The meaning of health and the experience of coronary heart disease in Italian-speaking cardiac patients: Implications for cardiac rehabilitation programs

BY

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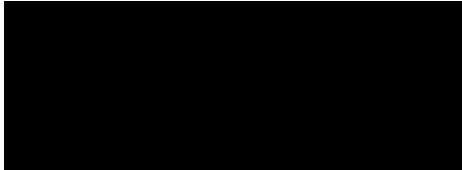
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DECLARATION

I certify that this thesis contains no material which has been accepted for the award of

any other higher degree or graduate diploma in any university, and that to the best of

my knowledge, this thesis contains no material previously published, except where

reference is made.

Signed

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TABLE OF CONTENTS

List of Appendices

List of Figures

List of Tables

ABSTRACT

The study of the lay meanings of health has shown that good health can have a variety of meanings and that these meanings can influence health behaviour. Health and illness are subjective experiences which are determined by the interrelations of individual, social and cultural factors. The influence of these factors on the experience of CHD have implications for secondary prevention programs such as cardiac rehabilitation and the capacity of these programs to address the increasing importance of psychosocial factors in CHD. The Common Sense Model (CSM) of health and illness, proposed by Howard Leventhal and colleagues, provides a dynamic model for the understanding of health and illness behaviours which can contribute to a better understanding of these social and cultural factors. Perceptions of health and illness are especially important when considering the health behaviours of culturally-diverse groups, such as Italian-speaking cardiac patients. This thesis explores the lay meanings of health and the illness perceptions of Italian-speaking cardiac patients who have participated in a language-specific cardiac rehabilitation program. Semi-structured interviews with Italian cardiac patients and health professionals were conducted. Findings established *a priori* and *a posteriori* themes and the themes served to demonstrate how the response to cardiac illness was influenced by the personal experiences and broader psychosocial contexts of the participants. Implications for traditional cardiac rehabilitation programs include the potential benefits of addressing the psychosocial needs of culturally-diverse cardiac patients, which can accommodate the subjective meanings that they make of their illness experience and of their broader health and social needs.

Chapter 1

Introduction

The study of health and illness has been explored using a number of approaches. The contributions of the biopsychosocial approach and behavioural medicine to the understanding of health and illness have been limited by the adoption of methodologies which have remained essentially reductionist and created static constructs (Levin, 1999) with little relevance to the experience of illness. This dissatisfaction with behavioural medicine and the need to understand the lived experience of illness has led to increased interest in the subjective experiences of cardiac patients and the influence of this experience on recovery. Hughner and Kleine's (2004) review of studies about the lay meaning of health has shown that health can mean many things other than the absence of disease, as traditionally understood by the biomedical approach.

Psychosocial factors have been increasingly studied for their role in the aetiology of coronary heart disease (CHD) and in their implications for recovery (Krantz & McCeney, 2002). Literature reviews of the many potential psychosocial risk factors have confirmed the important part played by social support and depression in the onset of and the recovery from CHD (Bunker et al., 2003).

Cardiac rehabilitation has been recommended for all patients with cardiovascular disease, including those from culturally-diverse backgrounds (Goble & Worcester, 1999). Language-specific cardiac rehabilitation programs developed in Australia for immigrant groups have become based on the encouragement of strategies for the reduction of traditional risk factors. Immigrant communities represent groups where differences between the

assumptions of mainstream health services such as cardiac rehabilitation programs and culturally-derived perceptions and beliefs may be vast (Lee, 1990). These culturally-diverse groups also represent patients who are likely to experience psychosocial barriers to cardiac rehabilitation.

Poor attendance rates and questions about the role and function of cardiac rehabilitation programs where minority and marginalized populations are concerned, have led to an increasing call for greater individual attention in programs for the secondary prevention of CHD (Murray, Manktelow, & Clifford, 2000). These groups include the elderly, those from social and economically disadvantaged areas and immigrants to Australia from culturally-diverse backgrounds (Cooper, Jackson, Weinman, & Horne, 2002). While being at greater risk of poor health (Wilkinson, 1996), they are also the same groups who are less likely to attend cardiac rehabilitation.

Scope of the present study

This present study aimed to explore the health and illness experiences of a group of Italian-speaking cardiac patients referred to a language-specific cardiac rehabilitation program in Melbourne, Australia. The study also aimed to explore the contribution of attending a cardiac rehabilitation program to recovery in this special group and the views of health professionals associated with the provision of the program. The Italian Healthy Hearts Program (IHHP) was developed following the guidelines for the provision of cardiac rehabilitation programs (National Heart Foundation and Australian Cardiac Rehabilitation Association, 2004), but is presented in the Italian language.

The scope of the present study was to determine the health and illness experiences of this group and to explore the influence of individual perceptions of

illness on recovery from CHD, including the impact of the cardiac rehabilitation program. The Common Sense Model of health and illness (Leventhal, Brissette, & Leventhal, 2003) provided a dynamic theoretical model for the cognitive representations of illness which can impact upon health and rehabilitative behaviours.

The research questions of the present study are formulated with a view to the potential development of specialised programs, such as language-specific cardiac rehabilitation, and their ability to meet the needs of special groups in the community.

Structure of the thesis

An outline of the structure of the present thesis is provided in this section. Chapter 2 provides an outline of approaches to the study of health and illness. It also discusses some of the limitations of the biomedical and biopsychosocial approaches to the study of the subjective experience of illness. The importance of social and cultural factors in the experience of health and illness is also discussed. Chapter 3 provides a brief description of the nature and extent of CHD in Australia, including a brief description of the various surgical interventions aimed at curbing the disease progression. The chapter also provides a summary of the empirical literature investigating cardiac rehabilitation programs and highlights the problems faced by such programs.

Chapter 4 presents the literature on the importance of psychosocial risk factors in the onset and recovery from CHD, including the important part played by socially determined aspects of illness. The conceptual model proposed by Berkman and Glass (2002) is used to explain how social factors play a part in the development of poor health and the mediating function of psychosocial

influences. The model allows for an integrated approach to the study of poor health. This includes the social, economic and cultural forces acting on an individual, and the important part played by social networks in recovery. The relevance of psychosocial factors for the health of immigrant populations is also discussed, in light of the concept of relative deprivation (Wilkinson, 1996).

Chapter 5 introduces the Common Sense Model of the self-regulation of health and illness (Leventhal, et al., 2003) and its suitability for the study of the illness experience in culturally-diverse groups. The dynamic process of coping with health threats is described, and the components of the cognitive representations associated with the coping process is outlined. Studies of the illness perceptions of cardiac patients are reviewed and particular attention is paid to the influence of illness perceptions on attendance at cardiac rehabilitation and health directed behaviours. Chapter 6 provides a rationale for the research questions in the present study.

Chapter 7 describes the methodology and research design within the broader context of the need to understand the subjective experiences of health and illness and the suitability of the case study method. It also provides a description of the IHHP, from which the participants were recruited.

The findings from the present research are divided into three chapters. Chapter 8 presents the findings from the thematic analysis of the interview data from the IHHP participants. Both *a priori* and *a posteriori* themes are presented in this chapter. Chapter 9 presents three individual case studies, analysed using the development of a case description and chosen on the basis of adjustment to CHD. Chapter 10 presents the findings from the thematic analysis of the interview data obtained from the IHHP health professionals.

Finally, Chapter 11 presents the discussion of the research, drawing upon the findings of the all three data sources and reviewing the findings with previous research. The chapter also discusses implications for the development of cardiac rehabilitation programs and study limitations.

Chapter 2

The meaning of health and the importance of cultural factors

Health, illness and the biomedical model

The concepts of health and illness have been of interest to researchers from various disciplines for hundreds of years. Since early in the nineteenth century, the study of health and illness has traditionally been approached from the biomedical model. This model, which arose from the foundations laid by Cartesian dualism, that is, the acceptance of the separateness of the mind from the body, resulted in the major advances of medicine which characterised the nineteenth and twentieth century (Samson, 1999). The biomedical model regards disease as an affliction of the body caused by disturbances in the physical processes contained within the body.

According to Blaxter (2004), the biomedical model of health is characterised by four principles. First, disease is caused by a specific aetiology that can be identified and verified. Second, diseases each have their own distinguishing features that are universal in humans. Third, the biomedical model defines ill health as being a deviation from what is normal. Health is the opposite of illness. Fourth, the biomedical model was said to be based on principles of objective neutrality on the part of the observer. Blaxter argued that while modern biomedicine is no longer based entirely on an acceptance of these four postulates, residues of them remain in the practice of modern medicine. The shift towards a broader understanding of the causes of disease, including the role of psychological and social factors, has influenced the traditional biomedical approach.

The shift away from the biomedical model

The twentieth century saw increasing interest in other perspectives on health and disease. A social model of health and illness emerged from dissatisfactions with the biomedical model and its preoccupation with physical disease. The social model attempted to understand health and illness more broadly and located biological processes within the social context that they exist in. Blaxter (2004) stated that the social model was more organic and holistic compared with the mechanistic and reductionist approach of the biomedical model. According to this new model, being healthy cannot simply be described by an assessment of risk factors because the health of the individual consists of more than just interacting biological components. A social model of health reflects health as a "positive state of wholeness and well-being associated with, but not entirely explained by, the absence of disease, illness or mental impairment" (Blaxter, 2004, p.19). The widening of the meaning of health and the growing acceptance of the role of social and ecological factors during the twentieth century culminated in the definition of health provided by the World Health Organisation in 1948 as "a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity" (Blaxter, 1990, p. 3).

The twentieth century has also seen a shift in focus from acute illness to chronic illness in medicine. This shift has been associated with the increasing importance of the role that psychological factors play in health and illness. This shift contributed to the development of behavioural medicine, which Moos (1984) claimed was a "valuable step beyond the biomedical model" (p. 433). This development was stimulated by the rising importance placed on what have

become known as "lifestyle diseases" such as coronary heart disease and cancer. The behavioural perspective has arisen from the application of behavioural science to the biomedical problems of disease prevention and treatment. This shift towards the inclusion of social and psychological aspects of health has been aptly noted by Karoly (1985) when he quoted the words of an eminent cardiologist who described this shift as the confrontation with "diseases of choice rather than chance" (Karoly, 1985, p. 4). Karoly goes on to further describe the changing perspective:

> *it is now taken as axiomatic by most medical and non-medical health authorities that illness and disease in modern industrialised societies are not rigidly bounded biological events resulting solely from the action of specific micro-organisms and requiring specific biomedical treatments (p. 4).*

Karoly (1985, p. 4) claimed that the acceptance of health defined as the "confluence of propitious physical, social, psychological and ecological factors" has meant the development of other platforms for inquiry. This acceptance placed a greater emphasis on the active role of the individual in the cause, management and prevention of illness (Moos, 1984). A trend towards a systems approach to health and illness, which could incorporate the psychological and biological, along with the social environment, produced the integration of the multi-faceted definition of health into a conceptual framework (Moos, 1984). This conceptual framework became known in behavioural medicine as the biopsychosocial model of health and illness.

The biopsychosocial model of health and illness

The biopsychosocial model was first proposed by Engel as a critique of the dualism normally accepted in biomedicine (Engel, 1992). Engel suggested that disease might also be influenced by social and psychological factors, as well as biological ones, and that the human body was an example of a continuous and dynamic system, which is itself interrelated with other systems around it. Engel argued that the biomedical model was limited when clinical medicine needed to be considered and that the application of the biomedical model was unscientific when it was used beyond its limits in these circumstances. The biopsychosocial model, which is fundamentally based upon systems theories (Moos, 1984) offers an alternative paradigm for the study of medicine because it can encompass what Engel calls "the human domain" (Engel, 1992, p.343).

The biopsychosocial model allowed the examination of the psychosocial aspects of illness to be investigated and it offers a valuable context for experimental research on the social and psychological links to health and illness. Turp (2001) claimed that subjective elements in research were previously thought of only as contaminants by behavioural psychology. According to Turp, the biopsychosocial model, identified important psychological and social variables as variables that can be measured and controlled in the attempt to study the individual contributions of these elements to disease and illness. Turp emphasised the potential of this approach in being able to study the idiosyncratic experience of the person and the "entanglement of physical and mental aspects of the human subject" (Turp, 2001, p. 53).

Limitations of the biopsychosocial model

Some researchers have argued that the biopsychosocial model of health, as applied in behavioural medicine, has important methodological constraints which limit its suitability for the study of illness. Radley (1994) has argued that the interpretation of the biopsychosocial model in quantitative research designs by behavioural medicine, is only an extension of the biomedical model, with the same limitations and underlying assumptions. Radley believed that the extension of the medical model into the social and psychological domains came at a price. The biopsychosocial model, while allowing the theoretical understanding of the links between mind, body and society, has, in a practical sense, required the reduction of complex variables, and their relationships to each other, to be removed from the investigation. This is done to ensure that they can be identified and measured to resemble data normally obtained from medical and physiological designs. This invariably required quantification which permitted complex statistical operations to be performed. According to Radley, this reduction of complex variables to data able to be manipulated has added little to a better understanding of the subjective experience of health and illness.

Levin (1999) claimed that behavioural medicine was constrained by this positivistic bias and that it has remained conceptually unable to explore the domain of subjective experience. He stated that this positivistic bias in behavioural medicine had led to the construction of "static" constructs which attempted to account for personal experience (p. 116). These constructs are quantified and tallied, but the subjective meanings attributed to these constructs are not explored. This leaves a gap between the observed existence of static constructs and the dynamic subjective meanings attributed to these constructs.

Levin highlighted the importance of learning about the directly felt experience of illness especially if this knowledge about illness is to be applied to therapeutic and rehabilitation settings.

The subjective nature of illness, compared with disease, is emphasised by Radley (1994). The word "disease" is defined by Radley to be the pathological processes that occur in the body that can be diagnosed, and sometimes, treated by physicians. Disease is reflected by the visible physiological processes, such as tumours or tissue degeneration and is usually the concern of biomedicine. Illness, on the other hand, is defined by Radley as the subjective experience of disease. Illness includes the responses of the person to disease, his or her thoughts and feelings about how the changes in the body affect them. The extent of illness, or whether a person regards themselves as ill at all, is subjectively determined. Illness concerns the manner in which a person bears the consequences of the ailment concerned.

Radley (1994) noted that the biopsychosocial model, like the biomedical approach to health and illness, accepted that health and illness existed as opposites on a continuum, rather than representing different constructs. According to Radley, being "healthy" implied a general state of being that is taken for granted in the absence of symptoms and is open to a much broader interpretation than illness. Radley demonstrated this using an example of the linguistic usage of both being healthy and being ill. When the question "how healthy are you" is considered, answers can reflect many forms of interpretation of the question and being healthy can acquire many meanings. The same question posed of illness produces a different result, the question "how ill are you" assumes the presence of illness and then inquires about the degree. It is only when health is compromised

by disease and symptoms appear that the concept of health becomes more precisely illuminated, as Radley stated, by the "shadow that this figure of illness casts upon the backcloth of health" (1994, p.5).

Despite this difference in meanings, Radley (1994) noted that in the biopsychosocial model, illness had become conceptualised as being synonymous with the presence of disease and health had retained its meaning as that condition which is disrupted by illness. This confused dichotomy between health and illness had led to an increasing effort towards the study of health care behaviours at the risk of an over reliance in the promotion of individual lifestyle modification as the way to remain healthy by avoiding disease. The simple inversion of research findings based upon the confused dichotomy of health and illness does not necessarily produce complementary results concerning health. The biopsychosocial approach has therefore become characterised by conceptual efforts, which include the biological and the psychological contributions to disease. The model pays little attention to the subjective illness experience and the widespread influence of social factors on health.

Backett and Davison (1995) argued that all health-related behaviour was a product of the complex combination of biographical, social and cultural forces. Drawing on two qualitative studies in the United Kingdom, they reported that individuals accounted for their responses to illness by referring to social circumstances and obligations, as determined by their stage in the life. The uniqueness of this interplay for each person was emphasised by them, as was the importance of working with, rather than against, the cultural norms. This provided for a better understanding of what health care behaviours may be relevant for recovery. Backett and Davison (1995) stated:

it is axiomatic to the social sciences that health and illness are not simply matters concerning human bodies and their function. Rather these states and the transition between them represent a complex interplay of physiological conditions, the cultural structures which give them meaning and the social organizations and interactions within which they are situated. (p.629)

The subjective meanings of health, and the experience of illness, are therefore concepts to be studied in their own right. Health cannot be regarded as purely an observable physical property of the human body. Health is also located within the social and cultural experiences of individuals. Cultural understandings of health and illness are important because it has been generally accepted that cultural factors play a large part in determining health and adjustment to illness when it occurs.

The influence of culture on health and illness

Lupton (2003) has argued that the ongoing growth and sophistication of the biomedical approach to understanding health and illness has led to the diminished value that has been placed upon personal accounts of health and illness. Alternative approaches brought by disciplines such as medical sociology and medical anthropology have long argued the centrality of lay beliefs and cultural practices in attempts to understand what concepts such as health and illness mean as well as how people respond to illness (Helman, 2000).

Culture has been defined by Lee (1990) as the way of life of a community or group of people, a learned set of practical activities, beliefs and values which together make up the lifestyle followed by this particular social group. Culture provides the guidelines which inform people how to view the world around them and how to relate to others within it. These guidelines tend to be transmitted to

successive generations and subsequently adopted by them. Helman (2000) described culture as the "inherited lens through which the individual perceives and understands the world that he inhabits and learns to live within it" (p. 2).

Biopsychosocial research on mortality and morbidity has been conducted with numerous ethnic minority groups (Myers, Kagawa-Singer, Kumanyika, Lex, & Markides, 1995; Johnston et al., 1995). These studies concluded that differences in morbidity and mortality were partly attributable to differences in the behavioural risk profiles of different cultural groups. Cultural affiliations have also been found to have an important influence on the perception of and response to pain (Bates, Edwards, & Anderson, 1993) as well as the interpretation of symptoms (Zola, 1973).

According to Fine (1990), culture directly and indirectly affects the development of disease and illness in four ways. First, health can be directly affected by specific cultural attitudes or behaviours which impact on health status. Second, cultural practices and beliefs determine the identification and reporting of symptoms which can lead to diagnosis of a condition. Third, illness behaviour is influenced by cultural factors, such as the shared beliefs about what constitutes health and how illness can be treated. Finally, treatment regimes and secondary prevention programs are determined by the cultural practices of the health care system and its health providers. Culture can, therefore, be conceptualised as playing an important part across the health care system, from influencing the origins of pathological disease process to the provision of treatment regimes and individual recovery.

Schmeid (1990) noted the importance of the consideration of cultural beliefs and differences between the mainstream cultural practices of the health

system and people such as immigrants who make up the fabric of multicultural Australia. Schmeid was critical of the culture of the health care system and situated the problems of the system in the cultural beliefs of the system, which arise only from the dominant groups in society. For Schmeid, the failure of the Australian health care system was that it does not accommodate cultural difference and this will have implications that require consideration by health care workers at many levels. Lee (1990) stated that this problem is particularly relevant for immigrants to Australia because the difficulty of engaging immigrants in health services is essentially the mismatch of cultural beliefs and practices. This mismatch represents cultural differences in the meanings of health and the unascertained subjective experiences of illness and the suitability of secondary prevention programs.

Kleinman (1978) identified three contexts of knowledge about health and illness. Professional knowledge of health represents the orthodox knowledge usually produced and associated with scientific discourse and the biomedical model. Alternative knowledge of health includes traditional and folk understandings. Finally, lay knowledge is that knowledge which is informal, popular and usually derived from experience. Research in the lay experience of health and illness has provided a rich source of empirical data concerning the personal meanings of health and illness and how these affect illness behaviour (Lupton, 2003). Eliciting illness narratives from people undergoing medical interventions and experiencing chronic illness is one approach that has been used to illuminate the lay perspective on illness.

Illness narratives have been proposed by Frank (1998). Frank interviewed people with serious physical illness and concluded that certain narratives are

employed to help make sense of the illness experience and situation. Frank found that these narratives could be grouped into three main categories. He called the first one the restitution narrative. The restitution narrative concerned being optimistic and was characterised by efforts to gain control over the illness and becoming well. The second, the chaos narrative, on the other hand, was characterised by the decline in health, and poor progress in treatment, coupled with social, financial and other consequential problems. Finally, Frank identified the quest story, which emphasises what can be learned about oneself while on a journey to defeat the illness. This narrative is more optimistic than the chaos narrative, even though recovery may be difficult, by focusing more on the positive ways that serious illness has influenced life.

According to Herzlich and Pierret (1987), the need to find explanations for illness has persisted, despite the success and pervasiveness of the biomedical approach. The explanation of illness can be conceptualised as a need to go beyond medicine and the dysfunction of the body. Herzlich and Pierret claimed that individuals made sense of their illness experiences using their own perceptions and that this made medical knowledge "superfluous" (p. 100). Although the biomedical knowledge provided by the modern physician has acquired total legitimacy, individuals remain in need of an interpretation of illness based upon their individual experiences because the biomedical model remains limited in providing a totally satisfying explanation for illness. According to Herzlich and Pierret, the search for a cause, adopted by biomedicine, becomes a quest for meaning for the individual.

Kleinman (1978) proposed the existence of explanatory models to explain how people, across cultures, construct narratives about illness and bodily

symptoms. Explanatory models reflect social class, cultural attitudes and religious beliefs, as well as incorporating prior experience with illness (Baumann, 2003). Explanatory models may include explanations for cause and onset of symptoms, pathophysiology and treatment. These explanatory models are constituted by the subjective interpretation of the illness experience as influenced by cultural factors (Kleinman 1978). According to Kleinman, explanatory models play a vital part in permitting people to cope with their health problems, offering established ways of treating illness and providing opportunities for meanings to illness to be made.

The importance of research into lay knowledge for better understandings of contemporary health problems is stressed by Popay and Williams (1996). While not undervaluing the importance of professional knowledge and expertise, they argued that the development of appropriate public health policies required a better understanding of the underlying structure of both professional and lay knowledge. According to Popay and Williams, developments in social science about lay knowledge have remained relatively unrecognized and lay knowledge has not been employed in the development of health policy. This would contribute to a better understanding of contemporary illness and has implications for a better understanding of individual health care behaviours and improving public communication strategies (Hughner & Kleine, 2004).

Beliefs about the cause of illness and the way in which a person responds to disease are largely determined by factors other than the disease process and they have an impact upon how recovery can proceed. Personal beliefs about illness and individual adjustment to illness are culturally derived, and therefore, affect the relevance of health care behaviour to recovery. Differences between

different explanatory models imply that individuals can understand their health and illness differently from others, including those in the health care system. These explanatory models and the individual experiences of health and illness become an important consideration when health programs for secondary prevention are provided to different groups, particularly immigrant populations. Rather than ignoring the idiosyncratic contexts of individuals, Backett and Davison (1995) believe that an understanding of why individuals behave as they do is central to the view adopted by risk factor modification and any success of primary and secondary health care. Backett and Davison stated:

> *Without a working knowledge of the motors which drive health-related behaviours and the conceptual structures within which they find meaning, it is unlikely that either mass campaigns or one on one communications will meet with marked success (p. 637)*

The lay meaning of good health

There has been a series of studies, using personal accounts, which have explored the various meanings that individuals have of health. This area of research has shown that the concept of health is not a simple unchanging entity and can indeed be understood and experienced differently by different people at different times. Research aimed at ascertaining the personal accounts of health and illness have shown that health can acquire meanings which extend beyond the physiological limits of the body to include the person's social domain and "feelings and capacities involving activities and other people" (Radley, 1994, p. 41).

A comprehensive summary of the views of health in the lay sector has been collated by Hughner and Kleine (2004). These authors identified studies which emphasised the importance of the views of the lay person. They claimed that while there have been many attempts to study health beliefs pertaining to medical conditions, there have been few studies that have focused on an in-depth analysis on how people think about health. Hughner and Kleine's compilation of studies identified eighteen themes which summarised the lay view of health. They showed that lay beliefs of the causes of good health do not directly correspond to professional views about the cause of illness. Rather, that people were more often influenced by personal practices and responsibilities when considering the cause and control of illness. Hughner and Kleine concluded that opportunities existed for the investigation of cultural differences in lay health beliefs. The remainder of this chapter will present the research by Herzlich (1995), Pierret (1993) and Blaxter (2004) because they have made important contributions to the contemporary understanding of health and illness.

Herzlich (1995) conducted her studies in France and based her approach on how health was subjectively represented. Herzlich interviewed 80 people about their ideas of health and being healthy. Her interviews produced three themes which summarised the important characteristics of health identified by her respondents. These themes could also co-exist in one account. The first Herzlich called "health in a vacuum". This was a conception of health which referred to the absence of illness and relied upon the impact of illness for the realisation that health had been lost. The second theme Herzlich called "reserve of health". This representation of health referred to a capacity that people have to be healthy and to be resistant to illness, which was seen to be inherited and built upon by

favourable circumstances in one's life. It is deduced in comparison with others, and can be depleted, but not lost altogether, when illness prevails.

The third theme proposed by Herzlich (1995) was called "health in equilibrium". In this conceptualisation, health is neither a presence nor an absence, but rather determined by environment and social events that surround the person. Health was something that could be depleted but regained, depending on events in the person's life. The equilibrium can be present in some circumstances but be disturbed in other situations. This conception of health provides a norm that people can compare themselves to at different times and in different circumstances. Importantly "health in equilibrium" is linked with other factors in a person's life. Blaxter (2004) commented that these three themes, or representations of health, can be understood as health as "having, doing and being" respectively (p.49).

In a further study of the construction of various interpretations of health, Pierret (1993) conducted and analysed interviews with over 100 participants from three parts of a large European city. Content analysis identified four registers (or discourses) that interviewees took when asked about what health meant to them.

The Health-illness register

In this register, health was understood and represented by participants to be the absence of illness and not being sick. Health was something that you either had or you did not, and Pierret believed that it corresponded with what Herzlich called "health in a vacuum" because it emphasised a simplistic tendency between being healthy and not being healthy.

The Health-tool register

In this register, health was presented as the most important aspect of their lives and the principal form of wealth. Health was the tool which allowed you to achieve all that you needed, everything was possible. It corresponded with what Herzlich called the "health in reserve", since it implied a kind of capital, that came at birth, and that the person needed to constantly renew, as it inevitably decreased over time. In this register health was closely aligned with notions of being able to work and of having the capacity to do the things to lead a productive and well organised life.

The Health-product register

In this register, health was described as the outcome of factors over which control could be exerted. Health was an ideal that demanded management and restraint over aspects of life and pleasure. Being healthy was an objective to aim and to strive for which required constant control over uncontrollable factors. The tension is generated by the conflict between the quest for pleasure and the need to control risks.

The Health-institution register

The final register proposed by Pierret (1993) was called the Health-institution register. In this register health was seen from a collective standpoint, rather than from a personal or individualistic point of view. Health was a matter for public policy and preventing illness was the domain of national or local programs. Health went beyond considering personal management but was concerned with the overall health of all citizens. According to Pierret, the discourse of this register was characterised by an impersonal approach.

The third important study exploring the different meanings of health has been conducted in the United Kingdom by Blaxter (1990). Blaxter reported the findings of a nationwide study, called the Health and Lifestyles Survey, which collected responses from 9000 participants to open-ended questions about the experience of being healthy. Responses and subsequent analysis of these questions produced six main categories (Blaxter, 2004) and these will each be described under the respective headings.

Health as not ill

This category was characterised by the emphasis on the absence of symptoms and medical attention to define being healthy. Health was distinguished from disease and a person could be healthy despite having disease.

Health as fitness and vitality

In this category, physical strength, playing sport and fitness was prominent, particularly in the descriptions provided by young men. It was also represented as having energy to do what ever you wanted. Blaxter (2004) noted the correspondence of this category with Herzlich's register of "health in reserve".

Health as social relations

This definition of health encapsulated the importance placed on having good relations with others, especially, family and children. This response was almost always given by women. Elderly respondents expressed this by referring to being able to remain socially active and help others.

Health as function

Blaxter (2004) claimed that this category overlapped with health as vitality and health as social relationships because it focused upon being able to do things

rather than a description of feelings. It was often described by men who placed great emphasis on being able to work hard and having pride about their abilities. This category resembled the register identified by Pierret (1993) called "health as a tool" and also the theme reported by Herzlich which she identified as "health in reserve" (Herzlich & Pierret, 1987).

Health as psychosocial wellbeing

In this category, health was expressed as a mental state and indicated the attainment of positive states of mind. These states of mind permitted life to be enjoyed and the category was reserved for expressions of health that were purely described as mental, rather than physical. This was the most frequent response category in all age groups except young men.

Health as a healthy life

This final category was described by Blaxter (2004) as being in the minority. In this category, health was expressed by reference to healthy behaviours which were accepted as causing good health, such as eating well and not smoking or drinking. Blaxter believed that this category reflected the difficulty that some people have with defining good health and instead they resorted to answering the easier question of what might influence good health.

Summary

This chapter has briefly outlined the limitations of traditional approaches of biomedicine in elucidating the lived experiences of people as they confront disease. By definition, illness requires a closer scrutiny of the idiosyncratic experiences of disease as it effects the afflicted. Research into the lay perspective of health has shown that good health can take a variety of meanings. That is,

23

being healthy can mean different things to different people. These meanings are influenced by the cultural and social contexts in which the person is a part. Treatment regimes are influenced by the cultural practices of the health care system and the professionals working within it. These factors become important considerations where treatment programs are provided for populations from different cultural backgrounds, such as non-English speaking immigrant groups.

Cardiac rehabilitation programs have become an important part of the secondary prevention of CHD over the last 30 years. The next chapter will present a summary of the literature which has examined the effectiveness of cardiac rehabilitation programs and review studies that have attempted to gain a better understanding of the subjective experience of CHD. In particular the chapter will include research which has attempted to explore the individual experience of CHD within the context of attempts to improve the effectiveness of cardiac rehabilitation programs at improving health behaviours.

Chapter 3

Coronary heart disease and rehabilitation

Coronary Heart Disease in Australia

Coronary heart disease is a condition where the coronary arteries of the heart, which provide the heart muscle with its own supply of oxygen, gradually become occluded and blood flow to the heart muscle is restricted. Fatty deposits which accumulate in the coronary arteries and cause the occlusion are the result of a disease called atherosclerosis. Atherosclerosis occurs when there is an accumulation of these fatty deposits under the lining of the arterial wall which gradually occlude the flow of blood through the coronary artery and restrict the elasticity of the vessel. The pathogenesis of atherosclerosis is a complex interaction between white blood cells, various fatty materials, principally cholesterol, and the muscle cells of the artery. Over time, a thickening of the arterial wall, commonly called a plaque, develops within the inner lining of the artery.

When parts of the heart are deprived of sufficient oxygen, angina, or chest pain can result. If the heart muscle is substantially denied the oxygen it requires, then a heart attack can occur. This is also known as a myocardial infarction and can result in ischemia, or the death of the oxygen-deprived heart muscle. Angina normally occurs when demands on the heart are increased by physical exertion or emotional responses. Coronary heart disease affects people from all over the world, although it is generally accepted that its prevalence is closely related to frequently preventable lifestyle factors.

Traditional risk factors for atherosclerosis include high blood pressure, high levels of blood cholesterol, cigarette smoking, and obesity (Australian Institute of Health and Welfare [AIHW], 2003). Diabetes and insufficient exercise are also associated with a higher prevalence of coronary heart disease (AIHW, 2003). Genetic conditions, such as hypercholesterolemia, a disease that interferes with the normal production and metabolism of fats, are not considered to be traditional risk factors.

Coronary heart disease has consistently been at the very top of causes of death in Australia since the 1960s. While there has been a significant reduction in the mortality rate from CHD over the last 30 years, data from the Australian Bureau of Statistics show that in 2002 CHD was the underlying cause of death in 19.5% of all deaths in Australia (a total of 26,063 deaths), second only to all malignant neoplasms (cancers) (Australian Bureau of Statistics [ABS] 2003). The proportion of years of potential life lost from CHD was 13% and 8% for men and women respectively (ABS, 2003). Data from the Australian Institute of Health and Welfare show that CHD was the largest single cause of death in Australia in 2000 (AIHW, 2002). Rates of CHD are also twice as high among people from lower socio-economic groups, when compared to those from higher socio-economic groups (AIHW, 2002).

According to Goble and Worcester (1999), the apparent decline in the national death rate over the last 30 years does not necessarily mean that the overall prevalence of the disease has lessened. The fall in the death rate is, instead, largely attributable to the continued development of effective and sophisticated interventions after acute cardiac episodes which have reduced the mortality rate. These interventions, which include coronary artery bypass graft surgery (CABGS)

and coronary angioplasty, have resulted in an increase in the number of hospital admissions and of discharges. Coronary artery bypass surgery consists of the grafting of new veins, usually taken from the leg, from the aorta to the coronary artery, providing a new pathway for the blood to the heart muscle and bypassing the damaged part of the artery. Coronary angioplasty results in the increase in coronary blood flow by compressing the atherosclerotic plaque back into the lining of the coronary artery and thus reducing the obstruction. A coronary stent can also be used to ensure the artery remains open. Coronary angiograms are used to determine the need for interventions such as CABGS and angioplasty have also contributed to the rise in hospital admissions for coronary complaints. In 2000-2001, approximately 50% of all hospitalizations for CHD were for diagnostic and surgical procedures (AIHW, 2002). There are, therefore, an increasing number of patients being discharged from hospital with diagnosed CHD morbidity and it is these patients which form the major group of patients eligible for secondary prevention programs such as cardiac rehabilitation programs.

