Health-related quality of life in chronic heart failure: Development and validation of a patient-centred health-related quality of life measure.

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Abstract

Chronic Heart Failure (CHF) is one of the major reasons for hospitalisation in the developed world. There have been considerable improvements in medical treatment with consequent improved outcomes. Despite this, the condition causes considerable impact on patients' health-related quality of life (HRQL), which if measured in studies, is usually from the professionals' perspective in terms of negative outcomes, rather than the patients. Review of the literature confirmed there is no appropriate patient-centred disease-specific tool which adequately explains the impact of CHF on the patients perspective of HRQL, and in addition generated suggestions for inclusion in a patient-centred measure.

The first, and qualitative phase of the thesis, explored patients' views on HRQL generating further themes for potential inclusion in the HRQL measure. Subsequently an initial questionnaire was subjected to response-altemative and factor analysis until redundant items were excluded.

In the quantitative phase of the study reliability and validity of the final instrument were tested using Cronbach's alpha statistic, item-total correlations and face/content validity respectively. Comparison was made with the gold standard generic measure (SF-36), and the Minnesota Living with Heart failure Questionnaire, the most directly applicable pre-existing disease-specific measure. In both cases the results were favourable.

Limitations of the study, in terms of the CHF population studied are fully discussed. These are principally the exclusion of patients from ethnic groups and the relative youth of the patients interviewed.

The final phase of the thesis describes how such a tool might be used in clinical practice and makes a number of suggestions for future research; such as monitoring the effect of medical treatment from the patients' perspective and how such a questionnaire might be used to influence health policy.

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List of Abbreviations

AMED	The Allied and Complementary Medicine Database
ARC	Academic Reference Centre
BIDS	Bath Information & Data Services
BNI	British Nursing Index
CABG	Coronary By-pass Graft
CCTR	Cochrane Clinical Trials Register
CDSR	Cochrane Database of Systematic Reviews
CHD	Coronary Heart Disease
CHF	Chronic Heart Failure
CHFQoL	Chronic Heart Failure Quality of Life
CHQ	Chronic Heart Failure Questionnaire
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CRD	Centre for Reviews and Dissemination
DARE	Database of Abstracts of Reviews of Effectiveness
EFA	Exploratory Factor Analysis
EMBASE	Excerpta Medical Online
GP	General Practitioner
HMIC	Health Management Information Consortium
HRQL	Health-Related Quality of Life
KCCQ	Kansas City Cardiomyopathy Questionnaire
LREC	Local Research Ethics Committee
LVF	Left Ventricular Dysfunction
MEDLINE	Index Medicus online
MLHFQ	Minnesota Living with Heart Failure Questionnaire
MIDAS	Myocardial Infarction Dimensional Assessment Scale
NHP	Nottingham Health Profile
NHS	National Health Service
NLM	National Library of Medicine
NRR	National Research Register
NSF	National Service Framework
NYHA	New York Heart Association
PAF	Principal Axis Factoring

List of Abbreviations (continued)

PCA	Principal Component Analysis
PTCA	Purcutaneous Transluminal Coronary Angioplasty
QALY	Quality Adjusted Life Year
QLQ-SHF	Quality of Life in Severe Heart Failure Questionnaire
RAG	Research Advisory Group
RCN	Royal College of Nursing
R&D	Research & Development
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
SF-12	Medical Outcomes Study 12 – Item Short Form Health Survey
SF-36	Medical Outcomes Study 36 – Item Short Form Health Survey
SIGLE	System for Information on Grey Literature in Europe
SIP	Sickness Impact Profile
UK	United Kingdom
WHO	World Health Organisation

Preface

I have been a cardiac specialist nurse for 11 years. My interest in investigating this research topic stemmed from working with individuals with chronic heart failure and a desire to find out how their health-related quality of life was affected by this debilitating condition. I had previously used health-related quality of life measures to assess chronic heart failure patients but I knew from my own clinical experience that these measures did not seem to derive from a patient's perspective.

The focus of this thesis is the development and validation of a health-related quality of life measure for use in a chronic heart failure population, which is patient-centred. This thesis describes an account of my research and experience.

The research described in this thesis was undertaken part-time over six years, whilst I was in full-time clinical practice. A Florence Nightingale, Band Trust Research Scholarship, funded one year of the programme (Phase 2). In the future, I hope to implement this health-related quality of life measure in my clinical practice and disseminate its use to a wider audience.

Acknowledgement

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Special thanks go to, firstly to my husband, Gary, for his tolerance, constant support and encouragement during this last six years; and for proof reading this thesis. Secondly to Leo, my son, who arrived during the final year of my studies and who has given me endless pleasure and made the whole process worthwhile.

Thank you to all the patients and their relatives who took the time and effort to participate in my research study. Without whom I would not have been able to complete this research.

Author declaration

I declare that this thesis is the original work of the author. The author has undertaken the research contained in this thesis under the supervision of the Research Advisory Group as directed by the University of York.

Chapter 1 - Introduction and study background

1.0 Introduction

This thesis presents a three-phase study conducted in United Kingdom (UK) district general hospitals to develop and validate a patient-centred, health-related quality of life measure for the use in chronic heart failure. This chapter presents the background to the research and provides an overview of current health-related quality of life measures in chronic heart failure; their benefits and limitations. Subsequent chapters will describe the rationale for a new instrument; the development of patient generated items for the health-related quality of life measure and the testing of the reliability and validity of the health-related quality of life measure in a chronic heart failure population. The thesis will conclude with a discussion and recommendations for future research.

1.1 Literature review

The review will concentrate on work already undertaken in the area of quality of life assessment tools and in particular that of coronary heart disease and chronic heart failure. A comprehensive review of quality of life evaluations in chronic heart failure found there are important differences between quality of life questionnaires (Berry & McMurray 1999). This paper reviewed the design and validation of both generic and disease-specific quality of life questionnaires, which have been used in clinical trials in chronic heart failure. The aim of their review was to consider the impairment in quality of life that may occur in a patient with chronic heart failure. Firstly, the authors reviewed the characteristics of a quality of life questionnaire, which would make it a useful instrument to evaluate quality of life in chronic heart failure. Secondly they evaluated the performance of both generic and disease-specific quality of life questionnaires when used in clinical trials in chronic heart failure. They argue that quality of life is an opinion formed by a person's interpretation of their own health status in comparison to what they might hope to be able to achieve. This review concluded by saying that no instrument has measured quality of life in heart failure trials in a reliable or valid way, and therefore an obvious need exists for the development of valid and reliable instruments (Berry & McMurray 1999). The current knowledge base in the area of patient-centred quality of life measures in chronic heart failure is lacking and there is a lack of consensus as to which measurers are appropriate for research and clinical practice. The author is interested in any work undertaken which takes into account the patient's perspective in measuring quality of life.

Currently the knowledge base in the area of patient-centred, quality of life measures in chronic heart failure suggests there is a caveat to this field and there is uncertainty as to which measure to use.

1.1.1 Aim of the literature review

The literature review is the first step in carrying out any piece of research. The literature review should be comprehensive and include all the pertinent and valid papers (Bowling 2002). The literature review aims to integrate the evidence in the area of generic and disease-specific measures in chronic heart failure and to identify the theory and methods in their development. This review will inform the development of a patient-centred health-related quality of life measure for a chronic heart failure population.

1.2 Aim of the search strategy

The search strategy will aim to locate all trials conducted, which report quality of life and health-related quality of life in a chronic heart failure population.

1.3 Search procedure

Due to the large quantity of the literature, articles were rejected through the title and abstract if they did not meet the search criteria. There was a language restriction to English publications only. Searches were limited to humans and adults (over 18). Due to financial constraints trials that were reported in foreign languages were not translated.

Search strategies were developed using key words, free text terms and thesaurus terms, described by Brettle et al. 1998; Hunt et al. 2003; Colclough 2003. An example of the search strategy is displayed from the Medline database (Figure 1.0)

Figure 1.0 Medline (index medicus online) database search strategy (1996-2006)

1. quality of life.mp.
2. ((quality adj3 life) or qol or hrqol or hrql or health-related quality of life or health related quality of life).mp.
3. ((quality adj adjusted adj life) or qaly).mp.
4. exp quality of life/
5. outcomes.mp.
6. "exp outcome and process assessment (health care)"/ or "outcome assessment (health care)"/
7. exp "outcome assessment (health care)"/
8. *"outcome assessment (health care)"/ or *"outcome and process assessment (health care)"/
9. health outcome$.mp.
10. health status.mp.
11. exp health status/
12. *health status/
13. ((health adj status) or (health adj state)).mp.
14. (health adj profile).mp.
15. (qwb or (quality adj3 (wellbeing or well-being))).mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading]
16. activities of daily living.mp.
17. health care survey.mp.
18. exp health care surveys/
19. patient assessment.mp.
20. exp patient satisfaction/
21. health status indicator$.mp.
22. health status indicators/
23. *questionnaires/
24. health care quality.mp.
25. sf$36.mp.
26. minnesota living with heart failure questionnaire.mp.
27. sickness impact profile.mp.
28. exp sickness impact profile/
29. *severity of illness index/
30. patient generated index.mp.
31. 1 or 2 or 3 or 4
32. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
33. 16 or 17 or 18 or 19 or 20 or 21 or 22
34. 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
35. 31 or 32 or 33 or 34
36. 31 and 35
37. chronic heart failure.mp.
38. *heart failure, congestive/
39. heart failure.mp.
40. left ventricular dysfunction.mp.
41. *ventricular dysfunction/
42. low cardiac output.mp.
43. exp cardiac output,low/
44. exp coronary disease/
45. heart disease.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading]
46. adult/
47. human/
48. 46 and 47
49. 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45
50. 36 and 48 and 49
51. 49 and 50
52. limit 51 to (English language and yr=1983-2006)

Each database was searched separately to avoid any translation difficulty with the search terms and to avoid any articles being missed. Several databases were searched to increase the coverage (NHS CRD 2001).

