

**ADULTS WITH CONGENITAL HEART DISEASE:
THE PATIENTS' PERSPECTIVE**

Joy E Lyon

A thesis submitted in partial fulfilment of the
requirements of Bournemouth University for
Doctor of Philosophy

March 2006

ABSTRACT

Over the last 50 years technical and other advances have resulted in more than 90% of children born with congenital heart disease (CHD) surviving and reaching adulthood. This new patient population has been largely overlooked in recent policy and practice developments in health and social care. Evidence available at the start of the study confirmed increased survival and suggested the need for life long follow up. There was found to be limited research exploring the view of what was required by adults with CHD or into psychosocial aspects of living with a heart condition. The purpose of this phenomenological study was to discover the adults' experience of living with CHD.

Twenty-eight people, over the age of 20 years, who had undergone surgery for their heart condition, participated in semi-structured interviews during which they recounted their experience of growing up and living with CHD. Five people, who epitomised being well, contributed to second interviews during which they told stories that demonstrated what being well meant for them.

Thematic analysis revealed participants had a positive view of themselves and were highly motivated to maintain their health. Their heart condition was an integral part of who they were, but did not dominate their life. Three main areas influenced the positive view held by participants. These were: first the perceptions of wider society, second when the CHD impacted on available choices, and third when hospital attendance occurred. Second interviews revealed 'being well' developed through participants' ability to make their own decisions, which was done in a responsible manner, resulting in informants being able to get on with life, engaging in activities of their choosing.

The study findings inform proposals for services to develop in ways that can enhance opportunities for adults with CHD to achieve their full potential. Developing skills relevant to 'non-patient' activities and managing the misconceptions of wider society are key factors in adults with CHD being able to participate in meaningful activities of their choice. It is essential for health and social care to be delivered in ways that promote patient autonomy and self-management.

Areas for further research emerge from the findings. Hearing the way living with CHD is experienced during childhood and adolescence can contribute to transition processes. Hearing the experience of other groups including parents, partners and health professionals, as well as people surviving with other chronic childhood conditions, can add to the findings presented here.

Contents	Page
Title page	1
Abstract	2
List of contents	3
List of tables	7
Acknowledgments	8
CHAPTER 1	
INTRODUCTION AND BACKGROUND	9
Introduction	9
How I came to this study	11
History of surgery for congenital heart disease	14
Classifying CHD	16
The adult CHD population	18
The international context	21
The UK context	25
UK nursing contribution to care for adults with CHD	26
Synopsis of the chapter	27
CHAPTER 2	
REVIEW OF THE LITERATURE	28
Introduction	28
Purpose of the literature review	28
Literature selection	29
Background and structure of the literature review	30
Physical aspects	31
Psychological aspects	35
Social aspects	43
Quality of life	47
Nursing role	48
Summary	49
Rationale for this study	51
Synopsis of the chapter	51

CHAPTER 3	
METHODOLOGY	53
Introduction	53
Methodological considerations	55
Phenomenology	58
THE STUDY DESIGN	64
Turning to a phenomenon which seriously interests us and commits us to the world	64
Investigating experience as we live it rather than as we conceptualise it	64
Ethical aspects	65
Potential harm to participants (informants)	66
Potential for deception	67
Informed consent	68
Invasion of privacy	69
Sample	71
Negotiating access and informant selection	71
Data collection	79
Interviews	80
The role of the researcher in data collection	80
Reflecting on the essential themes which characterize the phenomenon	82
Generating descriptive themes	83
My interpretation of the data	85
Identifying patterns within the data	85
Describing the phenomenon through the art of writing and rewriting	88
Trustworthiness of the study	88
Truth-value	89
Applicability	89
Consistency	90
Neutrality	92
Completing the cycle of human science research	92
Synopsis of the chapter	92
CHAPTER 4	
FINDINGS FROM THE INTERVIEWS	93
Introduction	93
Findings from initial interviews	96
Interpretive themes	97
Peace of mind	98
I am fit and well	98
CHD is not an issue	99
Individual's view of self	101
Understanding of own CHD	102
Social network	103

Health carers	105
Readiness to hear	107
Perception of others	108
Scar	108
Ability to perform activities	109
Impact on choices	110
Changes in health	113
Adaptation	116
The outpatient clinic visit	117
The 'little things'	121
Findings from second interviews	122
I make my own decisions	124
Choices and rejection	125
Being told I cannot do something	126
I am a responsible adult	127
Lucky to be alive	128
Useful information	132
Understanding heart condition	134
Being mature	135
Keeping fit	136
Other people with CHD	137
Giving something back/patients' association	137
I get on with life	139
I am aware of it (heart) all of the time but I don't think of it	139
Worry when you need to	141
Other people	142
Clinic visit	143
Synopsis of the chapter	145

CHAPTER 5

DISCUSSION OF THE FINDINGS	146
Introduction	146
Pattern themes	147
Health within illness	151
Health behaviour change	154
Positive health	155
Salutogenesis	156
Comprehensible	160
Manageable (other people)	161
Meaningful	164
Manageable (self)	166
Boundaries	170
Synopsis of the chapter	171

CHAPTER 6	
CONCLUSIONS AND IMPLICATIONS FOR PRACTICE	172
Introduction	172
Critical evaluation of the study	172
Key conclusions	177
I make my own decisions	178
I am a responsible adult	179
I get on with life	180
Implications for practice	180
Patient participation	181
Information provision	183
Future developments	184
Synopsis of the chapter	184
CHAPTER 7	
POST SCRIPT	187
Introduction	187
The study records	189
Undertaking the interviews	189
Language (What's in a name?)	191
The role of nursing	194
APPENDICES	
1. Anatomical diagrams of CHD	196
2. Degree of complexity of CHD	202
3. CHD: incidence and survival	203
4. Functional classification and Ability index	204
5. NYHA functional classification	205
6. Timeline of reports and guidelines related to adult CHD	206
7. One example of search strategy	207
8. Ethical approval letters × 3	208
9. Patient information sheet × 2	211
10. Patient consent form	213
11. Interview guides × 3	214
12. Presentations related to this study	217
13. Early analysis diagram	219
14. Analysis guidelines (Hycner 1985)	220
15. Example of early coding	221
16. Examples of development of descriptive and interpretive themes	222
GLOSSARY	224
REFERENCES	228

TABLES AND FIGURES

	Page
Chapter 3	
3.1 Methodological structure of human science research	63
3.2 Informant selection, response and participation	78
Chapter 4	
4.1 Notation used to indicate source of data	95
4.2 Descriptive and interpretive themes from initial interviews	97
4.3 Informants' perception of themselves	100
4.4 Descriptive and interpretive themes from second interviews	124
Chapter 5	
5.1 Relationships between interpretive themes, existing theory, and conclusions	150
5.2 A sense of coherence for adults with CHD (adapted from Antonovsky 1987)	160

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the support and help from many people, to whom I will always be grateful.

Thanks are therefore extended to my employers at the School of Nursing and Midwifery, University of Southampton. The value of periods of study leave cannot be overstated. Thanks also go to work colleagues; their concern for me and my study has contributed to my being able to reach this stage.

The British Heart Foundation scholarship, awarded through the Florence Nightingale Foundation in March 2000, enabled me to visit Canadian and UK adult congenital cardiac centres. The opportunity to meet other health professionals involved in service delivery, has contributed to the recent development of national and international nursing networks.

Thanks are extended to my supervisors Dr Jerry Warr and Dr Eloise Carr. The time given and interest shown by them, to intellectually challenge and support me have been influential in my thinking and growth.

Family and friends have also played a part. Special thanks go to Ben, my husband, and my children Graeme, Claire, and John her husband, and to my mother. All have contributed in different ways. Close friends have been there for me and sustained me throughout.

Particular acknowledgement goes to the adults with congenital heart disease who agreed to meet with me and so willingly shared their experiences. Without their participation this study would not have been possible, I am indebted to them.

CHAPTER 1

INTRODUCTION AND BACKGROUND

During the past 50 years there have been rapid advances in caring for children with congenital heart disease (CHD) including diagnostic, anaesthetic, surgical techniques and post-operative intensive care. These developments have resulted in the survival of a new group of patients, many of whom require lifelong follow-up. The number of children with CHD reported to be reaching adulthood is increasing. In 1985 Gortmaker stated that 52% of children with CHD survive to age 15 years; twelve years later, Somerville (1997) and Hunter (1997) predicted that 70%-85% of children born with CHD would survive to become adults, with other social and psychological aspects becoming increasingly relevant to enhance their quality of life. More recently Wren and O'Sullivan (2001) estimated that survival of children born with CHD to age 16 years had increased to 92%. As a result health carers will be more frequently required to provide advice on aspects other than the CHD. This study is timely in that the numbers of adults with CHD have recently become greater than the number of children with CHD (Murphy 2003).

Introduction

This chapter provides an orientation to the study through a description of relevant experiences gained through providing care for patients with CHD. This study has come from my life; it is a natural progression of the personal and professional journey I have travelled, and as such is important to me.

To guide readers the structure of this thesis will be outlined. This first chapter provides the introduction to the study and my personal experience of cardiac services in the United Kingdom (UK). An overview of the historical background of cardiac services is given followed by a review of significant international reports that focus on adult CHD. To locate the study within the National Health Service (NHS) context, a brief review of policies related to cardiac services and nurse training is given. The patient profile is outlined and the anticipated increase in patient numbers surviving to adulthood.

Chapter 2 reviews literature relevant early in the study, and recommendations from international conference reports are used to provide a review of specific health and social care needs. The research aims are stated and the philosophical framework guiding this study is introduced. Chapter 3 outlines the research approach taken. The interpretive paradigm that underpins the study is explored, selection of the phenomenological approach is outlined, and consideration given to methodological and ethical issues. Chapter 4 presents findings from the interviews, which are then discussed in Chapter 5 in light of literature pertinent to the findings. Limitations of this study are discussed in Chapter 6, conclusions and implications for practice are presented, and future research areas identified. Chapter 7 provides reflection on some areas that have generated tension for me throughout the study.

The thesis design has been used to provide a structure within which to report the complex, iterative activities that comprise qualitative studies. However in contrast to the objective, disease-centred approach to writing traditionally adopted in CHD texts, I have utilised a subjective, person-centred style usually associated with narratives. This approach provides opportunities to make available to readers some of the reflections that occurred throughout the research process. Throughout this study I have experienced a struggle with conflicting feelings that appeared irreconcilable; I have experienced tension, and at times extensive deliberation resulting in an inability to act. The struggle has resulted from my multiple roles as a research student, nurse and teacher. Therefore I have selected a dialogic style to present this thesis that can acknowledge my thoughts and feelings as the study proceeded and enhance the authenticity of this research report (Jasper 2005).

The remainder of this first chapter will provide an orientation to the study topic and introduce the research aims.

How I came to this study

This study has grown from my nursing practice. I began caring for adult and child cardiac patients in the late 1970s in a tertiary cardiac centre where medical and surgical expertise was developing in treatment for both congenital and acquired heart disease. At that time it was usual practice for general trained nurses to provide care for both children and adults with heart disease. As a part-time staff nurse, it was usual to be asked to work where there were gaps in staffing. This provided an opportunity for me to gain experience in providing care for adults and children who required treatment for a wide range of heart and chest conditions. Through my practice experience, a breadth of knowledge was gained that would not be possible today.

The pace of change was rapid with increasing specialisation within cardiac medical and surgical procedures that required greater theoretical understanding in order to provide effective nursing care. Theoretical knowledge was gained to underpin my practice experience through completing a post-registration nursing course. By the 1980s I was working more regularly in a cardiothoracic intensive care unit that accommodated adults and children who required cardiac surgery for both acquired and congenital heart disease. The children I had met in the 1980s, I was meeting again in the 1990s as adults. I was curious about how some of the adults with CHD appeared to be able to live well, while others could not; their ability to live a full life did not seem to be related to the complexity of their heart condition.

My practice experience left me thinking of the gaps within services for adults with CHD, and I assumed other people shared that view. I had met other patients, nurses and acquaintances who expressed distress as a result of events related to CHD. One person was a neighbour who told me about her daughter who had undergone successful surgery to repair a 'hole in the heart' during infancy. Her daughter had subsequently had no exceptional health problems, however had recently been excluded from a school skiing trip abroad due to lack of affordable health insurance cover. She had grown up thinking herself a 'normal' person and was shocked by her exclusion.

Around the same time I read a paper, published in an American journal that encapsulated my thinking (Sparacino et al 1997). I was encouraged to know other health professionals were expressing similar concerns. When I showed this to medical colleagues however, it was dismissed; the journal was not recognised, possibly due to its nursing focus. Shortly afterwards I was approached by one of the doctors who suggested I might be interested to read a study recently published in a medical journal; it was the findings from the same study presented for a medical audience (Tong et al 1998). What appeared to be lacking in providing care for these patients, was a holistic approach taking account of psychosocial aspects of living as an adult with CHD.

At the start of this project I undertook a study tour of three Canadian and four UK centres. The purpose was to meet with health and social carers who had experience of developing and delivering services for adults with CHD. The Toronto Congenital Cardiac Centre for Adults (TCCCA), established in 1959, was the first centre specifically for adult CHD. Following initial contact with staff at TCCCA, contact was made with nursing staff in other Canadian centres. North America required care to be transferred from paediatric to adult centres when the patient reached approximately 18 years of age. Benefits are that adult patients receive health care in appropriate centres from adult trained medical and nursing staff; however, transfer between centres can be unplanned. Within the UK, services for adults with CHD were evolving predominantly related to paediatric services. I had experience with one tertiary centre and, using existing contacts, located other centres in which developments were occurring and arranged visits as part of the study tour. Through the opportunities created by the study tour, I met nurses with whom I have remained in close contact; many shared my views and concerns regarding the limited recognition of the non-hospital aspects that seemed relevant to this growing patient population. Key areas highlighted from the study tour that I wanted to explore further included: ways in which patients with CHD were accommodated within adult cardiac services; the transition from child to adult health care service; how adult health carers understood CHD; and ways in

which nurses who provide services for adults with CHD share information and good practice.

When adults with CHD require hospital admission in the UK, care is provided in settings where the main nursing expertise is with acquired heart disease. Care for adults with CHD is developing as a cardiac subspecialty (Perloff 1991). It is important for nurses to contribute to these developments; currently there is limited research evidence to inform nursing care for this patient group. More recent personal experience as a nurse teacher has demonstrated an increase in requests from qualified nurses working in acute and critical adult care, as well as community and maternity settings, to provide education regarding adults with CHD. It is from this experience that the study emerged.

The heart has been used within literature and poetry as a symbol of special significance, making it a central organ both physically and metaphorically. Meanings are carried beyond physical well-being into emotional, religious, psychological and social aspects of life (Glaser & Bentovim 1987; MacLachlan 2002). How the heart is perceived has an impact on how CHD is perceived, resulting in beliefs within society which may not reflect the reality of living and growing up with CHD. To understand recent developments related to adult CHD, it is necessary to briefly describe the background from which these have emerged.

In the UK services for people with CHD are situated within cardiac services in the NHS. Understanding the historical perspective can help appreciate the present context within which services for adult CHD are situated.

Developments in surgical techniques and changes in nursing roles have both occurred over the recent past, and together contribute to the current context.

The following section will provide an account of significant developments that contribute to the complex national and international background to this study.

History of surgery for CHD

This section will provide an overview of cardiac surgery for CHD and the ways that the UK, North America and Europe are beginning to address health and social care as patients reach adulthood. The extensive writings and personal contact with Dr Joseph Perloff, who has been contributing to medical care for people with CHD since 1960, have been used to inform this historical overview of the developments in cardiac surgery for CHD. To assist reading, a glossary of frequently used terms, abbreviations and organisations associated with conditions has been provided on pages 224-227.

During the nineteenth century congenital heart disease was recognised but was of little clinical interest as it was incompatible with life, and there was no medical or surgical treatment possible to relieve symptoms (Perloff 1998). The late 1930s saw developments in classifying anomalies, providing a practical and clinical structure to the wide range of defects that are encountered (Perloff 1978). During the 1940s, surgery was performed to alleviate aortic coarctation, a left heart obstruction; ligation of patent ductus arteriosus (PDA), a connection between the aorta and pulmonary artery; and the Blalock-Taussig shunt was used to increase pulmonary blood flow by connecting left or right subclavian artery to the pulmonary artery. The 1950s saw developments in cardiac techniques and in 1953 the heart/lung bypass machine was used for the first time by Gibbon to repair an atrial septal defect (ASD) in an eighteen-year-old woman (Perloff 1998). Diagrams are provided in Appendix 1 to demonstrate some of these conditions, and the relevance of technical developments, such as heart-lung bypass, that have made open-heart surgery possible.

Developments have occurred in both timing and type of surgical procedures undertaken to limit the effects of CHD. Stark (1989) considered use of the word 'corrective' in the surgical literature regarding CHD to be misleading, due to the long-term medical follow-up required. Closure of PDA and ASD, in appropriate patients, is now routinely undertaken by interventional cardiology procedures that insert devices to close defects, thus avoiding the need for surgery. This rapid transition from life threatening condition to high levels of survival may account for

the limited services available for adult CHD. Development of services is confounded by the complexity of estimating the number of adults with CHD who are likely to require follow-up.

The difficulty in calculating the number of adults with CHD is acknowledged by both the American College of Cardiology (ACC) (2001) and the British Cardiac Society (BCS) (2002). There is general agreement, however, that the number of children reaching adulthood is increasing due to advances over the last 50 years. The lack of accurate statistics is due in part to the wide spectrum of CHD that can occur, and makes defining the exact size and composition of the patient group challenging.

Studies have attempted to predict numbers of adults with CHD. Calculations are based on the incidence of CHD, with the prevalence reported to be between 2-12 per 1000 live births (Hoffman 1995; Šamánek 2000; Wren and O'Sullivan 2001). The wide variation was explained by increases in skills, resources and technology to accurately diagnose CHD, with the reported incidence appearing less in earlier reports. The advent of echocardiography has enabled the accurate diagnosis of mild lesions such as mitral valve prolapse and bicuspid aortic valve that were omitted from early reports. One example of confusion during the early reporting of CHD is of Šamánek's (2000) claim that aortic stenosis made up 7.77% of all CHD, while Perloff (1978) considered bicuspid aortic valve to be the most frequent congenital abnormality occurring in approximately 2% of the population. A further technical advance that has had a significant impact in ways in which records are maintained has been the revolution in computer technology.

Early records for incidence and outcomes of surgery for CHD were maintained using a range of computer programmes. More recently efforts have been made to maintain records in ways that allow comparison across centres and conditions with evaluation of the accuracy of databases continuing (Maruszewski et al 2005). In today's world of advanced software programmes that perform complex calculations at the touch of a button, it is difficult to appreciate that in the 1970s when surgery for CHD was becoming more commonplace, computer

programmes had to be designed to allow records to be kept in an electronic format. Comparison of data was difficult not only because of different computer programmes, but also due to ways in which the extensive range of CHD were defined. In 1998 the TCCCA had a list of one hundred and fifty two conditions, more recently a shorter list has been prepared to simplify the diagnostic coding process for adult CHD (Canadian Adult Congenital Heart Network (CACHNet) 2000). This list comprised fifty-two congenital heart conditions and fifty-one procedures. Research reports however continue to use different approaches to coding CHD.

While acknowledging the unlikelihood of a perfect system for detecting and classifying CHD, Hoffman (1995) provided a detailed report of the incidence of CHD that summarised figures from studies carried out in international centres. The studies used to inform the report, spanned time and place; publication dates were from 1955 to 1993, across geographical areas including Europe, North America, Scandinavia, Australia, Africa and Asia. The report stated that data collected before 1980 were less complete or accurate, with mild lesions being generally unreported; the technology to detect these defects was not available and resulted in them being undiagnosed or misdiagnosed. The incidence of specific lesions was provided with claims that the overall rate had not increased over the previous 30 years. Hoffman (1995) postulated a worldwide incidence of 10 per 1,000 live births, based on the reported incidence in areas where modern technology was used, and applying this to population figures in areas where modern methods of detection may not be available. The report closed with the recommendation to develop standard diagnostic criteria for worldwide use. The classification (Appendix 2) of CHD by ACC (2001) has gone some way to provide these standard diagnostic criteria. Three levels of complexity of CHD are defined as being of great complexity, moderate severity or simple.

Classifying CHD

Similar principles were used to inform how CHD was classified in a study from one UK health region (Wren and O'Sullivan 2001). Records kept between 1985 and

1994 were used to predict the need for follow-up for adults with CHD, an incidence of 5.2 per 1,000 live births, lower than that identified by Hoffman (1995), was reported. The numbers predicted in this study were used by the ACC (2001) to estimate the number of adults with CHD who were likely to require follow-up in the United States. Using these two predictions the number of adults with CHD in the UK, based on a population of 50 million, were approximately 21,000 with complex CHD and 54,000 with moderate CHD; more than 1,600 new cases were predicted to require follow-up each year. Assumptions made by the authors were acknowledged, with predictions made on published reports. The calculation methods were provided allowing readers to make comparisons using their own experience in providing care for this patient group. Discussions with local paediatric cardiologists have resulted in the same conclusion based on experience with a similar patient population in a different UK health region.

According to Wren and O'Sullivan (2001) all except the simplest defects were likely to require follow-up, with this being the main growth area in providing care for all patients with CHD. Complex lesions, while being less common, require more intensive follow-up, re-investigation and re-intervention. These authors claimed that eight defects made up 77% of CHD, with predicted survival to age 16 years ranging from 80% to 99% depending on the defect (Appendix 3).

An alternative to diagnostic criteria to classify heart disease is the subjective assessment of physical function provided in 1994 by the New York Heart Association (NYHA). Originally published in 1928, the NYHA classification does not include diagnostic categories; nevertheless it has been widely used in practice and research to indicate physical functional status of people with heart disease. Adaptations were made to the wording, but not the essential meaning of the classification (Warnes and Somerville 1986; Perloff and Miner 1998), in order to make it more accurately reflect physical function of adults with CHD (Appendix 4). The NYHA classification of functional capacity is based on clinical severity of heart disease using subjective symptoms. Despite wide use of the NYHA classification, Bennett et al (2002) reflecting concerns expressed by the 1964 Criteria Committee

of the NYHA, questioned the reliability and validity of it as a functional outcome measure in research. Due to the inferential nature of the classification, researchers were encouraged to report the methods used to determine the NYHA classification to which sample members are allocated (Bennett et al 2002). In 1994, revision of the NYHA classification included an objective section that indicates the extent of cardiovascular disease (Appendix 5).

The claims made for the classification however, are that it is based on *subjective symptoms*; therefore it might be argued that it is an appropriate measure when obtaining the subjective view of the individual with heart disease. This discussion reflects how reliability and validity are interpreted within different research approaches. Using a qualitative research approach might accept the subjective view as reflecting the individual's reality when using criteria proposed by Lincoln and Guba (1985) and Sandelowski (1986). It would be necessary to identify whose subjective view was obtained (patient or clinician). However the objective assessment section is rarely referred to. Use of this section would result in the subjective functional capacity of adults with CHD being qualified by the inclusion of the objective assessment component of the NYHA classification as recommended by the American Heart Association (2002).

The adult CHD population

Recent convention considers a person over 16 years of age who has congenital heart disease, to be an adult with CHD. Traditionally in the UK, the patient group have been referred to as GUCHs (grown up congenital hearts). The term was used by Dr Jane Somerville to describe an innovative hospital unit designed in 1975 for cardiac patients who had outgrown paediatric departments, but were not ready to join older heart patients on traditional cardiac wards (GUCH Dec 2001). Dr Somerville was also instrumental in the formation of the UK patients' association in 1993, with GUCH being the name given to this group. A collective term to appropriately distinguish adults with CHD from adults with acquired heart disease and children with CHD has been

the topic of debate within the letters section of the UK patients' association newsletter (GUCH March 2002 and Summer 2002), as well as between health professionals (Shinebourne and Gatzoulis 2002). More recently the term ACHD (adult congenital heart disease) has been more often used in an effort to develop a common understanding; agreement for an acceptable collective title remains elusive.

In this study the use of terms to identify people with CHD is important for two reasons. Firstly the term influences how a person is viewed, both by themselves and others; this aspect gained significance as the study progressed and is explored further in Chapter 7. The second is the need to discuss precise details of CHD with others in order to understand the complexities, compare treatment options, potential problems and outcomes that have contributed to increased survival. I have experienced pleasure when discussing clinical conditions with other people who understand CHD. Not having to explain anatomical or physiological concepts enabled discussion to move into realms that extended my existing knowledge and understanding. Few clinicians are involved in service provision, therefore they work in relative isolation; this is due to the relatively small numbers of people with CHD. According to the British Heart Foundation (2003) CHD makes up approximately 5% of all heart conditions.

The ACC report (2001) proposed an incidence of 10 per 1,000 live births as being the most probable, which correlated with Hoffman's (1995) estimate. The predictions made by Wren and O'Sullivan (2001) were used to estimate survival numbers to age 16 years in the United States (US) over the coming decade. Survival into adulthood of patients with complex lesions was recognised, with an associated increased need for follow-up due to the risk of associated acquired health problems. The changing profile was identified as being due not only to increased survival, but also as a result of the rapidly evolving methods of surgical treatment, for example use of Jatene procedure (arterial switch) in preference to Mustard or Senning procedures (atrial switch) for transposition of great arteries (see Appendix 1).

The literature demonstrated that survival of adults with CHD was increasing, resulting in a need for developing this specialism. Perloff (1991) considered the heavy investment of time and resources that had resulted in over 85% of children with CHD reaching adulthood should now also be available for adults with CHD. Experts in CHD in adults have described a new cardiovascular subspecialty and identified the need for the development of a comprehensive specialist service in care provision (Perloff 1991; Celermajer and Deanfield 1991; Hunter 1997; Somerville 1997; Olley 1998; Webb 2001; Webb and Williams 2001). This increased need for specialist adult CHD services was also demonstrated in a retrospective analysis of patient records carried out by Gatzoulis et al (1999) at a tertiary referral centre with over 40 years experience in providing care for this specific patient population. Records of patients attending the adult CHD clinic over a three-month period were examined at five year intervals, showing a 269% increase in workload over 10 years. An associated increase in workload and new referrals to a UK paediatric cardiology clinic was demonstrated in a separate study by Wagstaff et al (1998), where the only age group not to be increasing were those over 16 years. The authors claimed this resulted from their practice of referring older patients on to adult clinics. These two studies indicated the numbers of adults with CHD attending clinics is likely to continue increasing for the foreseeable future. Surgery for CHD is frequently seen as corrective rather than curative, therefore ongoing surveillance is likely to result in further investigation, intervention and admission to hospital.

The increasing numbers of adults with CHD surviving and requiring ongoing health care has had an impact on the demand for cardiac and other services, resulting in the need for agreement on how health care should be provided for this new and rapidly growing group of patients. Details are provided on establishing services in reports dedicated to CHD in the adult (CCS 1998; ACC 1991; 2001; British Cardiac Society 2002; European Society of Cardiology 2003). The reports complement each other by including details of proposed service delivery, health carer education programmes as well as recommended health care for specific cardiac defects in adults. These reports aimed to provide a guide on the principles of managing adults with CHD. The changing nature of health care for adults with CHD is demonstrated

by the need and ability to update the CCS (1998) report in 2001 using recent research findings.

The international context

As the number of children with CHD reaching adulthood increases there has been an associated recognition by professional organizations to develop services in order to meet changing needs. Conference reports and guidelines relevant to adult CHD began to appear from 1991; a chronological table of publications is provided in Appendix 6.

One early publication from New Zealand, took the form of a review of current literature (Wilson and Neutze 1993a/b). Green Lane Hospital in Auckland, New Zealand appears to have been one of the centres at the forefront of surgery for CHD, with paediatric cardiologists recognising the need for principles to inform care for adults with CHD. Guidelines were provided that are informative, drawing on research available at that time (Wilson and Neutze 1993a/b). However, while there was detail of individual lesions, there was no consideration of broader issues related to service development.

The growing adult CHD population was the focus of an annual conference organised by the ACC (1991), as well as being recognised as a significant group in a similar conference jointly hosted by the ACC and The American College of Sports Medicine (1994). Contributors to both conferences were predominantly people with medical or surgical experience with the main focus in 1991 being medical responsibilities and physical aspects of CHD. The wider psychological and social value of exercise was briefly noted in 1994, and cautious advice given in an attempt to increase participation in recreational and competitive sports for children with CHD.

In 1996 the Canadian Cardiovascular Society (CCS) commissioned a report on adult CHD. While international experts contributed to this conference report, the majority of participants were CCS members. Publications from the New Zealand

authors were accessed, although experts from that country were not involved, and no reference made to the guidelines provided by Wilson and Neutze (1993a/b). The CCS conference was followed in 2000 by a further ACC conference. Both conferences drew on the knowledge and expertise of members and international specialists and used details obtained through medical audit and from medical research. The result was the publication of two reports CCS (1998) and ACC (2001), which are now reviewed, as these have become seminal texts that are freely available through patient association websites.

The CCS (1998) and the ACC (2001) commissioned conferences that were devoted to care of the adult with CHD. The panels for both conferences comprised predominantly of medical experts who provided care for adults and children with CHD (CCS 24 of 25 conference participants; ACC 52 of 61 conference participants); one patient representative and two nurses contributed to the ACC conference. At this stage of a growing service, where medical expertise was essential to ensure the survival to adulthood, this representation may be considered appropriate. The reports reflected the medical perspective however, through the emphasis on physical conditions. The CCS and ACC reports were disseminated through medical journals and more recently on the Internet, making them available to a wide international audience. Other countries, including the UK, have used the reports to inform service recommendations for adults with CHD.

The CCS (1998) report has similarities to a systematic review. Although the search strategy was not provided, extensive evidence was accessed and used to provide guidelines to inform the health and social care for this patient group. The objectives were to provide recommendations for cardiologists using the best available knowledge at that time. It was recognised that the recommendations would require substantial refinement and strengthening over the next few years in order to reflect the dynamic and evolving nature of knowledge specific to adults with CHD. This report, and the subsequent update (CCS 2001) have become seminal texts.

The report provided a comprehensive medical resource. The first section considered the development of local and national services and identified personnel and training needs. The main body of the report comprised thirteen sections that focused on specific anomalies; common headings were used that made the document straightforward to use. Existing evidence was accessed to provide details on each defect, covering the background of un-operated history and management, diagnostic recommendations, indications for intervention, surgical/interventional options, surgical outcomes, and follow-up. This structure resulted in repetition of information, but did reflect how the report was likely to be used by practitioners.

The recommendations contained in each section indicated the grade and level of evidence accompanied by a reference source. Areas where there was a lack of evidence, receive the grade of 'consensus' indicating the use of evidence that did not concur with the research criteria agreed, with the outcome being the result of debate between panellists. The areas identified in the section on psychosocial issues received a consensus grade, indicating a lack of empirical evidence to inform care provision. The report was reviewed and updated in 2001, however the psychosocial section remained unchanged.

The entire CCS report (1998) covered fifty-seven pages, of which two pages were allocated to psychosocial issues and two pages to reproductive issues. The imbalance may reflect the importance given by medical practitioners to the physical survival of adults with CHD; however, as this group of patients survive to adulthood other issues become important to them.

Greenhalgh (1997) described a traditional 'hierarchy of evidence' that was used to indicate the perceived importance of different types of primary research when making decisions about health care. A similar hierarchy was used to grade evidence accessed to inform the CCS report (1998) with a well-conducted randomised control trial being considered as the 'gold standard'. Use of the hierarchy may account for the omission from the CCS (1998) report of the research published by Doucet (1981) and Gantt (1992). This traditional view of

research has more recently been questioned with growing recognition of the contribution that may be made by qualitative research studies (Sackett et al 1996). The lack of randomised control trials regarding psychosocial issues related to adults with CHD may have led to the limited consideration of this area.

The first section of the CCS (1998) report (the development of local and national services and identified personnel and training needs) was used by the ACC to inform the 32nd Bethesda conference held in 2001. The aim of the conference was to produce a clinical guideline to inform the development of the US health care system in providing care for the growing number of adults with CHD; it was thought that

'...the frequency with which these patients (adults with CHD) appear late at tertiary centers with avoidable complications indicates that health care delivery to this population falls far short of that for adults with acquired heart disease or children with CHD.'

(ACC 2001:1161)

A summary of the recommendations was provided under the headings: organization of care; workforce description and their educational requirements; access to care; and special needs of adult patients with CHD. Proposals were made for a national structure that could make effective use of resources, while developing professional expertise in the health and social care required by a relatively small group of patients in need of expert care. Similar to the CCS (1998) report, the content and recommendations of the ACC (2001:1167) report reflected the large medical input; however the recommendations included the establishment of training programmes for key staff such as nurses and other *'non-physician personnel'*, and acknowledged areas including the transition to adult life, reproduction, exercise and psychosocial aspects. European and UK adult CHD centres have developed in similar ways to centres in North America, and health carers involved with this small patient population have been sharing expertise.

UK context

UK hospital care for people with CHD takes place in tertiary cardiac centres where expertise has developed and resources are available to provide services for both congenital and acquired heart disease. The National Service Framework for Coronary Heart Disease (NSF) was published in 2000 (Department of Health), and has subsequently been used to guide the development of UK cardiac services. Congenital heart conditions were not included within the NSF, however have been acknowledged in more recent service recommendations (Department of Health 2003). Tertiary cardiac centres provide heart surgery, and more recently cardiology interventional treatment, for coronary artery disease. Procedures less commonly performed or for unusual heart diseases tend to be located in a few centres. Expertise is achieved and expensive resources can be used efficiently and effectively; one example is heart transplantation surgery, another is CHD.

While CHD makes up 30% of all congenital conditions, it remains rare (Jordon and Scott 1991). Survival to adulthood is complex and influenced by the intervention/surgery and subsequent residua and sequelae as well as the original defect (Stark 1989; Perloff & Child 1998). To maximise personnel and technical resources, hospital care for adults and children with CHD is usually delivered within the same clinical setting as people with acquired heart disease. Medical staff deliver care across the age range according predominantly to physical need; nursing staff, since 1990, provide care according to their field of training eg adult or child. Currently nurses who care for infants and children with CHD have the majority of expertise in the physical complexities of this cardiac subspecialty; it is not unusual as children reach adulthood for them to continue to receive care from child trained nurses in paediatric settings.

The British Cardiac Society (BCS) and the European Society of Cardiology have used the CCS (1998; 2001) and ACC (2001) reports to develop guidelines to inform the organization and delivery of health and social care for adults with CHD in the UK and other European countries (BCS 2002; The European Society of Cardiology 2003). Despite the commendable developments that are occurring, the provision of services continues to reflect a predominantly medical focus. The

medical perspective was apparent in the BCS (2002) report in which the heading of 'medical issues' was used to discuss areas such as infective endocarditis, arrhythmias, cardiac catheterisation and death, as well as lifestyle advice, contraception and pregnancy. The search of databases revealed extensive medical research in which the focus was on survival rates (for example, DiDonato et al 1985; Gewillig et al 1992; Thorne and Deanfield 1996), and the comparison of surgical developments (Bellinger et al 1999); there was less research available on non-medical aspects of living as an adult with CHD. The psychosocial aspects of adult CHD are lacking.

UK nursing contribution to care for adults with CHD

Opportunities for nurses to expand their role are identified in The National Health Service Plan (Department of Health 2000a), and recommendations are incorporated into national and international reports including The Royal Liverpool Children's Inquiry (Redfern 2001) and The Bristol Royal Infirmary Inquiry (Kennedy 2001). One consequence of changes in UK nurse training and career structure has been the appearance of new roles including the clinical nurse specialist. Canobbio and Day (1994) provided an overview for this role in an adult CHD programme and list the functions as being a practitioner, programme coordinator, educator, counsellor, consultant and researcher.

Currently the nursing contribution to adult CHD services varies considerably. In some centres the paediatric nurse specialist is listed as the person to contact, while others have an adult clinical nurse specialist. Patients' understanding of their CHD is limited (Kantoch et al 1997, Moons et al 2001a); centres with well established nursing input are aiming to enhance patient's understanding and develop their ability to recognise potential risks, ask appropriate questions and take appropriate actions. Issues that arise, as children with CHD move into adolescence and adulthood, will be different to those encountered during childhood; if nurses are to contribute to the care of this specific patient group they require the necessary skills and knowledge.

Synopsis of the chapter

This study is set during a time of expansion in services for adults with CHD and has arisen from my experience as a nurse and a teacher. Opportunities exist for practitioners to develop roles in order to meet new demands. The purpose of this research is to promote awareness of the unique needs of this new patient population, and their position within existing paediatric and adult cardiac services. This introductory chapter has set out the concerns that prompted me to commence this research endeavour.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter uses current available understanding to explore literature related to adults with congenital heart disease (CHD). Concepts will be identified that provide a framework which will inform the selection of the research approach to meet the aims of this study. The review will demonstrate there is a lack of clarity about the evolving needs of the patient group. However, several issues will be evident: that the patient group is expanding at an unprecedented rate; the range of perceived health and social care needs, as well as delivery methods are variable; and the nursing contribution remains undefined.

Purpose of the literature review

The purpose of reviewing existing literature is to identify current knowledge regarding aspects that impact on every day life of adults with CHD. As stated in the previous chapter, increased survival has been confirmed through studies that focus on surgical, medical, and pharmacological techniques. The focus for this study is that of patient perspective, therefore literature that focused on a holistic perspective of physical, psychological and social aspects of living with CHD was sought.

In this section the foundational forestructure is provided and a review of health and social aspects relevant to adults with CHD is undertaken.

‘Foundational forestructure’ was the term used by Thorne et al (1997) to describe clinical knowledge that existed regarding phenomena despite the lack of formal research. The revelation of the foundational forestructure allows researchers to demonstrate how their existing knowledge has informed the research process, as well as how that knowledge has been questioned throughout the study. The initial literature search therefore focused on areas that were identified through previous clinical and education experiences. The

literature selection was informed by reports produced by the Canadian Cardiovascular Society (CCS) (1998), and the American College of Cardiology (ACC) (2001) both referred to in the previous chapter. Literature selection was also influenced by a model of nursing (Roy 1976) that viewed people as an integration of physical, psychological and social aspects that adapt to life changes; this model recognised the patient perspective and nursing role that were central to my thinking.

Literature Selection

An electronic literature search of health and social care databases was commenced in 1998 in preparation for submission for ethical committee review, and has continued throughout the study. Databases included CINAHL (Citation Index for Nursing and Allied Health Literature), Medline, EMBASE, BNI (British Nursing Index), PsycLIT (now PsycInfo), Web of Science, and the Social Science Citation Index. Records going back to 1980 were available and searched electronically. A range of search terms was used with congenital heart, adult, and psychosocial being the most successful. An example of a search strategy and results is given in Appendix 7. Electronic searching was not as comprehensive as anticipated, neither was it a straightforward process. Expertise with different databases and thoughtful, time-consuming detective work was necessary to identify potentially relevant publications. Reference lists were therefore, also scrutinised to discover sources that may not have been identified through electronic searches. While a large amount of literature was available electronically, this was a recent development and it was possible for early or seminal work to predate development of electronic databases. One example, which did not appear on early electronic searches, was the report by Doucet (1981). The Cochrane Library and Dissertation Abstracts International were searched revealing one systematic review (Lip et al 2002; 2004) and two American PhD studies (Greenwood 1999; Simko 2000) relevant to this study. Grey literature is the term used to describe documents produced by, for example government departments and institutions, which are publicly available. UK government

recommendations relevant to CHD were obtained, as well as the guidelines produced by professional groups reported in the previous chapter. Care for adults with CHD was concentrated to a relatively small number of centres; existing contacts were used to discover research being undertaken in this area. Literature was also accessed that was personally recommended from direct contact with individuals involved with adults with CHD. Regular electronic searches have continued throughout the study to identify new literature.

Searches revealed extensive literature related to surgical outcomes and physiological sequelae; however limited information beyond the physical aspects of mortality and morbidity for adults with CHD, further endorsed the need for this study.

Background and structure of the literature review

The evolution of surgical techniques and potential for long-term consequences being now more imminent makes the population of adults with CHD different to children with CHD. Similarly, being younger, having a diverse disease process that is unrelated to the risk factors generally associated with heart disease, the adult CHD population are also different to other adults with acquired heart disease. While commonalities between groups exist, adult CHD was seen by some as a new cardiovascular subspecialty (Celermajer and Deanfield 1991; Perloff 1991; Hunter 1997; Olley 1998; Gatzoulis et al 1999; Grech and Savona-Ventura 1999). The British Heart Foundation (2003) classified 56% of all heart conditions as coronary heart disease, and 5% as CHD, which may account for the greater awareness of acquired heart disease. However as the number of adults with CHD is likely to exceed the number of children with similar conditions (Murphy 2003), the need for specialist services was recognised.

There is growing interest in the psychosocial implications of chronic physical illness in children due to the ability to treat conditions which were once life threatening (Eiser 1998). Until physical survival is ensured, emotional, social

and spiritual needs might be compromised (Hymovich and Hagopian 1992). Once physical survival is assured however, other psychological and social aspects become increasingly relevant to enhance quality of life. Studies that specifically examine these areas for adults with CHD are few, and reveal areas that are unique due to the episodic nature of health care required. This contrasts to the continuous nature of other chronic childhood illness, such as cystic fibrosis. Physical, psychological and social aspects of living with CHD will be used to structure the literature reviewed.

Physical aspects

The focus of literature reviewed in this section relates to the physical aspects of CHD associated with adapting to life events. Literature exploring how patients understand their CHD and the impact of hospital admission will be considered. The contribution by patient education to ways in which CHD is understood is included in this section as the focus of much information is on anatomical and physiological aspects, especially if hospital admission is required.

For patient education to be effective it has to be understood by the people for whom it has been designed (Feudtner 2001). When a person considers they are well, there may be no reason for them to seek patient education, and yet understanding the implications of their heart condition, patients could develop their ability to prevent avoidable complications identified by ACC (2001). Studies to establish patients' understanding of their heart condition were used to make a case for greater resources to develop and deliver patient education programmes (Kantoch et al 1997; Moons et al 2001a; Veldtman et al 2001).

Kantoch et al (1997) set out to assess the knowledge adult patients had of their CHD, endocarditis risks and the need for antibiotic prophylaxis. Fifty patients, aged between 18-60 years, attending an outpatient clinic completed a two-part questionnaire. The patients' understanding was corroborated by a review of medical notes, and how scores were awarded was briefly explained.

Results were presented as simple tables, however it was difficult to establish how many patients had no knowledge of their CHD. This was important as part of the discussion hinged on the ability of the adult with CHD to provide informed consent; the outcome making a case for extra resources to develop a patient education programme.

Moons et al (2001a) attempted to assess adult patients' understanding of their heart condition, treatment and measures necessary to prevent complications. Four domains were assessed in this descriptive cross sectional study. These were: the disease and treatment, prevention of complications, physical activities, and reproduction. A questionnaire was developed from previous studies (Kantoch et al 1997, Cetta et al 1999), and completed during outpatient visits by sixty-two adults aged from 18-46 years of age. A range of understanding across different areas was reported including: good understanding in regard to treatment, dental care, and pregnancy. There was reported to be less understanding of CHD, endocarditis risk or physical activities, as well as poor understanding of the purpose of follow-up, and symptoms of deterioration. The understanding of contraception ranged from being good in regard to the oral contraceptive pill, and poor related to inter-uterine devices. The poor understanding of the purpose of follow-up may indicate being unable to appreciate the relationship between the different aspects of their CHD. This may be an unreasonable expectation as Feudtner (2001:174) considered that

'Understanding congenital heart lesions is difficult and eludes many of us who are unable to grasp abstract concepts or comprehend intricate 3-dimensional structures.'

Concern had been expressed previously (Miner 1994; Kantoch et al 1997) regarding the ability of adults with CHD to understand risks of endocarditis associated with routine activities such as dental care, ear piercing and tattooing (Cetta et al 1999), and with Moons et al (2001a) reiterating the need to further develop existing patient education programmes. The studies were single centre, used questionnaire survey approaches (Kantoch et al 1997; Cetta et al 1999; Moons et al 2001a), or provided an overview of infective

endocarditis related to CHD (Miner 1994). Results reported a low incidence of infections, yet recommendations were not made regarding the value of antibiotics in preventing infective endocarditis. The reasons given include insufficient data due to small sample numbers in the study by Kantoch et al (1997) or the low return rate in that carried out by Cetta et al (1999). The overall recommendations from these studies appeared to reflect health carers' genuine concerns rather than encouraging patients to consider the consequences of activities in relation to their heart condition.

The limited understanding that adults had of their CHD was of concern due to the reduced contribution patients can make in sharing responsibility for decisions regarding the management of their condition (Kantoch et al 1997; Veldtman et al 2001). The adult patients' lack of awareness and knowledge may result from information originally having been provided to parents when surgery was performed early in the child's life. The majority of CHD is diagnosed during infancy (Wren and O'Sullivan 2001) with 74% diagnosed before one year of age, and 92% by age 4 years. As surgery for CHD frequently takes place soon after diagnosis, the adult may be unable to recall their surgery, and grew up unaware of details of their heart condition. This lack of recall may explain what Horner et al (2000) called 'pervasive denial' used by children as a method of coping that explained them viewing themselves as normal. Feeling normal may contribute to the reported ambivalence shown by adults with CHD to information provided by health carers. Alternatively being normal may be as a result of only a minority of adults with CHD requiring hospital admission (Somerville 1997).

The majority of health care for adults with CHD will take place in an outpatient setting (CCS 1998; British Cardiac Society 2002), nevertheless as the population grows to adulthood other non-cardiac health issues arise which may require hospital admission. There is agreement that any surgical procedure in most adults with CHD will carry greater risk than in the general population. Evaluation of an adult with CHD prior to surgery should be undertaken, with surgery being performed where feasible, in centres where

specialist expertise is available for adults with CHD (CCS 1998; ACC 2001; British Cardiac Society 2002).

There is limited literature examining the non-cardiac in-hospital needs of this group, although Kools et al (1999; 2002) outlined the life course of CHD and focused on the impact of hospitalisation for cardiac reasons on adults with CHD and their families. Gillis and Tong are collaborators on these papers; both have contributed to other related studies, making the study a logical development, although the focus can appear to be from a paediatric, rather than an adult perspective.

The two papers report the findings from a study exploring psychosocial needs of adult patients and their families using a grounded theory approach (Kools et al 1999; 2002). Semi-structured interviews were carried out with thirty-four participants: eight patients (22-40 years of age), nine family members, eight paediatric nurses and nine adult nurses. Regardless of whether care was provided in paediatric or adult settings, dissonance was reported which led to confusion, distrust and dissatisfaction for all involved. Health carers reported that patients did not conform to staff expectations of behaviour, and were perceived as challenging by both adult and paediatric trained nurses. Patients and family members reported health care staff having limited understanding of either the physical condition (adult trained staff) or the psychosocial needs (paediatric trained staff) of the adult patient.

The paper described normal practice, in the centre where the study was carried out, of admitting adult CHD patients to the paediatric intensive care unit and to adult cardiology wards (Kools et al 1999). This practice occurred in other centres at that time, and may be due to the concentration of medical expertise within tertiary centres, with medical staff providing care across the age range according to physical need. Nurses in North America may also provide care across the age range; however since 1990, nurse registration in the UK has become adult or child specific (United Kingdom Central Council 1986), making dual registration necessary to provide care for both adults and

children. However in the 1970's and 1980's it was usual practice for infants and children with CHD to be cared for in an adult intensive care unit. The need for age specific settings was identified by Perloff (1999) and by the Department of Health (1997a/b).

The thought provoking papers by Kools et al (1999; 2002) identified the need to modify both adult and paediatric standards of care to include the psychosocial needs of patients and their families as well as an understanding of the different physical parameters for assessing adult patients in contrast to children. The authors concluded that nurses should develop a comprehensive knowledge of CHD in adults, including an understanding of how independence is achieved in the presence of chronic illness.

The issue of independence reflects concerns identified previously regarding the adults' ability to participate in decisions regarding medical management of their heart condition (Kantoch et al 1997; Veldtman et al 2001). Achieving independence requires not only physical maturity but also psychological and social development. Literature relating to psychological development will now be reviewed.