Cardiac rehabilitation

In 1993, the World Health Organisation (WHO) published a report prepared by an expert committee which recommended that cardiac rehabilitation should be an integral component of the long term comprehensive care of the cardiac patient and that rehabilitation programs should be available to all patients with cardiovascular disease (AIHW, 2003). The following section will provide a summary of the structure of cardiac rehabilitation programs and an overview of the literature examining the effectiveness of cardiac rehabilitation in reducing the mortality and morbidity from cardiac disorders. The low attendance rates for cardiac rehabilitation programs will also be examined against the context of the

failure of current rehabilitation programs to provide for an individualized approach to an understanding of the psychosocial factors which influence the onset of and the recovery from the disease.

Cardiac rehabilitation programs in Australia can be divided into three groups. Phase one cardiac rehabilitation programs are provided as an inpatient service to cardiac patients during their stay in hospital. Phase two programs refer to ambulatory programs conducted soon after leaving hospital. They can be provided within a hospital or community setting. Phase three programs are maintenance programs normally provided in the community after the completion of a phase two program.

According to the National Heart Foundation and the Australian Cardiac Rehabilitation Guidelines (2004), the specific aims of cardiac rehabilitation programs are to: facilitate and shorten the period of physical recovery after an acute cardiac event; promote strategies for achieving mutually agreed goals of secondary prevention; and to develop and maintain skills for long term behaviour change. The main elements of a phase two cardiac rehabilitation program are low or moderate exercise, group educational sessions and follow up (NHF & ACRA, 2004).

Cardiac rehabilitation programs exist in a variety of forms around the world and have differing emphases. Hare and Bunker (1999) provided a brief summary of the different approaches used in cardiac rehabilitation. In Europe, patients are sometimes admitted to specialised clinics for between three to six months and participation is mandatory for all employed people who have had a heart attack. The emphasis is on returning people to employment. In Scandinavia, the emphasis has tended to be on the reduction of risk factors. The

approach adopted in the United States is based primarily on an intense aerobic training program. The Australian model of cardiac rehabilitation, which has evolved from programs focused upon helping patients return to work, has tended to emphasize the importance of a light exercise component and includes group educational sessions. The group educational components frequently include information about heart disease, the resumption of normal activity levels and consideration of the psychosocial impact of the illness. They also have an increasing focus on secondary prevention and the modification of established risk factors (NHF & ACRA, 2004).

Both inpatient and outpatient programs are preferably run by a multi-disciplinary team of health professionals which can include nurses, psychologists, physiotherapists and dieticians. Minimum standards in Australia require that patients attend weekly for between six to eight weeks and that the program includes a light exercise program as well as educational sessions (National Heart Foundation & Australian Cardiac Rehabilitation Association [NHF & ACRA], 2004).

In an editorial published by the Medical Journal of Australia, Bunker and Goble (2003) stated that according to a directory of cardiac rehabilitation programs in Australia, there were 265 community and hospital cardiac rehabilitation programs in Australia in 2001. The growth of cardiac rehabilitation programs which occurred during the 1980's and 1990's largely represented the accumulating efficacy data from large scale clinical trials conducted in the United States and in Europe (Ades, 2001). In 1995, the United States Agency for Health Care Policy and Research (AHCPR) considered the accumulated literature on cardiac rehabilitation and made recommendations based upon the evidence of

over 1300 reports and scientific papers. The clinical practice guideline they

produced concluded that "cardiac rehabilitation, based upon exercise, education,

counselling and behavioural interventions should be incorporated into programs

of management for all patients with cardiovascular disease" (Goble & Worcester,

1999, p. 27).

Several meta-analyses of the literature on the effectiveness of cardiac

rehabilitation have been published. O'Connor et al. (1989) found that

participation in a cardiac rehabilitation program, with an exercise component,

reduced the rate of fatal myocardial infarction by approximately 20%, in the three

years following the program. Another meta-analysis of cardiac rehabilitation

programs with components other than just exercise showed a similar reduction in

the rate of myocardial infarction in patients that attended (Oldridge et al., 1989).

Randomised controlled clinical trials conducted in Scandinavia have shown a

long-term reduction in coronary heart disease mortality in patients who

participated in a multi-factorial intervention program (Hämäläinen, et al., 1989;

Hedbäck, Perk & Wodin, 1993).

There have been several other studies which have shown that risk factors

can also be favourably affected by cardiac rehabilitation. In a comprehensive

review article published in the New England Journal of Medicine, Ades (2001)

cites many studies in support of the efficacy of cardiac rehabilitation in favourably

altering the course of CHD. While he predominately reviewed the controlled

trials of exercise programs he also noted the importance of risk factor reduction in

successful programs, including cigarette smoking, blood lipid levels, and

hypertension. It was noted by Ades that medication can often play an important

part in reducing the risk factor status for hypertension or diabetes, but that cardiac

rehabilitation programs, which include psychosocial interventions and components, are more likely to have reductions in a variety of risk factors, including hypertension, depression and anxiety when compared with programs without a psychosocial component. Ades also cited evidence for a reduction in overall mortality and recurrent cardiac events after two years for patients who participated in cardiac rehabilitation programs with a psychosocial intervention.

In a randomised controlled study of 270 Italian cardiac patients Marchionni et al. (2003) have shown the importance of cardiac rehabilitation for more elderly patients. Quality of life improvements were noted only for the oldest patients completing the program, when compared to younger groups. Marchionni et al. emphasised the need for the active participation in the program by the older patients to ensure these improvements in quality of life. The program offered the opportunity to join a monthly group together with members of their family. It also included a comprehensive exercise training program. Exercise tolerance was improved in the oldest patients completing the program, compared with patients in the control group. Marchionni et al. concluded that cardiac rehabilitation programs can improve quality of life for elderly patients and also recommended that a home-based program may be more suitable and cost effective for low risk cardiac patients.

Depression has been shown to significantly effect adherence and maintenance to lifestyle changes aimed at reducing cardiac mortality after myocardial infarction (Frasure-Smith, Lespérance, & Talajic, 1993). Several studies have examined the impact of cardiac rehabilitation programs upon depression. Milani, Lavie, and Cassidy (1996) evaluated the effect of cardiac rehabilitation and exercise training on depression after a major cardiac event.

After comparing baseline and post program data, they reported that depressed patients had significant improvements in depression scores (as measured by a validated symptom questionnaire) and other behavioural parameters including anxiety, hostility and somatisation, as well as improvements in quality of life. In this particular program, as is typical of cardiac rehabilitation programs, individual attention to these areas was not routine, but cardiac rehabilitation had a favourable effect on other parameters associated with mood. Several more recent studies have also demonstrated that cardiac rehabilitation can help depressed patients by improving coping skills, self image, reducing social isolation, providing emotional support and improving quality of life (Zellweger, Osterwalder, Langewitz, & Pfisterer, 2004).

In a further study, Hudson, Board and Lavallee (2001) examined the nature and experience of loss resulting from coronary heart disease and the part played by cardiac rehabilitation. After completion of a six-week program, which included exercise and psycho-educational sessions, the authors interviewed patients about their personal experiences of heart disease and the rehabilitation program. Patients described loss of sense of purpose, sense of self and of lifestyle. Losses were also seen to represent two distinct groups.

The first group was loss which was objective and quantifiable, such as loss of employment, and the second group of losses was a phenomenologically-based loss, such as loss of a sense of purpose. Restoration of losses by the cardiac rehabilitation program were also categorized and the most frequent response was the gain in social support provided by the program. Other gains included an increased awareness, sense of achievement, sense of purpose and gains in psychological domains such as confidence. Hudson et al. further grouped the

gains into support and education and self-esteem, which they considered to be indicative of a regaining of the sense of self, lost through the experience of cardiac disease. The authors concluded that cardiac rehabilitation program can be "an instrumental force in shaping the balance of experienced gains and losses" (p. 309). Hudson et al. demonstrated the valuable part that cardiac rehabilitation programs can play in assisting the broader psycho-social aspects of illness and recovery from CHD.

Limitations of cardiac rehabilitation

There have also been studies which have not been as conclusive in showing that cardiac rehabilitation has any effect on risk factor status. A randomised controlled study conducted in the Netherlands suggested that cardiac rehabilitation produced some changes in both physical and psychological domains but the gains were small and not statistically significant (van Houten, Angenot, Lankhorst, Deville, & Beckerman, 2002). van Houten et al. concluded that quality of life variables and self-efficacy are likely to be important outcomes measures of cardiac rehabilitation. Another study conducted in a rural part of the United States found that while there were some gains in patients' self-reported health, cardiac rehabilitation had no effect on established risk factors, except for measures of obesity (Yates, Braklow-Whitton, & Agrawal, 2003). There is also some doubt about the effectiveness of cardiac rehabilitation for coronary artery bypass graft surgery patients (Goss, Epstein, & Maynard, 2002).

In a meta-analysis of studies of cardiac rehabilitation, Oldridge et al. (1988) concluded that cardiac rehabilitation reduced the recurrence rate of fatal infarctions in the three years following participation in the cardiac rehabilitation program, but that the same effect was not evident for non-fatal infarction. The

inconsistency of the evidence for the effectiveness of cardiac rehabilitation on non-fatal infarcts was also noted by Jelinek (2004). Jelinek referred to a large scale review (The Cochrane Library review) of exercise-based cardiac rehabilitation programs and claimed that the evidence indicated that while total cardiac mortality was reduced by 27 %, neither exercise alone, nor in combination with a comprehensive program, had any effect on non-fatal infarction. Jelinek noted that the reasons for the poor efficacy of cardiac rehabilitation on non-fatal infarcts remained unclear and that primary medical practice remained doubtful about the efficacy for these reasons. Published randomised controlled trials, such as those reviewed by the Cochrane Library study, also have limitations. These include a bias toward the inclusion of only low risk patients in the studies because of the tendency of high-risk groups not to participate in the cardiac rehabilitation programs made available (Jelinek, 2004).

In a recent attempt to demonstrate the value of cardiac rehabilitation in Australia, Sundararajan, Bunker, Begg, Marshall, and McBurney (2004) used links between Victorian data sets to describe patterns of use of cardiac rehabilitation and to examine survival rates. Their cohort study consisted of patients who had been admitted to hospital for coronary procedures and infarction. They found that there was a significant difference between attendees and non-attendees in the probability of survival after five years. At follow up, 8 % of attendees had died compared with 19 % of non-attendees. Another important finding from this study was that only 24 % of eligible patients attended cardiac rehabilitation programs. The authors claimed that this is consistent with the findings of other studies in Australia and around the world and that the reasons for poor attendance required further investigation.

<u>Barriers to cardiac rehabilitation and risk factor reduction</u>

Despite the apparent success of cardiac rehabilitation programs in reducing mortality and morbidity, and the potential of its contribution to the economic savings in health care, cardiac rehabilitation programs remain poorly attended around the world. Dafoe and Huston (1997) stated that while cardiac rehabilitation has been demonstrated to be helpful to all cardiac patients and that it is cost effective, it has remained under-utilised in Canada. According to Dafoe and Huston, only between 10 and 40 % of cardiac patients in Canada and the United States are referred for rehabilitation. They noted the reasons as being limited access, poor funding and the provision of risk-factor modification by the treating physician, who may also be sceptical about the effectiveness of cardiac rehabilitation. Under-utilisation of cardiac rehabilitation programs has also been reported in the United States and in the United Kingdom (Sanderson, Phillips, Gerald, DiLillo, & Bittner, 2003; Tod, Lacey, & McNeill, 2002). In another Australian study, under-referral and under-utilisation has also been noted by Scott and Lindsay (2003). They reported that just over half the patients who were eligible for rehabilitation were actually referred to programs. They also reported that less than one third of the patients referred completed the program.

In an editorial from the Medical Journal of Australia, Bunker and Goble (2003) claimed that there are several reasons which underlie the anomaly of poor attendance at cardiac rehabilitation programs. They identified the lack of routine referral by physicians, poor availability, poor relevance to certain populations such as indigenous people, older women and those unable to speak English as reasons for the low participation rate in Australia. Bunker and Goble also identify systemic reasons for the under-utilisation, such as physician reluctance and poor

discharge planning, but also noted that patient characteristics, such as depression or denial, have been found to be significant predictors of participation rates. They raised the importance of surveying patients about their preferences for different program models and delivery, as well as the need to consider the individual needs of each patient.

There has been a growing interest in published research which aims to elucidate the barriers to cardiac rehabilitation and risk factor reduction. In line with the recommendation of Bunker and Goble (2003), there have been attempts to elicit the patient view using qualitative approaches which focus upon interviews with patients and health professionals. Tod et al. (2002) conducted semi-structured interviews and group discussions with patients from a local shire in the United Kingdom. Aside from the failures of the system in place to provide adequate opportunity and communication about programs, they identified a lack of perceived appropriateness by the patient as a barrier to participation. This theme included being deterred from attending because of a dislike of groups and hospital settings, structural and family needs which required other commitments to be kept, and the refusal to interrupt established routines, particularly in older patients. Tod et al. also argued that certain groups, such as women, the elderly and those from traditional working class communities, are likely to have more complex needs which make barriers to attendance more pronounced. They also noted in their conclusion that ethnic minority groups are one of several groups that consistently have low participation rates because the programs are either too difficult to access or do not address their needs.

The importance of social and cultural factors in the effectiveness of secondary prevention for CHD has been identified by Clark, Barbour, and

McIntyre (2002). They used focus groups with primary care and secondary health professionals to explore important issues for the development of cardiac rehabilitation programs in Scotland. Clark et al. found that barriers to the effectiveness of secondary prevention in CHD were multi-factorial and included patient, social and service-related factors. Both primary care workers and secondary health professionals identified individual beliefs and motivation as important barriers to change. Individual circumstances were seen to be a crucial factor in the motivation for successful long term behaviour change.

In addition to this finding, the primary care professionals referred more frequently to the effect of social and cultural factors as the main barriers to effective secondary prevention in CHD. Social and cultural factors were referred to by the primary care professionals as influencing individual circumstances. These included the impact of deprivation and poverty. Clark et al. (2003), noted the important difference between the cognitive behavioural stance taken by health professionals when considering barriers to rehabilitation and the stance taken by primary care workers, which tended to place greater emphasis on cultural and social factors. They concluded that an emphasis on the traditional epidemiological evidence for the role of individual risk factors by health workers in cardiac rehabilitation can lead to the omission of the important social and cultural aspects of health and illness, such as cultural beliefs, social networks, income inequalities and racial inequalities when these programs are implemented. The findings of Clark et al. provided support for the relationship between low numbers of referrals from primary care physicians and the capacity of cardiac rehabilitation programs to accommodate the idiosyncratic circumstances of cardiac patients.

The role of patient characteristics, as well as social demographic factors, in poor attendance rates at cardiac rehabilitation programs have been reviewed by Cooper, Jackson, Weinman and Horne (2002). They completed a systematic review of published studies that have investigated factors associated with cardiac rehabilitation attendance. The results of their review, which surveyed up to 1210 peer reviewed articles, identified several important consistencies in the factors which influence participation in a cardiac rehabilitation program. Cooper et al. collected studies which examined variables from four groups: socio-demographic, clinical, psychological and centre-based. They confirmed that under-referral and under-utilisation phenomena in cardiac rehabilitation programs were evident internationally. Cooper et al. concluded from a close examination of 15 studies, which met all their criteria for inclusion, that older patients and those who have a lower income are less likely to attend for cardiac rehabilitation, despite low or waived costs.

Persons with lower education, unemployed people and those that had experienced greater social deprivation were also less likely to attend cardiac rehabilitation. Poor social support was also a significant predictor of non-attendance in the reviewed studies that included this variable. One study in the review identified the presence of an English-language barrier to be independently significant to non-participation (King, Humen, & Koon, 1999, cited in Cooper et al., 2002). Other important factors effecting attendance identified in Cooper et al. included practical issues such as travel time, strength of physician recommendation and receiving a follow up appointment.

Cooper et al. (2002) provided valuable information on patient characteristics associated with poor attendance. While consistencies were absent

from the psychological variables included, due in part to the various measures used to assess mood in the studies reviewed, Cooper et al. noted the trend towards better psychological health being important in predicting participation. Depression prior to and during hospitalization was also found to be associated with poor attendance. Importantly, their review also found that individual illness perceptions were important factors where attendance at cardiac rehabilitation was concerned. Non-attendees had different perceptions of their illness and their health. When compared with attendees, non-attendees did not perceive that they could have any control over their illness or that their illness could be cured. They also tended to attribute fewer consequences to their illness and did not attribute their lifestyle to having caused their illness.

Cooper et al. (2002) emphasised that illness beliefs are predictive of attendance and that while representative of the individual patient, these beliefs are essentially formed from social and cultural inputs. They noted the importance of consideration to culture-specific barriers when referring to cardiac rehabilitation programs. According to Cooper et al. specific information on the influence of ethnicity variables on participation in cardiac rehabilitation was absent from the studies examined, but is likely to play a part in the decision to attend rehabilitation programs. Cultural beliefs and practices specific to ethnicity are, therefore, likely to influence the effectiveness of current cardiac rehabilitation programs for those culturally diverse groups. The next section will present research which has tried to account for these individual and cultural factors by exploring the patient experience of CHD.

The patient's experience of coronary heart disease

As mentioned in Chapter 2, the positivistic approach of traditional behavioural medicine, under the cover of the biopsychosocial model, has not been suitable in identifying the patient's experiences of illness, other than providing information concerning static variables without any reference to the lived experience of illness. A more phenomenological approach in the study of illness experience has been advocated by Lupton (2003). The attempt to ascertain the personal meanings of illness and its consequences using a phenomenological approach allows the everyday lay experience of health and illness to become the primary object of study. The following section will review studies which have attempted to directly investigate the dynamic aspects of personal meanings and experience of cardiac illness against the background of a need to develop a more individualized approach to the provision of cardiac rehabilitation programs, in order to improve suitability and participation rates.

Research has argued for the importance of a more individualized approach to cardiac rehabilitation programs and that this would contribute to more perceived relevance for the cardiac patient and better attendance. Dafoe and Huston (1997) noted that the rehabilitation programs needed to better address the personal and psychosocial idiosyncrasies of the patient. They suggested that programs include efforts to understand the personal experience of heart disease and what impact it has on individual lives. They also proposed the importance of developing more flexible modes of delivery, including home-based programs for "hard to reach patients" (p.530). Ades (2001) also noted the apparent need for a more individualized approach and close collaboration with the patient's primary physician, to improve attendance at cardiac rehabilitation programs.

Dafoe and Huston (1997) suggested that attendance might be increased by eliciting patient's views about cardiac rehabilitation and helping to address misconceptions. They recommended a targeted and personalized approach to those patients who have misconceptions about their illness and persisting psychological problems. Like other individual studies (Clark et al., 2002; Mayou, 1996; Sanderson, Phillips, Gerald, DiLillo, & Bittner, 2003), Dafoe & Huston, advocated more flexibility in the programs and greater attention to individual needs.

Winters (1997) conducted a study aimed at specifically exploring the experience of living with chronic CHD. Semi-structured interviews with patients occurred 12 months after an acute cardiac event. The study included cardiac patients with coronary artery disease, cardiac myopathy and congenital heart disease and all had undergone at least one acute cardiac intervention ranging from angioplasty to heart transplantation. Four broad categories emerged from the interview data. Winters noted the importance of uncertainty in the experience of living with CHD and that this uncertainty extended to all aspects of the illness duration and treatment. Winters also noted the theme of change over time, which embodied the dynamic nature of living with CHD and how the impact of living with CHD had changed aspects of their lives. Patients reported periods of stability and uncertainty as well as changes in how they experienced the illness and aspects of themselves.

Conflicting emotions were also identified by Winters (1997). The conflicts expressed themselves in the battle between self-reliance and dependency on others, the need for medical intervention, which was often costly and intrusive and, finally, the desire to regain control over feelings of not having any control.

Patients also frequently expressed the personal work effort which was required to live with CHD, the desire to continue living and to do what was necessary to remain healthy. Winters also found that cardiac patients used strategies, such as keeping active, looking on the positive side of the illness, not thinking about it or surrender, in response to cardiac illness. Winters concluded that interventions, such as cardiac rehabilitation, should support patients' dynamic understanding and perceptions of their illness and the desire for self-care and control. Individual strategies for coping in response to CHD should be identified and facilitated as a part of rehabilitation. According to Winters, this required a greater understanding of individual circumstances and improved communication between patients and health care providers.

Bergman and Bertero (2001) interviewed patients with CHD to gain a better understanding of the subjective meaning of being afflicted with the disease. In particular, they were interested in examining the impact of the disease on lifestyle and barriers to lifestyle change. A semi-structured interview was used to elicit responses to particular topics, such as cause of disease, lifestyle changes and obstacles to behaviour change. Bergman and Bertero identified three main clusters of causes attributed to heart disease and called them heredity, lifestyle and demands. Hereditary responses tended to be associated with family characteristics and participants reported the cause as prior family heart disease. There were also signs of resignation in those patients who had had relatives die of heart disease. Lifestyle factors reported by patients to have caused their illness included smoking and poor diet. Demands were divided into three categories: demands on the self, demands made by others and work demands.

Bergman and Bertero (2001) found the prevalence of confusion, sadness and uncertainty throughout the interview transcripts and a resignation to a life-changing event which was often expressed by overt grief during the interview. According to the participants, sadness and grief was the chief obstacle to lifestyle change and this was in response to the perception that their health had been lost. Bergman and Bertero suggested that this emotional response needed to be overcome for efforts to reduce mortality and morbidity to be successful. Participants also believed that overcoming the response to loss and having social supports to be pre-requisites for successful rehabilitation.

Bergman and Bertero (2001) claimed that their data support two main conclusions: that individual volition is of "vital importance" (p.740) in making lifestyle change and that social support plays an important part in helping people make that change. The participants regarded making the capacity to make their own decision about lifestyle change as the most important element in beginning to re-build their health. This decision making was influenced by social supports which were reported to be able to assist by helping participants to overcome the feelings of confusion, loss and grief that they experience. These supports came from various sources, including family, the health care system and work friends. Bergman and Bertero concluded by saying that if a more individual approach to treatment and rehabilitation could be adopted, then individual factors that assist cardiac patients to make lifestyle changes can be identified.

In a qualitative study conducted in Australia, Gassner, Dunn, and Piller (2002) interviewed 50 myocardial infarct patients 48 hours after their hospital admission about their interpretation and experience of their symptoms. From their data emerged four major categories: the historical context, the metaphor of a heart

attack, labeling the symptoms and making sense of the illness experience. Participants tended to describe their experiences by reference to the historical context that they believed was relevant to the onset of the symptoms. This ranged from a few hours prior to 30 years earlier. Participants also used metaphors to convey meaning which was mostly frightening and worrisome. A significant number of patients did not interpret their symptoms as cardiac in nature and some of these patients had also had previous experience of cardiac symptoms.

With respect to personal theories about the cause of their illness, 60% of participants in Gassner et al. (2002) had an explanation for the cause of their symptoms. The most popular personal theory was the role that stress had had on their lives. Gassner et al. (2002) noted that participants did not attribute their CHD to the accumulation of risk factors. The only reference to a cardiac risk factor was reference to the potential effects of a gain in weight. Physical exertion, injury and family influences were also mentioned frequently as causes of CHD. Gassner et al. (2002) claimed that what each patient's story had in common was the importance of needing to understand the cause of their illness and to provide a rational explanation by linking important life events.

Gassner et al. (2002) noted how patient models of the reasons for his or her illness contrasted with the models of the medical profession. Patients searched for meaning within their life narrative rather than attributing their condition to cardiac risk factor status. Gassner et al. concluded by noting that risk factor models and the education about risk factor reduction is not always helpful to cardiac patients because of the lack of relevance ascribed to them by the patients. They concluded that this had effects for how treatments such as cardiac rehabilitation programs are structured and delivered. Gassner et al. suggested that

"participation and adherence to cardiac rehabilitation programs are likely to be improved by strategies that take into account patients' beliefs about their illness" (p. 352).

Murray, Manktelow and Clifford (2000) conducted an examination of social and cultural factors in the perceptions of cardiovascular disease in patients with CHD. Murray et al. proposed that current approaches to cardiac prevention and rehabilitation are based upon conclusions of epidemiological studies and that this prescriptive approach to the treatment of risk factors for all overlooks the personal and idiographic contexts of the patient. Patients derive explanations for their disease from various sources and differences between these explanations and the approach to rehabilitation undermine compliance with health care advice. Murray et al. (2000) reported results from a qualitative study of three groups: cardiac patients, their informal carers (spouses) and formal carers (nurses) to examine how different their perceptions of cause, risk and the need for lifestyle change were.

Murray et al. (2000) found that for the patients and their informal carers, perceptions of the cause of heart disease were based in the belief of destiny and fate, stress, and over-work, whereas the perceptions of the professional carers were based in the known epidemiological evidence of risk factors. For example, where fate was nominated in playing a part in the illness, patients attributed their disease to destiny and the acceptance that they were to die from CHD. Where stress was nominated, some patients were able to explain this with reference to a particular life event, such as being assaulted, or to wear and tear on the body. Some patients thought that stress would be difficult to reduce because of its part in the individual personality. Changes to lifestyle, such as changes to diet or to

increase exercise frequency, were required by all groups but the patients regarded those changes as being difficult or unlikely. Patients also described social networks, such as discussion with others and knowing others who had had heart disease, as the main source of information about cardiovascular risk.

This study, while employing a qualitative methodology which makes its generalizability limited, made several important conclusions. Murray et al. (2000) stated that the constant reference to stress reflected the social and cultural influences on the perception of CHD and that stress had become associated with people's misfortunes. The word "stress" had come to mean the same thing. Murray et al. claimed that the emphasis on these social and cultural factors by patients explained the choice of stress over and above any of the other risk factors chosen by the patients and their carers and used this as a way to explain how they had become afflicted with heart disease. They noted that while cardiac rehabilitation programs continued to be based upon a "traditional, reductionist approach, which assumes patients will respond to a prescriptive change in lifestyle, focusing on a limited number of practices such as smoking and eating fatty food" (Murray et al., 2000, p. 1229), the kind of social and cultural perceptions they identified amongst patients could act as barriers to the aims of cardiac rehabilitation.

Murray et al. (2000) concluded by saying that patients needed to be given individual attention and opportunity to talk about their experiences, and their belief in cardiovascular risks. Reference points for change can then be determined by the patient and their carer, rather than from the vantage of the professional, who has derived a viewpoint from an acceptance of risk factor reduction strategies. This study attempted to shift the balance away from the dominance of

the epidemiological-derived risk factor approach and towards the consideration of idiographic data, based in the social and cultural beliefs of the patient in the secondary prevention of CHD.

In summary, this chapter has outlined how studies of the individual experiences of CHD have provided valuable information about how improvements could be made to cardiac rehabilitation programs. There is substantial evidence from these studies to suggest that providing a more individualized and tailored approach to secondary prevention would allow the incorporation of patient beliefs and of social and cultural factors which constitute those beliefs, into those programs. The potential mismatch between the perceptions and beliefs about CHD and the prescriptive approach to behaviour change adopted by health professionals and secondary prevention programs may also undermine compliance with health care advice. The shift for cardiac rehabilitation indicated by this research represents a change from an epidemiological-driven risk factor approach to a more individually tailored style of program where these perceptions and beliefs can be recognised as crucial to successful recovery and risk factor reduction. Studies reviewed in this chapter have also demonstrated the potential relevance of cardiac rehabilitation programs in improving the psychosocial sequelae of CHD, such as depression, and the important part played by social support in recovery. The next chapter will review the role of psychosocial factors in the onset of and recovery from CHD. The important part played by these psychosocial factors will be outlined as will a theoretical model which allows these factors to be understood as part of the mechanisms implicating the social determinants of CHD.

Chapter 4

Psychosocial factors in coronary heart disease

An association between psychosocial influences and CHD has been studied and discussed by health researchers for many years. Stansfield and Fuhrer (2002) reported that this association has partly arisen because of the associations between exposure to chronic stresses and cardiac symptoms, such as chest pain and breathlessness. It is also partly attributable to the long standing cultural acceptance of the heart as the seat of emotional life. Stansfield and Fuhrer proposed that the association between the heart and emotions is the result of the awareness of the bodily responses to heightened emotions such as increased heart rate. The early published literature suggested that while psychosocial risk factors, commonly described under the catch-all phrase "stress", were consistently associated with traditional risk factors, there was no independent effect on the incidence of CHD (Bunker, et al., 2003). More recently, there has been an accumulation of published literature which has indicated the important part played by psychosocial factors in both aetiology and recovery (Krantz & McCeney, 2002).

Krantz and McCeney (2002) have critically examined the impact of psychosocial factors on the organic origins of coronary heart disease. They proposed that a combination of acute and chronic risk factors, both biological and behavioural, can explain the increased risk of cardiac events where traditional risk factors did not account for the onset of disease. Episodic risk factors, such as depression, are also noted to add to cardiac risk. Krantz and McCeney proposed that this framework helped to explain the unpredictable timing of cardiac events and the role of behavioural factors in the onset of clinical events. In their review,

Krantz and McCeney identified five broad variables which have been studied for their influence on CHD. The variables were; acute and chronic socio-economic status, stress, hostility, depression and social support. They concluded that extensive evidence from various sources, including animal studies, human clinical studies and large-scale epidemiological studies, consistently showed the significance of psychosocial variables on organic mechanisms associated with coronary heart disease. Krantz and McCeney acknowledged that the strength of the evidence differed among the various psychosocial variables and in different populations but assert that taken as a whole, the evidence is strong.

In Australia, an expert working group of the National Heart Foundation undertook to examine the systematic reviews of the evidence in the literature for the impact of the major psychosocial risk factors on the aetiology of heart disease. Bunker et al. (2003) identified 57 reviews in published literature which met the inclusion criteria and evidence was graded according to the 1995 NH&MRC classification. All the reported evidence which contributed to the position paper was "evidence obtained from well-designed cohort studies, preferably from more than one centre or research group" (Bunker et al., 2003, p. 273).

An important aspect of the working group's position was the decision not to use the word 'stress' in their review of the literature because of its largely imprecise use. Instead, they included commonly recognised aspects of stress, which included depression, social support and isolation, anxiety, life events, work characteristics, and the Type A behaviour pattern. The working group found strong and consistent evidence that depression, social isolation, and a lack of quality social support were important independent risk factors for coronary heart disease and its prognosis (Bunker et al., 2003). Bunker et al. claimed that the

"strength of the association is of a similar magnitude to that of the standard risk factors such as smoking or hypertension" (p. 273). While they did not find the same strength of evidence for the role played by acute life events, they did find "fair evidence" of an independent causal association between life events, such as bereavement, and coronary heart disease (p. 274). The evidence gathered from studies of anxiety, work characteristics, hostility or Type A behaviour pattern was found not to be consistently strong.

This investigation led the working group to make several important conclusions about the role of psychosocial factors in the aetiology of coronary heart disease. First, they concluded that depression, social isolation and a lack of social support are significant risk factors for heart disease, independent of other conventional risk factors. The magnitude of the risk factor is similar to other well-accepted risk factors, such as cigarette smoking. The second conclusion made was that acute life events can trigger coronary events. Third, the presence of psychosocial risk factors such as depression and social support may account for the variance in coronary heart disease that has traditionally been unexplained by the conventional risk factors. Fourth, those who are socially disadvantaged are likely to have greater levels of psychosocial and conventional risk factors. These groups included indigenous populations, people with depression, and immigrants. Finally, the expert working group called for the need to consider the burden imposed by these psychosocial risk factors and that attention to the social and cultural influences of patients may improve outcomes for heart disease patients (Bunker et al., 2003).

Marmot, Siegrist, Theorell, and Feeney (1999) have claimed that data from international studies have shown that traditional risk factors for CHD

account for less than 50% of the variation in the mortality rate for CHD. Marmot et al. stress the need to look at the broader social and economic organisation and structure for explanations for the remaining variance in mortality. Wilkinson (1996) examined the influence of social and economic factors which caused inequalities in health around the world and emphasised the important part played by psychosocial factors, such as depression and social isolation in CHD.

In his comprehensive treatment of the differences between countries and income differences within those countries, Wilkinson (1996) claimed that every major group of illnesses showed higher death rates in people who are lower down the social class scale in their respective community. His close examination of population data from many countries supported the conclusion that countries with the best health, as measured by life expectancy, are countries where the differences between the social classes are small. Wilkinson's examination of large amounts of population data indicated that it is the differences in living standards within a developing country which influence the health status of its population, not differences in living standards between countries. There is no relationship between the mean income of a country and mortality. Instead Wilkinson finds that there is a relationship between mortality and income inequality. Wilkinson concluded that in the developed world, it is not the richest most affluent countries that have the best overall health, but rather it is the most egalitarian. Individual health is influenced not by the absolute standard of living, but by relative social position determined by income. This relative income inequality has become known as the effect of relative deprivation (Wilkinson, 1996).