1.3.1 Electronic search

Electronic databases were searched because they have the advantage of covering literature in many health care areas (NHS CRD 2001).

There are a number of disadvantages of using electronic databases alone. Not all medical articles are indexed and many have been misclassified (Greenhalgh 1997). Entries of articles onto electronic databases are open to human error. Some sections of indexed journals are not available on some electronic databases. Therefore some material can only be accessed by looking through all the journals again by hand (Greenhalgh 1997). Publication bias is a crucial problem during a literature search. A review of the published literature can be bias towards a 'positive' result if 'positive studies' rather than 'negative studies' are more likely to be published. To reduce publication bias, unpublished studies should also be sought (Glasziou et al. 2001).

The following sources were used to electronically search a number of databases from the earliest possible date to February 2007:

- AMED via the OVID platform. The Allied and Complementary Medicine Database is a unique bibliographic database produced by the Health Care Information Service of the British Library. It covers a selection of journals in complementary medicine, palliative care, and several professions allied to medicine (2003).
- British Nursing Index (BNI), via the OVID platform, which is a bibliographic database that indexes articles from the most popular English language nursing journals published primarily in the UK. BNI also include the Royal College of Nursing Journals archived index of citations, covering more than 300 British and English language nursing related journals from 1985 to 1996. BNI is a comprehensive index covering all aspects of nursing, midwifery and community healthcare from 1985 to the present, and is updated monthly (2003).
- CINAHL (Cumulative Index of Nursing and Allied Health Literature), via the OVID platform, which indexes and abstracts more than 650 English

Language nursing and allied health journals, plus books and book chapters from 1982 to the present (Colclough 2003).

- MEDLINE (Index Medicus on line), via the OVID platform. MEDLINE is the United States. National Library of Medicine's (NLM) premier bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the preclinical sciences. MEDLINE contains bibliographic citations and author abstracts from more than 4,600 biomedical journals published in the United States and 70 other countries. The file contains more than 11 million citations dating back to the mid-1960's, including approximately 130,000 population-related journal citations unique to the former POPLINE® database, added to MEDLINE in October of 2002. Coverage is worldwide, but most records are from English-language sources or have English abstracts. Abstracts are included for about 52% of the records (2003; Greenhalgh 1997).
- EMBASE (Excerpta Medica online), via the OVID platform. The Excerpta Medica database (EMBASE) produced by Elsevier Science is a major biomedical and pharmaceutical database indexing more than 3,500 international journals. There is selective coverage for nursing, dentistry, veterinary medicine, psychology, and alternative medicine. EMBASE is one of the most widely used biomedical and pharmaceutical databases because of its currency and in-depth indexing. Frequent updates allow access to the latest medical and pharmacological trends. Approximately 375,000 records are added yearly (Greenhalgh 1997; 2003; Colclough 2003).
- PsycINFO, which covers books and journals in the areas of psychology and related behavioural and social sciences (Colclough 2003).
- BIDS (Bath Information and Data Services) Science and Social Sciences Citation Indexes (also known as ISI Web of Science), which is a multidisciplinary index. This is available from 1981 and references papers as well as the usual author, title, abstract and citation of papers themselves. It is useful for finding follow up work done on a key paper and for tracking down addresses of authors (Greenhalgh 1997).
- Cochrane Library which includes Cochrane Database of Systematic Reviews (CDSR), Cochrane Clinical Trials Register (CCTR), Database of Abstracts of Reviews of Effectiveness (DARE), NHS Economic Evaluations Database and Health Technology Assessment, via the National Electronic Library for Health (Colclough 2003).

- ZETOC. The British Library's electronic table of contents service, indexes journal articles and conference papers. Updated daily. Available from 1993 to the present (Cumberpatch 2002; Colclough 2003).
- HMIC (Health Management Information Consortium) via ARC (Academic Reference Centre), provides computerised access to two bibliographic databases covering health management and related topics. They contain more than 300,000 records citing journal articles, monographs, technical reports and a wide range of grey literature (Colclough 2003).
- NRR (National Research Register) via YorkDataNet includes NRR Projects Database, MRC Clinical Trials Directory, Register of Registers, Register of Reviews in Progress, Health Research at York Database. These registers record details of R&D projects which are taking place in, or are otherwise of interest to, the NHS (Colclough 2000).
- Theses, which indexes theses accepted for higher degrees in UK universities from 1950 (Colclough 2003).

1.3.2 Hand search and citation tracking

Quality of life journals were hand searched from first publication date; chronic heart failure journals and cardiology journals were hand searched for the previous 21 years (1985-2006), to identify recent publications that have yet to be cited or entered and indexed on electronic databases (NHS CRD 2001). The following journals were hand searched:

Quality of life journals:

- Quality of Life Research (1992 - 2006)
- Quality in Health Care (1992 – 2006)
- Medical Care (1992 – 2006)

Cardiology Journals:

- Heart (1996 – 2006)
- European Heart Journal (1985 – 2006)
- Congestive Heart Failure (1997 – 2006)
- Heart Failure (1986 – 1999)
- European Journal of Heart Failure (1999 - 2006)

Cross-referencing of the hand search and the electronic search showed most of the studies conducted were after 1990. The results of these searches were cross-referenced with the reference lists from the papers to identify any further studies. This was conducted with the use of reference manager (ISI ResearchSoft 2001).

1.3.3 Grey literature

An increasing amount of information is being published outside of conventional bibliographical control and by non-commercial publishers. Grey literature includes technical or research reports, doctoral dissertations, some conference papers and pre-prints, some official publications, discussion and policy papers (Colclough 2002). Searching grey literature may identify unpublished studies and minimise publication bias. However, there is a large amount of material and therefore it can be difficult to identify and obtain as well as being a costly process in terms of time and finances. Initially a search of System for Information on Grey Literature in Europe (SIGLE) was conducted to identify any literature. SIGLE contains bibliographic details and descriptions of reports and other semi-published literature produced in Europe between 1980 and 2007. The NHS NRR was also searched to identify current UK research projects. Attempts were made to acquire reports of relevant studies directly from the authors.

The World Wide Web was also searched using the Google search engine to identify quality of life links using key words. The following links were identified:

- International Society for Quality of Life Research: http://www.isoqol.org
- Health and Quality of Life Outcomes: http://www.hqlo.com
- Quality of Life Instruments database: http://www.qolid.org

Information regarding the development and use of quality of life measures in heart failure was sought from experts in the field (Table 1.0)

Table 1.0 Experts in the field

Expert	UK	Expert	Non-UK
Dr Rod Taylor	Birmingham	Prof David Thompson	Hong Kong
Prof David Brodie	Buckinghamshire	Dr Jeremy Miles	Santa Monica
Dr Angela Todd	Sheffield		
Dr Gill Furze	York		
Dr Stephen Beer	Scunthorpe		

1.4 Outcome measurement

In recent years, medical care has become increasingly concerned with the management of chronic diseases. In these cases, the aim of a medical management plan is to optimise the patient's quality of life. Over the past decade there has been a growth in the use of quality of life measurements as an indicator of health outcome (Wilson & Cleary 1995; Fallowfield 1996; Moons 2004). Chronic heart failure (CHF) has been no exception to this, where the goal of treatment is not only to prolong life, but also to relieve symptoms and improve function. Improving quality of life is an important goal of medical therapy; it is increasingly being seen as an important outcome to be measured in clinical research (Deyo 1991). The medical profession has been slow and, perhaps, reluctant to quantify such a subjective, personal, and human characteristic, preferring to rely on laboratory tests, objective measures or population statistics for information (Deyo 1991). Figures concerning demographics, socio-economic, and mortality data provide general information about the population and also evaluation of medical interventions but offer no insight into measures of morbidity (Donovan et al. 1992). The value of a treatment or health care system is measured using incidence data, severity of illness data or length of survival data. Quality of life information would enhance our ability to assess quality of care, compare management plans, and provide a good indicator of health outcome (Deyo 1991).