Psychological aspects

Themes included in the literature reviewed under this heading include normality, the dilemmas faced by patients and parents and psychopathology. Two early qualitative studies, one published in a nursing journal (Doucet 1981), the other written by a nurse (Gantt 1992) were among the first to explore psychosocial aspects of living as an adult with CHD. These studies reported similar findings to later research, but were presented differently, maybe due to writing conventions that existed at that time. These two early studies will be reviewed now.

Gantt (1992) utilised grounded theory techniques, whilst Doucet (1981) adopted an exploratory approach due to lack of existing research at that time.

The sample in both studies was accessed through outpatient clinic visits and data collected using semi-structured interviews. The purpose in both studies was to explore the young persons' experiences of living with CHD. Doucet (1981) selected twenty-five people between 18-30 years; the theoretical sample accessed by Gantt (1992) was thirteen young women with an age range of 13-28 years. Reading these papers approximately twenty years later, there were two main aspects that had an impact on me. The first was use of male terms to refer to the fourteen males and eleven females who took part in semi-structured interviews (Doucet 1981). The second was the predominantly numerical presentation of essentially narrative data (Doucet 1981, Gantt 1992). This was accompanied by an overall lack of detail regarding the research approach that made it difficult to appreciate how themes had been identified. Despite these limitations these early studies focused on aspects that have only more recently been perceived as important by the wider health care community. Perceptions of normality were identified as being important and necessitated further exploration.

Feeling different to others was reported by samples in both early studies (Doucet 1981; Gantt 1992) with childhood being consumed by their CHD as well as fearing death and decreased life span. Doucet (1981) reported a fear of hospitalisation. Hospitalisation is required when surgery is planned or if investigation of physiological status is deemed necessary by the cardiologist. Respondents did not consider cardiac catheterisation to be essential, this was reported to be a traumatic experience, and often the first realisation of their CHD. In contrast surgery was seen as essential and therefore better accepted. Negative feelings of decreased life span or fear were considered to be more prevalent in those people undergoing cardiac catheterisation.

Parents treated the child with CHD differently to siblings, being over protective and reluctant to discipline them. The CHD affected relationships with friends, with respondents perceiving they had more limitations on all activities than normal siblings. The CHD was not discussed outside of the

family; in fact not openly discussed by respondents with anyone (Doucet 1981).

Educational achievements were reported to be lower than the general population; however, while career choice may have been restricted due to CHD, most were employed (Doucet 1981). Concerns at the time of publication, were thought to be typical for the age group, being work, marriage and an enjoyable life. Some minimal concerns were expressed regarding their health, the need for future surgery, deterioration or shorter life expectancy (Doucet 1981). Reporting patients' lack of understanding regarding their heart condition, the lack of information regarding contraception, pregnancy and risk to offspring, and difficulties associated with body image specifically related to aspects of CHD, such as scars and cyanosis, Doucet (1981) and Gantt (1992) preceded similar findings from later studies (Kantoch et al 1997; Moons et al 2001a).

A subsequent study reported ten years later by Gantt (2002), exploring the effect of CHD on mother-daughter relationships, indicated developments in reporting qualitative studies. Greater detail of the research approach was provided, with the report using data chunks to show how themes were generated. The individual nature of experiencing life related to CHD was demonstrated through conflicting reports of people feeling they were 'caught in the middle' between having normal and not so normal lives (Gantt 2002: 487). Overall, while affected by their heart condition, people in the second study had a more positive outlook than had been reported previously.

Normality was a theme that emerged from a paper that was instrumental in commencing the research study that is the focus of this thesis, and used the heading of dilemmas to report findings (Sparacino et al 1997).

Two papers from the same study reported the dilemmas of parents (Sparacino et al 1997) and the dilemmas of adolescents and young adults with CHD (Tong et al 1998). The purpose of the qualitative, exploratory, descriptive study was to learn more about the subjective experiences of

adults with CHD and their parents; the dilemmas and challenges they faced, specific to their CHD, as they reached adulthood. A long-term aim of the study reported in these two papers was, that through learning about their potential needs, more specific support strategies could be provided. Eight adolescent/young adults with CHD aged from 13-25 years and nine parents took part in semi-structured interviews.

The intention to gain the patient and parent perspective is to be commended; there were however questions regarding the study design, as to whether this aim was fully realised. The interviews were carried out either in the patient's home or at their outpatient visit. The different venue was determined by patient convenience; nevertheless there are significant differences between the two settings that could impact on the interviewee's ability to engage fully in an interactive interview. The different venue may not have been the only aspect that influenced the data collected.

When using a semi-structured interview to collect data, the interviewer is considered to be the data-gathering tool (Kvale 1996). The use of more than one nurse to carry out the interviews could result in a lack of parity despite the use of an interview guide. Paediatric nurses may be experienced in talking with parents and children but may have less insight into adult issues raised during the interviews.

There was no explanation given of the selected age range with a wide developmental span being covered; some issues may only become apparent when the adult attempts to become financially independent of their parents. Despite these concerns the dilemmas identified have a sense of authenticity when compared with the results from Doucet (1981). The dilemmas identified are of normality, disclosure, strategies for management of illness, and the challenges of social integration/isolation, dependence/independence, uncertainty, and strategies for coping. The dilemmas have the potential to influence psychological health and well-being.

Long-term psychological health was the focus of a Dutch multidisciplinary study, the findings from which have been frequently cited since 1993. Five papers from this study reported emotional and behavioural problems of children, adolescents and adults with CHD (Utens et al 1993; Utens et al 1994; Utens et al 1998a; Utens et al 1998b; van Rijen et al 2003). This series of papers reported the follow-up of patients who had undergone cardiac surgery for CHD between 1968 and 1980 in one centre in the Netherlands and provided extensive information related to psychosocial function.

The papers identified a lack of information regarding long-term medical and psychosocial outcomes. Four papers are included here that reported findings specifically related to the psychosocial aspects of adolescent or adult patients (Utens et al 1994; Utens et al 1998a; Utens et al 1998b; van Rijen et al 2003). Utens et al (1993) has been omitted in this review, as the sample group were less than 17 years of age. The publications from this study are cross-referenced to each other and together provide extensive details of the study design. The study was designed to address methodological limitations identified in earlier studies such as small sample size, heterogeneous sample composition regarding type of CHD, different age ranges, low-response rate, and non-standardised assessment procedures.

The samples covered six diagnostic categories: atrial septal defect, ventricular septal defect, tetralogy of Fallot, transposition of great arteries, pulmonary stenosis, and a miscellaneous group. Apart from the miscellaneous group, the diagnostic categories used are included in the eight most common defects (see Appendix 1 for details of conditions and Appendix 3 for incidence). Reference groups from the Dutch population were used against which to compare outcomes.

The first paper (Utens et al 1994) identified that previous studies reported contradictory results regarding psychosocial effects of CHD in adults. It set out to compare emotional, intellectual and social functioning following

cardiac surgery, through comparison across specific congenital cardiac defects, using a similar group from the general population. Validated tools were used to gather information from 288 patients aged between 18-35 years of age. The results reported that patients in all six diagnostic groups were emotionally and socially 'well adjusted' (page 753). Caution was expressed, however, on the favourable results regarding intellectual functioning, this was due to missing data and patients with Down's syndrome being excluded from the sample.

Later, Utens et al (1998a) compared the level of behavioural and emotional problems of a group of 146 adults with CHD aged between 19-25 years, with a reference group of the same age. The findings concluded that there was overall satisfactory psychosocial functioning in adults with CHD. The risk for developing 'psychopathological problems' (page 651) was identified and recommendations made for future research. Potential risks had been identified in a study on younger patients aged 10-15 years, published around the same time (Utens et al 1998b). Risks were associated with an increased number of heart operations, and use of deep hypothermic circulatory arrest. No relationship with the severity of the heart condition was reported; however it could be proposed that a patient with a more severe condition would probably undergo a greater number of surgical procedures likely to require deep hypothermic circulatory arrest. Utens et al (1998b) included the miscellaneous diagnostic group which may impact on results; my personal experience has demonstrated that CHD classified as miscellaneous is frequently complex and can require multiple palliative procedures. Despite having identified small sample size as a limitation in previous studies, reporting the results according to diagnostic categories led to small group numbers in this study; the smallest group being five (pulmonary stenosis), and the largest thirty-nine (ventricular septal defect) patients.

The final paper from this series (van Rijen et al 2003) explored the psychosocial functioning of 362 adults with CHD aged between 20 and 46

years. Results were again compared with a reference group from the general population, and presented under the headings of biographical characteristics, emotional functioning and social functioning. The biographical characteristics of living conditions, marital status and offspring were highly similar to the reference group. A lower level of educational attainment was reported with a higher proportion receiving special education as well as being more associated with institutions for 'mentally handicapped' (page 676). CHD can occur with chromosomal and genetic syndromes that are associated with cognitive impairment; the sample for this study was consecutive patients, so could include people with syndromes linked to CHD. The report made reference to some data being missing from patients who were mentally retarded; however insufficient detail was given to assess the potential impact of cognitive impairment on results. Those working in lower occupational groups were related to lower educational attainment, with patients reporting positive perceptions of career potential. The authors considered this to indicate possible denial. The patient group achieved positive scores for both emotional and social functioning. Areas assessed included self-esteem and participation in leisure activities. While some differences are identified between the patient group and the reference group, the authors conclude that these were minimal.

Two factors make it difficult for comparisons to be made across this series of reports. The first is the lack of definition of terms used to refer to the outcomes being measured. Emotional, intellectual and social functioning were measured by Utens et al (1994). The paper by Utens et al in 1998(a) assessed intelligence and, behaviour and emotional problems that were collectively referred to as 'psychopathology'. The term 'psychopathology' was first encountered in Utens et al (1998a) and appeared to be used as a collective term to refer to a range of behavioural and emotional problems such as anxiety and depression. The term has also been encountered in other studies that explore psychosocial aspects (Spurkland et al 1993; Masi and Brovedani 1999; Cox et al 2002). The term 'psychopathology' remains poorly defined, appearing to be used in these studies to reflect a problem

orientation, yet a positive psychosocial adjustment was reported by Cox et al (2002) and Rietveld et al (2002). Terminology and the identification of problems may have been influenced by the professional backgrounds of the authors, these being psychiatry and medicine, in which the focus may be predominantly on psychological or physical illness and cure, in contrast to the social aspects of life.

The second aspect that impacted on clarity was the range of data collection tools used to measure outcomes. Examples include: Dutch Personality Questionnaire (Utens et al 1994; van Rijan et al 2003); Young Adult Self-Report (Utens et al 1998a); Child Behaviour Checklist (Utens et al 1998b). Evidence of reliability and validity for these tools was discussed within each paper; nevertheless it was difficult to determine if the same outcome was being referred to across the papers. The overall impression from these studies is of a focus on problems, yet the outcomes appear to indicate more positive results than anticipated.

The lack of agreement regarding psychosocial functioning was expressed in 2003 in an exchange of views between van Rijan/Utens and Tayebjee/Lip in letters written to the editor. The letters focused on the apparent conflict in the positive results reported by van Rijan et al (2003) and the reduced quality of life demonstrated by Lane et al (2002). Lane had collaborated with authors who had recently undertaken a Cochrane systematic review related to depression in adolescents and adults with CHD (Lip et al 2002; 2004). This review expressed concerns regarding physical functioning and overall health perception.

Other limitations in the Dutch papers are evident. Firstly in order to address limitations identified above it is likely that statistical support would be required, however this was not acknowledged. Despite small sample numbers being identified as a limitation of previous studies, the use of diagnostic categories in this study resulted in small numbers in some groups that prevented statistical differences being demonstrated. Secondly, ethical

committee review was not mentioned throughout the reports. The impact of developments in research governance requires ethical review to be undertaken and most publishers expect a statement of acknowledgement. Despite variations within the Dutch studies, some conclusions may be drawn from the results. All report minimal differences across the diagnostic groups selected. The complexities of classifying CHD have been discussed earlier, and while these studies have not acknowledged this, the groups included cover the clinical spectrum subsequently identified by the American College of Cardiology (2001) (Appendix 2).

Despite these limitations, this series of reports appears to be unique in providing a longitudinal account of psychosocial development related to CHD. They have also combined psychological and social aspects of life, other literature has focused more on primarily on the impact of CHD on social areas of life.

Social aspects

Social aspects of life change as people grow into adulthood; aspects include those that influence the individual's ability to gain employment, participate in exercise, form relationships, have children and purchase their own home. This section will explore areas where it was implied that CHD impacted on social aspects of life.

Education and career opportunities in adults with CHD were estimated to be lower than the general population (Doucet 1981; CCS1998). The effect of CHD and cardiac surgery on cognitive function was the subject of a prospective, randomised single-centre trial by Bellinger et al (1999); while Wernovsky et al (2000) tested intellectual function and academic skills using a cross-sectional review. Both studies reported intellectual performance to be lower than the general population. However Wray and Sensky (2001) used a prospective cross-sectional design to assess the effect of CHD and cardiac surgery. Cognitive function and academic ability were measured in children

aged between 3 and 17 years of age. Three groups were assessed, those awaiting either cardiac surgery or bone marrow transplantation, and those in a healthy group. These authors found that children with acyanotic CHD had a similar level of intellectual function to healthy children. Canobbio (2001), in a review of the literature, also claimed that the majority of young adults with CHD achieved educational levels equal or above the general population. Educational achievement is likely to impact on an individual's ability to gain employment.

Career and vocational advice should be an integral part of health programmes as employment options could be enhanced through realistic assessment of patients' physical capabilities, enabling appropriate job training and matching patient capabilities with employers' job requirements (Canobbio (2001; ACC 2001). Canobbio (2001) related employability to the New York Heart Association (NYHA) classification (Appendix 5) and claimed that people in classes III and IV faced most job discrimination.

Studies reporting employment levels for adults with CHD provided conflicting results. The respondents in Doucet's (1981) study were mostly employed, or did not consider unemployment to be related to their CHD. Yet some reported a reluctance to change jobs because of their CHD, with half of the respondents in permanent positions not informing their employer of their CHD. In contrast, Celermajer and Deanfield (1993) concluded from the analysis of a questionnaire distributed to a group of fifteen employers, that employment prospects were poor for adults with complex CHD, despite being free of symptoms and having a good prognosis. Results may reflect the different views held by adults with CHD and potential employers. Lack of employment may be due to over protective family or employer's reluctance to engage a person who has a chronic illness, and was seen as a cause of reduced social contact and failed aspirations (Popelová et al 2001). Developments in legislation regarding discrimination may have relevance to adults with CHD.

In America, the National Rehabilitation Act of 1973 makes it unlawful for employers to ask about disability or to request a physical examination. Employers who hire people with a disability are protected from financial loss through a state compensation fund if the disability progresses. State and Perloff (1998) recommend American patients be aware that they are not obliged to disclose their CHD, provided it will not interfere with the job for which they are applying. Discussion with a local university personnel department revealed this to be similar within the UK, with patients not having to inform potential employers about their CHD. Occupational health departments of large firms will perform health checks with details being confidential; however an employer cannot be held responsible for any deterioration in health.

As with employment, adults with CHD appear to face difficulties in obtaining insurance. The overall response rate was fifty from ninety-nine (Truesdell et al 1986) and twelve from thirteen (Celermajer and Deanfield 1993) to questionnaires sent to life and health insurance companies in the United States of America and Britain. Results indicated that life insurance was available to most adults with CHD, although they were likely to pay more than the standard rate. One major factor influencing the cost was the severity of disease as described by physicians. A patient with CHD that was described as mild may be able to obtain insurance, but if termed moderate insurance may be refused. There may be difficulty or lack of agreement regarding grading some CHD. Guidelines used by many British insurance companies considered complex CHD to be uninsurable, with simple CHD insurable at higher rates. The UK Patients' Association, GUCH (Grown Up Congenital Heart) advised members to withdraw an insurance application before it was refused, if that appeared to be likely. Being refused insurance can result in applicants being entered on a computerised list called the 'Impaired Lives Registry' held by the Association of British Insurers (GUCH 1998).

Health insurance, while a significant issue in the United States of America, does not have the same impact on UK patients. The main effect for UK

patients is the need for health insurance when travelling abroad; however, overall cost to the National Health Service (NHS) of providing ongoing services requires consideration. A pilot study by Moons et al (2001b) suggested costs vary considerably across the spectrum of CHD. Their results provided detail that could inform health care administrators and insurance companies.

The role of health carers and patient groups as local and national advocates regarding insurance and employment issues was raised by ACC (2001). More emphasis was given to health insurance, probably due to how American health care is funded, and was linked to the cost of health care provision and availability of health care cover for adults with CHD. While approximately 85% had health insurance, 67% reported having difficulties in obtaining cover; difficulties were reported to be associated with surgical repair rather than their current health status (ACC 2001). One reason proposed for insurance difficulties was lack of understanding of the health care delivery model.

Another significant aspect of social life is physical exercise. Also physical exercise is perceived as beneficial in maintaining a healthy heart, with supervised exercise forming part of cardiac rehabilitation programmes (Malotte and Gilbert 1989; King and Sivarajan Froelicher 1989; Kitchener 1996). Lack of appreciation of the physiological response to exercise in adults with CHD can result in limited advice being provided by health carers. Guidelines for participation in sports by patients with CHD, was provided in a report from a conference jointly sponsored by the ACC and the American College of Sports Medicine (1994). The report acknowledged a small risk, but considered excessive restriction of exercise had potential to cause physical and psychological harm. Individual patient assessment by a physician was recommended, with the guidelines being modified if necessary. Physicians' knowledge in this area may however, be insufficient. The study by Swan and Hillis (2000) concluded that improvement was required in patients' understanding of safe and effective exercise, as well as the advice given by

physicians to patients attending paediatric and adult specialist cardiac services.

As people with CHD survive to adulthood issues of sexual health become significant. Gantt (1992) identified a lack of information to help women with CHD make choices regarding contraception, pregnancy and awareness of the risk of CHD to their offspring. Advice prior to conception was recommended, and should include options for contraception, genetic assessment and counselling, risk to foetus of maternal medication, as well as timing of pregnancy (Schmaltz et al 1999, Siu et al 1999, Iserin 2001, Siu and Coleman 2001). Information regarding contraception was considered to be inadequate (Leonard et al 1996; Schmaltz et al 1999), with less than half of mothers with CHD being informed about the implications to their health of different contraception options. Discussion of relevant issues was advised when pregnancy was planned; however pregnancy was often the factor that initiated a cardiology review of the heart condition.

Quality of life

Two recent American doctoral studies have explored health related quality of life in adults with CHD (Greenwood 1999; Simko 2000). Both nurses accessed the sample group during attendance at a local cardiology clinic; the entire sample in both studies was over 18 years of age. Diagnostic categories were provided that reflected the spectrum of CHD; the endeavour to make comparisons across diagnostic categories acknowledged the wide clinical spectrum of CHD although appeared to indicate a focus on physical aspects. The sample accessed by Greenwood (1999) was adults who had undergone repair of complex CHD; Simko (2000) accessed the entire patient population followed at the clinic. No differences were demonstrated between the diagnostic categories, this may be due to small numbers in some categories; the smallest group comprised six people (single ventricle), and the largest group was twenty-three (tetralogy of Fallot).

Using validated tools including SF-36 (Greenwood 1999) and Sickness Impact Profile (Simko 2000), the two studies endeavoured to discover how adults perceived their quality of life. Both reported that the majority of adults with CHD perceived themselves to have no disability (Simko 2000), or that physical health was not a significant predictor of life satisfaction (Greenwood 1999). Recommendations made by Simko (2000) did not fully reflect the findings presented. For example, despite the majority of patients reporting having their questions answered or having no concerns, the author recommended nursing involvement to develop a comprehensive educational programme to address issues regarding birth control, pregnancy and genetic counselling.

Nursing role

Canobbio is an American nurse experienced in providing nursing care for adults with CHD and has published widely on the topic for over twenty years (for example 1984, 1994 and 2001). The papers appear to result from an audit of extensive records rather than of original research; nevertheless they provided detailed practical information and guidelines to help nurses in the management of adults with CHD. UK patient associations such as GUCH and the British Heart Foundation provided information on areas similar to those identified by Canobbio.

In 1984 Canobbio raised awareness of this new patient group; in 1994 she was guest editor of the June issue of *The Nursing Clinics of North America*, which focused on issues in care of adults with CHD. Discussion papers were presented in two parts. Part I, included management issues, provided details on the emerging population, long-term follow-up across the spectrum of CHD, implications of infective endocarditis and issues related to pregnancy for women with CHD. Part II covered counselling issues, provided information on educational assessment, employment, insurance, exercise as well as the clinical specialist role in an adult CHD program. This American perspective provided a comprehensive overview of

contemporary issues that remain relevant to adults with CHD living in the UK.

In 2001 an update was provided of issues important to adults with CHD; some areas were the same as those published in 1994 and included education, employment, sexuality and reproduction, and non-cardiac follow-up. The 2001 update was published in a journal whose target audience was paediatric nurses, and aimed to discuss issues that paediatric health care providers must begin to address. Preparation for the transfer from child to adult health care settings is an important aspect for children growing up with CHD and their families. There would appear to be growing interest in the need for specialist services for adults with CHD.

Summary

This section summarises key issues arising from the review of selected literature and integrates these within the personal, professional, national and international context presented in the preceding chapter. The focus of most of the available research was on physical outcomes of CHD or surgical corrections; fewer studies were found that focused on psychosocial aspects of living with CHD (Appendix 7). Due to the recency of greater numbers of children born with CHD reaching adulthood; there is a lack of information regarding aspects that enhanced the adults' ability to live well.

The study began with two main assumptions. The first was that nursing had the potential to contribute to the growing services for adult CHD; the second was that adults with CHD required more information/services than were currently available. I was aware that physical aspects were important to ensure the continued physical health that was a pre-requisite to engaging in life; however being healthy comprises more than physical well-being. The World Health Organisation (1946:2) defined health as

'... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'

The mental and social well-being, as well as the physical health that contributes to our ability to participate in life, are an essential part of nursing. I was aware that the focus of nursing and medicine were different; a medical focus is disease-oriented, the focus of nursing is health. Patients may have a focus that is different to both nursing and medicine. Quality of life is a concept that, when measured, has potential to indicate well-being (Holmes 1998). There is however, a lack of agreement on what constitutes quality of life, with tools reflecting concerns of clinicians rather than patient perspectives (Holmes 1998).

Services for adult CHD evolved initially through medical specialisation that has resulted in children born with CHD surviving to adulthood. The nursing contribution for children with CHD is established, however for adult CHD has only recently become apparent. Once basic survival needs are assured, other areas become important. This is reflected by Tong et al (1998) who identified what they referred to as 'dilemmas' faced by people growing up with CHD, which arise as a result of surviving, and may be considered psychosocial (being normal, telling people, social integration, independence, managing CHD, uncertainty, and coping). One informant reported 'how he 'lives in two different worlds', one dealing with hospitals and physicians, and 'the other half being the real world ...' (Tong et al 1998:307). I wondered what 'the real world' was for adults with CHD. It was necessary to obtain views from people who have adapted to living with CHD.

This study is situated within my professional areas of interest and reflects personal values. Rapid change is usual within contemporary health care, university education as well as in regard to medical/surgical management of CHD. Skills required to deal effectively with change, include the ability to adapt. Exploration of the literature has demonstrated that there has been a lack of empirical work exploring patients' perspective. Little attention has been directed towards gaining adults' experiences of living and growing up with CHD. The aim of the study therefore is to discover strategies, from the

perspective of adults with CHD that enhance their ability to effectively live with CHD, strategies that enhance independence, not to increase dependence or need.

The framework necessary to achieve the aims of this study has emerged from reviewing relevant literature. A theoretical framework has been identified as essential for a doctoral thesis (Holloway and Walker 2000); however Burnard (2004) proposed that nursing might still be searching for an empirically grounded theoretical base and that a less purist approach was sufficient. Nevertheless, it is necessary that the research process undertaken has a coherent structure that is congruent with the aim and research questions being pursued. The research questions guiding this study came from my practice and were informed by the literature reviewed in this chapter.

Rationale for this study

The need for this study emerged initially from my personal and professional experience of adult CHD, which was confirmed through a literature review. The emphasis on mortality and morbidity in the literature accessed at the start of this study reflects the recent increased survival to adulthood of children born with CHD. Until survival was assured, concerns regarding psychosocial aspects appeared less relevant, explaining the predominance of medically focused, quantitative studies. More recently interest has grown in adolescents with CHD, their growth to adulthood, and the ability of existing adult cardiac services to meet the needs of adults with CHD. There was, however, a lack of research seeking the views of adults who are presently living with CHD, indicating the need for this study.

Synopsis of the chapter

Extensive research was available related to mortality and morbidity associated with CHD in adults. Interest in psychosocial aspects has

increased as survival to adulthood has become more assured. Common difficulties have been identified in the literature and by patient associations leading to concerns by health carers regarding problem identification and reduction. The problem focus was not always evident when in contact with adults with CHD; the views of people who have experience of growing up and living with CHD were limited. A research approach gaining the patient's perspective would provide a framework for achieving the aims of this study.

CHAPTER 3

METHODOLOGY

Introduction

The purpose of this study was to explore the lived experience of adults with congenital heart disease (CHD). The background and literature review have demonstrated the change from high mortality to high survival for children born with CHD that has occurred over the last fifty years. Increased survival has occurred as a result of research, using a mainly positivist paradigm, that has informed surgical and other developments. In contrast this study intends to explore the adults' experience of growing up and living with CHD using an interpretive research paradigm. This chapter sets out the case for the phenomenological approach used and the principles of phenomenology are introduced.

Study aim and research questions

Drawing on personal experience, and supported through the literature the early research interest for this study was that of patient perspective and nursing roles. The initial aim was to discover strategies that enhanced the adult's ability to effectively live with CHD. Areas would be explored from the adult's perspective examining their views on information and service provision to identify areas relevant to them. The potential role of nursing in contributing to care for this patient group could then be identified.

The study comprised two main phases. The first phase comprised of interviews with twenty-eight adults with CHD between May 2001 and April 2002. The research questions at this time were:

- What is the experience of living as an adult with CHD?
- What are the characteristics of information and services that are valued by adults with CHD?

- What are the implications of these influences for development of the nursing role in provision of information and services for adults with CHD?

The second phase comprised in-depth interviews with five members of the original group to further explore themes that had emerged from analysis of the first interviews. The research aim had become more focused on the adults' experience of living with CHD. The research questions guiding the second phase were:

- What is the experience of living as an adult with CHD?
- What is being well from the perspective of an adult with CHD?
- How does experience of living as an adult with CHD influence selection and effective use of health and social care information and services that are currently available for adults with CHD?

As identified in the previous chapters, there was limited empirical evidence providing patients' views. Adult CHD was not included in the National Service Framework for Coronary Heart Disease (NSF) (Department of Health 2000b) despite patients being admitted to similar centres if treatment was required for the heart condition. The NSF is significant in determining the delivery, development of services and funding of research. The focus of existing research, related to adult CHD, was generally on physical aspects and problems that may be encountered as a result of residua or sequelae following surgery. There was more recent research exploring psychosocial areas; however again the focus was to identify problems that might occur. While problems were reported, the majority of patients appeared to be physically well and socially adjusted.

In contrast to looking at problems and how they may be prevented, this study explores adults' views of living with CHD and what 'being well' is in their opinion. Through gaining an understanding of how adults with CHD are well, it can be possible to propose ways in which well-being may be enhanced by providing services more able to meet their needs. The focus of conventional health promotion programmes has been the reduction of risk factors (Tones

and Tilford 2001); in contrast the intention of this study is to discover factors that promote an adults' ability to live well with CHD. Through accessing views of people who have experience of living with CHD, and discovering strategies used by them, which enhance their well-being, it may be possible to review health and social services and make recommendations that complement existing resources. Therefore it is proposed that this study design will use a qualitative, interpretive methodology. Putting the person into the nature of the disease can provide an opportunity for people to express their views of the experience of illness and treatment (Rapport et al 2005).

Methodological considerations

Methodology is the philosophical framework, the fundamental assumptions and characteristics that determine the view taken towards the knowledge being sought (van Manen 1990). Traditionally a distinction has been made between 'qualitative' and 'quantitative' research approaches; with the philosophical roots determining which end of a methodological continuum an approach will be situated. As the fundamental aim of this study was to obtain the adults' perspective of living with CHD, a qualitative, interpretive approach was most appropriate. Qualitative, interpretive methodologies however, differ in terms of their philosophical roots (Guba and Lincoln 1989). The basic set of beliefs provides a network of coherent ideas that underpin the study; rigour within a study can be established through demonstrating congruence between these beliefs (Maggs-Rapport 2001).

The interpretive research approach identified as being suitable to meet the aims of this study, was consistent with personal values, and the principles of phenomenology made it possible to gain accounts of individual's experience. The person centred approach provided opportunities for individuals to recount their stories of growing up and living as an adult with CHD. Hearing ways in which people understood and gave meaning to events offered a way to re-examine my existing understanding, which had been gained whilst providing nursing care. Phenomenology, through

gaining the lived experience of the adults' world, would enable me to explore the ordinary, taken for granted understandings that frequently go unnoticed (Madjar and Walton 1999). Consistency can be enhanced through consideration of the ontological and epistemological beliefs guiding this study (Holloway and Todres 2003).

Ontology explores the nature of reality. Reality is the subject of extensive debate within research communities. The context in which adults with CHD generally access, or are referred for health care, remains predominantly medical, where patterns and assumptions of natural science prevail. To answer the research questions for this study however, awareness of factors that contributed to the entire life experience of adults living with CHD was required; this included their social world as well as their hospital experience and the significance individuals gave to events. From an interpretive, human science view, reality considers that a person cannot be understood apart from the world in which they live. This is in contrast to the natural science view that supports the exploration of cause and effect relationships, which is appropriate to inform research that has contributed towards developing, for example, surgical techniques. Interpretive, or qualitative research approaches enable researchers to explore experiences as individuals live and interact within their own social world (Appleton and King 2002). Understanding the meaning that people construct through their experience of growing up and living as adults with CHD is central to this study. Reality for people in this study was individual and influenced by how they had, as individuals, interpreted events related to their CHD. Individually constructed realities may be shared, however this may not make them real, merely more commonly experienced (Guba and Lincoln 1989).

Deciding to adopt an interpretive approach required the epistemology to acknowledge awareness of the world in which adults with CHD existed, in order to understand their individually constructed realities. People, unlike objects, attribute meaning to events (Schwandt 2000). Gaining the

interpretation given to events by individuals could provide the patients' perspective of what it was like to live as an adult with CHD. Events occur within a context; ways in which people behave, values people hold must be understood in context. Actions can make sense when the context is understood. An example of this could be the way a journey is planned (action) using a road map prior to setting out (context), and how changes occur when driving (action) according to levels of traffic and road works (context). The intention for this study was to gain the constructions made by adults regarding the reality of living with CHD. To access knowledge gained through experience, methods used to collect data required interaction with adults with CHD to gain first-hand accounts of their views.

Data collection needed to be designed to enable adults with CHD to describe their world, with interviews being the most frequently encountered method used in interpretive research (Punch 1998; Bryman 2004). In contrast to natural science methodology, interpretive studies employ semi-structured or focused approaches to interviews, which facilitate gaining the interviewee's point of view. The interview process used in this study is further detailed on page 79.

Methodologically, a qualitative, interpretive research approach was suitable to achieve the aims of this study. Exploration of the literature revealed that qualitative research approaches have developed over the recent past making further review necessary to inform my decisions. As interpretive approaches have become more widely used as a method of exploring health and social care aspects, so debate around the tensions and contradictions has also developed. The evolution within qualitative health research was recognised by Thorne et al (1997; 2004), who captured the essence of the discussion regarding the use of phenomenology as a way to explore nursing practice. These authors considered, that to answer clinical questions, qualitative nurse researchers were pushing at the edges of methodological rules. The authors shared their understanding of how interpretive

approaches may be used in a consistent way that demonstrates a rigorous, coherent research process.

The method of 'interpretive description' was proposed as a research approach suitable for clinical nursing contexts that '*involves description of, and interpretation about a shared health or illness phenomenon from the perspective of those who live it*' (Thorne et al 1997:171). Previous criticisms of 'method slurring' were recognised and avoidance of an inconsistent approach proposed through use of a coherent epistemology that adhered to the key tenets of naturalistic inquiry as defined by Lincoln and Guba (1985). While this approach had resonance with what I was trying to achieve, Thorne et al (1997) provided minimal discussion to demonstrate the philosophy that informed this novel approach.

In order to achieve a congruent research approach, it has previously been considered necessary to debate philosophical ideas, with nurse researchers being criticised for not accurately interpreting these ideas (Koch 1995, 1996; Paley 1997, 1998; Darbyshire et al 1999). The debate between English (1993), Darbyshire (1994) and Paley (1996) regarding the accuracy of how Heidegger's philosophy was interpreted in the landmark nursing text *From Novice to Expert* (Benner 1984) is one example. I was aware of the need to explore the philosophical ideas to ensure a coherent study design. The design for this study has been informed through an exploration of the philosophical ideas relevant to phenomenology.

Phenomenology

Phenomenology has emerged from a philosophical movement that continues to evolve and, as a research approach, has a range of interpretations. Patton (1990) considered the meaning of the term 'phenomenology' to have become confused; being used to refer to a paradigm, a philosophy, or being synonymous with qualitative methods. In an endeavour to provide clarity regarding its use in health and social care, Todres and Wheeler (2001)

emphasised the relationship between phenomenology, existentialism and hermeneutics. Recognising the meaning (which comes from understanding and experience) given by individuals to events and feelings, can contribute to a comprehension of what life is like for them as a person. The aim of phenomenology is to discover the essence of the 'lived-experience' from the individual, with the interpretive, hermeneutic approach associated with Heidegger enabling links to be made between what is familiar to a person and what is unfamiliar (Struebert and Carpenter 1999).

The difficulty for researchers to discover ordinary, unnoticeable aspects, without imposing their own views has been recognised; and while not exclusive, the views of two philosophers dominate the debate regarding how this may be achieved. The philosophical ideas of Husserl and Heidegger have been contrasted resulting in two approaches to phenomenology that appear to be distinct; a descriptive approach associated with Husserl, and an interpretive approach associated with Heidegger. Husserl proposed researchers 'bracket' or suspend existing beliefs regarding the area of study in order to avoid biases resulting from current judgements. In contrast, Heidegger considered a person's history contributed to the way in which the area of study was understood, with both the researchers and participants contributing to the findings. As personal experience of working alongside people with CHD, was one of the reasons for embarking on this study, Heidegger's approach appeared to acknowledge my own experiences and feelings. Nevertheless it was essential that I remain open to hearing the unexpected, so not being bound by my existing assumptions, making the approach associated with Husserl also appear appropriate.

As the interpretive approach appeared to be relevant to my study an English translation of Heidegger's seminal text *'Being and Time'* was accessed (Guignon 1993). The original texts of Heidegger are the topic of much discussion with his ideas being difficult to capture in translations of his original German writings. I found it challenging to appreciate the ideas

being discussed and was left wondering how they related to living as an adult with CHD, which was the focus of my study.

The value of an experienced guide to offer a 'bridge between philosophy and method' was acknowledged by Dahlberg et al (2001:10), who drew together the views of Husserl and Heidegger, as well as Merleau-Ponty and Gadamer to provide an account of how their apparently contradictory philosophical ideas were inter-related. The aim of phenomenology is to focus on the essence of something within its associated context and history, making it possible to discover the unique meaning to each person. By recognising personal existing assumptions, and through exploring the meaning given to something, such as CHD, by people who have experience of it, an interpretation can be made that contributes to understanding how living with CHD is experienced. To remain congruent with this philosophy consideration of certain areas was suggested.

Key areas identified for consideration in order to reconcile the philosophical views included: openness in relation to pre-understanding; the relationship between researcher and informants; discovering deep meaning; and the uniqueness of individuals as well as commonalities between people (Dahlberg et al 2001). For this study, therefore, it was necessary for me to increase awareness of my existing common-sense understanding. A reflective stance was required in order to recognise and question my current understanding, and to be open to learning from people whose experience of CHD was situated within a context and history that was different to my own. The traditional hospital nurse/patient relationship was inappropriate; a more equal relationship, with people who had experience of living as an adult with CHD was necessary. A method of gathering data was required that promoted the giving of life stories to be received by an open, interested, active listener. Life stories illustrate embodied knowledge, which was the phrase used by Dahlberg et al (2001) to describe all of a person's understanding and how this influences the way an individual relates to their world. While appreciating the importance of debating philosophical,

metaphysical issues, an approach was required that allowed me to focus on aspects relevant to my nursing and teaching practice.

Phenomenology was considered by van Manen (2002) to be a human science method as well as an influential and complex philosophic tradition. He used the term 'human science' to describe a research approach in which practice comes first, with theory emerging from a profound reflective inquiry into human meaning (van Manen 1990). In contrast to the philosophy of phenomenological method, he used his experience as a teacher to explain a phenomenology of practice, which resonated with my experience as a nurse and teacher. van Manen (2002) reflected my values when stating he believed professional practitioners tended to be more interested in the application of phenomenology to their practice than in its philosophical roots.

My attention was captured by three features of phenomenology of practice, as outlined by van Manen (2002). First was the focus on common everyday life experiences rather than 'weighty' epistemological, ontological or metaphysical issues. Second the impact of past experience on how events are interpreted is acknowledged, reflecting Heidegger's view of hermeneutics. Finally reflection being on concrete experiences in contrast to abstract theories, with skills of reflective scholarship and writing of insightful texts being required.

For van Manen (1990:62) phenomenological research enables the researcher

...to 'borrow' other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience ...

His approach to phenomenology provided a way for me to discover what it was like to live as an adult with CHD through gathering stories from people who have this experience. The focus of van Manen's explanations of human science research as applied to phenomenology of practice, is on educating children; nevertheless similarities with health and social care were

evident to me. One example was the need for security and trust, leading to the confidence to take risks that are important for growth. Growth in this study could be defined in two ways; the growth I was attempting to explore in adults with CHD, and the growth in myself as a researcher. To guide the research process a structure of human science research is provided by van Manen (1990:30):

- Turning to a phenomenon which seriously interests us and commits us to the world;
- Investigating experience as we live it rather than as we conceptualise it;
- Reflecting on the essential themes which characterize the phenomenon;
- Describing the phenomenon through the art of writing and rewriting;
- Maintaining a strong and oriented pedagogical relation to the phenomenon;
- Balancing the research context by considering parts and whole.

The structure of human science research identified by van Manen (1990) provided a logical, comprehensive approach. However the essential research components of sample selection, data collection and analysis, ethical aspects and rigour were not always explicit. Therefore the way I have used the six stages provided by van Manen (1990) as a framework to guide this study is provided in table 3.1. The stages are expanded in the following sections which provide details of the methods used in this study.

Methodical structure of human science research	How used to guide this study	Where situated within this thesis
Turning to a phenomenon which seriously interests us and commits us to the world	The commitment I felt from my nursing and teaching experience, that led me to this study	The introduction, background and literature review (Chapters 1 and 2)
Investigating experience as we live it rather than as we conceptualise it	Method of sample selection Consideration of ethical aspects Method of data collection	Current chapter
Reflecting on the essential themes which characterize the phenomenon	Process of data analysis	The presentation and discussion of findings (Chapters 4 and 5)
Describing the phenomenon through the art of writing and rewriting	The iterative, reflexive approach to data analysis and writing the research report Overall rigour of the research process	The presentation of findings (Chapter 4) and throughout thesis
Maintaining a strong and oriented pedagogical relation to the phenomenon	The discussion of findings	The discussion of findings (Chapter 5) in relation to literature reviewed prior to data collection, as well as that which has become available more recently
Balancing the research context by considering parts and whole	Consideration of the findings in relation to the context within which the study is situated	The relevance of the findings to current nursing and teaching practice

Table 3.1: Methodical structure of human science research as applied to this study (van Manen 1990).

THE STUDY DESIGN

The remainder of this chapter is structured using stages identified by van Manen (1990) within which, details are given of the methods used in this study. While the structure may be considered unconventional, it does however provide a logical framework, with all essential components of a study being included.

Turning to a phenomenon which seriously interests us and commits us to the world

The aim of phenomenology is to articulate the essence of lived-experience. That requires, for this study, making visible the taken for granted, common-sense understanding of living as an adult with CHD, as perceived by people who have experience of this. Phenomenological research is a deep questioning of a phenomenon situated within the social, historical context of an individual, and while recognising that a number of interpretations are possible, the questioning provides one interpretation of that phenomenon; the interpretation given in this thesis is my own. The phenomenon being explored in this study is that of living as an adult with CHD with the social and historical context in which their life is lived being significant. The meaning given by individuals to past and present social aspects, as well as past surgery, with more recent developments relating to their heart condition being relevant.

Investigating experience as we live it rather than as we conceptualise it

While my personal experience was the starting point that resulted in a commitment to the phenomenon of interest, methods of data collection were required that gathered descriptions of the phenomenon from people who have experience. The descriptions are the material which is 're-viewed' in a way that increases awareness of presuppositions made from the lived-experience. Advice given by van Manen (1990) on sample selection and data collection is outlined here as applied to this study. Prior to approaching people to request

their involvement however, it was necessary to submit a research proposal for Local Research Ethics Committee (LREC) review.

A review of the study by the Clinical Directorate Research and Development Committee of the centre through which patients were contacted took place, as well as the LREC review, and approval given (Appendix 8). Due to the flexible, developmental nature of the study, LREC approval was requested for the initial patient interviews stating that ongoing agreement would be sought for subsequent phases. The nature of qualitative research facilitated a responsive approach to findings, making changes possible. Multi-centre Research Ethics Committee (MREC) approval was sought following initial interviews. MREC approval was gained providing the option to obtain the views of health and social carers (Appendix 8). On commencing this study I had considered comparison between the views of service providers and service users could be beneficial; however, as the study progressed it became evident that exploring the views of patients in greater depth was preferable.

Ethical committee review took place; the forms however remained predominantly focused on physical interventions. It was imperative, as a nurse bound by a professional code of conduct (Nursing and Midwifery Council 2002) and a person who respects others, to consider the wider ethical implications of what I was doing.

Ethical aspects

As stated above ethical committee review took place prior to commencing this study; however the process of human science research requires application of ethical principles and ethical decisions to be made as the study evolves.

However, ethical aspects related to the process of completing research do not always fit easily into the traditional principles of autonomy, nonmaleficence, beneficence and justice as identified by Beauchamp and Childress (2001).

While I was not intending to cause harm, several components of the study required thinking through; these can be explored within Bryman's (2004)

headings of potential harm to participants, deception, informed consent and invasion of privacy. The four areas are not discrete and as such are complex to write about in a linear way.

Potential harm to participants (informants)

In this thesis the term 'informants', rather than 'participants', has been selected as being the most suitable to use when referring to the people who agreed to take part in interviews. Difficulties with terms was identified in Chapter 1 page 18, these areas are discussed together in Chapter 7.

The study set out to explore adults' experience of living with CHD; it is unlikely to directly benefit individual informants, although results of the study have potential to inform developments for the future. One unforeseen benefit expressed by some informants, was that of having an opportunity to talk about their heart condition in a way not done previously.

The possibility of causing harm existed through raising issues during interviews that might not have previously been considered by informants. A number of strategies were employed in the event of this occurring: through contacting informants General Practitioner (GP), or the relevant cardiologist, and provision of patient association information leaflet and contact details. One informant requested specific health care information during an initial interview, which I was unable to provide; it was possible to refer him to the cardiologist who could provide the necessary information. Despite patient association information being available at the outpatient clinic, only a few informants were aware of the group. One benefit was raising informants' awareness of the patient association, which was subsequently accessed by three people who took part in second interviews.

Harm may occur to groups of people as well as to individuals. The principle of justice (being fair) is based on Aristotle's concept of how individuals are treated relates to their position and worth within a given society (Beauchamp and Childress 2001). Justice informs decisions made regarding distribution of

scarce resources, such as costs involved in carrying out a research study. Justice may be compromised if minority groups are under represented in studies. Adults with CHD are a small subgroup of a larger group of patients who access cardiac services. The principle of justice supports the importance of this study as this patient group is under represented in current reports related to the delivery of cardiac services (Department of Health 2000b; Kennedy 2001). However justice may be compromised through excluding people who have syndromes that are associated with CHD. People with syndromes are a subgroup within the population of adult CHD who may have complex needs, such as cognitive impairment, and are challenging to include within studies.

The information sheet (Appendix 9) informed patients that their experiences would be requested; they may not be ready or willing to discuss their feelings and thoughts with the researcher. Sensitivity was required when exploring experiences of adults with CHD; they did not fully appreciate the research role of nurses and requested clarification of my role, often towards the end of the interview, indicating the potential for deception.

Potential for deception

Deception is the term provided by Bryman (2004) it does, however, imply a deliberate intention to mislead. While I did not intend to deceive or cause harm, nevertheless the possibility to mislead unintentionally has to be considered. I had chosen to wear my usual work clothes of smart trousers and blouse when attending the outpatient clinic, and introduced myself as a researcher who was also a nurse. The information sheet explained my role as a teacher based in a school of nursing, however informants expressed curiosity about me either during the introductory chatting as we met to undertake the interview, or during the interview closure. I was not permitted by informants to take on a novice researcher role, and was frequently addressed in ways that indicated I was viewed as an experienced nurse. As stated above informants have ongoing needs and had expectations of me as a nurse that I was unable to meet.

The role of '*comparative detachment: objectivity and sympathy*' in a continuum from complete participant to complete observer is defined by Junker in Hammersley and Atkinson (1995:104), and seemed the most appropriate to present when in contact with informants involved with this study. However a more reciprocal relationship evolved during interviews, and I was privileged to be told informants stories in an open and willing manner. The more equal relationship was confirmed when contacting people for second interviews.

Informants contacted for second interviews were selected in part due to their having stated their wellness during the first interview; this was confirmed to informants when telephoning to request their participation in the subsequent interview. Informants expressed interest in my study and pleasure at being involved; during these interviews I felt informants viewed me as a researcher who happened to be a nurse. I no longer required a continuum to identify an appropriate relationship; I was more able to act naturally. My honesty resulted in informants demonstrating interest in the study and concern for me as a research student; in return I was told about things that helped them and things that got in the way of their being able to get on with life. The willingness with which I was told their stories required consideration of aspects of consent.

Informed consent

Consent must be given voluntarily and therefore it was essential that details of my study were provided allowing sufficient time for people to make a decision regarding whether or not to participate. Details were comprehensive and written in a way that could be easily understood. Due to the tentative, exploratory nature of phenomenological research, it may be impossible to provide sufficient information. This was the case in this study, therefore gaining ongoing consent at each phase provided informants with a real opportunity to withdraw if desired.

Initial contact was made in one of two ways, either by letter or at an outpatient clinic. People who did not reply to the letter requesting their participation were

deemed to not be consenting; lack of personal contact may have influenced decisions to participate. At the outpatient clinic an information sheet was provided; patients gave initial consent and provided a telephone contact number. Subsequent contact was by telephone when arrangements were made to carry out the interview, providing an opportunity for patients to withdraw if wished; three people did (see table 3.2 on page 78).

Initially being given contact telephone numbers or invited into informants' homes implied consent; more formally, written consent forms were used and agreement to make subsequent contact was obtained verbally and audiotaped. As data collection progressed, I adapted the time when written consent was requested. During early interviews consent was requested before the audiotape recorder was turned on, however during the explanations that formed part of the consent process, informants began to tell me about aspects that were interesting and relevant to my study. I always requested permission to turn the audiotape recorder on. In later interviews, I accompanied this with a commitment that if informants did not agree at the end of the interview, through signing the consent form, the audiotape would be left with them. This never occurred.

Invasion of privacy

Privacy in human science research usually relates to anonymity and confidentiality of informants. Qualitative researchers usually work with small samples, making it difficult to protect the identity of sample members. However protection of all confidential information is necessary in accordance with the Research Governance Framework for Health and Social Care (Department of Health 2001a) and the Code of Professional Conduct (Nursing and Midwifery Council 2002). Adults with CHD are a small subgroup of cardiac patients and therefore may be easily identified. Anonymity in this study has been achieved through providing a code to identify the informant when reporting interview content; only I was aware of the real identity of informants. Names used during interviews were omitted from transcriptions. While I believe other people cannot identify informants, it may however, be possible for people who took part in interviews to identify

themselves from information given in this thesis. Details of informants have been included to provide readers with a sense of the lives of the people who contributed. Information given in this thesis has been prepared in an attempt to provide a sense of individuals' well being, as well as giving an overall impression of the reality of life for the patient population, while maintaining anonymity to other people who read this account.