Relative deprivation

Large scale epidemiological studies have lent support for the importance of relative deprivation on health (Kawachi, 2000). The Whitehall Studies (Marmot, Shipley & Rose, 1984; Marmot et al., 1991) have been a major source of data on the relationship between relative deprivation and CHD. Their first investigation studied the psychosocial variables influencing the health of British civil servants and the relationship with a range of health problems, including CHD (Marmot et al., 1984). Marmot et al. (1984) found a gradient in both mortality and morbidity which indicated that there was an indirect relationship between employment classification level and health. Marmot (2000) argued that because the participants in their study could all be reasonably expected to be living above the poverty line, it was not material poverty that led to their poorer health but relative poverty. The study also showed that this gradient in mortality could not be explained by the effects of traditional cardiovascular risk factors alone.

The Whitehall II Study, conducted 20 years later, further examined the role of psychosocial factors in a new cohort of workers (Marmot et al., 1991). This study found that differences between the socio-economic groups in the prevalence of angina and ischemia found in Whitehall I (classified from the highest status jobs to the lowest) persisted. There was an inverse relationship between employment grade and the prevalence of angina and ischemia. Among men, there was also an inverse relationship between employment grade and the number of symptoms reported. Perceived health status was also worse for both men and women in those employed in the lower grades. A 25 year follow up of the Whitehall II study has confirmed that the gradient in mortality from CHD between lower and higher grades of employment continued and that traditional

risk factors only explained one third of the variance between the groups (Marmot et al., 2000). Krantz and McCeney (2002) claimed that this gradient cannot be explained solely by pathways to disease which include access to medical care, living conditions, nutrition, or higher CHD risk factors.

In another prospective study conducted more recently in Finland, the relationship between socio-economic status and the mortality rates from CHD has been examined. Salomaa et al. (2000) used data from the Multinational Monitoring of Trends and Determinants of Cardiovascular Disease (MONICA project). Their analyses showed a higher prevalence rate of CHD incidence in the lower and middle-income group, when compared to the higher income group. Mortality in the lower income group from first myocardial infarction after one month was three times higher than in the highest income group. Similar results were found for both women and men. Salomaa et al. reported that their findings supported the importance of relative deprivation in the determination of health difference between income groups, rather than material deprivation.

According to Wilkinson (1996), the health gradients which result from relative deprivation are mediated by psychosocial factors. The links between social inequality and poor health are psychosocial. These psychosocial links concern the quality of social networks and individual responses to relative deprivation such as high rates of depression and anxiety. Wilkinson noted the importance of strong social networks amongst people in egalitarian communities where relative difference in social class and status are low. The health benefits of social cohesion, and therefore the quality of the social life, have consistently been shown by large scale epidemiological studies (Wilkinson, 1996). The next section will examine the relationship between social support and poor health in cardiac

patients. Social support has been studied both as a risk factor for illness and also as a variable which can affect recovery.

CHD and social support

Berkman and Glass (2000) provide a review of several large scale prospective studies across several countries which have consistently shown that social isolation and disconnection from others places people at greater risk of dying prematurely. According to House, Landis, and Umberson (1988), efforts to explain away the predictive association between social support and health have consistently failed. In a prospective study which assessed functional aspects of social support, Kaplan et al. (1994) found that mortality from CHD was higher in those who reported fewer people from whom they gave or received support, and in those who reported a low quality of social relationships. This remained the case when other traditional risk factors for illness and socio-economic status were controlled.

In a large scale study by Rosengren, Wilhelmsen, and Orth-Gomer (2004) low social integration and low emotional attachment to others were predictive of CHD, independently of other risk factors. With a particular focus on a functional analysis of social networks they conducted a prospective cohort study in Sweden of 741 men drawn from a random sample of all men born in 1933, including data on socio-economic status. Data was collected on all conventional risk factors including family history of heart disease. Data was also collected on numerous psychosocial variables which included a functional and structural assessment of social support and occupational status. Rosengren et al. found that social supports are protective of new coronary events over a period of 15 years. Occupational status (blue or white collar workers) did not affect incidence of CHD and the

relative risk ratios were not altered by the inclusion of data on occupational status or data on conventional risk factors. Rosengren et al. stated "of the social factors assessed, the availability of good social integration was the best protective factor with respect to coronary disease" (p. 59).

According to Rosengren et al. (2004), being socially integrated in this study meant "having perceived access to both practical help (tangible support) help to master difficulties in life (appraisal support) and having a sense of embeddedness by sharing values and interests with a group of people (belonging support)" (p.59). While the authors recognised that their study had several important limitations which reduced its generalizability, they concluded that social integration was confirmed as consistently being predictive of coronary heart disease in middle-aged men over a 15 year period. Rosengren et al. emphasised the need to consider social integration as a standard risk factor for the disease.

The influence of social networks and support on recovery from CHD has also been the object of study. In their review, Berkman and Glass (2000) concluded that the evidence for social networks or support being a causal factor in the onset of CHD was limited, but that this was not the case where survival and recovery from CHD are concerned. Berkman and Glass claimed that studies consistently showed the relevance of social support, for both men and women, older and younger and with varying degrees of disease, for recovery from CHD. They reported relative risk ratios of recurrent cardiac events or mortality between 1.5 and 3.4 for patients without lower levels of social and emotional support, depending on the study. They also noted that this research suggested the importance of belonging to informal groups where common values and collective

goals provide a sense of belonging for recovery and well-being after coronary heart disease.

Social support and life events

As described by Krantz, Sheps, Carney, and Natelson (2000) acute mental and emotional stressors have been identified as potent triggers of cardiac events and angina. Life event stress has also been studied as a predictor of CHD events. In a prospective study using a structured interview technique, Tennant (1994) found the relative risk rates of re-infarction or death ranged from 2.3 to 4.1 over 3 years for patients who had experienced acute life events after initial myocardial infarction. In his review of published prospective studies on the predicative value of social support and life events for CHD events, Tennant (1999) concluded that life events are also a significant risk factor for coronary heart disease, although the literature was based primarily on retrospective studies. The data from his review was more convincing for the role of social support. Tennant argued that social class (socio-economic status) was closely associated with poor social support and this had been poorly controlled for in previous studies of the impact of social support on CHD.

Tennant (1999) examined studies which had controlled for social status, along with traditional CHD risk factors. His review claimed that studies which controlled for social class continued to show a significant independent relationship between social support and CHD. He concluded that social support was a significant independent risk factor for CHD. According to Tennant, poor social support is not the medium through which life events affect CHD but both life events and poor social support appear to be independent risk factors. Tennant also noted the clinical importance of this finding for secondary prevention

because of the increased relative risk of CHD in those who are socially isolated or with significant life events.

CHD and depression

The interest in the role of depression in CHD has a long history. As early as 1973, Cassem and Hackett claimed that 75% of all cardiac patients showed evidence of clinical depression (Cassem & Hackett, 1973). Since that time, it has become generally accepted that depression plays an important part in the level of recovery in cardiac patients. Schleifer (1989) reported that up to 33 % of cardiac patients met criteria for either major depression or minor depression four months after myocardial infarction. More recently, studies have also begun to indicate that depression may be just as important as other traditional risk factors in the onset and development of CHD.

Several studies have found that the presence of depression places the cardiac patient at greater risk of further cardiac complications and higher rates of mortality. A meta-analysis by Booth-Kewley and Freidman (1987) showed that depression had the strongest association with eventual outcome of coronary heart disease, increasing both morbidity and mortality. In a landmark study, Frasure-Smith, Lespérance and Talajic (1993) conducted a prospective investigation of the association between depression and cardiac disease. They demonstrated that cardiovascular mortality was six times more likely six months after myocardial infarction in patients who were depressed during hospitalization, compared to those who were not. In a further study by Frasure-Smith, Lespérance & Talajic (1995), depression while in hospital remained a significant predictor of cardiac mortality 18 months after their heart attack. In a study by Levine et al. (1996) re-hospitalization was consistently found to be related to depression in cardiac

patients independent of disease severity. Levine et al. also noted the substantial costs to the community for their re-hospitalization.

Zellweger, Osterwalder, Langewitz, and Pfisterer (2004) recently reviewed the published literature on coronary artery disease and depression. Up to 25% of patients with acute heart attack had severe and recurrent depression, while between 27% and 65% of these patients had symptoms diagnostic of either major or minor depression. Zellweger et al. reported a growing number of studies demonstrating evidence of the effect of depression on prognosis in patients with heart disease and claimed that the relative risk of an adverse outcome (such as cardiac death) reported by these studies ranged from 2.5 to 5.7. They reported that one study showed depression to be as relevant to prognosis as left ventricular dysfunction and history of previous myocardial infarction. It was also as significant a predictor of cardiac mortality for women as well as for men, independent of other risk factors. Zellweger et al. also suggested that this effect on prognosis had been demonstrated in patients with angina. They concluded that there is considerable evidence to link depression with poor prognosis in heart disease and the most prominent finding is the increased mortality in patients after myocardial infarction.

Zellweger et al. (2004) also reviewed studies investigating the relationship between depression and the development of CHD. While the authors claimed that even though the early studies required careful interpretation, the relative risk for myocardial infarction in patients with depressive symptoms ranged from 1.5 to 4.5 compared to non-depressive patients within the same cohort. The increased risk was also present for those with minor depressive symptoms and dysphoria. Stansfield and Fuhrer (2002) provided a summary of the longitudinal prospective

studies which have provided support for depression as an antecedent of CHD. These studies have predominately used community samples and included both men and women. Adjustments are usually made for traditional CHD risk factors such as smoking, hypertension, blood pressure and cholesterol level. Stansfield and Fuhrer reported that the relative risk for cardiac events, including death, range, from 1.1 to 2.3 in men over follow-up periods of between six and 40 years. Stansfield and Fuhrer concluded that the "associations between depression and both the aetiology and the prognosis of coronary heart disease are convincing" (p. 120).

Social support, depression and CHD

Tennant (1999) suggested that depression may provide a mediating link between coronary heart disease and social support. He argued that a mood disturbance such as depression may be the causal mechanism which links poor social support and CHD. This hypothesis is supported by data which supports the demonstrated independence of social support as a predictive factor in CHD when socio-economic status is controlled. In a study which examined the impact of both depression and social support in patients with myocardial infarction, Frasure-Smith et al. (2000) collected data on depressive symptoms and perceived social support after heart attack and 1 year after discharge from hospital. While finding that those patients with high levels of depressive symptoms had a significantly increased risk of cardiac mortality, this was not the case for those patients who had high levels of perceived social support. Depressive symptoms were also likely to improve in those patients with good perceived social support.

When they examined individual aspects of social support, Frasure-Smith et al. (2000) found that having a greater number of close friends with whom they

had regular monthly contact with, and living with at least one or more people, were both independently related to improvements in depression over the 12 months. Frasure-Smith et al. recognised that the study had some limitations because it was a secondary analysis of previously collected data, but concluded that interventions aimed at social support for cardiac patients are warranted because of the positive effects it can have on depression.

Bosworth et al. (2000) undertook a study of depression and social support in patients admitted to hospital with confirmed CHD. They also collected information on negative life events and proposed that low perceived social support and more exposure to negative life events were likely to be associated with clinical depression. The study found that those patients who were depressed had experienced a greater number of negative life events and reported lower levels of perceived social support than non-depressed patients after considering other socio-demographic factors. The authors found no support for their main hypothesis. Instead they found evidence for the buffering effects of social support. The detrimental effects on mental health of negative life events can be buffered against by high levels of social support. Bosworth et al. claim that interventions which provide social support or mobilise existing supports may be particularly important for depressed patients with CHD.

A conceptual model linking social structural conditions with psychosocial factors and health

With a specific interest in the psychosocial pathways to health, Berkman and Glass (2000) have developed a conceptual framework which incorporates the structural (social and cultural) conditions with the psychosocial influences in the development of disease. In their model, they were concerned with trying to be

more precise about the relationships between social determinants of health, such as relative deprivation, with the psychosocial pathways that lead to poor health, in particular the impact of the social environment and social networks. Berkman and Glass extended the original conceptualisation of social network theory into a framework that can examine how an individual's relationships to others, and the broader community, might affect that individual's health.

Social networks are proposed to exist at the macro (social structural), the mezzo (social networks) and micro (psychosocial) levels (Berkman & Glass, 2000). The model incorporates "upstream" factors, the macro and mezzo factors, which condition the shape and nature of social networks, as well as the "downstream" factors, the micro factors, which influence the impact of social networks on interpersonal and social behaviour. Figure 1 shows the model as proposed by Berkman and Glass. The upstream factors include the larger social and cultural structures (macro) which influence the potential characteristics of the social network. These macro factors include cultural conditions and socio-economic factors. Social networks are therefore embedded (mezzo) within the larger social and culture structures of the community.

The downstream factors of social networks are then proposed to influence health via the mediating mechanisms of the psychosocial (micro) factors. Berkman and Glass (2000) propose five main mediating pathways for how social networks might influence health. The micro psychosocial mechanisms are then proposed to impact upon the health of individuals directly via either behavioural, psychological, or physiological pathways. These five pathways represent the ways that social networks operate on the individual and can then influence the behaviour and health of individuals. They are not mutually exclusive, but rather
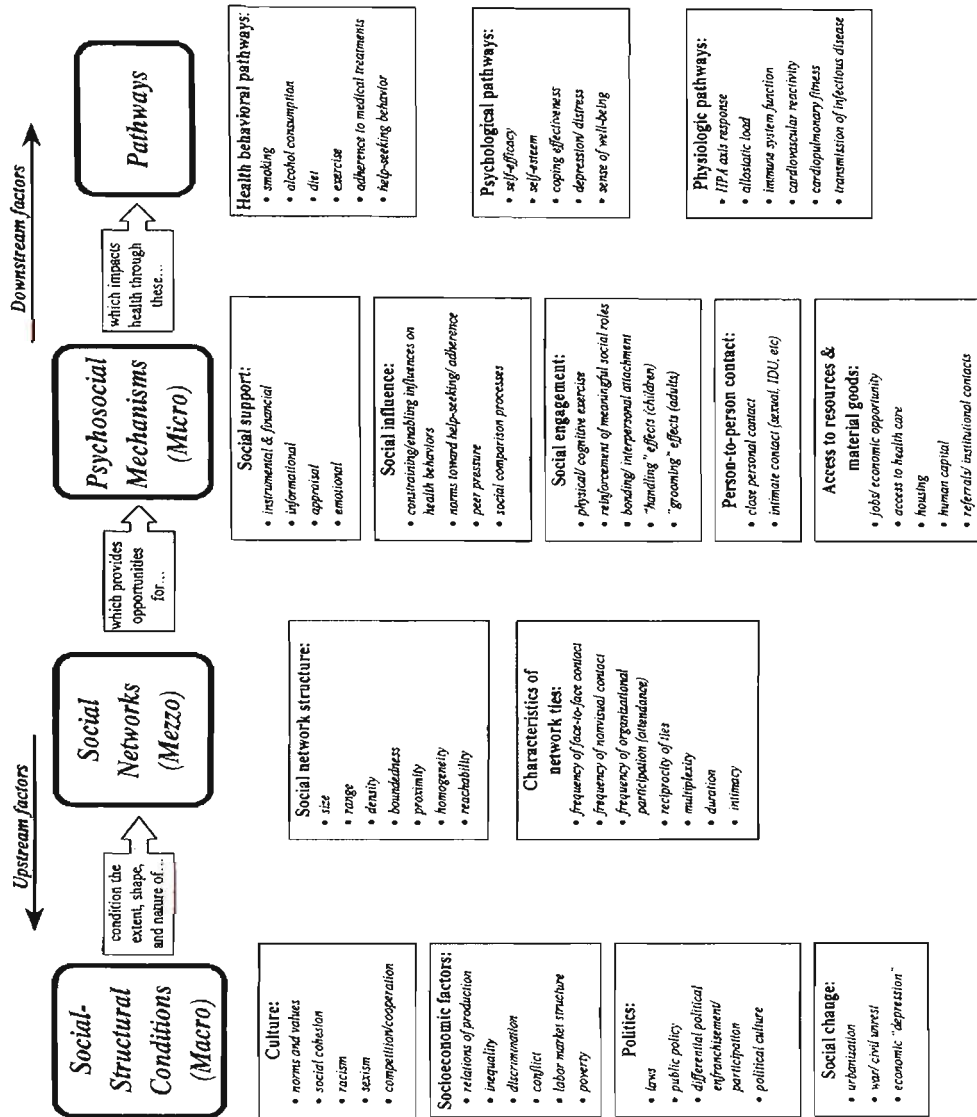
Figure 1: From Social integration, social networks, social support and health by L. F. Berkman & T. Glass, 2000. In L.F. Berkman & I. Kawachi, Social Epidemiology, p. 143.

are proposed to be more than likely operating simultaneously (Berkman & Glass, 2000). The five pathways are, social support, social influence, social engagement, access to resources and material goods and finally, person-to-person contact. Since CHD is not transmitted from person to person only the first four of these micro mechanisms will be discussed.

<u>Social support</u>

Berkman and Glass (2000) emphasised that their framework provided clarification about the influence of social support on health by embedding it within the broader social and cultural setting. They take the view that while many researchers have contributed to furthering the understanding of how social support is linked to health, social support is not the only critical aspect of social network theory. By permitting an examination of other potential pathways the model may in fact be able to explain instances where high levels of support and dense networks are linked to poorer health outcomes. The structural underpinnings in which social support is provided need to be examined. The positioning of social support as a downstream factor allows for the possibility that social support might not always be a positive influence on health and acknowledges that there can be variation in the type, frequency, intensity and level of support provided.

Berkman and Glass (2000) argued that social support is divided into four subtypes, which are all transactional in nature (involving giving and receiving). Instrumental support refers to assistance with practical needs, and can take the form of money or labour to help meet those needs. It is the help received or given for meeting tangible requirements. Informational support refers to the provision of supportive advice or concrete information in the service of a particular need. Appraisal support is assistance given to help in decision making and is aimed at helping a person come to a decision about the correct course of action. Finally, emotional support refers to the care and understanding provided to a person, usually by a close confidant or partner. Another important consideration in social network theory is the differentiation between cognitive and behavioural aspects of social support (Berkman & Glass, 2000). This is a differentiation between what

social support is perceived by the person to be available and what level of support is actually received when needed.

Social influence

Social influence is the second of the mediating psychosocial mechanisms proposed by Berkman and Glass (2000). This is the influence of shared norms of behaviour on another person's behaviour. Attitudes are either confirmed or altered as a result of comparison with a reference group and this is most critical where there is ambiguity or uncertainty about a course of action or attitude. This aspect of influence upon health comes from the influence of the network's values and expectations.

Social engagement

The third mechanism proposed by Berkman and Glass (2000) is social engagement. Social networks provide opportunities for engagement with others and this defines, and reinforces, meaningful social roles such as family occupational or community roles. This then provides a sense of esteem and value characterised by feelings of belonging and attachment. Engagement results from the enactment of "real life activity" (p. 146) and includes being with friends, joining social groups and attending social functions. Participating in a meaningful social context with others allows the possibility of companionship and integration which has consistently been shown to be a strong predictor of mortality in studies of illness adjustment (Rook, 1987, cited in Berkman & Glass, 2000). Berkman and Glass argued that the benefits of social engagement are not the result of the wider influence of social support, but that social engagement is beneficial in and of itself because of the importance of meaningful social contact with others. The social ties with others provide interdependent obligation and opportunities to feel

attached to the community in which one lives. Meaning and coherence is provided by ties to engagement with others.

<u>Access to material resources</u>

The fourth mechanism proposed by Berkman and Glass (2000) captures the influence that access to material resources and information has on health. Social networks provide access to services and information and this access is sometimes provided in the overlap with participation in social groups which provide engagement opportunities. These groups can include, but are not restricted to, employment based groups, including trade unions, support groups or religious groups. Berkman and Glass (2000) stated that this pathway is closely tied to instrumental social support and appraisal but suspect that further research in this area may demonstrate a link with social networks which is not defined by social support alone.

The psychosocial impact of immigration on health

Large scale immigration to Australia in the last century now means that 23% of Australians were born overseas (ABS, 2004). The 2001 census data from the Australian Bureau of Statistics also showed that immigrants from Italy made up the largest group of immigrants living in Australia, other than those from the United Kingdom, Ireland or New Zealand. The various theoretical perspectives on the effects of immigration on health and on mental health have been summarised by Ekblad, Kohn, and Jansson (1998). Ekblad et al. noted that immigrants often migrate to countries with a different culture to their own and that this requires facing difficulties acquiring a new language, learning new social customs while trying to adjust to their new resident country. While

conceptualising adjustment to these difficulties as being the ability to acculturate, or to adopt the culture of the new country, Ekblad et al. identified anomie, or the breakdown and loss of usual cultural systems and beliefs, as critical to the poor health of immigrants and refugees.

Anomie was first proposed by Emile Durkheim as one of the underlying social mechanisms which posed a risk for suicide and poor mental health (Stengal, 1964). According to Ekblad et al. (1998), immigrants to a new country need to adapt to new social and cultural domains, often losing their own social supports. The process requires that they abandon their shared cultural beliefs for new ones. In this approach, adaptation to a new country is seen to be the extent to which new immigrants acquire the cultural beliefs and practices of their new country. This breakdown, or loss in the case of immigrants, can resemble the anomic situation described by Durkheim and places immigrants at an increased health risk.

An alternative conceptualisation of immigrant adjustment has been proposed by Sonn (2002). Rather than conceptualise adaptation to immigration by analysing the shifts in attitudes and behaviour of people towards or away from old and new communities and practices, Sonn argued that immigration adaptation can be conceptualised as the capacity to maintain or to participate in a sense of community with others who share cultural settings, activities, and beliefs. While this approach also highlights the potential adverse effects of anomie as a result of a breakdown of structural social supports, it is more consistent with social network theory proposed by Berkman and Glass (2000). Sonn emphasised the centrality of larger social and community structures to be included when the impact of social and psychological factors on the sequelae to immigration are considered. A failure in the capacity to maintain and participate in a sense of

community can have adverse consequences on health. Jablensky (1992, cited in Ekblad et al., 1998) identified poor physical health as a risk factor for immigrants. This included unattended chronic illnesses, such as CHD. Socio-economic disadvantage, the collapse of social supports and marginalisation from the broader community are also listed by Jablensky as consequences of immigration.

Ethnic inequalities in health can largely be attributed to socio-economic differentials and relative income (Nazroo, 1998). Nazroo has argued that these inequalities in health are the result of relative deprivation and not caused by genetic factors or culture-specific behaviours. Shaw, Dorling, and Smith (1999) noted the relevance of relative deprivation for the health of disadvantaged groups relative to the broader community in which they belong. These groups include immigrants to a culturally diverse country and ethnic minorities. Shaw et al. proposed that explanations for the effect of relative deprivation on health can be found in constraints on the material conditions of life compared to others in society, including opportunities for social activities. Social exclusion often results from the economic hardship of relative deprivation and this term has been used to describe the marginalisation of individuals from various aspects of social and community life, including access to an acceptable supply of services or the opportunity to make a contribution to society (Shaw et al., 1999).

Several large scale epidemiological studies of the relationship between immigration and changes in blood pressure (a traditional risk factor for CHD) have been summarised by Elford and Ben-Shlomo (2004) in an attempt to explore the relative importance of later life environmental influences compared with early life factors in the development of coronary heart disease. Studies conducted in New Zealand, China, Israel, and Africa have shown that those people immigrating

to geographical areas with higher average blood pressure than their own original community will soon develop higher blood pressure, which is not seen in their counterparts who remained in their country of origin. These results could not be explained by selective migration, that is, a fundamental difference between those who immigrate compared to those who remain behind. Elford and Ben-Shlomo (2004) concluded that early life factors are not as important as later life factors in the development of CHD. While these studies do not specify what environmental or psychosocial factors led to the increase in blood pressure, they underscore the important impact that the cultural shifts required of immigrants can have on their long term health.

Summary

Psychosocial factors, such as poor social support, social isolation and depression have become increasingly accepted as independent risk factors for the onset and prognosis of CHD. Psychosocial factors have been implicated as the mediating processes for the influence of social conditions and relative deprivation on poor health. The conceptual model of Berkman and Glass (2000) provided an understanding for the relationships between macro social factors and the micro psychosocial factors which cause poor health. The model demonstrates the essential role played by social networks in the determination of health and healthy behaviours. It also proposed that the larger structural features of communities are implicated in the quality and quantity of social networks available to individuals.

Immigrant groups who have experienced large-scale social and cultural change as a result of leaving behind regular supportive networks are vulnerable to the effects of long standing poor social support and the consequential poor health. Language barriers may also mean that they have reduced access to the health care

system and their health care needs can remain misunderstood and poorly treated. Immigrant groups, such as the group of post World War Two Italian immigrants to Australia are a relevant group for study because of the potential problems they face in accessing secondary prevention programs as well as the likely adverse health effects they have experienced from the influences of relative deprivation and poor psychosocial adjustment in a new country.

The next chapter will present a cognitive model for the study of illness beliefs and coping that can explain how cultural and social factors can influence perceptions of CHD and illness behaviour. The Common Sense Model of the self-regulation of health and illness (CSM) provides a dynamic, self-regulating framework in which personal experiences and consequential meanings can be represented in cognitive representations of health and illness (Leventhal, et al., 2003).

Chapter 5

The Common Sense Model of the self-regulation of health and illness: A dynamic theory of health behaviour

In Chapter 2, it was argued that lay meanings of health demonstrated how good health can take a variety of meanings which differ from the simple biomedical definition of the absence of disease. Health and illness are also subjective experiences, which also influence the health behaviours of individuals. Chapter 3 outlined how individual perceptions of health and the subjective experience of CHD can affect decisions to attend cardiac rehabilitation and the success of behaviour change. Chapter 4 reviewed the role of psychosocial factors in the onset and recovery from CHD and emphasised the importance of relative deprivation and social support in the development of poor health. Psychosocial factors are proposed by social network theory (Berkman & Glass, 2000) as the mediating links between large social structures and poor health. The relevance of this approach to immigrant populations, which have consistently been found to be poor attendees of cardiac rehabilitation programs, was also discussed. This chapter will introduce a theory of the self-regulation of health and illness which places the dynamic nature of the interplay between the lived experience of illness and the active problem-solving capacity of individuals at the centre of its propositions.

The Common Sense Model of the self-regulation for health behaviour (Leventhal, et al., 2003) allows the important contribution of social and cultural influences on cognition to become part of the understanding of how people respond to illness. This makes the model particularly suitable in the consideration of the health practices and illness experiences of culturally-diverse communities,

such as those who have emigrated from countries where shared understandings of health and illness are different from the culture of their adopted home.

Karoly (1985) has drawn attention to the limitations of conceptual efforts to understand individual health behaviour. According to Karoly, the emphasis on trying to teach patients new ways of thinking about their behaviour and their health in health psychology has largely been unsuccessful. Karoly attributed this failure to a bias towards the study of the contents of the individual's beliefs and attitudes rather than a concern with how people come to think about their health and response to illness. Models of health behaviour have contributed to our understanding of situational factors and factors that focus upon the content of health beliefs and attitudes but little on the cognitive processes that lead people to develop their attitudes to illness and the part played by the active problem-solving agency. Karoly identified the Common Sense Model of health and illness as one approach which has been able to make propositions about cognitive processes where health and illness episodes are concerned.

The Common Sense Model of the self-regulation of health and illness (CSM)

The CSM is a theory of illness cognition and the manner in which people develop illness representations. The theory developed from the work of Leventhal, and his colleagues, from their efforts to understand the impact of fear messages on beliefs and attitudes (Leventhal & Diefenbach, 1991). They concluded that where illness threats were concerned, fear messages had a variety of short tem effects on beliefs and behavioural change but these changes were not durable and longstanding. Early studies conducted by Leventhal showed data that was "not consistent with the hypothesis that fear reduction reinforces and creates stable attitudes that lead to durable action" (Leventhal, et al., 1997, p. 20). This

71

led to the development of the illness representation model which incorporated parallel processing of affective and cognitive components of health threats.

The CSM allowed the individual to be able to construct their own representations of illness and health which then helped them to make sense of their own particular experience. Illness representations become important for helping to understand the illness experience across the entire trajectory of the illness, from the interpretation of symptoms to response to treatment (Weinman & Petrie, 1997). Leventhal, et al. (1997) claimed that other models for understanding health behaviour, which lacked a substantial effort to account for cognitive and emotional representations of illness, are incomplete. Models such as the Health Belief Model and the Theory of Reasoned Action have also been criticized because of their static approach to attitudes and beliefs, rather than acknowledging the dynamic nature of human cognition (Pitts, 1998). Both these approaches have also been criticized for a lack of operational consistency by researchers (Radley, 1994).

There are a number of assumptions about the human subject made by Leventhal and Nerenz (1985) which underlie the model.

1. people are active problem solvers, not passive responders to their environment. Their behaviour is directly related to their perceptions and interpretations of stimuli. Experience and behaviour reflect an interaction between the environment and knowledge drawn from both the cognitive and emotional aspects of the person (memory schemata). This process gives rise to the perceptions and representations which constitute the essence of the CSM.

2. for the most part, this processing and refinement of the knowledge

   base is not observable. Only the output is observable, that is,

   behaviour, speech and physiological actions.

3. construction and responding to specific illness problems has a time

   frame. There is a beginning and an end to the process of construction

   and refinement of representations.

4. both situational and individual factors are required for illness

   representations and their refinement is also influenced by both. The

   impact of unique circumstances and individual variation can lead to a

   vast array of common sense models, which makes prediction difficult.

<u>The dynamic theory of the self-regulation of heath</u>

An important characteristic of the model, which distinguishes it from other

models of health behaviour, is its dynamic nature. Its dynamic nature comes from

its capacity to incorporate the self-regulation of the system. The self-regulating

system is capable of testing its current status against a reference and can then act,

or produce an output, which is then able to provide information back to the system

to allow refinements of the input against the reference (Leventhal, et al., 2003).

The CSM adapts this self-regulation principle and applies it to the understanding

of the purposeful actions of people to protect their health. The CSM provides the

details that can begin to articulate the cognitive and emotional variables that

determine how identified goals are achieved.

Self-regulation theory proposes that people will behave in particular ways

in response to illness that are based upon their illness representations. The CSM

consists of two parallel processes that interact with each and are both self-

regulated. A diagram of the model is shown in Figure 2. Health threats generate

73

an emotional response, normally a fear response, and the corresponding need for

procedures to manage these responses. The second process which occurs

simultaneously is the generation of the cognitive representation which reflects the

representation of danger (Leventhal, et al., 2003). Procedures for the management

of this threat are derived from the five domains of mental representation of the

health threat. In both the affective and cognitive processes, appraisal functions as

part of the self-regulation process and allows the efficacy of the action plans to be

assessed and representations refined accordingly. Individuals are conceptualised

as actively thinking about their health threats, how to control their threat and the

fear at the same time.
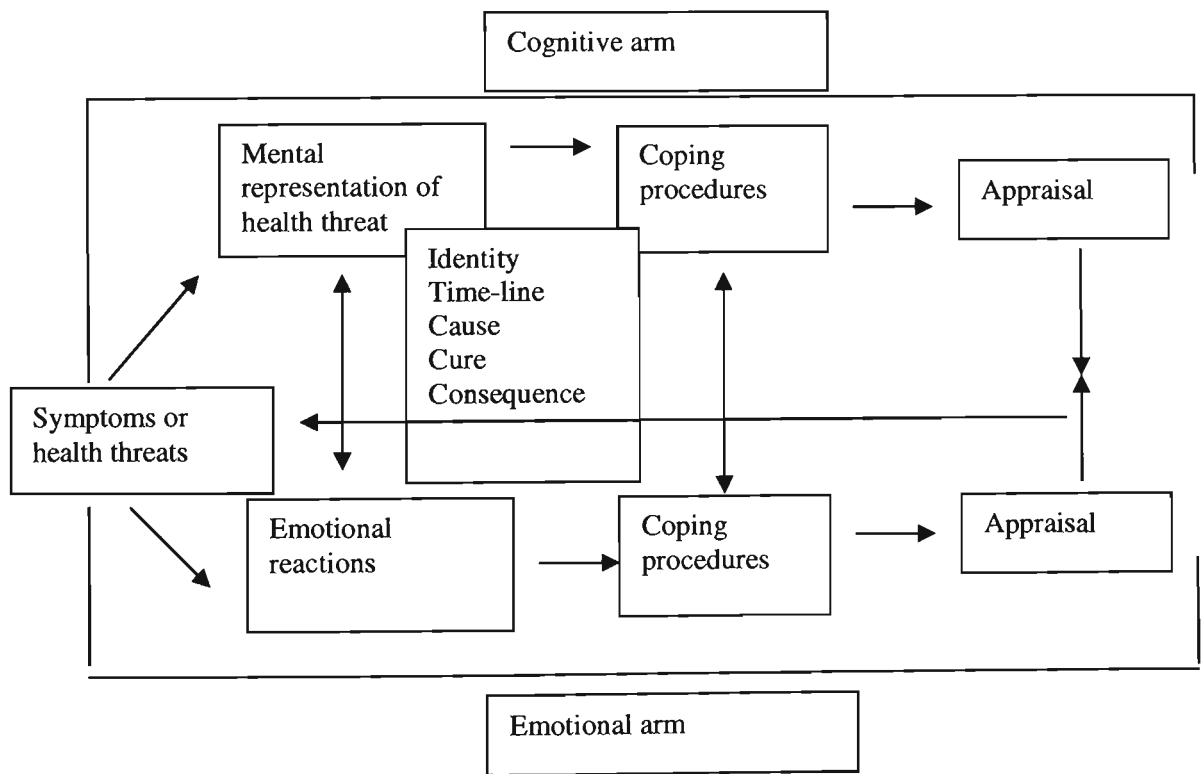
Figure 2: Leventhal's Common Sense Model of health and illness. Printed in
Shifren, K. (2003) and reproduced from "Psychosocial factors in medication
adherence: A model of the Modeler" by E.A. Leventhal, H Leventhal, C
Robitaille & S Brownless, 1999. In D.C. Park, R.W. Morrell & K. Shifren's
Processing of Medical Information in Aging Patients, p. 48.

