of sustaining good health, they did so to maintain quality and enjoyment of life in the long term. There were occasions when these endeavours were less successful for some participants. Although appearing to avoid these issues, these participants continued, however, to seek means of resolving these issues without losing their enjoyment of life.

So I actually need something that, doesn't have a point, but for me the point is enjoyment or fun...I would then be out there doing it because I was enjoying it (Petronella: 500-6).

They continued to do their best to successfully play by the rules of living with high cholesterol whilst Maintaining Enjoyment Of Life.

Conclusion

In the basic social process of Maintaining Enjoyment Of Life, the participants focussed on holding on to enjoyment throughout their process of living with high cholesterol. They lived within the context of being dealt the cards (of high cholesterol) throughout the categories of Accepting, Getting On With It and Maintaining Enjoyment Of Life. The causes and cutting points of these categories were influenced by enjoyment of life and therefore revolved around maintaining this enjoyment. In all their undertakings in living with their high cholesterol, the participants employed strategies which revolved around Maintaining Enjoyment Of Life. They did so by holding on to their enjoyment of life as much as possible whilst also preventing adverse events and maintaining optimum health, according to their individual understanding.

Consequently they did their best, in their individual ways, to successfully play by the rules of cholesterol self-management whilst Maintaining Enjoyment Of Life. At the end of the day, what mattered most to them was not longevity but enjoyment of life. This was the overriding factor in the participants' perception of quality of life. Maintaining Enjoyment Of Life gave them a reason to carry on.

....I hope you don't have to come and, cry over my box.

But if you have to, I would have had a lot of fun...

(Petronella: 1127-9).

CHAPTER SEVEN: DISCUSSION

Introduction

This chapter discusses the significance of Maintaining Enjoyment of Life in the lives of the participants with high cholesterol. The grounded theory analysis of the data in this study resulted in the identification of the basic social process of living with high cholesterol. The basic social process of Maintaining Enjoyment of Life influenced the participants' success or lack of success in implementing the recommended lifestyle modifications.

Because of the importance of enjoyment of life to the participants, this chapter will focus on aspects of maintaining that enjoyment, in association with literature relating to quality of life, adherence and the transtheoretical model of change (Prochaska, DiClementi & Norcross, 1992). Following this I will present the implications of the study, followed by the recommendations for future research, limitations of the study, strengths of the study and the conclusion of the chapter.

Enjoyment and Quality of Life

The Collins Pocket English Dictionary (1981) defines enjoyment as, "having or experiencing with joy or pleasure" (p. 284). This is the understanding I derived out of the participants' expression of enjoyment. They spoke of enjoyment in terms of having fun and deriving pleasure out of activities and life. Enjoyment of life, including being in good physical, mental and emotional health and being able to carry those on into latter years, as communicated by the participants, falls under the collective term of "quality of life."

The term “quality of life” was my conceptualisation, with the dimensions mentioned above derived from the participants’ data. “Quality of life” in this thesis is defined by the participants and does not necessarily exactly concur with the domains of the existing quality of life tools (WHOQOL-BREF, World Health Organization, 1996; SF-36, Ware et al, 1993). Enjoying life was the overriding element of quality of life in this study. Doing the right things, according to the recommended lifestyle modifications, was secondary.

I’ll be careful but, I’m not going to, change my lifestyle to make it, you know sack-cloth and ashes because it’s going to bring my cholesterol down by two points because, I don’t think it’s worth that (Petronella: 1250-1256).

The World Health Organisation (1996) defines quality of life as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goal, expectations, standards and concerns” (p. 3). Varicchio (1990) also touches on the concept of quality of life reflecting the degree to which a person finds life worth living. According to the participants in this study, the only life worth living is one with enjoyment.

Although enjoyment of life is addressed in the WHOQOL-BREF (World Health Organisation, 1996) tool, other tools such as the SF-36 (Ware et al, 1993) do not address enjoyment of life specifically. Details of the WHOQOL-BREF and SF-36 tools can be viewed in Appendix L and M. These tools, although covering a wide scope of domains and having been statistically validated, do not appear to allow for subjective interpretations of individuals’ quality of life in their personal and immediate contexts. As a result quality of life assessment tools may reflect of the health professionals’ perspectives rather than the patients’ perspectives (Carr-Hill, 1985; Staniszewska, 1999). Maryanne, a participant in this study, presented this view on quality of life during a

member checking interview (which was not transcribed), “You’re the only one who knows what/how those factors- especially things like the quality of life; no one else can tell you what you value as quality of life.” At the member checking interview the emergent theory is presented to some of the participants, individually, to ensure that the theory identified by the researcher fits the participants’ process. This statement reinforces the need for an open and participatory assessment and decision making process between patients and professionals in health care, to reflect the individual’s rather than health professionals’ perspective. Based on these observations and participant feedback, I would question the relevance of quality of life assessments which do not have a subjective component which allows self expression of the individuals’ values and concept of quality of life.

Enjoyment also had an impact on adherence/compliance to health directives. Maintaining Enjoyment of Life influenced the participants’ success in adhering to the recommended lifestyle modifications. This is discussed further in the following section.

Adherence

Aspects of adherence to directives which the participants enjoyed were the ones they found they had greater success in adhering to and vice versa. Much has been written on ‘adherence’ or ‘compliance’ to treatment and health directives. Problems with adherence and the lack of ‘motivation’ in relation to this aspect are widely recognised (Becker & Maiman, 1975; Kravitz et al, 1993; Kyngas, Hentinen, Koivukangas & Ohinmaa, 1996; Kyngas & Lahdenpera, 1999; Lahdenpera & Kyngas, 2001). Perceived non-adherence in this study appears to be a strategy taken by the participants, in some instances, to maintain the status quo and not upset their equilibrium, whilst adapting to their condition

and working out a means of managing their condition, without losing their enjoyment of life. For other participants, the impact on their enjoyment and what was important to them was too great, for them to integrate the unenjoyable aspect(s) of lifestyle changes in their lives, for example, exercise in Petronella's situation. Even in these situations, the participants still employed their creativity to discover enjoyable ways of performing an activity they disliked. Realising this process brought about a paradigm shift in the way I now view the issue of adherence. Perhaps as health professionals we need to be more comfortable with the patients' right to choose what does and does not work for them.

In a study on "heart health behaviour" (p. 60) in rural Queensland, Australia, Ray (2000) identified "enablers" (p. 62) and "impediments"(p. 63) to change. These "enablers" and "impediments" determined the adherence or non-adherence of individuals to health directives, of which managing high cholesterol was a part.