Quality of life reflects the way a person's mental and physical well-being is evident in their every day life (Nicolson & Anderson 2003). Health-related quality of life measures the effects of an illness or a treatment from the patient's perspective. Although health care professionals may be more interested in changes in objective physical measures, patients tend to be more interested in changes in symptoms, physical function and social roles (Thompson & Yu 2003). These health-related quality of life measures are particularly useful and important supplements to traditional physiological measures of health status because they describe or characterise what the patient has experienced as a result of health care (Deyo 1991). The main clinical symptoms in CHF patients that limit activities of daily living and lead to exercise intolerance are dyspnoea, tiredness and fatigue. The fundamental issue to patients is how these symptoms hinder their life. Individuals with CHF experience impairment of physical and functional capacity, which imposes limitations on their life (Dracup et al. 1992). Quality of life in CHF may be impaired by physical symptoms, psychological problems, adverse treatment effects and social limitations (Berry & McMurray 1999). These factors may lead to individuals withdrawing from activities and previous social contacts and losing their social relations and social support (Murberg 1999). Rifts between family members due to the member struggling to meet various illness-related demands, and the inability of family and friends to cope with the deterioration of a close friend, lead to withdrawal of contact with the CHF patient (Murberg 1999). The increasing severity of CHF leads to the individual being aware of their own mortality; this also leads to depression, sleep disturbances and anxiety (Berry & McMurray 1999). Personal relationships, eating, sexual activity and the ability to work are all limited whilst paralleled by an increasing dependence on others (Berry & McMurray 1999). Reduction in quality of life is an inherent problem to the individual with chronic heart failure.

There has been a change in emphasis away from survival towards quality of life as an endpoint in clinical trials because the treatment of chronic, fatal diseases often results in limited gains in survival or cure. (Parmley 1995) states that:

> *"Quality of life instruments highlight the increasing realisation that symptom control and quality of life are at least as important if not more so than quantity of life."*

Increasing attention is being paid to quality of life in clinical research due to the association with an increase in prevalence of chronic diseases within an ageing society (Van den Bos & Limburg 1995). The outcome of such diseases cannot lead to a cure, but must instead relate to the patient's well-being.

Croog et al (1986) used quality of life measures during their research into the effects of antihypertensive therapy. They found that assessing quality of life could substantially enhance current treatment regimens.

> *"By giving appropriate weight to quality of life measures, physicians will not only address the needs and concems of their patients, but they may also expect that fewer patients with hypertension will fail to adhere adequately to their prescribed regiments."*

Croog's study demonstrated that assessment of quality of life could substantially enhance other traditional measures of treatment outcomes (Gill 1995). It was recognised that in order to evaluate any medical intervention there needed to be assessment of the subjective well being of the patient (Selby 1986).

However, until the late 1980's this research was one of few which encompassed quality of life as an outcome measure (Spitzer et al. 1981; Bombardier et al. 1986; Bulpitt & Fletcher 1987; Williams 1987). Since the beginning of the 1990's quality of life measures, and particularly those related to health outcomes, Health-Related Quality of Life (HRQL), have been used increasingly in clinical trials, effectiveness research and research on quality of care (Wilson & Cleary 1995). This increase in usage has stemmed from accumulating data that shows HRQL is valid and reliable (Wilson & Cleary 1995). There is an increasing awareness that the assessment of physical outcomes alone is not sufficient. As a consequence of this, assessment of well being and HRQL is considered to be important (Mayou & Bryant 1993). The term health-related quality of life has resulted from the study of specific aspects of an individual's life which would be expected to respond to medical treatment (O'Boyle et al. 1994). Patients also support the need for more attention to quality of life, and want more insight into their disease and its treatment. In their editorial Goodare et al. (1995) stated that the patient must come first in research. They describe the conclusions of a paper relating to breast cancer which found the concerns of patients are not the same as those of researchers. For instance, women with breast cancer want more research on quality of life, environmental and psychosocial issues, and the optimum dose of radiotherapy to control the tumour but cause minimal damage to healthy tissues (1994).

The measurement of a patient's quality of life poses several questions; which dimensions should be included in order to assess the impact of intervention? Should the measure be generic or specific? Should the measure be a scale or questionnaire? Has the tool been tested for reliability and validity? The literature shows large variations in approaches. Goodinson et al. (1989) considered these questions when they reviewed some of the difficulties in defining and measuring quality of life and the ethical issues which arise in relation to their use in allocation of treatment resources. They concluded that quality of life instruments should be subjective. The information should be obtained from the individual and the information should not be viewed in isolation from the individual's coping strategies. Past experiences of illness and other variables should also be taken into account. The chosen quality of life instrument should incorporate the importance to the individual of the dimensions of investigation, the instrument should cover a range of dimensions known to contribute to quality of life and include a definition. Time differences and periods should be incorporated and further investigation should be carried out to establish the influence of adaptations and coping strategies to quality of life.

Quality of life outcomes generally assess various aspects of a patient's health or well-being, which provide two different kinds of information; functional status and the patient's view of how their health affects their quality of life.

1.5 Chronic heart failure

Coronary Heart Disease (CHD) is a major contributor to morbidity and mortality in Western societies (Kelly 1997). Both the longevity of the population and advances in treatment have led to an increase in the prevalence of CHD in the population in developing countries (Stewart & Blue 2001). Major advances in terms of prevention, treatment and rehabilitation have improved the prognosis for people who have CHD. As a result of these interventions, there is a population which is both older and more susceptible to morbidity due to advanced CHD. Modern management has led to improved survival, which is leaving more patients with a significantly damaged heart that is likely to fail at some time in the future (Stewart & Blue 2001).

Heart failure is a clinical syndrome caused by a reduction in the heart's ability to pump blood around the body. It is most commonly associated with the physical symptoms of orthopnoea, paroxysmal nocturnal dyspnoea, oedema, palpitations, sleeplessness and angina (Mayou et al. 1991; Dracup et al. 1992; Friedman & King 1995). Patients with heart failure commonly have abnormalities of skeletal muscle, metabolism and function as well as reduction or wasting in muscle mass. These problems contribute to symptoms of exercise intolerance, tiredness and fatigue. These problems lead to a poor prognosis and high mortality (Barefoot et al. 1996 and Frasure-Smith et al. 2000). Swedberg et al. (2005) defined objective evidence of dysfunction in addition to the signs and symptoms.

1.6 The burden of chronic heart failure

The majority of cases of heart failure in the Western World are attributed to CHD or hypertension or both. In the United States, the Framingham Heart Study found that 70% of cases of heart failure had hypertension as a contributory cause (McKee et al. 1971; Ho et al. 1993). In Europe, population based studies have confirmed the data from the Framingham Heart Study. For example, in the UK, the Hillingdon Heart Study found that 36% of patients with a new diagnosis of heart failure had CHD. Hypertension was also found in 44% of patients (Cowie et al. 1999). Other causes include valve disease, idiopathic dilated cardiomyopathy, myocarditis, alcohol, radiation, infiltrative disorders (amyloid, sarcoid, haemochromotosis), endocrine disorders, nutritional disorders and inherited conditions (Murphy & McMurray 2003).

1.6.1 Incidence of chronic heart failure

Epidemiological data in the area of heart failure in the general population is often lacking. This is due to differences in the diagnostic criteria and data collection world wide, making any national and international comparisons difficult. (Ho et al. 1993; Cowie et al. 1997). The overall annual incidence of heart failure in the UK, is between 0.1%-0.2% in those aged 50-60 years which rises to over 2%-3% in those aged 80 years and above (McMurray & Stewart 2000), the incidence of which is rising at about 10% per annum (DOH 2000). As a result of an ageing population, the number of hospital admissions due to heart failure in the UK alone is projected to increase by more than 50% over the next 25 years to 113,000 in year 2026/2027 (Cowie & Kirby 2003). Recent advances in treatment and pharmacotherapy have resulted in a reduction of heart failure related mortality. However, an update in 2002 from the Framingham Heart Study found that despite advances in care, the five-year mortality following a new diagnosis of CHF remained greater than 50% for those given a diagnosis during the 1990s (Levy et al. 2002). It is estimated that patients suffering from heart failure account for 1%-2% of the total UK National Health Service (NHS) budget and these costs are proportionally set to rise over the next decade due to the ageing UK population (McMurray et al. 1993; McMurray & Stewart 2000). Even in primary care, heart failure accounts for more consultations than angina, reflecting the limiting symptoms and reduction in well-being experienced by patients with heart failure. A consistent finding is that quality of life is reduced more by heart failure than by other chronic illnesses (McMurray & Pfeffer 2005). A re-examination of the cost of heart failure in the UK, using more contemporary and detailed information found that although better data was available on heart failure epidemiology and resource utilisation, there is no significant alteration in the original assumptions (Stewart et al. 2002).

1.6.2 Prevalence of chronic heart failure

There is slightly more information concerning the prevalence of heart failure in the population. There are wide variations in reports, but in general the prevalence of heart failure increases with age from between 3 and 20 people per 1,000 of the population below 75 years, rising to more than 100 per 1,000 of the population in people 75 years and over (McMurray & Stewart 2000; Bleumink et al. 2004). Prevalence data is estimated from hospital data, surveys of individuals requiring treatment from a general practitioner or from population screening. There are wide variations in the prevalence data but overall the data demonstrates that the prevalence increases with age (Table 1.1). A number of studies have been conducted to look at the prevalence of heart failure through visits to a general practitioner. In one study the records of patients in three general practices in North West London were examined (Parameshwar et al. 1992). A clinical diagnosis of heart failure was made in 117 cases out of a total of 30,204 patients. This gives rise to a prevalence rate of 3.9 cases per 1,000 population. Prevalence also increased strikingly with age (Table 1.1). However, objective evidence of left ventricular dysfunction was lacking in two thirds of the patients (McMurray & Stewart 2000). Therefore, it is not clear whether the diagnosis was correct in all patients. This suggests that in the absence of a proven diagnosis that prevalence data does not accurately reflect the epidemiology of heart failure.