All data were stored on two password-protected computers; tapes and transcriptions were stored in a secure location and will be destroyed on completion of the study. Changes in data protection regulations have occurred since commencing this study, and are discussed later on page 73. In 1999, when initial ethical committee review was undertaken, it was considered good practice for tapes and transcriptions to be destroyed; this was viewed as contributing to the promise of confidentiality. However more recent guidelines, applicable to student research projects, recommend that data be archived for a period of time following completion of a study (Department of Health 2001a). Archiving tapes and transcriptions could provide an opportunity for others to confirm the interpretation given by the researcher. The information sheet provided to informants at each interview (Appendix 9) clearly states that tapes and transcriptions will be destroyed on completion of this study.

The decision to destroy tapes and transcripts has not been reached without deep thought. Completion of a study is not a discrete event, therefore for this study will be three months following publication of interview data. This acknowledges recent changes in research governance as well as honouring the agreement made with informants.

Using Table 3.1 on page 63 as a guide to ensure the essential components of a study have been included within this thesis, an account will now be given of how people were approached to take part in this study.

Sample

Phenomenology aims to discover the lived-experience of a person; it was therefore necessary to select people who have experience of living as an adult with CHD. People gain knowledge through experiencing phenomenon; van Manen (2000) refers to this as noncognitive knowing, and is difficult to articulate, being demonstrated through actions, how we sense things, how we are in the world and with other people. A purposive sampling strategy focuses on selecting people with noncognitive knowing, or who are information-rich. A person who is information-rich is someone who has experience, and is able to provide details about the topic (Patton 1990). Information-rich people who illustrate the phenomenon for this study were people over 20 years of age, who had undergone surgery for CHD. One reason for undertaking this study had been observing that people's ability to live well did not appear to be related to the complexity of their heart condition; therefore a sample was identified that included adults with CHD from across the clinical spectrum (see Appendix 2).

The term 'adults with CHD' is a general term used to refer to people who are over 16 years of age who have a malformation of the heart or major vessels that occurred during foetal development; the malformations range from simple to complex (Alderman 2000). In this study the population was defined through reference to records based on surgical procedure required as a result of the anatomical malformation. Effort was made to include people across the degrees of complexity of CHD as defined by the American College of Cardiology (ACC) (2001) (Appendix 2), that is a purposeful approach was used to direct sampling in the initial phase. Using hospital records patients, from across defects/procedures were selected to cover the clinical spectrum of CHD.

Negotiating access and informant selection

Contact was made with medical and surgical consultants who agreed access to cardiac surgery records used for audit purposes. Presentations were made to clinical directorate meetings attended by medical and senior nursing staff.

Submission was made to the Clinical Directorate Research and Development Committee as well as the LREC; agreement was given by both committees to proceed (Appendix 8). A pragmatic decision was made to use a local tertiary cardiac centre to identify potential informants. Initial access was achieved through existing networks developed through my experience of working in different roles with multidisciplinary health carers involved with children and adults with CHD. Hammersley and Atkinson (1995) consider personal networks to be a legitimate source in gaining access. This is described as a convenient approach to sample selection (Patton 1990). Cardiac services are delivered in similar settings across the UK and it was anticipated that the centre used for the study would have a similar patient profile as other provincial UK tertiary centres. The similarity of the patient profile was observed during a study tour undertaken early in the study when three Canadian and four UK cardiac centres were visited. Some differences, however, were apparent. London centres tended to have more patients with complex CHD, possibly due to the international reputation of hospitals such as Great Ormond Street, and the early establishment of adult CHD services (GUCH News 2001). Differences in provincial centres were cultural rather than diagnostic, reflecting the composition of the local population of hospital catchment areas.

Potential informants were identified from hospital records. These were in two sections, the first being cardiac surgery audit records; the second being patient information records. Cardiac surgery audit records between January 1972 and September 1999 were searched with approximately seven hundred people over 20 years of age identified as potentially eligible for this study. Adulthood is frequently considered to start at 16 years of age; however in the UK this age is viewed as a period of adolescence and transition from childhood to adulthood (Eiser 1990). This study has chosen to focus on adults who are 20 years of age or over because they are more likely to have experience of areas identified as potentially problematic by patients associations and literature, for example employment, and trying to obtain life or health insurance. It was likely they would also have experienced

some of the usual events associated with adulthood such as relationships, leaving home or moving away from their family

From cardiac surgery audit records one hundred potential informants were selected, and patient information records accessed to obtain their address, GP name and address. Changes in data protection regulations would not make this approach possible now. However, this was the usual way of accessing informants in studies reviewed prior to commencing this study and was considered appropriate at the start of this study.

There were several difficulties in accessing up to date records. The patient information system was a dynamic electronic database that was in constant use. It was intended to be regularly updated to provide information, for hospital and community health carers, on all patients who had contact with the hospital. Hospital records take time to be updated and therefore were not always current. Details of patients who had not been seen at the tertiary centre for a period of time were not available; reasons included no follow up being considered necessary, care having been transferred to another centre, or patients electing not to attend. Patient information was not always complete due to information not being provided by patients at time of contact with the hospital, for example not being registered with a GP.

Since commencing the study, the ethical requirement of contact with GP is no longer needed. However preliminary contact with the GP ensured that letters were not sent to people inappropriately, for example those who had died since their last contact with the hospital. GPs were the health carers most likely to be aware if patients were having current health problems that might make a request for their participation unwelcome. A summary outlining informant selection, response and participation is given in table 3.2 on page 78.

It is not unusual in a qualitative study for processes to evolve as the study progresses and was the case as I prepared to commence data collection. At

the outset twenty-seven patients were identified from cardiac surgery audit records as potential informants, and letters sent to GPs; seventeen GPs agreed to patients being contacted to participate in the study. The ten GPs who did not agree said the patient was: no longer registered with them (five), having family problems (one), having rejection problems following heart transplantation (one). The remaining three GPs returned the letter unanswered, gave no reason or, in one instance responded but considered it to be 'a waste of time'.

Letters requesting participation in the study were sent to seventeen patients; thirteen did not respond. Four responses were received; one person did not agree to participate in the study. The remaining three people were contacted and interviews completed. The high number of people not responding may be explained in part due to an incorrect address on the patient information system. Addresses were subsequently checked prior to sending letters using the Internet site www.192.com. The implications of incorrect patient address may be significant in patients receiving hospital appointments and other information and may contribute to the large number of adults with CHD reportedly lost to specialist follow-up (Gatzoulis 2005).

Following the first three interviews the process of sample selection was reviewed to increase the number of potential informants. The opportunity was also taken to review the interview guide in response to early findings. To increase the number of potential informants, cardiac surgery audit records continued to be used, while also visiting an adult congenital cardiac outpatient clinic. Agreement to attend the clinic was gained from medical and nursing staff within the local tertiary cardiac centre. The clinic had been established for approximately one year, where patients over 16 years of age were seen. Previously adults with CHD were seen in paediatric cardiology clinics. The adult congenital cardiac clinic was scheduled weekly with between fifteen and eighteen patients booked to attend each clinic. At that time there was no adult cardiologist who specialised in providing care for adults with congenital heart disease within the tertiary

centre. There was a paediatric cardiologist with experience in caring for this patient group in attendance who usually saw the majority of patients. Fourteen of a possible eighteen outpatient adult congenital cardiac clinics were attended between August and December 2001.

Before the clinic commenced, all patients over 20 years of age were identified and their notes scrutinised to identify people appropriate to approach requesting their participation in this study. Not all people over the age of 20 years were approached to take part in this study. Groups not included were people who had not had surgery, people with cognitive impairment, and those receiving care from adult cardiologists. CHD is frequently associated with chromosomal and genetic syndromes that can affect cognitive development. Gaining ethical committee agreement to undertake studies involving people with learning difficulties requires special arrangements to be made (COREC 2003), and was a factor in excluding them.

Aspects of the 1998 Data Protection Act have been implemented over time, and have been included within the Research Governance Framework for Health and Social Care (Department of Health 2001a) and research codes of practice developed by universities (Bournemouth University 2000). Changes have occurred regarding activities that were considered to be best practice when this study was commenced. The nature of phenomenological research makes it possible to respond to developments; however in the interests of rigour it is essential that developments are made explicit. Two aspects of this study were affected. The first was archiving tapes/transcripts for a period of time following completion of the study and has been discussed above; the second was the way in which patient records were used to inform access to informants.

Agreement to access patient records had been sought as part of the ethical committee review; following changes in data protection it is unlikely this approach would now be supported. I accessed patient notes without looking

at details irrelevant to this study, for example, whether or not I had been involved in any previous hospital care. Due to the relatively young age at surgery, and my current role as a teacher, I had anticipated informants would not remember if I had previously provided nursing care, thus avoiding the potential that any feeling of obligation could influence what I was told during the interview. However it was possible that parents might remember me; during ten interviews I met parents, none of whom appeared to recognise me.

I was aware of the privilege of having access to patient notes; they were used only to inform sample selection, providing a safeguard to ensure only people who met the inclusion criteria were approached. I was aware it was possible to cause anxiety, and therefore wanted to avoid approaching people inappropriately. Twenty-six people were identified from the adult congenital cardiac clinic, and seven from the cardiac surgery audit records, making a total of thirty-three potential informants.

An information sheet was provided on initial contact at outpatient clinics. This included details of the study, what would be expected from them as well as my contact details (Appendix 9). Written consent was obtained to make contact within three months to arrange to carry out the interview (Appendix 10). Patients can be anxious during outpatient attendance and may feel coerced into agreeing to the interview; it was important to regain consent when they were away from the hospital setting.

Seven people accessed from the cardiac surgery audit records were contacted as outlined above. This approach was also used to request participation from five potential informants who did not attend their clinic appointment.

Informants were contacted to arrange a mutually convenient time to carry out interviews. This provided opportunity to gain ongoing agreement for interviews. Eight people either could not be contacted on the telephone

number provided or were unable to provide time for the interview. A total of twenty-eight initial interviews were carried out with nineteen men and nine women, aged between 20 and 52 years of age, who provided their story of growing up and living as an adult with CHD (Table 3.2).

The purpose of this study was to discover from the adults' perspective how they lived well with CHD. A theoretical sampling approach was used to select informants to participate in second interviews. Initial interview transcripts revealed some informants talked of specific events that had significance to them. These events could be considered a turning point, thus providing an opportunity for further exploration. Turning points were defined as 'significant life events, experiences, or realizations' by King et al (2003:185). People who talked of events that could be considered turning points were contacted and requested to take part in second interviews. The five people who took part considered themselves to be well and had identified an event that was significant to them being well. They appeared to be resilient, having adapted well to life with their heart condition.

Written consent (Appendix 10) was gained at each interview thus obtaining consent from informants for continued contact at each meeting. The first three interviews were undertaken between March and July 2001, the remaining twenty-five initial interviews between January and April 2002, and the five second interviews between July and December 2004.

Interviews completed between March/July 2001	Surgical data base	100 potential informants identified 27 had GP address and postal address	<p>27 letters sent to GP 10 did not agree for patient to be contacted 5 – patient no longer registered with them 3 – no reason given 1 – family problems 1 – rejection problems following heart transplant 17 agreed for patient to be contacted</p> <p>17 letters sent to patients 13 – did not reply 1 – did not agree to take part in the study 3 – agreed to take part in the study</p> <p style="text-align: right;">3 potential informants 3 interviews completed</p>
Interviews completed between January/April 2002	Surgical data base	85 potential informants identified 16 had GP address and correct postal address as identified on 192.com	<p>16 letters sent to GP 6 did not agree for patient to be contacted 2 – patient no longer registered 1 – patient polysymptomatic with poor health throughout family members 1 – patient has Down syndrome 2 – did not reply 10 agreed for patient to be contacted;</p> <p>10 letters sent to patients 3 – did not reply 7 – agreed to take part in the study</p> <p style="text-align: right;">7 potential informants 6 interviews completed</p>
Interviews completed between January/April 2002	Adult congenital cardiac out-patient clinic	14 clinics were attended between August-December 2001	<p>15-18 patients per clinic – 235 patients 145 were over age 20 years excluded patients who had not undergone surgery had another syndrome under care of adult cardiologist</p> <p style="text-align: right;">26 potential informants 19 interviews completed</p> <p>5 potential informants did not arrive for out-patient clinic appointment 5 letters to GP 3 did not agree for patient to be contacted 2 – patient no longer registered 1 – no reason given 2 agreed for patient to be contacted 2 letters sent to patients 0 responses</p> <p style="text-align: right;">0 potential informants 0 interviews completed</p>
	<p>8 people were not interviewed: 3 – contacted, too busy to meet 2 – phone number provided at clinic was not recognised 2 – unable to contact, messages left but calls not returned 1 – admitted from the clinic</p>		
A total of 28 initial interviews were completed			

Table 3.2: Informant selection, response and participation

Again using Table 3.1 on page 63 as a guide to ensure the essential components of a study have been included within this thesis, the following section provides an account of data collection for this study.

Data collection

Interviews are the most frequently encountered method used to collect data in a phenomenological study (Punch 1998), providing an opportunity for people to talk about their experiences and understandings of the topic being explored. Data collection should be designed to enable informants to describe their world to the researcher. To gain an individual's account it is usual for semi-structured or focused interviews to be prepared using open questions. Burgess (1984:102) described qualitative interviews as '*a conversation with a purpose*' and to form the basis of health assessment (Holloway and Wheeler 2002).

A strong orientation to the purpose of the interview is recommended by van Manen (1990:67) to avoid it going '*everywhere and nowhere*'. Therefore a semi-structured interview approach was selected. While I was confident as a nurse interviewing patients, I felt less confident as a researcher interviewing informants. Use of an interview guide could help maintain focus on reasons for the interview, as well as providing flexibility for conversation around areas identified by informants. Interviews generate data usually in the form of a transcript, which can be analysed using inductive approaches; that is findings emerge from the data.

Initial interviews were undertaken using a semi-structured approach; a guide was prepared to ensure areas necessary to address the research questions were included. One advantage of an interview guide is that good use can be made of the limited time that is available during an interview (Patton 1990). The guide was a list of questions and issues to be explored (Appendix 11); and, as recommended by Spradley (1979), contained an opening grand tour question asking for a description of how people were 'heartwise'. This question

encouraged informants to respond using their own words and recounting their experiences.

Interviews

During interviews, which lasted between fifty and ninety minutes, informants provided their personal story of living with their heart condition, when they had realised about their heart, how they saw their future, and people who had made an impact on them. Informants provided subjective interpretations, through which it was possible to learn from their personal experiences what life was like for them regarding their heart condition. The opportunity existed to request expansion on unexpected areas within conversations; one unexpected area was being told by informants that no further information regarding their heart condition was perceived to be necessary. However on probing, areas where more information might be useful were identified. An attempt was made to obtain the meaning given, by the informant, to the themes being discussed; rich detail was provided through conversations rather than using question and answer approach (Burgess 1984).

The initial interviews established that informants generally perceived themselves to be well. Satisfaction was expressed with current services; it was, however, apparent that predominantly physical aspects were addressed. Other significant health and psychosocial aspects might be addressed, but this happened in a more ad hoc manner. The purpose of the second interview was to discover greater detail of how informants obtained and utilised information about what one informant had called 'the little things'. Gaining greater understanding of the strategies developed by adults with CHD, through their experiential wisdom, had the potential to inform the development of effective and meaningful services for this group.

The role of the researcher in data collection

I approached the study with the interests of a nurse and teacher, which were likely to influence the significance given to aspects regarding the phenomenon being explored. This section offers an account of my role as the researcher in

this study, which grew from my nursing and teaching experience and led to the deep questioning, identified by van Manen (1990) that is part of phenomenological research. This thesis provides my interpretation of that deep questioning; this section begins to make explicit my role within the research process.

In qualitative research the researcher is seen as having an influence on the data due to the interactive nature of semi-structured interviews. One way that is suggested to make that influence explicit to readers of a research report is to maintain a reflective record as part of the research process (Silverman 2000). A further reason for maintaining reflective records is the nature of the interpretive phenomenological approach selected for this study; methods are not prescribed at the outset, but evolve as the study progresses. This makes it possible for the researcher to be responsive to events as they occur within the study, however it is necessary to demonstrate the thinking that has informed decisions made throughout. Reflective records are considered to be a source of data by Jasper (2005), which can make the thoughts and feelings of the researcher visible, with the act of writing contributing to the researcher's ability to articulate the essence of the phenomenon being explored (van Manen 1990). Throughout this study I have kept records in various forms including a research diary, field notes, reading records, early analysis diagrams, conference presentations and supervision records.

Maintaining a research journal was a way of highlighting presuppositions, and to recognise the potential influence of these on my interpretations of the data. The field notes were a record of informant details, with a summary of my thoughts and feelings as I contacted people to arrange meetings, and my impressions of the person, overall content and process of the face-to-face contact made as soon as possible following each interview. Throughout the study I have provided teaching sessions and conference presentations to a range of health carers (Appendix 12). These were informed by the early analysis diagrams (Appendix 13) and provided an opportunity for my views to be questioned by other people whose practice focus was on adult CHD,

adults with acquired heart disease, public health, midwifery, palliative care or child health.

For the research records to have value as data, as described by Jasper (2005), it is necessary for the researcher to interact with them in an interpretive, analytical way. The records are reviewed in Chapter 7 in which an account is given of some of my experiences and personal learning that has occurred through undertaking this study.

Reflecting on the essential themes which characterize the phenomenon

Continuing to use Table 3.1 on page 63 as a guide to ensure the essential components of my study have been included within the thesis, the focus of this section is on the reality of the data analysis process. The phenomenological interviews generated a large amount of data in informants' own words that was rich in experiential detail. The data were however, relatively unstructured making it necessary to have a framework to guide the process of reflecting on essential themes. An inductive approach was used which allows meaning given to words used by informants to determine how chunks of data are labelled and grouped. Coding is central to phenomenological data analysis, and is an iterative, rather than a linear process as it appears in the guides (Colaizzi 1978; Hycner 1985). Codes are described as '... labels for assigning units of meaning to the descriptive or inferential information compiled during a study' (Miles and Huberman 1994:56). Analysis begins through delineating units of general meaning, then clustering related units and finally determining themes from the clusters.

Hermeneutic phenomenological reflection is the phrase used by van Manen (1990) to describe the process of data analysis. Extensive discussion of phenomenological reflection and what constitutes a theme is provided, however, there is less detail given on how to carry out the process. The procedure outlined by Colaizzi (1978) was frequently used in

phenomenological studies, with Hycner (1985) spelling out the process in more detail. Early in this study, I had been introduced to the phenomenological analysis process outlined by Hycner (1985), and had found the step-by-step approach helpful. Hycner used stages similar to those set out by both Colaizzi (1978) and van Manen (1990), while expanding them to provide a guide to the iterative and difficult to articulate process that constitutes interpretive analysis. Hycner (1985) detailed fifteen stages (Appendix 14), making explicit a process of analysis suitable for this study. How these were used to guide generating descriptive themes, my interpretation of the data, and identifying patterns within the data will now be outlined.

Generating descriptive themes

Interviews were audiotaped, transcribed and analysis commenced. Analysis commenced during the data collection process. A brief summary of each interview was made as soon after completion as possible; the overall impression of what the informant had said as well as thoughts and feelings regarding the process were made. Field notes maintained following each interview informed this summary.

The audiotapes were transcribed; tapes were then listened to and transcripts read simultaneously. Notes were added to the initial brief summary providing a sense of the entire interview, and transcripts were printed. The next step was highlighting phrases as advised by van Manen (1990) in an effort to ensure nothing significant was overlooked. The initial highlighting and delineating units of general meaning generated descriptive themes that use informants' own words or phrases to label that particular section of the interview. Transcripts were read and using highlighter pens, key areas indicated; this involved reading transcripts several times. General areas were grouped together these were the descriptive themes; one example of coding is provided in Appendix 15. Unique areas were identified, and transcripts reread to check nothing had been omitted.

Within this study, the data were transcripts that had been produced from the audiotapes of interviews. Interviews had been scheduled to enable transcription to be completed the following day; whilst this process was intensive, it was possible to recall the meeting and inferences that were unclear on the audiotape. Transcripts were read to gain a sense of the whole; key areas were identified by highlighting a term or phrase that indicated the content. Descriptive themes were informants' own words, an example is provided in Appendix 15. The process was carried out using a paper copy of transcripts that had been printed to allow wide margins in which notes could be made. All terms and phrases that might be relevant to research questions were underlined; terms that indicated content were **highlighted**. This process provided descriptive themes that were informants' own words. Second interviews were scheduled to allow descriptive coding to be carried out prior to the subsequent interview. In keeping with the phenomenological approach used to guide this study, timing of interviews facilitated ongoing exploration of common areas as well as aspects significant to individual participants to be raised.

As the interviews continued, notes were made with reference to common areas; this began formulation of interpretive themes. Common areas were identified within an interview, as well as across interviews, which were amalgamated. One example is the interpretive theme of 'other people' being used to include the response of others when it was necessary for adults to disclose detail of their heart condition. Responses could be either negative '*... people don't believe you ... they think there must be something wrong ...*' (3:415); '*... you have to say well I have had a heart operation and then they are like uhhhh shock horror had a heart operation*' (5:297); or positive: '*... if you've had a heart operation you are well ahead of everybody else ...*' (5:128). Basic principles were followed to ensure interpretive coding reflected the data, such as including all data that might be relevant to the research questions, and that all labels reflected the essence of the informant's meaning and continued to use terms contained within the interview as much as possible.

My interpretation of the data

Each descriptive theme was examined and a label given that reflected the meaning of data chunks, and relevance to the research questions was considered. Related themes were clustered and the meaning, determined by me, generated interpretive themes informed through consideration of what I was being told in relation to my prior knowledge of nursing and the topic. Related areas were clustered within each interview, as well as across all interviews.

Identifying patterns within the data

The process of generating pattern themes was beginning, informed by the literature and existing experience. Pattern themes were more inferential, drawing on existing literature and theories to account for common and unique aspects from the data as well as being relevant to the context. Generating pattern themes continues in the discussion of findings provided in Chapter 5 and through the writing and rewriting of this thesis.

Not all fifteen stages identified by Hycner (1985) were undertaken, for example, the suggestion of 'bracketing and phenomenological reduction' was inappropriate for this study. Personal experience was a key factor in undertaking this study, with Thorne et al (1997:173) recognising the contribution of 'foundational forestructure' to the research process, reflecting Heidegger's philosophical approach. Nevertheless it was essential to be alert to the effect that existing assumptions may have on my ability to be open to hearing another's story. Highlighting all phrases that stood out, minimised the likelihood of significant aspects being omitted due to my presuppositions, so enhanced my questioning of existing assumptions.

Through following Hycner's (1985) guidelines to analyse data, it was possible to engage with the interview content in a manner that reinforced the iterative process of moving between delineating units of meaning and gaining a sense of the whole interview. This iterative process was an

essential part of coding; together contributing to the systematic and rigorous process required for data analysis.

More recently computer-aided analysis of qualitative data (CAQDAS) programmes have become available and initially appeared to assist the analysis process. While QSR N5 – NUD*IST (Non-numerical Unstructured Data Indexing, Searching and Theorising) (Richards 2000) provided an effective system for storing interview transcripts, limitations became apparent during early descriptive coding. This early attempt to use QSR N5 – NUD*IST was not pursued. Adapting to working on screen instead of paper was key in the decision to analyse data by hand, as it was difficult to remain close to the data when only viewing short data chunks on screen. The need to fully engage with data as an entire event in order to retain a sense of the overall impression gained at each interview reflected van Manen's (1990) observation that making something of a lived experience text requires a free act of insightful discovery rather than being a rule-bound process. The ability to move backwards and forwards in paper copies of interview transcripts facilitated closeness and allowed initial descriptive themes to emerge from the data. While using NUD*IST I found that once a theme (node) had been generated by me, it seemed to inform coding rather than themes being informed by the data. Limited personal experience with the qualitative analysis process, as well as with use of NUD*IST software contributed to the decision to code data by hand, and reflected concerns regarding the place of CAQDAS in qualitative data analysis (Webb 1999, Gilbert 2002, Crowley et al 2002).

Analysis of the second interviews continued to be informed by the model outlined by Hycner (1985) as this provided a coherent structure. As indicated by Hycner (1985), the reality of analysis activities did not occur in the linear way outlined in analysis models. The models did however provide a structure that guided the iterative activities that have been referred to as 'the analysis mire' (Ross 1994:135), and make up the analysis process. Moving between and within interview transcripts, as well as the evolving

themes, was necessary to ensure that the research questions were addressed, that credibility of the interpretation was demonstrated to readers, and that themes reflected what had been expressed by the adults with CHD who participated in second interviews.

The analysis process provided descriptive themes using informants' own words; one example is '*... I am lucky*'; interpretive themes, for example '*I understand my CHD*' drew on previous personal nursing experience when adults with CHD had demonstrated a level of understanding through asking questions during hospital admission; and early pattern themes, for example '*psychosocial development*' drew on previous study in which Erikson's (1986) theory of psychosocial development had been encountered. Revisiting this theory revealed aspects, the significance of which had not been well understood previously, that had relevance to the way adults with CHD made decisions.

As the list of interpretive themes developed, notes were made with reference to common areas as well as areas for exploration within the literature. The notes reveal the dialogue between the research process and myself and contribute to the reflexive nature of this qualitative study.

To enhance the trustworthiness of interpretive themes, comparison within and across interviews was carried out. Whilst this process took several days to achieve, it was beneficial as it enabled me to further clarify consistency of meaning expressed by informants, and confirm that themes reflected their meaning (Hycner 1985). One example was phrases used by adults to express their experience of living with a heart condition. Adults claimed not to think of it '*... I never think that I have a heart condition ...*' (1:16).

However, through comparing within and across interviews, this statement was refuted through all informants making reference to actions that took account of their heart condition. In an effort to explain how one person was aware of her heart I was told '*... I am aware of it (heart) all of the time, but I don't think of it*' (3:831). This phrase epitomised what all informants had

told me regarding how they lived with their heart condition, and the theme label was adapted.

The final stage of identifying pattern themes involved continued exploration of the literature informed by the notes that had been made throughout; this is anticipated as part of a phenomenological study. Existing theories, which were related to the interpretive codes that had emerged from the data, were examined for relevance to the group who are the focus of this study. Theories relevant to living as an adult with CHD are further explored in Chapter 5.

Describing the phenomenon through the art of writing and rewriting

The purpose of the phenomenological research report is to articulate what is known tacitly (van Manen 1990); tacit knowing according to Polanyi (1958) is part of the whole network of interactions that make up daily life. Tacit knowing can result in taken for granted understandings remaining unquestioned. The process of writing and rewriting meanings required words to be given to the essential nature of the taken for granted understandings. Through the process of applying language and thoughtfulness to the essence of the lived experience of being an adult with CHD, an account of the study can be generated that has authenticity to readers. The research journal mentioned previously has been used to inform the construction of this report; it can contribute to writing an account that feels authentic, and in which my role in the research is made visible (Jasper 2005). A rigorous approach to the research endeavour must be apparent and can be demonstrated through making explicit the trustworthiness of the study.

Trustworthiness of the study

For research to have credibility it is necessary for trustworthiness of findings to be demonstrated; in qualitative research this is the extent to which the findings represent reality (Field and Morse 1985; Angen 2000). Debate regarding how to demonstrate credibility in qualitative research is ongoing; a process referred to as 'the parallel perspective' by Sparkes (2001:540) offers options

corresponding to concepts of reliability and validity used within quantitative research approaches. The decision to use this approach to demonstrate rigour within this study was influenced by the predominantly quantitative studies traditionally associated with medical research. Research findings have to be disseminated and accepted as providing an accurate account of results. The parallel perspective provided a way to indicate the value of findings from this study to influential gatekeepers, including cardiologists and cardiac surgeons, who were unfamiliar with interpretive research approaches.

An audit-trail of decisions that demonstrates a consistent approach contributes to the trustworthiness and credibility of a phenomenological study.

Sandelowski (1986:29) provided a set of criteria, informed by Guba and Lincoln (1981), through which qualitative rigour may be demonstrated. The criteria of truth-value, applicability, consistency and neutrality will be used to discuss decisions made to demonstrate the diligence applied within this study.

Truth-value

Truth-value refers to the credibility of research findings. Individuals who provide accounts of their experiences determine the meaning in a phenomenological study. Credibility of findings is achieved when themes are recognised by another person on reading an account of the experience. The research report contains sufficient examples of data to demonstrate ways thematic categories were achieved. In this study these are included within Chapter 4.

Applicability

Applicability refers to how well the findings transfer into another context. The aim of phenomenology is to provide an account from the individual perspective, rather than to generalise to other contexts. Informants taking part are those who are accessible and able to articulate their life experiences as a vivid story. In this study, however, while the individual's story is central, the findings must be seen in the overall context of the group and make sense to other people outside the study. Practitioners who attended conference or

teaching presentations (Appendix 12) generated discussion that confirms findings are applicable to their settings. Applicability can also be demonstrated through comparison with information provided by the patient association newsletters and other information provision.

Consistency

Consistency refers to the demonstration of the decision making process, and has been likened to the audit process (Koch 1994). According to Sandelowski (1986:33) consistency is achieved when another person arrives '*at the same or comparable but not contradictory conclusions given the researcher's data, perspective, and situation*'. The decision trail is demonstrated throughout the thesis. Phenomenology provides one interpretation of the data. The interpretation given in this thesis is that made by me and for which I take responsibility (Rapport et al 2005), while recognising that other interpretations are possible (van Manen 1990).

Respondent validation is one strategy frequently proposed to demonstrate the consistency of the interpretation that has been given by researchers to data provided by informants (Hycner 1985; Bailey 1996). The process involves returning the researcher's interpretations to original informants and asking them to confirm that themes truly reflect what they meant. This process can appear a suitable method of confirming researchers have provided a true interpretation of the informant's understanding. The development in qualitative research approaches has led to the value of respondent validation being questioned (Barbour 2001; Bryman 2004; Rapport et al 2005).

While the aim of the study was to explore individual's experience, another purpose was to identify common themes that emerge and to provide an overview of living as an adult with CHD. Individuals can have difficulty recognising similarities between their individual, concrete description and the abstract synthesis provided by researchers (Sandelowski 1993; Hamersley and Atkinson 1995; Holloway and Wheeler 2002; Morse et al 2002; Bryman 2004). There may be discrepancies between the individual's interpretation and that

made by the researcher. Researchers then have to make decisions whether to accept the informant's interpretation and disregard their own. This may be seen as collusion; however rejecting the informant's view may result in the process being seen as exploitative (Barbour 2001).

The most appropriate time to seek respondent validation would have to be considered. Decisions are required to determine at what stage within the analysis process findings are considered to be sufficiently credible (Cutcliffe and McKenna 1999; Long and Johnson 2000). Requesting respondent validation too early is inappropriate; however the iterative nature of qualitative analysis makes it difficult to fully appreciate when the process is complete. Alternatively if respondent validation is undertaken later, it may be difficult to regain access, the informant's situation and/or views may have altered. Informant's reaction to emerging findings may help to refine explanations; this is not validation. However it may be another valuable source of data and insight (Hammersley and Atkinson 1995; Barbour 2001).

Throughout the study the interpretation I have been making has been presented to others for review. This has been achieved through presentations at national and international conferences related to research methods or adult CHD. This is a recognised means to inform other researchers of the study design and findings, and to attract and answer critical comment. A related method of peer debriefing is to present findings and implications to interested groups; this offers similar opportunities with emphasis on the relevance of the study. Throughout this study presentations have been made to groups of researchers, clinicians, and to patient association meetings (Appendix 12). Transcripts and themes have also been examined for consistency by other people including two nursing colleagues, one with experience in providing care for adults with CHD. This process is less overt than the quantitative equivalence of demonstrating reliability, however it contributes to maintaining an approach that questions my presuppositions.

Neutrality

Neutrality refers to lack of bias despite the subjective approach, and is achieved when truth-value, applicability and consistency are demonstrated (Sandelowski 1986). Writing the report of a phenomenological study is an iterative process that takes time; the entire time of a project. Writing and rewriting has continued throughout this study in an endeavour to provide a reflective, narrative account that indicates the thinking, reading and learning that has occurred through completion of this study. Details are integrated within all sections of this thesis, of sources of data, collection techniques, experiences, assumptions made, meanings given and influences on me. These are presented to contribute to an audit trail that can enable readers to appreciate decisions made throughout the study.

Completing the cycle of human science research

Returning to Table 3.1 on page 63, two further areas are identified by van Manen (1990) to complete the cycle of human science research. The first, 'maintaining a strong and oriented pedagogical relation to the phenomenon', relates to the discussion of findings, details of which are provided in Chapter 5. The second, 'balancing the research context by considering parts and whole' involves consideration of the findings to current practice and is given in Chapter 6.

Synopsis of chapter

Theoretical constructs provided by van Manen's (1990; 2000) approach to phenomenology have been used to make explicit the study design of this project. The way in which sample members were accessed, data collected and analysed have been given. Making decisions transparent is one way proposed by Rapport et al (2005) to enhance the credibility of a qualitative study through enabling readers to make judgements regarding the research process.

CHAPTER 4

FINDINGS FROM THE INTERVIEWS

Introduction

This chapter presents the findings from the thirty-three in-depth interviews with informants who had congenital heart disease (CHD). These comprised of three early interviews undertaken between May and July 2001, twenty-five further initial interviews undertaken between January and April 2002, and five second interviews undertaken between July and December 2004. Further details of informant selection are set out in table 3:2 on page 78 in the previous chapter.

Discussion of the analysis process also has been provided in the previous chapter; however details are briefly reiterated here to facilitate reading this section. The process outlined by Hycner (1985) was used to guide thematic analysis (Appendix 12). To gain familiarity with the content of each interview audiotapes were transcribed, and transcripts read while listening to the audiotape, and thematic analysis commenced. To promote clarity terms used by Miles and Huberman (1994) to identify data units are used throughout; that is descriptive, interpretive and pattern themes. The processes of delineating units of general meaning, identifying relevance to research questions, and clustering units of relevant meaning generated descriptive themes. Interpretive themes were generated through determining themes from clusters of meaning; and pattern themes through contextualization of themes. An overview of activities follows to provide readers with a sense of how these processes were applied in this study.

Significant statements were highlighted within transcripts, which were labelled using words/terms provided by informants; this contributed to the intention of staying as close to informants' own words/meanings as possible. Units of meaning relevant to the research questions were identified using the copy, cut, paste (CCP) facilities in a word processing programme. An electronic copy was made of the entire transcript; significant statements were CCP into a further document. The text that remained in the original document was then scrutinised to check if anything significant remained. Hycner (1985) recommends that if

there is any doubt regarding the relevance of statements they should be included, so keeping me alert to the risk of including only data units that confirmed the beliefs I had previously held. Related areas were then clustered.

The above process was undertaken with each transcript in turn. This stage of analysis had to be completed with one transcript at a time in order to retain a sense of the whole interview and the context within which significant statements had been made. It was possible to become immersed in the narrative, as well as begin to look at the emerging themes at a conceptual level. The process was completed with interviews in the same order in which they had been undertaken. I became more aware of how my thinking had been influenced by the people who had related their experiences to me.

I became more alert to the significance of the researcher as part of the data collection tool in qualitative research. I was reminded of the apparently conflicting philosophies of Husserl and Heidegger; however heightened awareness of my existing beliefs made it possible for me to remain open to hearing the unexpected. I was surprised nevertheless at how, despite my intention to maintain a role of comparative detachment, I became drawn to the people and their stories. Tensions arose as I began to communicate parts of my research to others.

I was aware of the need for confidentiality and anonymity for research participants as well as the convention to use pseudonyms, and had intended to follow this custom. Using pseudonyms however, made me feel remote from the people whose experiences were foundational to whatever aspect of my study I was presenting. Throughout the study I had developed a way of speaking of a person, the context and content of our meeting, in a way that enabled me to envision the individual without revealing who they were. Part of this was the number given to the order of the interview; I became able to think of and identify the person while speaking a number. This was unanticipated and has generated difficulties for me in reporting my findings, and has been resolved

through using both Roman and Arabic numerals for notation of the initial interviews.

Data are provided from interview transcripts. The number assigned to the interview ensures anonymity for informants and reflects the order completed during the fieldwork, no other value is implied; excerpts are referenced to the line number (table 4.1).

i, ii, iii	Denotes order of three initial interviews completed between May and July 2001
1, 2, 3 ... 25	Denotes order of the further twenty-five initial interviews completed between January and April 2002
1/11 ... 5/19	Denotes order of second interviews followed by order of first interview
1:620	Second number denotes line number within the interview transcript
(5, 9)	Within the text denotes interviews during which the theme under discussion was supported

Table 4.1: Notation used to indicate source of data

As described above interviews were undertaken during three discreet time spans, with early analysis occurring simultaneously. Findings from the twenty-eight initial interviews will be presented first, followed by findings from the second five interviews.

Findings from initial interviews

This section explores findings related to the twenty-eight interviews undertaken between May 2001 and April 2002. The research questions guiding the interview were:

- What is the experience of living as an adult with CHD?
- What are the characteristics of information and services that are valued by adults with CHD?
- What are the implications of these influences for development of the nursing role in provision of information and services for adults with CHD?

An overview of the biographical details of the twenty-eight people who contributed to this study is given here to provide a background to the stories from which the data have emerged. Despite literature reporting difficulty in gaining employment only two people were not working as a result of their heart condition. Twenty-one informants were employed; two people were unemployed, one due to her heart condition, the other person had been in temporary employment when surgery had been required. The remaining five people were full time students (two), on maternity leave (one), awaiting non-cardiac surgery (one), or medically retired due to his heart condition (one). Occupations requiring a range of skills and stamina were reported, these included being a teacher, police officer, nurse, paramedic, accountant, manager, carpenter, storeman, lifeguard and thatcher. Eight had higher or further education qualifications, despite literature suggesting people with CHD were at increased risk of lower intelligence. Sixteen people were in a stable relationship, eight of whom had children (three mothers, five fathers). None of the fourteen children had CHD despite the suggested higher risk to off-spring. Complexity of the heart condition was not the focus of this study, however people with heart conditions across the spectrum took part. Using the American College of Cardiology classification (2001) the conditions included simple (five), moderate severity (fifteen), and great complexity (eight).

The interpretive themes of peace of mind, readiness to hear and adaptation are presented; these emerged from undertaking an inductive analytic process. Excerpts of text from transcripts are used to indicate salient aspects of themes.

Interpretive themes

Eleven descriptive themes were identified that led to development of three interpretive themes labelled peace of mind, readiness to hear and adaptation. The relationship between descriptive and interpretive themes is demonstrated in table 4.2. Seven descriptive themes (I am fit and well, CHD is not an issue, the individual's view of self, understanding of own CHD, social network, and health carers) together contribute to the interpretive code of peace of mind; this has been achieved through the ability to adapt according to events arising as a result of the heart condition. The interpretive theme of readiness to hear comprises three descriptive themes (the perception of other people, the impact of CHD on choices, and changes in health). Two descriptive themes (the outpatient clinic, and 'the little things') contributed to the individuals' ability to adapt to changing circumstances as they occurred.

Interpretive themes	Descriptive themes
Peace of mind	I am fit and well
	CHD is not an issue
	Individual's view of self
	Understanding of own CHD
	Social network
	Health carers
Readiness to hear	Perceptions of other people
	Impact of CHD on choices
	Changes in health
Adaptation	The outpatient clinic
	The 'little things'

Table 4.2: Descriptive and interpretive themes from initial interviews

Peace of mind

The first interpretive code that emerged was that of 'peace of mind'. Peace of mind was a term used by informants to describe part of what they felt they gained from attending the outpatient clinic. Peace of mind existed due to surgery for CHD often having been performed before the individual was able to remember. Some adults were able to recall surgery, however, the outcome had been so successful that the CHD was not an issue to individuals; some believed the surgery had permanently repaired the CHD and there was no need for further treatment.

...it's only really been explained in the last year that I'd need another operation ...I suppose I probably thought 'oh it's done' I was going back for three year check up and then after a while it (clinic visit) just phase out... (11:233)

...all the time I had been at (other hospital) bear in mind this is the time before ultrasound they had limited resources they kept telling me I was A1 healthwise, so it was a big shock when I was told differently. (10:47)

I am fit and well

In response to the introductory grand tour question asking how they were, informants gave examples of every day activities to demonstrate their ability. During descriptive coding a recurring area was current or previous employment used to demonstrate physical stamina; social activities were used to demonstrate being able to do things that a 'normal' person does.

I seem to be doing everything a normal person does. I'm a storeman so I'm on the go all the time (ii:7)

I have worked as a bricklayer ... I did find that pretty hard going but I still managed to keep up with all the others ... I found it a bit of a problem but it was heavy work (iii:6)

... going out having a good time it's been no different to a normal person (ii:12)

I have always had the attitude that I don't let it stop me doing anything that I want to do ... so I have always been very active and I think that's quite important to make sure that there is something that I can do ... I don't like getting treated too differently just

because of that (CHD). It's not something that I've got any control over ... it wasn't that I had done something stupid (i:454)

Informants expressed how well they considered themselves to be; being fit was central, however 'fitness' may not fully describe what informants meant. The state of being 'fit' can be confusing due to being perceived as a peak physical condition.

Inpatient experience described by one informant reiterated his view of being fit, while indicating perceived differences between adults with CHD and patients with acquired heart disease.

... I am not a kid but I'm not like everyone else on the ward. They were between fifty and eighty ... it was either minor stuff or serious things. I only spent three days on the ward and then I was out of there ... I was obviously younger, fitter a bit healthier than them (i:214)

Despite having undergone three surgical procedures for his heart condition, the first at four months of age, this person considered himself to be healthier than people with acquired heart disease; reporting a rapid recovery following his most recent surgery.

All, apart from two, informants had their CHD diagnosed during infancy, therefore had never known life without their heart condition; this made it 'ordinary' for them, with them getting on with their life, and thinking about their CHD only when clinic appointments occurred. Individuals, through performing a range of activities, define the state of well-being for themselves, which was achieved through their ability to successfully adapt if changes occurred.

CHD is not an issue

Living with the CHD was ordinary for the informants. They reported memories of when they first realised that their CHD made them different to other children; not being able to run, or not as far as other children was mentioned as a moment of recognising they might be different (8; 10; 17; 23) or not being permitted to take part in running races by parents or teachers (8; 25).

...it was annual sports day and I wanted to do a long run, round the track five times, and my mum said I wasn't allowed. I was a bit cross and mum had to explain why and I can remember thinking 'that's not fair I want to run, everyone else is doing it' ... (8:96)

I loved cross-country running. I've always been running through fields and whatever as a child. I used to watch these people going on cross-country and come back covered in mud and I used to think I wish I could do that (25:183)

Although one informant reported being made to undertake sports even though he was unable to run as much as other children.

When I was at school I used to do sports and cross-country and they used to make me do it even though I had a letter saying I couldn't do it. (1:47)

Despite these memories, informants considered themselves to be well. During the interview informants were asked to place themselves into a category of the New York Heart Association (NYHA) (New York Heart Association Criteria Committee 1994) classification adapted for adults with CHD. The subjective view informants had of themselves indicated their perception of well-being (see table 4.3).

NYHA classification adapted by (Perloff & Miner 1998)	Number of Informants
1. No symptoms at all levels of activity.	10*
2. Symptoms are present but do not limit average, everyday activity.	13*
3. Symptoms significantly limit most but not all average, everyday activities.	3*
4. Symptoms significantly limit virtually all average, everyday activity and may be present at rest.	1

* 1 informant placed himself in three categories

Table 4.3: Informants perception of themselves

Individual's view of self

The view informants had of themselves contributed to achieving peace of mind; their view of themselves may be different to the views held by other people. Despite being aware of their heart, and stating the presence of high blood pressure, chest pain or palpitations, informants perceived themselves as fit, normal, and being the same as other people. Being told throughout childhood, by health carers, to get on with their life helped to confirm their perception of being normal.

...it still doesn't even today affect me that much I am not conscious of 'oh I've got a heart problem' it's not that great an issue... (9:160)

...during my school years I was fine, I was in all the school teams everything ...then 15 up to about 20ish fine ...(13:123)

...I had to go for check up but it was normal to me it has always been normal to me, but then when I was 15 and I had to go in for an operation I thought 'oh I don't know if I like this' ...they even scheduled it for the summer holiday so it didn't affect schoolwork which was important and I went on to university (13:205)

One informant reported forgetting about her CHD. She disliked anything that reminded her, such as having to include it on forms, and considered that she may in fact omit it because in her view, she had undergone successful surgery and no longer had a heart condition. The recurring message throughout was that the heart condition was not an issue. Another informant who reported never having considered there being anything wrong with him went on to say

... I suppose the only times were when I used to have to wear the twenty-four hour recorders, maybe then I knew I was different because I couldn't play football and I couldn't do what I was doing every other day at school (20:126)

This statement raises the question of how to accurately assess usual heart function if the method of assessment militates against usual activities. Another aspect raised during the early interviews, although claimed not to be something that was significant was of the risk of early death due to the CHD

I'm not sure whether they (doctors) know whether I need another operation in later life, whether it could affect me. Obviously I'm 23 now. How will I be in another 20 years time or 15 years time, depending on touch wood if you get there, you never know you could be run over by a bus tomorrow ... I'm not sure if there is any age

they say good life with it so to speak ... touch wood I'll have another 30 odd years maybe even longer you never know do you nowadays but there again I don't even think about that (ii:559; 676; 720)

The following statement from another informant implies it was his friends, rather than him who believed him to be at risk of dying

I don't really think about it; it's just my friends reminding me all the time saying I shouldn't be doing that shouldn't be doing this... I think they care for me actually they don't want me to pop it... like dying just pass away... got a heart defect I don't know perhaps they feel I'm not physically strong enough I suppose I don't know (iii:55; 62; 70; 74)

Areas raised by the early informants, that I had not previously thought to be significant were incorporated into subsequent interviews. Informants who did not mention their scar during the interview were asked directly for their feelings regarding this. I felt it was insensitive to ask a direct question regarding people's thoughts of their own death, so asked about how they saw their future. As a result informants mentioned the need for further surgery, and spoke of their own heart condition.

Understanding of own CHD

Informants were asked to describe or name their condition with a range of understanding demonstrated. While informants could usually describe components of their CHD, and identify if changes occurred; they were less able to appreciate the significance of changes or the implications to their well-being. In the absence of any changes the lack of awareness could contribute to maintaining peace of mind. Diagrams provided by health carers were kept but not fully understood without further or ongoing explanations. The CHD was often referred to as 'a hole in the heart' or informants described themselves as 'a blue baby' irrespective of the original heart defect. Some informants could describe their condition accurately using their own words, or medical terminology to name their CHD; others admitted that while they recognised the term when stated in the clinic they were unable to remember it.

...they always say it to me when I go to the clinic 'oh you've had (doctor names procedure) done' and I say 'yes' ...I should have it written down ... I don't know what it is ...my mum would know ... (8:473)

my heart is basically backwards and its got the stronger side pumping between my heart and my lungs and the weaker side pumping round my body, I had a mitral valve replacement in 1992 (12:15)

Sometimes doubt was expressed regarding the actual understanding of the terms used, demonstrating a lack of awareness of the relationship between the CHD and related aspects such as high blood pressure or palpitations. This doubt did demonstrate informants possessed a level of awareness of the boundaries of their understanding. The presence of 'leaky' valve(s) or valve repair, both of which may require extra care with aspects of life including dental treatment, were mentioned incidentally and the necessary precautions recalled only when prompted.

Social network

The social network of parents, partners, siblings, friends, employers and teachers contributed in various ways to the individuals' peace of mind. The impact of parents, especially mothers, was reiterated with informants stating that their mother would be able to provide answers, as they could not recall details. As informants had reached adulthood, they could appreciate how their parents had been affected by their CHD. As informants took responsibility for their own health, they reported trying to protect their mother by not always telling them everything about their CHD; this can cause conflict.