74

<u>Five domains of illness representations</u>

Figure 2 also shows the five illness representations as proposed in the Common Sense Model of health and illness. These five domains have commonly been identified with the representation of danger posed by health threats. Four of these (identity, consequences, causes and timeline) are attributed to the work of Leventhal and his colleagues (Leventhal & Nerenz, 1985). The fifth one, representations of illness cure, was added by Lau and Hartmann (1983, cited in Leventhal & Nerenz, 1985). Knowledge about threats to health are represented by each of the five domains. Illness representations contain both semantic and perceptual information about the illness. This includes labels and names (e.g. "I have the flu") and the perceptual somatic experiences, (e.g. "I'm feeling feverish and have aches and pains). The five illness domains are each described below and are based on descriptions from Leventhal and Nerenz (1985).

The Identity-representation represents the collection of variables that identify the presence of an illness, as described by symptoms or labels. Consequence representations are the perceived physical, social and economic consequences of the illness, including the emotional results. Representations of Causes are the perceived causes of the illness, which can range from the role of pathogens, genetic causes, social or personal causes, bad luck or fate. Timeline reflects the expected duration of the illness and is implicit in every action or coping procedure. Finally, representations of Control represent the extent to which the illness is perceived as curable or able to be controlled by the individual. The five illness representations produce coping procedures which then are appraised. Appraisals of the effectiveness of coping are then returned towards the reorganization of those mental representations.

75

<u>Coping and procedures in the CSM</u>

In the Common Sense Model of health and illness a distinction is also made between coping with illness and the coping procedures adopted to cope with a health threat. Leventhal et al. (1997) identified the reasons why this distinction is important for illness representations. It allows for the consideration of procedural (implicit) knowledge which is independent of conscious thought. Procedures are not imbued with a positive valence, as is coping, by lay people. The use of the word "procedure" does not imply any special virtue to the response to or control of illness. Leventhal et al. (2003) also noted that the use of the word procedure avoids the "pitfalls" associated with the vast literature on coping. Most importantly, procedures for coping with health threats are linked to the representations associated with it. This means that procedures are linked to a set of beliefs and cultural practices. It allows for greater precision when considering how people make selections about how to cope with health threats by connecting the coping strategy with the existing illness representations.

Procedures are, therefore, influenced by these representations, which in turn are influenced by personal experience and cultural effects. Representations shape procedures and this is most evident in folk cures and home remedies which have become part of shared cultural beliefs in all cultures. When procedures are linked both to the representation and to the action plan, "the self-regulation system is complete and coherent" (Leventhal, et al., 2003, p.53). The example provided by Leventhal et al. shows the connections between the various components of the model and is shown below.

If I am suffering from a headache (identity) due to a bad day at work (cause; timeline) then taking two aspirins (procedure) should eliminate the pain (consequences; control) in 20 to 30 minutes (timeframe).
(Leventhal, et al., 2003)

Illness representations and chronic illness

The study of illness representations in patients with chronic illness has continued to increase since the work of Leventhal and his colleagues. Scharloo and Kaptein (1997) conducted a review of the published studies which have described the illness perceptions of adult chronically ill patients between 1985 and 1995. They used several search terms such as cognition, beliefs, attributions, meanings, and connected them with chronic illness or disease. They collected a large number of studies (101) that met their criteria. Scharloo and Kaptein concluded that illness representations have been increasingly studied in many different groups of patients with various conditions. These conditions included chronic pain, rheumatic diseases, such as arthritis and fibro myalgia, respiratory conditions such as asthma, diabetes, cancer, AIDS and nervous conditions such as epilepsy. The illness perceptions of cardiovascular patients (myocardial infarction and hypertension) have also been frequently researched (Scharloo & Kaptein, 1997). Studies which have specifically examined illness perceptions and representations of cardiovascular disorders will be reviewed in the next section.

Illness representations and CHD patients

Sex and age differences have been found in the illness representations of cardiac patients (Gump et al., 2001; van Tiel, van Vliet, & Moerman, 1998). van Tiel et al. found that CHD was generally thought of as a man's illness by both women and men, and men considered their risk of CHD to be lower than an

estimated probability. Both men and women did not attribute symptoms of CHD to their heart. Women also had a long patient delay time in response to cardiac symptoms. Gump et al. studied patients awaiting coronary artery bypass surgery. The findings of this study indicated that older patients were more likely to attribute their CHD to old age when compared to health behaviours and significantly more likely to believe that they had little control over their illness. Gump et al. also found that older patients reported fewer post-operative behaviour changes than younger patients.

Pattenden, Watt, Lewin, and Stanford (2002) have also shown that perceptions of the symptoms of myocardial infarction (MI) affect the patient's decision to seek medical attention. They concluded that knowledge of cardiac symptoms, in and of themselves, may not be enough to ensure proper action is taken in the event of a cardiac event. The decision to seek treatment in an emergency is a complicated process which includes the influence of individual beliefs, emotional responses and the broader situational variables surrounding the event (Pattenden et al., 2002).

Gilutz, Bar-on, Billing, Rehnquist, and Cristal (1991) collected interview data from patients following myocardial infarction in both Israel and Sweden. The relationship between the type of causal attribution and rehabilitation was examined. Three causal attribution clusters were identified by the authors. They were the "fate and luck" cluster, the "limits and strengths" cluster and the "physical model" cluster. The study found that when independent variables such as age, education level and depression were controlled, patients who attributed their infarction to uncontrollable factors (the fate and luck cluster) had a lower rate of subjective rehabilitation six months after the infarction. Gilutz et al. also

found that patients who perceived that they had some responsibility for the development of the illness were more likely to report more successful rehabilitation. Gilutz et al. argued that because these patterns appeared to be independent of other factors, such as age, education level, MI severity and depression, that they should be considered independently in the rehabilitation process. They also noted that these findings were cross cultural because they were found in both groups of patients from Israel and Sweden.

In a study of cardiac patients and the interaction of appraised control over CHD with situational variables outside of personal control, Fowers (1994) found that contextual variables were more important than the effects of perceived control in the adjustment to cardiovascular disorders. Situational variables were measured using several instruments which provided an assessment of serious life events, affective disturbances such as depression and anxiety. When these background and situational variables were controlled, the study did not find a significant relationship between any of the measures of a sense of control and psychological adjustment to illness. Fowers highlights the importance of considering specific individual context when adjustment and recovery from illness is explored and that these contextual factors can be regarded as more important influences on adjustment than whether or not there is a perception of controllability.

Weinman, Petrie, Sharpe and Walker (2000) assessed causal attribution of myocardial infarction in patients and their spouses, and this was examined again with health-directed behaviour changes after six months. They found that infarctions were most frequently attributed to "stress", high levels of cholesterol and risk behaviours such as lack of exercise and eating fatty foods. There was

general agreement between spouses and patients in the causal attributions. Behaviour change scores were computed for each patient to allow comparison of the causal attribution scores and changes in health behaviour. Those patients who attributed their condition to lifestyle factors were more likely to have made more healthy behaviour change six months after their infarction. Weinman et al. (2000) concluded that there may be some benefit in eliciting causal attributions of cardiac patients to help in the planning of secondary interventions.

CSM and cardiac rehabilitation

The contribution and relevance of individual beliefs and perceptions about illness to attendance at cardiac rehabilitation programs have been studied using a variety of theoretical approaches (Cooper, Jackson, Weinman & Horne, 2002). The following section will focus upon studies that have used Leventhal's Common Sense Model of the self-regulation of health and illness as a means of providing a framework for the study of illness perceptions as factors in recovery from cardiac illness and the decision to attend cardiac rehabilitation programs. As shown in Chapter 3, the decision to attend cardiac rehabilitation programs is influenced by the individual experience of cardiac illness.

Petrie, Weinman, Sharpe and Buckley (1996) used various self-report questionnaires, to examine the relationships between illness perceptions and recovery from myocardial infarction. Attendance at cardiac rehabilitation was also examined. Participants' perceptions of illness (identity, timeline, consequences and controllability) were ascertained on admission to hospital and again three and six months later. Data on overall disability, including the time taken to return to work and overall functioning levels were collected. Petrie et al. (1996) found that patients who did not believe that their illness could be

controlled were significantly less likely to attend a cardiac rehabilitation program. There was also a trend for these patients to be less concerned about their heart attack and to perceive fewer consequences on their health as a result (although this result did not quite reach statistical significance). Patients who believed that their illness had fewer consequences and that their illness would last only a short time were able to return to work sooner. Overall functional disability was seen to be highest in patients who perceived themselves to have a greater number of consequences as a result of their illness.

Petrie et al. (1996) made some important conclusions about the importance of illness perceptions from this study. First, they found that illness beliefs are relatively stable over time and are largely unaffected by information provided to patients at hospital admission or later during cardiac rehabilitation. These illness perceptions are, therefore, likely formed well before becoming ill. Second, their results support the important part played by illness perceptions as demonstrated by the greater influence they have over recovery, when compared to the anxiety generated by the onset of illness, and the severity of the infarction. They concluded that it was the meaning attributed to the experience of illness, rather than the severity of the infarction itself, that had a greater influence on recovery and adaptation during rehabilitation. Finally, they noted the potential for the existence of differences between the beliefs of the medical staff and the largely unknown beliefs of the patients.

Cooper, Lloyd, Weinman and Jackson (1999) provided support for the importance of perceived controllability as a factor influencing attendance at cardiac rehabilitation. Their study was also a prospective study which included patients admitted to hospital for coronary artery bypass graft surgery (CABGS) as

well as those admitted for myocardial infarction. Cooper et al. were specifically interested in factors affecting attendance at cardiac rehabilitation so a variety of socio-demographic variables were collected, along with information about the patient's risk profile and history of coronary hear disease. Data was collected via self-report questionnaires at discharge and after six months.

Cooper et al. (1999) found no differences between the CABGS patients and the myocardial infarction patients on any of the socio-demographic variables or in illness perceptions. This supports the notion, as proposed by Petrie et al. (1996), that illness perceptions are formed prior to illness, likely based upon beliefs and knowledge informed by the social and cultural forces surrounding the person. Where illness perceptions were concerned, Cooper et al. also found that those patients who believed that they had some control over the course of their illness were more likely to attend cardiac rehabilitation. They also found that patients who attended were significantly more likely to believe in the importance of lifestyle factors as the cause of their illness. The study also found that patients who were older, unemployed and unaware of their blood cholesterol level were less likely to attend cardiac rehabilitation.

Cooper et al. (1999) noted the potential value of assessing illness perceptions in cardiac patients as a part of the overall rehabilitation and recovery phase. They proposed that information concerning illness perceptions could be used to assist the development of interventions in cardiac rehabilitation and identify those patients who may be less likely to attend for rehabilitation programs. The aim of such interventions would be to improve attendance at cardiac rehabilitation programs and the likelihood of long term behaviour change.

In a third study of illness perceptions of cardiac patients and their relationship to cardiac rehabilitation, Whitmarsh, Koutantji and Sidell (2003) investigated the influence of coping styles on the decision to attend rehabilitation programs to determine whether it increased the predictability of the CSM in attendance at cardiac rehabilitation. Unlike the previous studies (Cooper, et al., 1999; Petrie, et al., 1996) illness perceptions were not assessed during their initial hospitalization, but rather just prior to the beginning of the cardiac rehabilitation program. The study also collected data on coping style using a self-report questionnaire.

Whitmarsh et al. (2003) found that those participants who attended the program were found to significantly report more cardiac symptoms. Those patients who attended were also found to believe less that their illness had been caused by a germ or virus when compared to non-attendees. Significant predictors of non-attendance were a lower number of identified symptoms and poor controllability of the illness. Where coping style was concerned, attendees used a more adaptive problem-focused coping style more frequently than those who did not attend. Low frequency of an adaptive coping style was an independent predictor of non-attendance. Whitmarsh et al. concluded that the addition of knowledge about coping style to knowledge of illness perceptions improved the prediction of attendance behaviour for cardiac rehabilitation and that the further addition of demographic and social variables, such as relative deprivation, would strengthen the model even further.

The influence of social and cultural forces in CSM

The important part played by social processes in the Common Sense Model of self-regulation is also highlighted by Leventhal et al. (2003). The self-

83

regulation of health and illness behaviour is dependent on the input of others and self-regulation is not carried out in isolation. This is because social and cultural forces shape the illness representations and the procedures that are linked to them. People actively use the medical system and are subject to the cultural system to which it belongs. People also turn to others to determine whether or not they should indeed seek medical treatment and to make comparisons about the nature of symptoms. Social and cultural forces can also set the reference points for individuals to try to reach in the regulation of their health behaviour. According to Buunk and Gibbons (1997, cited in Leventhal et al., 2003), "self-regulation is inherently social" (p. 55).

Leventhal et al. (2003) claimed that cultural and social factors influence the shaping of illness representations in two ways. The first way is through the use of language, which helps to organise the large array of events that constitute illness. The second way is through the use of specific social contacts, such as family, friends and the medical system, to influence the interpretation of somatic symptoms and which procedures are then employed to manage the health threat.

Cultural influences on the understanding of the Common Sense Model of illness and the underlying self-regulating mechanisms have been proposed to be essential by Baumann (2003). According to Baumann, as active problem solvers, individuals are constantly making meaning of their experience which always involves cultural forces. This activity involves the interpretation of somatic sensations and experiences, deciding how to respond to manage the experiences and also evaluating the outcome. For Baumann, this activity makes cultural factors intrinsically relevant to self-regulation theory. Baumann stated;

The culture and the experiences of the individual are melded in their mental representations and health practices through the processing of information about the external and internal environments. (Baumann, 2003, p.243).

Steed, Newman and Hardman (1997) confirmed the importance of cultural factors in the development of illness representation. Their study was aimed at trying to closely examine the origin of these illness representations which constitute the self-regulating system. They did this by comparing the illness representations of symptomatic with asymptomatic atrial fibrillation patients attending clinics. Steed et al. found that, with the exception of illness identity, there were no differences between symptomatic and asymptomatic patients in illness representations. Symptom status and symptom chronicity did not influence illness perceptions. Steed et al. concluded that these patients relied more on the social and cultural explanations to elaborate the experience of their illness than actual somatic symptoms. Rather than finding that symptoms influence illness representations, Steed et al. proposed that the reverse may be occurring, that illness representations influence symptoms.

Illness perceptions are also unchanged by acquiring factual knowledge about cardiac disease and risk factors. Haugbolle, Sorenson, and Henriksen (2002) have shown that negative illness perceptions are not associated with limited factual knowledge. Haugbolle et al. noted that the acquisition of illness perceptions is not explained purely by acquiring factual knowledge, likely being much more complicated. This study also suggested the important part played by established cultural beliefs and attitudes in the development of illness representations.

The cultural background of the individual plays a critical role in the process of organising meanings for physical sensations and can therefore be regarded as forming the basis of illness representations and beliefs (Baumann, 2003). The influence of shared cultural beliefs in health and illness is typified by the notion of folk illnesses (Baumann, 2003). These reflect cultural constructions of illness remedies which are evident in the lay explanations of health and illness. These constructions provide procedures and guidelines for the self-regulation of health and illness. Cultural constructions exist in all groups of people, including those who adopt a purely biomedical approach to the understanding of illness. The modern biomedical approach itself can be considered a collection of culturally shared beliefs which help define and guide health and illness behaviour. (Radley, 1994)

The CSM of the self-regulation of illness is therefore a good approach to adopt when exploring the perceptions of health and illness adopted by individuals who are likely to have different beliefs about health and illness. The CSM proposed that the system of identifying and coping with health threats is a self-regulating one which provides a coherent "common sense" understanding of the nature of the health threat. The CSM is therefore able to conceptualise the importance of personal experiences in illness, as they affect the self-regulation of health behaviour and the creation of illness representations based upon cultural practices. This in turn can provide information about how best to ensure the maximum opportunity for treatment and help to develop appropriate secondary prevention programs. Leventhal et al. (2003) claimed that the future relevance of the CSM model would be determined by its ability to contribute to planning

effective interventions for improving the health status and coping capacities of

people with chronic illness.

Chapter 6

Rationale and research questions for the present study

A cardiac rehabilitation program conducted in the Italian language for Italian speaking immigrants has been available in Melbourne since 1999. The Italian Healthy Hearts Program (IHHP) is one of few cardiac rehabilitation programs specifically for non-English speakers in Victoria. The momentum for the present study was in part due to the growing concern from program staff about the suitability of the present approach to cardiac rehabilitation for a non-English speaking population such as Italian immigrants. An investigation into the illness experience and health perceptions of this group could assist the development of not only the IHHP program but provide valuable information for the development of other cardiac rehabilitation programs for non-English speaking groups.

Programs such as the IHHP draw heavily upon a risk factor-reduction approach to health and illness and provide a prescriptive approach to health behaviour change. As noted in previous research, this approach to secondary prevention has the potential to minimize the individual's own perspective on the cause of illness and the circumstances surrounding his or her experience of CHD. Cardiac patients from culturally-diverse groups such as Italians, represent a group of people from diverse cultures with the potential for a variety of different culturally-derived beliefs about health and illness. These beliefs are likely to influence their patterns of health preventive behaviour and the likely success of secondary prevention programs such as cardiac rehabilitation.

The potential for a mismatch between this prescriptive approach to cardiac rehabilitation and the individual needs and circumstances of the culturally-diverse cardiac patient can contribute to low attendance rates and poor health outcomes.

Culturally-diverse groups provide an exemplary challenge to health clinicians, not solely to ensure that they have the provision to engage in rehabilitation services but also to assist cardiac rehabilitation programs to become more efficacious by becoming more attuned to the patient's individual needs.

Italian immigrants with cardiac illnesses are an important group to include in research on CHD for several reasons. First, Italian immigrants in Australia are the largest non-English speaking group of immigrants in Australia (ABS, 2004). Attention to those groups of immigrants who arrived in Australia after the world wars appears timely given that they are now becoming elderly and likely to be regular users of the health system. Second, immigrant groups such as Italians, represent a group with a different cultural origin and a different set of cultural beliefs which has an important influence on their experience of health and illness. A better understanding of the experiences of health and illness in this particular group may provide opportunities for program development, as well as improved recovery and rehabilitation outcomes. Reviews of published literature have indicated that the health and illness experiences of Italian cardiac patients living in Australia has not been systematically investigated.

Third, Italian immigrants represent a group who are likely to have experienced adverse effects on their health as a result of being immigrants. Psychosocial factors which contribute to the onset and development of CHD, such as social isolation and depression, can arise from the relative social and economic deprivation and exclusion which characterises the immigration experience. Groups of immigrants are subjected to these social and economic forces as a result of their status as immigrants and may be more likely to develop chronic illnesses such as CHD as a result. Poor knowledge of the English language may also deny

them the proper use of available health services, further adding to the potential for poor health.

Research Questions

Within this context, the present study was designed to explore the health and illness experiences of participants from an Italian-language phase two cardiac rehabilitation program. The research questions were formulated for the exploration of the specific experience of individual good health and the various meanings that were attributed to good health, including how their perception of good health influenced recovery and adjustment from CHD. Illness beliefs and perceptions were explored using the Common Sense Model of the self-regulation of health and illness (Leventhal et al., 2003). The Common Sense Model of the self-regulation of health and illness is well suited to the exploration of the health and illness beliefs of culturally diverse groups because it provides a framework for understanding how cultural beliefs and their corresponding illness representations impact upon response to recovery and rehabilitation. Finally, the views of the health specialists were also sought to explore their perspective on the needs of this specific group of cardiac patients and the extent to which these needs are met by the IHHP in its present form.

A series of research questions was proposed as the aims of the present study. The questions pertain to the group of Italian-speaking patients who had been referred to the IHHP. These are described below.

1. What does the concept of "good health" mean to Italian-speaking cardiac patients and how might this differ from the traditional meaning of good health as the absence of disease?

2. How do this group of cardiac patients experience their cardiac illness and what themes characterise their adaptation to their condition?

3. What are the illness perceptions associated with their cardiac illness. Specifically, what themes characterise their representations of the cause of their illness, the consequences of their illness and the controllability of their illness?

4. How have the IHHP participants engaged with the provision of a language-specific cardiac rehabilitation program and what did they regard as the most useful aspects of that program?

5. What are the views of the health professionals who provided the language-specific cardiac rehabilitation program, concerning the needs of this specific group?

Chapter 7

Design and Method

Rationale for the design

Qualitative methods have become widely used in psychological research as methods of inquiry in their own right. It is now generally accepted that there are a multiplicity of qualitative methods available to the social scientist (Patton, 2002). Lupton (2003) has argued that qualitative approaches are well placed to be used in the study of illness experiences because they allow the personal experience of illness, and the meanings that people make of these experiences, to be the primary object of study. This epistemological position reflects the valuable contribution that can be made to the generation of knowledge of the phenomena under investigation from individual accounts of experience. An investigation of the subjective experience of illness as the primary research aim is, therefore, well served using a phenomenological perspective which can use people's accounts of illness as the primary data.

Interpretative phenomenology has developed as an approach to research in social sciences which combines the interpretative stance of the researcher with the phenomenological tradition of listening to subjective descriptions of phenomena (Willig, 2001). The phenomenological tradition is concerned with the ways that human beings gain knowledge of the world around them (Smith, Flowers, & Osborn, 1997). Interpretative Phenomenological Analysis (IPA), as proposed by Smith et al. (1997), is a method of analysing individual accounts of experiences which takes into account the necessary act of researcher interpretation required when individual accounts are to be used as research data. IPA attempts to bridge

the gap between a phenomenological epistemology and the so-called objective, or interpretative, place occupied by the social science researcher.

Willig (2001) has summarised the epistemological assumptions made by IPA. First, the objective of the analysis is to produce knowledge about another person's thoughts or beliefs, which are in turn implicated in the accounts of his or her experiences. The analysis conducted by the researcher accepts that the researcher is influenced by his or her own particular understanding of the phenomena in question. This anomaly is not regarded as a confounding factor in IPA, but rather it is seen as a "necessary precondition for making sense of another person's experience" (Willig, 2001, p. 66).

Second, IPA assumes a relativist ontology (Willig, 2001). This means that IPA assumes that individual participants experience reality differently and this experience is mediated by their particular thoughts, beliefs and expectations. At the same time, IPA also recognises that meanings ascribed to external events in reality are not entirely idiosyncratic to the person because they are heavily influenced by the social networks and cultural forces that impinge upon each individual. Third, the researcher using IPA acknowledges that insight, or knowledge, produced by the analysis requires an act of interpretation by the researcher of the participant's account (Willig, 2001).

In Chapter 2 it was demonstrated that studies attempting to explore the subjective meanings attributed to being healthy are largely conducted by the collection and analysis of personal accounts gained from interviews. In Chapter 5 it was also demonstrated that participants' illness representations have frequently been assessed by semi-structured interviews as part of a qualitative research design (Scharloo & Kaptein, 1997). The use of personal accounts of health and

illness, collected by semi-structured interviews can, therefore, allow for a close examination of participants' circumstances and the production of a detailed description of the response to illness within those circumstances. The interview uses the participant's words and ideas to allow access to phenomena which is not easily observed.

This qualitative approach to data collection and analysis is particularly suited to groups from different cultural backgrounds, for whom survey instruments have not been specifically designed or validated. Kleinman (1978) used situated discourse in his studies of explanatory models. Situated discourse provides for the collection of qualitative data in a manner not unlike a semi-structured interview. A series of open-ended questions is used which is directed towards eliciting these explanatory models and subjective meaning making. Baumann (2003) stated that the use of situated discourse was a particularly useful way to elicit qualitative data from culturally diverse populations that are normally not included in research. This is because it allowed for the social, historical and political contexts of individual behaviour to be elaborated.

Interviewing in their first language was considered a more culturally appropriate way to achieve accurate and valid data from a sample in which English language skills are typically poor. This sample of Italian-speaking immigrants was also considered unaccustomed to completing a large array of survey instruments and may have experienced potential difficulty in understanding the directions implicit in all survey instruments.

Case studies were produced from the information obtained from semi-structured interviews. The use of case studies allows further detail from a specific context to be explored, allowing elaboration of interview themes which contribute

to the data analysis. The study of individual cases represents an approach which has been used to analyse and present qualitative data where the understanding of context is important (Darke & Shanks, 2000). Yin has also defined the case study as "an empirical enquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomena and context are not clearly evident" (Yin, 2003, p.13).

Case studies allow the uniqueness of the particular phenomena under study to be observed. According to Stake (1994), this uniqueness is likely to take into account a wide range of contextual phenomena which include the nature of the case, the historical background and physical setting of the case and other contexts, including socio-demographic information. Willig (2001) has noted several important defining features of case study research. Case studies are concerned with an idiographic perspective - a perspective which aims to make conclusions about the particularities of the studied phenomena. In contrast, a nomothetic style of inquiry aims to make conclusions which can be generalised into laws of human behaviour (nomothetic) (Willig, 2001). Case study research, therefore, allows attention to context, rather than the removal of contexts, often sought using nomothetic methods. Case studies also have a temporal element which allows changing processes to be observed over time.

The use of triangulation in case studies allows the data to become richer by the inclusion of multiple sources and methods of data collection while also checking for internal validity. Two major types of triangulation were identified by Williamson, Burstein and McKemmish, (2000): methods triangulation and source triangulation. Methods triangulation provides cross-checking of data consistency by using multiple data collection strategies. Source triangulation

requires that data be collected from different sources or from different times to demonstrate data consistency. The addition of case studies to the present study allows an appreciation of the complexity of the data, while providing internal validity to study.

Design of the present study

The present study adopted a qualitative design based upon thematic analyses of semi-structured interviews and a collective case study (Stake, 1994). A collective case study is a case study which includes several instrumental cases jointly, and permits the researcher to explore a series of questions in a group. Collective case study designs also allow cross case analysis and comparison (Darke & Shanks, 2000). The collective case study data is based on data collected at two points in time for each of the cases, but is not longitudinal in nature. Rather, the second, or follow-up interview, was included to enrich the interview data and provide case elaboration where required.

The study also included data collected from the Hospital Anxiety and Depression Scale (HADS) (Zigmund & Snaith, 1983). These data were collected from each of the participants to provide data concerning the subjective reports of clinical symptoms of depression and anxiety. It was not intended to provide quantitative data to demonstrate the effectiveness of the cardiac rehabilitation program in reducing symptoms of depression and anxiety, but rather to contribute a reliable and valid measure of these impairments for each of the case studies.

The study was also exploratory as it aimed to identify, from the participant's perspective important themes and conclusions about the subjective illness experience of CHD. This exploration may inform the development of cardiac rehabilitation programs, specifically for special populations such as

culturally-diverse groups. While being exploratory, the present research remains guided by the stating of research aims established by the published research literature. The research design is, therefore, a combination of positivistic and interactional approaches which allows for the study to remain directed by purposive inquiry concerning its objectives but allows the participant's personal experience to emerge (Silverman, 1994). The use of IPA draws upon these personal accounts as primary data but acknowledges the part played the participants' cognitions and beliefs as the mediator of these accounts of personal experience.

Recruitment of participants (IHHP participants and health professionals)

Participants in the present study were drawn from one cohort of cardiac patients referred to the Italian Healthy Hearts Program (IHHP). The cohort consisted of those patients who attended the introductory session of the IHHP. The total number in attendance was 8, and all 8 agreed to participate in the study. The IHHP is a phase two cardiac rehabilitation program conducted by a community health centre in the north-western suburbs of Melbourne for Italian-speaking cardiac patients, and is presented entirely in Italian.

During the introductory session to the IHHP, participants were invited to take part in this study and provided with a plain language statement about the study (Appendix B). All documents provided to prospective participants were provided in the Italian language, including consent forms. Due to privacy issues, signed consent forms were firstly collected by the program co-ordinator and then conveyed to the researcher, with contact details of the consenting participant. An example of the consent form is contained in Appendix A. The decision not to participate in the research did not affect the patient's eligibility to participate in

the IHHP and participants were free to cease their involvement in the study at any time during the research.

The IHHP is conducted over 8 weekly group sessions and is co-ordinated by a local community health centre. The program is structured around an educative component (90 minutes in duration) followed by a light exercise component. Where possible, the educative sessions are conducted by Italian-speaking health specialists, who include nurses, dieticians, social workers and psychologists. Otherwise, professional interpreters are used. The light exercise component is facilitated by an appropriately qualified physiotherapist. Participants are typically referred to the program by hospital cardiac units, cardiologists and general practitioners.

The health professionals that participated in the study were those responsible for the delivery of each component of the program. They were recruited after the completion of the IHHP. Health professionals were invited to participate in the research by telephone and signed consent was obtained from them at the time of the interview (Appendix C). Health professionals were also provided a plain language statement, contained in Appendix D. Each health professional was interviewed once.

Data collection

Data was collected from two sources for the IHHP patients; from the semi-structured interviews and the Hospital Anxiety and Depression Scale (HADS) (Zigmund & Snaith, 1983). The semi-structured interview designed for use with the IHHP patients is contained in Appendix E. The Italian version of the HADS is contained in Appendix G and was obtained from the publisher.

The semi-structured interview

For the IHHP participants, the interview was developed using the literature on the lay perspective of health and from the literature on illness perceptions. The semi-structured interview was used to collect data for thematic analysis and for the case studies. The interview was modified to accommodate participants who consented to the research but did not complete the program. The semi-structured interview was also used to guide data collection from the follow-up interviews. Below is a summary of the domains of inquiry included in the semi-structured interview. The semi-structured interview used with the IHHP participants is provided in full in Appendix E.

1. Present health status and personal experiences concerning illness onset
   - Immediate reaction to illness
   - Effect of operative intervention
   - Presence of other illnesses

2. Beliefs about health and illness and illness representation domains
   - Meaning of 'good health'
   - Beliefs about cause, consequences and cure of illness (CHD)

3. Impact of illness on quality of life
   - family and friends
   - physical activity
   - diet
   - mood (periods of depression or anxiety)
   - lifestyle changes made as a result of illness
   - manner of adapting to illness

4. Satisfaction with IHHP and perception of impact upon recovery

The Hospital Anxiety and Depression Scale (HADS)

The IHHP participants were also given the Hospital Anxiety and Depression Scale (Zigmund & Snaith, 1983). The Hospital Anxiety and Depression Scale (HADS) is a brief self-report inventory used to assess symptoms of anxiety and depression and was developed for use in a hospital setting. The HADS was provided to participants written in the Italian language and was obtained from the publisher. The HADS was completed by consenting participants at the completion of the introductory session of the program (PREPRG) and at the end of the eight week program (POSTPRG1). It was also provided to participants at each of the subsequent interview times (POSTPRG2 and POSTPRG3).

Data Collection Procedure

Semi-structured interviews with IHHP participants

At the completion of the IHHP, IHHP participants who had consented to be interviewed at the introductory session of the program were contacted by telephone to arrange a suitable time to be interviewed. All interviews were conducted in the homes of the participants. The first round of interviews was completed between three and six months after the completion of the rehabilitation program. All participants were then contacted again between nine and 12 months after the completion of the program to arrange the follow-up interview.

Interviews were conducted in the Italian language and were audio-taped to allow transcription. Written notes, which recorded important observations and impressions, were made at the conclusion of each interview. Informal notes were also made by the researcher from the telephone discussions with the participants

who declined to be interviewed a second time. The participant's spouse was permitted to be present during the interview. While questions were not directly asked of spouses, their responses were also recorded, transcribed and analysed. No names were recorded on any written notes and only numbers were used to identify audio tapes and notes derived from those tapes. HADS data were collected at the conclusion of each interview.