Table 1.1 Reported prevalence of heart failure (Stewart et al. 2001)

Study	Location	Overall prevalence rate	Prevalence rate in older age group
Surveys of treated patients			
Logan & Cushion 1958			
Gibson et al. 1966	National data, UK	3/1000	-
RCGP 1988	Rural cohort, USA	9-10/1000	65/1000 (>65yr)
Parameshwar et al. 1992	National data, UK	11/1000	-
Rodeheffer et al. 1993	London, UK	4/1000	28/1000 (>65yr)
Mair et al. 1996	Rochester, USA	3/1000 (<75yr)	-
RCGP 1995	Liverpool, UK	15/1000	80/1000 (>65yr)
Clarke et al. 1995	National data, UK	9/1000	74/1000 (65-74yr)
	Nottinghamshire, UK	8-16/1000	40-60/1000 (>70yr)
Population screening			
Droller & Pemberton 1953			
Garrison et al. 1966	Sheffield, UK	-	30-50/1000 (>62yr)
McKee et al. 1971	Georgia, USA	21/1000 (45-74yr)	35/1000 (65-74yr)
Landahl et al. 1984	Framingham, USA	3/1000 (<63yr)	23/1000 (60-79yr)
Eriksson et al. 1989	Sweden (males only)	3/1000 (<75yr)	80-170/1000 (>67yr)
Schocken et al. 1992	Gothenburg, Sweden	-	13/1000 (>67yr)
RCGP 1995	NHANES data, USA	20/1000	80/1000 (>65yr)
	National data, UK	9/1000 (25-74yr)	74/1000 (65-74yr)

1.7 Outcome of chronic heart failure

The diagnosis of heart failure has a comparable mortality rate to that of a diagnosis of cancer. Comparison with the West Midlands Regional Cancer Registry showed that one-year survival rates for patients diagnosed with heart failure are worse than the one-year survival rates for those diagnosed with breast, prostate and bladder cancer (Cowie & Kirby 2003). These findings support those of Stewart and colleagues who studied the prognostic impact of heart failure relative to that of 'high-profile' disease states such as cancer (Stewart et al. 2001). They identified all patients with a first admission to any hospital in Scotland in 1991 for heart failure, myocardial infarction or the four most common types of cancer specific to men and women. Five-year survival rates and associated loss of expected life-years were compared. Their data showed that patients admitted to hospital with a diagnosis of cancer often survived longer than those with a diagnosis of heart failure. They concluded that with the notable exception of lung cancer, which is worse, heart failure is as 'malignant' as many common types of cancer and is associated with a comparable number of expected life-years lost (Stewart et al. 2001). Heart failure is associated with poor health-related quality of life (Rich et al. 1995) and increasing dependency (Dracup et al. 1992) and may result in prolonged and frequent hospital admissions (McMurray & Stewart 2000; MacIntyre et al. 2000). Successful management of this population requires intervention with appropriate pharmacotherapy as well as major long-term lifestyle adjustments, including dietary modification, promotion of activity and concordance to often complicated pharmacotherapeutic regimes.

1.8 Approaches to quality of life measures

Two approaches to measuring health-related quality of life (HRQL) are available. These are generic instruments and specific instruments (Guyatt et al. 1993). Generic instruments measure a wide variety of patients and usually cover a wide range of HRQL domains, including, for example, functional capacity, disability and distress. They include health profiles and tools which generate utility measures of quality of life. Utility measures are derived from economic theory. Specific instruments concentrate on particular areas of relevance to the patient group or area of function. The choice of which instrument to use is vital, because the content must be related to the nature of the medical condition being treated, as well as to the effect of the treatment under assessment (Bennett et al. 2002). Therefore, a questionnaire suitable for the assessment of hypertensive therapy may not be suitable for evaluating the impact of cardiac surgery (Barnett 1991). Most of the research that refers to HRQL has led to the development of measures that describe health status, which is not the same as quality of life. Quality of life research does share a number of similar fields to health status research, but it should be concerned with the individual rather than the group. Researchers have tended to use the terms quality of life; health status and health-related quality of life interchangeably (Gill 1995). There is no unified approach to the measurement of quality of life and little agreement has been found on what it means (Gill & Feinstein 1994).

There is no clear theoretical basis for quality of life measures and this has created confusion and misunderstandings amongst researchers and practitioners with regard to which tool to use in research (Leplege & Hunt 1997; Moons 2004). This has been echoed by a number of other researchers who have studied quality of life and acknowledge that the conceptual ambiguity, the doubtful validity and reliability, inappropriate methods and the weak statistical analysis of the data have held back the use of quality of life measures (O'Boyle et al. 1994; Fallowfield 1996).

1.8.1 Definition of quality of life and health-related quality of life

The complexity of the concept has compounded the issues surrounding the definition of quality of life, which has led to inconsistencies in the definition. The term quality of life has been used to mean many different things and therefore conceptual clarity is important when using the term in research. The inconsistencies and many definitions of quality of life have made comparison of findings difficult or impossible. A study by van Dam et al. (1981) cited in Ferrans (1990) found that in more than 250 articles citing quality of life in the title, only a few gave a definition. Gill et al. (1994) and Anon. (1995) also highlighted similar flaws in published work. The article by Ferrans (1990) identified a broad range of definitions used in health care. She groups quality of life into five categories, which include: normal life, happiness/satisfaction, achievement of personal goals, social utility and natural capacity. She also argues that consideration should be given to selecting an instrument that reflects: the definition of quality of life, recognition of the perception of the individual whose quality of life is being evaluated, the multidimensional nature of quality of life should be captured rather than focusing on health concerns and differences in individual values should be addressed. The definition of quality of life in many cases tends to be deduced from how researchers use and measure quality of life (Ferrans 1990). Muldoon et al. (1998) identified two operational definitions of quality of life, which are objective functioning and subjective well-being. They argue that quality of life is inherently subjective and that only perceived well-being should be used to determine quality of life. The World Health Organisation defines quality of life as the individuals' perceptions of their position in life in the context of the cultural and value systems where they live and in relation to their goals, expectations, standards and concerns. It involves aspects of physical health, psychological state, level of independence, social relationships, environmental factors and personal beliefs (The WHOQOL Group 1996). Stevens et al. (1998) in their systematic review documented a range of definitions and discussion of health and quality of life. This is replicated in (figure 1.1)

Figure 1.1 Illustrations of range of definitions and discussions of health and quality of life (Stevens et al. 1998).

Illustrations of range of definitions and discussions of health and quality of life
• Health as a 'state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' (WHO 1947) • 'Quality of life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.' (WHOQOL Group 1993) • 'Quality of life refers to patients' appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be ideal.' (Cella & Tulsky 1990) • 'Health-related quality of life is the value assigned to duration of life as modified by the impairment, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy.' (Patrick & Erickson 1993) • 'Health-related quality of life refers to the level of well-being and satisfaction associated with an individual's life and how this is affected by disease, accidents and treatments form the patient's point of view.' (Lovatt 1992) • 'Quality of life is enhanced when the distance between the individual's attained and desired goals is less.' (Bergner 1989) • 'Quality of life measures the difference, or the gap, a particular period of time, between the hopes and expectations of the individual and that individual's experiences.' (Calman 1984)

The concept of HRQL was initially developed with adult illness and refers to the specific impact of an illness or injury, treatment or health care policy on an individual's quality of life (Patrick & Bergner 1990). It encompasses five categories of concepts including; duration of life; impairment; functional status; health perceptions and opportunities. HRQL is described as different from quality of life in that HRQL is often used to exclude certain aspects of life that do not directly affect health issues such as income, freedom, quality of the environment (Guyatt et al.

1993). In HRQL, the subjective experience of patients is crucial. It is sometimes argued that subjectivity renders the term HRQL to be different from other, more objective, variables. However, not only is the patients' appraisal of their level of functioning important, but also the perceived level of satisfaction in the different domains which is increasingly acknowledged to be significant (Moons 2004). For the purpose of this thesis HRQL will be the variable under consideration.

1.8.2 Application of health-related quality of life measures

Work by Fitzpatrick et al. (1992) has centred on reviewing the extensive number of measurements and the issues surrounding the use of them. They discuss the many ways that health-related quality of life measures can be used in health care and the importance of using the right application. They define the application of health-related quality of life measures as the following: screening and monitoring for psychosocial problems in individual patient care, population surveys of perceived health problems, medical audit, outcome measures in health services or evaluation research, clinical trials and cost utility analysis. The most common and best-understood use of health-related quality of life measures is in the area of clinical trials, which as already stated is prone to flaws.

Researchers have been encouraged to select a measure that is reported as being reliable, valid and easy to complete. However, they are faced with a substantial number of instruments to choose from in some areas and a famine of tools in other areas. It would seem that researchers are guided towards instruments more by fashion than efficiency; instruments are used indiscriminately by researchers because so many others have used them before (Donovan et al. 1992). However, generic instruments are generalisable to a large patient population, and these instruments will be used repeatedly in different studies to allow for comparability of the client population.