... she (mother) gets annoyed with me ...she asks 'are you feeling fine?' They (parents) ask me every day and I get very annoyed with it and I say 'yes I'm fine' when I might have a bit of pain, just to shut them up (2:204)

... my Mum gets annoyed with me because I don't ask the doctor enough questions because I don't want to know. There's part of me that wants to know but I guess most of it and I always guess right ...my mum said 'did you ask any other questions' I said 'no', she wants to know more (2:265)

One other informant spoke specifically of protecting her mother (13), she considered herself to be well, placing herself into NYHA class 2. During the interview it was easy to understand what she was saying, however, on

attempting to transcribe the audiotape there were sections that were difficult to hear what she had said. This informant had become skilled in adapting her breathing to be heard/understood while with her; however she actually mouthed, rather than said aloud, some phrases making it impossible to reproduce her actual words. The field notes maintained during data collection acknowledge my impressions, however it is not possible to reproduce her actual words here in a manner that would be understood by anyone who was not present during the interview. The skill she had developed to demonstrate normal speech, while moderating her breathing to accommodate the limitations imposed by her CHD was impressive; it was impossible to recognise this while with her. This informant clearly demonstrated her ability to live life to the full; as far as she was concerned she was normal, but different.

... I don't want to be molly coddled as such, don't want special treatment (13:605)

Family members know the individual and while some informants see mothers as worrying or over-protective, siblings have known no difference and treat them as normal.

... I don't think she (sister) takes much notice of it because she's younger than me, I always had it and she's grown up with all this ... (20:844)

... I have got an older brother he used to beat me up ... my mum always used to get in the middle of us ... it was just part of growing up ... I am bigger than him now ... it's amusing 'this is my little brother' ... (22:855; 901)

Other people provided corroboration of individual's self perceptions that influenced their confidence and self-reliance. The individual's ability to be appropriately self-reliant influenced views held by other people, which in turn impacted on the other person's ability to treat adults with CHD as 'normal'.

one of the modules was anatomy and physiology ... my lecturer ... he said if you have got any extra knowledge put it in. I put my whole operation into this book with pictures of me strung out like this. He was one of my main instructors so maybe he gave me high marks – I got high marks but I was expecting that because of what I put into the book, it was a lot of work ... I got reasonable grades from some of the other lecturers as well (i:512)

I go clubbing, they (friends) always look on me every five ten minutes make sure I'm alright and they come up and say okay (name) and what ever. I say go away I'm enjoying myself, but yes they look after me in that respect. I think they are more of aware of what I have got (iii:630)

Partners were often unaware of the heart condition on initial meeting, and once they knew the adult with CHD, the heart condition was usually irrelevant. Friends, once they become aware of the heart condition, frequently expressed surprise at how well they perceive the individual to be. Informants reported taking trusted people into their confidence, making them aware of their heart condition, in order to participate in activities without other people being aware. This meant they were treated the same as everyone else, or questions regarding their suitability to participate were avoided.

Health carers

Informants expressed trust in the medical team based at the tertiary centre despite not always being seen by the consultant cardiologist. During periods of change, such as pregnancy or following surgery, they reported seeing the consultant; however junior medical staff frequently undertook routine follow up appointments. Informants stated that junior medical staff would refer to the consultant if they had concerns. The continuity of health carer generated confidence with informants stating that they felt that the consultant knew them.

... they do give you peace of mind if it's all alright which is what I like to have and somebody who knows my background ... he (cardiologist) knows there might be a sound that is not normal, and he knows what it is so that is why I decided to go back for the next appointment ... (19:314)

...I saw (cardiologist) when I was having my children, he's the type of man you trust and he knows me, whether he knows me or whether he just reads my history is irrelevant, he knows me ... now I see anybody I don't really distinguish between them because they are part of a team and they wouldn't do anything on their own if they didn't know. (4:252)

Moving out of the geographical area covered by the tertiary centre where the original heart surgery was carried out could result in lack of continuity and loss

of follow up. When the move was temporary such as going to university, follow up continued at the original centre (11). Two people had moved out of the area and chose to return to the original centre for follow-up to maintain continuity (12, 13); clinic appointments were associated with a visit to parents who still lived within the area covered by the original centre. Four people had undergone cardiac surgery at other tertiary centres (2, 7, 10, 13), with follow up now being provided at the centre that was accessed for this study. In one case (13) the original surgery was undertaken at a national centre, as at that time, sufficient surgical expertise did not exist at provincial tertiary centres.

Another informant expressed the desire to continue attending the outpatient clinic to ensure that any further problems were identified early.

... if they said they don't want to see me again, I would say I want you to see me just in case, get things picked up early this time rather than wait for something else to happen (7:393)

The relative lack of clinical expertise with CHD was recognised by one informant whose heart condition was discovered at age 20 years when he underwent a routine medical examination prior to joining the Territorial Army. Recalling his experiences he reported having the impression that CHD was rare due to the number of medical staff wanting to listen to his heart murmur while he was in hospital. The complexity of CHD and the value of specialist expertise were acknowledged.

... even after the murmur had been discovered by the military doctor, I came back and my own doctor couldn't hear it ...another doctor came in and had a listen and said 'I think I might be able to hear it but not sure' and it turned out to be quite a large hole. That worried me when they were checking (daughter) listening to her heart and maybe it's the same scenario that they couldn't hear it and so I was concerned ... no problems everything is normal but it would be nice to know that there is definitely nothing wrong. Don't want to find in a few years time like I did that there is something wrong ... lay the matter to rest, it would be a relief. (14:230)

Within the community continuity was not always possible, as informants had moved area or the General Practitioner (GP) had retired. All of the adults with CHD who were accessed for this study, apart from two (3, 14), had been

diagnosed during childhood; their current GP was not always the same as the GP who had provided care during the time of surgery. Differing views of the GP were expressed. Although informants recognised the GPs lack of specialist knowledge of CHD, the GP was often the first point of contact when health problems arose. Some GPs were viewed positively by informants (2, 4, 15, 20) and were considered to be a useful source for information regarding their CHD.

... I've got a great GP... I would talk to him about absolutely anything ...he's brilliant, fantastic, completely open ... I would talk to him if I had any problems at all or needed information. (15:468)

In contrast other informants reported having less confidence in their GP's ability to appreciate the significance of aspects related to their CHD (1, 3, 7, 8, 13, 19, 22).

... I don't bother with my own GP it's a waste of time, he told me I had mumps when I was full of liquid, a week later I was in hospital. (1:299)

... the old GP was very helpful, but he's retired because he was my doctor when I had my heart operation. I had a really dizzy spell I thought it was my blood pressure so I explained to the doctor and he didn't really take any notice whether I had a heart operation or not. He said 'It's probably a virus or something' (11:370)

The need for information, as one would expect, was influenced by changes in health or social status, impending surgery or investigations.

Readiness to hear

Being ready to hear or to seek information occurred when the individual's peace of mind was disrupted; this happened in three main ways. Peace of mind was disrupted by the perceptions of other people, when their heart condition impacted on the choices available to them, or when changes in health occurred. These areas could overlap, resulting in the individual being ready to hear or actively searching for information or accessing services.

Perceptions of others

Other people demonstrated their perception of the adult with CHD as a result of different events. Aspects within this theme include other peoples' perceptions of both the informants' scar or their ability to perform activities.

Scar

It was not unusual for informants to mention their scar and how other people commented on it. One informant, who had her operation as an adult, had discussed the approach with the surgeon who agreed to perform the surgery using a mini thorocotomy; this resulted in a scar that was easily concealed (3). Another person mentioned the surgical scar. His work as a lifeguard may have been a factor in his appearance being significant to him, and he reported strategies he had developed when other people passed comment

...when you look at me as an average young twenty-five year adult I don't look particularly crippled ... bendy ribcage it's a bit out of shape... I'm not trying to lose weight just trying to look a bit toned up... I've got a lot better at exposing my body ... I don't mind if someone says what's that? I don't openly walk around ... used to drape a towel over my shoulder ... which would cover up the scar a little but I've got a lot better since I've been at work...I've got a surf top keeps me warm in the water take that off ... I am getting more familiar and people know who I am and they don't question you ... I've got a tattoo between the shoulders ... now they say 'what's that?' I say 'the tattoo or ...?' they go 'Oh yes of course I meant the tattoo' so I've got a little more happy ... I never used to like to take my top off because of my scar (i:91; 179; 598; 649)

Informants reported being concerned about their scar as a child, nevertheless as they had grown up it became accepted and was no longer an issue for them.

... about four years ago I wouldn't take my t-shirt off in the summer but it doesn't bother me now ... I remember sitting in the garden without my t-shirt and (friend) going 'oh blimey that's a big scar where did you get that?' So yes it does lead to conversation more than anything else ...I'll tell anybody about it, I don't know why I wouldn't take my t-shirt off and why all of a sudden I decided it wouldn't bother me because as I got older I thought it's not a problem (12:780)

Informants' views of their scar varied widely, one informant who consistently stated that her CHD was not an issue for her said:

I've got a scar and it's never put me off wearing bikinis or low cut tops ... I do get people going 'ugh what's that?' But it's just something I've got there and something I've got to live with (5:104)

While another reported the opposite:

I don't wear anything low cut, bikini or anything like that. I am very conscious of my scar always have been ... I just think everyone is looking at it so I won't show my back. If people ask me about it I get all defensive (I) don't like it because people do actually ask if they see a great big scar down your back, but I have always been quite funny about it (8:411)

Informants recounted stories regarding their scar(s), and while it was an important issue as a child or adolescent, most adults were able to accept it with limited impact on their life. As they had grown to adulthood their scar was seen as being similar to freckles or a birthmark (15); the more the scar was exposed the less other people noticed it (15, 19). It was apparent that the scar could not be ignored, they had however, over time developed an acceptance of it; this may be similar to other aspects of appearance that are encountered during adolescence.

Ability to perform activities

Informants did not always reveal that they had undergone heart surgery, it was not a secret but unless asked directly they would not mention it. Terms such as prejudice and discrimination were used by informants (1, 4, 13, 20) to describe the response of other people once they were aware of the heart condition. Once other people were told about the heart condition they expressed surprise at how well the informant was and that it did not prevent them doing things (17, 20). Potential employers were often not informed until following the result of interview (1, 3, 4, 11, 13): some informants reported that they had not been offered jobs because of their heart condition, although this was impossible for them to prove. Other people made associations with acquired heart disease, and assumed that the individual was ill or unable to carry out activities.

...my work involves manual labour and they (employers) were worried because the boss's wife had one of her heart valves replaced and he said 'Are you OK to do all this?' (16:39)

... I never tell them before because I know what people are like ...I tell them afterwards ... they are usually pretty good (17:256)

One informant reported she did not tell other people about her heart condition because they became more worried about it than she was; through not telling she avoided further questions being asked (19). Informants reported difficulties when completing insurance form questionnaires. One informant who admitted having difficulty climbing stairs said she would say 'no' to being disabled because in her view she was not disabled; she did acknowledge that other peoples' perceptions may differ (13). Questions regarding heart disease led to confusion; the view expressed by one informant was that while she may have had heart disease, it had been repaired with surgery, therefore was in the past and not a current problem (19). The difference in perception between informants and others was a recurring theme; although once the person was known the CHD became irrelevant. Perceptions held by others, however, were important.

Impact on choices

The views of other people regarding the adult with CHD had an impact on the choices that were available to them throughout their life, disrupted their peace of mind and acted as a stimulus to obtain information. The impact on employment has been discussed above; however career opportunities may have been reduced due to the effect of the CHD on their education. The adults with CHD reported that while the cardiologist considered the impact of surgery on their schooling (see Individual's view of self page 100), events related to their heart condition resulted in important times being missed

... I missed the whole of the summer term at middle school in my last year ...they (other pupils) had exams to see which sets they were going in and I missed it all so I think that's why I didn't do brilliant at maths ... I missed so much of it in the last half of the year when I got out of hospital it was over my head ... (9:601)

... one thing I did miss was the tour around the school, so when I was going it was completely new ... everyone knew where they were going and I was like 'Oh where am I going; where's the classroom?' (16: 695)

Another informant who had undergone three surgical procedures talked of how his education had been disrupted

Well my last two operations have been in some way shape or form in the middle of my exams. First my GCSEs and second time my BTec so when I came out of my GCSEs I only did half days at school so I missed a lot of work um and uh that made things awkward but you know I sort of got through I didn't do particularly well in my GCSEs that's probably why (i:474)

Another person reported losing the motivation to achieve high grades during end of school exams after being told that, despite having no physical limitations due to his heart condition, he would not be accepted into the fire service (21). However difficulties may be avoided through pre-empting questions about the heart condition (14, 20).

...when I applied to join the police ... I anticipated they would kick up a fuss about the operation so I contacted the occupation health people before I even put in an application ... gave them information about the operation referred them to my doctor ... that was obviously the right thing to do because it takes a long time to apply and be accepted ... when I eventually joined they had all the information I even got a letter before hand to say there is no reason why this should affect your application ...(14:189)

This approach had benefits in other areas of social life. Once accepted into the police force it was possible to obtain insurance cover with no further health checks being required. The ability to obtain insurance with no further health check was also reported by another informant (11) who had a non-physical job that had required an occupational health check only.

It may be significant for adults with CHD to be in employment with companies that offer employees group insurance cover. The need to pay higher insurance premiums was reported (1, 10, 12, 15) or for one person, being refused altogether. This person was self-employed, had surgery at nine days of age with no further intervention required, he attended for annual checks and reported

... most of the insurance companies won't touch me ... because I have an annual check up although no surgery is performed, no blood tests taken they call it a recurring condition so I am not insured to go climbing on a roof. I've got public liability that's no problem but

insurance for myself if I fall off and break my leg tough luck ... I've even said if I fall off the roof through a heart attack fine don't pay me but if I slip off a roof in wet or icy conditions or something then you should pay me, but no they are just not interested. (25:366; 429)

The impact on choices occurred in all aspects of life. Informants reported difficulties or being unable to join a work-based gym (10), join a work-based savings scheme (7), go on a school trip (20), obtain mortgage insurance cover (12, 15, 22, 24, 25), emigrate or retire abroad (10). Another aspect of life that increased the need for information was the decision when, or whether to have children.

The information need regarding having children was two-fold, the first for both men and women was the likelihood of their child being born with CHD. The second for women was the effect of contraception and pregnancy on their heart condition. Three of the nine women who took part in the initial interviews had children (4, 5, 24), one of whom had been advised not to become pregnant. One other woman talked of needing surgery before she could contemplate becoming pregnant (23). Two others stated that they had been advised not to become pregnant because of the adverse effect it could have on their own health as well as the well-being of the infant (13, 24). One informant had accidentally become pregnant, having received no advice on appropriate contraception methods for her. She talked of her mixed feelings at having been told she was unable to have children, and may never have had her daughter except for, what she referred to as a momentary lapse of caution.

... I was very very shocked ... one lot of people were telling me I couldn't have children and then well yes I can. There were a lot of conflicting emotions going through me. All the way through I kept saying to my dad 'Am I doing the right thing?' Even though everybody was telling me I would be able to carry her there was still this 'am I going to get through this?' Then when I went into hospital it was quite a dark time. I had planned everything, my dad would have her if I wasn't around and it took a lot to come to terms with that. From being told that you can't have children, you shouldn't, you won't, to suddenly 'yes we will keep an eye on you, you will be fine.' (24:294)

At the time of the interview the child was well and the informant had placed herself in class 2 of the adapted NYHA classification used during the interviews.

Of the sixteen men who took part in the interviews, five had children (1, 7, 10, 14, 22). None of the fathers had sought advice regarding the risk to their children prior to conception, however, all expressed some anxieties and the children had been 'checked' after birth. Six men with CHD said they would like to have children in the future, and did not consider the risk of the child having CHD sufficient reason not to (12, 15, 16, 17, 18, 20). They reported that despite their heart condition, life had been good for them; they were aware of improvements in the management of CHD, which they anticipated would make things better for their children, if they did have CHD, as well as their own future.

Changes in health

Changes in health resulted in the adult with CHD becoming ready to hear, this was usually associated with hospital contact either during a clinic visit, or as a result of admission to hospital. Admission was now to an adult cardiac setting, where the majority of patients received treatment for acquired heart disease. The adults with CHD reported feeling themselves to be different to other patients who were usually older and more unwell. Those who could recall admission to a paediatric cardiac setting reported that there also they were different to other patients, being the oldest person on the ward and kept awake by crying children (9, 12). Despite infrequent hospital admissions, the adults felt the paediatric staff knew them; the adult staff seemed to have no understanding of CHD. One person reported feeling frustrated by the limits placed on him by adult trained nursing staff.

... that is the only time I ever came close to falling out with a member of staff. I thought 'Please, I am okay' I was ready I wanted to go home. There was a Sister, who wouldn't let me do anything, treat you like you're seventy (20:458)

This was not always the case (6); at age 20 years he had recently undergone a heart valve replacement, for which he was admitted to an adult ward. His original surgery was carried out when he was ten weeks old. He had been admitted to the paediatric ward for recent cardiac catheterisation, where he was in a room on his own. He preferred the adult ward, although thought that it was a shock for his mother.

The focus of adult cardiac care is acquired heart disease; one informant expressed his perception of lack of services for adults with CHD through talking of cardiac services for adults with acquired heart disease, and children with CHD

... people that are born with a heart condition you have the condition and cope with it more than if you've had a heart attack, when you've probably got ten twenty years to live, where we've got probably another fifty years (9:263)

He continued by saying

... I've got heart disease, but the government ... are focused on people who have had heart attacks, angina and coronary bypasses and things like that ...it's not focused on younger people who are born with it and you're all stereotyped into one category, you know obese, crap diet, no exercise and you've all got the same problem. There's more to us than having heart disease, I don't know how to explain it ...(9:279)

This informant was aware of recent developments in treatment for his heart condition, and considered that children's nurses might be aware of newer surgical procedures, while being unaware of aspects arising for adults with CHD who had undergone earlier surgical procedures. The number of adults with CHD is small and confusion can result.

... when I had my clinic appointment last year, on the back of the letter it says the adult clinic, if you have any problems contact the paediatric cardiac nurse specialist. I thought OK so the kids have got a nurse specialist, people with coronary heart disease have got nurse specialist, what about us, why isn't there anyone for us ...we're all lumped together (9:305)

Another informant demonstrated this point. A general lack of understanding of CHD by the patient, the GP and local hospital doctors resulted in his admission to a district general hospital cardiac unit for investigations and treatment of suspected coronary heart disease. The palpitations that caused the hospital admission could be a result of the original congenital heart defect and surgical correction.

...GP said I could go to either (tertiary centre) or (local hospital) which is just up the road ... I said to local hospital staff 'you must talk to my consultant at (tertiary centre) because he has all my notes'. I was like a little toy there everyone wanted to come in and see me, have a look and see the difference between the pulses and blood pressure ... I didn't really consider the fact that I should have gone to (tertiary centre), they (local hospital) know what they are doing, it's a decent heart unit (22:686)

Not surprisingly, parents and partners were also concerned by the hospital admission, often being more anxious than the patient (adult) and continually reminding health carers about the CHD.

... (husband) gets a bit panicky and when I was pregnant he was constantly on at them 'you do know that she's got a problem' ... he just wants everything to be alright ... he likes to double check ... I'm more worried about him when I go down than I am about myself ... he gets really nervous (5:164)

While routine investigations were accepted as part of the medical management the length of time required away from work could cause difficulties. Cardiac catheterisation was a routine procedure to assess heart function, with overnight observation being required. The appointment could be given at short notice with the timing having an impact on work commitments and career prospects (11, 15). One informant had been offered an appointment at short notice due to a cancellation, but could not accept. He had recently been promoted and being away from work at that time would have made 'life even more difficult' (11:697) despite recognising the importance of the investigation. He knew he should attend, but the timing was going to make everyday life more complex for him.

The perceived benefits by the patient, when balanced against the length of time required to attend hospital departments may not be fully appreciated by health carers. Twenty-four hour monitoring of heart rhythm or blood pressure required two visits to the hospital, the first to collect the monitor, the second to return it for evaluation. The object of this type of monitoring is for people to carry out normal activities and the impact on their heart function to be assessed. One informant talked of how he independently negotiated a convenient time to have a 24-hour blood pressure assessment, and questioned the accuracy of this form of monitoring.

... they have been quite good because when I had the heart monitor I would have to take two afternoons off work. I managed to go down on a Friday afternoon I didn't mind finishing work early, and take it back over the weekend. It was the first time I'd worn one of those, I didn't realise how big a contraption it was. I couldn't have gone to work with it, it was bad enough trying to drive home ... I had to suggest it, I'm busy I don't mind coming down for the weekend. They said lead a normal life but that was going to be very difficult. I tested it out by playing a bit of tennis, it was so hot all the things started to fall off so I thought 'I can't really do that.' (11:720)

During data analysis a recurring theme was that of how individuals had adapted to the ongoing dynamic life changes that resulted from their CHD; effective adaptation was required to achieve well-being as defined by the individual. Areas of everyday life including employment, social activities and being 'normal' were all influential in contributing towards successful adaptation.

Adaptation

This section explores the ways in which information and services were provided. Corroboration of their own perceptions, by health carers, generated the combined effect of increased self-reliance through increased confidence in knowing when to seek confirmation from others

... I found it (new job) a bit stressful and I had palpitations and I've moved away and all my hospital stuff is at (tertiary centre) I wasn't sure what to do. ... I went to a local doctor to give me the once over after I had finished work that night and I'd calmed down and relaxed. I was alright but I wanted someone to turn round and

say 'you are alright' ... which is what the doctor did. He said feeling alright now I said yes I do but I wasn't happy with myself and he said well in that case avoid similar stressful situation you were in ... I wanted clarification medically. So he had a listen and a little bit of a look and then said well I can't see anything wrong so there was obviously nothing wrong with me, which is what I wanted to hear, a bit of a back up really. (i:60)

The adults with CHD made proposals regarding how to enhance the usefulness of what was accessed as well as areas not covered. Similar to other people, the adults with CHD accepted their health and well-being as normal; until their heart condition made an impact on aspects of their daily life there was little need for information. Once information was required a tension existed between wanting and not wanting details (4; 8; 16; 19). Knowing a little was insufficient; there was a need to know nothing or everything. Despite needing to know, it was difficult to know what questions to ask (1; 7), because what was required was different for adults to that which was required as a child (5; 11; 12). The balance between what was considered to be sufficient varied and could be difficult to achieve; one informant reported having small chunks of information when needed, but found out things later that she wished she had known previously (23). The information required fell in to two main categories, one regarding changes in the heart condition, secondly the impact on 'things other than medical', 'the little things' (2; 3; 4; 7; 10; 11; 13; 15; 20).

The outpatient clinic visit

All except three of the informants (2, 3, 14) attended regular follow up visits to the adult congenital cardiology clinic; this clinic was a recent development. Informants were often under the impression that they were still attending the children's clinic. They told of clinic appointment letters or telephone calls being made to their parents. The outpatient clinic visit was a source of conflict generating both anxiety and reassurance for informants. Without exception the clinic visit was viewed positively. The regular check confirmed the individual's own sense of well-being and they would be concerned if they were told not to attend in the future. One informant who had recently undergone further surgery considered the clinic visit valuable.

... it's really a bit of reassurance, just because you feel OK doesn't mean you are, it could be getting gradually worse, which it was, and you don't really notice. (6:168)

Informants were required to acknowledge their CHD; nevertheless peace of mind was confirmed when no changes or problems were identified. While informants gained reassurance from the clinic, it was also a source of anxiety with the majority of informants reporting mixed emotions regarding the clinic visit.

... I don't like hospitals ... my blood pressure was always high when I went to the clinic (11:96)

... I remember saying to my mum 'I don't think I'll go to the hospital anymore, it gets my blood pressure up when I go' (4:32)

... you get peace of mind ... I dread to think going in and they say something's wrong you'll have to have another operation ... every time I go I get a bit nervous ... you get anxious about it but I would always go ... I have to get my blood pressure checked, see someone in a white coat, BP up at the clinic just going into the hospital you are a bit apprehensive; you don't know what they are going to say ... (16:214; 243;755)

... I get very anxious going to the clinic ... I forget what I wanted to ask ... it wasn't as bad as it has been in the past. I don't know whether it was because (partner) was with me ... he was brilliant at asking questions because I go to pieces and I just want to get out of the room whereas he was asking more things which made me feel calmer ... he just wanted to know and I've never asked (19:27;196;239)

... my views (of the clinic) have changed over the last year, before it would just be 'fine, no problems' I wouldn't worry about them ... it put my mind at rest that everything was alright still ... it was a bit of an up and down day really ... I was worried about it already ... told it was fine no problem ... then actually well nothing is fine at all we are really worried about this ... (15:37; 188; 224; 239)

The visit to the adult congenital cardiology clinic both confirmed and disrupted the individual's peace of mind. While the outpatient clinic visit was viewed positively, when changes in health did occur, despite information being provided by medical staff, the questions and anxiety generated were left unresolved.

Lack of knowledge of their CHD, new procedures, and changes resulted in increased anxiety. The following comments were made by an informant who had been admitted to hospital three times for surgery related to his CHD; once as an infant and twice that he was able to recall.

... once I had an MRI scan which is really dodgy it was like a coffin ... I'm not claustrophobic but I wasn't 100% happy because it was a new thing to me and I thought I'm not sure I like the idea of this ... that was the only scan that threw me quite a lot (i:822)

Anxiety was reduced through continuity of care and previous experience. Comments from the same informant demonstrate how attempts by nursing staff to provide patient information were perceived by this person, and dismissed as unnecessary, indicating the complex nature of providing appropriate details.

I'm quite arrogant actually. At the check up I know what they are going to do before they've even done it. I walk in and by the time they turn round to do ECG I'm already lying on the bed with my top off ... I'm quite laid back, sometimes you get a new nurse who tries to explain everything ... maybe I give the impression that I am a bit arrogant I mean since I can remember I've been having ECGs and stuff (i:797)

Altered levels of anxiety led to adults with CHD being more or less able to accurately estimate their own abilities and limitations, impacting on their ability to be appropriately self-reliant.

Clinic visits were routine having been established during childhood and continued to provide reassurance that all was well, however may not always be the best place to provide all information. When changes in health were identified the informants were often unable to recall specific details provided by health carers. The adults with CHD reported not being able to recall the details that were discussed with them during their appointment; one example provided was that of introducing new medication

... I was in there five, ten minutes he mentioned a drug, you think that sounds like a good idea ... I had already forgotten the name by the time I came out of the room (12:894)

While he thought the added medication could be beneficial, during the interview he expressed concern about the added cost to him, as adults with CHD are not exempt from prescription charges. An informant, who had undergone investigations for palpitations that may have been anticipated sequelae from his original surgery, provided another example of being unable to recall details (15). He had been told that treatment might be required following the cardiologist reviewing the results of the investigations; he could not remember the sequence of events that had been explained to him. He knew that a change in his heart condition had occurred, but felt at a loss as to what he could now expect to happen.

Availability of information used to enhance confidence and reduce anxiety was explored during the interviews. GPs who had known the adult with CHD since childhood, were identified as a useful resource, however expert medical staff, usually associated with hospital admission or outpatient attendance, were identified by informants as being the main source accessed.

... I've had more to do with the hospital ... even when you've just had a check up you know in two years time or a year's time you've got to go back. People don't plan to go back to hospital normally do they? They don't know if they're going back next week or next month whereas I know I'm going to go back... and if anything does happen I'm going back anyway. (ii:536)

Sources of information such as the Internet and patient associations were not widely used or known by this group, who reported feeling isolated. The group valued regular outpatient checks as one way of corroborating their own perceptions of their ability to participate in areas of every-day life.

... it's nice after you've been (to clinic) to know that you are okay at the moment, I wouldn't say a relief, but it's nice to hear ... because it reassures you, it's always nice to think I feel fine to do things, I am fine, but it's another thing for someone to say you are fine at the moment. Not finefine, but fine as I am as I can be ... (ii:340)

Patient association information (GUCH or British Heart Foundation) was accessed by only a small number of informants; nevertheless how it applied specifically to them was not appreciated and required further discussion (9, 10).

The Internet, if accessed, was used to obtain information regarding new surgical techniques that were not fully understood, with one informant considering it was not designed for people like him (10) and another reporting that he scared himself (9). While the ability to effectively adapt irrespective of health status results in feelings of well-being, other things raised awareness of their heart condition.

The 'little things'

The aspects identified in this section covered a wide range and related to the individual's ability to deal with everyday events that made up normal life.

The impact on the individual's choices led them to acknowledge that maybe they were not 'normal', and in order to make realistic choices they needed to know more about their CHD. There was a tension between both wanting and not wanting to know; one informant whose mother had accompanied her on clinic visits talked about how she began to take responsibility for herself.

... I do like to know now, since I've had the children ... it's changed me because before I never used to ask questions, I didn't want to know, now I do ... and you can't just know a little bit, you have to know it all or none ... it wasn't until I had the kids I was pushed into it ... I had to take over I was forced rather than a choice, but it was important' (4:282; 340).

The recognition for this person was influenced by events arising through her social life. Informants reported not knowing what questions to ask (1, 7); being told there were changes disrupted the individual's peace of mind making them want to know more, while also being unable to remember or understand what they were being told.

Informants had expressed satisfaction with existing information provision. While acknowledging that medical aspects were covered, however, other things that patients would not bother the doctor with were overlooked. A few examples of '*the little things*' included specific details regarding exercise: such as how high to push their heart rate, what is a 'light' weight, the need to take aspirin on a long haul flight, or a letter for an insurance company. Some

informants admitted as the interview progressed, that they realised the need for information on areas not previously recognised. Associated with this aspect, three informants said they have never talked in detail about their experiences prior to the interview. They perceived having the opportunity to express their thoughts and feelings as beneficial.

The adults expressed gratitude to the doctors who had treated them and a desire to give something back. This was achieved through participating in fundraising activities for the local heart or ambulance charities, raising awareness of CHD through an interview for a local newspaper, taking part in the British Heart Foundation London to Brighton cycle ride, or providing advice to others who were awaiting heart surgery. It appeared that a balance was sought between being helped, being independent, and helping others.

Findings from second interviews

Informants who had experienced what could be considered to be a turning point as defined by King et al (2003), as well as epitomising being well were contacted and requested to participate in a second interview. This section presents findings from focused interviews undertaken with five of the original informants. The original research questions had been explored through the initial interviews, however I was curious about the adults' ability to live well. The focus of the research questions guiding the second interviews related to how adults' living with CHD defined being well. The research questions are restated here.

- What is the experience of living as an adult with CHD?
- What is being well from the perspective of an adult with CHD?
- How does the experience of living as an adult with CHD influence selection and effective use of the health and social care information and services that are currently available for adults with CHD?

The five people who took part in second interviews were highly motivated to maintain their health, make their own decisions, and live a 'normal' life.

The purpose of the second interview was to explore what being well meant to them, and to discover the strategies that enhanced informants' ability to effectively live with their heart condition. Informants considered being well developed through their ability to make their own decisions, which was done in a responsible manner, resulting in being able to get on with life, engaging in activities of their own choosing. Literature regarding the emerging concepts was sought. An example of this is the extensive writings on living well with chronic illness (Lindsey 1996; Thorne 1999; Thorne et al 2002; Ironside et al 2003). This began the process of generating pattern themes that were related to existing theories.

The themes became more interpretive as I developed them according to my understanding from experience and literature, while also maintaining the meaning given by informants. When related significant aspects of each interview had been clustered, areas that were common were grouped across all five interviews. The result was some general and some unique areas. The result was interpretive themes that comprised descriptive themes (table 4.4). Three main interpretive themes emerged from the data these were: I make my own decisions, I am a responsible adult, and I get on with life. The interpretive themes show progression through adults with CHD making their own decisions, because they are responsible people, who want to get on with living their life.

Interpretive	Descriptive
I make my own decisions	Choices and rejection
	Being told I cannot do something
I am a responsible adult	Lucky to be alive (doctors)
	Useful information
	Understanding heart condition
	I am mature
	I keep myself fit
	Other people with CHD
	Giving something back/patient associations
I get on with life	I am aware of it (heart) all the time but I don't think of it
	Worry when you need to
	Other people
	Clinic visit

Table 4.4: Descriptive and interpretive themes from second interviews

These three interpretive themes will be explained; descriptive themes will be discussed to demonstrate how they informed generation of interpretive themes. Data will be provided as data chunks using informants' own words to demonstrate decisions made during the analysis process. Some examples of the move from informants' words to descriptive and then interpretive themes can be found in Appendix 16.

I make my own decisions

The interpretive theme of 'I make my own decisions' emerged as informants described how they used information to make choices regarding career options, participation in sports, and options to deal with aspects related to their CHD. Information was used to balance decisions to engage in activities, because outcomes were acceptable to them, or to avoid the risk of being rejected as a consequence of their heart condition. Two descriptive themes made this interpretive theme, 'choices and rejection' and 'being told I cannot do something'.

Choices and rejection

The adults preferred to make their own choices and would elect not to do something rather than be rejected by someone else, especially if rejection was due to their heart condition. One participant since childhood, had an ambition to join the police force, but had never applied; he preferred to choose not to apply rather than risk rejection.

... if the recruitment officer had turned round at the time 'why don't you just go for it' I would have done it I would have definitely done it but he was saying 'I'm not sure' and I didn't want the rejection of it and I didn't want to have to associate my heart with that rejection although I do. I also think to myself 'well no I didn't go for it' because if they definitely said something 'you can't have this job because of your heart' I might then have started thinking 'well hang on this is something that has limitations on me' but I made a choice myself to not go that route (2/22:374)

Rejection due to their heart condition was not considered by most informants, however this same person expressed his fear of rejection when he revisited comments made by his wife earlier in the interview. His comments indicate the importance of advice being delivered in ways that recognise the person's desire to make their own decisions.

... she can read me better than I can read myself. Yes that is very true, I can't stand rejection in any way shape or form especially to do with my heart. I've made so many efforts over the years to make my life normal and I don't want anyone telling me I can't do anything because of my heart full stop. I wouldn't even like it if one of the doctors told me I couldn't do something (2/22:610)

The potential of having to take daily medication to control raised blood pressure was seen as an imposition by another person, who preferred to consider alternative strategies, such as meditation or hypnotherapy first.

... got to have a positive attitude mentally ... possibility of what mind over matter can do ... can change not only your mind but also your body by hypnotherapy (1/11:87;128)

The response to hypnotherapy when raised during his clinic visit, implies a lack of understanding of the perceived impact the need for daily medication had on this person's autonomy and sense of independence.

... I don't know which doctor it was but I was on about this, he said jokingly 'oh next operation I'll bring someone along and I just get

on without anaesthetic' and I said 'really no probably not' ... but there are pain barriers you can get over by hypnotherapy (1/11:135)

While this informant accepted dismissal by the doctor, of alternative options to taking medication, at the clinic, his intention to consider these was expressed within the interview. The acceptance of the doctors' comment indicates the high regard placed on medical advice and is revisited later (lucky to be alive on page 127). Informants recalled medical advice provided throughout childhood related to the impact of their CHD on potential future options.

Being told I cannot do something

One informant had been told in the past that he would not pass a medical to join the army or police force, which caused him to doubt his ability to do other things

... maybe they are fitter than me ... with any sports I have done I have done it quite well but I know my limitations. It's always in the back of my mind thinking 'well yes I have got a heart condition so maybe I am not going to', but then again I think that is one of the things when I was about seven or eight before I had the operation I was told 'you are never going to join the army never going to pass the medical for being in the police force or things like that.' So maybe that has always been a barrier thinking 'well you've been told you can't do it.' I don't want to join the army or police force anyway but I think when I was about to do the bike ride I was thinking 'sixty miles can I really do this?' I did get a little bit, not concerned, but thinking 'I've got a heart condition' (1/11:197)

However, all informants said if other people told them that they were unable, or should not do something, they became determined to show their heart condition did not impose restrictions. When asked if *'following results of an exercise test you were advised by doctors not to continue with aerobic classes what would you do?'* I was told

I would carry on because I feel fine I'm not silly if I had a funny turn I wouldn't do it if I felt ill it's like any normal person doing an exercise class if you don't feel well half way through it you stop (3/8:591)

The following data excerpts from the remaining informants demonstrate the significance of this theme.

... when someone tells you something that you can't do, you are going to do it anyway and I suppose in a way that's not battling against it but its like well I am going to do it ... (1/11:269)

... nothing stops me if I want to I will do it and I can't bear the thought of someone telling me I can't do something because of my heart I might have a go at it (2/22:537)

... I was told that I wasn't allowed to do cross country long distance running ... by the doctors ... I did it anyway ... tried not to run too long, but I don't like running long distances anyway, no good at it, I imagine it's probably because of my heart, but I don't like doing things that I'm not very good at, so tried it a few times, no good at it, so gave up the idea (4/6:284)

... go diving and someone goes oh 'what's that scar from' and 'oh no you can't dive' ... I went to the diving and disease centre in Plymouth and had sixty pounds worth of medical ... started wearing high swimming costumes and don't tell them (5/19:70;81;92)

Informants claimed they took sensible precautions. Throughout interviews they talked of knowing when the time was right to perform activities, not allowing others to push them into undertaking activities for which they did not feel ready, and balancing risks. The ordinary, everyday weighing up that guides decisions for most people; the alternative was to worry about everything and to do nothing.

I am a responsible adult

The adults reported making decisions in a responsible manner. Engaging in similar activities to other people, they recognised that some things may be more risky for them due to their heart condition. This section explores descriptive themes of being lucky to be alive, useful information, understanding heart condition, being mature, keeping fit, other people with CHD, and giving something back. The descriptive themes demonstrate the responsible way in which adults with CHD made choices.

Lucky to be alive

A consistent theme expressed was that of being lucky to have survived. Informants referred to the revolutionary nature of surgical developments, and expressed their appreciation of doctors' knowledge and skills.

... my attitude has always been I have been quite lucky. To have a heart condition and had a heart operation when I was young had a really good surgeon who operated on me and I've never smoked in my life thinking well I had someone has been good enough to learn to be a surgeon to operate on me and I've got through the other side and I'm ... going to keep myself fit because I want to keep going and I am appreciative of what people have done because years ago if you had a heart condition you may not have always survived or led a normal life which I am doing now, so I have always been appreciative of what has happened (1/11:472)

... one of the main things that I think of is that when I was going through my operations as a kid it was all quite revolutionary so for me I think a couple of years earlier and I might not have been around at all; ... I am one of the fortunate ones I'm fortunate because I've survived the situation that I was in at the time and it was only down to sheer hard work and determination of certain people (doctors) at the time that learned the techniques; ... these guys (doctors) have got to do this day in day out and they have got to get it right first time otherwise disaster and every time (2/22:72; 1336;1374)

... I'm fine doing everything that I want to do but I've also had the feeling that you only get one opportunity go for it it's almost like you've been given a gift and you could have been really poorly: ... if I hadn't had my heart operation I wouldn't be able to do this, this is brilliant (5/19:146;170)

Through recognising technical expertise, trust had been established. Despite not always understanding the information that was provided by doctors, it was heeded and used to inform decisions. Having reported not wanting to be told they could not do something, medical advice was in some circumstances, accepted unquestioningly; this acceptance was reported in hospital settings. One informant throughout pregnancy had anticipated a normal delivery, however required caesarean section due to raised blood pressure as a result of her CHD.

... it was one of the situations that you have to come out and which one's best and you just have to go along with it and trust them (3/8:130)

Following the birth of her baby her blood pressure remained elevated and medication was prescribed.

... if they (doctors) say I have to go on tablets I have to go. I do trust them. I don't really understand what they are trying to say (3/8:463)

Parents, usually mothers, confirmed trust in doctors; the same informant went on to say

... I trust them because obviously they've saved my life. They gave me the operation and otherwise I would have died so that's why I trust them and I have absolute trust in my mum, she trusts them (doctors) 100% because of what happened. I think that's where the trust comes from (3/8:516)

Views of the mother of another informant contributed to his accepting medical advice, when he was told further surgery was necessary.

that was something ... gave you a bit more confidence because M (doctor) who was gonna do the operation and you (Mum) were always going on about how good he is (4/6:802)

Nevertheless doctors and patients may have had a different perception of the purpose of information exchange when they met, and some shortcomings did emerge throughout interviews. One informant expressed trust despite a lack of communication between hospital and her GP as well as between doctors and herself.

... he (doctor) wanted to keep an eye on my blood pressure and that they would write to the GP ... I went to the GP about something else and mentioned it and he had had no correspondence ... so it is both ways they are not very good they know what they want to do but they just don't communicate very well. You've got to tell them yourself ... if I go through it again I would tell them myself, I wouldn't leave it to my GP (3/8:169)

This person talked of how, through using experience of previous clinic visits and her understanding of her heart condition, she was able to take the initiative. A responsible approach was demonstrated throughout the interview.

... over the years they ask the same questions ... by now I know that there are certain things that if I experience it 'oh well they ask me that every year so that obviously isn't right' so I would get in contact with someone (3/8:532)

The same informant talked of how she had developed an understanding of her heart condition, while not understanding explanations provided by professionals. This also raises issues of how information is provided which is discussed in the following descriptive theme 'useful information' on page 131.

... I have got my head round some of it now but that's only through years and years thinking explain it to me again. It's like they'll say something to you 'cause you know what that means' and I'll say 'no' and it's 'well why don't you know' 'cause you don't explain it to me' (3/8:480)

While trust in medical staff was expressed, this was balanced by different expectations regarding communication. Another example of difficulty in communicating with doctors was provided; this person considered good communication required active listening. He had been admitted to hospital for investigations of chest pain and was seen by an adult cardiologist experienced in treating patients with coronary heart disease.

... they need to listen to their patients a bit better ... I've said to them 'this feels like this' you get the feeling that they are like well 'no it doesn't' ... cause they've got own ways that they know. They have been dealing with this for years ... I've been talking to the adult cardio guys telling them how I feel and they have made assumptions based on what I've said which I know are wrong ... things like some of the pains that I was experiencing it wasn't a pain and it wasn't shifting across here and down here and it wasn't pressing directly in the middle. It was like I was hungry but in my chest but they couldn't understand that, it wasn't in their list of symptoms so therefore they were very much 'well yes but does it feel like' 'no it doesn't feel like something pressing on me' 'but are you getting' 'no I'm not getting a pain across there, you're not listening to me'. I think especially with people like myself that have lived with it and grown up with it sometimes they need to just hear what you are saying as opposed to knowing what they've learnt (2/22:1443)

The need for vigilance and follow-up was acknowledged; however again lack of communication led to questioning the value of some procedures related to the individual's ability to perform activities. A test had been scheduled to assess the effects of exercise on one informant's heart function, and was booked after she informed the cardiologist she attended an exercise class.

... that's their (doctors) job I suppose they have be to vigilant ... I think they do keep an eye sometimes it can go too far all the poking and prodding: ... it's (exercise test) a waste of time, they didn't get

anything from it, I never had any results back from it, never heard a thing back from my exercise test, so I assume everything was OK (3/8:561;566;578)

Failure to send results to patients raises questions regarding the purpose of the test, and for whose benefit, doctor or patient. Later this person told me she would continue to do the exercise class even if doctors advised her to stop. Information that is relevant is required in order to make responsible decisions, while information was provided during the clinic visit the relevance appeared to vary between doctors and patients.

Following clinic visits patients did not routinely receive specific information; however one person requested a letter when she was discharged from follow up. This was the first time she recalled having the correct terms to use when explaining her heart condition to other people.

... I have a letter to say that I am well ... I don't understand much of it, it's all axis this and something that ... since having that letter it said ASD and right that's what I need to do, that's how I deal with it now (5/19:625)

During the initial interviews one informant spoke of how the information required changed as she grew up. Doctors providing the adult congenital heart service accessed for this study were paediatric cardiologists, indicating the sub-specialty nature of the patient group. The same person spoke of how useful the letter had been subsequently.

... I make sure that they've got the facts without needing anything else. They've got the information it's there in front of them and that's IT. That's the way that I am going to do life insurance again, because if I give the no waffly, very correct information and know the right terms and things then I won't have to deal with all this paper shuffling and things. It just seems to work, it would have been useful I guess to know the correct terms for it. (5/19:711)

The letter, sent to her GP, had been copied to her, providing a summary of her heart condition and surgical treatment. Since having the terms she had used them with good effect to provide information of her heart condition to obtain life insurance, change GP, and to provide her medical history to a midwife. She had been unable to remember details provided during her clinic visits due to a

high level of anxiety, therefore considered a concise summary would have been beneficial previously.

Useful information

The previous section identified ways of communicating to be important to informants; this section considers the content of what is communicated. Information found useful by the adults with CHD was different to that usually provided by health care professionals. Information perceived to be useful by the adults with CHD provided details of activities that could be undertaken; this is in contrast to being told what they cannot do as discussed previously (page 126).

... one of the things that did come out was when I was saying how much running I was doing. He (doctor) said 'you may be in a good position to do running because the way the valve leak is that when you are running the valve leakage stops' I thought 'well that's interesting (1/11:38)

Information provided by professionals in order to prepare the adults for future events, such as the need for surgery, had the effect of making the same person believe the surgery to be imminent

... before the bike ride that was when I was sat down and told for the first time that you are going to need a second heart operation and that is when I thought oh hang on a moment and then my mind started playing tricks ... (1/11:329)

He said

... I had this angio whatever they call it ... doctor came and said 'I think you will be having a second heart operation sooner than later' and I did get thinking. When I went down there for the check-up I thought they are going to say 'Oh yes next year we're going to pencil you in for everything' I got down there and I was sitting in the waiting room ... looking around and thinking 'I am fine, I don't need another operation for at least three or four years'. I looked around and it's like other people were really quite, not unwell, but I think they were struggling and I was thinking 'I am sitting here I am as fit as a fiddle, I have done the bike ride. No it's not going to happen' and it didn't. They said 'you have done really well, we probably don't need to see you for another two years' and I think 'Well hang on, yes that's from the doctor's point of view they always have that cautious side of things' ... (1/11:273)

In contrast, another person who had always known further surgery was required, when told this was now necessary, initially refused, reiterating different ways in which the relevance of information is heard and understood. Further examples were given of how information provided by professionals and that required by adults with CHD may vary

... you ask in the hospital it can be too much you don't want to know too much you just want to know the basic things that what you're doing isn't hazardous, I suppose not doing anything stupid ... can be too much, too much information is not always a good thing but information ... for the normal person quite accessible quite easy and that's good (3/8:1047)

Prior to surgery one informant reported he found some information provided too much detail. As part of gaining consent for surgical procedures, patient understanding of the condition and potential physical risks are considered to be essential for consent to be informed. Adults with CHD are likely to understand their condition in ways that are different to a cardiac surgeon; information provided prior to surgery is likely to be given in ways that are understood by clinicians.

I didn't want to know too much ... I wanted to know what they were doing I didn't want to know how they were doing it didn't want to hear about the whole breast bone being cut and stuff like that rather not know about that I understand they do it and I know roughly what they've got to do but I'd rather not know exactly what they're doing (4/6:502)

Information was available from different sources, however, predominantly it was obtained during the clinic visit. Not all information was found to be useful by the people who took part in this study.

... I also go on the Internet you get on that you never come out but I am very very objective about what I look at ... because you can frighten the hell out of yourself ... there's loads of stuff I see on there about my heart ... you just think what's going on, this ain't me ... this is rubbish and if you know that it's rubbish believe it's rubbish because you'll see things on there that will make you stop trying to live your life and I hope that I'm not going to do that (2/22:678)

Information related to CHD was available from national and international patient associations and available on Internet sites. Patient associations frequently have links with clinical staff who have expertise with the

management of conditions. Details of anatomical and physiological components of CHD form a large part of the information as understanding physical aspects can contribute to recognising complications that may arise.

Understanding heart condition

Useful information that was related to the adults' daily life, also contributed to their understanding of their heart condition. Informants in this study demonstrated understanding of their heart conditions in ways that were different to health carers. One person who until recently could not remember the name of her heart condition, demonstrated understanding throughout her interview.