The "enablers" in Ray's (2000) study did resonate in part with my participants' process, such as wanting to be more healthy, the issue of self image, self monitoring to keep track of health status, becoming more aware through information sources, deriving motivation from other people's illness experiences and having the support of significant others such as a spouse or partner. These aspects, identified by Ray (2000) as "enablers," were associated with enjoyment of life, be it short term or long term, in the participants of my study.

Maintaining Enjoyment of Life could influence the "impediments" to change of health behaviour identified by Ray (2000). These were identified as "lack of motivation, self discipline and bad habits" (p. 63). The "bad habits" in Ray's (2000) study appear to refer to dietary preferences with high cholesterol food being identified as "the tastiest" (p. 63) by the participants. In the process demonstrated by the participants in this study, the

issue of lack of motivation and self discipline were the result of not being able to maintain enjoyment of life. The “bad food habits” Ray (2000) identified, resonated with the struggles of some of the participants in this study. For them, they revolved around enjoyment of food, the lack of which caused them to at times indulge in foods not recommended as part of their low cholesterol diet. The findings of this study on living with high cholesterol indicate that enjoyment played a part in enabling and impeding adherence to, as Ray (2000) expressed, “positive health behaviour” (p. 62). Maintaining Enjoyment of Life provided the participants with the motivation to adhere to lifestyle modifications required for self management of their high cholesterol. Motivation is discussed in further detail in the next section.

Motivation

Motivation, in this study, was influenced by cutting points at which the participants chose to move towards one direction or the other. This resulted in the formulation of strategies. For example, the cutting point of being/not being in control generated the strategy of negotiating, which involved constant exercise and dietary compromise or bargaining. This enabled the participants to incorporate the lifestyle modifications into their lives, whilst maintaining enjoyment of life.

Da Silva (2003) found that “negotiations and creative strategies to balance exercise, diet and medication were central” (p. 158) to attempts to sustain adherence to self management of heart disease. Da Silva also discussed “shifts in priorities” (p. 159) influenced principally by what was important to the participants in her study. This resonates with the cutting points in this cholesterol study, which were influenced by the most important element in the participants lives. This element was enjoyment of life.

Maintaining this enjoyment of life was central to this study's participants' process of living with self management of high cholesterol. It gave meaning to their lives and a reason to carry on. Da Silva (2003) asserted that "women's meanings and priorities" (p. 159) influenced motivation in the participants in her study. The principal element contributing to meaning and priority in the lives of the participants in this study on living with high cholesterol, was Maintaining Enjoyment of Life.

Consequently, maintaining enjoyment of life influenced the attitudes of the participants with regard to their high cholesterol. It also shaped their behaviour in achieving change, in relation to lifestyle modifications recommended for self management of high cholesterol. Behaviour change in response to recommendations from health professionals has been widely studied. As a result theories explaining health behaviour have been developed. One of these theories, the transtheoretical (stages of change) model developed by Prochaska, DiClemente and Norcross (1992) is discussed in the next section, in association with the findings of this study. Although identified as applying to change of addictive behaviour, this model fits the process of living with high cholesterol as well.

The Transtheoretical (Stages of Change) Model

Behaviour change in the participants in this study was a process of Accepting and Getting On With It, which revolved around Maintaining Enjoyment of Life. This concurs with the transtheoretical model (Prochaska, DiClemente & Norcross, 1992). According to Nutbeam and Harris (1998), the transtheoretical model recognises that change of behaviour is a process and that individuals have "varying levels of motivation, or readiness to change"(p. 26). This model of change (Prochaska, DiClemente & Norcross,

1992) identified five stages of change. They are, precontemplation: “the stage at which there is no intention to change behaviour in the foreseeable future” (p. 1104); contemplation: “the stage at which people are aware that a problem exists and are seriously thinking about overcoming it but have not yet made a commitment to take action” (p. 1104); preparation: the stage at which a person intends taking action in the near future. The individual might have undertaken some changes but has “not yet reached a criterion for effective action, such as abstinence from smoking, alcohol use...” (p. 1105); action: the stage at which “behaviour, experiences or environment” (p. 1105) are modified to overcome the problem. Modifications of behaviour at this stage “tend to be most visible and receive the greatest external recognition” (p. 1105); and maintenance: the stage of preventing relapse and sustaining the changes achieved.

Prochaska, DiClemente and Norcross (1992) also recognised the stage of “relapse” where individuals “regress to an earlier stage” (p. 1106), hence their identification of the “spiral pattern of change”(p. 1106). The “spiral pattern” illustrates that change is not linear but that individuals move to and fro between the stages, in their process of change. This happened quite frequently through the stages as individuals attempted to modify their behaviour.

The participants’ process in this study is reflected to a certain degree in Prochaska, DiClemente’s, Carlos and Norcross (1992) transtheoretical model. Examples of this are provided in association with each stage.

Some of the participants in this study of living with high cholesterol reflected the precontemplation stage when they had no immediate intention of changing behaviour, such as integrating exercise into their lives. This was because of a dislike for exercise or

any other activity that they had difficulty with. Hence engaging in these activities encroached on their enjoyment of life.

The contemplation stage is reflected in the discovering and becoming more aware phases of the category of Accepting (Chapter Four) of the findings of this study. As the participants acquired more knowledge about high cholesterol, following their discovery, they become more aware of this risk factor and its ramifications. As a result they considered “do(ing) something about it.”

Preparation is reflected in the participants’ process of learning to live with the cards they had been dealt, in the category of Getting On With It. By learning to live with the cards they had been dealt, which was the risk factor of high cholesterol, the participants worked out ways of living with the recommended lifestyle modifications without losing enjoyment of life.

The category of Getting On With It also demonstrated the stage of action. In this stage, the participants integrated the lifestyle changes for the control of high cholesterol, into their lives. They employed different strategies to achieve this. For example, cutting down on fats by switching from butter to margarine; changing their cooking style; joining the gym to incorporate exercise; walking or cycling.

The consequence of “doing your best” in my findings reflects the maintenance stage. Whilst doing their best, the participants endeavoured to sustain the changes they had achieved. They accomplished this to different levels of success, depending on which side of the cutting point was active in their lives at a given time. All these stages revolved around Maintaining Enjoyment of Life. Their level of success in the maintenance, as well as other stages, was determined by how well they were able to maintain enjoyment of life.