Interviews with IHHP health professionals

Health specialists who had provided the series of educative sessions in the IHHP were contacted by telephone and invited to participate in research. These interviews were conducted after the completion of the IHHP. Interviews were normally conducted in their place of employment. A semi-structured interview was also used (Appendix F) and interviews were audio-taped and transcribed. Interviews with the health specialists were conducted in English. All four health specialists were interviewed once. A second semi-structured interview was developed. The interview structure is summarised below:

- Perceptions of their component contribution to the IHHP

- Perceptions of the IHHP overall

- Most valued component/aspect of the IHHP

- Needs of Italian cardiac patients

- Perceived effectiveness of IHHP

- Potential improvements to IHHP

Transcription and translation

The researcher conducted the interviews in Italian and also transcribed and translated all interviews into English, including follow-up interviews. This

occurred in two stages. The first stage was completed by listening to each of the recorded interviews and translating only the general intention of the participants' responses to important elements of the interview. This produced a first group of partially translated and transcribed interviews. The second stage produced the entire interview transcription completed by the researcher, with the assistance of a comprehensive Italian-English dictionary (Hazon, 1961) where required. The assistance of a qualified Italian-language interpreter was sought where necessary. Interviews with health specialists were also transcribed by similar method.

Data analysis strategy

Interpretative Phenomenological Analysis (IPA) (Smith et al., 1997) was used to analyse the interview data from both the IHHP participants and the health professionals. IPA is well suited to research in health psychology because it allows for study of the phenomenology of health and illness but, maintains a concern for the individual cognitive beliefs and attitudes. IPA acknowledges the value of engaging in the analysis of individual text, which can reflect important elements of the individual's cognition. Thus, IPA is particularly suitable as an analytic method in health psychology because it can emphasize the lived experience of health and illness while recognising that the body remains the "exemplary unit for determining the existence of and possible boundaries for the illness" (Smith et al., 1997, p. 71).

The data analysis strategy consisted of two parts. First, a thematic analysis was completed using IPA and the procedure outlined by Willig (2001). Excerpts are isolated from each of the crystallized themes and these are used as demonstrations of the salient theme. Second, three case studies from among the IHHP participants were prepared. These case studies were chosen as examples of

the different qualities of the lived experience of illness and the adjustment to CHD. The case studies allowed important themes to be observed within the real lived circumstances and experiences of the participant. It allowed further exploration of the broader contexts and settings that individual participants find themselves in and the impact that this has on their adjustment to CHD. Cross case analysis (comparing across the group) is also possible using case studies (Yin, 1994).

<u>Thematic analysis</u>

The analysis of the transcribed text from all interviews consisted of two phases. The first phase was the creation of a partially ordered data display (Miles & Huberman, 1994), or summary table, derived from the first level analysis of the text. This data display contained a summary of the responses provided by each of the participants to the various domains of the semi-structured interview questions. This first order data display was constructed by referring specifically to the responses of participants to questions from *a priori* themes associated with the semi-structured interview and was obtained by listening to the record of the interview. These themes reflected the responses to the *a priori* concepts as determined by the research questions and allowed a preliminary survey of the data. Willig (2001) has also called this phase an initial encounter with the text (p. 54). This phase of analysis also allowed the first glimpses of other themes from the interviews which could then be further scrutinised in the second phase of the analysis. This part of the data analysis also provided important information about the transcription and translation requirements for the next phase of analysis.

The second phase of the analysis was applied to the translated and transcribed text of all of the interviews and consisted of data coding and memoing

(Punch, 2000). This phase had several stages. The first stage involved the identification and coding of first order themes. This first order coding has been described by Punch (2000) as descriptive coding. Descriptive codes have a low inferential quality and provide the basis for further second level coding. During this stage, memoing was also employed to allow the identification of text associated with emerging themes as well as the *a priori* themes. It also allowed notes to be made which had a more speculative quality. From this first stage, approximately twenty first order themes were identified.

The second stage consisted of second level coding which allowed the reduction of these first order themes into fewer more meaningful units. Willig (2001) identified this stage of the analysis as the introduction of structure because the themes are considered in relation to one another and clusters are allowed to emerge. These clusters are called second order themes and they represent "a more abstract concept which brings together less abstract more descriptive codes" (Punch, 1998, p.205). This stage of the analysis was characterised by the use of sensitising concepts (Patton, 2002) to provide organisation to these clusters.

Sensitising concepts

Patton (2002) referred to sensitising concepts as concepts derived from theory which provide an external reference point and "directions along which to look" (Patton, 2002, p.456). Sensitising concepts provide the researcher with a device for the final coding of the data when it is important to explore *a priori* concepts derived from theoretical propositions. Sensitising concepts were therefore used for the establishment of meta-themes which provided grouping for the second order themes. Illness representation domains (Leventhal et al., 2003) and categories derived from the Health and Lifestyle Survey (Blaxter, 2004), were

used as sensitising concepts. This second phase of analysis allowed the comparison of themes from the present study to be made with previous published literature and represented the *a priori* themes.

A posteriori themes

Emergent or *a posteriori* themes were also identified by the data analysis during the first and second phases of the analysis. These themes were not derived by comparison with sensitising concepts provided by the published theory but reflected important aspects of the participant's illness experience and perceptions of recovery from CHD.

Chapter 8

Findings Part 1: Thematic analysis and meta-themes

The findings of the present study have been organised into three chapters. This chapter presents the findings from the data analysis of the interviews with participants recruited from the IHHP. Chapter 9 provides for the further elaboration of the thematic analysis using three case studies to highlight the context of the relevant themes and the relationships between them. Lastly, Chapter 10 presents the main themes derived from the interviews with the health professionals who deliver the various components of the IHHP.

Participant characteristics-IHHP participants

The characteristics of IHHP participants are shown in Table 1. The final sample comprised of 8 participants who agreed to be interviewed on at least one occasion. A total of 12 interviews were conducted with IHHP participants.

Table 1:   IHHP Participant characteristics

Pseudonym	SEX	AGE (yrs.)	No. of IHHP sessions attended	Cardiac event	Follow-up interview
Lina	Female	80	8	ICD#	Yes
Paolo	Male	70	1	Angina	No
Angelo	Male	69	8	Angioplasty	Yes
Maria	Female	65	1	ICD	Yes
Guido	Male	57	8	CABGS%	No
Roberto	Male	66	8	Angioplasty	Yes
Carmela*	Female	66	8	CABGS	No
Pietro	Male	77	8	CABGS	No

Implanted Cardioverter Defibrillator

% Coronary Artery Bypass Graft Surgery

The average age of the participants was 68.75 years. First interviews were completed between three and six months after the completion of the IHHP. Four of the participants declined to be interviewed in person a second time. In one of these cases, a follow-up interview was obtained by telephone from the daughter of the IHHP participant. This case is indicated in Table 1 by an asterisk (*). Follow-up interviews were, therefore, completed in person with 4 of the 8 participants.

Thematic analysis: *a priori* and *a posteriori* themes

This present chapter is divided into a presentation of the *a priori* meta-themes and the *a posteriori* themes from the interviews with IHHP participants. The final list of themes from the thematic analysis of the interviews with IHHP participants is presented in Table 2.

The following section presents these themes divided into the *a priori* meta-themes and the *a posteriori* themes. Excerpts from the interview transcripts are presented to illustrate each of the themes. In this chapter, the reference to participant refers to those IHHP participants who took part in the present research, as distinct from the IHHP health professionals.

The meaning of good health

IHHP participants were asked to consider how they defined being healthy. Responses were coded into themes and then organised into the sensitising themes derived from the Health and Lifestyles Survey (Blaxter, 2004). Four themes concerning the meaning of good health were identified from the interview data with the IHHP participants.

Table 2: *A priori* and *a posteriori* themes derived from the thematic analysis of interviews with IHHP participants.

A priori themes	*A posteriori themes*
The meaning of good health	CHD as a secondary consideration
Health as function	Interactions with medical professionals
Health as psychosocial wellbeing	The value of social contact in recovery
Health as social relations	
Health as healthy behaviour	
Illness identity	
Illness cause	
Life events	
Diabetes and family history	
Uncertainty and confusion	
Illness consequences	
The importance of activity	
The importance of family	
Living with psychological consequences	
Illness control and cure	
Fate and destiny	
Self-control	

<u>Good health as a function</u>

The most popular theme from the interviews was that good health was perceived to be functional. Health as function meant being able to do all that you wanted to do without restrictions. The consequence of poor health was a restriction in activities which included working, exercises and accessing social

supports. Roberto perceived this functional capacity to be the most important

thing to ensure happiness.

Being healthy is the most important thing. It's the basis of a person's

life, their happiness. When you are healthy you feel happy, you can

walk, you can do all that you want to when you're healthy. (Roberto).

This response suggested a similarity to the category proposed by Pierret

(1993) called "health as a tool", since it places health at the centre of being able to

have all that is needed. Carmela described being healthy as being able to confront

difficulties and having a positive outlook on her future. This was gained from

being physically strong and able enough to be productive.

When you're healthy you feel joyous, you can work, you can confront

your challenges, be with others. You can make things happen, you have

a future in front of you because you feel strong. (Carmela)

Angelo noted how important the restriction in functional ability was for

his perception of his health. Angelo had several features of clinical depression

and he felt physically unable to lead a productive life. He referred to a depletion

of what he called "coraggio" or translated as spirit. The word "corragio" can also

mean to "have heart" in English.

Yes I've been healthy, I've been productive. Being healthy is to have

the spirit to do what you want to do, instead today, I feel confused, my

poor health stops me from doing anything, I'm always out of breath, I

don't feel like doing anything. (Angelo).

Angelo had lost the "heart" to live the life he had been able to previously.

Angelo's perception of good health was also intermingled with his psychological

health, as the reference to his spirit implies, but being healthy had become closely associated with his ability to work.

Good health as psychosocial well-being

Two participants viewed good health as a state of emotional and psychological well-being. This category emphasises the expression of health through a mental state, without reference to other conditions. This is demonstrated by the next excerpt from a woman who also made the contrast to physical health. Physical complaints were seen as less important than psychological disturbances.

Being healthy concerns the mind. If you feel good in the mind you don't need much else. It's better to have pains than to lose your memory. (Lina)

Maria reflected upon her current state of poor health and remembered being healthy as having feelings of joy which she had now lost. For Maria, pain could also be used to describe mental disturbances.

Being healthy is to feel joy inside of you, but now all I have is pains, not just physical ones but mental ones because I'm always thinking about how unwell I am. (Maria)

Maria had had a long history of medical conditions, other than her cardiac condition, which she perceived to have remained essentially untreated. Maria also had several features of clinical depression and very frequent contact with medical specialists. Maria's health was associated with the anguish she felt from an inability to return to a previous state of good health.

Being healthy is worth all the gold in the world, because I'd eat only bread and water if only I was healthy again. (Maria)

Maria placed enormous value on being healthy, a value that no amount of money could compensate for.

Good health as social relationships

Good health was also described as having good relationships with others. Blaxter (2004) claimed that women provided this description of health much more frequently than men. The importance of happy relations with others is stated by Lina.

My husband is good to me, so are my children, they don't make me angry, they make me happy, being healthy is to live happily with others. (Lina)

In the next excerpt, there is also reference to health as tool, or function, which can provide for all that one needs. A monetary value cannot be placed on good health, and instead Paolo mentioned the value of social relationships in achieving good health.

When you are healthy you've got it all. You could have millions of dollars but if you're sick what can you do with money, instead if you're healthy, you can be active, and be with others. (Paolo)

For Paolo, being healthy meant being able to be around others, rather than socially isolated, which also provided feelings of functional capacity.

Good health as healthy behaviour

Two participants referred to health as the behaviours that were required to look after themselves and avoid disease. These responses were characterised by the importance of self-regulation, moderation and personal responsibility. Guido thought that being healthy required care, self-monitoring and vigilance.

To be healthy means to be careful about what you do, the need to look after yourself and think about the future. You need to be able to look after yourself and observe what you do each day. (Guido)

One participant believed that health-directed behaviours needed to underpin the entire personality and provide the basis of personal actions. He also believed there was a need to control a propensity towards vices or bad habits.

Being healthy must direct your personality and behaviour, to control over eating, drinking and smoking for example, all the vices and activities. The mind also has to working and you have to have the desire to look after yourself, with that, the rest will follow. (Pietro)

The importance of self-regulation and self-motivation for healthy habits and behaviours is exemplified by this participant. For Pietro, this motivation came from the person, is self-determined, and if present, allows for health to emerge. Good health required a healthy mind.

Illness representations

The following section provides a thematic analysis of the interviews using the illness representations proposed in the Common Sense Model of the self-regulation of health and illness (Leventhal et al., 2003) as the meta-themes. Excerpts are used to illustrate the themes.

<u>Illness identity</u>

This domain of illness experience was characterised by the symptoms that are generally associated with heart disease and impaired cardiac functioning. These symptoms were breathlessness, chest tightening, arm pain and coughing. IHHP participants frequently discussed their cardiac symptoms against the backdrop of the circumstances surrounding the onset of their symptoms. Cardiac symptoms were rarely identified as such at the onset of the illness and normally resulted in a visit to hospital or to the family doctor after symptoms had persisted. Carmela described classic symptoms of myocardial infarction which she had not been able to identify at the time of her infarct. She had been rushed straight to hospital after going to visit her family doctor.

> *I was feeling heavy, out of breath easily, I couldn't breathe properly and I had a pain in this arm, a very strong pain. So we went to the doctor and the doctor called an ambulance and took me straight to hospital. At the hospital, that same day, they told me that I had had a major heart attack. (Carmela)*

Paolo recognised the need to visit the doctor only after enduring breathing problems during the night. His breathing difficulties and his coughing were not recognised as cardiac symptoms.

> *I couldn't breathe, my breathing became very difficult and I'd been coughing a lot. I was awake all night so I tried sleeping on the couch. In the morning I went to the doctor and he sent me to have an angiogram. (Paolo)*

Carmela and Paolo recognised the need to visit a doctor or a hospital after symptoms had persisted for some time, even thought they didn't know they were

experiencing cardiac complications. On arrival at hospital Lina was still confused about what was happening to her and what specialists were proposing.

I was really out of breath and I couldn't cope with it anymore. I wondered what was happening to me so I went to the hospital and they wanted to help me but I was frightened at first. Eventually they did help me and everything went well. (Lina)

One participant was able to recall how he had learnt to recognise the symptoms of CHD after initially not being able to. Roberto had previously had a heart attack while away from home on his country farm and had waited three days before returning home and contacting a doctor.

I had the pains for three days before I went to the doctor and I didn't know what it was, because previously I didn't know the symptoms. Now I know the symptoms, should they happen again. The symptoms came in bursts of pain, not all the time. (Roberto)

Cardiac symptoms were also attributed to other conditions such as diabetes. Carmela had initially perceived that her symptoms originated from her diabetes.

I felt breathless and I'd cough, I'd be extremely tired even after short walks, I didn't know what it was that was making me tired, I thought it might have been my diabetes, instead it was something else. (Carmela)

Symptoms of cardiac malfunction were frequently unrecognised by IHHP participants, causing delays in seeking medical attention. The initial encounter with hospital can also be confusing because of poor English language skills. Poor English language skills may also have contributed to poor knowledge of cardiac symptoms.

In summary, participants reported a variety of traditional cardiac disease symptoms which they did not initially attribute to CHD. Some participants were uncertain about the origin of their symptoms at the onset of their illness and were not able to recognise symptoms of cardiac impairment. It is also possible that symptoms such as breathlessness are appraised as being identified with health problems other than coronary heart disease.

Illness cause

The meta-theme of the perceived cause of CHD included two main themes. These were the impact of life events and family history of CHD or diabetes. A third important theme from the interviews with the IHHP participants was continuing uncertainty about what had been the cause of their CHD.

Life events

Life events were frequently associated with the cause of CHD. In particular family disturbances, loss and grief and the impact of other medical conditions were perceived to have been involved in the development of their illness. Paolo had been diagnosed with a skin cancer that required treatment and his wife explained that he had developed angina the night before he was to begin his cancer treatment.

He was very worried and he couldn't decide whether to have the treatment or not, but he wasn't sleeping at night so after two or three days, after finding out what they had to do, I rang and told them to make the appointment for him to begin treatment as soon as possible. I didn't want him to keep feeling like that. So that was the night he got his angina, he was supposed to have the treatment on Monday and on Sunday night he felt unwell and had pain all down his arm. (Paolo's wife)

Paolo did not have a history of CHD or of diabetes. He had accepted a connection between his emotional response to being diagnosed with cancer and his angina. He explained the events using a metaphor.

Because you heart is like a motor, but it's also where people say they feel their emotions. (Paolo)

Paolo's angina was treated with medication and he had had no further cardiac complications at the time of his interview. Emotional disturbances produced by strained family relationships were also perceived as causing CHD. A link was often made by participants between emotional upheavals, such as anxiety and sadness, and the cause of CHD or disease in general. Roberto had been told that the cause of his CHD was diabetes, but he also perceived a link between the onset of his diabetes and a significant family disturbance.

Troubles in the family are dangerous for me, because they are even worse than what happens in your body. If you've got family troubles, that can kill you. For example, our oldest son got married when he was 24 years old and after five years, they separated. So of course we were very upset, we didn't want that for him. After this I got my diabetes and things were never the same, I felt that things were not going well. (Roberto)

Roberto emphasised the severity of disturbances such as family disharmony and this was perceived by him to be far worse than any potential for physical disease. The strain placed on him and his family during a family break-up had become an important part of his explanation for his illness. Carmela also referred to emotional strain when considering the cause of her sudden onset of

CHD. Her anxiety was caused by the strain of caring for her husband who had previously developed Parkinson's Disease and signs of dementia.

It happened all of a sudden, OK, I've got plenty of worries (agitation) because he's always argumentative, he stops me from sleeping, he's always warring with me. I'm always agitated because of him, he's a lot to cope with. (Carmela)

Traditional family role expectations meant that Carmela had assumed the responsibility of caring for her husband at home, rather than seeking the help of other services. His illness had produced substantial changes in her mood and quality of life. The pain and loss from several family deaths over a short period of time in a very close family was described by Maria's husband as having had a profound influence on Maria's physical condition, including her CHD. The series of deaths was described by her husband.

Her father died first, he was only 57 years old, he died from a tumour in his shoulder and they didn't diagnose it soon enough, then one of her sisters died of diabetes just after giving birth to a still born child....after that one of her married sister's children died in a motorbike accident, and then her brother-in-law died, and they died in the same year. And then another of her sisters died of Parkinson's Disease, in a short amount of time 7 or 8 people died. (Maria's husband)

The variety of health problems that Maria subsequently experienced was perceived to have been the culmination of an intense period of loss and grief, evident in the following excerpt.

117

One after the other, then, after the sister who died of Parkinson's, my brother died. That was one year ago, the family was destroyed in a short time, pain builds upon pain. (Maria)

Diabetes/family history of diabetes

Six of the eight IHHP participants had been diagnosed as having type II diabetes. Diabetes, or a family history of diabetes, was perceived to have played a part in their CHD. Roberto believed that his heart was healthy but that diabetes had caused his veins to become occluded by sugar.

It was my diabetes that caused it I think, because I don't have a sick heart, they told me that my veins are blocked and that my heart muscle is as strong as steel. I think it's the diabetes because I can feel that when my diabetes is high I lose my spirit. And that's what affects my veins, like high cholesterol. I've got too much sugar in the blood, so they close. (Roberto)

While diabetes is a strong risk factor for CHD, Roberto had a poor knowledge of how diabetes functions to be a risk factor for CHD. English language difficulties may have proved to be a barrier for Roberto in understanding the pathology of CHD and diabetes. It also highlighted the potential differences between professional knowledge and lay-person knowledge where the understanding of CHD is concerned.

A family history of diabetes was also perceived to be a cause of CHD. Pietro situated his diabetes in the family history of the illness and perceived that his CHD had arisen from this predisposition.

118

My family all have diabetes, my mother, my father, my brothers. The only one with a heart condition is my brother, no, there are two brothers with heart problems, but the heart problems come from having diabetes. (Pietro)

Uncertainty and confusion about the cause of CHD

Some of the participants expressed uncertainty or confusion about the cause of their CHD. This was despite frequent contact with health professionals, including cardiac specialists, and of having attended the IHHP. This uncertainty is demonstrated by the next two excerpts. In some cases, this narrative became part of efforts to construct a story about the onset and cause of CHD.

I have no idea really, I don't understand what has happened, I've had other minor health problems but nothing quite like that. (Carmela)

I can't understand why I got this heart problem so suddenly, because I was feeling well at that time. (Maria)

There was also some confusion about the nature of CHD in some patients. These tended to be errors in how patients described the likely disease pathology and confusion about the nature and progression of arterial occlusions. The following excerpt again shows how Roberto's lay knowledge of CHD was poor or confused.

I asked him [the doctor] why I had this blockage, my wife cooks me very good meals, and he said it wasn't my diet, it was my diabetes, because some people say that fat from food gets into your veins, but how does fat get into veins? (Roberto)

119

Some of the uncertainty about the precise causes and pathology of CHD in IHHP participants is likely the result of their difficulty to fully understand and retain complex information provided in English. Efforts to explain this information in Italian may also have been unsuccessful given the complexity of the disease pathology and the participant's prevailing lay interpretation.

According to Herzlich and Pierret (1987), the differences between lay and professional understandings of illness arise because people search for meanings for their condition which go beyond the biomedical explanation. Often, this meaning is found in the everyday experiences of life events, which are also present in the explanations of CHD and also seen in IHHP participants.

Consequences of illness

Consequences of illness have traditionally been divided into three categories: physical, social and psychological consequences. For ease of presentation, these three categories have been used to organize the themes from the interviews. Specifically, each of the three categories was given a theme name which summarises the content for that category.

The physical consequences of illness: The importance of physical activity

IHHP participants perceived that their physical abilities had been reduced but in some cases, only for a short while. Reduction in physical abilities was seen to occur in walking and doing domestic chores and was normally represented by changes in activity levels. Carmela's most notable consequence of her CHD was her reduced capacity for work, which she had done for many years, both in the home and as a hospital laundry worker.

I felt like I was at rock bottom, without any energy, without strength. Now and again I still feel like that, I do something and I need to stop. I never needed to stop. I was always doing something, now I have to stop. It's taken all the energy I had. I worked 20 years in the hospital laundry, I always worked very hard there and I was happy. (Carmela)

Carmela emphasised the importance of her physical capacity in her perception of health and this was associated with being happy. Her CHD had forced her to reduce her physical activity, much to her disappointment. The importance of taking care to do things more slowly was also evident in her excerpt and in others. Carmela was also motivated to try to return to previous activity levels by trying to exercise at home.

I like to go for a walk after dinner. I go out and walk up and down the driveway, then I come inside. I do that three or four times......I want to be able to walk around the block again, very slowly, because I don't have a lot of energy. (Carmela)

Pietro, who would often walk substantial distances to and from work before he became ill and prided himself on his physical abilities, tried to regain his ability to walk the distances he had previously, while recognising the need to do things a little more slowly than usual.

I couldn't walk the two kilometres that I used to without stopping and having a rest. I would sit down for five minutes after one kilometre before going on. But last week I did the two kilometres without sitting down. I don't walk fast, I don't march, it's a little slower these days. (Pietro)

Other activities, such as gardening, or walking the dog regularly were also perceived as important ways of regaining lost physical capacities. Guido

explained that he had returned to doing the gardening but was spreading the work over several days, rather than doing it all at once.

I have to be careful what I do now, I have to do things a little slowly, a little at a time, rather than all at once. For example in the garden I'll do a little today and a little tomorrow, slowly everything returns to normal. (Guido)

Staying busy and active was described as being important for recovery and general health. Being able to return to previous activity levels was perceived to be an important part of returning to good health. Roberto and Lina both identified the exercise that they got in their everyday life.

I go out and walk the dog everyday and I walk for a minimum of half an hour, then I come back, sit and rest and then sometimes I go and work in the back yard. I try to stay active because I feel better. (Roberto)

During the day sometimes I visit my sister or I visit my daughter, sometimes I wash clothes, do the ironing, cook, the day passes quickly and I walk a lot, it's important to walk often. (Lina)

In one participant, the physical impairment was perceived to have become worse after her hospital procedure. Maria had been given a Implanted Cardioverter Defibrillator (ICD), commonly referred to as a pacemaker, to assist her cardiac condition, after complaining of dizziness while shopping with her husband one day.

Before I used to walk a lot, I used to walk for an hour around the oval with my friend and I did this often, but after having the pacemaker inserted, I can't do that anymore, I get breathless straight away. Before I used to go out more often, but now I feel weak and weary.

Maria had been told by her doctor that she needed to walk regularly but she was finding it difficult to increase her physical activity level. This was attributed by Maria to feelings of unexplained anxiety and fatigue, rather than solely on breathlessness. Her feelings of anxiety and poor energy were associated with other depressive and anxious features which were acting as barriers to her walking more regularly.

The social consequences of illness: The importance of family

The social theme that was evident from the participants' consideration of the consequences of their illness on social life reflected the reliance on family supports. In Lina's case, this was emphasised by the availability of family support during her own illness and after the death of her husband, which occurred during the period between her first and follow-up interviews. This support was readily available to her because of the close proximity of her family members, which meant that Lina could also spend time going to visit her various family members. Lina's younger sister also attended both interviews.

I live alone now but my children come to visit often, the other night we were all here together. My grandson also comes to visit me, he's studying music but he comes by almost everyday and asks me if I need anything. (Lina)

Family members living close by assisted her in adjusting to the changes brought about by serious illness and death. Lina had been able to maintain good

123

social links with her family despite deciding to continue to live alone after her husband's death. Her family provided valuable instrumental and appraisal support during her illness. Her family also provided important emotional support for her after the death of her husband which contributed to her adjustment to life without her husband. Her sister had also stayed with her for three months after his death. Lina had had no further cardiac complication after the insertion of her ICD.

In some participants, this reliance on immediate family was seen as more important that relying on friends for support, especially in the face of illness and hardship. The traditional role of family was to provide a reliable source of support in times of need. Negative aspects of social contact with people outside family were identified by these participants. Angelo perceived that there were limits to how helpful friends could be when compared to family members.

You don't talk about these things [illness] with your friends because they're not really interested. I just tell them I'm not feeling well if they ask, otherwise I don't tell them anything. The ones who care are your family. Good friends are your family, because a friend can always leave when the going gets tough, instead family will always help you. (Angelo)

Angelo considered the regular discussion of personal problems was regarded as helpful when shared with others as part of a rehabilitation program but not always helpful between friends or neighbours. Talking with friends about health matters was not always perceived as helpful. The value of social contact with friends depended on what was discussed as Maria explained in the next excerpt.

It depends what you talk about. At the program you're expected to talk about illness but whenever we speak to our neighbours we are always complaining about our ills. If I've taken my mind off being sick for a while, when I meet them, they can't wait to tell you about their complaints and problems. (Maria)

Sometimes there was no immediate family to rely upon as a source of social support. Maria's husband described this as a consequence of immigrating to Australia and leaving many family members behind. He explained how they had enjoyed good social links to other members of the Italian community but once that it was lost, there were few other sources of social support.

We don't have many people around us, there is only the two us really, we have one close friend. We used to go out a lot, to social clubs and parties. I was the Secretary of an Italian Social Club for eleven years, life was good then, but it all ended because of her illness and I resigned from the club. (Maria's husband)

Maria's ill health and increasing anxiety about leaving the house had led to social isolation and a disruption to established social networks. This further contributed to the existing predicament of being away from close family and isolated from other social networks. Maria's husband perceived the value of social contact for them and its impact on overall health.

What we need is to have a place to spend time together with other
Italians where we can talk and people can talk to us. Because if we
learn to do exercises in a group, then go home, this doesn't help
because the exercise can be done at home once you know how to do it.
Instead if you can spend the day together with others, make friends and
exchange viewpoints and experiences, that would be helpful. That
would make me feel better because I can also talk about something
other than being sick, I'll still be sick but could tolerate it better.
(Maria's husband)

Regular social contact with others was perceived to provide opportunities
for social engagement and discussion of matters other than health concerns. This
was also perceived as helpful for coping with illness. For some participants,
maintaining social contact with others outside the family remained important
during recovery. Engagement in club activities provided an important focus for
these activities. Like Maria's husband, Paolo noted the important part played by
Italian social clubs in the social networks of Italian immigrants.

Yes a lot can change [when you get sick]. I go out a little, and have
some fun, Saturday afternoon and evening I go to the club.....we go and
visit others and I try to keep myself busy. (Paolo)

Italian social clubs provided an important source of activities with others
and various kinds of social support which can influence the perception of illness
and aid recovery.

Psychological consequences of illness: Living with the psychological

consequences of illness

Several participants spoke at great length about the psychological changes
which they had experienced since becoming ill. In some cases, this was directly

126

attributable to the development of CHD, but in other cases the psychological

problems that IHHP participants had were the product of other conditions. Some

participants had been living with psychological disturbances for a time which

went beyond the onset of CHD. The themes concerning the psychological

consequences of illness that emerged from the interviews were feelings of

hopelessness, sadness, anger and anxiety. Clinical features of a mood disorder

were evident in two IHHP participants. Some IHHP participants also preferred to

avoid thinking about their illness, as a protective strategy.

Roberto explained that the state of his psychological health was largely

dependent on his physical health. The psychological consequences of his illness

became most obvious when he felt unwell, causing him to feel and behave

differently.

I keep active, I work in the garden, but when I feel ill, I change. When
I'm sick, I get angry easily, even when my wife talks to me, I feel
anxious, that's the difference. I am already a little anxious, but when
I'm sick, it's worse. (Roberto)

Roberto became easily angered and anxious when experiencing illness and

this made relations with his family difficult. Roberto preferred to be alone when

he felt ill. This included his family. His health and subsequent poor mood, had

wide-spread effects on his relations with others.

If you feel happy, you feel like being with others, but when I was sick, I
felt like I wanted to be alone. When I'm upset I don't want to go out, it
all depends on whether you're happy or not. You can do everything
when you're happy, but when I'm upset I can't even say hello to my
children. (Roberto)

In order not to feel anxious about his CHD and therefore avoid becoming angry and withdrawn, Roberto preferred not to think too much about his CHD. He only perceived himself being ill when in the throws of acute symptoms. Thinking about his illness was not perceived to be helpful to Roberto.

When I'm feeling good, I don't feel sick, I don't acknowledge it. I only think about being sick when I'm sick. When I'm well, I don't want to waste time talking or thinking about being sick. When I'm sick, I can't even cope with losing my keys. (Roberto)

A more pervasive and widespread psychological impairment was evident in Angelo. He had several features of clinical depression, including feelings of hopelessness and insomnia, which he explained had arisen since becoming ill with chronic inflammation to his oesophagus and stomach. Despite concerted efforts at treatment by a variety of medical specialists, his poor health had continued and he had remained in substantial physical and psychological distress.

I always feel tired, not because of my heart problems, I feel very sad. I go to sleep around midnight and if I'm lucky I'll get three or four hours sleep. Then I wake up and all the failures in my life keep coming into my mind and I feel sad and a lot of pain. (Angelo)

Angelo perceived that the main consequence of his condition was anxiety. This anxiety was associated with feelings of hopelessness and persistent negative thoughts about himself. He perceived himself as having lost the courage to do anything properly since becoming ill and he was poorly motivated to remain active.

The main impact of my condition is anxiety. I'm always thinking about bad things, this is what makes me miserable. Before then [the illness] I was fine. I could do everything I wanted to do, now I don't feel like doing anything and if I do I feel as though I am doing it wrong. I think that everything I do will be wrong, I don't have the courage to do anything. (Angelo)

Angelo's psychological condition was a significant barrier to any potential for behaviour change for Angelo. Angelo had also begun to feel increasingly hopeless about any possibility of regaining his health.

Maria had begun to experience a high level of emotional disturbance after she was given an ICD to assist a cardiac condition. The ICD had had a profound effect on her psychological state and she perceived that her situation had worsened because of the ICD. The ICD functioned to provide electrical impulses to stabilise her arrhythmia. Maria's response to feeling the electrical activity of the ICD was a heightened level of anxiety and fear of her physical symptoms. Maria cried several times while talking about this fear.

This is the worse thing that could have happened to me. I would have preferred any other operation than this one, because when I go to sleep it always bothers me. You can't understand how bad it is. When I go to bed at night, I'm always thinking whether I will wake up in the morning, especially when I feel it vibrating inside of me. This happens every night. (Maria)

Maria did not attend the IHHP. Like Angelo, she had developed feelings of hopelessness about returning to good health and had several clinical features of a mood disorder, including phobic anxiety, and insomnia. She was also dissatisfied with her treatment by the medical specialists.

129

Several IHHP participants also displayed avoidance, or a reluctance to think about their cardiac condition. Fear was Paolo's initial reaction to his diagnosis of angina. He coped with this fear by trying to avoid thinking about his condition. For Paolo, thinking too much about the illness was worse than the illness itself.

To tell the truth I was a little frightened but the more I thought about it, the worse I felt. Not thinking about it is better because if I think about it makes it seem worse. You could say that the thought is worse than the illness. Now that I'm sick, there's not much use to thinking about my sickness. (Paolo)

The perception that thinking about the illness was worse than the illness itself is also shown in an excerpt from Guido. Guido found it easier to accept his CHD if he didn't think about the effect his illness had on his mortality.