I can remember to say what I had done, years ago I couldn't say that, but I've got that down to a T now ... (3/8:150)

I don't classify myself as being ill, I was ill when I was a baby ... (3/8:373)

I know I shouldn't have high blood pressure... (3/8:505)

I was always told that smoking and drinking is bad for you anyway ... (3/8:677)

can be more prone to heart disease, so if I am more prone then I should be that bit more careful, everyone should be careful no-one should do it (3/8:727)

Understanding may not be well demonstrated in ways that can be appreciated by clinicians, however adults with CHD may not need to know in the same way as health and social carers. Diagrams were not well understood or remembered and hence not useful in helping the adult to understand their heart condition. Information that is relevant to the adults' daily life was recalled and used to inform decisions regarding the likelihood of risks, and how to avoid or minimise these. One person expressed his awareness when things were not right with his heart

... there's times when you can really feel uncomfortable within and you think something's not right and that's when I went through with the palpitations and all that lot and ending getting it checked out because I really felt within myself that something wasn't right ... (2/22:288)

He continued to explain how he recognised his limits and would not be pushed into activities for which he did not feel ready

... I think there is probably a little bit of knowing your limitations as well if I am doing a lot of exercise I'll know not to push myself not really hard: ... I knew I needed to work it (heart) but not to overstretch ... I wouldn't have done that ... I knew that I couldn't and I wasn't going to get badgered into it: ... it's an awareness rather than a limitation its just an awareness of what you can do at that time ... I don't see it as a limitation because I can do those things but there are times when I think to myself no I can't do those today (2/22:292; 570; 738)

Information was accessed predominantly from the tertiary centre during clinic visits, and was used by people in this study to inform decisions. Adults with CHD may be unaware of aspects that may be relevant to them; this became apparent during initial interviews. Informants had 'peace of mind' reporting no information requirements until prompted by a list prepared from patient association sources. However when information was accessible it contributed to their ability to make mature decisions.

Being mature

Informants considered they made responsible decisions during their life, as a result of understanding the need to consider activities that posed a specific risk to them. The adults described themselves as being mature in decisions made regarding their heart, while having engaged in other less responsible activities during their adolescent years.

... I think we mature at an early age if you are dealing with this sort of thing I really do feel like I've been quite mature from quite a young age I feel like I've been making these decisions all my life responsible decisions (2/22:857)

... now I make decisions and take more thought over it and I do think well if it's going to harm me it's going to make me ill then I don't do it because I never want to be ill (3/8:658)

Two informants reported engaging in activities that might be considered less responsible, although maybe not unusual adolescent behaviour. Activities such as getting drunk, or going to all night raves; but avoiding illegal recreational drugs probably because of the potential effect on well-being due to their heart condition. The need to maintain well-being was associated with exercise and keeping fit.

Keeping fit

All informants took part in exercise and considered this important in staying well. Gender had not been a significant aspect in this study, however differences began to emerge. The three males who took part in these second interviews considered themselves to be competitive, reporting that they wanted to show they were more fit than others. A range of activities were undertaken to keep fit and to manage weight; these included football, cycling, running and T'ai Kwando. It was not unusual to be told that people had been advised they would not pass a fitness medical to join the police service or army, although one person remained eager to join the police service. The impact/influence of advice given during the clinic visit was significant for some informants

... I can go a lot further, get fitter than I am now because I think it was when I was first told 'oh yes your valve is leaking and you're going to need a second heart operation maybe in a year or two or three years time' I thought there was going to be this gradual slow down and I was going to get unfitter and get harder to do things but now I'm thinking I can get fitter and I can push myself even further (1/11:350)

This person continued to expand on how he did more exercise and related it to aspects other than his heart condition

... I was playing football twice a week and then five a side ... since 2002 I have done a lot more exercise and a lot more running. Last summer I could run up to five miles and that's the first time in my whole life I have ever done that (1/11:455)

it's more to lose weight actually, I can put on weight quite easily and it is keeping fit and just losing weight keep in shape so that I can fit in the right clothes and look good ... (1/11:467)

One person did a lot of exercise and related it to his heart condition

... I do a lot (exercise) ... it is probably a conscious effort to make sure that I'm fit ... I do a lot more exercise because I want to make sure that I'm as fit as I can possibly be ... I know that if I get my heart pumping and get it moving I know that it will benefit from it so I probably make a little more effort to do that than someone else perhaps would (2/22:303)

Other people with CHD

Informants were interested to know how well others involved in this study were; all considered themselves to be less affected than others by their heart condition.

... I never think there is anything wrong so I suppose other people may have more appointments or check ups with doctors or maybe their life is just affected more so with me it's not so you don't think about it so you carry on (1/11:66)

... do I seem par for the course with all these people? ... and I wondered if everyone else is the same (2/22:1007)

... is that you have found then that majority people were just well, that's good ... I've always thought to myself that I have to be careful but there's a lot of people out there who are ill and can't do things they want to do (3/8:1096; 1242)

... a lot of people worse off than I am ... (4/6:661)

... I don't know how successful everybody's operation is but it sounds like mine was really successful (5/19:146)

One result of being well was that it was not thought that the patient association could offer anything.

Giving something back/patients' association

Participants appreciated being well, possibly better than other people, and were prepared to give 'something back'. Patients' association (GUCH) contact information, provided during the initial interview, had been used in some cases. Views of the value of accessing patients' association were volunteered during the subsequent interview.

... I have seen the grown up congenital heart groups and I don't want to get involved in that because for me that's for people that are sick and that need help and although I'd love to get involved in helping those people my life is so normal at the moment I don't want that coming into my life (2/22:1011)

Another person also thought he might be selfish not wanting to be involved with patients' association; he could see no benefit in spending more time on things connected specifically with his heart condition

I don't think I need any help I don't necessarily need to know any other people that got the same don't see how that's gonna help me ... already have to take a day out every couple of years ... don't want to take any more time out for anything else, just the way I am, quite selfish I suppose just want to live as normally as possible ... (4/6:681)

Another person had found the patients' association helpful; she had accessed the website when she was pregnant, and now receives regular newsletters.

... I found the website and that was helpful they sent me a whole literature on pregnancy that was good (3/8:1041)

She continued to say how she would not have known where, other than the clinic, to find information. In fact the clinic did provide details of the patients' association; I believe this to be an example of the difficulties patients experience in receiving information that is provided at the clinic.

In contrast another person had accessed the patients' association by telephone and was ambivalent regarding its usefulness

... I phoned them to try to find out about insurance, they were fairly helpful. I don't remember coming off the phone thinking 'wow, excellent, phone them again' I don't know whether they just didn't have that information or something ...' (5/19:1291)

Another person had taken part in the British Heart Foundation London to Brighton cycle ride to raise funds; he said

... my manager, strangely enough I didn't know at the time, his son had a heart condition, I was going for a check up and he said 'which hospital?' ... I think he (son) even had the same ... the bike ride came up and because it was for heart foundation 'yes' we'll both do it to raise some money (1/11:491)

... there is a little box on there to tick for publicity and I did want someone to just come along and take my photo afterwards ... there was 20 000 of us doing it but it would have been nice if someone had come along and taken a photo at the end because I would have happily had my photo taken and said 'look you can do this, I had a heart operation twenty-five years ago but I can still do sixty mile bike ride and I am raising funds ...' (1/11:504)

Through behaving in a responsible way, taking account of their heart condition as necessary, enabled informants to engage in activities of their choice and get on with life.

I get on with life

The interpretive theme 'I get on with life' developed as informants provided accounts of how their heart condition was part of the background tapestry of life, only coming to the forefront at certain times. This section explores descriptive themes of being aware of it (heart) all the time but not thinking of it, worry when you need to, other people, and the clinic visit. The descriptive themes show how informants accommodate aspects related to their heart condition into their every day life.

I am aware of it (heart) all of the time, but I don't think of it

This descriptive theme emerged despite the claim by one informant that '*... I never think that I have a heart condition ...*' (1/11:16). He went on to provide accounts of ways in which he accommodated his heart condition into every day life, demonstrating the normality and reality of life in which contact with the hospital was usually only during the clinic visit. The heart condition forms part of the background to the adults' life; it does not dominate other aspects, but is integrated within life in the same way as being either tall or short.

... I don't see myself as different to anybody else ... even to the point where I don't remember I've got the scars (2/22:46)

The adults recognised activities that were difficult for them and developed strategies to prevent the heart condition being a limitation, in the same way as a tall/short person would. All participants expressed this experience, initially claiming they forgot about their heart, then going on to provide accounts of how it was accommodated throughout every day activities. Their ability to live a full life resulted in other people either being unaware or expressing surprise when they learnt of the heart condition.

... I don't think I've got a heart condition people at work think 'you've got a heart condition, didn't know that' well my cousin after we did a bike ride, he didn't know, we went to the blue lagoon and all of a sudden he came over and said 'what happened to you?' I thought maybe I had cut myself and had blood pouring out of my foot and he said 'no the scar' and I said 'oh yes I had a heart operation I don't know twenty years ago' and he goes 'you've just been on a sixty mile bike ride the other day' and I said 'yes so?' and he goes 'oh' so again its like you just get on with life and don't think you've got a condition (1/11:40)

Several times one informant said that she thought about her heart as she made decisions, however it did not dominate her thoughts.

... I am aware of it (heart) all of the time but I don't think of it. I do think about it a lot but I don't ponder over it but it's always there ... (3/8:772)

Having grown up with other children who were healthy the adults considered themselves to be the same.

I don't see anything different ... because I've grown up with other kids that are total healthy lives ... I don't see myself as having any limitations (2/22:285)

This theme was consistent throughout interviews, and demonstrated how informants were able to live well and safely without letting their heart condition dominate their life. Sometimes events occurred, such as the clinic visit, which heighten adults' awareness of their heart. Occasionally problems were found during the clinic visit that required medical or surgical intervention, however, usually all was well. Despite having been aware that further surgery would be necessary, this person told me:

... it was quite a shock to be told that. Got to come in again. Space for you in about two weeks ... (4/6:509)

Another person, who was told at the clinic that he might require medication to treat his raised blood pressure, told me:

I don't think I worried it was more the hassle of having to take a pill everyday ... just feel like you're tied to something ... there's not a weight round your neck but by taking that pill every day that you have got a heart condition (1/11:374)

Implying that taking daily medication was an inconvenience, making him more aware of his heart condition.

Worry when you need to

Participants did not consider themselves to be ill; they had something that has been repaired, while recognising the need for ongoing medical follow-up. As already said the heart condition formed part of the background to life, which the adults did not think of all of the time, getting on with life doing everything they chose.

... if you spend your whole life thinking about it panicking about it you wouldn't do anything ... (3/6:331)

I don't think you can worry about it, if you worry about it you'd drive yourself mad... it's something that happened ... I'm not ill, I am not ill at all, that's the way I think ... (3/6:365)

... you don't think about it, and because I don't take tablets I don't take medicine I don't need anything ... do what I want when I want I fly, I run, I bike I get on with normal life so I never think there is anything wrong ... (1/11:57)

This can appear to be a denial of events; however this is not so. Events are acknowledged, but rather than brood on them, the person moves on. One participant who had suffered a serious illness six years earlier, which was unrelated to his heart condition, provided the following account.

... we have drawn a line over it they said well that was that part of my life and I think that's how we really get by you know with all of it just to literally draw a line over it and say you know that happened that's beyond move on ... (2/22:208)

Later in the interview he talked of how the heart condition was always there and how he had adapted because he was usually well

... I've always had the heart problem and the heart problem always been there so you kind of grow a barrier against it ... it is just pure adaption to what's going on around you you do just adapt to the situation that you are in, I've not been taught to be the way I am I've just grown into that because of the situations that have happened through my life ... it's (clinic visit) every two years I block it completely after I've been, I think you adapt to it ... (2/22:1408; 1456)

The role of doctors to be cautious was related to it being easy to not do things; this person thought he could do more than expected, but identified the need to be aware of limitations.

... from the doctor's point of view they always ... that cautious side of things simply because they are always looking at peoples' best interest ... I have always had that attitude you say I can't do these things but I'll prove that probably I can (1/11:288)

The adults had a positive view of themselves and expected things to go well. The general impression given by informants was of dealing with problems if they arose; rather than anticipating problems, the expectation was of being well. Other people, including parents and partners, may be more worried and talk about potential problems; however informants did not and could not expect the worst all the time. The ability to recognise problems when they do occur has been discussed earlier (understanding heart condition page 133).

Other people

The role played by other people varied. Informants reported parents who encouraged them to be involved in everything as a child; however they would now question the safety of activities undertaken. One informant reported being regularly questioned about her safety to go diving when others saw her scar. Having made a responsible decision, taking their heart condition into account, informants felt it was unnecessary to explain to other people.

... it (heart) is an issue but for me I do something I think about, I make the decision and I get on with it. Other people they should know that I am an adult I can make that decision. I'm not silly but they don't always know to leave it and say 'are you really sure?' I think 'yes I am, I'm sure that will be OK.' (3/6:428)

... it's other people issues with it because I really enjoy diving but the minute that somebody starts questioning me I just think 'Oh for goodness sake' it's not what I want to do I don't want to have to talk about it (5/19:104)

Informants considered others saw problems, rarely a positive aspect, needing to check for themselves that problems had been considered. Merely being told by the adult was insufficient, making the adult feel not believed despite having taken a responsible decision. Other people questioned further or requested

explanations from the adult, raising awareness of the heart condition during normal activities for the adult. The 'other people' who required confirmation included employers, insurers, other clinicians such as midwife, obstetrician, or when the adult changes GP registration due to moving to another part of the country, and almost anyone who saw their scar.

... people think because it's your heart ... you'd explain and they were 'are you OK?' You have to go through the whole thing. I don't think people believe you sometimes ... they think there must be something wrong ... it's because it's the heart as well (3/8:375)

This informant went on to tell how other people avoided asking her directly when there was potentially a problem.

Clinic visit

The potential for problems to be found caused high levels of anxiety when attending the outpatient clinic, despite the fact that the adults felt able to assess their own physical condition. The clinic visit made the adults aware of their heart condition. Four informants reported the clinic visit 'raised their blood pressure'. The following extracts threaded throughout one interview provide insight into how this person viewed the clinic visit. A large extent of data has been included here because it vividly demonstrates the impact of the clinic visit for this person. Her emotion was tangible during the interview, which is identified as 5/19. The numbers included here are the line numbers in the transcript (see table 4.1 on page 95).

... I just completely panicked and I was like that every time ... I don't have to go back now ... and it's brilliant not having that looming feeling. It was always October time and I always hoped it would be before my birthday (204)

... I knew it was coming up then the letter got here (221)

... I don't know why I just used to really really worry about it (887)

... I was still going with my Mum until I was quite a bit older, I really needed my Mum to be there and she was my voice ... I sat there ... I didn't want to know anything nasty want it all to be happy don't tell me anything nasty (1083)

... I got myself wound up for the appointments I don't remember a great deal about them other than them being completely traumatic (1129)

... I can always remember feeling better when I am coming away so obviously things were good but I can't actually remember anything useful other than OK it's still alright. That's what I used to come away thinking that's OK it's still alright hasn't gone wrong yet ... I'm fine for another two years ... I never used to think I'm well I'm fine excellent I used to just think OK I don't have to go back for another two years. I always felt I was waiting for the inevitable because I had to go back again (1134)

I always felt that the inevitable was they are going to say 'you need another operation' and I think once they said 'you don't need to come back' I was like 'oh they obviously think that nothing's going to happen. Oh I'll be alright then' (1145)

... until they said 'we don't really need to see you any more', until that point I was waiting for them to say 'OK it has got worse it has gone wrong we need to do something about it' (1162)

In contrast another informant provided a completely different perspective

... I'm back to the hospital every two years for a check up I put everything out of my mind until it's time for that check up ... think about it a week beforehand and even then it's become so normal its just nip down to the hospital just nip in have a few tests and nip back out again and you're not even looking for any results when you go down there because you know everything is fine (2/22:268)

Despite the clinic visit raising his blood pressure another person told me

... I've only been up there once and they've said anything bad ... I go up there every year, fifteen appointments whatever, one went bad ... they say will be over twenty years this operation so I don't see any point in going back ... go back in about fifteen years and check me out unless I'm feeling any worse ... (4/6:590)

Without exception the clinic visit prompted informants to think about their heart condition irrespective of whether anxiety was caused. This example encapsulates the uniqueness of individuals, which was possible in the phenomenological approach selected for this study.

Synopsis of chapter

The descriptive and interpretive themes that developed from the data have been outlined. Informants' words have been given to indicate the decisions made during as analysis progressed. My interpretation has been given of the lived experience of the adults with CHD, who provided their stories during interviews. As a result of the findings from the initial interviews, the research questions guiding the second interviews became more focused on informants' ability to live well.

CHAPTER 5

DISCUSSION OF FINDINGS

Introduction

As part of this phenomenological study twenty-eight people participated in initial interviews during which they provided personal accounts of their experience of living with congenital heart disease (CHD). A key theme throughout the transcripts was the positive view informants have of themselves, which contributed to their well-being. The heart condition was an integral part of who they were, but did not dominate their life.

Informants made sense of their CHD with a range of resources, such as their social network as well as health carers, contributing to their ability to adapt as necessary. Three main areas influenced the positive view held by informants, and generated a need for information or services. These were: the perceptions of other people, when the CHD impacted on available choices, and when hospital attendance for outpatient appointment or inpatient treatment occurred.

I had entered this study curious about how, irrespective of the complexity of the heart condition, some people were able to live well, while others could not. I was aware from my practice experience that information was regularly given by health carers to patients regarding their heart condition, a recurring theme within the literature, however, was of patients being unable to appreciate the significance of specific details regarding their CHD (Kantoch et al 1997; Moons et al 2001a). Rather than being unable to understand their heart condition, what became apparent during interviews was that informants valued details of their heart condition when related to the everyday aspects of their life. This was in contrast to the primarily disease focus, which is the usual way health professionals understand CHD. Ways in which adults with CHD understood their heart condition differed from health carers; hence information was given a different meaning by them to that intended by health carers. As the study progressed I became more aware that informants were 'patients' only when they attended

hospital appointments. I wanted to better understand ways in which informants accommodated their heart condition into the 'non-patient' aspects of their life.

This discussion chapter examines the study findings within the context of contemporary theories and makes manifest the new knowledge that has come from informants' stories. Initially data were organized into themes as they unfolded from informants' own words. Comparing these themes with literature on positive health I found that they closely matched components of Antonovsky's (1987) sense of coherence and salutogenic model of health; these are discussed in detail later in this chapter. The relevance to adult CHD, of theories of chronic illness, health behaviour change and psychosocial development were also apparent. These theories are the pattern themes referred to by Miles and Huberman (1994).

Pattern themes

Informants in this study reported a range of strategies used to successfully adapt as they grew to adulthood; referring to '*the little things*', things other than medical aspects. The descriptive and interpretive themes emerging from initial interviews had revealed aspects that led to being well. Having the knowledge and confidence to successfully adapt once informants became aware that their heart condition could have an impact on the choices available to them. The themes were similar to stages of health behaviour change. Readiness to change was achieved once the individual considered change important, confidence and knowledge of how to change was then required for change to occur (Rollnick et al 1999:22). While 'change' had not emerged through the data analysis, adaptation had. Parallels were apparent with adults with congenital heart conditions as they made the transition (or change) from childhood to adulthood.

Readiness was central to making change. Convincing others that they were 'normal' became important if adults with CHD were to be able to pursue

activities and careers of their choosing. It was essential that what they knew intuitively be expressed in ways that could be understood by other people. The ability to do this became a necessary skill.

The tacit knowledge that informants had gained through living with their heart condition optimised their ability to assess risks and make judicious choices regarding the activities in which they participated. These activities contribute to making life worthwhile, enabling them to live a full life rather than always taking the 'safe' option. The ability to make appropriate choices was key in achieving health within illness, or living well with a condition that required long-term follow-up.

The ability to make appropriate choices had been developed through experience of living with their heart condition; 'self-efficacy' is the term used by Bandura (1997) to describe a person's belief in their ability to make effective decisions. Making their own decisions was important to informants. They were able to weigh up the risk themselves, taking account of advice from others such as parents and health carers, and then participate in activities of their choosing. Decisions were mature and responsible, not foolhardy, with a strong desire to maintain 'fitness', while joining in the activities of life.

The interpretive theme of peace of mind identified within the data developed as a result of informants' view of themselves. Having become aware of their heart condition as a child, they had grown up with few limitations and considered themselves to be the same as their peers. As adulthood was entered routine activities such as choosing employment, were frequently questioned by other people. It is not unusual for the views of wider society regarding disease processes, to vary from (be more pessimistic than) the reality of living with that condition. Corner (1997) reported this counter culture in relation to cancer, and the symbolic nature of the heart has resulted in a wide range of associated emotional and social meanings that impact on how CHD is perceived (Glaser and Bentovim 1987). In

order to make their own choices in life it was necessary for informants to convince others that the heart condition was not an impediment. Knowing how to show they were fit and well (different to adults with acquired heart disease) became important. An intuitive understanding had been gained through experience, making this explicit was essential to allay the anxieties of other people.

Once interpretive themes had been identified and related to contemporary theories, this was represented diagrammatically (Figure 5.1). The research questions guiding this study provided the context within which existing theories were related to the findings, forming the pattern themes. The pattern themes are not discrete; rather they form an inter-related, dynamic mosaic reflected by the sense of coherence central to the salutogenic model of health proposed by Antonovsky (1987). The descriptive and interpretive themes, set out in the previous chapter, are now re-examined using the pattern themes to provide structure. Discussion of the relationships with adult CHD will begin using pattern themes as headings; these are health within illness, health behaviour change, and positive health.

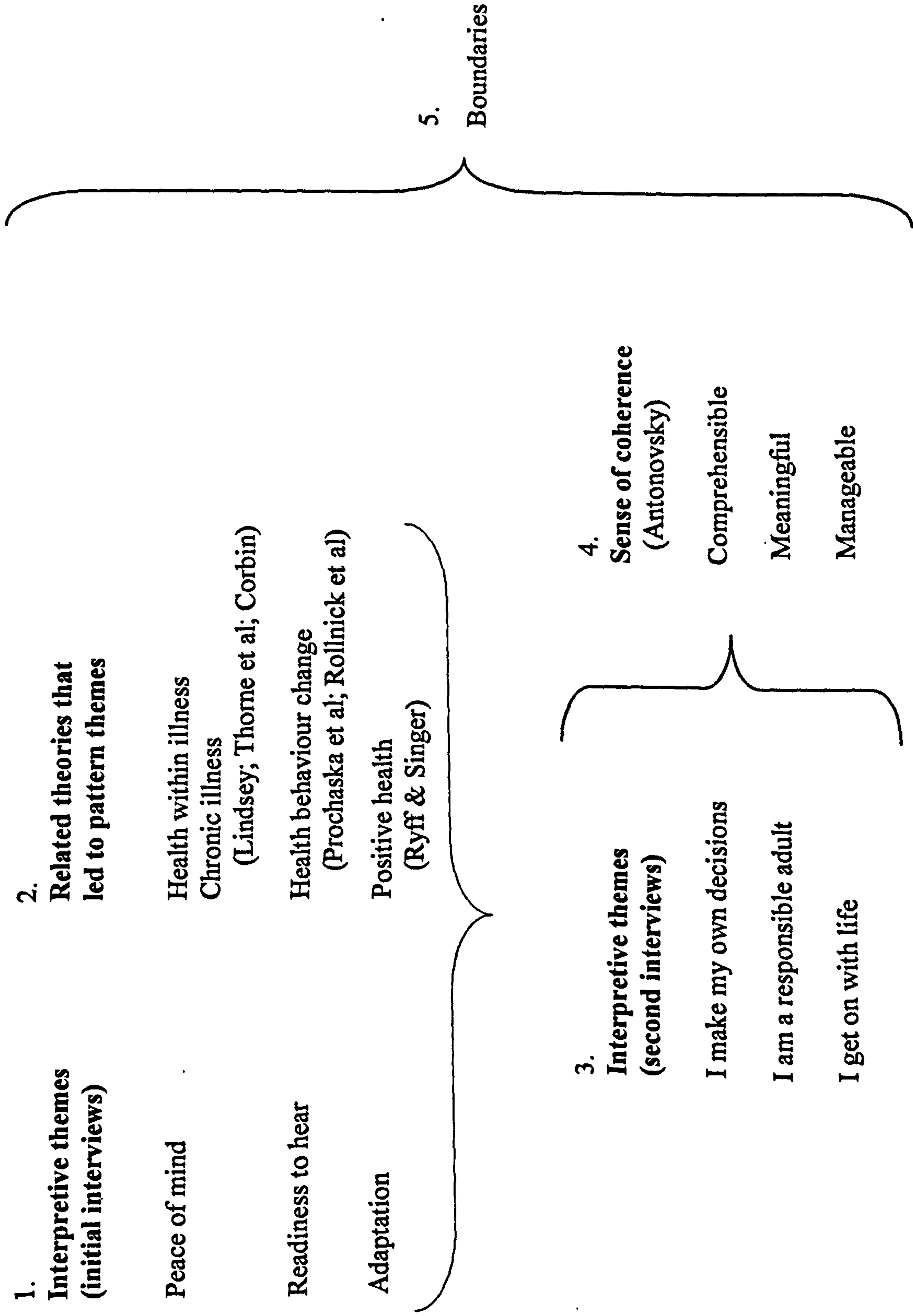


Figure 5.1: Relationships between interpretive themes, existing theory, and conclusions

Health within illness

Health within illness is the pattern theme that relates to the interpretive theme of peace of mind. Informants in this study demonstrated an understanding of their heart condition that was not always evident during clinic visits. More recently it has been acknowledged that people living with long-term conditions can have a better understanding of the physical, psychological and socio-economic effects than health professionals (Long Term Medical Conditions Alliance (undated); Department of Health 2001b; Picker Institute 2005). The concept of using patient expertise to develop service user self-management programmes has the potential to include patients' perspectives to inform service provision. Examples were provided in the literature, however, the focus was on the 'illness' aspect of chronic medical conditions including arthritis and asthma, and using self-management principles. The exact meaning of terms was confusing, chronic disease, chronic illness, and long-term conditions were used interchangeably. The Department of Health used 'long-term conditions' to refer to conditions such as asthma and diabetes, and while heart disease was included, what was considered was acquired heart disease (Department of Health 2005). Clarification regarding how terms related to CHD was required.

CHD is a condition that will require life long follow-up for the majority of people; definitions of chronic illness, however, seemed inappropriate when used in relation to informants in this study. Initially the definition provided by Price (1996:275) appeared to offer a tentative fit

(chronic illness is a lived experience, involving) ... permanent deviation from the normal, caused by unalterable pathological changes

Although CHD is not a pathological change, it is an anatomical defect that may lead to pathological changes. The views of informants, however, were not reflected as Price (1996:275) continued

... chronic illness involves a permanent alteration in the individual's way of life, and a reappraisal of that which may be hoped for in terms of function and health

Having had the heart condition since birth, limited alteration or reappraisal was reported, unless to accommodate the perceptions of other people.

Even less suitable was the definition used by Ironside et al (2003:172) who say that chronic illness is

... a disease or injury that has lasted more than 6 months and has caused an individual to significantly alter his or her day-to-day activities.

While terms such as chronic disease/illness were inappropriate, as they did not reflect the well-being expressed by informants, the term 'palliative' was used with regard to surgery for CHD; however, this term also has the potential to generate confusion. This term has been associated with the hospice movement that provides end of life care for people with terminal illness, specifically cancer, and as such may have connotations that are in contrast to the well-being expressed by informants. While surgical procedures for CHD may be palliative, that is not fully corrective, long-term survival for this population remains largely unknown due to the recency of technological developments. Survival does, however appear to be better than originally anticipated in the literature reviewed early in this study.

As stated in the introduction to this thesis the meaning of 'corrective' and 'correction' in relation to surgical procedures for CHD was questioned (Chapter 1: 14). Seventeen years ago Stark (1989:1) went on to propose that 'normal life expectancy' should be replaced with '*normal health during the long-term follow-up*' (my italics), indicating an anticipation of patients being well, while needing ongoing observation.

Like most people, informants in this study were able to recognise when they felt unwell, and were aware of specific features related to their heart, sensing when something was different with their body. Despite the different

sensations, they did not consider themselves to be ill unless their daily life was disrupted. Knowing their own heart contributed to informants' ability to make responsible decisions, allowing them to get on with life, do normal, everyday things, the same as other people. Similar accounts of 'knowing one's body' (Corbin 2003:258) and 'body watching' (Thorne et al 2003:1342) have been reported as contributing to every day self-care decisions. The recognition of patient expertise relating to chronic illness was the focus of a series of studies by a team of nurse researchers in Canada (Thorne and Paterson 1998; Thorne et al 2000; Paterson and Thorne 2000; Paterson et al 2001; Thorne et al 2002; Thorne et al 2003). Unlike CHD, the conditions within these studies required daily actions by patients to remain well; nevertheless similar areas, to those reported by informants in this study were identified as contributing to peoples' ability to remain well. Common areas included: being able to participate in meaningful activities of life taking precedence over activities specifically related to the disease; having a wellness, in contrast to an illness perspective; and being able to sense when things were not right.

The notion of patients with chronic conditions understanding their disease better than clinicians is central to the United Kingdom (UK) government concept of expert patients (Department of Health 2001b). However, despite its appeal, CHD may at present be unsuitable for self-management programmes as proposed within expert patient recommendations. The term CHD covers a variety of conditions with a range of outcomes and patient experience. One reason for not accessing CHD patient association support, given by informants in this study, was a perceived lack of specific relevance to them. Expert patient proposals are for selected disease-specific self-management initiatives, such as asthma, arthritis and diabetes mellitus. CHD comprises a wide spectrum of conditions with relatively recent survival to adulthood, as such there is limited evidence regarding long-term aspects. Evolution of surgical procedures continues as a result of research into postoperative survival patterns; the relevance of findings across the range of conditions has not yet been established. The intention of expert

patient initiatives to generate a concordant relationship between patients and health carers can inform the development of services for adults with CHD. Ways in which partnership between patients and professionals can develop are currently being proposed (Department of Health 2006). A more participatory relationship has potential to inform the evolution of the UK patient association, GUCH; this is becoming apparent in the style of more recent newsletters. Similarly, the theory of health behaviour change (Rollnick et al 1999) offers a person centred approach to giving information that fits with views expressed by informants in this study.

Health behaviour change

Health behaviour change is the pattern theme relating to the interpretive theme of readiness to hear. Being well according to informants, involved making their own choices regarding all aspects of life. In order to make choices in ways that avoided other people being over cautious meant the heart condition was not always revealed; it was not a secret, but sometimes would not be mentioned by informants unless directly asked. Similar to strategies reported by Livecchi (2004), one informant (5/19) provided examples of how, when she talked about her heart condition to other people, this was done in ways that demonstrated she was well, therefore preventing further questions being asked. This informant found it irritating when other people expressed doubts regarding how suitable it was for her to engage in activities, when she had taken appropriate precautions to ensure her own safety. The majority of people who expressed concerns had little or no understanding of her heart condition, and would tend to err on the side of caution and so prevent her participating in activities. Informants made decisions in a responsible way that took account of their heart; once other people were aware however, the decision could be questioned. The questioning and need to explain to others resulted in the heart condition becoming an issue, but it was an issue for other people, not informants. The views of other people, through having an impact on available choices,

had the potential to limit the boundaries within which informants had elected to live their life.

Informants saw being advised not to do something as a lack of choice, affecting the boundaries within which they got on with their life. A more recent study by van Rijen et al (2004) has identified being told not to do something as having a negative impact on a person's psychosocial well-being. The subsequent disruption caused in the sense of well-being can be likened to 'turning points' as defined by King et al (2003); turning points can be positive or negative. The nature of turning points can result in readiness as defined by Rollnick et al (1999) in their work on health behaviour change. Informants in this study had developed their own strategies to develop confidence and knowledge if other people expressed doubt regarding their decisions or ability.

Traditionally there have been expectations that patients will comply with advice provided by clinicians, in order to maintain or regain health (Shilling 2002); encouraging self-reliance may be at odds with compliance, with patients deciding to engage in activities considered to carry risk by clinicians.

Positive health

Positive health is the pattern theme that relates to the interpretive theme of adaptation. Informants' stories reflected both the World Health Organisation (1946) definition of health as being more than the absence of disease, and some of the fundamental beliefs identified as necessary for adaptation in the model of nursing by Roy (1976). The desire to engage in the processes of living was reported by informants, describing aspects of well-being similar to the account of positive human health provided by Ryff and Singer (1998:2)

... human well-being is ultimately an issue of engagement in living, involving expression of a broad range of human potentialities: intellectual, social, emotional, and physical.

The desire by individuals to make their own choices, to pursue projects that provide personal fulfilment, and to have reciprocal caring relationships, are amongst findings reported in accounts of positive health while living with chronic illness (Lindsey 1996) or disability (Watson 2002).

The early pattern themes developed from the initial interview data augmented the disease, problem focus that had been identified within the CHD literature reviewed early in this study. The approach to achieving well-being expressed by informants focused on what could be done rather than what to avoid. This reflects a salutogenic approach, which in contrast to only reducing risk factors, also promotes factors that enhance being well (Antonovsky 1987).

Salutogenesis

The salutogenic model and sense of coherence proposed by Antonovsky provided a framework within which informants' stories of living well with their heart condition could be located. In contrast to the problem orientation of existing research regarding adult CHD, it was possible to focus on ways in which people maintained or achieved well-being. Antonovsky considered nurses might be open to his ideas due to their attempts, at that time, to formulate a new professional identity. From my practice and previous study I was aware of literature that attempted to define the discipline of nursing, and clarify its contribution to health care and to theory generation. A collection of papers published between 1962 and 1978 (Nicoll 1992), and an account of nursing developments in Australia (Gray and Pratt 1991) indicate the 'fascinating throes of formulating a new professional identity' referred to by Antonovsky (1987:xiv). While the professional identity of nurses was not the focus of this study, it has

nevertheless been an integral part of my nursing and teaching practice, giving further resonance to Antonovsky's thinking.

Antonovsky was a medical sociologist who used the term 'salutogenesis' to describe an approach to achieving health that focused on enhancing ways in which people remain well; this is in contrast to pathogenesis in which factors that make people unhealthy are avoided. He described a health ease/dis-ease continuum on which people were located. Antonovsky wondered why people were healthy when, according to him at least one third of modern society had some form of pathological condition; this estimate was more recently confirmed in the 1996 UK census (Office for National Statistics 1998).

Antonovsky had been working on the salutogenic model of health since 1970 when, during a study of ethnic groups, he reported an almost accidental finding. The 'fundamental turning point' (Antonovsky 1987:xi) that led to formulating the salutogenic model in 1979, was that twenty-nine percent of women were in his words, in reasonable emotional and physical health. This was despite having survived being in a concentration camp, followed by years of being a displaced person and then having to establish themselves in a new country. Central to salutogenesis is the sense of coherence, which promotes the person's ability to stay well despite experiencing stressful events.

A 'sense of coherence' comprises three attributes: that events are comprehensible, manageable and meaningful, occurring against a background of flexible boundaries. Antonovsky (1987:19) defined the sense of coherence as being:

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

Events that are comprehensible make sense because they may be predicted. An example provided during this study was of the need for further heart surgery. Having had surgery early in life and being aware that a subsequent operation was likely, when told it was now necessary one informant (4/6) initially found the information a shock, but was able to accept it. While events may not always be desirable, they are explicable, for example the death of an elderly parent; such events are comprehensible they make sense and can be manageable if appropriate resources are available.

The contribution made by available resources to making events manageable was apparent on many occasions during interviews. One example being parents and partners supporting attendance at outpatient clinic appointments through taking time off work to attend with informants or to provide child care (3/8); and with informants accepting their parents expressions of caution. Resources may reside in other people from whom it is usual to request assistance. Other people include parents, partners, friends and colleagues; also included are health and social carers. Resources contributing to making events manageable also reside within the individual; these enable growth towards independence. The reciprocal relationship between self and others contributes towards the ability to cope with untoward events in life and to move on.

Areas of life important to individuals make up the third construct of Antonovsky's sense of coherence, that life is meaningful. Meaningful activities identified by informants in this study included career choices and having their own children. Meaningful events are those that require emotional commitment; individuals welcome challenges, and endeavour to overcome them with dignity.

Events of life occur within boundaries established by the individual; the scope of boundaries can be broad or narrow, expanding and contracting

according to stages and events in life (Antonovsky 1987). Establishing boundaries can impact on a person's ability to achieve their full potential.

The sense of coherence described by Antonovsky has been considered '*Panglossian*', that is to be excessively or naively optimistic (Tones and Tilford 2001:106). This optimism may, however, serve to balance the problem orientation of existing research related to adults with CHD. Efforts to avoid potential problems occurring in a minority of patients can result in the entire group being perceived as being at risk, and therefore less able to participate in activities.

Findings from all interviews will be discussed in relation to the sense of coherence provided by Antonovsky (1987). The focus of the initial interviews was broad, and as such the findings inform the background canvas within which informants got on with life. Related to the sense of coherence the background comprised the boundaries, comprehensibility, manageability, and meaningfulness.

The focus of this study has been on the experience of people who have grown up and are living as adults with CHD. Other people including parents and partners, also have experience, their stories, however were not directly sought during the interviews. It is likely that their experience is different; therefore how other people contributed to making life manageable is presented separately to ways in which informants talked of how they made their own life manageable. Figure 5.2 indicates how the sense of coherence model was adapted for adults with CHD.

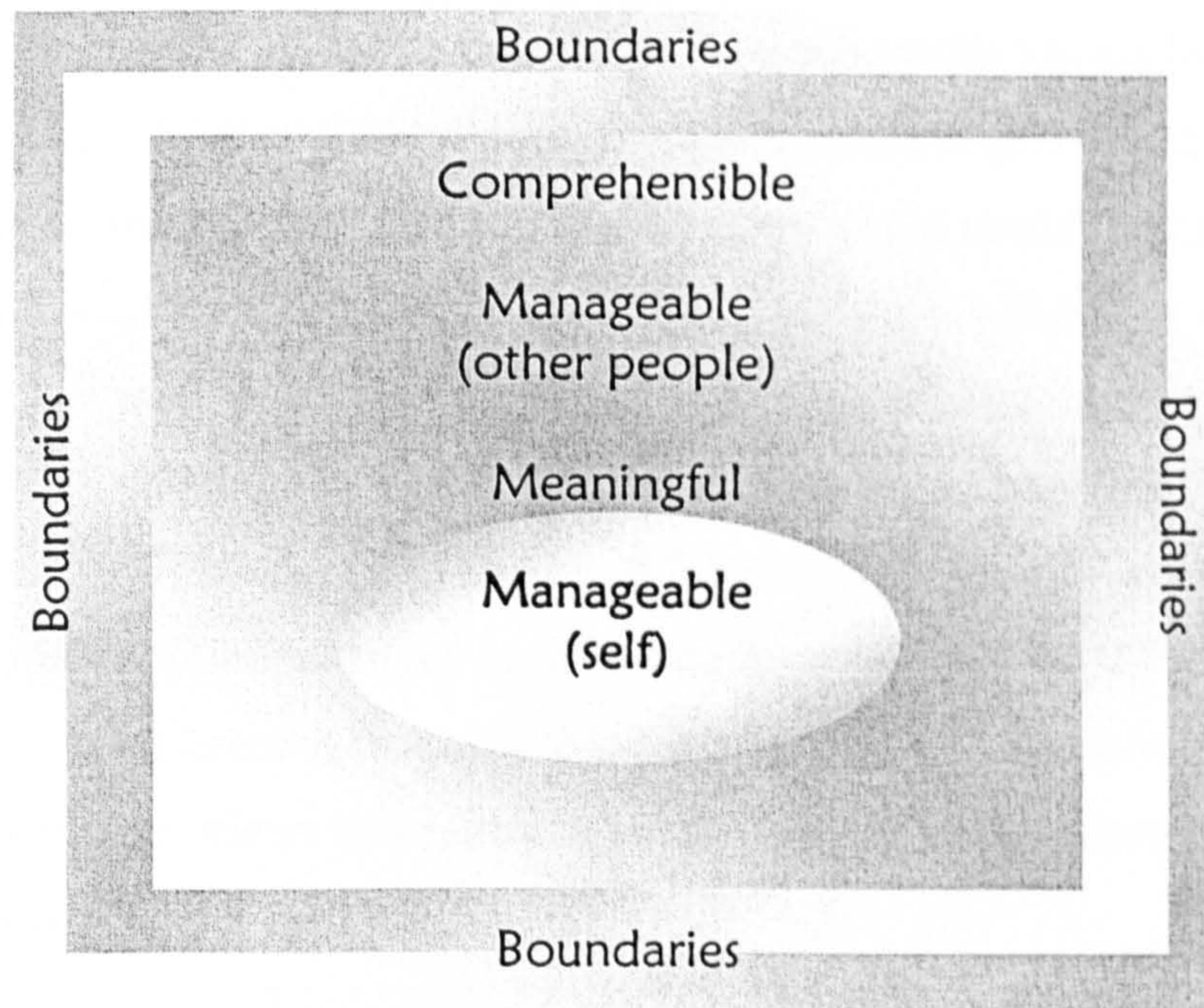


Figure 5.2: A sense of coherence for adults with CHD
(adapted from Antonovsky 1987)

The three components of the sense of coherence will be separated and explored in the following discussion; it is important, however, to recognise they form an ‘intricate unity which we call the lifeworld – our lived experience’ (van Manen 1990:105) that make up being well for the people in this study.

Comprehensible

Events occurring within boundaries set by informants, while not always being desirable, should be understandable and explicable. For adults with CHD this included taking medication that required regular blood tests, or attending outpatient clinics. Knowing this meant while it was not desired, it was possible to make sense of it; however knowing it does not dominate life, it merely forms part of the background canvas within which informants got on with life.

Included within the background canvas is the potential for future complications to arise in a minority of people as a result of the CHD and was recognised in the introduction to this study. Informants accepted the

cautious approach, to avoid risks associated with their specific heart condition, as being *'the doctors' job'*. It was comprehensible having been usual during their childhood for parents and health carers to provide advice. However informants reported that vague guidance was not useful; being told not to do *'too much'* or to lift *'only light weights'* left them wondering what was meant. The ways in which information was presented could have led to the lack of understanding reported in literature reviewed in Chapter 2 (Kantoch et al 1997; Moons et al 2001a). Informants felt that the information they required changed as they became adults, and what they now needed was different to that available for adults with acquired heart disease. Informants' views can contribute to developing health education programmes that reflect their needs.

The dynamic, interrelated mosaic of informants' stories referred to above is apparent in the seamless move in writing about events being comprehensible, into the role other people have in making events manageable.

Manageable (other people)

Antonovsky (1987) considers manageability to comprise resources that are available from people including family, friends and physicians, as well as resources within oneself. The focus of this study is the lived experience of adults with CHD; therefore for this discussion other people and self have been separated, with self being discussed on page 166.

The lived other, is the term used by van Manen (1990) to refer to the relationship we have with others in the interpersonal space shared with them. People do not live in isolation; a sense of belonging generated through relationships with others contributes to ways in which meaning is created in everyday life (King et al 2003). While developing independence is part of growing to adulthood, individuals are connected with other people in different ways. This inter-dependence includes family members, social groups at work and leisure, as well as intimate relations; we rely on others

who in turn rely on us. An example within this study of inter-dependence was provided when one person spoke of how she now helped her mother who was finding it difficult to accept the deterioration in her daughter's physical condition.

Other people have been a consistent feature throughout this study and made a significant contribution towards promoting informants' well-being. The contribution made by other people to positive health and patients' quality of life has been recognised in other studies (Ryff and Singer 1998; Moons et al 2004). Informants in this study reported other people having both a positive and negative effect. Social persuasion was the term used by Bandura (1997) to describe how views held by other people influence how we perceive ourselves; with social persuasion contributing to developing self-efficacy.

Parents (especially mothers), siblings and partners contributed positively to how informants viewed themselves. When partners or parents expressed concern or questioned informants' decisions, it was tolerated; informants recognised that while they could not remember being ill, parents had experienced extreme anxiety. The need for caution was not ignored; however informants wanted to make their own decisions. Informants said if they worried about everything they would not do anything. Through living with their heart condition, experience had been gained and strategies developed to deal with limitations if they existed, in the same way that a tall person avoids low beams.

Informants appreciated being alive and well themselves, implying they were among a fortunate minority. The perception that being well was fortunate may reflect the connotations given to heart conditions by wider society that include: symbolic ways in which the heart is perceived, the relatively recent change from high mortality to high survival in this patient population, and associations with acquired heart disease. Informants provided accounts indicating they perceived themselves to be less affected than most by their heart condition, thus reflecting the understanding of wider society that

people with CHD are unlikely to be able to live a normal life. Eight informants had required hospital admission as an adolescent or adult for investigations or further surgery. They reported being not only different from other patients in both child and adult cardiac settings, but also not being as unwell as older adult patients with acquired heart disease.

Societal views of the heart and associations with acquired heart disease influenced how other people reacted once they became aware of informants' heart condition and could generate negative effects (Livecchi 2004).

Informants were surprised when other people expressed concern regarding their ability to engage in activities or fitness for employment. This was a significant event when it happened, and in some cases had a negative influence on commitment to education or employment applications. A person's view of his/herself is also influenced by seeing others who are similar (Bandura 1997); this vicarious view may be a factor for informants' reluctance to participate in patient association activities.

Informants reported involvement in fund raising for heart related charities, desiring to give something back because they were well. The role played by GUCH, the UK adult CHD patient association, was limited for informants in this study, and was linked with being needy rather than being well.

Informants were curious to know how well other people were who had contributed to this study, and expressed surprise, and pleasure when told that most people were well. When informants made contact with the patient association it was by telephone or Internet in preference to participating in group meetings or activities. Davison et al (2000) explored reasons for participation in what they referred to as illness support groups. The main reason identified was as a result of anxiety, with young adults being less likely to take part in group meetings than older people. Internet forums were identified as having a role for people who may have limited time due to work and life commitments (Davison et al 2000), making them appear suitable for adults with CHD. Timing of the interviews for this study was strongly influenced by informants being able to find time that

accommodated work and social activities, reflecting how their CHD was not preventing them from participating in meaningful aspects of their life, which did not include attending patient association meetings.

Meaningful

Informants told me stories drawing on past experiences and their hopes for the future; meaningful activities told during the stories included being able to make career choices, participating and achieving well at sport, and having children. Lived time was how van Manen (1990) described meaningful activities. It is subjective time as opposed to clock time, and illustrates the way time appears to speed up when we enjoy something, or slow down when we feel bored or anxious. The dimensions of past, present and future make up a person's temporal landscape. A person's account of being in the world is given through telling of their past and their hopes and expectations for the future. Technical developments have contributed to children born with CHD surviving to achieve adulthood, making engagement in meaningful activities necessary in order to fulfil their potential.

Activities that are meaningful are those that individuals consider to be worthy. They provide a purpose in life; engagement in such activities requires a willingness to be effective, to meet challenges and to invest energy. Through successful engagement in activities such as education informants were able to make realistic career choices. A commitment to education and job were together identified in a recent study (Moons et al 2004) as the second most important domain contributing positively to quality of life, leading to financial security, and indicating a future orientation.

Together with comprehensibility, and relationships with other people, the meaningful activities in which informants engaged made up the background canvas within which resources were developed that contributed to their ability to maintain (or regain) peace of mind. This was not a return to the

childhood understanding, or dependence on others; it was a transition into adulthood in which their heart condition was accommodated.

When asked during the initial interviews how they were heartwise, informants expressed how well they considered themselves to be; being fit was central, however 'fitness' may not fully describe what informants meant. The state of being 'fit' can be confusing due to being perceived as peak physical condition; rather informants were indicating their sense of well-being. Perceiving themselves to be fit and well was not denial of their heart condition, rather normality for them in which they were able to perform activities of their choice, similar to their peers who did not have CHD. According to Taylor and Brown (1998) individuals hold an unrealistically positive view of themselves, referring to this as an illusion. This claim is based on the positivist idea of a single reality rather than the phenomenological concept of multiple, individual realities that has guided this study. The notion of multiple realities is implicit however, when the authors conclude by saying

... the mentally healthy person appears to have the enviable capacity to distort reality in a direction that enhances self-esteem, maintains beliefs in personal efficacy, and promotes an optimistic view of the future.

(Taylor and Brown 1998:34)

The benefits of this positive view can lead people to achieve more than anticipated either by themselves or other people. The views of other people had informed the literature reviewed in Chapter 2, in which adults with CHD were reported to be less successful in activities that make life meaningful; activities included education, employment, exercise, and pregnancy. It was the positive view informants had of themselves that was explored in greater depth during the second interviews and contributes towards the resources that exist within individuals to make events of life manageable.

Manageable (self)

It is within the manageable (self) that the new knowledge from this study is predominantly situated. Manageability has been separated into self and others in this discussion because while recognising that others, such as parents and partners have a story, the focus of this study was the lived experience of adults with CHD. Exploring resources people have developed within themselves can reveal how the strong sense of self, that is central to well-being, may be achieved. When we meet others, it is first through our physical, bodily presence; a critical or admiring gaze can limit or enhance the lived body (van Manen 1990) making the concept of manageable (self) central to this study.