The choice of health-related quality of life instrument should be based on issues relating to the ability to demonstrate reliability and validity to change over time or the psychometric properties of the measure (Draper & Thompson 2001). A reliable measure produces consistent results from the same subjects at different times. Reliability is assessed in two ways: test-retest reliability and internal consistency. The former requires the administration of an instrument on two separate occasions to the same population. The correlation of scores provides an estimate of the reliability of the measure. It is determined using Pearson's correlation (Bowling

2002). Internal consistency involves testing for homogeneity of the items contained in the questionnaire and is usually determined by Cronbach's alpha (Bowling 2002); however, item homogeneity is often mistakenly believed to be equivalent to unidimensionality by researchers (Shevlin et al. 2000).

The validity of an instrument refers to its ability to measure what it is supposed to measure. There are four main forms of validity. Face validity refers to the researchers subjective assessment of the presentation and relevance of the questionnaire (Bowling 2002). Content validity refers to the appropriateness of the content of the instrument to measure what it is intended to. Criterion validity is the correlation of the measure with another measure, which is valid. Construct validity refers to the ability of the instrument to measure the underlying concept it claims to measure (Bowling 2002).

Reliability and validity are not fixed qualities of an instrument - the fact that the reliability and validity of an instrument has been established in one population does not mean that it will be valid and reliable in other populations. Once the reliability and validity of a measure have been shown in one population, it must be re-established in other populations (Vacha-Haase 1998; Miles et al. 1999; Vacha-Haase & Thompson 2002).

Some measures of health-related quality of life may be insensitive to change and produce a floor or ceiling effect. Patients with a very poor HRQL who obtain minimum scores before treatment may have no scope to register any further deterioration (floor effect), conversely in patients with an excellent HRQL who obtain maximum scores before treatment there may be no scope to register any further improvement (ceiling effect) (Fitzpatrick et al. 1992).

Although there are a number of health-related quality of life instruments many of them share similarities of content. Wenger et al. (1984) and Fitzpatrick et al. (1992) described some common dimensions of health-related quality of life tools, for example: physical function, emotional function and social function. Wenger describes the general approach of self-perceived health status where as Fitzpatrick specifically describes pain and other symptoms. They identify different assessments of role performance (Fitzpatrick et al. 1992), intellectual functioning and economic status (Wenger et al. 1984).

There is strong evidence that people with heart failure have a poor quality of life in comparison to people with most other common medical conditions (McMurray & Stewart 2000). (Cancer has already been given as an example of this). Quality of life reflects the way a person's mental and physical well-being is evident in their every day life (Nicolson & Anderson 2003). Appropriate diagnosis, treatment and ongoing support can improve quality of life and help reduce morbidity and mortality. It can be seen from the evidence presented thus far that quality of life is a complex issue.
The two approaches to health-related quality of life measures, which have been described, will now be reviewed in more detail.

1.9 Generic measures

This section of the review will identify some of the benefits and limitations of generic health-related quality of life measures.

As previously stated, health-related quality of life measures are vital for assessing the effect of interventions in clinical trials and practice. Often health-related quality of life instruments are unavailable to measure the responsiveness to clinical changes, which occur as a result of treatment. There are a number of generic measures available that measure health-related quality of life. For example, the Nottingham Health Profile (Hunt et al. 1986), the Sickness Impact Profile (Bergner et al. 1981), Dartmouth COOP charts (Nelson et al. 1987), The Duke Health Profile (Parkerson et al. 1990), the Medical Outcomes Study 36-item Short Form Health Survey or SF-36 (Ware & Sherbourne 1992), and EuroQol (The EuroQol Group 1990). These are applicable for a wide range of groups and cover a wide range of quality of life domains. These instruments are health profiles, which are single measures that score several aspects of quality of life. They are usually brief, easy to administer and have a large coverage.

1.9.1 The Nottingham Health Profile (NHP)

The Nottingham Health Profile (Hunt et al. 1986) is a measure of perceived distress relating to severe disabling diseases. Originally developed using public perceptions of health status to assess factors which predict the need for health care (Anderson et al. 1993), it provides a description of how people feel during ill health. The NHP consists of 38 items that are grouped into six scales; emotional reactions and social isolation, physical mobility, pain, energy and sleep. Each scale ranges from 100 to 0, 0 being optimal.

Table 1.2 Summary of Nottingham Health Profile

Measure	Nottingham Health Profile (Hunt et al. 1986)	
Description	Measure of broad health status among patients with angina. Developed in UK based on descriptive material collected from lay perceptions of health status.	
Acceptability and Appropriateness	Short, simple, inexpensive, self-administered, postal administered. Designed for use as a population survey.	Does not provide comprehensive assessment. High non-return rate if high number of zero scores. Focuses on negative experience. Does not detect minor illness and minor improvements over time (Wallwork & Caine 1995). Large numbers of relatively fit members of the population survey would gain low NHP scores.
Validity	Established in the development method where items were drawn from lay experience. Numerous applications in clinical and community settings. Successful outcome measure with heart transplant patients in UK (O'Brien et al. 1988).	Content validity is reduced, as pain is an important item; this symptom is uncommon in CHF.
Reliability	Test re-test technique reported as high (Hunt et al. 1986).	May lack sensitivity to symptoms experienced by patients with CHF (Ekeberg et al. 1994; Cowley & Skene 1994; Guyatt et al. 1989; Johnson et al. 1998).
Comments	Limited measure of function; some disabilities are not assessed. Requires supplementation if used as a broad measure of health-related quality of life. People who score zero cannot show improvement over time.	

The main aim of the measure is that it should reflect the individual's rather than the professional's definition of health. The NHP is a short scale and, thus, can be self-administered and is suitable for use in postal questionnaires; however, its short length means that it does not provide a comprehensive assessment. Extensive testing has found the NHP to be reliable and valid (O'Brien 1988; O'Brien et al. 1988; Jenkinson et al. 1988; Hubanks & Kuyken 1993). However, it has been used in a number of clinical trials in heart failure and produced variable results (Ekeberg et al. 1994; Cowley & Skene 1994; Guyatt et al. 1989; Johnson et al. 1998). This may have been due to its lack of sensitivity to symptoms experienced by patients with CHF. It may also be caused by its inability to detect minor illness, and therefore, minor improvements over time are not detected (Wallwork & Caine 1995). The assessment of pain is important in the NHP. This symptom is uncommon in CHF, and therefore, the content validity in relation to CHF is reduced. More studies are required on the validity and use of this measure in CHF.

1.9.2 The Sickness Impact Profile (SIP)

The Sickness Impact Profile (Bergner et al. 1981) is a generic measure which is widely used in angina.

Table 1.3 Summary of Sickness Impact Profile

Measure	Sickness Impact Profile (Bergner et al. 1981)	
Description	Measure of perceived health status that would provide a descriptive profile of changes in a person's behaviour due to sickness. Developed in USA. Based on items collected from patients, individuals concerned with patient care, healthy subjects and health care professionals.	
Acceptability and Appropriateness	Self-administered, postal and interview administered. Wide application. Used in chronic and acute illness. Adapted for UK population.	Lengthy, repetition of items, major commitment to interviewer training.
Validity	Validity trials compared SIP with subjective ratings made by respondents with clinical assessment and functional assessment instruments (Bergner et al. 1981; Katz et al. 1963).	May not discriminate adequately between different severities of CHF (Rector et al. 1987).
Reliability	Test re-test technique is high (Bergner et al. 1981). Interview administrated score better than self-completed and postal version. Sensitive to change in clinical trials (Bergner et al. 1981; Ware et al. 1995).	May lack sensitivity in CHF due to HRQL changes in these patients.
Comments	People need to be regarded or regard themselves as ill.	

This was developed as a measure of perceived health status for use across a wide range of health problems. Sickness is measured in its relation to behaviour. The emphasis is on the impact of sickness on daily activities rather than feelings. It can be administered by interview, self-administered and by postal questionnaire. High scores for validity and reliability have been shown (Katz et al. 1963; Pollard et al.

1976; De Bruin et al. 1992; Hubanks & Kuyken 1993; Ware et al. 1995). However, it is lengthy and this can be a disadvantage. When the SIP has been used in interventional trials in CHF, it has shown variable results in improvements of quality of life in the intervention group (Rector et al. 1987; Bulpitt et al. 1998). This may be due its lack of sensitivity to HRQL changes in patients with CHF. Results in one study suggest that the SIP does not discriminate adequately between different severities of CHF (Rector et al. 1987).

1.9.3 The Dartmouth COOP Charts

The Dartmouth COOP Charts (Nelson et al. 1987) were developed by a group of medical practices to provide a brief assessment tool of patients' overall function, which could be easily completed.

Table 1.4 Summary of the Dartmouth COOP Chart

Measure	Dartmouth COOP Chart (Nelson et al. 1987)	
Description	A chart system developed for the purpose of making a brief, practical and valid method to assess the functional status of adults and adolescents. Items were developed by a network of community practices that cooperate on research activities and expert advice from clinicians.	
Acceptability and Appropriateness	Simple, easily administered, self-scoring system for screening, assessing, monitoring and maintaining patient function. Has been tested in many different practices.	Relies on a person-based approach in comparison to the individual's usual level of functioning.
Validity	Validity has been assessed using clinical status and diagnostic measures, and existing HRQL profiles and dimension-specific measures (Nelson et al. 1990; McHorney et al. 1992; Landgraf et al. 1990). It demonstrated low to moderate correlations with clinical status indicators.	Content validity in the physical fitness measure is too restricted in scope to be sensitive to disability in older individuals (Anderson et al. 1993).
Reliability	Test re-test technique was assessed at two study sites (Nelson et al. 1990). Correlation coefficients are variable.	Needs full assessment of reliability and sensitivity to change, as this is not fully established.
Comments	No comments.	