If you think about it too long it's worse than the illness because you begin to think your day will come and you don't know when that day will come, it could be today or it could be tomorrow. You don't have to worry about that if you don't think about it. It may also be worse when the day finally does come, not thinking about it means that I'm not expecting anything, so I feel better. (Guido)

Themes from the psychological consequences of CHD were characterised by features of depression, anxiety and avoidance of thinking about illness. The psychological state of two IHHP participants was associated with a long history of untreated and unexplained physical symptoms. This was also accompanied by a history of long and unsatisfactory contact with medical specialists. On the other hand, thinking too much about illness and dwelling on its consequences were also not perceived to be helpful by several of the IHHP participants. Coping with the

130

psychological consequences of illness in this way can have important

consequences for the ability to make long-term behavioural changes and recovery.

Psychological conditions which result from cardiac interventions, or other

physical complaints, can interfere with recovery.

Cure/Controllability themes

This illness representation domain reflects the extent to which participants

believe that their condition is amenable to cure or control. Analysis of the

interview data revealed two themes. These were the relevance of fate and destiny

in illness and the importance of self control and self monitoring of behaviour.

Fate and destiny

Several participants perceived their illness as difficult to change, in

particular, that the fate of their illness was bound by uncontrollable destiny. Lina

emphasised the fatalism of serious illness by perceiving that ultimately little could

be done to affect one of two outcomes.

There's not much you can do in the face of illness, there are only those
who make it and those who don't. (Lina)

Paolo explained his perception of the fate of his illness philosophically by

comparing his heart to the engine of a motor car. Like an engine, his heart could

fail at any time, without warning. This failure was perceived to be inevitable and

unavoidable.

I don't know, the car's motor seems to run well but then it can suddenly
and inevitably stop, right now I feel well. If your time comes, it comes,
if it's not today, it's tomorrow, or the day after tomorrow, we all have
to die sometime. (Paolo)

Paolo's wife also emphasised the lack of control over illness. The development of an illness such as CHD was perceived to be a sign of mortality and that a predetermined destiny influenced when that heart failure might occur. Fate determined whether recovery was possible.

Yes, but when someone's time doesn't come, we say that he wasn't destined to die at that time. We all have to die, when your time arrives, it arrives and there's nothing you can do about it. (Paolo's wife)

Angelo's perceived perceptions of cure and controllability had been influenced by his experience of the medical system and its failure to help treat his complaints. Angelo had the expectation that medical science, with all its achievements, should be able to cure his symptoms. He did not know whether his symptoms could be cured.

I don't know, [if the illness can be cured] if it can, it will, but how do I know, I'm not a doctor. You go to see specialists to find out these things. I want to know how it is that these days, they can make so many discoveries, medications, operations, make dead people walk, how come they can't help me, that's what I don't understand. (Angelo)

Angelo's excerpt also demonstrated the difference between lay expectations of biomedicine and the highly specialised professional knowledge that biomedicine produces and is used by health professionals. Angelo couldn't understand how biomedicine had failed him because of this difference between lay and professional knowledge. Angelo's wife introduced a fatalistic perception of illness, influenced by a reliance on religion and God to provide an understanding for suffering in life. Angelo's wife found her friends with similar

beliefs more useful than other sources of support and information provided by the medical system.

> *What we say is that it was the will of God, what you have to do in life is to suffer and to have patience and to be strong. To tell the truth, I prefer to speak with friends who support you, they tell me 'don't worry, it's the will of God'. God is there looking over you, to help you keep your spirits up and that gives me comfort in life. (Angelo's wife)*

Self-control

Some participants perceived that their CHD could be cured, using self control and responsibility. Guido believed that his CHD could be cured by exercising caution about behaviour.

> *Yes I think so, if you are careful you can become better, if you're not careful you won't get better. (Guido)*

Pietro believed that his CHD could be cured if illness was respected and he maintained moderation and self-control over bad habits, such as over eating or drinking too much alcohol. Respect for his illness was important for Pietro.

> *If I respect it and don't abuse it [the illness], it can be cured. For instance, I'll only have one glass of wine, no more, I don't overindulge in food, not to be greedy, not to eat for two people, that's important. If you don't help yourself, you can't help your illness. (Pietro)*

Pietro was recovering well from his bypass surgery. He was highly motivated to return to previous activity levels and had even returned to working for part of the day in the family business. Pietro also proudly spoke about his

133

exercise regime which he had begun after completing the IHHP. Routines for the care of his health were strictly adhered to.

> *I do my exercises in the morning. First I have breakfast and take my medication. Then I do 15 minutes of exercise, like we did at the rehabilitation program. I do that every morning, one after the other. Then if I feel like it, I will do a little work at the shop. (Pietro)*

There were also limits to the capacity to control illness. Roberto believed that he could control his diabetes but in times of emotional turmoil, his medication could not help him. Roberto could control his illness if he could control his emotions.

> *The diabetes can be controlled when I'm calm and don't have family troubles but if there are family troubles, no medication, not even insulin can help. I try to stay calm but if I'm feeling troubled, nothing can stop my diabetes from rising, it's stronger than all the medications I have. (Roberto)*

Roberto perceived that his physical health was influenced by his emotions. The existence of strained relations in the family caused his diabetes to worsen and this was not controllable with his insulin.

Summary of the *a priori* themes

Several important *a priori* themes were gleaned from the analysis of interviews with IHHP participants. IHHP participants perceived the meaning of good health to be closely aligned with the capacity for being productive and having functional abilities, such as being able to work or look after the home. Life events and the emotional turmoil that they produced played an important part

134

in the understanding of the cause of CHD for IHHP participants. Sometimes this search for meaning in life events was associated with uncertainty and confusion about how CHD develops and affects cardiac functioning. Cardiac symptoms were not often recognised by IHHP as cardiac symptoms and could be mistaken for other conditions.

Physical capacity and a return to previous activity levels was perceived as important in recovery. The loss of functional capacity was closely associated with poor health. Family became an important source of support for IHHP participants and IHHP also use Italian social clubs to access other social contact outside of family. In some cases, IHHP participants had other mental health disturbances which provided significant barriers to recovery from CHD. Frequent contact with the medical system and the persistence of unexplained medical symptoms characterised those IHHP participants with high levels of anxiety and features of depression. Finally, IHHP participants frequently expressed doubts over their ability to control their CHD. For some, concepts such as destiny and fate were used to help understand the onset and unpredictability of illness. For others, efforts at self-control and self-regulation helped them perceive control over CHD.

A posteriori meta-themes

The thematic analysis of the interviews with IHHP participants produced three a posteriori, or emergent, themes on the experience of CHD. The following section presents these additional themes which were not part of the analytic strategy using meta-themes derived from the reviewed literature. The themes concern the experience of CHD but specific research questions were not directed to their purposive exploration. The a posteriori themes are listed in Table 2.

<u>Cardiac condition as a secondary concern</u>

This theme was characterised by reference to other conditions or situations by IHHP participants that were perceived to be more primary to their cardiac condition. Two female participants were looking after sick spouses at the same time that they had been referred to the IHHP. One of the spouses died during the interval between research interviews. Lina's husband had become very sick with a cancer and he was attending regular hospital treatment sessions at the time of her first interview. Her husband's illness lasted only five months and her family had been helping her adjust to her new circumstances. She had had no further cardiac complications, but noted the impact of her husband's death on her health and on her social life.

I've had no further troubles with my heart, and I told the specialist last month that I was feeling pretty good, but I've got other things that worry me, I have pain in my arm from gout which keeps me awake at night. Lately I've been feeling older, I had a very difficult time because of my husband becoming sick, my children visit me often but I still feel as although I'm always alone, that's what it is. (Lina)

Lina was able to attend the IHHP with travel assistance from the local community health centre. Despite having to care for her husband at home, Maria attended the IHHP with transport assistance. Her husband had had Parkinson's Disease for eight years and he had begun to dement, placing extreme strain on her family situation. Both Maria's daughters were also employed and Maria had assumed most of the responsibility for his daily care.

I can't go out with him, he doesn't understand anything anymore, it's like being a prisoner in your own home, he needs help around the clock, even to help pull his trousers up. My health needs help, but I have to help him instead. He's a lot to cope with, and I don't even have high blood pressure. The doctor thinks it's amazing that I don't have high blood pressure given my situation. (Maria)

Maria's own health needs were seen as less important than the care that she needed to provide her husband at home. Traditional expectations meant that Maria had assumed the responsibility for his care. She was emphatic about her situation and her feelings towards her husband, recognising her own needs but unable to obtain any comfort from him because of his condition. Her husband's illness had begun to sadden her.

There's a saying in life, that you can't have it all, but neither is it good to have nothing at all, never to have had anything. It would be great if he [her husband] could see that I do everything for him and give some support in return, see that I am sick too, to not give me so much angst, but he doesn't see that, he's not interested in my situation. (Maria)

While Maria was perceived by her family to be making a good recovery, the strain placed on her by this particular family situation made it difficult for her to address any of her own health needs to help prevent future cardiac complications. She also had other physical complaints which impaired her ability to exercise, for example sciatica pain and back pain from a spinal injury.

My leg and foot hurt now, how can I do all those exercises? I enjoyed doing them but I can't do them now. (Maria)

Other health conditions were also more pressing than CHD for other IHHP participants. Angelo spoke of the impairments in his life as a result of having a gastrointestinal complaint which had remained untreated and had continued to be a greater source of ill-health than his CHD.

My health problems don't come from my heart condition, yes I've had them too but my problems are different. I've had lots of tests but I always feel tired, not because of my heart but my problems come from my problems with digestion. (Angelo)

Most of Angelo's impairments had arisen from his gastrointestinal complaint rather than from his CHD. Angelo attributed his poor health to his gastrointestinal symptoms which he recalled beginning after retiring from full time employment. Angelo had had an angioplasty three years after retiring, to relieve angina but had had no further CHD complications for several years. While his CHD did not appear to pose him trouble, his other health problems were proving to be a significant source of emotional and psychological unrest and a barrier to improving his cardiac health. Symptoms of breathlessness had led Angelo to have a cardiac examination, but Angelo associated his breathlessness to his gastrointestinal complaint. Angelo also had several features of depression.

Value of social contact during rehabilitation

The second emergent theme from the interviews was the value placed by IHHP participants on the social contact provided by the IHHP. All the participants who completed the program believed that the most valuable part of the program was the opportunity to have contact with others and to spend time in the company of others.

Lina emphasised the value that she found in being with others because she preferred to be in the company of others rather than being alone. Her husband had died in the interval between research interviews, which meant that she now lived alone, with her dog and family close by.

I was happy being with others and very comfortable at the program, I like company, I don't like being alone. I've also got a dog to help keep me company, even at night despite his barking. I've lots of good friends near me, and so are my children, grandchildren and nephews. (Lina)

The rehabilitation program provided Lina opportunities to meet and spend some time with others who spoke Italian. Angelo said that he believed that the social aspect of the program had helped encourage him to exercise in the group setting. Angelo normally finds it difficult to do any exercise alone.

It was good to exercise with others, I did it willingly because otherwise I wouldn't have had the courage to do it alone, instead with others it's easier to do. (Angelo)

Angelo had felt better after each session and attributed this to the opportunities the group provided to speaking and listening to others. The social contact with others also allowed participants to think about their own situation differently.

Yes the program helped a little, I felt better after each session because I had spoken with others, I was social for a short while, to be able to speak with others listen to others, instead of arguing. Listening to others gives you support because it helps you take your mind off your own problems and to think more clearly about your situation. (Angelo)

The IHHP provided Angelo opportunities for social appraisal and influence. This helped him to think more clearly about his own situation and to take his mind off his own negative thoughts. The social influence from the IHHP was also noted by Guido, who thought that this could contribute directly to recovery. He emphasised the effect of social influence when hearing about familiar things from a different viewpoint.

It was good to meet others, to hear from others in similar situations, it made you feel a little better when you can listen to others speak.
(Guido)

Maria only attended the first session of the program. She attributed her inability to attend to travelling difficulties. She believed that the social aspect of the program would have been very beneficial for her general mood.

The program could help a lot, I would have gone if I'd lived closer but it was too far to go for me. These kinds of things can help how your feeling, your mood. The first thing that helps is that you are with others and you can exercise together.(Maria)

Maria and her husband had become gradually more socially isolated from others, as she had become more anxious about leaving the house. The IHHP could have given her opportunities for social contact to ease the tension and anxiety she was experiencing. Maria's husband explained how the social aspect of the IHHP could have helped her psychologically.

What she needs from the program is the company of others, being in company allows you to off load a little tension in the mind and the body, but unfortunately it was too far away.(Maria's husband)

A friendly context to listen to others and discuss their health problems was the most valued aspect of attending the IHHP. This was perceived as helpful by IHHP participants because they valued the opportunity to meet others in similar situations and listen to various points of view. It also aided their recovery by providing opportunities to relieve psychological symptoms such as tension and anxiety. Learning new activities such as exercise routines and other healthy behaviours was also perceived to be easier when conducted in a group setting. For those IHHP participants who have little social contact, the program provided valuable opportunities to meet others in similar situations who could speak Italian and access various forms of social support.

Interactions with medical professionals

During the interviews, IHHP participants frequently referred to their contact with the medical profession, specialists, and their experiences in hospital, both at the time of their cardiac event and at other times. Frequent contact with doctors was reported by some participants. This contact was sometimes very positive and effective, but at other times confusing and unsatisfying. There were also instances of poor communication between medical staff and IHHP participants, likely due to the participants' limited understanding and expression of English.

Lina reported being confused and frightened by doctors at her hospitalization for breathlessness. She explained that her poor understanding of English may have affected her ability to understand what was happening to her. Lina perceived that efforts had not been made to explain her situation and procedure to her fully.

Actually I don't understand a lot of English to tell the truth, but they didn't tell me very much, how I got sick, how it would turn out, what to expect. They didn't tell me anything at all except that I had too much water in my lungs. (Lina)

Poor knowledge of English seemed to be implicated in incidents at the hospital. Paolo was admitted to hospital for observation of angina. While in hospital he had been given an injection of morphine which caused an emergency situation. He lost consciousness and required the intervention of several hospital staff. Paolo's wife, who was present during the incident, recalled the event and the difficulty in communication between she, Paolo and the hospital staff.

They did all sorts of things to him, gave him oxygen and they made me call the children. But I wondered why they had given him that injection and I couldn't get this out of my mind. So I asked them why they gave him the injection and they said 'why, is he allergic to morphine?' And I told them I didn't know, I wasn't a doctor, but I kept asking them why they had given him morphine. (Paolo's wife)

Neither Paolo, nor his wife, were aware of why he was given the morphine. English language difficulties may have led to the confusion. The situation also demonstrated differences between lay people and professional medical staff. Hospital patients are subjected to the authorised knowledge of the hospital staff and the gulf between this knowledge and those patients such as IHHP participants, who come from culturally-diverse backgrounds, can be extremely wide. The gulf can be perceived as even wider when information is not provided to them.

Maria believed that poor communication between two members of the medical staff and herself had led to the insertion of the incorrect ICD. The

psychological consequences of the ICD had subsequently become a significant barrier to her health and the hospital system was perceived to be responsible for her anxiety and despair.

The pacemaker [ICD] wasn't for me, it was for another patient. During the night, they noticed that I had had a small heart attack, so in the morning the doctor wanted to speak with a relative who could speak good English. I don't have any relatives here, only the daughter of a friend of mine, so he spoke to her and we had a three way conversation on the telephone. (Maria)

A failure in the continuity of care was blamed for this error, but English language difficulties may have contributed to this failure upon arriving at the hospital impromptu. Maria's husband attributed the medical error to a failure in the continuity of care, despite efforts to provide an opportunity for Maria's request to be understood by a third party. A doctor, with whom she had established a good rapport, was not in the hospital on the day she arrived.

He wasn't there on the day she had the surgery, they should give you the same doctor, even in public hospital, instead of giving you another. How are they supposed to keep track of what's already happened? If one doctor knows all about my situation why do they then send you to another for treatment and make you go over things again? I might not even recall things very well, I'm not a doctor, I don't write everything down. (Maria's husband)

Maria's husband blamed the hospital system for the error. Maria had endured several years of psychological unrest from her ICD and had also seen many other doctors and specialists for various unexplained symptoms. Maria had begun to perceive that the medical profession thought of her as a malingerer and

143

did not believe her reports of pain, adding to her poor experiences of the hospital system.

> *You know what a doctor told me once? It even made me laugh, but he*
> *told me that I had spent more time at the hospital than I had at home.*
> *It's true, I can show you the appointment booklet, in [one year]*
> *between the two of us we had 16 or 17 appointments in one month.*
> *(Maria)*

Maria's husband perceived that the medical system had failed to properly treat Maria because it had failed to understand the true nature of her distress.

> *They could change it [the ICD] over but they won't, they think that she*
> *is all right, they don't know the pain she goes through, they don't feel*
> *her pains, they just expect her to take her medication and everything*
> *will be OK. (Maria's husband)*

Maria's many unexplained physical complaints may have been a reflection of her elevated anxiety, which resulted from the dissatisfaction with her hospital procedure. Maria and her husband had begun to identify that the medical professionals were unable to truly understand what she experienced. The high expectations of the medical system, set by Maria and her husband, were unmet and the system had become non-responsive for her. The potential difference between the lay expectations of the patient and the limitations of the medical system to treat effectively are explained in the next excerpt by Maria's husband.

For example if you have a stomach problem the doctor tells you what to do, which foods not to eat, or which medication to take. The doctor should also be able to tell me something about why I have the problem and how to treat it. So whenever we go to the doctor and tell them about our complaints they always say this and that and the other but never the reasons for her illness. (Maria's husband)

The dissatisfaction has arisen from the expectation by the IHHP participant that medical professionals should be able to explain the cause of illness as well as being able to give directions for behaviour change and prescribe medication to manage conditions. This illustrated the difference in what is expected of the medical profession and what it can provide. This difference had not been understood by Maria or her husband. Angelo, who also had several medically unexplained symptoms, also explained a misunderstanding of what the medical system can provide.

I want to know how it is these days that they do so many experiments, new medicines, surgery, they can make dead people walk, how come they can't make me walk? That's what I don't understand. (Angelo)

On the other hand, there were also three participants who reported having a very positive experience with the medical professionals involved in their care. This included comments about the quality of nursing care while in hospital. Roberto had had several heart attacks and angioplasties and he perceived the doctors in a venerable light, for allowing him to continue to live.

They are like Jesus Christ, maybe they're not quite Jesus Christ but they're very close. If it wasn't for them I'd be dead, they saved my life. I was extremely happy with the hospital, on both occasions. The nurses who work there are blessed, they do their duty very well and without the doctors I'd be dead, the work done was very precise and successful. (Roberto)

Guido was also very satisfied with his medical care. He drew attention to the differences in opinions between people that he had known and himself on whether the doctors had treated their patients well.

Yes they did treat me well, especially the ones who did my surgery. Many people say that they don't know what's going on to them and the doctors don't tell them anything, but that wasn't my experience. They came to see me each day, asked me how I was, made sure I was well looked after. The nurses were very good to me also. (Guido)

Guido believed that he had been very well informed about his situation by medical staff and that they had treated him extremely well in hospital. Efforts to communicate with him were noted and appreciated. Carmela noted how being treated well in hospital by the people looking after you made the whole experience of illness more pleasant for her.

Yes they were all very good to me, they got to know me pretty quickly. When you're with kind people the days pass quickly, but when you're with nasty people, you feel like dying. They were always making sure that I was all right and not over doing it. (Carmela)

Carmela emphasised the importance of personal qualities in hospital staff. Kindness by staff towards patients can assist them in coping with the adverse circumstances often present when they are subjected to hospital stays and surgery.

Summary of the *a posteriori* themes

The three *a posteriori* themes identified in the analysis of interview data with the IHHP participants highlight important aspects of the experience of CHD in this group of cardiac patients. In some instances, CHD was not perceived to be the main health problem, or circumstances in the IHHP participant's life make focused attention to behaviour change aimed at reducing cardiac risk difficult. Psychological disturbances were also evident in some IHHP patients and this was associated with dissatisfaction with the medical system and many unexplained medical symptoms other than cardiac symptoms. These, along with family responsibilities were often barriers to efforts aimed at improving cardiac health.

The most salient theme concerning the IHHP was the value placed by IHHP participants on the social aspects of the program. The importance of the social contact was referred to by all the IHHP participants. Social contact with others was perceived to have a direct influence on psychological health improving the illness experience. Being in the company with others was also perceived to assist in the appraisal of one's own condition. Access to the social opportunities, like those provided by the IHHP, was perceived as very useful in recovery from illness, particularly by those IHHP participants with few established social supports.

Finally, IHHP participants frequently referred to hospital experiences and contact with medical professionals. Poor English-language skills sometimes led to confusion and misunderstandings. The gap between the lay knowledge of the IHHP and the medical staff was evident during this confusion. IHHP participants also expected the medical system to be able to cure their symptoms in instances where medically unexplained symptoms persisted. Dissatisfaction with the

medical system was characterised by a difference between what specialist medical

knowledge could provide and what the patient expected.

Chapter 9

Findings Part 2: Individual case studies

Introduction to case studies

Chapter 8 presented a thematic analysis of the participant interviews,

conducted after the completion of the IHHP. Two of those participants did not

complete the program but were also interviewed. The thematic analysis allowed

for the close scrutiny of *a priori* and *a posteriori* themes produced by the

interviews with the IHHP participants. It therefore represented a cross-case

analysis of the data and the analysis was organised by a case-ordered data display

to arrange the themes (Miles & Huberman, 1994). This chapter will present three

individual case studies to provide further elaboration of some of the themes

identified in the previous chapter. Individual case studies allow the particularities

of the individual context for the experience of illness and illness perceptions to be

considered within the case rather than across cases. Multiple case studies can also

draw attention to what is common among cases but ultimately emphasises

uniqueness rather than generalisability (Stake, 1994).

Intrinsic case studies are presented (Stake, 1994). The cases studies are

intrinsic because they are used to provide elaboration of the themes identified in

the cross-case analysis and to shed light on the identified research questions.

They are also explanatory because the case study identifies concepts such as

illness perceptions and personal history to illustrate the response to illness and

quality of the subsequent adjustment (Willig, 2001). The choice of which case

studies to present was based upon the expectation that each case demonstrated a

different quality in the adjustment to cardiac illness. Hospital Anxiety and

Depression Scale (HADS) scores were also used to provide supporting self-report data for the psychological state of the participants and an indication on the extent of psychological adjustment.

HADS scores were collected at four points during the research: prior to the start of the program (PREPRG); immediately after the completion of the program (POSTPRG1); at the time of the first interview (POSTPRG2) and at the time of the follow-up interview (POSTPRG3). The presentation of HADS data has been limited to the data for the participants in the selected case studies, since low participant numbers made any conclusions of the efficacy of the cardiac rehabilitation program based on the HADS scores inconsequential. HADS scores are included at the end of each case study.

Three cases are presented to provide one example each of good (Case study 1), fair (Case study 2) and poor (Case study 3) adjustment to cardiac illness. All three participants whose case is presented attended and completed the IHHP. Important elements for determining the quality of illness adjustment were identified and provided a means to organise material for each case. These elements also allowed the broad social contextual factors for each case to be presented and the impact of these contextual factors upon recovery to be illustrated. These elements are listed below.

- Illness history: This element provided a brief medical history, including significant illnesses other than cardiac events and procedures, as described by the participant.

- CHD onset: This element provided information specifically about the onset of cardiac symptoms which led to a cardiac intervention and subsequent referral to the cardiac rehabilitation program.

- Personal and social history: This element provided a brief background to information concerning the participant's personal circumstances, including family history, employment history, social circumstances, immigration and other significant experiences.

- Illness perceptions: This element provided a summary of important perceptions that the participant had of his or her illness.

- Response to cardiac rehabilitation: This element provided a summary of the participant's experience of the Italian language cardiac rehabilitation program.

- Follow-up: This element was used to summarise information gained at the second interview.

- Hospital Anxiety and Depression Scale scores (HADS): The HADS data provided supporting self-report data for the psychological state of the participants, described within the context of their lived experience by the participants and presented in the case studies.

Case study 1: Lina

Illness history and CHD onset

Lina was an 80 year-old woman with a 25-year history of high blood pressure and a 10-year history of diabetes. She also had strong arthritic pain associated with gout that caused her to have pain in her arm and wrist at night. At the onset of her cardiac condition, she had begun to complain of breathlessness,

fatigue and lethargy. She was subsequently told by medical staff that she had accumulated water in her lungs and she had received an ICD (Implanted Cardioverter Defibrillator). She attended the IHHP a few months later and was interviewed twice for the research, with an interval of six months between interviews. Lina's younger sister, who lived close by, was present at both the interviews. Lina's husband had cancer and was undergoing regular treatment at the time of the first interview. She had always been a non-smoker and enjoyed a small glass of wine at night with her dinner.

Personal and social history

Lina had three children and lived with her husband in a north-western suburb of Melbourne. They had married in Italy in 1946. Her husband had immigrated to Australia from Salerno (Campagnia) in 1951 and she and her three children had followed, but were required to wait 10 more years. Her three children were all younger than five years old when her husband left for Australia. Lina and her children had continued to live with her mother-in-law in Italy, who was reluctant for her to leave and join her husband in Australia. After arriving in Australia with her children, Lina worked in a shirt factory, with her sister, until she injured her hand in a work accident. She did not return to work after that because her husband did not approve, and she received a small sum of money in compensation.

Lina's children live close by and she has several grandchildren, some who also live in the same area. Her son's father-in-law is a general practitioner who she visits regularly. Her children and grand-children also visit her often, as does her younger sister. Lina frequently walks to visit her relatives and is very appreciative of having several family members living close by because she enjoys

the company of her family. Lina's husband had begun treatment for cancer and was frequently attending hospital. Lina's family provided valuable support for the care of her husband, including transport to and from hospital.

<u>Illness perceptions</u>

Lina did not have a good understanding of the cause of her symptoms and, since receiving the ICD, had also thought that her arthritic pain might have been associated with the pacemaker's operation. When Lina was admitted to hospital, she was frightened and confused by what medical staff were proposing. She claimed that her understanding and knowledge of English was poor and that she believed she had not been told very much about the cause, nature and prognosis of her illness. She was unsure about whether she had any control over the progress of her illness. She also said that after the insertion of her pacemaker, she had continued to develop water on her lungs until she was prescribed a medication to assist her. Since she began to use this medication, Lina has had no further cardiac symptoms and she has been pleased by this outcome.

Since her surgery Lina appeared to be making a good recovery but remained concerned about the arthritic pain in her arm. She had quickly returned to previous activity levels, looking after her home and her husband, working in the garden and spending time visiting her family. Lina's perception of her health was that she had made a full recovery and felt as though she had never had any cardiac problem at all. She had been helped and supported by various members of her family, including her grandchildren, who regularly dropped by to see if she needed anything. Lina also had a pet dog, which was loved by her and all the members of her family, including her husband.

Response to cardiac rehabilitation program

Lina enjoyed the cardiac rehabilitation program, and especially noted the benefit of the transport assistance that she received from the program to ensure that she attended each session. She also mentioned the value of being able to speak with others and to spend time in the company of others whom she could become friends with. Lina perceived herself as enjoying the company of others and hearing the experiences of other participants in the IHHP. She also thought the exercise program was useful because of the benefits of staying active and moving the body. She had made little change to her diet as a result of attending the program. She had previously made some changes to her diet as a result of her diabetes, which she had learnt to manage very well.

Follow-up

Lina's husband died of cancer in the interval between research interviews. Lina had had the close support of family during this period and while she was saddened by his death and at times felt lonely, she had continued to be able to live independently and maintain her level of daily activity. Lina's sister had moved in to live with Lina for three months immediately after his death. While preferring to live in her own home, Lina said that she always liked to have company rather than to be alone.

Hospital Anxiety and Depression Scale scores

Lina completed and returned the HADS at each stage of the research. Her POSTPRG1score indicated some improvement in her mood after the IHHP when compared to her PREPROG score. At both POSTPRG2 and POSTPRG3, her depression score had increased slightly. This may reflect changes in her mood as

154

a result of her husband's worsening illness and eventual death in between

POSTPRG2 and POSTPRG3. While there is an increase in her depression score,

it remained within acceptable limits and her anxiety score showed no

corresponding increase. Lina's scores are shown in Table 3.

Table 3: Hospital Anxiety and Depression Scale scores for Lina

Lina	PREPROG	POSTPRG1	POSTPRG2	POSTPRG3
Anxiety	5	2	2	2
Depression	2	3	4	5

Case study 2: Carmela

Illness history and CHD onset

Carmela was a 66 year-old woman who had had triple coronary bypass

surgery. She had been suffering breathlessness after short bursts of activity,

fatigue and was coughing, especially at night. After seeing a specialist, she was

admitted to hospital almost immediately and told that her coronary arteries were

96 % occluded. At that time, she was told that, if she had waited another week

before seeking treatment, she may have died. She spent six days in hospital and a

further six days in a rehabilitation setting. She experienced her illness as being

very sudden, since she had no prior history of cardiac problems or major health

worries. Carmela has diabetes, evidence of osteoporosis and elevated cholesterol.

After her surgery, her diabetes had been well controlled but at the time of the

interview, her blood sugar level had increased substantially. She also had a

history of back pain which she said also needed surgery and had recently developed sciatica nerve pain. Carmela was referred to the IHHP following her triple bypass and was interviewed for the research five months after completing the program.

<u>Personal and social history</u>

Carmela lived with her husband and two daughters in a northern suburb of Melbourne. Carmela and her husband were married in 1956 and they, along with their young children, immigrated to Australia in 1964 and settled in Geelong. In 1972, the family chose to return to live in Italy so they could look after Carmela's parents while they were sick. Carmela's parents died and the family then returned to Australia in 1976, after four years of living in Italy. The family had to virtually start their life in Australia again, after having sold all their possessions, including their home. On returning to Australia, Carmela began work as a laundry worker in a hospital, where she remained until the work was privatized in 1992 and she was no longer required.

Carmela believed that she might still have been working if it had been possible. Carmela worked while raising the family and emphatically explained the effort that she had gone to, to ensure that her children and husband had everything that they needed, before heading off to work herself early in the morning each day. Carmela had hoped that all the sacrifices she had made for her family might make her life happier as she became older, but her prospects for healthy old age changed dramatically after she stopped working at the hospital.

Not long after she had stopped working, in 1994, her husband was diagnosed with Parkinson's Disease. He had since begun to experience dementia and had continued to live in the family home, cared for by his family, especially

Carmela. Carmela confirmed, as did her daughter, that the health of Carmela's husband was the family's major problem at the time of Carmela's diagnosis of CHD and bypass surgery. Carmela explained how he had begun to hallucinate, would keep her awake at night and required assistance dressing and washing himself. Carmela found his ongoing care difficult and she is not eligible for community assistance because her daughters live at home with her, despite their having to work. Carmela believed that the pressing needs of the care of her husband meant that she was not always able to care for herself and had wished that her husband would be more sympathetic to her health needs but Carmela recognised that his deteriorating mental condition prevented him from doing so.

Carmela has limited social contact with others because her husband had refused to leave the house and if he did, he was usually a nuisance to others, limiting her enjoyment in social settings. Carmela described herself as an outgoing, lively person who enjoyed the company of others, but that her husband had not been a very social person and now preferred to have little contact with others. Carmela said that her situation made her feel depressed, desperate and her husband's confused behaviour agitated her.

Illness perceptions

Carmela had made a good recovery since being released from hospital and paradoxically, this was attributed by her daughter to having to resume the care of her husband. After returning home, she had felt weak and unable to do very much, but she quickly returned to trying to do her normal chores, such as washing, ironing and cooking. After one month, she had almost returned to her previous activity level, to the amazement of those around her. Carmela believed that she had not entirely returned to her pre-surgery activity level although she did

perceive that she had made significant gains. She had not been able to return to taking care of her vegetable garden and she occasionally needed to slow down and have a rest when doing housework. She compared this restriction in her abilities to the time when she was employed full time and physically able to work very hard. This ability to work hard made her happy and Carmela believed that she was much healthier while working.

Carmela had no definite explanation for why she had developed heart disease. She said that she had had few health problems in the past but that since her husband had begun to dement, she had become more anxious and depressed. Carmela said that the difficulties in caring for her husband constantly strained the family relationships and she had become more agitated. The difficulties in the family had made Carmela think of her hospital stay for bypass surgery as respite from her family troubles.

Response to cardiac rehabilitation program

Carmela enjoyed attending the Italian cardiac rehabilitation program, particularly the opportunity to go out and do something for herself. Carmela received transport assistance to the program because she had no other way of getting to the program. She found the group exercise program helpful for her motivation to exercise and she had continued to try to exercise at home by walking up and down the drive way in the evening. Carmela said that she found going out and spending time with others "calming" and her daughter had also perceived that the program had been good for her. Carmela noted though that sometimes changes to behaviour, like dietary changes, are not always possible when consideration of other family members' needs have to be taken into account.