The “spiral pattern of change” resonates with the influence of the cutting points, on the participants living with high cholesterol. The participants moved from one stage to the other or relapsed to a pre-change stage, depending on which side of the cutting point was more evident in their lives at the time. For example, the interplay between the cutting point of high cholesterol being/not being evident influenced the choices and strategies of the participants. As a result, they mostly maintained the recommended lifestyle modifications, but would also at times ‘cheat a little bit’ and occasionally ‘indulge’ in foods or meals which are not within the recommended low fat category. In this fashion they reflected the “spiral pattern of change.”

The findings of this study give an understanding of the needs and motivation of the participants, thus also giving a better appreciation of their problems with self management. The participants needed to maintain enjoyment of life. Being able to maintain enjoyment of life motivated them to undertake and achieve lifestyle modifications for self management of high cholesterol. The instances where the participants were not as successful at undertaking lifestyle modifications were the ones where enjoyment was lost. By applying this understanding of the individuals’ processes to the model of change, we could develop programmes more suitable to the needs of the individuals, to achieve a better outcome.

These findings have implications for the delivery of health care. The implications are presented in the following section.

Implications of the Study

The basic social process of Maintaining Enjoyment of Life gives a new perspective on the issue of motivation and adherence. As mentioned earlier, non-

adherence and the issues of changing and influencing patients' attitudes and motivation (Lahdenpera & Kyngas, 2001), have been widely discussed. Based on the basic social process of this study, I suggest that what is identified as lack of motivation and non-adherence could be a process of holding on to enjoyment. The participants' process revolved around maintaining enjoyment of life, without which life, they stated, would be "pointless". Based on the findings grounded in the data of the participants of this study, I would recommend that when looking at "non-adherence", attention to enjoyment of life could point the way to a creative solution or compromise to a problem. This would enable Maintaining Enjoyment of Life and promote adherence to treatment and directives. This has implications for health professionals in dealing with patients with high cholesterol.

As nurses, understanding the basic social process of Maintaining Enjoyment of Life for patients with high cholesterol, around which their acceptance and getting on with it revolve, should help provide more patient-centred care and support. This would promote patient adherence and better success at managing this problem.

Before data collection for this study I did a pre-suppositions interview with my supervisor, to clarify my thoughts and biases. This interview was put aside until after completion of the findings chapters. A review of this interview revealed that I had identified issues with patient adherence and management of their diet, exercise and cardiac programme. For instance, I described patients in CCU who claimed not to eat much but were very obese. Some of them were observed slipping in fast foods, chocolates, biscuits and other treats. My response then was one of frustration since I believed that people had to take responsibility for their health. I called it a "compliance" issue. It seemed patients were looking for a magic bullet. I actually did then realise that I was being presumptuous as a health professional and that there were lots of factors which

influenced adherence and compliance. I wanted to meet patients halfway, to work out ways that would suit them and their situations. The question was where to start and how to go about it. Looking back I could see that I displayed a judgemental attitude and this I am sure, if it was obvious to a patient, would hinder communication and undermine any attempt at a collaborative relationship. Lahdenpera and Kyngas (2001) discussed that health professionals can hinder or promote patient “compliance” (p. 193) and I see this as an example of hindering patient “compliance.” Interestingly, in my presupposition interview, I touched on the need to maintain enjoyment of life but had forgotten about it. I was surprised to discover it after the analysis and writing up of the findings, even more so because the basic social process revolved around maintaining enjoyment of life. I was thankful that I had not attempted to analyse the interview and that, after I had identified my biases, I had put it aside until after the data analysis. As far as I can tell the presuppositions interview did not feature at all in any aspect of interviewing or analysis. In identifying and understanding the basic social process of Maintaining Enjoyment of Life which has emerged from this study, I see now that the adherence issue is not about not taking responsibility, but about trying to hold on to something important, which the participants’ lives revolve around. This is Maintaining Enjoyment of Life.

The participants in this study conveyed creative methods of handling the different areas of their lifestyle modifications. By focussing on these with patients, we as health professionals could work more effectively and empower patients to identify their own individualised strategies to meet the recommended directives for managing their condition. Working with patients to maintain their enjoyment of life in the moment, short term and long term, would promote adherence and hopefully result in improved patient outcomes.

Patients will gain more autonomy in their self-management of high cholesterol, without feeling guilty about falling short of health directives. For example, the Royal New Zealand College of General Practitioners High Blood Cholesterol (2004 edition) hand-out to patients (Appendix A) provides a brief but clear explanation of cholesterol, the associated problems, “good” and “bad” cholesterol, the different types of fats, how to keep the “bad” cholesterol down and “changes everyone can make to eat well.” It also explains the measurement of cholesterol and ends with the Heart Foundation contact details for “further information and support.” It is a well presented and useful guide for patients. It is also a good tool for nurses working with patients with high cholesterol. However, when working with patients it is important to keep in mind that self management and behaviour modification is a process. This needs to be reflected in patient hand-outs and health education. The General Practitioners high blood cholesterol pamphlet addresses process in relation to advice regarding exercise. Enjoyment is addressed in the suggestion to find an enjoyable activity to undertake and to gradually increase activity each day. This guides the patients towards more effective strategies because the important element of their perception of quality of life is being addressed and satisfied. This, however, is not reflected in the dietary recommendations of the handout, which is directive without attending to process.

For instance, “include legumes (dried peas, beans, lentils) in meals” (Appendix A): a participant stated that she disliked lentils and beans. Others may not like them because of the way they have been cooked. How do we as nurses assist individuals in this process?

“Leave out full fat dairy food, meat fat or hardened vegetable fats” (Appendix A): This could be very difficult for someone to whom ice-cream, chocolates, cakes and cream

are comfort foods. How does one address this issue? Perhaps recommending lower fat options of these foods, such as low fat ice-cream and light cream could be a start. But what if cost was an issue and the lower fat options cost more?

“Limit red meat to about 150mg a day”: How does someone, to whom meat is an essential part of every meal, deal with this? To some, the fat off the steak is the best part of the meat. What are acceptable and enjoyable alternatives to meat and fat? This needs to be addressed when handing out directives, otherwise one could ignore such advice on the basis that it is too difficult to implement.

“Eat fish at least twice weekly”: This might not be possible for someone on a tight budget. It could even be that some may not like fish. Perhaps interesting ideas on how to cook fish would be a useful part of addressing this process of change for individuals, so that they can enjoy this aspect of lifestyle modification.