Resources within individuals were brought into greater focus during the second interviews during which I was told of ways significant events related to their heart condition, acted as a stimulus for personal growth. The five people who took part in second interviews had a belief in their ability to achieve in the activities in which they chose to engage. While aware of their heart, it did not dominate their thinking. Factors contributing to their ability to live what they referred to as a 'normal' life included having a positive outlook, and despite other people worrying, informants reported they only worried when it was necessary. A common theme from the people who took part in second interviews was if they thought about their heart all the time, they would not do anything. Their sense of self included their heart condition, which was integral to their identity as a person. The second interviews revealed areas that contributed to the person's ability to get on with life, participating in activities of their choice. As informants grew to adulthood their view of themselves could be brought into question when trying to obtain employment or insurance. Cautious other people could result in informants being unable to engage in activities, or careers of their choice, these being aspects to which informants had given due consideration and made responsible decisions about. Being told not to do something made informants more determined, especially when it appeared unreasonable, making it essential that appropriate risk assessment skills had

been developed, with experience contributing to this. The following section will discuss informants' views of themselves, how they were able to make responsible decisions, and participate in chosen activities.

Informants in this study wanted to make their own decisions because they considered they best knew their capabilities, and disliked other people questioning their ability to do things because of their heart condition. Being committed to something meaningful required engaging in activities that may be new and challenging, with personal growth occurring as a result of participation. Through choosing to engage with life, participate in activities, and take up challenges, resilience developed that contributed to their ability to recover from setbacks, learn from them and move on. Informants were able to make their own choices regarding how they lived their life because they were responsible and mature; they were appreciative of medical skills and aware of the need to maintain their own fitness. Appreciating being well, informants were keen to maintain this through engaging in healthy heart activities such as exercise, healthy eating, and stress reduction strategies. While not always able to express their understanding of their heart condition using medical terminology, informants talked of knowing when it was, or was not, right to participate in activities. This understanding was enhanced when information provided by health professionals was related to their every day activities.

Informants spoke of being able to identify activities that may pose an unacceptable risk, and how it was necessary to achieve a balance between taking up challenges and developing greater confidence, or not engaging in activities. Completing a sixty-mile charity cycle ride was one example provided of an activity that was new and challenging, but at which with perseverance, success was achieved. Success contributed to this person's ability to identify and engage in subsequent appropriate challenging activities. The experiential knowing achieved through living with CHD contributed to the adults' ability to make wise choices that were appropriate for them. Numerous examples were given during interviews that reflected

different parts of life including joining the police service, having children, and participation in a wide range of sporting activities. In contrast, examples were also given of a lack of success, included were: not being considered for police and fire service, not running at all, and a moving account of accidental pregnancy resulting in anxiety regarding her own survival and potential subsequent impact on her child. Due to being well informants made decisions regarding career and social activities, which acknowledged their heart condition without considering it to be a limitation.

Taking responsibility for themselves, while recognising the part played by doctors and parents, contributed towards informants' current well-being. However the decisions adults made may not concur with parental/medical advice. A growing sense of autonomy was based on previous experiences and increasing confidence in their own ability to make appropriate choices. They have learnt to identify their boundaries and understand their heart condition in ways that draw on experiences of living with their CHD. This different way of knowing may account for the apparent lack of understanding of CHD that was reported by Kantoch et al (1997) and Moons et al (2001a) and can make traditional physically focused explanations incomprehensible (Feudtner 2001). Information that was remembered was that which had relevance to the adults' daily life.

The outpatient clinic visit was a routine part of life for informants; it was nevertheless a significant event causing heightened awareness regarding their heart condition. As the clinic visit occurred only occasionally, information, if it was sought, was available from a variety of other sources including the Internet. The clinic visit, however, was the most usual way for the individual's risk of complications to be established. Yet explanations were not always understood nor remembered; sometimes due to increased anxiety regarding the clinic visit.

Well-informed patients frequently make different decisions to physicians (Deyo 2001), reiterating that optimal treatment for individual patients may

not be as straightforward as risks/benefits identified by physicians. Decisions made by adults with CHD may not always be 'safe' decisions in the eyes of other people such as parents or doctors; nevertheless informants considered themselves to be mature, responsible adults and, as such, able to make decisions that accommodated their heart condition as one component of life that required consideration. Patient expertise within chronic illness creates contradictions regarding who is 'the expert' (Thorne et al 2000). Informants recognised they understood their own particular heart condition in a sophisticated way, while valuing the expertise clinicians demonstrated regarding patterns of CHD. It was not unusual for medical follow-up to be carried out by a cardiologist who had known the person since childhood, and who was trusted. For adults with CHD independence has to be gained not only within relationships with parents but also within the cardiology team. The Expert Patient proposals (Department of Health 2001b) can contribute to developments, however due to the evolutionary nature of surgical options for CHD, what constitutes expertise may require consideration.

In the UK, health care services have been established around diagnostically related groups, for example the tertiary centre through which informants were accessed. Service development has been informed by existing research, the focus of which in the case of CHD, has traditionally been medically led and related to specific conditions. In contrast to making inferences from diagnostic labels, the aim of this phenomenological study has been to learn from the experience of individuals living as adults with CHD.

Despite claiming that nothing extra was required, it became apparent during initial interviews that informants had developed ways to deal with changes that occurred. The first interpretive theme of peace of mind indicated a time when all was well, and could be considered to be the pre-contemplation stage of health behaviour change (Prochaska et al 1994; Rollnick et al 1999), during which events were comprehensible. Growing to adulthood

involved making choices regarding employment, which was one area that generated the second interpretive theme of raised awareness and readiness to hear. Informants' peace of mind was disrupted due to limitations imposed by other people, as a result of their heart condition, which impacted on activities that contributed to life being meaningful for them. The limitations may be considered as the boundaries within which the events of life considered important by the individual occur.

Boundaries

Factors influencing boundaries for adults with CHD include the complexity of their heart condition (which has always existed even if not understood), physical and mental functioning, and age. Lived space is felt space, the world in which people move and feel themselves to be at home, with home being a secure inner sense where we feel protected and able to be what we are (van Manen 1990). Lived space has social and psychological components as well as a physical dimension, corresponding to the flexible boundaries that contribute to a sense of coherence. An essential feature of boundaries is that they are dynamic, expanding or contracting as changes occur. For example two informants provided stories of going on backpacking holidays. One person, who had felt unwell while away, made the decision to return home early; the other person was making plans to undertake another similar trip in the near future, this time travelling further and for a longer time. Boundaries related to how the future was considered. Limited evidence regarding long-term outcomes and the ongoing checks gave a sense of waiting for something to go wrong, and may account for the raised anxiety reported in this study regarding the clinic visit.

Lived space is the felt space that includes informants' confidence to engage in activities; accurate self-appraisal is necessary to avoid activities that may have negative consequences. The body in health is described as a background canvas which only emerges as a problem when illness disrupts actions (Shilling 2002); this was reflected by informants who did not think of their heart condition until changes occurred, or other people perceived

there to be a problem. We become the space we are in (van Manen 1990); informants talked of having doubts, feeling uncertain, sometimes due to views expressed by other people. However, they also spoke of having considered the possible consequences and making responsible decisions to participate. Setting of boundaries was influenced by how understandable events were; the ability to make responsible decisions was influenced by events being comprehensible to informants.

Informants in this study had a strong desire to establish their own boundaries, doing this in a responsible way that included aspects relating to their heart condition. They expressed frustration when the choices they had made were questioned or they were prevented from participating in the selected activities. The ability to set boundaries and effectively manage other peoples' concerns were key factors in achieving well-being.

What this study has emphasised to me, is that contrary to early expectations, adults with CHD participate fully in life, without seeing this as being exceptional. This optimism and the adults' ability to make wise choices for themselves have not been apparent in previous literature.

Synopsis of the chapter

The relevance of existing theories to adults' experience of living with CHD has been presented as pattern themes. Pattern themes of health within illness, health behaviour change and positive health have been discussed in relation to the sense of coherence which is central to the salutogenic approach to health (Antonovsky 1987). Perceptions of being well were predominantly influenced by the individual's ability to establish the boundaries within which significant life events occur. The boundaries can vary considerably between individuals as well as throughout life. It was less the extent of boundaries, rather having opportunities to determine them that were important to informants.

CHAPTER 6

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Introduction

This chapter provides a critique of the selected research approach and design of this study, the key conclusions emerging from the study are provided and the implications for practice are explored. The salutogenic theory provided by Antonovsky (1987) provided a framework in which to situate how adults with congenital heart disease (CHD) maintained being well, so achieving the aim of this study which was to discover the adults' experience of living with CHD. The aim was achieved through addressing the following research questions

- What is the experience of living as an adult with CHD?
- What is being well from the perspective of an adult with CHD?
- How does the experience of living as an adult with CHD influence selection and effective use of health and social care information and services that are currently available for adults with CHD?

Critical evaluation of the study

Before conclusions can be presented, an evaluation of the research process has to be undertaken in order to highlight areas that have potential to influence the findings. This research was a phenomenological study utilising an interpretive approach to explore individual's experience of living with CHD. As stated previously (Chapter 3), phenomenology has a range of interpretations. These may not be well understood by health and social professionals more familiar with quantitative research approaches.

Phenomenology of practice, proposed by van Manen (2002), rather than focusing on philosophical roots and metaphysical debate, enables use of phenomenological principles to explore practice issues. The focus on practice can make available the meaning patients gave to events related to

their heart condition. Health and social care practitioners can recognise the value of findings through their practice. As findings from this approach resonate with experiential knowing, they can be understandable to those unfamiliar with the research methods, making sense to clinicians who may be more used to measuring outcomes through statistical testing. For findings to be applied in practice practitioners need to consider them credible.

The human science method developed by van Manen (1990) draws on the philosophical ideas of both descriptive and interpretive phenomenology. It was not unusual for these two approaches to be thought discrete, with combining them being a topic of debate (Lawler 1998, Draucker 1999, Lavery 2003). The philosophical perspectives identified in Chapter 3 have continued to be discussed and applied to phenomenological research approaches. The ideas of philosophers including Jaspers, Merleau-Ponty, Gadamer, as well as Husserl and Heidegger, have informed developments in qualitative research methods that facilitate exploring health related aspects. Methods include interpretive description (Thorne et al 1997), and reflective lifeworld research (Dahlberg et al 2001; Dahlberg and Dahlberg 2004). These approaches endeavour to include patients' voices, which are heard usually through their stories, which are then interpreted by researchers who are attempting to address clinical questions.

Phenomenology of practice provided a way to hear the voices of adults with CHD. It was not possible, however, to relate findings to specific conditions, and while this was not the purpose of this study, it has been identified as a limitation in previous studies. A recent attempt has been made to explore individual perspectives which are then related to specific heart conditions (Moons et al 2005).

A growing need for methods that examine quality of life from the individual's perspective, rather than generic tools, was recognised with a range of relatively new instruments becoming available (Haywood et al

2005). The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) was designed specifically to assess individual quality of life (O'Boyle et al 1995). An adapted version of this, The Schedule for the Evaluation of Individual Quality of Life: a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW) was used to identify domains important to adults with CHD by Moons et al (2005). Domains identified by 48%-70% of respondents as being important to them were: family, job/education, friends, health, and leisure time. These have resonance with the findings in this study. Future work might be possible combining the areas identified as being important by informants in this study, with the SEIQoL-DW, however this would require exploration.

What this phenomenological study has captured is the experience of informants at this moment in time. Comparing the views of children with CHD, as they grow into adolescence and adulthood, using a longitudinal research approach, might contribute to effective transition from paediatric to adult cardiac services. This move has been identified as a significant event (Higgins and Tong 2003; Bjornsen 2004; Tong and Kools 2004; Canobbio and Higgins 2004).

In this study data were gained from one source, interviews; stories of lived experience are gained in this way. Informant interviews provided the unique view of the adults with CHD who participated in this study. As such, findings are not generalisable in a traditional sense, however an account is provided of experiential knowing (patient perspective) that offers a foundation for developing participatory programmes between health and social carers and adults with CHD. This approach has the potential to recognise patients' expertise within a resource conscious service; resources include finance, personnel, time and experience. Because the findings do not focus on the heart condition, rather on the person's experience of living well, they may apply to people with other chronic childhood conditions, in which survival to adulthood is also increasing, for example cystic fibrosis, however further research would be required to confirm this.

Interviews provided an opportunity to hear how informants experienced living with a heart condition. Interviews, however, are not random events, there are identifiable stages, with some stages requiring more than one interview. People in this study expressed appreciating my interest in their lives, however more than one interview may be needed to explore sensitive or difficult areas (Rubin and Rubin 1995). It was positive, rather than difficult areas that were explored in this study.

The openness and flexibility of qualitative interviews, rather than a prescribed approach, made it possible to request clarification of what I was being told. Readers of this thesis are given an opportunity to make their own interpretation through providing details of the context within which interviews took place, as well as informants' own words. While it is not feasible to provide data in their totality in a report, there should be sufficient for readers to gain the essence of what was intended (Kvale 1996). What people say and how they act can vary, however I was exploring the meaning given to events by adults with CHD, making their story significant. Nevertheless it is my interpretation of the stories that is provided in this thesis; other interpretations are possible. The interpretation of meaning given by me may be different to that intended by informants.

Analysis guidelines were used as a framework for my interpretation of the interview data. Hycner (1985) highlighted that phenomenology is more an attitude than a set of instructions, and presented the guidelines to alert researchers to issues that required consideration when attempting phenomenological analysis. Guidelines can appear to be inconsistent with the goals of phenomenology (Hycner 1985; Kvale 1996), however, they were useful, providing a way to commence data analysis and for me to experience the process. As data analysis progressed I recognised myself being engaged in what Colaizzi (1978:59) referred to as

'... that ineffable thing known as creative insight: he (the researcher) must leap from what his subjects say to what they mean'

I can now appreciate how the guide became absorbed into an attitude towards the phenomenon. Doing it helped me develop a phenomenological attitude, which remains illusive to articulate. This was a dialectic process.

The people, who provided their stories were well; hence the findings may not reflect the experiences of all adults with CHD. People may be affected differently irrespective of the complexity of the heart condition. People who do not consider themselves to be well, or are more affected by their heart condition make the implications for practice identified below inappropriate for all. People not included, who may have a different experience, are those who had not undergone cardiac surgery, those who did not attend the clinic or did not respond to letters, people with cognitive impairment, and those with genetic or chromosomal syndromes associated with CHD.

Other people have related stories. As the study progressed I became increasingly aware that parents and partners were often more anxious than the person with the heart condition. Other people made a significant contribution to informants' ability to remain well. One interview particularly stands out for me, when I found it necessary to remind parents that it was not their story I was requesting.

Accounts of the experience of parents of children with CHD are available (DIPEX 2002); the story of parents of adults with CHD could be different to that of parents of infants and young children. Parents, especially mothers have been identified as influencing adults' ability to achieve normality and were reflected in informants' stories. Informants, more often mentioned mothers, rather than fathers. The impact, on fathers, of a child's chronic illness may be different (Goble 2004). Partners and siblings also have a story that is different again to that of informants or their parents. These are interesting areas that require exploration, as would comparison with the views of health and social carers, as intended at the start of this study.

An initial difficulty in accessing informants was partially due to patient addresses being incorrect. The result would be that clinic appointments were not received. Maintaining accurate records over an extended time is problematic; when people consider themselves to be well there may be no perceived need to inform cardiac centres of a change of address. A further reason for persistent non-attendance attributed by clinic staff for one person was excessive anxiety. The level of anxiety generated by the clinic visit surprised me and cannot be underestimated. People who neither attended the clinic nor responded to letters requesting participation could have a different story to that provided here.

The way in which health related information is prepared and received has been the subject of extensive debate. Ways in which details of CHD are understood, received, prepared and given have implications for a range of situations involving clinicians and patients. This area also requires further exploration.

Having critically evaluated the study and recognised areas that require further research, it is also possible to reach conclusions and to appreciate implications for nursing and teaching practice from the study findings.

Key conclusions

The conclusions from this phenomenological study emerged through people telling their life stories, and pertain to their ability to establish appropriate boundaries for themselves. As stated in the previous chapter, informants in this study perceived themselves to be fit and well. This was not denial of their heart condition, rather normality for them in which they were able to perform activities of their choice, similar to their peers who did not have CHD. Thematic analysis revealed that informants were aware of their heart, but it did not dominate life, it was an integral part of their existence. Interwoven through the transcripts were accounts of how scars were

forgotten, or viewed in the same way as freckles; the heart condition was accommodated in the same way as being tall or short.

Resources within individuals influenced whether life events were positive or negative. It is the resources that existed within the adults with CHD who contributed to this study, that form the basis of my conclusions, with the outpatient clinic visit being a pivotal event. The ability to establish the boundaries within which informants engaged in meaningful activities of life emerged from the discussion of findings. Boundaries were part of the taken for granted background tapestry within which informants got on with life. For the people in this study the ability to make appropriate decisions regarding boundaries had been developed through taking part in activities of life. The well-being demonstrated by informants had been gained through selecting and participating in events that were meaningful to them. Interpretive themes from the second interviews will be used to structure the conclusions, these were: I make my own decisions, I am a responsible adult, and I get on with life.

I make my own decisions

The people in this study wanted to make their own choices and disliked being told by anyone, including health professionals, they could not do something, especially if it was related to the heart condition. In contrast, being told what could be done was remembered and used to make informed decisions regarding taking risks while engaging in activities of their choosing. Providing information in a positive way has the potential to enhance peoples' ability to apply information specifically to their selves, as well as providing an opportunity to ask questions that are relevant to their life style. Decisions made by informants related to the boundaries of their life included career choices, or whether to have children. Informants were able to make decisions because, not wanting to be unwell, they were responsible regarding their heart condition.

I am a responsible adult

There are times in life when choices are made and boundaries may change, these times can be turning points for adults with CHD. They provide opportunities when details of the heart condition are more likely to be found useful and contribute to making informed decisions in a responsible way. Informants became ready to hear details of their CHD at three key times.

First during childhood when they initially realised about their CHD.

While the heart condition was congenital, and therefore present at birth, informants could recall an occasion when they recognised, because of their heart, they were different to their peers. This occurred often around seven or eight years of age, it was a significant event for informants, and was frequently associated with running, a sports day or some form of exertion. The majority of informants had undergone surgery early in life, and had no recollection of life before that time, others could recall the hospital admission for surgery, and recounted the difference it made in their exercise capacity. Second, as they grew up and other people saw a problem and questioned their choices. Examples provided during interviews include career options for which they were considered unsuitable (such as the armed forces, police and fire services), or their ability to participate in sports/activities. Finally information was required when changes occurred in their heart condition that required increased medication, investigations or hospital attendance.

Other people could influence the adult's perception of being fit and well. Friends and family, who were aware of the heart condition, were able to express a need for caution, which informants saw, and accepted, as caring. Caution expressed by members of wider society, who did not understand the heart condition, was considered inappropriate. Establishing their own boundaries varied with informants' skill in managing the misconceptions of wider society. This skill was a key factor in their being able to participate in meaningful activities of their choice, including employment, exercise and travel.

I get on with life

Whether or not information was heeded, or even remembered, was influenced by the adults' ability to listen to their own body. Informants talked of knowing their body, knowing when things were right (or not), and being able to pace themselves appropriately. They reported occasionally pushing themselves beyond their perceived limits, but talked mostly of how they managed to resist pressures to undertake activities for which they did not feel ready, indicating their ability to establish the boundaries of their own life. Informants, however, did not always appreciate the significance of changes in their physical ability. Their heart condition was understood in relation to everyday activities in contrast to physiological principles, making explanations that related to daily life more useful for them.

Informants were able to recognise some changes in their heart condition as well as appreciating that not all health carers fully understood their heart condition. Enhancing individual's ability to 'body watch' (Thorne et al 2003:1342) and their skills to articulate this in ways that can be understood by others, has potential to ensure their views are heard by people who may have less understanding of CHD, including health and social carers. This raises the possibility for health professionals to learn from people who have experience of living with long-term conditions.

The clinic visit was an event that all informants reported made them think of their heart condition. Hospital admission is required only occasionally (Somerville 1997), with follow-up taking place in outpatient clinics making this an opportune time for information to be received. The outpatient clinic visit is central to the practice implications resulting from this study.

Implications for practice

The number of adults with CHD predicted to require follow-up in the UK has been estimated to be 75,000, and is anticipated would increase by approximately 1,600 new cases each year (Chapter1: 16/17). More recently

the number of adults with CHD in the United Kingdom has been estimated to be over 250,000 (Gatzoulis 2006); there are, however, limited details given on how this figure was calculated. While the precise number of people with CHD reaching adulthood is unclear there is agreement that numbers will increase. Technical and other developments make the adult CHD population profile different to that of childhood CHD. The move to adult congenital cardiology clinics, where they exist, has the potential to become a positive turning point. The transition from paediatric to adult services has become a topic of debate as the number of people reaching adulthood has increased, usually because there is a lack of available or appropriate adult services (Webb 2001; Bjornsen 2004; Tong and Kools 2004).

Implications from this study centre around the clinic visit process; this was an event which all informants identified as being significant. Developing skills at establishing the boundaries of their life can contribute to the adults' ability to make decisions that are appropriate for them. Consideration of ways to enhance individual's ability to set suitable boundaries is fundamental to the implications for practice arising from this study. Boundaries that are narrow may prevent people taking part in activities through which skills are developed. If boundaries are broad people may engage in reckless behaviours that carry long-term risks. Key aspects of the following section are patient participation, information provision, and future developments.

Patient participation

Informants initially reported limited need for information regarding their heart condition beyond that which was currently provided. The clinic visit was a significant event, and despite causing anxiety was generally viewed as being useful. Awareness of the heart condition was raised around this time. In contrast to their confidence in every day life, however, they appeared more willing to accept advice and less prepared to question the impact of it on everyday activities. This willingness seemed to be due partly to trust in

the cardiology team, which was a result of the longstanding relationship, making the clinic visits a key opportunity for establishing a more inter-dependent relationship.

The clinic visit can be structured to provide a forum in which adults with CHD can identify areas that are important to them at that specific time in their life. Offering an opportunity to express how people feel they are in relation to their heart, can promote a patient-centred environment. Listening to how adults make sense of their world has the potential for information to be provided in ways that have greater meaning to the person and therefore enabling them to understand and recall details provided during the clinic visit, and relate them to their current every day activities. Making current life events central to the clinic visit has several potential benefits.

A patient-centred clinic process, including coaching in how to ask questions, can improve participation, make better use of clinic appointment time as well as result in improved physical health (Rollnick et al 1999). Through identifying areas that are relevant to their life a forum is provided for the person to talk about their heart condition in ways that demonstrate their experiential understanding. Adults with CHD can be encouraged to talk about their heart condition in ways they understand. By rehearsing ways of expressing their understanding, self-assurance can be gained in talking to other people who have less knowledge of CHD, so demonstrating well-being to potential employers, insurers, other health and social practitioners. This process can become self-perpetuating with increasing confidence and self-regard achieved through demonstrating self-care abilities to self and others, as well as highlighting aspects that are meaningful to the individual. This approach captures the motivation to maintain health and well being demonstrated by informants, which can be used in everyday life, enhancing realistic self-reliance in partnership with clinicians, parents and partners.

A realistically optimistic approach during clinic visits can promote a more participatory environment. Information provided during clinic visits contribute to turning points, therefore it is necessary to appreciate the way in which information is given. Informants in this study considered themselves to make decisions regarding their heart in a mature and responsible manner. This level of engagement towards maintaining health was identified as essential in the assessment of future health service resources (Wanless 2004). Taking patients' daily life as the starting point can provide opportunities to address areas that have relevance to them, hence being more likely understood and remembered.

Information provision

An approach to providing information for adults with CHD, more usually associated with changing behaviour such as smoking cessation, is motivational interviewing. The aim of motivational interviewing is to support and promote patients' perceptions of their own capacities (Astolfi and Evans 1997). The components of motivational interviewing focus on a person recognising the importance of, and having the confidence to undertake change as well as being ready to change; these components are applicable to the change that occurs as a result of transition from a paediatric to adult health care service. Applying principles of motivational interviewing to clinic visits could provide a framework for continual follow-up that includes the heart condition, while enhancing individual's self-reliance and goal setting that is an integral part of their life as they move towards adulthood.

A further way to providing information that is useful, is giving a written summary of the heart condition and procedures. This makes available terms that can be used by adults with CHD when talking about their heart condition to other people, such as their General Practitioner. Adults with CHD are a minority patient group who require specialist care in relation to physical aspects of their heart condition. However as survival increases, other age related situations or disease processes are likely to result in

contact with health practitioners who will have limited expertise in CHD. Developing self-reliance regarding their heart condition has potential for adults to promote participatory relationships as necessary in the future. Because the long-term physical residua and sequelae of CHD are only just becoming realised, the need for life long follow-up provides opportunities for ongoing psychosocial development that can prepare young adults with CHD to become realistically independent.

Another source of extensive information is the patient associations. During the initial interviews, only three people had previously been aware of the UK adult congenital heart patient association, GUCH. Patient association contact details had been given to informants as part of the interview process, although none expressed the need to contact the patient association. During the second interviews, three people told me they had contacted GUCH either through the Internet or by telephone for information when changes such as pregnancy occurred. This indicates the potential for a collaborative relationship between clinic visits, the patient association, and the events of every day life.

Future developments

While the findings do not directly relate to staff development aspects, several areas became apparent as the study progressed. Recommendations for training programmes for health carers have been made (Hoffman et al 2004; Sanders 2004), although the focus is predominantly on medical training. However, patients exist now regardless of training programmes for health and social care professionals. Informants reported recognising when practitioners did not understand their heart condition, indicating the need for education, across health and social care disciplines, related to adult CHD.

Paediatric trained staff can begin the preparation for transition into adult cardiac services. Through being more alert to children becoming aware of their heart condition, age specific information can be made available. Areas can include not only understanding the heart condition but also realistic

career preparation. The people in this study reported an extensive range of careers, and changes in the Disability Discrimination Act (2005) will make further options available in the future. A key factor when asked about their heart condition was the adult's ability to present information, which showed understanding and confidence so pre-empting possible misunderstandings held by wider society.

Opportunities for nurses to develop new roles provide openings for working towards nurse led clinics for adults with CHD. Generating a guide to assist adults with CHD prepare for the clinic visit could include social, psychological as well as physical areas that are relevant to them, making that person's every day life central to the visit. The CHD functional classification, adapted by Perloff and Miner (1998), and used in this study was well understood by informants. This classification could inform the guide, as might the quality of life tool more recently utilised by Moons et al (2005); these can enable adults to identify areas relevant to them, as well as provide their own evaluation of physical functioning.

Informants in this study understood their heart condition in ways that related to their daily life, as skills in expressing this to other people increases, the potential for effective follow-up to be carried out away from the tertiary centre is possible, with the patient recognised as having expertise in their own condition. This is in line with recent UK government proposals (Department of Health 2005). The need for supra-regional, regional and community collaborative services for adult CHD has been recognised (Canadian Cardiovascular Society 1998 and 2001; American College of Cardiology 2001; British Cardiac Society 2002; European Society of Cardiology 2003).

Synopsis of chapter

The conclusions from this study have been presented, and discussed in relation to research that has become available since commencing this study.

Implications for clinical practice, nursing, education and ongoing research have been identified. Realistic ways have been provided in which findings for patient centred initiatives may be used to complement, and develop existing services for adults with CHD.

What this study has added to existing knowledge is the patients' perspective of living with CHD, providing details of how individuals respond in unique ways to events related to their heart condition. Contrary to expectations that adults with CHD will experience problems or behave unwell, the people in this study expressed being well and having an optimistic view of their future. Informants participated in life undertaking activities of their choice and contributing to society. Having a future orientation can promote self-reliance within a reciprocal, interdependent relationship between health and social carers, parents, partners and wider society. The problem focus of previous research, with important recommendations on risk avoidance, can foster over cautious approaches in which opportunities for individuals to achieve their full potential are reduced.

The majority of time for adults with CHD is spent in non-patient activities. Providing an opportunity for adults to talk about these activities in relation to their heart condition can further enhance their ability to make realistic decisions. Having an optimistic view of the future can make expressions of caution seem irrelevant; making responsible, informed decisions can encourage safe participation in activities without being reckless.

Recent government proposals related to long-term conditions recognise similar areas to those reported in this study, this relationship has potential to inform evolving services for adult CHD. Providing health and social services in ways that optimise adults' ability to hear and use information related to their heart conditions is essential.

CHAPTER 7 POSTSCRIPT

Introduction

The purpose of this final chapter is to provide an account of some of my experiences as I journeyed through this study. There have been two main activities necessary to complete the project. Firstly carrying out the study, and secondly writing the thesis, these activities have occurred concurrently. I have learnt both through planning anticipated activities, and dealing with unanticipated events as they occurred.

One advantage of the interpretive phenomenological approach selected was that methods were not prescribed at the outset, but evolved as the study progressed. Decisions made regarding the evolution of the study, however, should be made transparent throughout the thesis to demonstrate rigour and provide readers with confidence in the findings (Sandelowski 1986; Koch 1994). Reflexivity is the process through which the researcher can make explicit to readers the ways the complexities of human science research have been integrated within the study. Schön (1987:3) used the phrase 'swampy lowland, messy, confusing problems' to describe the complex nature of practice based problems.

The term 'reflexivity' describes the process through which consideration of what has been learnt through experience is used to inform developments. Rolfe et al (2001) considered reflexivity to be similar to reflection-in-action (Schön 1987), and to be more than the thoughtful practice that is demonstrated by an intuitive expert (Benner 1984). Reflexivity infers the process of appropriate, informed, as well as thoughtful application of knowledge within unique situations. The process can appear deceptively simple and is difficult to articulate. One purpose of maintaining a research diary throughout a qualitative study is to provide a written record that can be reviewed later. The researcher's records are seen as another source of data

by Jasper (2005), which require analysis in a similar way to data given by informants.

The use of reflexivity has conventionally been associated with establishing trustworthiness in phenomenological research. More recently Jasper (2005) discussed the contribution made by reflective writing to qualitative studies. She proposed the reflective records might be considered to be primary data as they provide an account of the analytical processes that led to the interpretation given to interview data by the researcher. Three levels of reflection were identified in a study on reflective learning journals with critical reflection, the most advanced level, being considered to be demanding and time-consuming (Thorpe 2004). I am unsure that my records demonstrate this high level of reflection. The time required to provide a critical reflection was not always possible, making my records, in my view less suitable as primary data as proposed by Jasper (2005). While I acknowledge the value of reflective writing, and some sections contain critical reflection, other sections comprise descriptive records of feelings and context that, while useful, contribute only towards enhancing my recall of events. Therefore the value of my records as primary data is debatable.

The process of putting thoughts and feelings into words does encourage the early articulation of processes that may be conceived only as images (Vaughan 1992). During previous study I had found the value of a study diary to be inestimable, however the time required to produce this type of record should not be underestimated. Diary writing may be viewed as reflection-on-action (Schön 1987); something has to be done with diary entries in order to achieve the reflexivity or reflection-in-action. This chapter aims to provide the 'something' for this study, the 're-view' of my study records.

The study records

The entire reflective record comprised several components as recommended by Silverman (2000). Throughout this study I have kept a research diary, field notes, early analysis diagrams, also records of reading, conference presentations and supervision meetings. On re-reading the research records there were common areas that generated tension for me throughout. Three examples will be presented here: undertaking the interviews, the importance of language, and the contribution made by nursing. While these were not the only areas that caused me concern, these topics are relevant to both adults with congenital heart disease (CHD) and to qualitative research approaches.

Undertaking the interviews

Interviewing is a skill that I use regularly as a nurse and a teacher.

Listening to the interview tapes I found it hard to understand how I had missed cues and failed to follow-up significant points. Only on listening to the tapes did I realise how much I had been told; I also felt privileged that informants were so willing to discuss openly their personal world.

Listening may be a more important skill than formulating questions.

As I prepared for the interviews I was surprised at how nervous I felt about meeting the adults with CHD in my new role of researcher; as a nurse and teacher, I felt confident, however as a researcher I had less experience and felt less secure. I was unprepared for one interview to be used by the adult as a way of telling his story to his partner. The interview was scheduled during time he had taken off work to move house. I was surprised when his partner settled herself onto the settee; she appeared to have taken it for granted that she was included. I enjoyed seeing their pleasure and confidence as they moved into their first home together. The issue of confidentiality also arose. The informant and his partner were clearly prepared for the interview to commence while a telephone engineer was working in the same room. I had planned to carry out two interviews over two days at some distance; I was reluctant not to proceed, and therefore lose

an opportunity and waste precious time. I felt uncomfortable regarding the presence of the telephone engineer and my assurance to the informant of confidentiality. When I identified the presence of the telephone engineer the informant apologised to me in a way that indicated he thought it was a problem for my research. I am not sure I could have provided an explanation of why it was a problem for me if it was not a problem for him, without recourse to ethical committee rhetoric. I believe I acted in an ethical and professional manner, although confidentiality was not maintained, however this event highlighted the difference between procedural ethics and ethics in practice as identified by Guillemin and Gilliam (2004).

I was aware that being contacted by me also generated some anxiety for the adults. Initial contact with people identified from surgical audit records was by letter. Despite returning my letter and providing a telephone contact number, one person who answered when I called, told me the person I was asking for was out but he would ask them to call back; the call was returned a short while later. From details gained during the interview I am certain that he had answered my initial call. Another person, who had initially been met at the outpatient clinic, provided her mother's telephone number as a means of contact. When I called her mother I was given her daughter's contact number and asked to wait before I called as she wished to prepare her daughter for my call. The fact that the people I did contact were willing to take part in my study did not allay my trepidation when calling. I became aware that the interview prompted some informants to think of their heart in a way similar to the clinic visit, and may be the reason some people did not agree to meet me.

A further area that prompted consideration of ethical aspects was regarding a suitable term to use when referring to the people, individually and collectively, who took part in the interviews.

Language (or What's in a name?)

Language is powerful, indicating roles and perceptions of others and, as such influencing behaviour and attitudes (Ironsides et al 2003). Generating a more participatory relationship between health and social carers and adults with CHD may require consideration of terms that better reflect the intended reciprocal, collaborative roles that are required to achieve this. Finding a suitable term to use when referring to people has been challenging throughout this study. I found several aspects awkward; these were use of the term patient, how to refer to the adults with CHD who took part in interviews, and how to refer to the heart condition.

One issue that arose early in the study was how to refer to sample members as a collective group and as individuals (Chapter 1:18). Qualitative research approaches use a range of terms to refer to people from whom data is collected. When sample selection was initiated the term 'patient' was used. Gatekeepers of records being accessed were health carers whose contact with the group was predominantly during hospital admissions or outpatient clinic visits. 'Patient' was the term used by health carers in these settings, and by group members, when referring to themselves, so appeared acceptable. Nevertheless 'patient' may reflect the relationship that exists between service users and service providers and has been more recently questioned in patient participation initiatives. As the study progressed I began to recognise that promoting self-reliance required a more collaborative relationship between health carers and adults with CHD. An expectation of equal but different responsibilities would require a change of attitude by both patients and health carers. Terms indicate roles, with 'patients' traditionally being compliant with 'doctors' advice; the service user being passive, and the provider all knowing and powerful (Neuberger 1999). Informants in this study considered themselves to be well and were prepared to accept responsibility for aspects of their care.

During data collection interviews were carried out in informants' homes with 'patient' being inappropriate. The term 'respondent' was rejected as it implied a one-sided stimulus/response reaction rather than the reciprocal relationship being intended. 'Participant' was frequently encountered in the literature, and used to reflect the collaborative, dialectical nature of relationships between researchers and those who provide information on the topic being studied. Participation requires all groups to have equal involvement at all stages of the research process; this can be unachievable if the study population is difficult to define or access (Ray and Mayan 2001). As sample members in this study were not included in the planning stage the term 'participant' did not fully reflect the role of adults with CHD who agreed to take part.

Throughout the study an acceptable collective title remained elusive; terms used during interviews were determined by how individuals referred to themselves, frequently accompanied by discussion of the lack of an appropriate 'title'. A dictionary and thesaurus search provided the term 'informant' which was defined as 'one who informs' (Dawson 1973); and was used in a specific way by Spradley (1979:25) to mean people who 'are a source of information; literally, they become teachers for the ethnographer.' I have remained uncomfortable with the term 'informant', however it was the most appropriate as it more accurately described contributions made by sample members, and has been used within this thesis when referring to adults with CHD who took part in this study.

A related issue was terms used to refer to the heart condition. The word 'congenital heart defect' has more recently been replaced by 'congenital heart disease', due to negative connotations associated with the word 'defect'. The president of the American Adult Congenital Heart patients' association provided an example of how views of patients and health and social carers differ. I wrote in my research diary after talking with her at an international conference

*... she uses 'heart defect' deliberately, not congenital, not disease
(June 2004)*

She told me that the American group use the term 'defect' in preference to alternatives such as 'disease' because, they consider it more accurately describes their heart condition, with members having moved beyond feeling 'defective'. An adult who took part in one of the initial interviews reflected this view; he told me

'... most cardiac things are focused on people who had heart attacks ... its not focused on younger people who are born with it, you are all stereotyped you know, obese, crap diet, no exercise. All got the same problem, but there's more to us than having heart disease ...'
(9:277)

I am aware that using terms such as 'disease/defect' while addressing some areas such as inequality, can be misleading, inaccurate, cause offence and not fully reflect the complexity of the reality for the individual. As the study progressed I became aware that informants referred to their 'heart condition'; I have tried to reflect this in terms used as I have written this account. This is not a trivial issue, and has been mentioned within the literature related to chronic disease management (page 151). The difficulty remains unresolved for me, and I adapt terms depending on the message I am delivering and the intended audience.

For research to be more than an academic exercise, findings have to be disseminated to relevant groups. When I present findings from this study to medical colleagues, it is usual to be asked to provide the diagnostic label, despite my assertions that this is not the focus of my study. It is necessary, however, to gain medical acceptance due to their key role in developing services for this 'new breed and endangered species', which was how the president of the American Adult Congenital Heart patients' association referred to herself at a medical conference. She had developed ways to get the patients' voice heard in a cardiac sub-specialty where the nursing input was often by nurses trained in caring for children.

The role of nursing

I started this study with ideas of developing nursing roles. Nursing care for adult CHD has developed within a medical sub-speciality, paediatric cardiology. My experience has been that doctors treat 'people' who have medical conditions; in order to do this effectively the main focus is to apply biological knowledge to individuals. Until recently survival to adulthood was a successful outcome, reflected by informants considering themselves to be lucky. Nursing is changing and, for adults with CHD can complement existing medical expertise; however there is a risk due to medical dominance and nursing's lack of enterprise, for nurses to take on minor medical tasks rather than forging a role that has potential to contribute in unique ways. Early diary entries made during the study tour to Canadian and UK centres, describe various roles that nurses were developing as services evolved.

The nursing contribution varies considerably. Some have separate first meeting with patient and assess a wide range of life issues such as career options, plans for coming year such as marriage, pregnancy etc. Others sit in on medical consultation and check patient understanding afterwards. One is a 'chat' about important life events that may affect CHD, including physical things, the other follows medical model, and is rushed.

The nurse was the person who orchestrated outpatient process making sure any non-routine investigations happened at that visit. This involved her knowing the person, as well as having a good understanding of the defect, potential complications and knowing how to play the hospital system. (March 2000)

Knowing patients as people, and the apparently more equal and collaborative approach to multi-disciplinary team working led to what seemed an efficient and effective clinic visit. I wrote

The team work well together generally, those who don't, seem to have less contact with patients as individuals. The ECG person thinks that adult congenital people are coddled and don't consider other people. (March 2000)

A different experience was gained when meeting health care staff at another centre

The sonographer described adult congenital patients as 'non-attenders' or 'latecomers'. Due to the service structure, it was difficult to coordinate test appointments, making it necessary to attend hospital on more than one occasion. Adult congenital patients often travel long distances to attend specialist centres, therefore require investigations to be coordinated; this is essential where young adults are employed, developing a career, and not seeing themselves, neither wishing employers to see them as 'sick'. (April 2000)

The different approach to adult CHD patients by paediatric and adult trained nurses was apparent at an international conference, after which I wrote

During one of the nursing sessions today (30.05.01) a paediatric trained nurse considered it best for adult cardiac patients to receive care in a PICU. She thought paediatric nurses had skills and knowledge to do this. When I asked her what patients' views were – she said the nurses knew the patients through previous contact and liked it

My diary entry continues reflecting my thoughts that her reply implied a desire that patients liked her, rather than considering the broader needs of adult patients and their relatives if hospital admission was necessary.

Medical programmes have been established within tertiary centres with the focus on technical interventions, nursing has a different focus. What has become evident over time is that a blueprint does not exist to guide the nursing contribution to adult CHD programmes. I believe the opportunity exists for innovative nurses to make a unique contribution.

As with most learning the final outcome, rather than an answer, is more questions. Rather than a feeling of satisfaction, what remains is a desire to know more about those things of which I was once unaware. The following quote captures the essence, although not the totality, of what I have learnt through undertaking this study.

'... early in professional years I was asking the question, How can I treat, or cure, or change this person? Now I would phrase the question in this way: How can I provide a relationship which this person may use for his own personal growth?

Carl Rogers (1961:32)

Appendix 1

The following anatomical diagrams are provided as a brief guide to some common congenital heart defects.

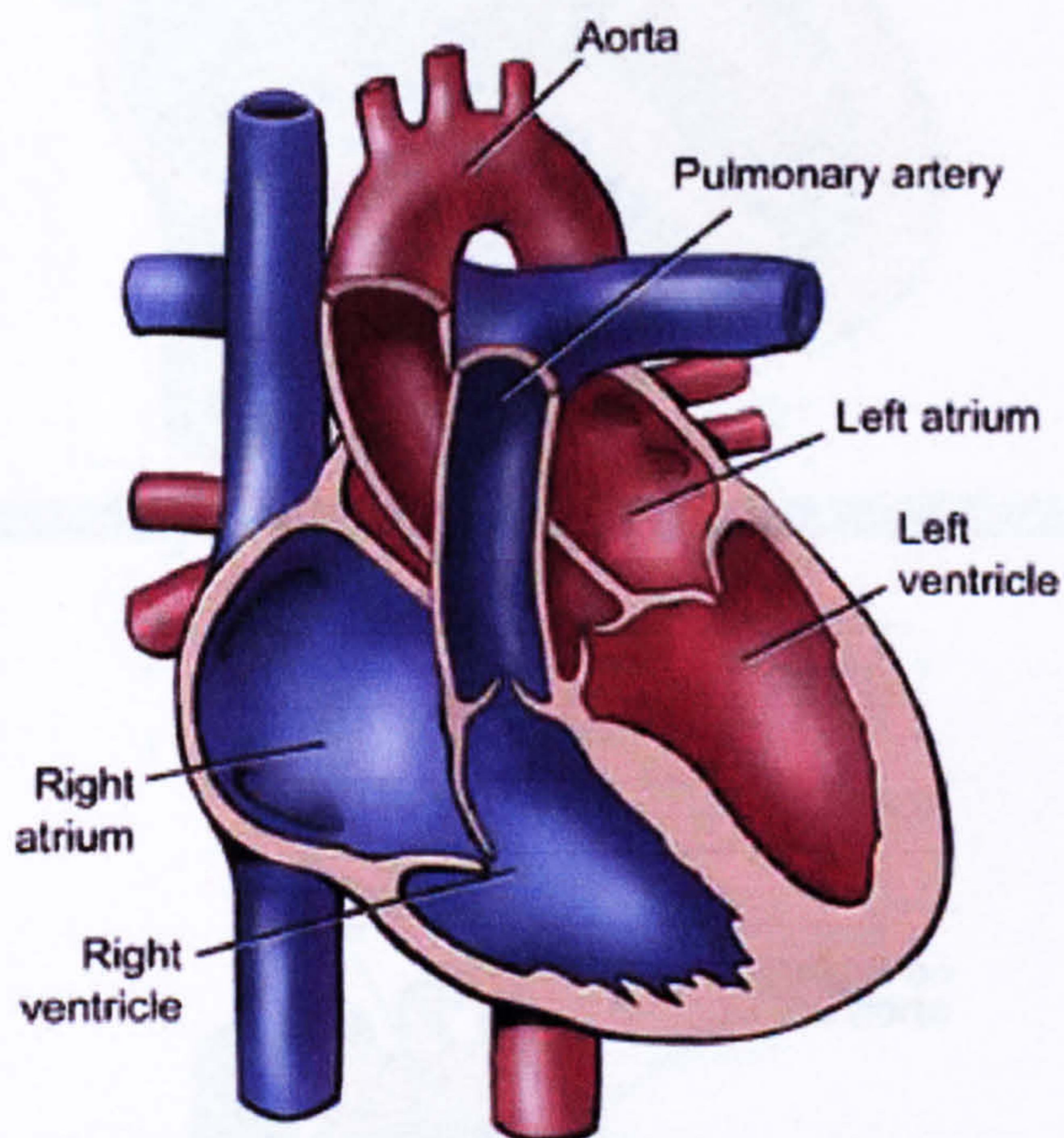
The diagrams have been accessed from the following Internet sites. These are comprehensive sites with diagrams of other heart conditions also available.

Mayo Clinic (2005) Slide show: common types of congenital heart defects.
www.mayoclinic.com [Online 02.03.06]

The Nevil Thomas adult congenital heart library (1999)

www.achd-library.com/heart_pictures/index [Online 02.03.06]

This diagram of a normal heart is provided for reference

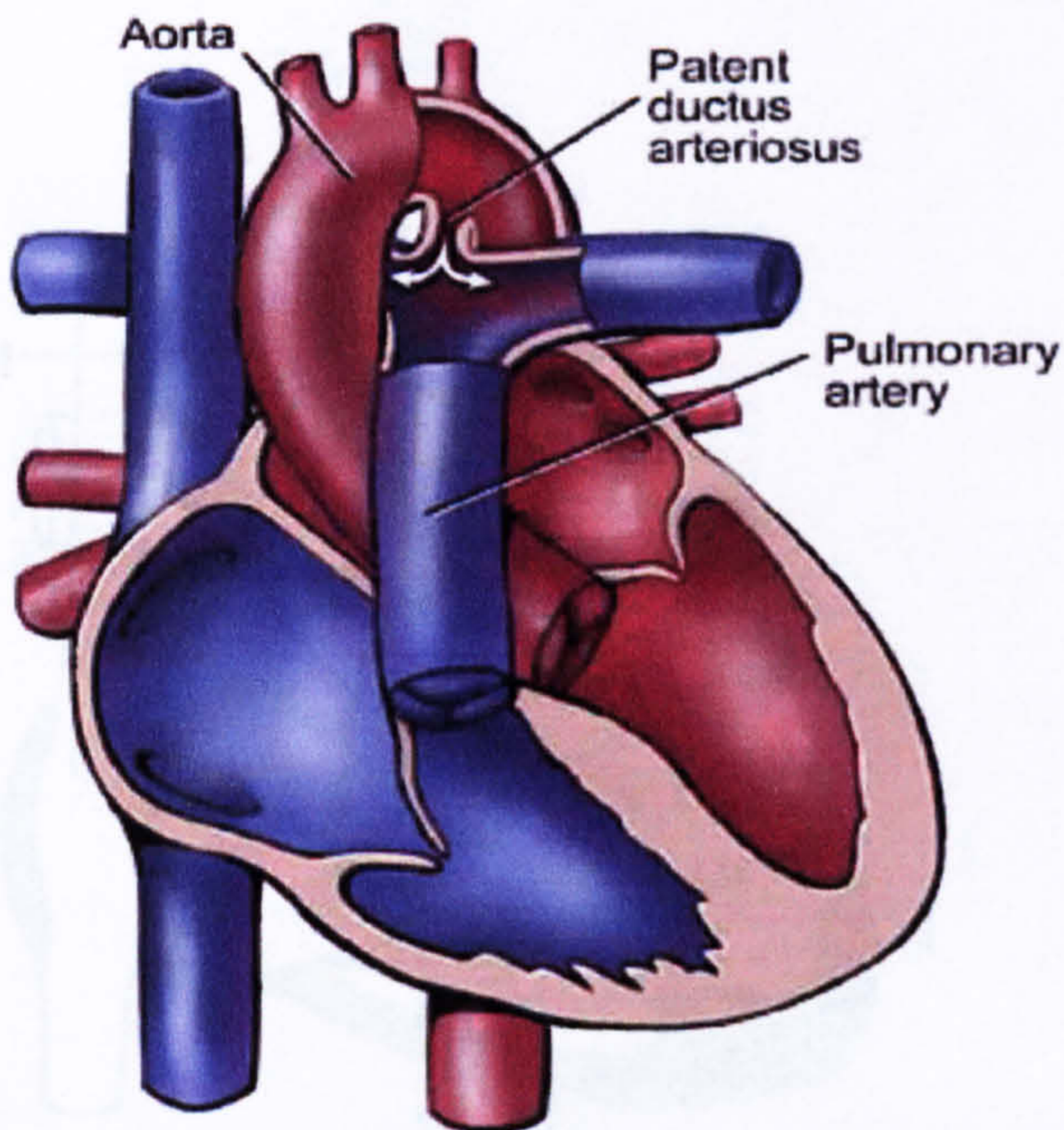


© Mayo Foundation for Medical Education and Research. All rights reserved.