The charts are administered by a health care provider or self-administered. Tests for reliability, validity and sensitivity to change need to be fully assessed. Some of the charts may be too restrictive to detect changes in disability in older people. (Anderson et al. 1993). This may be problematic for elderly heart failure individuals.

1.9.4 Duke Health Profile

The Duke Health Profile (Parkerson et al. 1990) was developed for the use in a clinical setting as a measure for the study of medical, economic and social interventions on health and disease.

Table 1.5 Summary of Duke Health Profile

Measure	Duke Health Profile (Parkerson et al. 1981; Parkerson et al. 1990)	
Description	A measure to assess adult health status along four dimensions: symptoms, physical function, emotional function and social function. Items were derived from the 63 item Duke UNC Health Profile.	
Acceptability and Appropriateness	Interview or self-administered. Quick to complete.	Has some measurement difficulties.
Validity	Acceptable levels of validity.	
Reliability	Acceptable levels of reliability.	
Comments	No comments.	

This measure assesses adult health status by the dimensions of physical function, emotional function, social function and symptom status. It can be administered by interview or be self-administered. Acceptable levels of reliability and validity have been demonstrated (Hubanks & Kuyken 1993).

1.9.5 The Medical Outcomes Study 36-item Short Form Health Survey (SF-36)

The SF-36 (Brazier et al. 1992; Ware & Sherboume 1992) was developed to gather information about the individual's multidimensional health concepts and a measurement of the full range of health domains, including well-being and personal evaluations of health. It was developed for a health insurance study by the Rand corporation (Ware & Sherbourne 1992) and is the most widely and extensively used generic measure (Brazier et al. 1992; Hubanks & Kuyken 1993).

Table 1.6 Summary of The Medical Outcomes Study 36-item Short Form Health Survey (SF-36)

Measure	The 36-Item Short Form Health Survey (SF-36) (Brazier et al. 1992; Ware & Sherbourne 1992)	
Description	Measure of function and well-being. Used in a wide variety of circumstances. Developed out of the Rand corporation health insurance experiment which was a comprehensive evaluation of alternative methods of financing health care in the US. The authors shortened the original 108 item measure (Brazier et al. 1992).	
Acceptability and Appropriateness	Short, inexpensive. Self-administered, postal and interview administered. Becoming the generic measure of choice. Widely used as a proxy measure. Multidimensional. Response rates are high. Covers a wide range of areas affected by ill health.	Too long for some trials (Ware et al. 1996). High degree of missing responses in the elderly. Fails to address some areas of function e.g. sleep.
Validity	High degree of validity in a number of populations (Garratt et al. 1993; Jenkinson et al. 1993; Brazier et al. 1992).	Reported ceiling and floor effects in chronic diseases (McHorney et al. 1994).
Reliability	Test re-test technique and internal consistency is high in physical and mental health domains (Brazier et al. 1992; Jenkinson et al. 1996; Bowling et al. 1999). More sensitive to small degrees of disability than the NHP.	Insensitive to small clinical change which may be due to influences of comorbidity (Spertus et al. 1994).
Comments	No comments	

This is due to the fact that it is short and has been tested for reliability and validity and found to be reliable and valid across numerous population samples (Brazier et al. 1992; Jenkinson et al. 1993; McHorney et al. 1993; Hubanks & Kuyken 1993; Garratt et al. 1993; Jenkinson et al. 1996; Bowling et al. 1999). It has also been found to be more sensitive to small degrees of impairment in quality of life compared to that of the NHP. However, the SF-36 proved to be too long for inclusion in some large-scale health measurement and monitoring studies (Ware et al. 1996), and abbreviated forms, SF-12 (Ware et al. 1995) and SF-8 (Ware et al. 2001), are also available and widely used (Bennett et al. 2003; Ni et al. 2000; Turner-Bowker et al.

2003). All of the SF surveys measure the same eight domains of health; physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems and mental health. The decision to which survey to use hinges on making a trade-off between respondent burden and score precision. The SF-8 can be completed in one to two minutes on average, while the SF-36 requires between five and ten minutes. The SF-8 scales are the most simple, offering the least amount of precision and generally covering a narrower range for each of the eight domains of health. The longer SF-36 offers a greater degree of precision than the SF-12 or SF-8.

A comparison of the SF-12 and the disease-specific Minnesota Living with Heart Failure Questionnaire in a heart failure population found the SF-12 was not sensitive enough to detect minimal improvements in a patients health status (Ni et al. 2000). There is little evidence of comparisons of the SF-12 and SF-8 instruments in evaluating HRQL in CHF.

The SF-36 and SIP are the best generic health-related quality of life measures in chronic heart failure (Berry & McMurray 1999). The SF-36 is suitable for use in heart failure trials and it can and should be used in conjunction with disease-specific questionnaires (Garratt et al. 1994). However, the incidence and prevalence of heart failure in the elderly population is high and when this is taken into account, the usefulness of the SF-36 is doubtful. A study of older adults found that there were missing responses associated with the questions on work and vigorous activity, frequently regarded as not applicable by elderly people (Hayes et al. 1995). Hayes and colleagues surmised the people under 75 years old could usually complete the SF-36 without difficulty, but those older than 75 years may need assistance, especially if they have poor physical and mental health. It has been suggested that administration by interview may be the best way to use the SF-36 in the elderly population (Lyons et al. 1994). O'Mahony et al. (1998) found that there was a high response rate to the SF-36 in older stroke patients when it was administered as a postal questionnaire. However, the poor completion rates in older stroke patients and consequent inability to compute scores for a large proportion of responders in certain scales raised concerns about the perceived relevance of these sections (O'Mahony et al. 1998). When data quality indicators were examined, it appeared that postal administration of the SF-36 is not appropriate for assessing quality of life of older stroke patients (O'Mahony et al. 1998). The use of an interviewer improves response, but factors which influence health status, such as physical and cognitive dysfunction, have a significant effect on response rates. Therefore, the usefulness of the SF-36 in a predominantly elderly heart failure population is questionable (Parker et al. 1998). Co-morbidity associated with elderly patients may also cause insensitivity to small clinical change (Spertus et al. 1994).

1.9.6 EuroQol

The EuroQol (The EuroQol Group 1990) is a measure of health for clinical and economic appraisal.

Table 1.7 Summary of EuroQol

Measure	EuroQol (The EuroQol Group 1990)	
Description	A measure of health for clinical and economic appraisal. Developed by a multidisciplinary group of researchers from five European countries. There is some ambiguity as to where the items were derived.	
Acceptability and Appropriateness	Self-administered. Easy to complete. Developed in other languages.	
Validity	Examined and compared to the SF-36 in a general population. Discriminates between individuals with recent use and non-use of medical services.	Few reports of validity. Only pain/discomfort score, discriminates chronicity of medical problems (Anderson et al. 1993).
Reliability	Comparable scores across centres for the same health states.	
Comments	Intended to be used in conjunction with other quality of life instruments to aid in the collection of a reference group of data.	

The EuroQoL consists of two parts: a descriptive system of health (EQ-5D) and a visual analogue scale (EQ_{vas}). The EQ-5D is composed of five single-item attributes each of which is scored at three levels; it can be converted into a weighted health state index ($EQ\text{-}5D_{index}$). This can be used to generate a single outcome measure, which can be used to calculate Quality Adjusted Life Years (QALYs). This measure is designed to be self-administered. The EuroQol has also been translated into other languages. It was specifically designed to use alongside disease specific or other generic measures of quality of life. It is a standardised measure, which can be used in the collection of a reference group of data (Brazier et al. 1993). Recent research to evaluate the appropriateness of using the EQ-5D in patients with heart failure patients found the EQ-5D to be an acceptable valid measure for use in patients with heart failure although further evidence of the responsiveness of the measure in such patients is required (Calvert et al. 2005).

1.9.7 Cardiovascular disease

Generic scales have frequently been used to assess health outcome in cardiovascular disease (Kaplan et al. 1976; Chambers et al. 1982; Wenger et al. 1984; Fletcher et al. 1987; Fazio 1997). These scales have their similarities and differences. They are all different in length; the longer scales are inherently more reliable, due to the Spearman Brown Prophecy formula (Nunnally & Bernstein 1994), but they are time consuming for the respondent.

Traditionally in chronic heart failure, the New York Heart Association (NYHA) classification system has been used to assess functional status (The Criteria Committee of the New York Heart Association 1964; Goldman et al. 1981). This scale assesses a combination of physical symptoms and limitations. Table 1.8 illustrates the NYHA classification system.

Table 1.8 NYHA classification system (Gibbs et al. 2000).

Class	Description
NYHA I: asymptomatic	No limitation in physical activity despite presence of heart disease. This can be suspected only if there is a history of heart disease which is confirmed by investigations for example, echocardiography.
NYHA II: mild	Slight limitation in physical activity. More strenuous activity causes shortness of breath for example, walking on steep inclines and several flights of steps. Patients in this group can continue to have an almost normal lifestyle and employment.
NYHA III: moderate	More marked limitation of activity which interferes with work. Walking on the flat produces symptoms.
NYHA IV: severe	Unable to carry out any physical activity without symptoms. Patients are breathless at rest and mostly housebound.