“Avoid preprepared (sic) foods, snacks and meals unless the fat and salt content are known”: This too can be a problem for someone who loves salt or who has a busy lifestyle so that “preprepared” meals are the only option on certain days. Addressing these issues and others listed in the hand-out alongside the directives, keeping in mind *Maintaining Enjoyment of Life*, would assist individuals in their process of change.

Recommendations for Future Research

As this study progressed, more questions emerged which could not be attended to as they would have caused a digression from the focus on the process of living with high cholesterol. Some of the questions would have required further theoretical sampling, which, because of the time-constraints of a masters thesis, were not an option to follow. The following two questions arose out of theoretical possibilities highlighted during

comparative analysis. First, how different would the process be, for participants who do not accept having high cholesterol? Second, what are the processes for a more culturally and ethnically diverse group of participants?

Other questions which arose included one about the patients' process of negotiating fat levels. Negotiating fat levels emerged as a possible core category of the process of living with high cholesterol, at one stage. Although the participants provided examples of their strategies for negotiating fat levels, it appeared that there could be more to negotiating fat levels and that this could be a study on its own.

Another was how childhood dietary patterns influence cholesterol levels and CVD risk later in life. All the participants discussed having a diet high in saturated fat as children because cholesterol was not known in those days. This went back three to four decades ago for most participants and even further for others.

The patient's versus the health professionals' perspective of quality of life is also of interest. This emerged out of the participants' discussion on refusing to live a life of "sackcloth and ashes" to accommodate the lifestyle changes they struggled with. They indicated that a life of sacrifice to that degree was not worth living. They were happy to compromise longevity for quality of life which preserved enjoyment. This seems to clash with health professionals' objective which measures success of treatment in terms of lowered morbidity and mortality rates.

Interest in how younger people (under 40) manage their high cholesterol was also generated in this study. This is discussed further under limitations, in the next section.

Limitations of the Study

This study has limitations in the areas identified. Firstly, there was a lack of cultural and ethnic diversity. Although the participants came from three different countries, they were all of European background. There were no Maori participants for this study and the only participant from an Asian ethnic group moved to another city before I was able to interview him. Keeping in mind differences of priorities and philosophies, participants from different ethnic groups and cultures could have a different basic social process.

Another limitation involves age. Although the ages of the participants interviewed ranged from 40 years to 80 years, it would be useful to also find out how different the process of people under 40 would be. This concept was prompted by feedback (following a presentation of this thesis) from someone with a family member in their thirties who “denies” having high cholesterol and “refuses to do anything about it.”

This study could still be explored in greater depth but the time constraint of a masters thesis was a limiting factor. Although no new data came through after about the fourth interview, there was still room for further theoretical sampling along the domains of acceptance of this risk factor, ethnicity and age. These limitations could constrain the fit and generalisability of this study.

Having identified the limitations, there are also strengths of this study. These are presented in the next section.

Strengths of the Study

The concepts, categories and properties of the findings are grounded in the participants’ data, as demonstrated in the findings chapters. There was no imposition of the researcher’s bias. Many of the concepts, categories and properties were in-vivos

codes and those which weren't, derived from participants' discussions around the concept (e.g. quality of life), therefore supporting it well. The next strength is the extensive member checking.

Member checking was done with five out of eight participants. I view member checking as another way of avoiding deceit in that any misrepresentation of data would be identified. The feedback from all participants was positive. They all affirmed that the findings of this study adequately captured their process, "what you said is exactly what, probably goes through, probably everybody's mind I think" (Paul).

They communicated seeing themselves in different aspects of the process. For example, Maryanne sees herself as making some sacrifices now in order to enjoy better quality of life later because she needs to be fit and well for the activities that she would like to enjoy when she retires.

Further feedback on the process identified in this study came from a source outside the study group. On sharing the findings of this study with a friend with high cholesterol who was not part of this study, feedback was given that an important part of the process for him was, "peace of mind – knowing you've done all you could do. Functioning in a structure I've developed." This threw me into turmoil as this aspect of the process of living with high cholesterol did not feature at all in the data collected and so had not been given any consideration. This raised the question of modifiability and tractability of this study.

On further reflection this statement appeared to capture the process of Accepting, Getting On With It and Maintaining Enjoyment of Life by having "peace of mind" through knowing he had done all he could (as discussed in Chapter Three). Despite the

new perspective coming through, the theory and process identified in this study showed modifiability and tractability, in his situation.

Conclusion

This study provides new understanding of the process which influences individuals' motivation and adherence to change of behaviour. In this case, the change of behaviour involved lifestyle modification for self management of high cholesterol.

A basic social process was identified. This was Maintaining Enjoyment of Life (discussed in Chapter Six), around which two stages, Accepting and Getting On With It (Chapters Four and Five, respectively) revolved. These stages were also identified as categories. Each category was supported by properties which were explained by a modification of Glaser's 6Cs family. The 6Cs family consists of theoretical codes. The theoretical codes identified as offering the best explanation of this data were: context, cause, cutting point, strategy and consequence.

The categories of Accepting and Getting On With It revolved around Maintaining Enjoyment of Life. Without this enjoyment the participants in this study would have had difficulty Accepting and Getting On With living with their high cholesterol. Accepting and Getting On With It also interacted with each other in that Accepting assisted with Getting On With It and vice versa, whilst Maintaining Enjoyment of Life remained central to each category. This led to the discussion (in Chapter Seven) on the influence of enjoyment on quality of life, adherence, motivation and the transtheoretical model of change. This central process was also applied to the General Practitioners' (2004) high cholesterol patient leaflet to identify a more process orientated system of delivering health education to patients, whilst focusing on Maintaining Enjoyment of Life. By

addressing what people themselves identify as important, in the ways they self-identify as meaningful, nurses could enable individuals to successfully integrate and maintain lifestyle modifications for high cholesterol self management in their lives.

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APPENDIX A

HIGH BLOOD CHOLESTEROL

2004 EDITION

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LOW CHOLESTEROL LIVING

On its own, a high blood cholesterol level is not necessarily a problem, but coupled with one or more of the other risk factors for heart disease, such as being a man aged over 45 years or a woman over 55, smoking, high blood pressure, diabetes or a family history of heart disease, it is often 'the straw that breaks the camel's back'. Therefore, it's really important to know what your cholesterol levels are and to keep them at a healthy level before you have any problems.