Follow-up

Carmela was invited to be interviewed again for the research but declined. Discussions with her daughter by telephone revealed that Carmela's husband had had a stroke during the research interval and had been hospitalized for a substantial period of time. He had then returned home to be cared for by his family. Further discussions with Carmela's daughter by telephone 12 months after the first interview revealed that Carmela's husband had become bedridden and now required 24 hour care in the family home. At that time, Carmela complained of heart palpitations and she had also developed high blood pressure which required medication. Her daughter attributed this development to the strain of caring for her husband.

Carmela was contacted again a further 12 months later. Her husband continued to be bedridden and to be cared for by her in the family home. The situation had essentially remained unchanged for almost two years. Carmela had begun to find walking difficult and had also begun to have problems with her vision. She had also been told that her cerebral arteries had narrowed, presumably from developing disease. Her cholesterol levels had also increased. The family had been granted some external care but most of the work and care for her husband was still being carried out by Carmela. She had not been able to get out of the house very much lately but had tried to do a little hydrotherapy. The family remained committed to the care of Carmela's husband at home rather than in a nursing home.

Hospital Anxiety and Depression Scale scores

HADS scores were only available for POSTPRG1 and POSTPRG2 for Carmela. Carmela's scores over that time, which represented the time

159

immediately following her completion of the IHHP (approximately four months), show an increase in her anxiety score. Her depression score remained elevated during this time. The increase in her anxiety is consistent with the increasing difficulty of her home situation, characterised by the requirement to care for her husband. The anxiety evident in her interview responses and her case study are reflected in her elevated anxiety score. Carmela's HADS scores are shown in Table 4.

Table 4: Hospital Anxiety and Depression Scale scores for Carmela

Carmela	PREPROG	POSTPRG1	POSTPRG2	POSTPRG3
Anxiety	-	6	13	-
Depression	-	9	9	-

Case study 3: Angelo

Illness history and CHD onset

Angelo was a 69 year-old man who had a history of high blood pressure and diabetes. He lived at home with his wife in an inner Melbourne suburb. Angelo had undergone an angioplasty and the insertion of an arterial stent and was subsequently referred to an 8-week phase two cardiac rehabilitation program at a private hospital. Angelo completed that program and was then referred by a private specialist to the IHHP. He completed the IHHP also and was interviewed four months afterwards and again a further eight months after his initial interview. Angelo had no further cardiac complications since his last surgery and he saw his cardiologist at regular intervals. Angelo smoked regularly until he was 65 years

old. At that time, he sometimes smoked up to 20 cigarettes each day. He drinks an occasional glass of wine in the evening. Angelo's main symptoms are breathlessness and stomach swelling especially in the morning.

Angelo said that before he retired, he had experienced good health for many years, which rarely required him to see a doctor. Since retiring, he has had several major health problems which had meant frequent contact with doctors and the medical system. Angelo underwent his first gastroscopy for a suspected digestive disorder soon after retirement and had three more gastroscopies in the years prior to participating in the cardiac rehabilitation program. Angelo had been told by medical specialists that he had an "inflammation of the stomach" (GI tract) which has essentially remained untreated by medications. Despite having no further cardiac complications, he continued to complain of breathlessness. Angelo also had a hernia operation, after he retired, in 1997.

Personal and social history

Angelo arrived in Australia from Sicily in 1954 and worked for 41 years as a cleaner with a railway company before retiring in 1997. He and his wife have four children born in Australia. Angelo also had a grandchild who is cared for at home by his wife, while their son works. Angelo said that he enjoyed caring for his grandchild.

Angelo had several features of clinical depression and was very low in mood when interviewed. Angelo had trouble sleeping, saying that he was not able to sleep more than three or four hours once going to bed. Angelo experienced profound sadness, low motivation and critical self-thoughts upon waking each morning. He believed that he had lost the courage to lead a productive life and no longer felt able to successfully do anything worthwhile. His negative self-thoughts

prevented him enjoying activities and he experienced times of high levels of anxiety and sweating. He also had a poor appetite.

Angelo perceived that he had little contact with others outside his immediate family. His poor mood often made him easily angered with others and he had become cynical and contemptuous about his friendships. Angelo relied heavily on his family and believed that family was much more important than friends when it came to support for illness. Angelo believed that family ties were much stronger than any social ties that he had with friends and he was reluctant to talk about his health with anybody outside the family.

Illness perceptions

Angelo regarded his main health problem to be associated with his gastric inflammation and not his cardiac condition. He experienced his GI disturbance as extremely disabling and his contact with the medical system was perceived as unsatisfactory. Angelo had once purchased some equipment, on the advice of doctors, to help treat suspected sleep apnea but this had been no help at all to him, saying that it was more of an inconvenience, because his trouble was insomnia, not difficulty breathing at night. He was confused and frustrated by the failure of medical science to help him and had no explanations for the cause of either his gastro-intestinal condition or his cardiac illness. He wondered why in times of large technological advancements and progress that medicine had not been able to help him and restore him to his previous self.

The consequences of Angelo's illness were mainly psychological. For Angelo, being healthy meant having courage, desire to live your life, without fear and anxiety and to have the energy to do the things you wanted to do. Angelo believed that his illness had caused him to lose this courage and that he now found

162

himself going backward in life, "never achieving anything". Angelo had held onto the belief that his illness could be cured if he could find the right treatment. His wife, while being extremely supportive, placed her faith in God to help her husband. She believed that he had a physical illness but that he needed more courage to help him confront the adversities that his illness brought him. She also highlighted a perceived need for more social opportunities for Italians in her local community emphasizing the importance this could have for coping with illness.

Response to the cardiac rehabilitation program

Angelo completed the phase two cardiac rehabilitation program for Italian speakers and said that he found the opportunity to meet others the most useful part of the program. He also benefited from the group exercise program because he felt encouraged by the group to exercise together and said that he was normally unable to be motivated to do any exercises alone at home. He had also acquired more knowledge about his heart and decreased his ignorance about illness. Angelo found the nutritional information particularly useful because of its relevance to his gastrointestinal problems. While he enjoyed the IHHP, he thought that the earlier phase two rehabilitation program, which he completed at a local hospital, had a better exercise component because they did a variety of different exercises, including walking, under supervision. He had made little change to his diet since his coronary angioplasty but was trying to walk more frequently, even short distances, since having attended the rehabilitation program.

Follow-up

Angelo had a further gastroscopy in between interviews for the research. His condition had remained unchanged and he had begun to consider alternative medicine as an option for the treatment of his GI complaint. His mood remained

163

low and his sleeping problems persisted. Angelo also remained uncertain about his prognosis because of the on-going failure of his doctors to treat him successfully. He had had no further cardiac complications.

<u>Hospital Anxiety and Depression Scale scores</u>

Angelo returned HADS data for each stage of the research. His PREPROG scores for both depression and anxiety are considerably lower than his elevated scores at all three remaining times (POSTPRG1, POSTPRG2, POSTPRG3). Angelo's scores remained elevated for both depression and anxiety 12 months after the completion of the IHHP. In particular, his score for anxiety is extremely high. Both Angelo's scores on depression and anxiety reflect several features of a disabling mood disorder which is also evident in his interview responses and the case study. The reason for the low scores at PREPROG was unclear. The sharp increase at subsequent stages of the research may reflect a more accurate self-assessment of his symptoms, if his initial response to the HADS was to present a more favourable impression before the start of the IHHP. It may also reflect the presence of denial or uncertainty about how much of his situation to disclose before becoming entirely at ease with the research project. Angelo's HADS scores are shown in Table 5.

Table 5: Hospital Anxiety and Depression Scale scores for Angelo

Angelo	PREPROG	POSTPRG1	POSTPRG2	POSTPRG3
Anxiety	5	13	12	14
Depression	6	9	9	8

Chapter 10

Findings Part 3: Thematic analysis of interviews with Italian cardiac rehabilitation program health professionals

Introduction

As described in Chapter 7, interviews were arranged and conducted with the four health professionals responsible for the delivery of the phase two cardiac rehabilitation program (IHHP). A second interview schedule was developed and used to guide semi-structured interviews with the relevant health professional. The interview focused upon both their own contribution to the program and general thoughts and opinions of the program. In particular, health professionals were asked to give their perceptions of the needs of Italian-speaking cardiac patients and what aspects of the IHHP they believed to be the most valuable. Consent for participation in the research was gained and interviews were conducted in their usual place of employment. The health professionals interviewed were the community nurse/educator, the dietician, the social worker and the physiotherapist.

The physiotherapist did not provide an educative group session and was only responsible for conducting a short light exercise program at the conclusion of each group session. The following section provides an overview of the main themes which emerged from the interviews with the health professionals. The themes were; the ineffectiveness of the IHHP at behavioural change, limitations of the IHHP for addressing individual patient needs and the importance of social engagement and opportunities for discussion in the IHHP. Excerpts from each of these themes are presented in the next section.

Ineffectiveness of IHHP at behavioural change

While all the health professionals claimed that it was very important to continue to provide a phase two cardiac rehabilitation program for Italian cardiac patients, all four of the health professionals also noted that the effectiveness of the IHHP at establishing long tem behaviour change was largely unknown. This was described as a lack of patient follow-up and not knowing whether any behavioural changes adopted by participants had led to a reduction in cardiac risk factors. Some of the participants were regarded as not being willing to change their behaviour and this was attributed to cultural features of working class communities.

One bloke said to me "nobody's teaching me anything new at this stage in life". I think it's the culture of elderly working class European people (Social worker)

This cultural belief made it difficult for one health professional to know how to encourage long term behaviour change. The health professional identified this struggle as a difference between his own value system and the value system of the group.

These people have done well, they have property, raised children and grandchildren, they have come a long way, but their value systems are not open to change, it was beyond my understanding and knowledge to know how to engage those people to make significant change. (Social worker)

This cultural difference was also evident in specific health behaviours. The following excerpt showed the difference between the social worker's concept of relaxation and the participants' ideas of what relaxation meant.

I think I asked them what they thought relaxation was, most of them didn't have any idea of what active relaxation was, something where you look inside your body and become aware of what's going on, they were more likely to say television for instance, and I'd say, well, television can be relaxing but this is different. (Social worker)

The ineffectiveness of the IHHP to promote behavioural change was also attributed to established behaviour patterns. The following comment was made by the IHHP physiotherapist when asked about the value of the program for behaviour change.

I think many of them understand the need to change their diet or to exercise more, but whether they can do it (change) or not is a different question. Most are elderly, they have been doing the same things for many years, their taste buds have been trained to specific foods and it's not easy for them to change their diet, or to motivate them to exercise regularly. (Physiotherapist)

The limitations of the IHHP for addressing individual patient needs

The limitations of the IHHP in addressing behavioural change were also explained by the inherent limitation of the IHHP to deal with individual needs. The IHHP dietician identified this limitation by making a distinction between a patient-focused approach and the disease-focused approach adopted by the IHHP. Tailoring of advice was fundamental to the success of the intervention.

You need a patient-centred approach rather than a disease-centred approach. By that I mean not focus on the illness but focus on the person. When I look at the kinds of conditions that need treating, unless you take a patient-centered, individually tailored approach, you often don't get anywhere. So for example if you have ten people with an Italian background with diabetes who come to you and you give them all the same diet and expect them to have the same outcome, that's wishful thinking, it doesn't work that way. (Dietician).

A similar concern was explained by the community nurse educator. She perceived that her work in helping participants understand the importance of traditional risk factors had little impact, especially because of the failure of traditional risk factors to account for many cases of CHD and the widespread acceptance of the association of these risk factors to CHD. Individual experience could not always be explained by providing information on risk factors.

I didn't think I had much impact talking to them about risk factors for CHD because most of them knew them back to front and upside down, and some of them didn't even have any of these risk factors and had still had a heart attack. How do you deal with these people? You're giving them information which on the whole explains how it happens and they have an entirely different story. (Nurse educator)

The importance of social engagement and opportunities for discussion in the IHHP

As did the IHHP participants, the health professionals of the IHHP emphasised the social value of the program. All three educative health professionals (all except the physiotherapist who only provided the exercise program) saw the importance of allowing ample time for discussion with the

168

group and that part of their role was to listen to the individual experiences of the group members. The need to be listened to was identified by them as one of the group's most important needs. The nurse educator compared this role with the role of providing them with risk factor management.

I don't think the information that I delivered is very effective because, strangely enough, here is a group who don't have good English language skills but most of them have a pretty good understanding of risk factors for CHD, but I think that I helped them most by listening to them, especially how it all began. And I think the others in the group enjoy listening to this, it was a time in the group when they are all listening to each other. (Nurse educator).

Despite having English as a second language and being culturally diverse, the group was perceived to have a good knowledge of CHD risk factors. The most beneficial part of the group session was perceived to be the opportunity they had to speak about their experiences and this is perceived by the health professional to be more valuable than the provision of more information aimed to promote behaviour change. Another health professional drew a distinction between those who might benefit from behaviour change and those who would benefit more from working through their experiences with others. This was called the "mental stuff."

I thought that for some of them, the best thing for them would be to change their diet, but some of them look pretty good, and what they need is... some of them are incredibly agitated and emotional, and it's very good for them to be doing the mental stuff. (Social worker)

This excerpt also noted the presence of anxiety and emotional distress in participants that was seen to be the focus of a working through. Having the

opportunity to do this in the group was seen as beneficial by the health professional. The chance to do this was located squarely on the notion of community and having a context to provide opportunities for engagement with others, including health professionals. This was regarded as the most important aspect of a cardiac rehabilitation program for a group such as the Italian-speaking cardiac group.

They need to have a context where you can see them and interact with them around their issues. The idea of community health is that there is a community, there is a notion of community, so the program is not just a thing that you show up for once in a blue moon. (Social worker)

The provision of a sense of community is important when considering the program setting. A public and central location, which is well accessed by many people for various reasons, could provide more participation and involvement in cardiac rehabilitation programs. This is because the program forms a part of the other functions and opportunities provided by the sense of community, rather than being seen in isolation and provided infrequently. According to the health professionals, a sense of community had been fostered by the co-ordinator of the IHHP and it was this feature that had provided the opportunity for the strong engagement with the program witnessed by the health professionals.

Chapter 11

Discussion

This chapter will provide a discussion of the findings presented in

Chapters 8, 9 and 10 and will refer to data collected from interviews with the

IHHP participants and IHHP health professionals, as well as the three case

studies. The chapter begins with a consideration of the findings for the research

questions proposed in Chapter 6. Findings will be discussed with reference to the

literature reviewed in the first five chapters of the present study. Further

clarification of these findings will be made with reference to the three case studies

presented in Chapter 9. The discussion will also examine the implications of the

findings for cardiac rehabilitation programs using social network theory (Berkman

& Glass, 2000). An assessment of the strengths and limitations of the present

study is also presented. Finally, implications of the findings for phase two cardiac

rehabilitation programs for culturally diverse communities are discussed,

addressing the ongoing development of cardiac rehabilitation programs in

Australia.

The meaning of good health

The findings for the question concerning the meaning of good health were

gathered by asking participants directly about what being healthy meant to them.

The findings from the present study were analysed using Blaxter's (2004)

definitions of health as sensitising categories (Patton, 2002). Italian-speaking

cardiac patients interviewed did not regard good health as the absence of disease.

No participant described the meaning of good health in this way. Instead, the

findings support the meaning of good health as defined by functional ability and being able to complete activities.

Blaxter (1990) regarded the concept of health as function as overlapping with health as social relationships and also with health as psychosocial health, although the latter category was reserved for expressions of health as purely a mental state. Both these categories were also found in the Italian-speaking cardiac patients. This further reinforces the emphasis placed upon health as function by this group of cardiac patients. The participants placed this emphasis on physical abilities, both in employment and domestic domains, and on the ability to maintain positive social relationships with other people. Health as psychosocial well-being also reflected the importance given to psychological health rather than to the health of the physical body. The strong prevalence of health as function in the thematic analysis of interviews also supports Blaxter's (1990) finding that health as function was more likely to be expressed by older participants. The participants in the present study had an average age of 69 years, so the importance of health as function can be explained by the restrictions and limitations in life that are endured as age advances.

Health as function corresponds to the health register that Pierret (1993) called health as a tool. For the Italian-speaking patients in the present study, this represented their belief that good health provided the way of achieving all that was needed and represented the most important aspect of their life. Health is the tool that allowed all things to be possible and is often used as a way of organising how a life can be lived. The findings of the present study demonstrated that the ability to work and maintain domestic duties and family life is considered an

important aspect of having good health. Good health was seen to be a means to an end, not the goal itself.

Two of the case studies also highlighted another important feature of health in this sample. In the cases of Carmela and Angelo, good health was not only represented by the association with function, such as the capacity for employment, but also that this capacity had been lost by the onset of illness. In their study of the losses and gains incurred from cardiac events, Hudson, Board, and Lavallee (2001) identified the loss of physical capacity as an important aspect of the overall loss of a sense of purpose and quality of life. These losses can contribute to an overall sense of loss and increases the likelihood of depression in cardiac patients. Both the cases of Carmela (case study 2) and of Angelo (case study 3) demonstrated how far-reaching the loss of functional ability can be and how it becomes associated with poor health. In the case of Angelo, the loss of his functional ability, the ability to work and lead a productive life, had also contributed to his depression and feelings of hopelessness.

Bergman and Bertero (2001) also noted the theme of lost health in their research and the importance of overcoming this obstacle in efforts for rehabilitation. The case of Angelo provided an example of how the loss of health had been represented by a loss of functional ability and how that can lead to a more profound feeling of depression, which can then be an important barrier for rehabilitation. The depressed and anxious mood of both Angelo and Carmela is also supported by self-report data from the HADS, which indicated clinical levels of depression in both participants which persisted many months after the completion of the IHHP.

The significance of health as a function in the overall conceptualisation of health by immigrant workers is discussed by van Moffaert (1998). van Moffaert proposed that the concept of health for immigrant workers is largely determined by their distinctive situation in the society to which they immigrate. van Moffaert argued that having an able body and being able to work are central to this conception of health because the survival of the immigrant in a new country is based upon their ability to use their bodily integrity for the improvement of their standard of living. Hudson et al. (2001) argued that cardiac rehabilitation can have a role in assisting people to recover some of the losses incurred from cardiac illness, including functional losses which have reduced their sense of purpose. According to Hudson et al., this occurs by increasing a sense of achievement, increased awareness and increased social support provided by the sharing of experiences.

Implications for cardiac rehabilitation

The finding that participants had acquired a meaning for being healthy which departed from the traditional view taken by the biomedical approach of health as the absence of disease, has several implications for cardiac rehabilitation and recovery from CHD. The model of cardiac rehabilitation adopted in Australia has focused upon the importance of education to encourage risk factor reduction and long term behavioural change, the aim being that the impact of cardiac disease can be retarded or even reversed. This principle of behaviour change, while recognising the important influence of environmental factors which influence disease, maintains that health can be improved when the progression of disease is controlled using risk factor reduction strategies to increase healthy

behaviours. Phase two programs, such as the IHHP, have adopted the same approach which focuses on behaviour change to improve health.

Fine (1990) has identified the importance of the cultural practices of the health care system. The eventual treatment of ill health is largely determined by the biomedical approach to illness which in and of itself, represents a cultural practice, with its own shared beliefs about how illness can be treated. Schmeid (1990) has identified the biomedical basis to the cultural practices of the Australian health care system and limitations it poses for people of different cultural beliefs. The cultural practices of cardiac rehabilitation programs have largely been influenced by this biomedical approach and its focus upon the reduction of risk factors. The findings of this present study have shown that participants from culturally diverse backgrounds may have developed different conceptualisations of what being healthy means and therefore place less emphasis on behaviour change and risk factor reduction. The findings support Lee's (1990) claim that there is a potential mismatch of cultural beliefs and practices between the health care system and those from a culturally diverse background who use it.

The potential for a mismatch is supported by other aspects of the present findings. Thematic analysis of interviews with IHHP participants revealed that the IHHP had had only a small impact on their day-to-day behaviour. All participants regarded the most valuable part of the IHHP to be the social context that it provided for meeting and talking with others. Most of the participants already perceived themselves as having made the required behavioural changes, where those changes were possible.

Limitations of the current approach to cardiac rehabilitation for behavioural change in the Italian-speaking sample were also observed by the

health professionals who delivered the IHHP. The health professionals interviewed also placed a strong emphasis on the success of the program in providing social support and opportunities for discussion. Specifically, the analysis of the interviews with the health professionals showed that there was potential for a mismatch between the individual needs of the participants in the program and the limitation of the program, in its current form, to meet those needs. The health professionals noted that the participants had already acquired the relevant information concerning the importance of risk factor reduction and behaviour change. They also noted that in some instances, the focus upon traditional risk factors did not meet the individual needs of the participant, where traditional risk factors could not account for the presence of CHD.

Clark, Barbour, and McIntyre (2002) have previously reported the importance placed, by health professionals of cardiac rehabilitation programs, on the influence of individual social and cultural circumstances on motivation for behaviour change. The findings from the health professionals in the present study also revealed that there are limitations to the effectiveness of cardiac rehabilitation without some consideration of the social and cultural contexts of the individual. Clark et al. argued that a disproportionate emphasis on individual risk factor status in an attempt to decrease the risk for further cardiac events leaves the contextual factors and individual circumstances neglected and unattended. This sentiment was also evident from the health professionals in the present study and raised the question that was also observed by Murray et al. (2000). The difference between the cultural assumptions of traditional cardiac rehabilitation programs and the social and cultural perceptions of the IHHP participant can provide a barrier to the aims of the program and to participation in it.

The perceived cause of CHD

The likelihood of behaviour change in cardiac patients has also been shown in previous literature to be effected by the patient's attribution of the cause of CHD (Gilutz et al., 1991; Weinman et al., 2000). Cardiac patients who perceived their CHD as caused by external uncontrollable factors, rather than lifestyle choices, were less likely to have made healthy behavioural changes six months after myocardial infarction. IHHP participants interviewed in the present study did not perceive their cardiac illness to have been caused by lifestyle factors or an accumulation of cardiac risk factors. Instead, IHHP participants perceived their CHD to have been caused by uncontrollable factors such as hereditary factors and life events. Hereditary factors were also attributed to the contribution that diabetes made to the onset of their CHD. Given the elderly age of the IHHP participants, it may be that this finding is consistent with the findings of Gump et al. (2001), who found that older patients were more likely to attribute the cause of CHD to external factors, such as old age, rather than lifestyle choices. While older patients may be more likely to attribute their ill-health to becoming elderly, the most important of these external explanations for CHD was the role of life events, which have frequently been studied in the illness beliefs of cardiac patients.

The interviews with IHHP participants revealed that for IHHP participants, life events remain an important consideration in understanding the cause of CHD. The impact of life events, such as family discord or the diagnosis of other illnesses, is described as being mediated by emotional responses. Emotional responses to misfortunes in life have been associated by cardiac patients to stress and frequently identified as the cause of illness (Helman, 1994). IHHP

participants did not use the word "stress" when discussing the cause of their illness but explained their illness experience against the context of an accumulation of misfortune and negative life events. Murray et al. (2000) explained this emphasis on misfortune in the perception of cardiovascular risk as being the product of social and cultural constructions for CHD and reiterated that perceptions of cardiovascular risk do not exist in isolation from the cultural milieu in which cardiac patients live.

IHHP patients did not perceive their cardiac illness to have been caused by the accumulation of risk factors, despite the widespread public health approach to CHD as a lifestyle illness, caused by lifestyle risk factors. In an Australian study of cardiac patients by Gassner et al. (2002), illness cause was not attributed to cardiac risk factors, such as hypertension. Gassner et al. also found that stress was the most common lay theory about the cause of CHD and that patients had tried to provide a rational explanation of their illness by linking together life events to provide a meaningful account of the reason for their illness. This attempt to find some meaning by cardiac patients using life events was also evident in the IHHP participants. In the case of Carmela, the perceived sudden onset of her cardiac condition and subsequent surgery caused her to remain unsure about the reason for her illness and had led her towards the search for an explanation in the strain placed on her by her dependent husband. The failure of medical knowledge and expertise to explain Angelo's poor health caused him enormous dissatisfaction and his search for the cause and meaning of his discomfort had continued, despite his doctor's diagnostic advice.

This attempt at meaning-making and the failure of medical knowledge to provide a totally satisfactory explanation to illness has been discussed by Herzlich

and Pierret (1987). Answers to questions about illness demand interpretations that go beyond medical explanations of bodily symptoms. Herzlich and Pierret explain that patients make these interpretations in their attempts to go beyond the answers given by biomedicine, because of the fundamental inability of medicine to provide this meaning. Patients also use their own observable perceptions to provide explanations for illness, making medical knowledge "in a sense superfluous" (Herzlich & Pierret, 1987, p. 100). The findings in the present study from IHHP patients, along with the findings of other studies (Gassner et al., 2002; Bergman & Bertero, 2000) indicated that the role of life events in the construction of explanations of CHD remains an important factor when considering patient causes of the illness.

IHHP patients experienced the onset of their symptoms as confusing and cardiac symptoms were rarely identified as such when first experienced. Onset symptoms were associated with other pre-existing conditions, such as diabetes, or were sometimes down-played. The symptoms experienced were described as severe and debilitating, but were not recognised as cardiac symptoms. IHHP participants generally proceeded to either their family physician or directly to hospital when the symptoms had not ceased. IHHP participants tended to become more aware of the symptoms of CHD after their first cardiac event and perceived that they were able to respond more quickly to further cardiac complications.

The findings from the present study support the findings of Pattenden et al. (2002) who studied the onset of cardiac symptoms and decision-making associated with attending hospital. Pattenden et al. found that the appraisal of the onset symptoms in cardiac patients was not a simple matter. Symptoms were poorly recognised in the first instance and were often reported to have a slow

onset, making the appraisal of myocardial infarction difficult to make. The subjective perception of perceived risk also influenced the decision to seek medical attention. Pattenden et al. found that participants in the study tended to down-play their seriousness. The findings from the present study indicated that IHHP participants also had a tendency to down-play the seriousness of the symptoms and the perceived risk. Pattenden et al. concluded that the simple provision of information may not be sufficient to promote prompt action in response to cardiac symptoms and the interview data collected from the IHHP participants supported this conclusion.

Implications for cardiac rehabilitation

Patients' explanations about the cause of cardiac illness are therefore relevant when considering recovery from CHD. These explanations arise from their experiences and their cultural beliefs about illness in general. Traditional cardiac rehabilitation programs are based upon an acceptance of individual responsibility for cardiac disease, driven by theories of behavioural risk factor accumulation, and therefore imply the individual responsibility for changing unhealthy practices for healthier ones. If illness cause is sought in the construction of meanings made from uncontrollable life events by cardiac patients, then patients may be better served by cardiac rehabilitation programs which can allow this meaning-making to be appreciated as a valuable source of discussion among participants. Cardiac rehabilitation programs able to incorporate a more individualized approach to understanding the cause of illness may have benefits for secondary prevention by providing opportunities for improvements in quality of life.

Improvements in quality of life have been identified by van Houten et al. (2002) as an important outcome measure for cardiac rehabilitation. This is in contrast to a focus upon changes in risk factor status. The positive effect of cardiac rehabilitation programs on the quality of life of elderly Italian cardiac patients has been demonstrated by Marchionni et al. (2003). In their randomised controlled trial, Marchionni et al. showed that changes in health-related quality of life were greatest for the oldest patients in the study but only when a cardiac rehabilitation program was used in treatment. Marchionni et al. concluded that cardiac rehabilitation appeared particularly useful for elderly patients, over and above the improvements in exercise tolerance, which was not significantly improved in the most elderly participants. Marchionni et al. lend support to the conclusion that improvements in the health quality of life were possible for elderly Italian cardiac patients completing a structured cardiac rehabilitation program.

The consequences of CHD

Themes associated with the perceived consequences of cardiac illness were organised into physical, social and psychological consequences. Participants in the IHHP frequently referred to the restrictions in physical endurance that cardiac illness had brought. Many of the IHHP participants noted the need to reduce their levels of activity or to reduce the pace of their activities. These activities were normally activities that they had been doing prior to the onset of CHD, such as walking regularly and working in the garden. Several of the IHHP participants were committed to returning to their prior levels of activity and some had soon noticed a significant improvement in their activity levels after returning home. This group of cardiac patients regarded a return to normal activity levels as

an indicator of recovery and this is consistent with their emphasis on their functional capacity and body integrity in the meaning of health.

On a social level, the importance of family support was often expressed. Illness can have an effect on relationships in the family, but families are more likely to offer unconditional support for IHHP participants than neighbours or friends. Illness can interrupt social activities normally pursued and in some cases, lead to isolation. Italian social clubs were used to maintain social links with others outside of the family but illness can interrupt active participation in these activities. In cases where depression and high levels of anxiety were present, as is demonstrated in case study 3 (Angelo), there was little or no positive social contact outside the family and a sense of hopelessness about the value of contact with others. Participation in the IHHP provided Angelo with opportunities for social support and engagement and he perceived this aspect of the program to be very useful for his recovery. As Berkman and Glass (2000) suggested, cardiac rehabilitation has the potential for improving health, both psychological and physical, using psychosocial mechanisms, which mediate between larger social factors and individual health.

The psychological consequences of cardiac illness ranged from perceptions of changes in mood, which were a result of cardiac surgery and were experienced as brief disturbances upon returning home from hospital, to more widespread and longstanding emotional complications. These disturbances can also be perceived to have been caused by the surgical intervention intended to help the patient. The present study has shown that cardiac interventions, such as the insertion of an implanted cardioverter defibrillator (ICD) can cause new fears and anxieties in cardiac patients which can then become barriers to recovery.

ICD's have been reported to have many negative consequences of their own, including anxiety and fear, which can tend to counteract any reductions in anxiety expected by its use (Lewin, Frizelle, & Kaye, 2001).

Consequences of an ICD are evident both in the thematic analysis and in the case of Lina. In Lina's case, she had begun to attribute pain in her arm to the ICD and this had caused her some anxiety. The thematic data analysis on the consequences of cardiac illness also demonstrated that an inserted ICD was perceived by Maria to have profoundly impaired her recovery and had become the principle source of her anxiety and fear. Maria had not been able to return to her previous activity levels, which had included regular walking and domestic duties. She also had several features of depression and anxiety, including inability to sleep, sadness and fear associated with the functioning of the ICD. It is also important to note that Maria did not complete the IHHP and had a long history of frequent contact with physicians and health specialists. While Maria presented with several health concerns, the effects of the ICD on her psychological condition had become her most paramount health problem.

There was also evidence that some IHHP participants regularly avoided thinking about their illness to help them cope with the reality of having a chronic illness. Winters (1997) identified not thinking about illness and looking on the positive side as strategies used by cardiac patients to help them cope with cardiac illness. IHHP participants interviewed in the present study also used this strategy. Thinking too much about illness, especially in times when symptoms were absent, was not seen favourably by participants. There was also evidence that participants had tried to stay positive about their condition and to emphasize the periods of time that they felt well as indicators of good progress and good health

rather than periods of remission. This kind of response to illness, which focuses more upon a desire to return to previous activity levels and an avoidance of thinking about illness, may represent a cultural preference in the IHHP participant for being stoic in the face of illness, rather than considering their illness mentally using cognition. Blair (1993, cited in Radley 1994) found that respondents from a working class culture tended to speak about their health with reference to their body, rather than to their thoughts, as did middle class respondents. Blair called the former response physicalistic in comparison to the mentalistic response. The tendency for working class immigrant populations to consider illness physicalistically, rather than mentally, could be factored into cardiac rehabilitation programs for special groups such as Italian immigrants to improve their participation and relevance to the perceived consequences of the illness.

The perception of control and cure of CHD

The importance of fate in the shaping of beliefs about cardiac illness in cardiac patients was shown by Murray et al. (2000). Beliefs about fate and destiny were also found in the thematic analysis of the interviews with the IHHP participants. There were only two participants that perceived their illness to be controllable and this was explained using the notion of self-restraint and responsibility. As described in Chapter 3, a poor perception of personal control of CHD has been associated with low attendance at cardiac rehabilitation programs and with poorer subjective recovery (Cooper et al., 2002; Gilutz et al., 1991; Whitmarsh et al., 2003). Participants in the IHHP continued to perceive the importance of fate and destiny in their cardiac illness, despite having attended the IHHP. It is difficult to draw many conclusions from this because of the lack of a comparison group of patients without a fatalistic view, but perception of control

184

over the illness did not appear to affect attendance at the IHHP in this small sample.

This could be explained by the age of the participant. Illness representation can be a function of age. Gump et al. (2001) found that older cardiac patients were more likely to believe that they had little control over their CHD and reported making fewer behavioural changes after surgery. Backett and Davison (1995) have shown how people respond to health and illness using perceived social circumstances and social obligations, largely determined by their stage in the life course, which is frequently overlooked in studies of recovery from cardiac illness. Fowers (1994) has also demonstrated that appraisals of control of CHD were unrelated to psychological adjustment among cardiac patients. Instead, Fowers stressed the importance of contextual factors in the adjustment to CHD. Contextual factors included situational variables, such as life event stress, and these were found to be an important part in the development of illness control beliefs. Beliefs about control of illness do not act in isolation on recovery.