The NYHA is the most widely used system but it has been shown to be unresponsive to change, there is a high degree of inter-observer variability and the perspective applied is that of the doctors rather than the patients (Green et al. 2000; Raphael et al. 2006).

A review of health-related quality of life in cardiovascular disorders concluded that there are doubts about current concepts and measures (Mayou 1990). HRQL measures have been poorly developed in relation to cardiovascular disease. CHD patients usually have other comorbid conditions, which generic instruments may not detect (Spertus et al. 1994). If only generic instruments such as the SF-36 are used to assess differences in, or changes to, HRQL in CHD patients then the probability of making an incorrect conclusion is altered, in an unpredictable manner (Spertus et al. 1994). The majority of cardiology research has used inadequate HRQL measures (Mayou & Bryant 1993) and until recently very little work has been undertaken into chronic heart failure.

1.9.8 Cost-utility measures

Generic measures can also take the form of utility measures. The earliest statistical attempts to measure quality of life arose in the context of a need to evaluate economic policies following the Second World War (Draper & Thompson 2001). The emphasis on the purchase of health and social services that are effective and cost-effective has led health care professionals and researchers to be aware of the basic concepts of health economics. The theory of economics assumes that there are scarce resources available and that decisions have to be made about their use. This leads to competing demands on resources, which inevitably leaves some areas without adequate funds.

Different interventions often have different health outcomes, in the case of chronic heart failure length of, versus quality of, life. Health economists have used cost utility analysis where the different changes in health status are valued relative to each other (Bowling 2002). Cost utility analysis is a technique that relates the cost of the development to a measure of its usefulness of outcome (Bowling 2002). The rationalisation of health care resources has led to the development of quality adjusted life years (QALYs), which have been developed as a measure of health based on longevity and quality of life. That is, QALYs simultaneously captures the gains from reduced morbidity and reduced mortality and combines this into a single figure (Drummond et al. 2001). The usefulness of QALY as a measure of health relies on the assumption that an individual would prefer a shorter, healthier life to a long period of survival with severe disability or pain.

However, some people will accept that an increase in survival means a decrease in quality of life. Lewis et al. (2001) found in a study of new therapies which improve functional status without increasing survival benefit for patients with heart failure, that patients express meaningful preferences about quality versus length of life. Lewis states that:

> *"Enthusiasm for both patients and physicians for therapies that carry substantial risk suggests a willingness to consider factors other than survival in advanced heart failure."*

Health-related quality of life measures have therefore become the standard means of assessing the results of health care intervention and prioritising funding in health economics through cost utility analysis (Twycross 1987). Health economists have used quality of life to ration health care resources. Generic measures are therefore essential in cost utility studies, which aim to quantify the benefits in relation to cost of different services or interventions.

1.9.9 Summary

An advantage of generic instruments is that they make it possible to compare outcomes across disease groups and different types of intervention. Health economists frequently employ these measures as they can be used to guide resource allocation. However, these general measures are likely to be insensitive to change that is related to CHD, and coupled with other problems, specific measures for particular patient groups have emerged. For example, in the areas of cancer patients (Spitzer et al. 1981), cardiac spouses (Ebbesen et al. 1990), heart failure patients (Rector et al. 1987), and arthritis care (Meenan et al. 1980) to name but a few. The remainder of this review will concentrate on cardiology assessment instruments, which are disease-specific.

1.10 Specific measures

This section of the review will identify some of the benefits and limitations of specific measures. Researchers started to use specific measures of health-related quality of life in order to increase the responsiveness of the measures to the patients being studied (Guyatt et al. 1993; Nanda & Andresen 1998). There are a number of types of specific measures: disease-specific measures, function-specific measures and informal measures. These can be used on their own or grouped together and used as batteries. Disease-specific instruments have been developed to be suitable to the problems associated with a specific medical condition, although these may have a narrow range of application (Guyatt et al. 1986). A comparison of generic and a disease-specific measure for pain and physical function after knee replacement found that the idea of including both measures when assessing patient outcomes is successful (Bombardier et al. 1995). The author believes that assessment must be disease-specific and the use of measures found to be helpful in other chronic illness will be of little relevance for CHD patients.

The findings from a survey of households in Great Britain by Bowling (1996) suggested that disease-specific quality of life questionnaires rather than generic measures should be developed. Bowling (1996) states that respondents with cardiovascular problems were more likely to report the ability to get out and about as important. What the public rank as important are missing in popular generic tools.

Since the advent of the National Service Framework (NSF) for Coronary Heart Disease (DOH 2000), disease-specific measures have become even more necessary to enable health service professionals to demonstrate the maintenance of standards and national targets. Each standard in the NSF for CHD describes the standard, implementation and measurement of specific conditions, such as heart failure. The rationale underlying these standards is largely clinical, and the approach assumes that each condition has specific outcomes. Therefore it is difficult to obtain information about these patients if a generic instrument is used which is designed for use with any population.

The majority of cardiology research has used inadequate health-related quality of life measures (Mayou & Bryant 1993). Other areas of medicine, for example, cancer, has used standard measures, this has not been the case in cardiology (Mayou 1990). However, cancer measures have tended to be used in group comparisons and little research has been undertaken into individual differences. Most clinical interest and research in cardiology has taken place in the area of myocardial infarction with less interest in revascularisation including coronary artery by-pass graft (CABG) and percutaneous transluminal coronary angioplasty (PTCA). Until recently very little work has been undertaken in chronic heart failure. Bennett et al. (2002) studied the properties of commonly used health-related quality of life measures in heart failure. The purpose of the study was to compare the reliability and validity of three health-related quality of life measures in 21 heart failure patients. They used the Chronic Heart Failure Questionnaire (Guyatt et al. 1989), Living With Heart Failure Questionnaire (Rector et al. 1987) and the Short Form 12 (SF12) . Patients reported moderate to low HRQL scores. Floor and ceiling effects were noted in the disease-specific instruments. All three instruments were satisfactory for measuring HRQL, but the disease-specific instruments were preferable to the generic instrument. The decision of which instrument to use depends on the purpose of the study.

1.11 Disease-specific measures in chronic heart failure

Disease-specific questionnaires are designed to obtain information about health-related quality of life in patients with heart failure. There are several tools in this area including: the Quality of Life in Severe Heart Failure Questionnaire or QLQ-SHF (Wiklund et al. 1987), Chronic Heart Failure Questionnaire or CHQ (Guyatt et al. 1989), the Kansas City Cardiomyopathy Questionnaire or KCCQ (Green et al. 2000) and the Left Ventricular Dysfunction Questionnaire, (O'Leary & Jones 2000). According to the literature, the most commonly used tool is the Minnesota Living with Heart failure Questionnaire (MLHFQ), (Rector et al. 1987; Riegel et al. 2002).

1.11.1 Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF)

The QLQ-SHF is a 26-item questionnaire which uses a Likert scale to quantify physical activities and a visual analogue scale to assess life satisfaction, social and emotional factors (Berry & McMurray 1999).

Table 1.9 Summary of Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF)

Measure	Quality of Life in Severe Heart Failure Questionnaire (Wiklund et al. 1987)	
Description	Measure of HRQL in patients with severe heart failure. Items were derived from existing scales and the literature.	
Acceptability and Appropriateness	Short. Self-administered. The scale's domains are summed to form an overall score. The higher the score the worse the patients.	
Validity	Determined by correlation of the results with those from comparable domains of the SIP. Construct validity is acceptable for the domains of psychological symptoms and life satisfaction. Internal consistency is satisfactory (Wiklund et al. 1987).	Lack of a gold standard. Needs to be compared with other well-validated questionnaires. Construct validity is weak for domains of somatic symptoms and physical limitations.
Reliability	Test re-test technique is reported as high (Wiklund et al. 1987). Trial of metoprolol detected improvements in the treatment group (Wiklund et al. 1996).	Unable to distinguish between different severities of heart failure.
Comments	Trial results suggest the measure is moderately sensitive to small changes in quality of life in patients with CHF (Berry & McMurray 1999). Needs to be used and tested further in CHF research (Nanda & Andresen 1998).	

The higher the score, the greater the impairment of quality of life. The QLQ-SHF has been used in a number of clinical trials (Wiklund et al. 1996), and its validity was determined by correlations of the results from the questionnaire with those from comparable domains of the SIP. The construct validity is acceptable for the domains of psychological symptoms and life satisfaction. However, it is weak for the domains of somatic symptoms and physical limitations (Berry & McMurray 1999). Results from these trials have shown that it is moderately sensitive to small changes in quality of life in patients with chronic heart failure (Berry & McMurray 1999). However, there is no evidence to suggest that this questionnaire is able to distinguish between patients with different severities of chronic heart failure, and therefore, this questionnaire needs to be explored and tested further in chronic heart failure (Nanda & Andresen 1998).

1.11.2 Chronic Heart Failure Questionnaire (CHQ)

The CHQ is a 20-item questionnaire, which was developed for use in chronic heart failure (Berry & McMurray 1999).