WHAT IS CHOLESTEROL?

Cholesterol is a white, waxy substance which, despite its bad reputation, is essential for life. Without cholesterol our bodies could not manufacture a number of important hormones, and it also forms the outer membrane of some cells. Our liver actually manufactures about 70 to 80% of it, while the rest comes from the food we eat.

What causes problems?

Our liver makes all the cholesterol we need so, if we eat a lot, we get too much circulating in our blood. It tends to get stuck in the blood vessel walls, narrowing the vessels and making their walls harder, and increasing the risk of heart disease.

While a high saturated fat diet is the usual cause of a high blood cholesterol level, some people have a high level because of an inherited susceptibility.

What is 'good' and what is 'bad' cholesterol?

Cholesterol, like fat, cannot move around the bloodstream on its own because it does not mix with water, the major ingredient of blood. So it hitches a ride with carriers called lipoproteins, of which there are several types – very low density lipoprotein (VLDL); low density lipoprotein (LDL); and high density lipoprotein (HDL).

What foods should I avoid?

The more saturated fats you eat, the more VLDLs your

VLDL

VLDLs are made in the liver and their job is to carry fats around the body. Once they deliver some of their fat load, they become LDLs ...

LDL – the 'bad' cholesterol

... LDLs carry the remaining cholesterol around the body. LDL has been dubbed the 'bad' cholesterol, and it is important to have low levels of LDL.

HDL – the 'good' cholesterol

HDLs, on the other hand, carry cholesterol back to the liver. HDL is known as the 'good' cholesterol, and you want to have high levels of HDL in your blood.

liver makes, and these eventually become LDLs. If at the same time you do not have many HDLs, you end up with too much cholesterol in your blood. Saturated fat is found mainly in animal foods. Plant foods – fruits, vegetables, grains and nuts – contain no cholesterol.

How do I keep my 'bad' cholesterol levels low?

- Aim for a healthy body weight. The more you weigh, the more your body stores fat and cholesterol.
- Be active: it raises HDL levels, helps you lose weight and lowers other risk factors for heart disease.
- Aim to accumulate at least 30 minutes of moderate physical activity on most days. Find an enjoyable activity you can stick to, and try to put a little more activity into each day.
- Change your diet. Healthy eating is essential to lower your blood cholesterol levels and improve your heart health.
- Cut down on saturated fat. Only 30% of your day's calories should come from fat. It is also important to know your fats and choose those that are less harmful.

The secret
to a longer life.



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07-04-ZCR-03-NZ-4151-0

APPENDIX A

This information is intended solely for New Zealand residents and is of a general nature only. No person should act in reliance on any statement contained in the information provided, but at all times should obtain specific advice from a health professional. All rights reserved. © Copyright 2004 CMPMedica (NZ) Ltd. No part of this publication may be reproduced without the written permission of the publisher, ph +64 9 488 4278.

Visit www.everybody.co.nz for information on health conditions, NZ health news and research, NZ support groups and more. For more information on this topic ask your G.P.



Saturated fats should be eaten sparingly. They are found mainly in animal foods such as meat, butter, cream, cheese, dripping and lard. Two vegetable oils, coconut and palm oil, are high in saturated fat and are often used in commercially baked biscuits and cakes. Saturated fats increase LDL cholesterol.

Polyunsaturated fats should be eaten in moderation. They occur in the oils of seeds and grains, such as sunflower, safflower and corn, and in soybeans and nuts. Polyunsaturated fats decrease LDL cholesterol but may also reduce the level of HDL cholesterol at very high levels. Omega-3 oils are a type of polyunsaturated fat found in oily fish, canola-based oils and margarine, flaxseed and walnut oils. These may help reduce blood clotting, blood pressure and blood cholesterol levels.

Monounsaturated fats should be eaten in moderation. They are widely found in both animal and plant foods. Olive and canola oils are rich sources, as are avocados and peanuts. They decrease LDL cholesterol and increase HDL cholesterol.

Fat is hidden in processed food – read the label!

CHANGES EVERYONE CAN MAKE TO EAT WELL

- Eat generous amounts of fruit and vegetables (aim for at least eight servings each day). They contain high levels of vitamins that may protect against a high blood cholesterol level.
- Choose plenty of wholegrain breads and cereals (at least six servings each day). They contain types of fibre that can help lower blood cholesterol levels.
- Include legumes (dried peas, beans, lentils) in meals.
- Choose lean meats (fat removed), poultry without skin, fish, and low fat milk, yoghurt and cheese.
- Prepare meals with as little added fat as possible. Grill,

boil, steam, bake or microwave rather than fry.

- Use polyunsaturated or monounsaturated margarine or oil sparingly for thin spreading and cooking.
- If eating preprepared foods, snacks and meals choose those low in fat (especially saturated fat) and salt.
- Limit salt and alcohol intake.

For those with high blood cholesterol

- Leave out full fat dairy food, meat fat or hardened vegetable fats in cooking or spreads and avoid commercially prepared foods with such ingredients.
- Limit red meat to about 150g a day.
- Eat fish at least twice weekly. Choose fish and shellfish with a high oil content such as tuna, kahawai, trevally, salmon, dory and sardines.
- Avoid preprepared foods, snacks and meals unless the fat and salt content are known.

If changing your diet and increasing your activity do not improve your high cholesterol levels, your doctor may advise you to take a cholesterol-lowering drug, depending on your other heart risk factors.

MEASURING BLOOD CHOLESTEROL

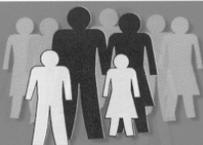
Your blood cholesterol level can be measured from a blood sample, which can be arranged by your doctor. You may need to fast before giving the sample. A total cholesterol level of less than 5 mmol/L is good, between 5 and 6.5 mmol/L is borderline and over 6.5 mmol/L is high.

These results are not interpreted on their own – any other heart risk factors will be assessed by your doctor as well.

FURTHER INFORMATION AND SUPPORT

Heart Foundation
PO Box 17-160, Greenlane, Auckland
ph (09) 571 9191; fax (09) 571 9190
email info@nhf.org.nz; web www.heartfoundation.org.nz
Original material provided by the Heart Foundation.