Appendix 1

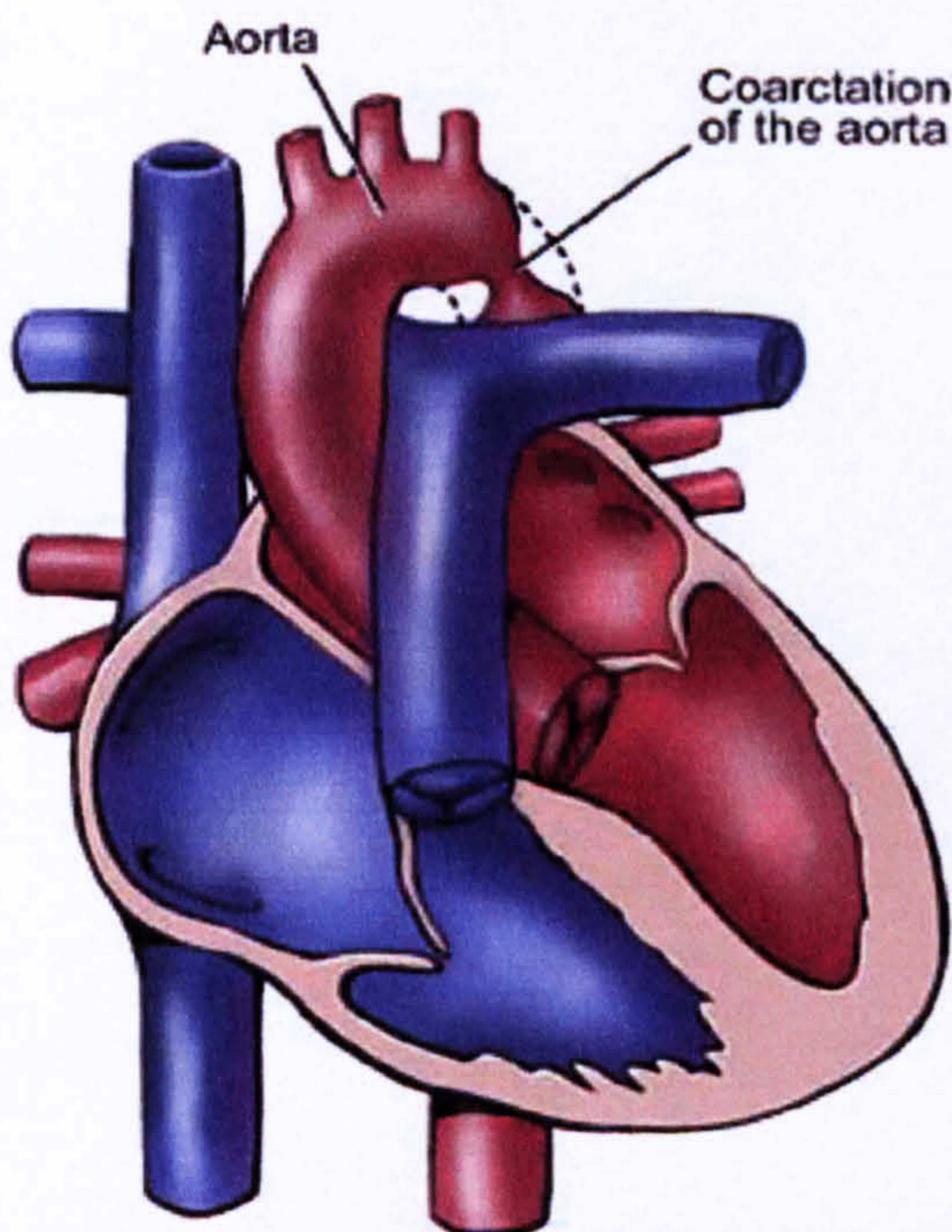
The structures affected in these two conditions are outside the heart. While open chest surgery would be required, the heart would not be opened, and heart-lung bypass is not necessary.

Patent Ductus Arteriosus



© Mayo Foundation for Medical Education and Research. All rights reserved.

Coarctation of the Aorta

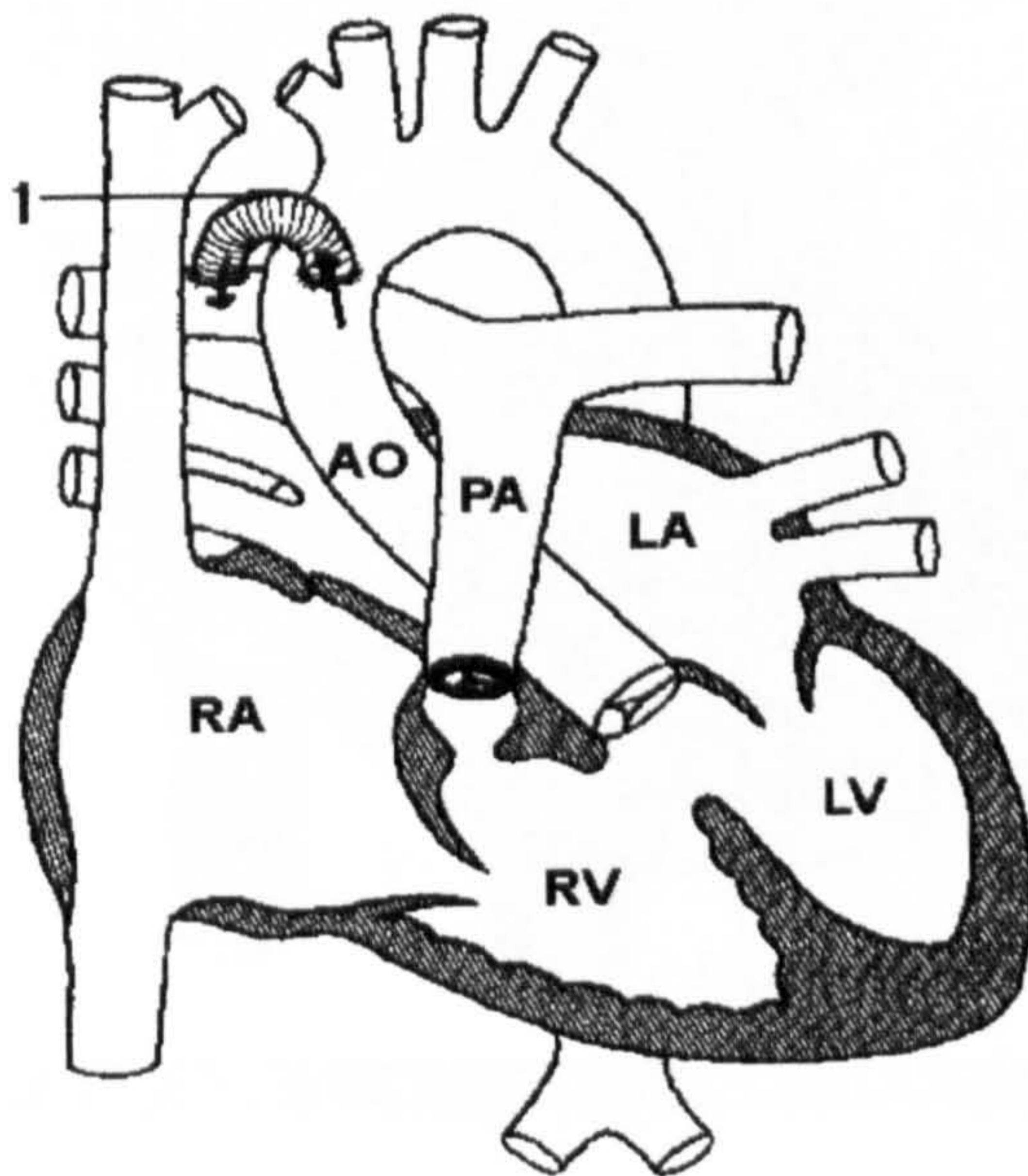


© Mayo Foundation for Medical Education and Research. All rights reserved.

Appendix 1

This is a palliative shunt that was frequently used to increase pulmonary circulation in infants with complex heart defects. This procedure could be performed without heart-lung bypass as it involves structures outside the heart.

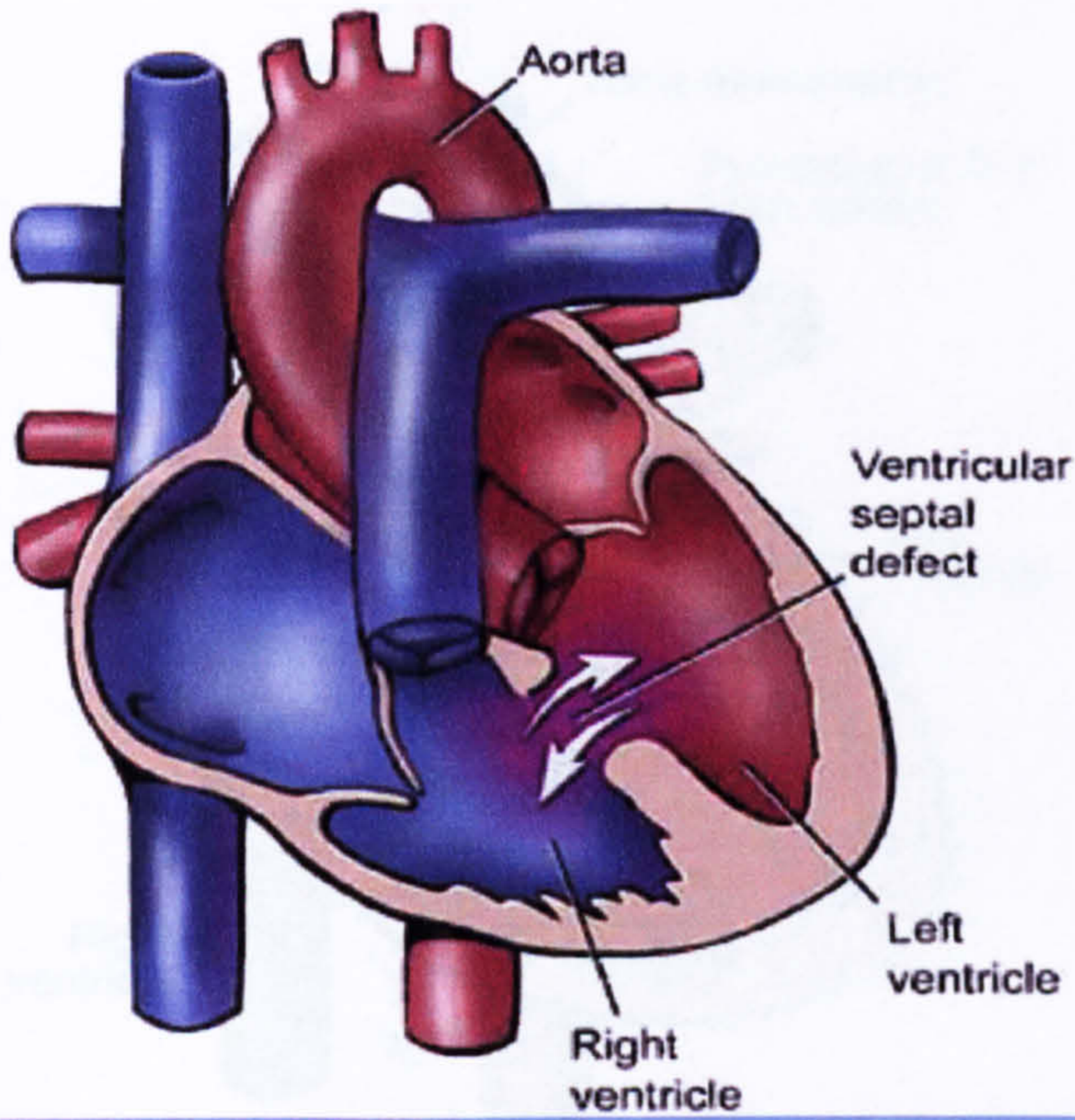
Modified Blalock-Taussig shunt



Appendix 1

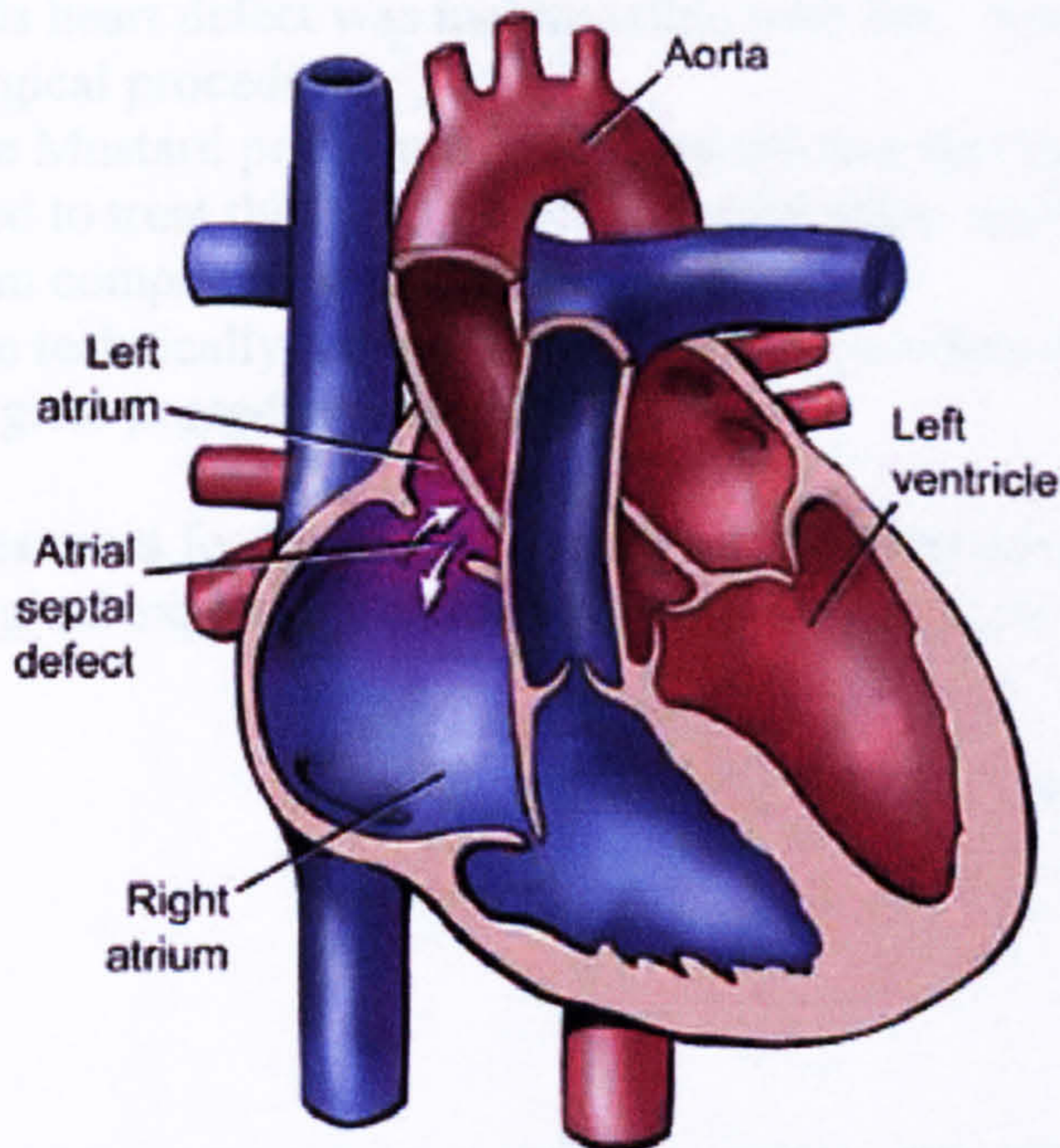
The structures affected in these two conditions are inside the heart. Open-heart surgery was necessary using heart-lung bypass.

Ventricular Septal Defect



© Mayo Foundation for Medical Education and Research. All rights reserved.

Atrial Septal Defect

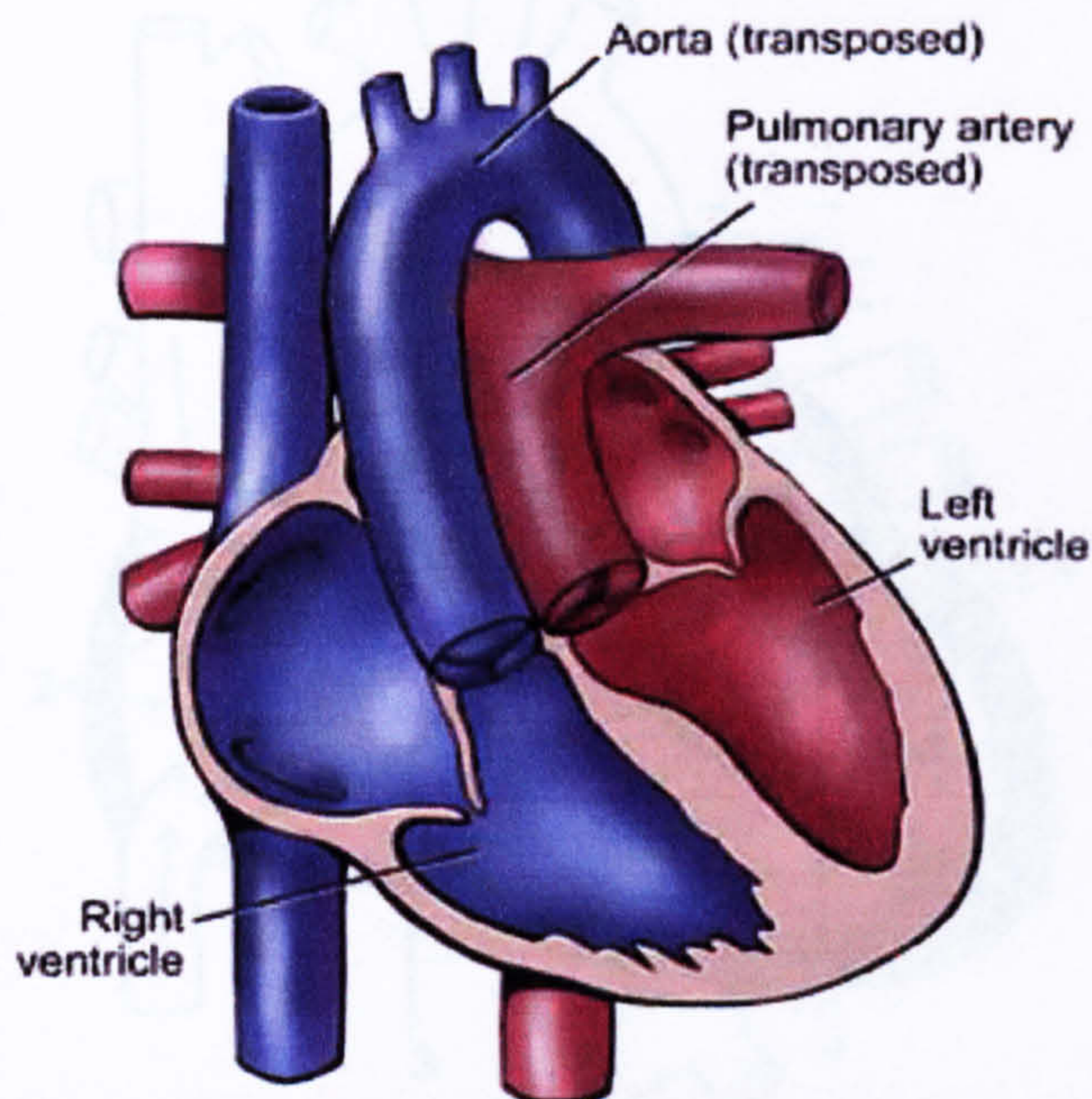


© Mayo Foundation for Medical Education and Research. All rights reserved.

Appendix 1

In order to palliate this condition, it was necessary to open the heart, so needing heart-lung bypass.

Transposition of Great Arteries



© Mayo Foundation for Medical Education and Research. All rights reserved.

This heart defect was incompatible with life. The following page shows two surgical procedures.

The Mustard procedure (atrial switch) was the original surgical procedure used to treat this heart defect. Despite initial survival, life threatening long-term complications became evident.

The technically more complex Jatene procedure (arterial switch) is now the surgical procedure carried out.

Treatment for this heart condition epitomises developments in technology and surgical expertise that has had a major impact on survival rates.

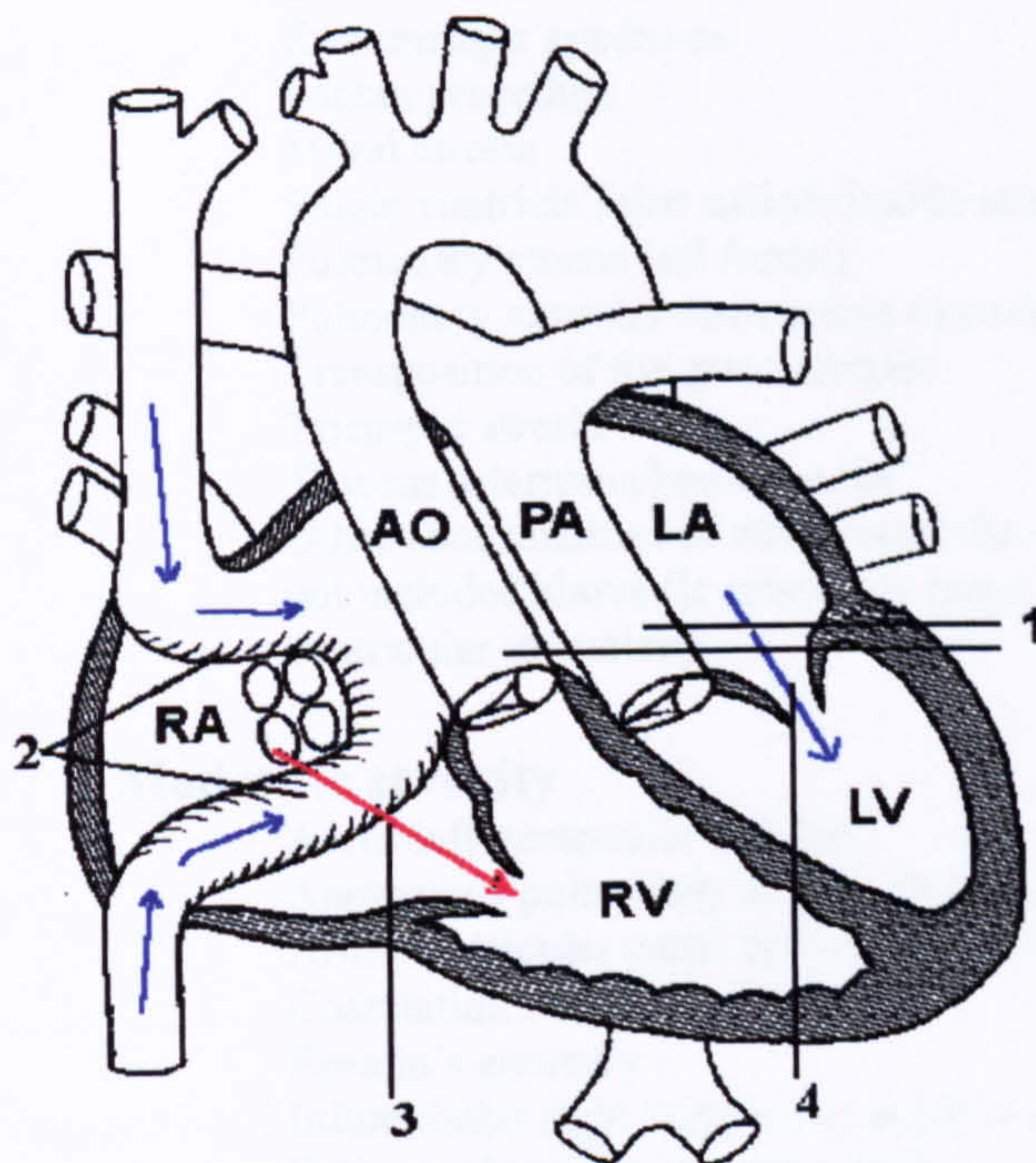
Appendix 1

Degree of complexity of CHD as defined at 32nd Bethesda Conference (AFC 2001)

Great Complexity

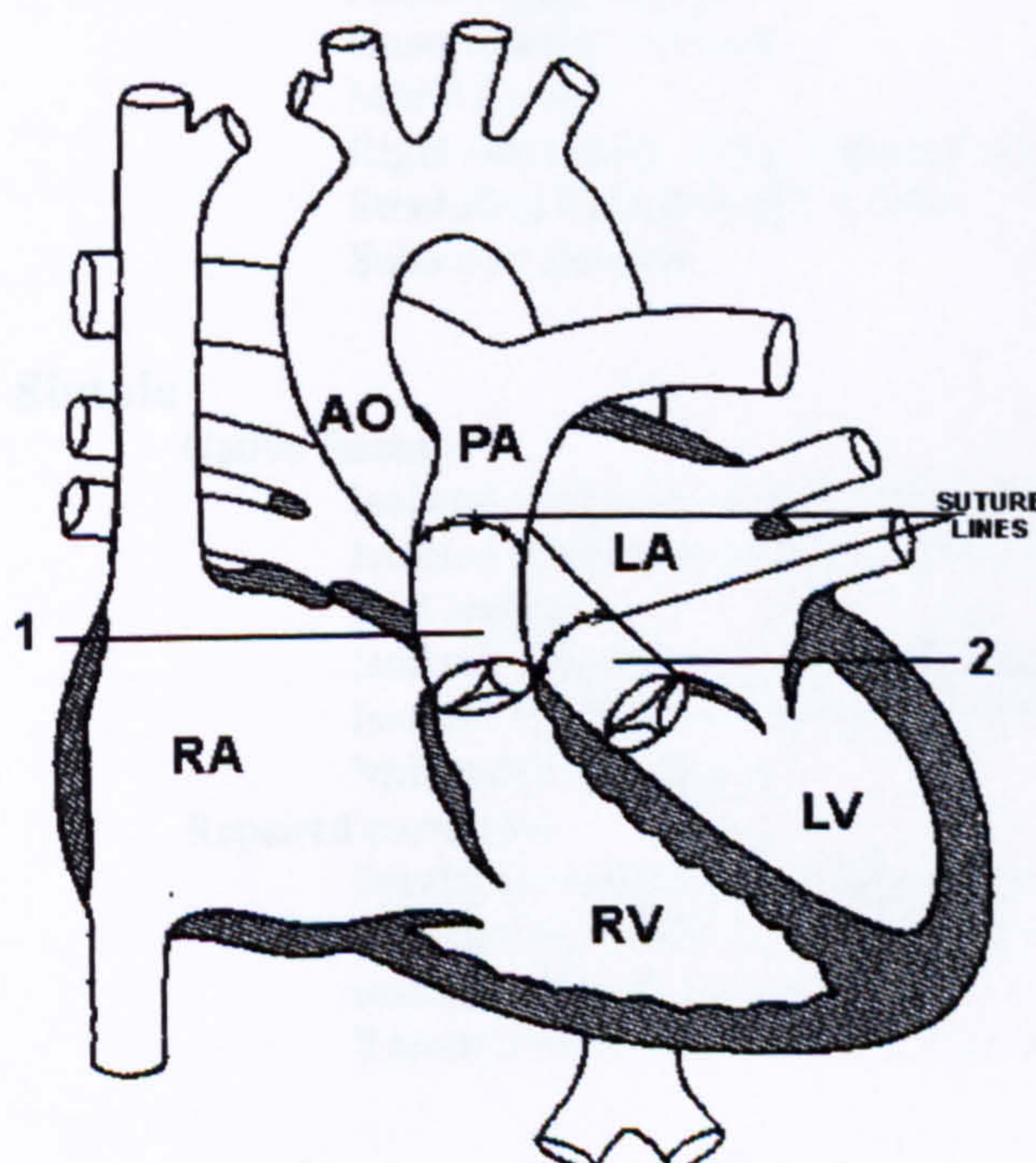
Transposition of the great arteries
 Atrial septal defect
 Ventricular septal defect
 Pulmonary stenosis
 Aortic stenosis

Mustard procedure
 (atrial switch)



1. Transposition of the great arteries
2. Atrial baffles
3. Pulmonary vein flow through tricuspid valve to right ventricle
4. IVC and SVC flow through mitral valve to left ventricle

Jatene procedure
 (arterial switch)



1. Original aortic root
2. Original pulmonary artery root

Appendix 2

**Degree of complexity of CHD as defined at
32nd Bethesda Conference (ACC 2001)****Great Complexity**

Conduits, valved or nonvalved
 Cyanotic congenital heart (all forms)
 Double-outlet ventricle
 Eisenmenger syndrome
 Fontan procedure
 Mitral atresia
 Single ventricle (also called double inlet/outlet, common/primitive)
 Pulmonary atresia (all forms)
 Pulmonary vascular obstructive diseases
 Transposition of the great arteries
 Tricuspid atresia
 Truncus arteriosus/hemitruncus
 Other abnormalities of atrioventricular or ventriculoarterial connection
 not included above (ie crisscross heart, isomerism, heterotaxy syndromes,
 ventricular inversion)

Moderate severity

Aorto-left ventricular fistulae
 Anomalous pulmonary venous drainage (partial or total)
 Atrioventricular canal defects (partial or complete)
 Coarctation of the aorta
 Ebstein's anomaly
 Infundibular right ventricular outflow obstruction of significance
 Ostium primum atrial septal defect
 Patent ductus arteriosus (not closed)
 Pulmonary valve regurgitation (moderate to severe)
 Pulmonic valve stenosis (moderate to severe)
 Sinus of Valsalva fistula/aneurysm
 Sinus venosus atrial septal defect
 Subvalvar or supra-valvar aortic stenosis (except HOCM)
 Tetralogy of Fallot
 Ventricular septal defect with

- Absent valve or valves
- Aortic regurgitation
- Coarctation of the aorta
- Mitral disease
- Right ventricular outflow tract obstruction
- Straddling tricuspid/mitral valve
- Subaortic stenosis

Simple

Native disease

- Isolated congenital aortic valve disease
- Isolated congenital mitral valve disease (except parachute valve,
 cleft leaflet)
- Isolated patent foramen ovale or small atrial septal defect
- Isolated small ventricular septal defect (no associated lesions)
- Mild pulmonic stenosis

 Repaired conditions

- Previously ligated or occluded ductus arteriosus
- Repaired secundum or sinus venosus atrial septal defect without
 residua
- Repaired ventricular septal defect without residua

Appendix 3

**Congenital Heart Disease: incidence and survival
(Wren & O'Sullivan 2001)**

The eight most common defects	Incidence	Predicted survival to age 16 years
Ventricular Septal Defect	39% 29.7% no surgery 9.3% had surgery	80%
Pulmonary Stenosis	7.3% 5% no surgery 2.3% had surgery	90%
Transposition of Great Arteries	5.8%	87%
Tetralogy of Fallot	5.8%	94%
Atrio Ventricular Septal Defect	5.3%	91%
Patent Ductus Arteriosus	4.8%	99%
Coarctation of the Aorta	4.6%	98%
Atrial Septal Defect	4.3%	97%
TOTAL	76.9%	92%

Appendix 4

Congenital Heart Disease Functional Classification
(Perloff and Miner 1998:11)

Class 1	Asymptomatic at all levels of activity
Class 2	Symptoms are present but do not curtail average, everyday activity
Class 3	Symptoms significantly curtail most but not all average, everyday activity
Class 4	Symptoms significantly curtail virtually all average, everyday activity and may be present at rest

Ability index classification
(Warnes and Somerville 1986: 535)

Grade 1	Normal life Full time work or school Can manage pregnancy
Grade 2	Able to do part time work Life modified by symptoms
Grade 3	Unable to work Noticeable limitations of activities
Grade 4	Extreme limitation Dependent Almost housebound

Functional Capacity	Objective Assessment
<p>Class I. Patients with cardiac disease but without resulting limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.</p>	<p>A. No objective evidence of cardiovascular disease.</p>
<p>Class II. Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.</p>	<p>B. Objective evidence of minimal cardiovascular disease.</p>
<p>Class III. Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain.</p>	<p>C. Objective evidence of moderately severe cardiovascular disease.</p>
<p>Class IV. Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.</p>	<p>D. Objective evidence of severe cardiovascular disease.</p>

New York Heart Association classification (1994)

Appendix 6

Timeline of reports and guidelines related to adult CHD

Date	Authors	Title
Conference held 18-19 October 1990 Report published 1991	American College of Cardiology	22 nd Bethesda Conference. Congenital Heart Disease after childhood: an expanding patient population
1993	Wilson and Neutze Green Lane Hospital Auckland, New Zealand	Adult congenital heart disease: principles and management guidelines. Parts I and II
Conference held 6-7 January 1994 Report published 1994	American College of Cardiology American College of Sports Medicine	26 th Bethesda Conference. Recommendations for determining eligibility for competition in athletes with cardiovascular abnormalities
One personal meeting, followed by electronic communication Report published 1998	Canadian Cardiovascular Society	Canadian Consensus Conference on Adult Congenital Heart Disease 1996
December 1999	British Paediatric Cardiac Association British Cardiac Society	Adult congenital heart disease: recommendations for service provision in the UK (draft)
Conference held 2-3 October 2000 Report published 2001	American College of Cardiology	32 nd Bethesda Conference. Care of the adult with congenital heart disease
2000	Department of Health	The NHS Plan
2000 (congenital heart disease not included)	Department of Health	National Service Framework for coronary heart disease
2001	Canadian Cardiovascular Society	Recommendations for the management of adults with congenital heart disease. 2001
2002	British Cardiac Society	Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK
2003	Department of Health	Specialised Services National Definition Set: 13. Specialised cardiology and cardiac surgery (adult) including cardiothoracic transplantation (all ages)
2003	European Society of Cardiology	Management of grown up congenital heart disease

One example of search strategy

Page 1 of 2

Ovid: Search Results

CINAHL - Cumulative Index to Nursing & Allied Health Literature 1982 to December Week 2
2005

#	Search History	Results
1	congenital heart.mp. [mp=title, subject heading word, abstract, instrumentation]	1287
2	limit 1 to yr="1960 - 2000"	621
3	adult.mp. [mp=title, subject heading word, abstract, instrumentation]	151101
4	limit 3 to yr="1960 - 2000"	73485
5	adult congenital heart.mp. [mp=title, subject heading word, abstract, instrumentation]	247
6	limit 5 to yr="1960 - 2000"	99
7	2 and 4	124
8	psychosocial.mp. [mp=title, subject heading word, abstract, instrumentation]	25074
9	limit 8 to yr="1960 - 2000"	14952
10	7 and 9	8
11	6 and 9	8
12	from 11 keep 2-7	6
13	from 12 keep 1-6	6

Appendix 8

Institution name

Institution address

Ref: CPW/DBL

5th January 2000

Mrs J Lyon

Personal address

Dear Mrs Lyon

Submission No:354/99 - An exploration of information and services required by young adults with congenital heart disease (CHD).

Following the conditional approval and in response to your letter dated 6th December 1999, I am pleased to confirm full approval having received the amended Patient Information Sheet, Consent Form and G P Letter and clarifying question 19 ii.

This approval was granted by the Chairman *Name* and will be brought to the attention of the Committee at their meeting on 26th January 2000.

This committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely,

Name and signature

Appendix 8

Institution name

Institution address

Date: 27th January 2000

This is to certify that the research proposal:

**An Exploration of Information and Services Required by Young Adults With
Congenital Heart Disease (CHD)**

Submitted by the lead investigator:

Joy Lyon

was given approval by the *Clinical directorate name* s Non-Medical Peer Review
Group on the 6th January 2000

Signed:

Name and signature

Name and signature

Appendix 8



South East Multi-centre Research Ethics Committee

Chairman of the South East MREC – Dr J M Lamberty FRCA

Mrs Joy Lyon

Institution address

Room 76, B Block
40 Eastbourne Terrace
London W2 3QR

Tel: 01227 831 662
Fax: 01227 831 662
Email: jane-martin@stmrec.fsnet.co.uk

4th April 2003

Dear Mrs Lyon

MREC 03/01/016 Information and services required by adults with congenital heart disease: A case study.

Application for dated revised 24 March 2003
Introduction for health and social carer letter version 1 December 2002
Information sheet for health and social carer – version 1 December 2002
Consent form for health and social carer – version 1 dated December 2002
Patient information sheet – version 1 dated December 2002
Patient consent form – version 1 December 2002
Interview schedule – version 1 December 2002
Protocol – version 1
Indemnity agreement
Curriculum vitae – Ms Joy Lyon

The Chairman of the South East MREC has considered the amendments submitted in response to the Committee's earlier review of your application on 12th February 2003 as set out in our letter dated 19th February 2003.

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the use of an existing database collected for previous research or other purposes with subsequent patient contact patient. For this reason you are asked to read carefully the sections concerning LREC involvement and local NHS management set out below as there are specific requirement involved when undertaking such research.

MREC Conditions of Approval

Appendix 9

Initial interviews

(to be on headed paper)

Patient Information Sheet**Adults with Congenital Heart Disease: an exploratory study**

My name is Joy Lyon and I am a Teaching Fellow at (*institution name*). I teach a course to qualified nurses caring for patients requiring cardiac surgery. I am writing to ask you to participate in a research project designed to explore the information and services required by young adults with congenital heart disease.

The initial part of the study is to interview a small group of people with congenital heart disease. The interviews will be audiotaped, and in due course the information may be used to generate a questionnaire. You can stop the interview at any time with no adverse effects to you. The interview will ask for your experiences of growing up with a congenital heart defect. Confidentiality is assured. The information gained may be used for publication, but no details of individuals will be used. All tapes and transcripts of interviews will be destroyed on completion of the study.

The aim of the study is to identify if there are limitations, from a patients perspective, in existing information and services provided for this emerging patient group. It is anticipated that this information will contribute to the ongoing development of services and plans for future health care provision.

Interviews will take place in patients' homes, unless this is unsatisfactory to you, in which case a suitable venue will be agreed. It is anticipated that interviews will last between 1-2 hours. If you would like a copy of the transcript of your interview for your information or for you to make comments on, it will be made available to you. Your participation in this study is entirely voluntary, and you may withdraw at any stage without giving a reason and without affecting your treatment.

If you require any further information or have any concerns please contact me, Joy Lyon through (*telephone number*) or by e-mail at (*e-mail address*). If you agree to participate in this study please could you complete and return the attached sheet in the envelope provided.

Thank you for taking the time to read this letter.

Yours faithfully

Joy Lyon
Teaching Fellow

Appendix 9
Second Interviews

**(to be on headed paper)
to include telephone and e-mail contact details**

Date

Patient Information Sheet

Information and services required by adults with congenital heart disease: an exploratory study.

Thank you for agreeing to meet with me for a second interview. You may recall that I am completing this study to explore your perspective of growing up with congenital heart disease. The study aims to explore information and service needs from your perspective, and mindful of expanding and extending nursing roles, consider if other members of the multidisciplinary team have the potential to provide aspects of care. It is anticipated that the information gained from this study will contribute to ongoing developments of services and plans for future health and social care provision.

As with the first interview, this second interview will be audiotaped and will ask for your understanding of some of the areas that have emerged from the analysis of the earlier interviews. Confidentiality is assured; the information gained may be used for publication, but no details of individuals will be used. All tapes and transcripts of interviews will be destroyed on completion of the study. If you would like a copy of the transcript of your interview for your information or for you to make comments on, it will be made available to you. Your further participation in this study is entirely voluntary.

Thank you for taking the time to read this information sheet.

Joy Lyon

Appendix 10
Patient consent form

(to be on headed paper)
to include telephone and e-mail contact details

PATIENT CONSENT FORM

Title of Project: Information and services required by adults with congenital heart disease: an exploratory study.

Researcher: Joy Lyon

1. I confirm that I have read and understand the Information Sheet dated December 2002 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Researcher

Date

Signature

Interview guide (1)

Introduction

reason for interview - who I am, why the study, why them, how them;
 confidentiality, right not to answer, consent form
 small talk – where to sit, position of recorder

What they know from their experience of living with a congenital heart defect

How are you now – heartwise?

I know some totally well, no problems, and others always aware of heart

Individual perceptions of available information/services. (RQ 2, 3, 4)

Have you ever felt the need for info/services?

What did you need?

Was it available?

Where?

What kinds of info have you obtained?

Who provided?

How useful was it?

What info/service not accessed?

Can you tell me more about this?

What info/service has not been available, that you would have liked?

Who could best provide this?

Where could this best be provided?

How might this have been useful?

What would you like to see happen?

What is your opinion of?

What do you think of?

Suppose there was a small group of 12-16 year olds with CHD – I asked you for advice about what to tell them, what would you say to me?

Suppose I was with you during out-patient appointment – what would I see – take me there. Tell me what is going on. What it is like for you.

How knowledge and experience influence actions in their contact with adult health care services

Biographical information

Name

Age

Occupation

Defect

Procedures

Consultant (if applicable)

Post interview talking – restate role; thank for participation; seek appropriate agencies, if necessary.

Interview guide (2)

Introduction

Reason for interview; who I am; why this study; confidentiality; consent form; small talk – where to sit, position of recorder

Wellness as defined by individual

Tell me how you are heartwise

Use Perloff & Miner(1998) classification

Information required

Do you attend for regular checks?

Do you attend if OK?

What is the value of regular checks for you?

You are now grown up; tell me about when you realised about your heart?

What did you want to know then?

How did you find out?

What have you wanted know since?

How has this arisen?

How have you found out?

What is easy/difficult?

How?

Use GUCH list as prompt as necessary

(areas identified from GUCH Patients Association website)

Perception of future need

Tell me what you think about the future for you

Tell me about other people who make a difference

Positive and negative – friends, teachers, employers, doctors, parents etc

Post interview talking

Restate role; thank for participation; may contact again (next year); seek appropriate agencies if necessary; confirm consent.

Interview guide (3)**Telephone/e-mail contact**

Coming back because you appear well; you epitomise this aspect of wellness; I just want to explore this further.

Interview

Greetings; plans for consent, recording etc; restate why them, their story, views.

Opening question:

What aspects from your experience contribute to your ability to live a full life (or live well) with your CHD?

Stages in life where things appear to have changed for the better (worse)
(deliberately ask for turning points)

Is there anything you have noticed yourself doing?

What does being well mean to you?

Theory checking:

resilience

adaptation

turning-point

health in illness

sense of coherence – understandable

manageable

meaningful

peace of mind/readiness to hear

?others

age – usual maturation

identity

self-efficacy

stigma/stereotype

patient's perspective

Reflect words and phrases back

Elicit story telling around the areas

Are there examples?/Could you give me an example of ...?

Can you tell me a bit more about that?

Other people? Who? How?

Normal for you? How different?

You say ...

Presentations related to this study

- 2001
May Poster presentation at The 3rd World Congress of Pediatric Cardiology and Cardiac Surgery. Toronto, Canada.
- 2002
May Teaching session to health care team based at Peter Lougheed Centre, Calgary, Canada
- Concurrent presentation at The 13th Annual Congenital Heart Disease in the Adult: a combined international symposium. Skamania, USA.
- September Poster presentation at Qualitative Research in Health and Social Care, Annual Conference, Bournemouth, UK.
- 2003
March Three-day course for qualified nurses working in acute settings in which adults with congenital heart disease received care. Southampton General Hospital, UK
- July Poster presentation at The 2nd Annual Scholarship Conference: Developing Scholarship through Partnership. University of Southampton, UK.
- October Teaching session for midwifery students
- November Teaching session for paediatric cardiology nursing course
- 2004
May Poster presentation at The 14th Annual Congenital Heart Disease in the Adult: a combined international symposium. Skamania, USA.
- July Poster presentation at The 3rd Annual Scholarship Conference: Innovations in partnership, practice and education. University of Southampton, UK.
- September Concurrent presentation at The 5th Qualitative Research Conference in Health and Social Care, Bournemouth University, UK
- October Teaching session for cardiac surgery nursing students
- December Article included in Adult Congenital Heart Association newsletter

Appendix 12

- 2005**
- March** **Concurrent session at The International Nursing Research Conference, Belfast, UK**
- Teaching session for midwifery students**
- April** **Question accepted for difficult cases session at The National Symposium on Congenital Heart Disease in the Adult, Southampton, UK**
- Session for palliative care nursing students**
- May** **Concurrent presentation at The 15th Annual International Symposium on Congenital Heart Disease in the Adult. Toronto, Canada**
- June** **Teaching session for primary health care nursing students**
- Presentation to Wessex Children's Heart Circle, Southampton General Hospital**
- July** **Poster presentation at The 4th Annual Scholarship Conference, Developing partnerships: research, practice and education. University of Southampton, UK.**
- December** **Teaching session for midwifery students**
- 2006**
- March** **Presentation at The Biannual meeting of Association of European Paediatric Cardiology on Psychosocial care in Congenital Heart Disease. Belfast, UK**
- Teaching session for cardiac surgery nursing students**
- April** **Teaching session for palliative care nursing students**

Peace of mind

Peace of mind is confirmed by:

- CHD is not an issue
- Individuals view of themselves
- Understanding of their CHD
- Social network
- Health carers

Peace of mind is disrupted by:

- Social activities (stopped holiday, joining gym, driving Employment)
 - Insurance of savings plan
 - Pregnancy (female)
 - Others said they would have children irrespective of risk of child having CHD as life had been good for them and treatments improving (male)
- Perceptions of other people (Stigma)**
scar/acq heart disease/employers

Readiness to hear

Impact on choices:

- Social activities (stopped holiday, joining gym, driving Employment)
- Insurance of savings plan
- Pregnancy (female)
- Others said they would have children irrespective of risk of child having CHD as life had been good for them and treatments improving (male)

Changes in health resulting in:

- Hospital admission or need for further surgery
- Extra medication
- Further tests

Clinic Visit both confirms and disrupts peace of mind

Recommendations for practice

- Exercise prescription informed by health carer to be used in gym following surgery
- Ask what is 'normal for them' and if anything is different
- Contact person after clinic visit
- Letter for insurance company
- Out of hours service for some investigations
- Information aimed at living life as well adult
- Revisit areas that have been previously covered
- Patient held record
- Continuity of care
- Check understanding at clinic
- Resource for GP
- Career planning
- Internet access at clinic
- Smoking cessation

What – Tension between wanting and not wanting

- details – need to know nothing or everything
- Changes from child to adult
- Things other than medical
- The little things
- Doesn't know what questions to ask
- Summary of history
- Exercise details
- Local GUCH contact

When – Timing is essential as before 'ready to hear'

- things are not relevant to them
- Where – clinic; maybe Internet; GP
- Who – expert; GP

How – needs to be reciprocal (avoid patronising)

**Some Guidelines for the Phenomenological Analysis of Interview Data.
Hycner R.H. (1985)**

1. Transcription.
2. Bracketing and the phenomenological reduction.
3. Listening to the interview for a sense of the whole.
4. Delineating units of general meaning.
5. Delineating units of meaning relevant to the research question.
6. Training independent judges to verify the units of relevant meaning.
7. Eliminating redundancies.
8. Clustering units of relevant meaning.
9. Determining themes from clusters of meaning.
10. Writing a summary for each individual interview.
11. Return to the participant with the summary and themes: conducting a second interview.
12. Modifying themes and summary.
13. Identifying general and unique themes for all the interviews.
14. Contextualization of themes.
15. Composite summary.