This belief in fate and the perception of having little control over illness has been contrasted with the self-responsibility over the cause of illness by Lupton (2003). Lupton claimed that the perspective taken by biomedicine, that illnesses such as CHD are caused by poor lifestyle choices, places a moral dimension on the experience of illness. Personal responsibility is stressed which can be interpreted as personal blame. The limits of a lifestyle discourse in preventive medicine are also taken up by Davison, Frankel, and Davey-Smith, (1992). Davison et al. (1992) argued that lifestyle and its relationship to health is embedded in the wider context, subject to many forces outside of the individual's control and that the use of the term "fatalism" to mean anything but a total belief

in personal responsibility, is inappropriate "where cultural understandings of the balance between behaviour and environment are concerned" (p. 680).

IHHP participants experienced their illness within the context of their environment and cultural beliefs. Cardiac rehabilitation programs could adopt a approach which gives proper attention to unhealthy behaviours within the context of the broader environment and not dismiss perceptions of poor control over illness as a poor indicator of recovery and which requires cognitive treatment.

Recovery and barriers to recovery from CHD

The case studies in Chapter 9 highlighted the importance of contextual factors when considering recovery from CHD. In this section, the case studies will be discussed in light of the *a posteriori* themes and the backdrop of the social networks available to each participant. This is done to interpret the data using the micro psychosocial mechanisms proposed by Berkman and Glass, (2000). All three case studies presented completed the IHHP.

An example of good recovery from a cardiac illness was presented in case study 1 (Lina). This case study showed the importance of micro psychosocial mechanisms in the perception of good recovery from illness. The feature of this case study was the evidence of the strong social networks that have contributed to Lina's recovery. The structure and the character of this support was wide and strong, essentially based on family ties and the close proximity to each other. Lina perceived that her good health was connected to the health of her family and that she was able to maintain harmonious relationships with them. The strength of her social networks was manifested several ways. Lina's sister, who lived near by, attended both interviews with Lina and both the structure and character of the tie with her was extremely supportive and reciprocal. Lina's family physician

was her son's father-in-law and she felt very well treated by all the medical specialists she had seen. This was despite having had problems understanding what was happening to her when she was admitted to hospital. Her family provided help in caring for her husband and could take him to hospital for his medical appointments. After the death of her husband from cancer, which occurred in the interval between research interviews, her sister had come to stay with her for three months to provide assistance during a time of many changes.

In comparison, Carmela (case study 2) felt lonely and isolated as a result of her husband's illness. Her husband's Parkinson's disease and deteriorating mental health had a more destabilising effect on her family than the illness in Lina's family. She had felt the loss of her social contact with others, including the loss of employment opportunities, profoundly. Her social network structure had been reduced, not by her cardiac condition, but her husband's illness. Carmela considered the care of her husband primary to her own health needs. She had begun to feel depressed and saddened by her situation, while continuing to be committed to the care of her ailing husband. Aside from the support of her two adult daughters, who were employed but shared some of the family duties, she perceived herself as having little opportunity for social contact. Carmela perceived that her happiest years were the ones when she was employed and looking after the needs of her family at the same time. The loss of her employment had signaled important changes in her life and her husband had become ill soon after.

Case study 2 provided an exemplary case of how other considerations, especially family ones, can interfere with the trajectory of expected recovery of some cardiac patients. Carmela was observed by her family to be recovering well,

but at the time of follow-up, Carmela had begun to experience further CHD symptoms and increasing levels of CHD risk factors such as hypertension and high blood cholesterol levels. Carmela had enjoyed attending the IHHP and had especially enjoyed the opportunity to meet others and partake in an activity outside her normal domestic duties, but she perceived that her family situation was a considerable barrier to her being able to address her own health needs by adopting healthier behaviour, such as more frequent exercise or an alternative diet.

Commitment to the collective, in contrast to a person-centred approach, has been likened by Bates, Rankin-Hill, and Sanchez-Ayendez (1997) to a cultural concept called "familismo". According to Bates, familismo is the high value placed on receiving and giving family support and stresses family interdependence and reciprocity. The needs of the collective are emphasised over the individual. Both case study 1 and case study 2 have elements of familismo, the difference being that in case study 1, Lina is the recipient of the care directed towards her health, but in case study 2, Carmela is the source of the care for another member of her family. Cultural values such as familismo, which can exist in culturally diverse communities such as the Italian immigrant community are not adequately explored within the current prescriptive approach to behaviour change in cardiac rehabilitation.

The relegation of the cardiac illness as a secondary consideration is also seen in case study 3 (Angelo). In this case, other medical complaints predominated and had become associated with psychological complications. Angelo's response to his on-going health problems are characterised by depressive features and high anxiety, which became the most salient features of the barriers to his cardiac health. Angelo's cardiac problems had not recurred but

his main health complaint, his gastrointestinal symptoms, had not been adequately treated or explained.

Angelo's poor adjustment to illness had been influenced by several factors. His depression had not prevented him from attending the IHHP and he also enjoyed the group setting, which helped his motivation towards exercise. But his low feelings of self-worth and hopelessness concerning his physical condition had severely affected his functional ability and this was perceived as the most important loss associated with his health. He perceived his contact with the medical profession to be confusing and unsatisfying, which added to his feelings of hopelessness and anxiety about whether his condition could be improved. Angelo preferred to turn to his family for support. He had negative perceptions about the value of friendships and the sincerity that they offered, when compared to his family. He did not talk to people outside his family about his health and he had little contact with anybody outside his immediate family. The structure of social networks outside of his family were poor and any social contact he had with others had become characterised by low reciprocity and low frequency. This, in turn, had not provided many opportunities for the positive influence of psychosocial mechanisms upon his health.

Dissatisfaction with the medical system, of the type displayed by Angelo, was an important theme that emerged from the thematic analysis of the IHHP participants. The thematic analysis also showed that dissatisfaction with the medical system was associated with frequent attendance at health specialists. The regular attendance at specialists was perceived as necessary but did not provide satisfactory relief from bodily complaints and symptoms. This dissatisfaction had led to confusion about the general ability of medicine to cure their conditions and

these participants were quick to point out the failings of their treatment by physicians.

As demonstrated in the case of Angelo, frequent but unsatisfying contact with the medical system was present in participants who had high levels of depression and anxiety. His disturbance appeared to provide a significant barrier to any possible perceptions that health could be improved. Psychological disturbances can be expressed via somatic phenomena more frequently in culturally diverse populations because of the inclination to communicate their distress non-verbally, using physical symptoms (van Moffaert, 1998). The frequent contact with medical specialists may represent attempts by IHHP participants to find solutions for psychological disturbances which are expressed as bodily impairments and physical symptoms. This is consistent with the notion that working class populations express their health using a physicalistic style rather than a mental style. The prescriptive approach of cardiac rehabilitation, with its emphasis on personal responsibility for health and the ability to think mentalistically about illness, could have important limitations for the success of behavioural change strategies in the recovery of culturally-diverse cardiac patients.

Limitations of the IHHP in being able to affect behavioural change in the IHHP sample were noted by the health professionals providing the IHHP. These limitations were explicitly attributed to a cultural artefact of elderly working class people by one health professional and that this differed from his own mentalistic value system. Limitations were also attributed to age and the difficulty in motivating IHHP participants to alter established behaviour patterns. Most importantly, the IHHP was also regarded by health professionals as not being

entirely able to address the specific health needs of the IHHP participants. This limitation was attributed to the adoption of the prescriptive approach to cardiac rehabilitation, which focused upon the management of CHD risk factor status. One health professional referred to the disease-centred approach of cardiac rehabilitation and noted the need to shift the focus of the health intervention towards the individual, in a more patient-centered approach, to improve the chance for a positive outcome. This failure of the IHHP to focus upon wider patient circumstances was also explained by the perception of health professionals that some participants in the IHHP may have developed CHD despite having low levels of traditional risk factors. The IHHP was therefore perceived to be inadequate to meet these other needs, which were also perceived to be largely unknown by the health professionals.

The perceived value of social contact and the social function of cardiac rehabilitation

Despite the limitations of the IHHP, the program was perceived very positively by the IHHP participants and by the health professionals concerned. The interviews with both the IHHP participants and with the health professionals indicated that this was largely because of the importance placed on the social aspects of participation in such a program. This theme was the strongest theme to emerge from the interviews with the IHHP participants and their satisfaction with the program. IHHP participants found the most useful aspect of the IHHP to be the opportunity to meet with others and to hear about their experiences of CHD, in particular, the circumstances surrounding the onset of their CHD. This was also evident in the three case studies. For both Carmela and Angelo, this aspect of the IHHP was particularly emphasised as helpful to the motivation for behavioural

change and for increasing the frequency of social contact where social contact with others had become restricted.

The importance of the social opportunities provided by the IHHP was also evident in the views of health professionals. The health professionals were aware of the social value of the group and noted that, in light of the IHHP participants having good knowledge of healthy behaviours, giving them the chance to speak about their illness experience was the most valuable contribution that could be made by the specialists. Participants were also observed to enjoy this opportunity and the group was most attentive when others were discussing their circumstances. The social contact and group discussion were also perceived by the health professionals as being useful in coping with psychological consequences of CHD. Given the importance placed on social support in the recovery from CHD and the growing acceptance that psychosocial factors can play a part in the aetiology of the disease, the importance of the social contribution of cardiac rehabilitation should not be undervalued.

According to Berkman and Glass (2000), social network theory provides a framework for understanding how social and structural conditions can provide opportunities for psychosocial influences on health and health behaviours. Structural social features, such as size, range and proximity of social contacts combine with the frequency and quality of the contact to provide opportunities for social support, social influence, social engagement and access to material goods. The impact upon health can be via the influence of health behaviour or via the influence of psychological pathways such as depression (Berkman & Glass, 2000). The important contribution of cardiac rehabilitation to health via the influence of the social aspect of the program is evident from the analysis of the

interview data with both IHHP participants and the IHHP health professionals. The social influence of cardiac rehabilitation and its value on the health of participants can become meaningful when considered within the context of social network theory (Berkman & Glass, 2000). The social value of the IHHP can be understood using the psychosocial (micro) mechanisms proposed by social network theory.

Groups such as Italian immigrants are likely to have experienced significant social disruptions which have required concerted adjustment as they have become accustomed to life in Australia. Social networks provided by groups such as cardiac rehabilitation groups provide access to social networks which can influence the psychosocial mechanisms leading to poor health. The IHHP provided valuable opportunities for several types of social support other than informational support, including appraisal and emotional support. The IHHP also provided important social influences which flow from group participation and comparison with others. According to Berkman and Glass (2000), this influence can have important effects on enabling or restricting healthy behaviours. As was clearly evident from the interviews, the IHHP provided opportunities to build social ties with others by promoting social engagement. These opportunities for engagement provided more than opportunities for companionship. As described by Berkman and Glass, instances of social engagement:

> *"define and reinforce meaningful social roles, including parental, familial, occupational and community roles, which in turn provide a sense of value, belonging and attachment" (Berkman & Glass, 2000, p. 147)*

Berkman and Glass (2000) believed that research had shown social engagement to be largely responsible for the maintenance of cognitive abilities in old age and reductions in mortality, independent of other types of social support. Access to a cardiac rehabilitation such as the IHHP also provided participants with material resources and a link to a community health setting and all the other opportunities a community health centre can provide.

The strengths and limitations of the present study

The primary strength of the present study is the depth of data that has been collected from each of the IHHP participants. The depth of data allowed a close examination of the illness experiences against the backdrop of the illness perceptions and the specific circumstances in which the participant lived. Qualitative research designs are well suited to the collection of depth data and two key methods have been used in the present research: thematic analysis from interviews and individual case studies. Popay and Williams (1997) described qualitative methods as the more appropriate method of research when research questions concern an idiographic perspective on complex phenomena, such as what it is like to have a chronic illness. Popay et al. also noted the value of using qualitative methods in the study of lay perceptions of health and illness. Case studies are especially appropriate when a close examination of context is required, as is the case for increasing knowledge of the experience of chronic illness such as CHD.

In addition to the interview data and case studies from the IHHP participants, interview data was also collected from IHHP professionals. This constituted a third data source. A fourth data source was also collected using the Hospital Anxiety and Depression Scale scores. This multiple data collection

194

strategy allowed for triangulation of the collected data and contributed internal validity to the findings.

As described in Chapter 7, the present study used method and source triangulation, adding strength to internal validity. A method triangulation strategy was employed by collecting data from both semi-structured interviews and the HADS. Sources were also multiple, providing source triangulation. Follow up interviews were conducted, providing cross checking of data over two interview times. Interviews were also conducted with health professionals who also provided a further point of comparison and cross checking of data. Finally, in some cases, spouses and family members also contributed to the interview data with IHHP participants, providing a further source for the checking of the consistency of accounts and responses to illness.

While the triangulation of the data from various sources improved the internal validity of the present study, several important limitations are also noteworthy. The number of IHHP participants able to participate in the present study could be considered low. The potential sample used in the present study was purposive and restricted to those patients who had been referred to the IHHP. Recruitment of participants for the present study was also confined to the restrictions placed on the frequency of program availability (twice yearly) and consent being obtained by the participant by the community health centre prior to the release of participant details. Since the aim of the study was to explore the health and illness experiences of a clearly defined group of participants, any potential for generalisability to other groups of cardiac patients should be made with caution. External validity or the capacity to infer conclusions from the present study to other samples is low, although conclusions may be more valid for

other samples of Italian-speaking cardiac patients and similar groups of immigrants to Australia.

Data collected from interviews and preparation of case studies is also subject to interviewer effect (Williamson, 2000). This was reduced in the present study by using the same interviewer for all the interviews and by the use of a semi-structured interview. However, interviews can still be subject to interviewer bias which can compromise internal validity. Case studies are also subject to interviewer effect (Darke & Shanks, 2000). The reporting of the case study relies heavily on the material gained in the interview and the interpretation of reported events. The use of cases studies allowed the presentation of rich and complex descriptions for each participant and required the researcher to use interpretative techniques to explore the inter-relations between the illness experience and social and cultural contexts. The use of Interpretative Phenomenological Analysis (Smith et al., 1997) acknowledges the role of the researcher in making interpretations about such inter-relations.

Recommendations for specialised cardiac rehabilitation programs

Cardiac rehabilitation programs such as the IHHP are therefore well placed to provide psychosocial interventions for culturally diverse cardiac patients, but, in light of the present study, several adjustments could be considered. First, the psychosocial elements of such programs should be emphasised and made a primary objective for the secondary prevention of CHD. Social engagement was perceived to be the most valuable aspect of the IHHP by both participants and health professionals and social network theory suggests that social conditions can play a large part in the onset and recovery from illness. Social opportunities for this group of immigrants appear important given the

increased likelihood of cases of social isolation. Social isolation can result from the potential consequences of needing to make the social adjustments required to live in a new country.

As mentioned by one of the health professionals interviewed, the importance of the social context could be underlined by providing the program within a setting that links participants to community activities and other resources, rather than being provided in isolation. The present research suggests that Italian-speaking cardiac patients may benefit from an extension of the phase two program, into a phase three program, provided as an ongoing social group for participants to join. Cardiac rehabilitation programs such as this could be conducted within a community setting, such as an Italian social club, to provide a setting which links participants to other aspects of social activity in the Italian community.

Second, the primary focus upon the reduction of risk factor status in cardiac rehabilitation should become more balanced towards a greater focus on individual circumstances and the broader context of the participant's situation. In many instances, the patient's capacity for adopting healthy behaviours to reduce risk factor status is influenced by factors other than the mere presence of CHD. Culturally-diverse groups such as those referred to the IHHP are likely to be influenced by the needs of their family as an expression of a more collective approach to health. Cardiac rehabilitation programs could be tailored to provide an understanding of participants' circumstances rather than adopt a prescriptive strategy for risk factor management.

Other physical illnesses and poor mental health may sometimes be the primary health concern of participants in cardiac rehabilitation and these

circumstances provide barriers to expected behaviour change not dealt with by a prescriptive approach to cardiac rehabilitation programs. In some cases, this primary concern may be the expression of a psychological disturbance via somatisation. As van Moffaert (1998) noted, this is common in immigrant populations, where linguistic barriers exist. This somatisation, or the presence of unexplained medical symptoms, manifests itself in the participant's frequent and dissatisfying contact with the medical system, as observed in case study 3. Cardiac symptoms such as breathlessness, along with other disabling medical conditions, may be the result of social impairments, which have prevented them from speaking openly about traumatic events in their lives, as well as in their family (van Moffaert, 1998). Cardiac rehabilitation programs provided for those groups with linguistic barriers to English should be sensitive to the broader psychological needs of patients because of the tendency for psychological disturbances to be expressed in physical symptoms. Improvements in psychological health may then lead to a better capacity for individual health behaviour management.

Third, health and illness should be addressed in cardiac rehabilitation programs as a subjective experience, characterised by social and cultural influences constructed over the life course and which go beyond the meaning of traditional meaning of health as the absence of disease. In the IHHP participants, health was most often experienced in relation to functional capacity and the experience of living with CHD was characterised by impairments in this functional capacity. The majority of IHHP participants did not perceive health to be a function of healthy behaviours or of not being ill. The value of considering health more broadly in cardiac rehabilitation programs is underscored by the

interview data which emphasised the importance of the social contact provided by the IHHP. This consideration would allow cardiac rehabilitation for groups such as Italian immigrants to focus upon helping patients to return to previous levels of activity and to identify potential barriers to this return.

The importance placed on the functional abilities of the IHHP participants is consistent with the tendency for working immigrants to place greater emphasis on physical integrity as central to their concept of what it means to be healthy. Cardiac rehabilitation programs for culturally-diverse groups should take into account that immigrants have been subjected to special circumstances because of their dependency on hard manual work (usually unskilled) to achieve a better earning capacity and improved social status. This is reflected by the central part that functional capacity plays in the understanding of their health. Helping participants to return to normal activity levels, and providing access to resources to develop and maintain productive social links with others, may be more beneficial to their health than educational information about how to reduce their CHD risk factor status.

Lastly, cardiac rehabilitation should give participants the opportunity of speaking about their illness experience and the personal meanings that they have made from their experience. The interviews with IHHP participants demonstrated that life events and fatalism continue to be important when participants are trying to make sense of their CHD. IHHP participants used life events to help them construct a narrative about their illness which went beyond the discourse of risk factors. The role of fatalism and destiny also remain important concepts when IHHP participants consider how much control they can have over their illness. The presence of fatalism in cardiac patients should not be dismissed by cardiac

rehabilitation programs as an unscientific distortion of thinking, but rather seen in the context of the patient's attempt at making sense of the influences of both behavioural and contextual factors, which often lie outside of the patient's individual control. Behavioural factors, which are associated with lifestyle choices, do not exist in isolation and their influence on poor health must be understood within the wider social and cultural contexts in which the cardiac patient lives.

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201

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APPENDIX A

CONSENT FORM FOR IHHP PARTICIPANTS

APPENDIX A

Modulo semplice di consenso per i soggetti che fanno parte della ricerca
Informazioni per i partecipanti:

>Vorremmo invitarvi a fare parte dello studio che esamina quanto sia
>efficace il programma di riabilitazione cardiaca al Doutta Galla nel
>rimettervi dalla malattia cardiaca e se il programma incontra i bisogni
>della comunità italiana oppure no

CERTIFICAZIONE DEL SOGGETTO

Io

dichiaro di avere almeno 17 anni e che volontariamente do il mio consenso a partecipare all'esperimento chiamato:
Riabilitazione cardiaca per la Comunità italiana di Melbourne: una valutazione di una fase 2 (gruppo di malati esterni) programma di riabilitazione per la comunità di madrelingua italiana e il suo impatto nella qualità della vita.

Sarà condotto presso la Victoria University of technology da:
sig. Carmelo S. Scuderi (ricercatore)
Dr. Adrian Fischer (capo reparto)

Dichiaro che gli obiettivi dell'esperimento, insieme con ogni rischio a me associato con le procedure elencate qui sotto, che potrebbero venire fuori mi sono state pienamente spiegate dal sig. Carmelo S. Scuderi
e che acconsento liberamente che siano usate su di me tali procedure.

PROCEDURE:

- Partecipazione in colloqui clinici alla fine del programma
- Completamento di un questionario auto relazione all'inizio e alla fine del programma
- Completamento di questionari al 3 e al 6 mese dopo il termine del programma

Dichiaro di aver avuto la possibilità di avere risposte ad ogni mia domanda e che ho capito che posso ritirarmi da quest'esperimento in qualsiasi momento e che il ritiro non mi causerà alcun tipo di conseguenza.

Mi hanno informato che le informazioni che darò saranno conservate in via confidenziale.

Firma:................................

Testimone oltre lo sperimentatore: Data:...................
....

Qualsiasi domanda circa la vostra partecipazione in questo progetto potrà essere sottoposta al ricercatore (sig. Carmelo S. Scuderi tel. 9406 6062 o Dr. Adrian Fischer tel. 9688 5221). Se avete qualsiasi domanda o lamentela riguardanti il modo in cui venite trattati potrete mettervi in contatto la segreteria, University Human Research Ethics Committee, Victoria University of Technology PO Box 14428 MCMC Melbourne 8001 (tel. 03-9688 4710).

APPENDIX B

PLAIN LANGUAGE STATEMENT FOR IHHP PARTICIPANTS

APPENDIX B

Linguaggio semplice per i partecipanti

Il mio nome è Carmelo Scuderi e sto completando un dottorato in psicologia clinica presso la Victoria University. Come parte dei miei studi m'interessa scoprire se partecipando ad un programma di riabilitazione cardiaca, potreste essere aiutati a rimettervi e adattarvi alla vostra malattia cardiaca. Partecepesti in un programma di riabilitazione cardiaca al Doutta Galla Community Health Centre e richiedo la vostra partecipazione in questo progetto di ricerca. Vorrei chiedervi se il programma di riabilitazione vi ha aiutato in questo senso.

Sono interessato anche nella ricerca di cosa esattamente voi e la vostra famiglia credete vi a aiutato a rimettervi e a meglio adattarvi alla vostra malattia e se il programma al Doutta Galla include queste cose oppure no. Queste informazioni inoltre saranno utili al Doutta Galla Health Centre per eventuali suggerimenti per miglioramenti verso i prossimi gruppi di riabilitazione cardiaca per la comunità italiana.

La vostra decisione di participare a questo studio non influisce sul vostro diritto di partcipare al programma di riabilitazione cardiaca. Se decidete di partecipare allo studio vi sarà richiesto di effettuare un colloquio con il ricercatore (Carmelo Scuderi) e di completare diversi questionari. Nessuna delle informazioni da voi fornite saranno identificabili dal nome ma solo dei numeri saranno utilizzati per identificare i partecipanti. I vostri dati saranno protetti in ogni momento. Se in qualsiasi momento sentite di volervi ritirare dalla partecipazione al progetto siete assolutamente liberi di farlo e il ricercatore capirà che è un vostro diritto farlo.

Vi ho dato il mio numero di telefono e quello del mio capo reparto il Dr. Adrian Fischer. Vi ho dato anche ulteriori numeri di telefono in caso abbiate bisogno d'assistenza durante l'orario di lavoro e non. Per favore non esitate a mettere in contatto il sottoscritto o il Dr. Fischer per qualsiasi cosa di cui vogliate discutere riguardante questo progetto.

Grazie per il vostro tempo e per aiutarmi con questo progetto.

Carmelo S. Scuderi MAPS
Psicologo
Numero di registrazione 3524

Numeri di telefono per le vostre informazioni

Carmelo Scuderi (ricercatore e capo gruppo)	9406 6062
Dr Adrian Fischer (capo reparto)	9688 5221
Reparto di psicologia del campus di St. Albans Victoria University	9365 2336
Doutta Galla Community Health Centre (Niddrie)	9370 4794
Co-As-It (Assistenza Italiana)	9347 3555
Servizio interprete (24 ore)	13 14 50
Centro assistenza (24 ore)	13 61 69

APPENDIX C

CONSENT FORM FOR IHHP HEALTH PROFESSIONALS

APPENDIX C

<div align="center">

Victoria University of Technology

Consent Form for Subjects Involved in Research

</div>

INFORMATION TO PARTICIPANTS:

We would like to invite you to be part of a study which examines how effective the cardiac rehabilitation program at Doutta Galla is in helping patients to recover and adjust to heart disease and whether or not you believe the program meets the needs of the Italian community

CERTIFICATION BY SUBJECT

I,

of

certify that I am at least 17 years old* and that I am voluntarily giving my consent to participate in the experiment entitled:

> **Cardiac rehabilitation for the Italian community of Melbourne: An evaluation of a Phase 2 (community outpatient) cardiac rehabilitation program for the Italian-speaking community and its impact on quality of life.**

being conducted at Victoria University of Technology by:

Mr Carmelo S. Scuderi (researcher)
Dr Adrian Fisher (supervisor)

I certify that the objectives of the experiment, together with any risks to me associated with the procedures listed hereunder to be carried out in the experiment, have been fully explained to me by:
Mr Carmelo S. Scuderi
and that I freely consent to participation involving the use on me of these procedures.

Procedures:

• Participation in a semi-structured interview

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this experiment at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ....   }

Witness other than the experimenter: }   **Date: ....**

....}

> Any queries about your participation in this project may be directed to the researcher (**Mr Carmelo S. Scuderi ph. 9406 6062 or Dr. Adrian Fisher ph. 9688 5221**). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

APPENDIX D

PLAIN LANGUAGE STATEMENT FOR IHHP PROFESSIONALS

APPENDIX D

Plain Language Statement for Professional Participants

My name is Carmelo Scuderi and I am completing a Doctorate in Clinical Psychology at Victoria University. As part of my studies, I am interested in finding out how effective the cardiac rehabilitation that you have worked for is in helping Italian cardiac patients recover from and adjust to heart disease. I am also interested in finding out your opinion about the best aspects of the program and the aspects of the program that need improving. This information will therefore provide Doutta Galla Community Health Centre with suggestions for improvements for future cardiac rehabilitation groups for the Italian community. In this regard, I am requesting your participation in this research project.

If you decide to participate in the study you will be invited to participate in a semi-structured interview with the researcher. The interview will be completed at a time and place convenient to you and should take approximately one hour. The interview will be audio-taped to facilitate transcription of the interview. None of the information that you provide will be identifiable by name, only numbers will be used to identify participants. The confidentiality of your data will be protected at all times. If at any time you feel as though you would like to withdraw from participation in the study you are absolutely free to do so and the researcher understands that it is your right to do so.

I have provided you with my telephone number and the telephone number of my supervisor, Dr. Adrian Fisher. I have also provided several other telephone numbers in case you require any other assistance, either during or after normal hours. Please do not hesitate to contact myself or Dr Fisher if there is anything concerning this research project that you which to discuss.

Thank you for your time and for helping me with this project

Carmelo S. Scuderi MAPS
Psychologist
Registration No. 3524

TELEPHONE NUMBERS FOR YOUR INFORMATION

Carmelo Scuderi (researcher and group facilitator)	9406 6062
Dr Adrian Fisher (supervisor)	9688 5221
Department of Psychology-St Albans Campus	
Victoria University	9365 2336
Doutta Galla Community Health Centre (Niddrie)	9379 4794
Co-As-It (Assistenza Italiana)	9347 3555
Interpreter service (24 hour)	13 14 50
Care Ring (24 hour)	13 61 69

APPENDIX E

SEMI-STRUCTURED INTERVIEW GUIDE FOR IHHP PARTICIPANTS

APPENDIX E   Semi-structured interview guide-IHHP Participants

1.   Demographics
- Name
- DOB AGE
- year of migration
- married or single or widow
- time and nature of operation

2.   Health perceptions and illness experience

Cosa hai pensato quando ti hanno detto che avevi questo malattia?

Cose pensavi?

E ora come la tua salute?

In genere, secondo te, cosa significa a stare in buona saluta, a stare bene?

Come ti senti ora, in questi l'ultime settimane?

Cosa pensi ha causato la tua mallatia?

Credi che la tua mallatie po essere guarito?

3.   Impact of the illness

Cose stato impatto per te della mallattie, su la sua stile di vivere?

Dopo l'intervento, come ti sentivi?

Come a cambiato la sua vita dopo la malattia?

nel ambito della famiglia (sulla moglia e figli)
nel ambito delle amici
nel ambito del activita fisico
nel ambito del affettivita (per esemplio, la depressione, l'ansia)
nel ambito di alimentari e altri compotamenti

Ora pensi che stai addatando alla mallatie?

Che cambiamenti hai fatto per addatare alla sua mallatie?

4.   IHHP Program perceptions

Perche hai deciso a participare nel programma cardiaca?

APPENDIX E (cont)

Pensi che hai ricevuto informazioni sufficienta dai i dottori?

Come stato la tua salute da completando la programma cardiaca?

Credi che il programma cardiaca ha cambiato il tuo atteggiamento verso la malattia e verso la tua stile di vivere?

Da quando hai participato nella programma cardiaca come ti senti?

Riguardo la programma cardiaca ti ha auitato in recovero in questi ambiti? Come?

Pensi che il programma cardiaca ti ha auitato?

La programma cardiaca ti hai aiutare addatare alla sua malatie?

Quale parte della programma ti hai piaciuto di piu?

Quelli che non hai piaciuto?

Discorso di Anna
Discorso di Rocco
Discorso di Ray con interpreter
Discorso di Ambi la co-ordinatrice
Exerciscio con Ben

Informazioni scritti erano utili?
Locale?
Transporto?

Come pottresteno migliorare questo programma cardiaca?

5.   Personal and social history

famiglia
amici
oltre mallatie
lavoro
ritirato quando

smoking
esercizio prima e dopo
mangiare prima e dopo
alcohol prima e dopo

APPENDIX F

SEMI-STRUCTURED INTERVIEW GUIDE FOR IHHP PROFESSIONALS

APPENDIX F-Semi-structured interview with IHHP staff

Professional training
History of involvement with the program

What was your role in the program

From your point of view;

        what were the most effective aspects of your contribution

        what were the least effective aspects of your contribution

How relevant do you think a cardiac rehabilitation program is for Italian speakers

What is the most important aspect of a cardiac rehab group for Italian speakers

        Does the program meet this requirement

What are the needs of Italian cardiac patients

How can these needs best be met

What could be provided by the program but is currently not provided

What do you perceive to have been the most useful parts of the program overall

What can be improved by the program

What would you like to be able to do to improve your contribution to the program

What needs to be done better in the future

How can Italian cardiac patients best be helped to improve their cardiac health

What is your personal experience of working with this group

How effective do you believe the program to be in helping Italian speakers manage their illness and improve their quality of life

APPENDIX G

HOSPITAL ANXIETY AND DEPRESSION SCALE

APPENDIX G   SCALA HAD

Questo questionario è stato fatto per aiutarci a capire come vi sentite. Leggete ogni paragrafo e cerchiate il numero vicino alla risposta che meglio descrive come vi siete sentiti durante la settimana trascorsa.

Non impiegate troppo tempo a dare una risposta, la reazione immediata ad ogni domanda è probabilmente piu' accurata che non se ci pensate a lungo.

1. Mi sento teso o "fuori posto":
1. La maggior parte del tempo
2. Spesso
3. A volte occasionalmente
4. Mai

2. Mi piacciono ancora le cose che mi piacevan prima:
1. Allo stesso modo
2. Non tanto
3. Solo un po'
4. Difficilmente

3. Sento un senso di spavento come se qualcosa di terribile stia per accadere:
1. Costantemente e in modo grave
2. Si, ma non in modo grave
3. A volte, ma non mi preoccupa
4. Mai

4. Riesco a ridere e a vedere il lato divertente delle cose:
1. Sempre, come meglio ho potuto
2. Adesso non tanto
3. Adesso assolutamente non tanto
4. Mai

5. Preoccupazioni varie mi passano per la testa:
1. Moltissimo
2. La maggior parte del tempo
3. A volte, ma non spesso
4. Solo occasionalmente

6. Mi sento sereno:
1. Per niente
2. Non tanto spesso
3. A volte
4. La maggior parte del tempo

7. Posso sedermi tranquillamente e sentirmi rilassato:
1. Costantemente
2. Di solito
3. Non spesso
4. Mai

8. Mi sento come "rallentata":
1. Quasi sempre
2. Molto spesso
3. A volte
4. Per niente

9. Ho una specie di sensazione di spavento come avere "farfalline" nello stomaco:
1. Mai
2. Occasionalmente
3. Abbastanza spesso
4. Molto spesso

10. Ho perso interesse nel mio aspetto:
1. Assolutamente
2. Non me ne interesso come dovrei
3. Potrei ma non me ne interesso abbastanza
4. Ho cura del mio aspetto come sempre

11. Mi sento agitato come se fossi in movimento:
1. Veramente molto spesso
2. Abbastanza spesso
3. Non molto
4. per niente

12. Vedo le cose che verranno in modo positivo:
1. Come ho sempre fatto
2. Un po' meno di prima
3. Decisamente meno rispetto a prima
4. Difficilmente

13. Mi prendono improvvisi attacchi di panico:
1. Veramente molto spesso
2. Abbastanza spesso
3. Non molto
4. Per niente

14. Riesco a godermi un buon libro, radio o tv:
1. Spesso
2. A volte
3. Non spesso
4. Molto raramente