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07-04-ZCR-03-NZ-4151-O

APPENDIX B

21.5.04, 1435 hrs. Interview with Thomas C. This took place at LLH Hospital in the office that I had for the day. T.C was given the option of having the interview at his house but he chose this option, saying his place would be too noisy with dogs etc. around the place. There was a fair amount of road noise, aircraft noise – flying overhead, cell phones were switched off but the office phone unexpectedly rang a couple of times after being quiet all day. That was disconnected. Had to interrupt the interview another time to shut a window because of a motor noisily starting up outside. It didn't seem to put T.C. off his stride but it would have been nice to have had a clear run nonetheless. T.C. seemed relaxed and says he is used to being 'studied' and being mentioned in the studies where he was involved and so didn't feel he needed a pseudonym. I wasn't comfortable about using his real name because of ethical issues and mentioned it. Managed to convince him to choose a pseudonym in the end. He also declined a copy of his transcript, as did all the others. The interview was short, T.C. was very succinct and said a lot in the short time. Asked some theoretical questions as will be evident in the interview transcript and EUREKA! I think he has confirmed the central process from completely the opposite direction. He takes the cholesterol situation very seriously and denies himself treats etc. and does so in order to improve his health status so that he can be around for a while yet to enjoy quality time with his wife whom he calls his soul mate and loves. So, Enjoying life and having quality of life feature again. Speaking of quality of life, I suppose when PC doesn't want to deny PJ his cheese etc which he enjoys so much, and says what sort of a life is that if he can't have some of these treats, she is trying to maintain quality of life for him. Having quality of life has different facets: good health to enjoy good quality of life and be around for a while longer, still be able to enjoy some of the foods that are treats rather than life becoming a drag because of denying oneself altogether, not having to force oneself to exercise in ways that are totally unpalatable and a nuisance and to find enjoyable ways of exercising instead.....

APPENDIX C



Lakeland Health *Mai i Maketu ki Tongariro*

Te Whakaruruhau

21 March 2003

Val Raethel
PO Box 108
Kawerau

Dear Val

Firstly I wish to acknowledge your efforts to date with your Masters programme and also to wish you well with your thesis. I am very encouraged that you may have the opportunity to include Maori participants in your research, as I believe that the greater understanding we have of the impact of disease on Maori, this places us in a better position to target strategies that contribute to reducing the disparity in health status between Maori and non-Maori, for the benefit of all New Zealand/Aotearoa society.

In my role as Hunga Whakarite with Te Whakaruruhau Maori Health, Lakes DHB, I am very happy to provide what support, advice and assistance I can in order for you to include Maori participants in your study. My understanding is that this may include:

- Ongoing consultation and guidance from me regarding protocols for the involvement and interview of Maori participants and assistance with requirements such as Karakia.
- Assistance in negotiating with the whanau, hapu or iwi of Maori participants, if required, and guidance as to if and when this may be required.
- Facilitation of interviews if requested by the participant or whanau, including follow-up interviews as required.
- Guidance and assistance as to the appropriate method of dissemination of information to Maori participants and their communities at the end of the study.
- Assistance with explaining and gaining consent from participants for the publication of the study as well as publication of articles from the study.
- Information and guidance should unforeseen issues arise

Once again I congratulate you on your efforts and look forward to supporting you where I can in carrying out your research project.

Naku noa,

Rotorua Hospital
Corner Arawa and Ranolf Streets (Pukeroa Street)
Private Bag 3023, Rotorua, New Zealand. Telephone 07-348 1100 Facsimile 07-349 7907

APPENDIX C

Na,

VIX

Vicki Greeks
HUNGA WHAKARITE

APPENDIX D

Bay of Plenty Ethics Committee

The Strand
P.O. Box 134
Whakatane
Phone (07) 308 5030
Fax (07) 308 5033
Email: adcam@ihug.co.nz

27 June, 2003

Valerie Raethel
PO Box 108
KAWERAU

RE: A grounded theory study exploring the process of living with high cholesterol levels. **BOP/03/03/018**

Investigator: Valerie Raethel
Location: BOP Site Specific

Thank you for forwarding the amended Patient Information Sheet and Consent Forms by email. The committee is satisfied that all its concerns have been met, and advise that the Bay of Plenty Ethics Committee has given the above study final approval under delegated authority of the Chair.

Approved Documents

Information Sheet and consent form *Version 3 dated September 2000.*
for Valerie Raethel. Rotorua

Certification

The committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation

This Committee by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports

The study is approved until 11th July 2004). The Committee will review the approved application annually. A progress report is required for this study on 13 May 2004). You will be sent a form requesting this information. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Requirements for SAE Reporting.

Please advise the Committee as soon as possible of the following:

- any study in another country that has stopped due to serious or unexpected adverse events
- withdrawal of Investigational product from continued development
- withdrawal from the market for any reason
- all serious adverse events which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.

APPENDIX D

Amendments:

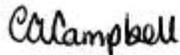
All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementations is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

General

It should be noted that: Ethics Committee approval does not imply any resource commitment of administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please quote the above ethics committee reference number in all correspondence.

Yours sincerely,



Carol Campbell
Committee Administrator

APPENDIX E



Lakeland Health

3 September 2003

Val Raethel
PO Box 108
KAWERAU

Dear Val,

APPLICATION FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

Thank you for providing the necessary documentation in order to consider your application to undertake a study exploring the process of living with high cholesterol levels.

As all processes have been followed in respect to the requirements with the various parties concerned, Lakeland Health is satisfied that you can now proceed with your research study.

I wish you all the best for your study.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Cathy Taylor'. The signature is fluid and cursive, with a prominent loop at the end.

Cathy Taylor
Director of Nursing & Midwifery

The logo for the Lakes District Health Board features a stylized mountain range with a sun or moon rising behind it. Below the graphic, the text reads 'LAKES DISTRICT HEALTH BOARD'.

Lakeland Health is the provider division
of the Lakes District Health Board
Healthy Communities - Mauriora!

Rotorua Hospital
Corner Arawa & Ranolf Streets (Pukeroa Street)
Private Bag 3023, Rotorua, New Zealand
Telephone 07-348 1199, Facsimile 07-349 7897

APPENDIX F

NOTICE OF INVITATION TO PARTICIPATE IN A RESEARCH STUDY: LIVING WITH HIGH CHOLESTEROL.

Individuals living in the Bay of Plenty region with a history of high cholesterol and who speak fluent English, are invited to take part in this study conducted by Valerie Raethel, Master of Health Science student, Auckland University of Technology.

Details of the study are given in the participant information sheet enclosed in the envelope provided. Also attached, is a stamped self-addressed envelope with a response leaflet.