Example of data analysis

- 156 your life and actually its not is a very small part so that ring any bells would
 157 you describe yourself as resilient
 158
- 159 ** I think I am yes yes I think I am resilient I have always had that kind of OK I am
 160 not always the most confident person to do things but I am always like can
 161 battle through sort of get through on things I've set my mind on something I
 162 do it so and nothing is going to hold me back and if I want to something I will
 163 do and I am quite stubborn as well if I make my mind up it takes a lot of
 164 changing it but no I wouldn't say that I think a lot of people don't even know
 165 that I have had a heart operation and it doesn't I am not thinking of they are
 166 thinking I have a heart operation I am going to prove them wrong it is not like
 167 that because its like because nobody hardly anyone knows about it
 168
- 169 JL yes its like you said with your cousin when he said what's that what has happened
 170 to you
 171
- 172 ** yes yes well what has happened to me (puzzled, surprised)
 173
- 174 JL and that's to me that's the normalness of life for you (yes) you said about this idea
 175 of sort of being resilient is there anything that may be you can think of that
 176 would be an example of that in your life you said you are determined
 177
- 178 ** I suppose doing the bike rides actually because that I must admit I knew that other
 179 people about were going to do it a lot easier but I did do a lot of practice and
 180 it was towards the end quite difficult to keep well not to keep up but just
 181 other people could do it a lot more easier than me so I had to really dig in
 182 (right) the second time lot easier
 183
- 184 JL why do you think they could do it easier then
 185
- 186 ** I don't know maybe they are fitter than me I don't know really I think some of
 187 them were quite sort of fit but cause I suppose with any sports I have done I
 188 have done it quite well but I have always I know my limitations lets say and
 189 that is always like in the back of my mind thinking well yes I have got a heart
 190 condition so maybe I am not going to but then again I think that is also one of
 191 the things when I was about seven or eight the first I think it was when before
 192 I had the operation I was told that you are never going to join the army you
 193 are never going to pass the medical for being in the police force or things like
 194 that so like maybe that has always been a barrier thinking well you've been
 195 told you can't do it so I didn't want to join the army or police force anyway
 196 but and I think sometimes that may I think when I was about to do the bike
 197 ride I was thinking sixty miles can I really do this I did get a little bit not
 198 concerned but thinking I've got a heart condition here that's when it did come
 199 up a little bit
 200

Development of themes – initial interviews

Examples of informant's own words	Descriptive theme	Interpretive theme	Pattern theme
It doesn't affect me that much ... it's not a great issue	CHD is not an issue		Turning points and resilience (King et al 2003; Masten 2001) Identity (Watson 2002) Psychosocial development (Erikson 1968)
During my school years I was fine, I was in all the school teams	Individual's view of self		
When I used to have to wear the 24 hour recorders, maybe then I knew I was different because I couldn't play football or do what I was doing every other day	Understanding of their own CHD	Peace of mind	
My heart is basically backwards and it's got the stronger side pumping between my heart and my lungs and the weaker side pumping round my body	Social network		
I don't think my sister takes much notice of it because she's younger than me, I always had it and she's grown up with it	Health carers		
I've got an older brother he used to beat me up ... my mum used to get in the middle of us			
He (cardiologist) is the type of man you trust and he knows me ... I see anybody ... they are part of a team			
I've got a scar ... I do get people going 'ugh what's that?'	Perceptions of other people	Readiness to hear	
My work involves manual labour and they (employers) were worried because the boss's wife had one of her heart valves replaced and he said 'Are you OK to do all of this?'	Impact of CHD on choices		
Most insurance companies won't touch me ... because I have an annual check up although no surgery is performed ... they call in a recurring condition	Changes in health		
GP said I could go to either (tertiary centre) or (local hospital) which is just up the road ... I said to local hospital staff 'you must talk to my cardiologist'			
I was in there five, ten minutes he mentioned a drug ... I had already forgotten the name by the time I came out	How to remember	Characteristics of information	
The little things, things not medical	What information		

Appendix 16

Development of themes – second interviews

Examples of informant's own words	Descriptive theme	Interpretive theme	Pattern theme
I can't stand rejection in any way shape or form especially to do with my heart I do anything I want, I fly, run, bike, get on with normal life When someone tells you something that you can't do you are going to do it anyway	Choices and rejection Don't tell me I can't do something	I make my own decisions	Health in illness (Lindsey 1996; Corbin 2003; Thorne et al 1997-2004) Self-efficacy (Bandura 1997) Health behaviour change (Prochaska et al 1994; Rollnick et al 1999) Positive human health (Ryff & Singer 1998) Salutogenesis (Antonovsky 1987)
I trust them because obviously they've saved my life	Lucky to be alive	I am a responsible adult	
I know I shouldn't have high blood pressure I am aware to stay healthy not to smoke	I understand my CHD		
When you are running the valve leakage stops	Useful information		
I think we mature at an early age if you are dealing with this sort of thing	Being mature		
I am fit as a fiddle	Keeping fit		
I do a lot of exercise, probably a conscious effort to make sure that I'm fit I do try (to be fit), I like exercise, eating well			
I don't think I've got a heart condition I don't see myself as different to anybody else ... even to the point where I don't remember I've got the scars	I am aware of my heart but I don't think of it		
You can't spend your whole life thinking about it panicking about it you wouldn't do anything	Worry when you need to		
It's other people issues ... someone starts questioning me	Other people		
I just completely panicked and I was like that every time ... I don't have to go back now ... and its brilliant not to have that looming feeling I'm back to the hospital every two years for a check up, I put everything out of my mind until it's time for that check up	Clinic visit		

Abbreviations frequently used within this thesis for organisations related to adult congenital heart disease

Professional Organisations

American College of Cardiology	ACC
Association of European Paediatric Cardiology	AEPC
British Cardiac Society	BCS
British Paediatric Cardiac Association	BPCA
Canadian Cardiovascular Society	CCS
European Society of Cardiology	ESC

Patient Associations

American Congenital Heart Association	ACHA
Canadian Adult Congenital Heart Network	CACH Net
Grown Up Congenital Heart (UK)	GUCH

Glossary of terms and abbreviations associated with congenital heart disease: adapted from Canadian Cardiovascular Society Consensus Conference (1998), Callow and Wild (1990) and Children's Heart Federation (2002).

<i>ACHD – adult congenital heart disease</i> or <i>GUCH – grown-up congenital heart</i>	Both terms are used to denote a person over 16 years of age who has congenital heart disease.
<hr/>	
<i>Amplatzer</i>	A double umbrella shaped device used to close an <i>atrial septal defect</i> ; the device is placed using a <i>cardiac catheter</i> .
<i>Aortic stenosis</i>	A narrowing which restricts red blood from moving from the left ventricle into the aorta.
<i>ASD – atrial septal defect</i>	A hole between the atria that produces a modest left-to-right shunt.
<i>Bicuspid</i>	A valve that has two cusps or leaflets.
<i>Blalock-Taussig</i>	A palliative shunt which increases blood flow to the lungs by connecting left or right subclavian artery to the pulmonary artery.
<i>Cardiac catheter</i>	(procedure in which) a tube which is put into the heart through a vein or artery. It is used to help diagnose, can widen arteries that have narrowed, or insert devices that close a hole.
<i>Coarctation of the aorta</i>	A narrowing of the main artery taking blood from the heart to the body.
<i>Ebstein's anomaly</i>	The tricuspid valve is abnormal and situated within the right ventricle.
<i>Eisenmenger's syndrome</i>	An extreme form of pulmonary vascular obstructive disease arising as a consequence of pre-existing systemic-to-pulmonary shunt, wherein pulmonary vascular resistance rises such that pulmonary pressures are at or near systemic levels and there is reversed (left-to-right) or bi-directional shunting at great vessel, ventricular and/or atrial levels.

<i>Fontan procedure</i>	An operation for a single ventricle circulation; a connection is created between the atria and pulmonary artery, diverting the blue blood returning from the body into the pulmonary artery; the single ventricle pumps red blood to the body. There are many variations, all leading to improvement of systemic oxygen saturation and reducing volume overload of the single ventricle.
<i>Infective endocarditis</i>	An infection of the lining of the heart.
<i>Mustard procedure</i>	An operation for complete <i>transposition of the great arteries</i> ; this redirects the flow of blood to the atria and leaves the left ventricle pumping to the lungs, and the right ventricle to the body.
<i>Pacemaker</i>	A small battery placed under the skin and joined to the heart by pacing wires, which measure the pulse and corrects too slow rhythms.
<i>PDA – patent (persistent) ductus arteriosus</i>	A passage used for circulation before the baby is born remains open, instead of closing shortly after birth. Causes red blood to return from the aorta back to the lungs.
<i>Rastelli</i>	An operation for repair of <i>transposition of the great arteries</i> that is associated with other anomalies such as <i>ventricular septal defect</i> and pulmonary stenosis; the right ventricle supports the systemic circulation.
<i>Senning</i>	Similar to <i>Mustard</i> (technically different, functionally similar)
<i>TGA – transposition of the great arteries</i>	The big arteries, which should be taking blue blood from the heart to the lungs, and red blood from the heart to the body, are round the wrong way. This means that deoxygenated (blue) blood goes back to the body, and oxygenated (red) blood from the lungs is directed back into the lungs.
<i>CC TGA – congenitally corrected transposition of the great arteries</i>	An anomaly where the aorta arises from the right ventricle and the pulmonary artery from the left ventricle, in addition the right atrium connects to the left ventricle and the left atrium to the right ventricle. The right ventricle supports the systemic circulation. There are usually associated anomalies.

<i>ToF – tetralogy of Fallot</i>	A hole between the two ventricles (<i>ventricular septal defect</i>), and a narrowing between the right ventricle and the artery carrying blood to the lungs (<i>pulmonary stenosis</i>).
<i>Tricuspid atresia</i>	The tricuspid valve is absent.
<i>Truncus arteriosus</i>	There is one single artery arising from the heart which then divides into the lung artery and the body artery. There is in addition, a large hole between the two pumping chambers (<i>ventricular septal defect</i>).
<i>VSD – ventricular septal defect</i>	A hole between the two ventricles – the pumping chambers of the heart.
<i>Waterston shunt</i>	A palliative operation to increase blood flow to the lungs, and increase oxygen delivery to the body. Involves creating a small communication between the main pulmonary artery and the ascending aorta. Often complicated by the development of pulmonary vascular obstructive disease if too large. Not uncommonly causes distortion of the pulmonary artery.

References

- Alderman, L.M. (2000) At risk: adolescents and adults with congenital heart disease. *Dimensions of Critical Care Nursing*, 19, 2-15.
- American College of Cardiology (1991) 22nd Bethesda Conference: Congenital heart disease after childhood: an expanding patient population. *Journal of the American College of Cardiology*, 18, 311-342.
- American College of Cardiology & American College of Sports Medicine (1994) 26th Bethesda Conference: Recommendations for Determining Eligibility for Competition in Athletes with Cardiovascular Abnormalities. *Journal of the American College of Cardiology*, 24, 854-899.
- American College of Cardiology (2001) Care of the adult with congenital heart disease. Presented at the 32nd Bethesda Conference, Bethesda, Maryland. October 2-3 2000. *Journal of the American College of Cardiology*, 37, 1161-1198.
- American Heart Association (2002) 1994 Revisions to Classification of Functional Capacity and Objective Assessment of Patients with Disease of the Heart. www.americanheart.org [Online 23.08.2003].
- Angen, M.J. (2000) Evaluation interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10, 378-395.
- Antonovsky, A. (1987) *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. Jossey-Bass Publishers, San Francisco, USA.
- Appleton, J.V. & King, L. (2002) Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*, 40, 641-648.
- Astolfi, H. & Evans, M. (1997) Motivational Interviewing. www.aodgp.gov.au/resourcekit/b3/handout4_interviewing.pdf [Online 05.01.2006].
- Bailey, P.H. (1996) Assuring quality in narrative analysis. *Western Journal of Nursing Research*, 18, 186-194.
- Bandura, A. (1997) Exercising of personal and collective efficacy in changing societies. *Self-Efficacy in Changing Societies* (ed. by A. Bandura), pp. 1-45. Cambridge University Press, UK.

- Barbour,R.S. (2001) Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal*, 322, 1115-1117
- Beauchamp,T.L. & Childress,J.F. (2001) *Principles of Biomedical Ethics*. Oxford University Press, UK.
- Bellinger,D.C., Wypij,D., Kuban,K.C., Rappaport,L.A., Hickey,P.R., Vernovsky,G., Jonas,R.A. & Newburger,J.W. (1999) Developmental and neurological status of children at 4 years of age after heart surgery with hypothermic circulatory arrest or low-flow cardiopulmonary bypass. *Circulation*, 100, 526-532.
- Benner,P. (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Addison-Wesley Publishing Company, Inc. USA.
- Bennett,J.A., Riegel,B., Bittner,V. & Nichols,J. (2002) Validity and reliability of the NYHA classes for measuring research outcomes in patients with cardiac disease. *Heart and Lung*, 31, 262-270.
- Bjornsen, K.D. (2004) Health care transition in congenital heart disease: the providers' view point. *Nursing Clinics of North America*, 39, 715-726
- Bournemouth University (2000) *Code of Practice. Research Governance and Ethics in Postgraduate Research*.
- British Cardiac Society (2002) Grown-Up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart*, 88, i1-i14.
- British Heart Foundation (2003) Introduction to Heart Conditions. www.bhf.org.uk [Online 22.01.2004].
- Bryman,A. (2004) *Social Research Methods*. Oxford University Press, UK.
- Burgess,R.G. (1984) *In the Field: an Introduction to Field Research*. Routledge, UK.
- Burnard,P. (2004) Writing a qualitative research report. *Nurse Education Today*, 24, 174-179.
- Callow,L. & Wild,L. (1990) *Cardiac Resource Manual*. C.S.Mott Children's Hospital, University of Michigan Medical Centre, USA.

- Canadian Adult Congenital Heart (CACH) Network (2000) Canadian Diagnostic Codes (Shortcodes2000) for Adult Congenital Cardiac Patients. www.library.utoronto.ca/nevil_thomas/shortcds. [Online 07.11.2002]
- Canadian Cardiovascular Society (1998) Consensus Conference on Adult Congenital Heart Disease 1996. *Canadian Journal of Cardiology*, 14, 395-452.
- Canadian Cardiovascular Society (2001) Consensus Conference 2001 update. *The Canadian Journal of Cardiology*, 17.
- Canobbio, M.M. (1984) Congenital heart disease in adults. *The Nursing Clinics of North America* 19[3].
- Canobbio, M.M. & Day, M.J. (1994) The role of the clinical specialist. *Nursing Clinics of North America*, 29, 357-366.
- Canobbio, M.M. (1994) Issues in the care of adults with congenital heart disease. *Nursing Clinics of North America*, 29.
- Canobbio, M.M. (2001) Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 5, 363-370.
- Canobbio, M.M. & Higgins, S. (2004) Transitional care issues for adolescents with congenital heart disease. *Nursing Clinics of North America*, 39 (4) xii-xiv.
- Celermajer, D.S. & Deanfield, J.E. (1991) Adults with congenital heart disease: a comprehensive specialist service is needed. *BMJ*, 303, 1413-1414.
- Celermajer, D.S. & Deanfield, J.E. (1993) Employment and insurance for young adults with congenital heart disease. *British Heart Journal*, 69, 539-543.
- Cetta, F., Graham, L.C., Lichtenberg, R.C. & Warnes, C.A. (1999) Piercing and tattooing in patients with congenital heart disease: patient and physician perspectives. *Journal of Adolescent Health*, 24, 160-162.
- Children's Heart Federation (2002) *Information Sheets. Terms parents have asked to be explained*. www.childrens-heart-fed.org.uk [Online 07.11.2002]
- Colaizzi, P.F. (1978) Psychological research as the phenomenologist views it. *Existential Phenomenological Alternative for Psychology* (ed. by R. Valle and M. King), pp. 48-71. Oxford University Press, New York.

- Corbin, J.M. (2003) The body in health and illness. *Qualitative Health Research*, 13, 256-267.
- COREC (2003) Application for Ethical Committee Review. www.corec.org.uk [Online 05.01.2006].
- Corner, J. (1997) Inaugural lecture. Nursing and the counter culture for cancer. *European Journal of Cancer Care*, 6, 174-181.
- Cox, D., Lewis, G., Stuart, G. & Murphy, K. (2002) A cross-sectional study of the prevalence of psychopathology in adults with congenital heart disease. *Journal of Psychosomatic Research*, 52, 65-68.
- Crowley, C., Harre, R. & Tagg, C. (2002) Qualitative research and computing: methodological issues and practices in using QSR NVivo and NUD*IST. *International Journal of Social Research Methodology*, 5, 193-197.
- Cutcliffe, J.R. & McKenna, H.P. (1999) Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing*, 30, 374-380.
- Dahlberg, K., Drew, N. & Nystrom, M. (2001) *Reflective Lifeworld Research*. Studentlitteratur AB, Sweden.
- Dahlberg, K.E. & Dahlberg, H.K. (2004) Description vs interpretation – a new understanding of an old dilemma in human science research. *Nursing Philosophy*, 5, 268-273.
- Darbyshire, P. (1994) Skilled expert practice: is it 'all in the mind'? A response to English's critique of Benner's novice to expert model. *Journal of Advanced Nursing*, 19, 755-761.
- Darbyshire, P., Diekelmann, J. & Diekelmann, N. (1999) Reading Heidegger and interpretive phenomenology: a response to the work of Michael Crotty. *Nursing Inquiry*, 6, 17-25.
- Davison, K.P., Pennebaker, J.W. & Dickerson, S.S. (2000) Who Talks? The social psychology of illness support groups. *American Psychologist*, 55, 205-217.
- Dawson, L.H. (1973) *Nuttall's Concise Standard Dictionary of the English Language*. Frederick Warne & Co Ltd, UK.

- Department of Health (1997a) *A Bridge to the Future. Nursing Standards, Education and Workforce Planning in Paediatric Intensive Care. Report of the Chief Nursing Officer's Taskforce.* The Stationery Office. UK
- Department of Health (1997b) *Paediatric Intensive Care 'A Framework for the Future'. Report From the National Coordinating Group on Paediatric Intensive Care to The Chief Executive of the NHS Executive.* The Stationery Office. UK.
- Department of Health (2000a) *The NHS Plan: a Plan for Investment; a Plan for Reform.* The Stationery Office. UK.
- Department of Health (2000b) *National Service Frameworks: Coronary Heart Disease.* The Stationery Office. UK.
- Department of Health (2001a) *Research Governance Framework for Health and Social Care.* The Stationery Office. UK.
- Department of Health (2001b) *The Expert Patient: a New Approach to Chronic Disease Management for the 21st Century.* The Stationery Office. UK.
- Department of Health (2003) *Specialist Services National Definition Set: 13. Specialised Cardiology and Cardiac Surgery (Adult) Including Cardiothoracic Transplantation (All Ages).* The Stationery Office. UK.
- Department of Health (2005) *Supporting People with Long Term Conditions: improving care improving lives.* The Stationery Office. UK.
- Deyo R.A. (2001) A key medical decision maker: the patient. *BMJ*, 323, 466-467.
- DiDonato,R.M., Fyfe,D.A., Puga,F.J., Danielson,G.K., Ritter,D.G., Edwards,W.D. & McKay,R. (1985) Fifteen-year experience with surgical repair of truncus arteriosus. *New England Journal of Medicine*, 89, 414-422.
- DIPEX.org (2002) Personal experiences of health and illness www.dipex.org [Online 05.01.2006]
- Doucet,S.B. (1981) The young adult's perceptions of the effect of congenital heart disease on his life style. *Nursing Papers*, 13, 3-16.

- Draucker, C.B. (1999) The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30, 360-373.
- Eiser, C. (1990) *Chronic Childhood Disease: an Introduction to Psychological Theory and Research*. Cambridge University Press.
- Eiser, C. (1998) Editorial: children with physical illness. *Child: Care, Health and Development*, 24, 1-4.
- English, I. (1993) Intuition as a function of the expert nurse: a critique of Benner's novice to expert model. *Journal of Advanced Nursing*, 18, 387-393.
- Erikson, E.H. (1968) *Identity: youth and crisis*. Faber and Faber Ltd, London, UK
- European Society of Cardiology Task Force (2003) Management of Grown Up Congenital Heart Disease. *European Heart Journal*, 24, 1035-1084.
- Feudtner, C. (2001) What are the goals of patient education? *Western Journal of Medicine*, 174, 173-174.
- Field, P.A. & Morse, J.M. (1985) *Nursing Research: the Application of Qualitative Approaches*. Chapman & Hall, London, UK..
- Gantt, L.T. (1992) Growing up heartsick: the experience of young women with congenital heart disease. *Health Care for Women International*, 13, 241-248.
- Gantt, L. (2002) As normal a life as possible: mothers and their daughters with congenital heart disease. *Health Care for Women International*, 23, 481-491.
- Gatzoulis, M.A., Hechter, S., Siu, S.C. & Webb, G.D. (1999) Outpatient clinics for adults with congenital heart disease: increasing workload and evolving patterns of referral. *Heart*, 81, 51-61
- Gatzoulis, M.A. (2005) President's message. *ISACCD update*, Winter.
- Gatzoulis, M.A. (2006) Adult congenital heart disease: education, education, education. *Nature Clinical Practice Cardiovascular Medicine*, 3, 2-3
- Gewillig, M., Wyse, R.K., deLeval, M.R. & Deanfield, J.E. (1992) Early and late arrhythmias after the Fontan operation: predisposing factors and clinical consequences. *British Heart Journal*, 67, 72-79.

- Gilbert,L.S. (2002) Going the distance: 'closeness' in qualitative data analysis software. *International Journal of Social Research Methodology*, 5, 215-228.
- Glaser,D. & Bentovim,A. (1987) Psychological aspects of congenital heart disease. *Paediatric Cardiology. Vol II* (ed. by R.H.Anderson, E.A.Shineborne, F.J.Macartney and M.Tynan), Churchill Livingstone, UK.
- Goble,L.A. (2004) The impact of a child's chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing*, 27, 153-262
- Gortmaker,S.L. (1985) Demography of chronic childhood disease. *Issues in the Care of Children With Chronic Illness* (ed. by N.Hobbs and J.M.Perrin), Jossey-Bass, San Francisco, USA.
- Gray,G. & Pratt,R. (1991) *Towards a Discipline of Nursing*. Churchill Livingstone, UK.
- Grech,V. & Savona-Ventura,C. (1999) Declining mortality from congenital heart disease related to innovations in diagnosis and treatment: a population-based study. *Cardiology in the Young*, 9, 78-80.
- Greenhalgh,T. (1997) How to read a paper: getting your bearings (deciding what the paper is about). *British Medical Journal*, 315, 243-246.
- Greenwood,R. (1999) *Living With Heart. A Study of Health-Related Quality of Life in Adults With Congenital Heart Disease*. Boston College. PhD thesis.
- Guba,E.G. & Lincoln,Y.S. (1981) *Effective Evaluation: improving the usefulness of evaluation results through responsive and naturalistic approaches*. Jossey-Bass, San Francisco, USA.
- Guba,E.G. & Lincoln,Y.S. (1989) *Fourth Generation Evaluation*. Sage publications Inc, USA.
- GUCH (undated) Grown Up Congenital Heart Patients Association. www.GUCH.org.uk. [Online 05.01.2006].
- GUCH News (2001) GUCH returns home to the National Heart Hospital. *The Newsletter of the Grown Up Congenital Heart Patients' Association*, 31, 1.
- GUCH News (2002) My Name is ... GUCH? *The Newsletter of the Grown Up Congenital Heart Patients' Association*, March 32, 10.

- GUCH News (2002) No new name for GUCH. *The Newsletter of the Grown Up Congenital Heart Patients' Association*, Summer 33, 11.
- Guignon, C.B. (1993) *The Cambridge Companion to Heidegger*. Cambridge University Press, UK.
- Guillemin, M. & Gillam, L. (2004) Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*, 10, 261-280.
- Hammersley, M. & Atkinson, P. (1995) *Ethnography: Principles in Practice*. Routledge, UK.
- Haywood, K.L., Garratt, A.M. & Fitzpatrick, R. (2005) Older people specific health status and quality of life: a structured review of self-assessed instruments. *Journal of Evaluation in Clinical Practice*, 11, 315-327
- Higgins, S.S. & Tong, E. (2003) Transitioning adolescents with congenital heart disease into adult health care. *Progress in Cardiovascular Nursing*, 18, 93-98.
- Hoffman, J.I.E. (1995) Incidence of congenital heart disease: 1. Postnatal Incidence. *Pediatric Cardiology*, 16, 103-113.
- Hoffman, J.I.E., Kaplan, S. & Liberthson, R.R. (2004) Prevalence of congenital heart disease. *American Heart Journal*, 147, 425-439.
- Holloway, I. & Walker, J. (2000) *Getting a PhD in Health and Social Care*. Blackwell Science Ltd, UK.
- Holloway, I. & Todres, L. (2003) The status of method: flexibility, consistency and coherence. *Qualitative Research*, 3, 345-357
- Holloway, I. & Wheeler, S. (2002) *Qualitative Research in Nursing*. Blackwell Science Ltd, UK.
- Holmes, S. (1998) The quality of life. *International Journal of Palliative Nursing*, 4, 108.
- Horner, T., Liberthson, R. & Jellinek, M.S. (2000) Psychosocial profile of adults with complex congenital heart disease. *Mayo Clinical Proceedings*, 75, 31-36.
- Hunter, S. (1997) Management of adults with congenital heart disease. *Heart*, 78, 15.
- Hycner, R.H. (1985) Some guidelines for the phenomenological analysis of interview data. *Human Studies*, 8, 279-303.

- Hymovich, D.P. & Hagopian, G.A. (1992) *Chronic Illness in Children and Adults. A Psychosocial Approach*. W.B.Saunders Co, USA.
- Ironside, P.M., Scheckel, M., Wessels, C., Bailey, M.E., Powers, S. & Seeley, D.K. (2003) Experiencing chronic illness: cocreating new understandings. *Qualitative Health Research*, 13, 171-183.
- Iserin, L. (2001) Management of pregnancy in women with congenital heart disease. *Heart*, 85, 493-494.
- Jasper, M.A. (2005) Using reflective writing within research. *Journal of Research in Nursing*, 10, 247-260.
- Jordon, S.C. & Scott, O. (1991) *Heart Disease in Paediatrics. 3rd Edition*. Butterworths, London, UK
- Kantoch, M.J., Collins-Nakai, R.L., Medwid, S., Ungstad, E. & Taylor, D.A. (1997) Adult patients' knowledge about their congenital heart disease. *Canadian Journal of Cardiology*, 13, 641-645.
- Kennedy, I. (2001) *The Inquiry into the Management of Care of Children Receiving Complex Heart Surgery at the Bristol Royal Infirmary*. <http://www.bristol-inquiry.org.uk>. [Online 23.04.2002]
- King, G., Cathers, T., Brown, E., Specht, J.A., Willoughby, C., Polgar, J.M., MacKinnon, E. & Havens, L. (2003) Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research*, 13, 184-206.
- King, S.C. & Sivarajan Froelicher, E.S. (1989) Cardiac Rehabilitation: activity and exercise program. *Cardiac Nursing. 2nd Edition* (ed. by S.L.Underhill, S.L.Woods, E.S.Sivarajan Froelicher and C.J.Halpenny), pp. 739-756. J.B. Lippincott Company, Philadelphia, USA.
- Kitchiner, D. (1996) Physical activities in patients with congenital heart disease. *Heart*, 76, 6-7.
- Koch, T. (1994) Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976-986.
- Koch, T. (1995) Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21, 827-836.
- Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing*, 24, 174-184.

- Kools,S., Gillis,C.L. & Tong,E.M. (1999) Family transitions in congenital heart disease management: the impact of hospitalization in early adulthood. *Journal of Family Nursing*, 5, 404-425.
- Kools,S., Tong,E., Hughes,R., Jayne,R., Scheibly,K., Laughlin,J. & Gillis,C.L. (2002) Hospital experiences of young adults with congenital heart disease: divergence in expectations and dissonance in care. *American Journal of Critical Care*, 11, 115-127.
- Kvale,S. (1996) *Interviews: an Introduction to Qualitative Research Interviewing*. Sage Publications Inc, USA.
- Lane,D.A., Lip,G.Y. & Millane,T.A. (2002) Quality of life in adults with congenital heart disease. *Heart*, 88, 71-75.
- Laverty,S.M. (2003) Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *International Journal of Qualitative Methods.*, 2, article 3.
- Lawler,J. (1998) Phenomenologies as research methodologies for nursing: from philosophy to researching practice. *Nursing Inquiry*, 5, 104-111.
- Leonard,H., O'Sullivan,J.J. & Hunter,S. (1996) Family planning requirements in the adult congenital heart disease clinic. *Heart*, 76, 60-62.
- Lincoln,Y.S. & Guba,E.G. (1985) *Naturalistic Inquiry*. Sage Publications Inc, USA.
- Lindsey,E. (1996) Health within illness: experiences of chronically ill/disabled people. *Journal of Advanced Nursing*, 24, 465-472.
- Lip,G.Y.H., Lane,D.A. & Millane,T.A. (2002) Psychological interventions for depression in congenital heart disease (Protocol for a Cochrane Review). *The Cochrane Library*, 2, Oxford.
- Lip,G.Y.H, Lane,D.A., Millane,T.A. & Tayebjee,M.H. (2004) Psychological interventions for depression in adolescent and adult congenital heart disease. *Cochrane Library*, 1, John Wiley & Sons Ltd, UK
- Livecchi,T.A. (2004) Psychosocial issues affecting adults with congenital heart disease: one patient's perspective. *Nursing Clinics of North America*, 39, 787-789.
- Long Term Medical Conditions Alliance (undated) Expert Patients: who are they? www.lmca.demon.co.uk [Online 05.01.2006].

- Long, T. & Johnson, M. (2000) Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4, 30-37.
- MacLachlan, M. (2002) *Take Heart! A Guide to Coping With Cardiac Surgery for Patients and Their Families*. Librario, UK.
- Madjar, I. & Walton, J.A. (1999) *Nursing and the Experience of Illness: Phenomenology in Practice*. Routledge, London, UK.
- Maggs-Rapport, F. (2001) 'Best research practice': in pursuit of methodological rigour. *Journal of Advanced Nursing*, 35, 373-383.
- Malotte, C.K. & Gilbert, J. (1989) Cardiovascular Health Promotion in the Young. *Cardiac Nursing. 2nd Edition* (ed. by S.L. Underhill, S.L. Woods, E.S. Sivarajan Froelicher and C.J. Halpenny), pp. 682-686. J.B. Lippincott Company, Philadelphia, USA.
- Maruszewski, B., Lavour-Gayet, F., Monroe, J.L., Keogh, B.E., Tobota, Z. & Kansy, A. (2005) An attempt at data verification in the EACTS Congenital Database. *European Journal of Cardio-thoracic Surgery*, 28, 400-406.
- Masi, G. & Brovedani, P. (1999) Adolescents with congenital heart disease: psychopathological implications. *Adolescence*, 34, 185-191.
- Mayo Clinic (2005) Slide show: common types of congenital heart defects. www.mayoclinic.com [Online 02.03.06]
- Miles, M.B. & Huberman, A.M. (1994) *Qualitative Nursing Research: an Expanded Sourcebook*. Sage Publications Inc, USA.
- Miner, P.D. (1994) Infective Endocarditis: implications for care of the adult with congenital heart disease. *The Nursing Clinics of North America*, 29, 269-283.
- Moons, P., DeVolder, E., Budts, W., DeGeest, S., Elen, J., Waeytens, K. & Gewillig, M. (2001a) What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart*, 86, 74-80.
- Moons, P., Siebens, K., DeGeest, S., Abraham, I., Budts, W. & Gewillig, M. (2001b) A pilot study of expenditures on, and utilization of resources in, health care in adults with congenital heart disease. *Cardiology in the Young*, 11, 301-311.

- Moons,P., Van Deyk,K., Marquet,K., Raes,E., De Bleser,L., Budts,W. & De Geest,S. (2005) Individual quality of life in adults with congenital heart disease: a paradigm shift. *European Heart Journal*. 26, 298-307
- Morse,J.M., Barrett,M., Mayan,M., Olson,K. & Spiers,J. (2002) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1.
- Murphy,D.J. (2003) The patient population and requirements for optimal care. *Progress in Pediatric Cardiology*, 17, 3-7.
- Neuberger,J. (1999) Let's do away with 'patients'. *BMJ*, 318, 1756-1758.
- New York Heart Association (1994) Classification of Functional Capacity. www.nyha.com [Online 23.08.2003].
- Nicoll,L.H. (1992) *Perspectives on Nursing Theory*. J.B. Lippincott Company, USA.
- Nursing and Midwifery Council (2002) *Code of Professional Conduct*.
- O'Boyle,C.A., Browne,J., Hickey,A., McGee,H.M. & Joyce,C.R.B. (1995) *The Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW)*. Department of Psychology, Royal College of Surgeons in Ireland
- Office for National Statistics (1998) *Living in Britain: 1996 General Household Survey*. HMSO, London.
- Olley,P.M. (1998) Meeting an emerging need. *Canadian Journal of Cardiology*, 14, 182-184.
- Paley,J. (1996) Intuition and expertise: comments on the Benner debate. *Journal of Advanced Nursing*, 23, 665-671.
- Paley,J. (1997) Husserl, phenomenology and nursing. *Journal of Advanced Nursing*, 26, 187-193.
- Paley,J. (1998) Misinterpretive phenomenology: Heidegger, ontology and nursing research. *Journal of Advanced Nursing*, 27, 817-824.
- Paterson,B.L., Russell,C. & Thorne,S. (2001) Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing*, 35, 335-341.
- Patton,M.Q. (1990) *Qualitative Evaluation and Research Methods*. Sage Publications Inc, USA.

- Perloff,J.K. (1978) *The Clinical Recognition of Congenital Heart Disease*. W.B.Saunders Co, USA.
- Perloff,J.K. (1991) Congenital heart disease in adults. A new cardiovascular subspeciality. *Circulation*, **84**, 1881-1890.
- Perloff,J.K. (1998) Historical Perspective. *Congenital Heart Disease in Adults*. (ed. by J.K.Perloff and J.S.Childs), W.B.Saunders Co, USA.
- Perloff,J.K. & Miner,P.D. (1998) Specialized facilities for the comprehensive care of adults with congenital heart disease. *Congenital Heart Disease in Adults* (ed. by J.K.Perloff and J.S.Child), W.B.Saunders Co, USA.
- Perloff,J.K. & Child,J.S. (1998) *Congenital Heart Disease in Adults*. W.B.Saunders Co, USA.
- Picker Institute Europe (undated) The NHS patient survey programme. www.pickerinstitute.eu [Online 05.01.2006].
- Polanyi,M. (1958) *Personal Knowledge: Towards a Post-Critical Philosophy*. Routledge and Kegan Paul, Great Britain.
- Popelová,J., Zdenek,S. & Škovránek,J. (2001) Are cyanosed adults with congenital cardiac malformations depressed? *Cardiology in the Young*, **11**, 379-384.
- Price,B. (1996) Illness careers: the chronic illness experience. *Journal of Advanced Nursing*, **24**, 275-279.
- Prochaska,J.O., Norcross,J.C. & DiClemente,C.C. (1994) *Changing for Good. A Revolutionary Six-Stage Program for Overcoming Bad Habits and Moving Your Life Positively Forward*. Reprinted in Quill 2002, HarperCollins, USA.
- Punch,K.F. (1998) *Introduction to Social Research: Quantitative and Qualitative Approaches*. Sage Publications, UK.
- Rapport,F., Wainwright,P. & Elwyn,G. (2005) 'Of the edgelands': broadening the scope of qualitative methodology. *Medical Humanities*, **31**, 37-42.
- Ray,L.D. & Mayan,M. (2001) Who decides what counts as evidence? *The Nature of Qualitative Evidence*. (ed. by J.M.Morse, J.M.Swanson and A.J.Kuzel), Sage Publications Inc, USA.
- Redfern,M. (2001) *The Royal Liverpool Children's Inquiry*. The Stationery Office. UK.

- Richards,L. (2000) *QSR N5: Using N5 in Qualitative Research*. QSR International Pty Ltd. Bundoora, Victoria, Australia.
- Rietveld,S., Mulder,B.J.M., van Beest,I., Lubbers,W., Prins,P.J.M., Vioen,S., Bennebroek-Everez,F., Vos,A., Casteelen,G. & Karsdorp,P. (2002) Negative thoughts in adults with congenital heart disease. *International Journal of Cardiology*, 86, 19-26.
- Rogers,C.R. (1961) *On Becoming a Person: a Therapist's View of Psychotherapy*. Constable & Robinson Ltd, UK.
- Rolfe,G., Freshwater,D. & Jasper,M. (2001) *Critical Reflection for Nursing and the Helping Professions: a User's Guide*. Palgrave Macmillan. UK.
- Rollnick,S., Mason,P. & Butler,C. (1999) *Health Behavior Change. A Guide for Practitioners*. Harcourt Publishers Limited.
- Ross,K. (1994) Making sense of qualitative data. *The Research Experience in Nursing* (ed. By J.Buckeldee & R.McMahon), pp. 131-146. Chapman & Hall, UK.
- Roy,C. (1976) *Introduction to Nursing: an Adaptation Model*. Prentice Hall, New Jersey, USA.
- Rubin,H.J. & Rubin, I.S. (1995) *Qualitative Interviewing: the art of hearing data*. Sage Publications Inc, USA
- Ryff,C.D. & Singer,B. (1998) The contours of positive human health. *Psychological Inquiry*, 9, 1-28.
- Sackett,D.L., Rosenberg,W.M.C., Gray,J.A.M., Haynes,R.B. & Richardson,W.S. (1996) Evidence-based medicine: what it is and what it isn't. *British Medical Journal*, 312, 71-72.
- Šamánek,M. (2000) Congenital heart malformations: prevalence, severity, survival, and quality of life. *Cardiology in the Young*, 10, 179-185.
- Sandelowski,M. (1986) The problem of rigor in qualitative research. *Advances in Nursing Science*, 8, 27-37.
- Sandelowski,M. (1993) Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16, 1-8.
- Sanders,S.P. (2004) We know how many - but how? *American Heart Journal*, 147, 398-400.

- Schmaltz, A.A., Neudorf, U. & Winkler, U.H. (1999) Outcomes of pregnancy in women with congenital heart disease. *Cardiology in the Young*, 9, 88-96.
- Schön, D. (1987) *Educating the Reflective Practitioner*. Jossey-Bass Inc, California, USA.
- Schwandt, T.A. (2000) Three epistemological stances for qualitative inquiry. *Handbook of Qualitative Research* (ed. by N.K. Denzin and Y.S. Lincoln), pp. 189-213.
- Shilling, C. (2002) Culture, the 'sick role' and the consumption of health. *British Journal of Sociology*, 53, 621-638.
- Shineborne, E.A. & Gatzoulis, M.A. (2002) Adult congenital heart disease. *Current Paediatrics*, 12, 220-226.
- Silverman, D. (2000) *Doing Qualitative Research: a Practical Handbook*. Sage Publications Ltd, UK.
- Simko, L.C. (2000) *Quality of Life of Adults With Congenital Heart Disease*. Duquesne University, PhD thesis.
- Siu, S.C., Chitayat, D. & Webb, G.D. (1999) Pregnancy in women with congenital heart defects: what are the risks? *Heart*, 81, 225-226.
- Siu, S.C. & Colman, J.M. (2001) Heart disease and pregnancy. *Heart*, 85, 710-715.
- Somerville, J. (1997) Near misses and disasters in the treatment of grown-up congenital heart patients. *Journal of the Royal Society of Medicine*, 90, 124-127.
- Sparacino, P.S.A., Tong, E.M., Messias, D.K.H., Foote, D., Chesla, C.A. & Gillis, C.L. (1997) The dilemmas of parents of adolescents and young adults with congenital heart disease. *Heart and Lung*, 26, 187-195.
- Sparkes, A.C. (2001) Myth 94: Qualitative health researchers will agree about validity. *Qualitative Health Research*, 11, 538-552.
- Spradley, J.P. (1979) *The Ethnographic Interview*. Holt, Rinehart and Winston.
- Spurkland, I., Bjornstad, P.G., Lindberg, H. & Seem, E. (1993) Mental health and psychosocial functioning in adolescents with congenital heart disease. A comparison between adolescents born with severe heart defect and atrial septal defect. *Acta Paediatr*, 82, 71-76.

- Stark, J. (1989) Do we really correct congenital heart defects? *The Journal of Thoracic and Cardiovascular Surgery*, 97, 1-9.
- State, M.W. & Perloff, J.K. (1998) Psychiatric and psychosocial disorders. *Congenital Heart Disease in Adults* (ed. by J.K. Perloff and J.S. Child), W.B. Saunders Co, USA.
- Streubert, H.J. & Carpenter, D.R. (1999) *Qualitative Research in Nursing. Advancing the Humanistic Imperative*. Lippincott Williams & Wilkins, USA.
- Swan, L. & Hillis, W.S. (2000) Exercise prescription in adults with congenital heart disease: a long way to go. *Heart*, 83, 685-687.
- Tayebjee, M.H. & Lip, G.Y.H. (2003) Letters to the Editor: Psychosocial functioning of adults with congenital heart disease: a neglected area. *European Heart Journal*, 24, 2159-2160.
- Taylor, S.E. & Brown, J.D. (1998) Illusion and well-being: a social psychological perspective on mental health. *Social Psychology. A General Reader* (ed. by A.W. Kruglanski and E.T. Higgins), pp. 23-41. Psychology Press, Ltd, UK.
- The Nevil Thomas adult congenital heart library (1999) www.achd-library.com/heart_pictures/index [Online 02.03.2006]
- Thorne, S. & Deanfield, J. (1996) Long-term outlook in treated congenital heart disease. *Archives of Disease in Childhood*, 75, 6-8.
- Thorne, S., Reimer Kirkham, S. & MacDonald-Emes, J. (1997) Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20, 169-177.
- Thorne, S. & Paterson, B. (1998) Shifting images of chronic illness. *Image: Journal of Nursing Scholarship*, 30, 173-178.
- Thorne, S.E. (1999) The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36, 397-404
- Thorne, S.E., Nyhlin, K.T. & Paterson, B.L. (2000) Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, 37, 303-311.
- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G. & Jillings, C. (2002) Chronic illness experience: insights from a metastudy. *Qualitative Health Research*, 12, 437-452.

- Thorne,S., Paterson,B. & Russell,C. (2003) The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research*, 13, 1337-1352.
- Thorne,S., Reimer Kirkham,S. & O'Flynn-Magee,K. (2004) The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3, Article 1.
- Thorpe,K. (2004) Reflective learning journals: from concept to practice. *Reflective Practice*, 5, 327-343.
- Todres,L. & Wheeler,S. (2001) The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies*, 38, 1-8.
- Tones,K. & Tilford,S. (2001) *Health Promotion: Effectiveness, Efficiency and Equity*. Nelson Thornes Ltd, Cheltenham, UK.
- Tong,E.M., Sparacino,P.S.A., Messias,D.K.H., Foote,D., Chesla,C.A. & Gillis,C.L. (1998) Growing up with congenital heart disease: the dilemmas of adolescents and young adults. *Cardiology in the Young*, 8, 303.
- Tong,E.M. & Kools,S. (2004) Health care transitions for adolescents with congenital heart disease: patient and family perspectives. *Nursing Clinics of North America*, 39, 727-740.
- Truesdell,S.C., Skorton,D.J. & Lauer,R.M. (1986) Life insurance for children with cardiovascular disease. *Pediatrics*, 77, 687-691.
- United Kingdom Central Council (1986) Project 2000: a new preparation for practice. *UKCC*.
- Utens,E.M.W.J., Verhulst,F.C., Meijboom,F.J. & Duivenvooren,H.J. (1993) Behavioural and emotional problems in children and adolescents with congenital heart disease. *Psychological Medicine*, 23, 415-424.
- Utens,E.M.W.J., Verhulst,F.C., Erdman,R.A.M. & Meijboom,F.J. (1994) Psychosocial functioning of young adults after surgical correction for congenital heart disease in childhood: a follow-up study. *Journal of Psychosomatic Research*, 38, 745-758.
- Utens,E.M., Versluis-Den Bieman,H.J., Verhulst,F.C., Meijboom,F.J., Erdman,R.A. & Hess,J. (1998a) Psychopathology in young adults with congenital heart disease. *European Heart Journal*, 19, 647-651.

- Utens,E.M., Verhulst,F.C., Duivenvoorden,H.J., Meijboom,F.J., Erdman,R.A. & Hess,J. (1998b) Prediction of behavioural and emotional problems in children and adolescents with operated congenital heart disease. *European Heart Journal*, 19, 801-807.
- vanManen,M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. USA State University of New York Press, USA.
- vanManen,M. (2002) Phenomenology Online. www.phenomenologyonline.com [Online 24.08.2004].
- van Rijen,E.H.M. & Utens,E.M.W.J. (2003) Letters to the Editor: Reply to: Psychopathology in adults with congenital heart disease: the attribution of longitudinal cohort studies. *European Heart Journal*, 24, 2159-2160.
- vanRijen,E.H.M., Utens,E.M.W.J., Roose-Hesselink,J.W., Meijboom,F.J., vanDomburg,R.T., Roelandt,J.R.T.C., Bogers,A.J.J.C. & Verhulst,F.C. (2003) Psychosocial functioning of the adult with congenital heart disease: a 20-33 years follow-up. *European Heart Journal*, 24, 673-683.
- vanRijen,E.H.M., Utens,E.M., Roose-Hesselink,J.W., Meijboom,F.J., vanDomburg,R.T., Roelandt,J.R.T.C., Bogers,A.J.J.C. & Verhulst,F.C. (2004) Medical predictors for psychopathology in adults with operated congenital heart disease. *European Heart Journal*, 25, 1605-1613.
- Vaughan,B. (1992) Exploring the knowledge of nursing practice. *Journal of Clinical Nursing*, 1, 161-166.
- Veldtman,G.R., Matley,S.L., Kendall,L., Quirk,J., Gibbs,J.L., Parsons,J.M. & Hewison,J. (2001) Illness understanding in children and adolescents with heart disease. *Western Journal of Medicine*, 174, 171-173.
- Wagstaff,M.H., Rigby,M.L. & Redington,A.N. (1998) Increasing workload and changing referral patterns in paediatric cardiology outreach clinics: implications for consultant staffing. *Heart*, 79, 223-224.
- Wanless,D. (2004) *Securing Good Health for the Whole Population: Final Report*. The Stationery Office. UK.
- Warnes,C.A. & Somerville,J. (1986) Tricuspid atresia in adolescents and adults: current state and late complications. *British Heart Journal*, 56, 535-543.
- Watson,N. (2002) Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. *Disability and Society*, 17, 509-527.

- Webb,C. (1999) Analysing qualitative data: computerized and other approaches. *Journal of Advanced Nursing*, 29, 323-330.
- Webb,G.D. (2001) Care of adults with congenital heart disease - a challenge for the new millennium. *The Thoracic and Cardiovascular Surgeon*, 49, 30-34.
- Webb,G.D. & Williams,R.G. (2001) Care of the adult with congenital heart disease: introduction. *Journal of the American College of Cardiology*, 37, 1166.
- Wernovsky,G., Styles,K.M., Gauvreau,K., Gentles,T.L., duPlessis,A.J., Bellinger,d.C., Walsh,A.Z., Burnet,J., Jonas,R.A., Mayer,J.E. & Newburger,J.W. (2000) Cognitive development after the Fontan operation. *Circulation*, 102, 883.
- Wilson,N.J. & Neutze,J.M. (1993a) Adult congenital heart disease: principles and management guidelines: Part I. *Australian and New Zealand Journal of Medicine*, 23, 498-503.
- Wilson,N.J. & Neutze,J.M. (1993b) Adult congenital heart disease: principles and management guidelines: Part II. *Australian and New Zealand Journal of Medicine*, 23, 697-705.
- World Health Organisaton (1946) Constitution of the World Health Organisation. www.who.int/governance/en/ [Online 05.01.2006].
- Wray,J. & Sensky,T. (2001) Congenital heart disease and cardiac surgery in childhood: effects on cognitive function and academic ability. *Heart*, 85, 687-691.
- Wren,C. & O'Sullivan,J.J. (2001) Survival with congenital heart disease and need for follow-up in adult life. *Heart*, 85, 438-443.