I look forward to your response.

Thank you.

Valerie Raethel.

Participant Information Sheet

Project title

Living with high cholesterol levels.

Invitation

You are invited to take part in a study conducted about how you live with a high cholesterol level.

What is the purpose of the study?

The purpose of this study is to hear your story about how you live with high cholesterol. Hearing your side of the story will help me understand the real issues that you face in living with this condition. I am doing this study as part of completing a Master of Health Science.

How are people chosen to be asked to be part of the study?

Anyone who speaks fluent English, has a history of high blood cholesterol levels (total cholesterol greater than 5mmol/l) and lives in the Bay of Plenty region is eligible to take part in this study. Participation is totally voluntary.

Can I join the study?

If you meet the criteria mentioned above, you are most welcome to join the study. You can contact me by phone on 0800 362 222 or by mail: P.O. Box 108, Kawerau. A stamped, self-addressed envelope is provided.

What happens in the study?

I will interview you. I will ask you about your experience of living with high cholesterol. The interview will be taped recorded and later transcribed by me. The length of the interview is expected to take 60 to 90 minutes. It is dependent on how much information you wish to share. It should take no longer than 90 minutes. The interview needs to take place at a venue which is quiet (because of the tape recording), and where we will not be interrupted or disturbed in any way. One option is a room booked at Lakeland Health Hospital but it can also take place at another venue, which is mutually agreeable to us both.

You do not have to answer all the questions and you may stop the interview at any time. For the sake of your privacy, you will be invited to choose a different name (pseudonym) to keep your identity confidential. A copy of the audio-taped interview will be available for you to keep. All the information derived from this study will be held by the Auckland University of Technology under locked storage for ten years and then destroyed. It is hoped that the results of the study will also

be published in journals and presented at conferences. If you like, I would be most happy to present the results to you as well.

I may need to interview you a second time or, if you agree, a phone call might be sufficient to get any extra information I may require. Because of the qualitative nature of this study, some of your data might be quoted anonymously, using your pseudonym. In this way, you will not be identified in any way. I can provide you with examples of this, from published studies, before you give your consent to participate. Your interview might also be used in future studies.

What are the benefits?

Your contribution to the findings of this study might not benefit you directly but will help health professionals in the future to plan more effective strategies for delivery of services to health consumers.

What are the discomforts and risks?

I will be asking you to tell me your story about living with high cholesterol levels. If you decide later that there is information you would like to withdraw, you have the freedom to do so prior to completion of data collection. Similarly, you have the freedom to withdraw from the study prior to completion of data collection. Should you decide to do this, any material pertaining to you will be destroyed immediately.

What compensation is available for injury or negligence?

One session of counselling will be made available, at no cost to you, should you require it as a result of taking part in this study. The counsellor will have been selected prior to the commencement of the study.

Should you have any questions about ACC, contact your nearest ACC office (freephone 0800 735 566) the ACC website:

(www.acc.co.nz/claimscare/making-a-claim/medical-misadventure/index.html), or the investigator.

How is my privacy protected?

You will be invited to provide a pseudonym so that any statements or information published will have no connection with you. Your participation in the study will be kept strictly confidential and all material will be locked away.

Costs of participating

There is no payment for participating in this study.

Opportunity to consider invitation

With participation in this study being totally voluntary, it is up to you to decide whether or not you want to take part. You are welcome to take up to a week to decide whether or not you would like to participate, once I've contacted you.

Participant Concerns -

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Grace Wong, Senior Lecturer, School of

Nursing, Division of Health Care Practice, Faculty of Health, Auckland University of Technology, Private Bag 92006, Auckland. Phone: 09-9179999 Ext 7501. Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, madeline.banda@aut.ac.nz, 917 9999 ext 8044.

If you have any queries or concerns regarding your rights as a participant in this study, you may contact a Health and Disability Advocate (telephone 0800 555 050).

The advocacy number for the central North Island is 0800 423 638.

For the Rotorua region, an alternative contact is Advocacy Network Services: Ph. 07-3490182.

APPENDIX H

Letter to intermediary, Rosemary Feary, Cardiac Nurse Educator, Lakeland Health Hospital, Rotorua, for approach to prospective participants for the study.

Dear Rosemary,

Thank you for agreeing to act as my intermediary for my thesis project titled: A grounded theory study exploring the process of living with high cholesterol levels.

The inclusion criteria for the study is: 1. A history of high cholesterol level,

(total cholesterol > 5mmol/l).

2. The participant resides in the Bay of Plenty region.

3. Speaks fluent English.

Participation in this study is totally voluntary.

Being a qualitative study, I will be interviewing participants, with each interview being of up to 90 minutes' duration. A second interview or follow-up phone call might also be necessary. Further details are in the participant information sheet.

Please find enclosed (in the large envelope), packs for prospective participants. In each pack is a participant information sheet (I have enclosed a spare copy for you), an expression of interest form and a stamped, self-addressed envelope for replies. Please read the participant information sheet before you approach prospective participants.

I would prefer, if possible, to meet with you before recruiting participants, to discuss the study and clarify questions.

If you have any queries you can ring me on 07-3627742.

Note: my contact phone number to participants, for the study, is 0800 362 222.

Thank you again for your support.

Regards,

Val Raethel.

APPENDIX I

Memo – 16.6.04

Accepting identified as a category on 13.6.04. Or maybe a property? No category. CC, TC, AJ, talk about acceptance, PC, PJ, MA indicate acceptance too because if they didn't accept they would not be doing the things they're doing to deal with it. Accepting runs throughout.

Codes clustered in 13.6.04 diagram. Also include – being fatalistic, being surprised – part of accepting? Participants are not fighting it (high chol) when fatalistic – accept it as is. This cluster initially under umbrella of Discovering.

More codes under this umbrella: being dealt the cards, realising mortality – part of discovering or accepting? Certainly could contribute to accepting. So should the umbrella be accepting or discovering? Is it a category or property? Does it stand on its own? It could do but then it could also contribute towards something else....Learning to live perhaps?

21.8.04 – 1452 hrs.

? subsume “accepting” under “learning to live?” therefore have Learning to Live, Getting on With It and Maintaining Quality of Life as the process? Any of those could be the core category. Lots of playing to be done.

22.8.04 – 0010hrs.

Not sure about Accepting, whether it fits at all. Should this category be Discovering or Knowing instead? This leaves a gap however between this and Learning to live, whereas Accepting flows well. Maybe it is OK and leave it alone?

Accepting is more all-encompassing. When you accept you have gone through the discovering process and knowing. When you're discovering you may not necessarily have accepted yet. Same for knowing.

Will stick with Accepting for now.

Memo: 5.9.04 1625 hrs:

Accepting – AJ (320-327) – accepting mortality as a ramification of high chol. Accepting therefore not just the discovery of high chol. Accepting therefore not just the discovery of high chol but an ongoing thing, a continuum of life, living, things will change, accept it.

1851 hrs: I've found it! TC has given me the other condition for Accepting. It's in 815-824 – “facing up to the fact” or “just facing up”. Part of my writing up has turned out to be a memoing process as well!

Facing up to the fact is part of the process of “discovering” that facilitates Accepting, which TC confirms in his quote (941-961). “Discovering” helps to explain part of the process of accepting and so facilitates accepting qualifying as a category.

APPENDIX J

CONCEPTS / CATEGORIES SO FAR

1. DISCOVERING ©
2. CHANGING ©
3. BECOMING MORE AWARE
4. CHANGING PRIORITIES (PREFERENCES)
5. KEEPING OUT OF IT
6. FINDING IT DIFFICULT
7. NOT PERCEIVING CHOL AS A PROBLEM
8. ACCOMMODATING OTHERS
9. HAVING CHILDHOOD DIETARY PATTERNS
10. LEARNING TO EAT EVERYTHING THAT WAS PUT IN FRONT OF YOU
11. NOT ACHIEVING ENOUGH RESULT
12. DOING YOUR BEST / DOING WHAT'S BEST
13. PAYING ATTENTION TO WHAT IS EVIDENT (VISIBLE / INVISIBLE CONDITION)
14. STARTING A NEW LIFE (PHASE)
15. MAKING A FRESH START ©
16. BEING A GOOD ROLE MODEL
17. RULE IT DON'T LET IT RULE YOU / HAVING CONTROL
18. QUE SERA (BEING FATALISTIC)
19. WANTING / NOT WANTING TO KNOW
20. DOING SOMETHING
21. FORMULATING STRATEGY (C)
22. BEING / NOT BEING MOTIVATED
23. BEING OBSERVED / HAVING SOMEONE KEEP AN EYE
24. BEING UNAFRAID OF DEATH
25. REALISING MORTALITY
26. NEGOTIATING FAT LEVELS ©
27. LEARNING TO LIVE WITH IT ©
28. FORMULATING A STRATEGY ©

29. ENJOYING LIFE
30. MAKING LIFE WORTH LIVING / HAVING QUALITY OF LIFE ©
31. MAKING COMPARISONS
32. HAVING AN OBLIGATION / FEELING HONOUR BOUND (T.C. says no)
33. ATTRIBUTING CAUSE
34. PLAYING GAMES (one participant only)
35. SELF MONITORING / KEEPING AN EYE ON IT
36. HAVING SELF PERCEPTION OF BEING FIT AND HEALTHY
37. NOT WANTING TO BE ON MEDICATION
38. HAVING CHOICES
39. MINIMISING STRESS
40. GETTING ON WITH IT ©
41. BEING TIRED OF MUST DOs
42. CROSSING THE BRIDGE WHEN THE TIME COMES
43. BEING CONCERNED ABOUT LONG TERM RISK
44. NOT WORRYING
45. TAKING ACTION ©
46. ACCEPTING.
47. LEARNING TO EAT EVERYTHING THAT WAS PUT IN FRONT OF YOU.
48. BEING A GOOD EXAMPLE.
49. MAKING ASSUMPTIONS
50. REALISING MORTALITY
51. ACQUIRING KNOWLEDGE.
52. FACING UP TO IT.
53. HAVING RESTRICTIONS.
54. HAVING UNCERTAINTIES.

Table 1 - WHOQOL-BREF domains

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Development of the WHOQOL-BREF

The WHOQOL-100 allows detailed assessment of each individual facet relating to quality of life. In certain instances however, the WHOQOL-100 may be too lengthy for practical use. The WHOQOL-BREF Field Trial Version has therefore been developed to provide a short form quality of life assessment that looks at Domain level profiles, using data from the pilot WHOQOL assessment and all available data from the Field Trial Version of the WHOQOL-100. Twenty field centres situated within eighteen countries have included data for these purposes (see Table 2). The WHOQOL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included.

APPENDIX L

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

APPENDIX L

WHOQOL-BREF
Page 4

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....
.....

THANK YOU FOR YOUR HELP

APPENDIX M

TABLE 5.1 ABBREVIATED CONTENT FOR ITEMS IN EACH SF-36 SCALE

Scale	Item ^a	Abbreviated Item Content
Physical Functioning (PF)	3a	Vigorous activities, such as running, lifting heavy objects, strenuous sports
	3b	Moderate activities, such as moving a table, vacuuming, bowling
	3c	Lifting or carrying groceries
	3d	Climbing several flights of stairs
	3e	Climbing one flight of stairs
	3f	Bending, kneeling, or stooping
	3g	Walking more than a mile
	3h	Walking several blocks
	3i	Walking one block
	3j	Bathing or dressing
	Role-Physical (RP)	4a
4b		Cut down the amount of time spent on work or other activities
4c		Accomplished less than would like
4d		Difficulty performing the work or other activities
Bodily Pain (BP)	7	Intensity of bodily pain
	8	Extent pain interfered with normal work
General Health (GH)	1	Is your health: excellent, very good, good, fair, poor
	11a	My health is excellent
	11b	I am as healthy as anybody I know
	11c	I seem to get sick a little easier than other people
	11d	I expect my health to get worse
Vitality (VT)	9a	Feel full of pep
	9e	Have a lot of energy
	9g	Feel worn out
	9i	Feel tired
Social Functioning (SF)	6	Extent health problems interfered with normal social activities
	10	Frequency health problems interfered with social activities
Role-Emotional (RE)	5a	Cut down the amount of time spent on work or other activities
	5b	Accomplished less than would like
	5c	Didn't do work or other activities as carefully as usual
Mental Health (MH)	9b	Been a very nervous person
	9c	Felt so down in the dumps nothing could cheer you up
	9d	Felt calm and peaceful
	9f	Felt downhearted and blue
	9h	Been a happy person
Reported Health Transition (HT)	2	Rating of health now compared to one year ago

^a Item numbers correspond to Standard form in Appendix B.