Table 1.10 Summary of Chronic Heart Failure Questionnaire (CHQ)

Measure	Chronic Heart Failure Questionnaire (Guyatt et al. 1989)	
Description	Measure of subjective health status in people with heart failure. Items were constructed by researchers from published reports, consultation with cardiac nurses, cardiologists and patients.	
Acceptability and Appropriateness	Interview administered. Personal information is obtained from the participant in three categories of dyspnoea, fatigue and emotional function.	Lengthy. Well trained interviewer. Complex to administer.
Validity	Able to distinguish between patients who improved with those who did not in an RCT of Digoxin in CHF (Guyatt et al. 1988).	Small scale trial, needs further investigation.
Reliability	The authors report reproducibility with 25 patients. Sensitive to different severities of CHF.	Small numbers needs confirmation.
Comments	Most sensitive to changes in dyspnoea and physical function.	

It is a complex questionnaire to administer. The questionnaire is administered by interview. It has three categories: dyspnoea, fatigue and emotional function. An increase in score shows an improvement in quality of life. This questionnaire was validated in a randomised, placebo-controlled trial of digoxin in chronic heart failure (Guyatt et al. 1988). It was found to be most responsive to changes in dyspnoea and fatigue. The CHQ appears to be sensitive to patients with different severities of chronic heart failure.

1.11.3 Kansas City Cardiomyopathy Questionnaire (KCCQ)

The KCCQ (Green et al. 2000) is a self-administered 23-item questionnaire that quantifies physical limitations, symptoms, self-efficacy, social interference and quality of life.

Table 1.11 Summary of Kansas City Cardiomyopathy Questionnaire

Measure	Kansas City Cardiomyopathy Questionnaire (Green et al. 2000)	
Description	23-item instrument that quantifies physical function, symptoms (frequency, severity and recent change), social function, self-efficacy and knowledge, and quality of life. Items were developed after examination of the literature, current HRQL measures and focus groups with patients and CHF specialist.	
Acceptability and Appropriateness	Self-administered.	
Validity	The validity of each individual domain has been independently established; all components of the summary score are considered valid representations of their intended domains.	Limited use in the elderly. Needs full assessment of validity.
Reliability		Needs a full assessment of reliability and sensitivity to change.
Comments	No comments	

It was developed to provide a description of quality of life in patients with chronic heart failure. The KCCQ is a valid, reliable and responsive health status measure for patients with CHF and may serve as a clinically meaningful outcome in cardiovascular research, patient management and quality assessment. The KCCQ is built on a causal model and its focus is primarily in fluid retention or the perception of it by the patient. Unfortunately, this limits its use in elderly patients, where the majority of CHF occur and who frequently do not have fluid overload as a primary factor (Rich et al. 1995).

1.11.4 Left Ventricular Dysfunction Questionnaire (LVD-36)

The LVD-36 (O'Leary & Jones 2000) is a 36-item questionnaire for patients with left ventricular dysfunction.

Table 1.12 Summary of Left Ventricular Dysfunction Questionnaire (LVD-36)

Measure	Left Ventricular Dysfunction Questionnaire (O'Leary & Jones 2000)	
Description	Developed specifically for patients with chronic left ventricular dysfunction. It was designed to measure the impact of left ventricular dysfunction on daily life and well-being. The measure was derived from a pool of 179 items which were created from published reports, existing questionnaires and discussion with clinicians and patients.	
Acceptability and Appropriateness	Short and simple.	
Validity	Measures changes in health. Correlates significantly with SF-36 in physical and mental domains. Correlates marginally better than MLHFQ.	
Reliability		Small numbers in the study. Did not include NYHA IV.
Comments	Further research is needed with this measure in CHF.	

Responses are marked as true or false. True responses are summed and the sum is expressed as a percentage, so that 100 is the worse possible score and 0 the best score. The LVD-36 takes approximately five minutes to complete (O'Leary & Jones 2000). The LVD-36 shows a high level of reliability and validity, and appears to measure changes in health. It correlates significantly with the SF-36 in terms of mental and physical domains. It also performed similarly to or marginally better than the MLHFQ (O'Leary & Jones 2000). It provides a short, simple, valid, and reliable measure of health status in patients with left ventricular dysfunction. However, this study was conducted using small numbers and did not include patients with NYHA class IV, therefore further work is required with this measure in chronic heart failure.

1.11.5 Minnesota Living with Heart Failure Questionnaire (MLHFQ)

The MLHFQ was designed specifically for use in heart failure. It assesses the patient's perceptions of heart failure on physical, socio-economic and psychological aspects of their life.

Table 1.13 Summary of Minnesota Living with Heart Failure Questionnaire (MLHFQ)

Measure	Minnesota Living with Heart Failure Questionnaire (Rector et al. 1987)	
Description	Measures patient's perceptions of the effects of CHF on their daily lives. Items were derived from a comprehensive list of sickness related dysfunctions on the SIP. Items frequently attributed by patients to heart failure were used to formulate the questionnaire.	
Acceptability and Appropriateness	Short, inexpensive, simple. Self-administered. Designed specifically for heart failure.	Respondents must be instructed on how to complete it. Designed specifically for use in clinical trials.
Validity	Correlation has been reported with NYHA and patients self rating (Rector et al. 1987). Internal consistency has been found to be good (Gorkin et al. 1993).	Does not distinguish well between different severities of CHF.
Reliability	Test re-test technique reported no bias. Sensitivity to effects of medication.	Regression to the mean has been found with scores (Rector et al. 1987).
Comments	Patient's ability to separate symptoms of heart failure and comorbidities may affect the usefulness of this measure.	

Patients respond to 21 items using a six-point Likert scale (0-5). It is also possible to obtain subscale scores for physical and emotional domains. The questionnaire is easy to administer, short and easily understood. It can be administered by interview, self-administered and by postal questionnaire. The measure has been found to be valid in comparison with other health outcome scales (Gorkin et al. 1993; Berry & McMurray 1999). It has been shown to discriminate between patients with chronic heart failure and those with symptomatic left ventricular dysfunction. However, it does not distinguish well between different severities of chronic heart failure (Berry & McMurray 1999).

Concerns have been raised about the MLHFQ in terms of the patient's ability to separate symptoms and impairments related to heart failure from their co-morbidities (Sneed et al. 2001). The MLHFQ subscales may be less useful in quality of life assessment than the total score (Sneed et al. 2001). Although the MLHFQ is the most popular measure, when using it one needs to bear in mind it was designed to be a patient self-assessment measure for use in clinical trials to assess the effects of drugs or devices (Sneed et al. 2001) and not as a complete health-related quality of life assessment, thus, it is of value for some purposes, but not for others (Rector et al. 1987). A recent comparison of health-related quality of life measures in heart failure found that the CHQ and MLHFQ were more sensitive than the SF-12 in detecting clinically important changes over time in a patient's condition (Bennett et al. 2003). More recently a qualitative validation of MLHFQ found the introduction to the questionnaire which contains essential instructions was not read; patients did not interpret items as intended; and some items posed problems to respondents due to their wording or because they were considered irrelevant (Hak et al. 2004).

1.11.6 Summary

A valid measure of health-related quality of life should be defined in individual terms. Therefore, there is a caveat to current health-related quality of life measures for use in chronic heart failure, as their meaning and relevance to the target population is suspect. The measure must focus less on functional disability and include aspects of life that give it meaning and purpose. Physiological measurements of health status describe only limited aspects of the individual's life and may not have meaning and relevance in the context of that life (Calman 1984). Traditional outcomes of treatment for coronary heart disease such as mortality and objective physiological or exercise tests give little information about the impact of either the condition or treatment from the patient's perspective (Hofer et al. 2004). The subjective and individualistic nature of quality of life has been defined as "the extent to which our hope and ambitions are matched by experience" (Calman 1984).

Therefore, further research needs to be carried out to look at patient-led health-related quality of life measures for use away from the clinical trials in every day practical care in a chronic heart failure population.

1.12 Rationale for a new approach

1.12.1 Introduction

In the past, health-related quality of life instruments have always been seen as long, time consuming and unresponsive assessment tools, but since the introduction and availability of shorter, easier to understand and administer tools there has been an increase in their use in clinical trials. (Hunt et al. 1985; Nelson et al. 1987; Stewart et al. 1988; Parkerson et al. 1990; McHorney et al. 1992; Ware & Sherbourne 1992; McHorney et al. 1993; McHorney et al. 1994). This reflects increasing interest in the need to know how the patient feels and how satisfied they are with the treatment. Although it has been recognised that these tools are reliable, they may not be relevant to individual patients; therefore, their validity may be suspect if they do not measure components of health-related quality of life important to the patient. Many instruments are not derived from patient populations but from an expert, medical viewpoint; yet, there is no guarantee that the medical professionals understand patient's quality of life. Health-related quality of life measures usually comprise a number of items to which patients respond. To maximise the relevance of these items, they should be derived, wherever possible, from a patient population. Many scales, for example, the generic and disease-specific measures already described, were not derived from a patient's perspective. Instead, they relied on the perspective of professionals, and it may be the case that medical professionals may have a different view of the aspects of function that are important to quality of life (Paul & Sneed 2001).

Health-related quality of life measures are not aimed at the correct target, unless an opportunity to express the patient's opinions and reactions is provided (Gill & Feinstein 1994). Quality of life is a personal perception, which shows the way an individual feels about their health and/or non-medical aspects of their lives (Gill & Feinstein 1994). Most measures of health-related quality of life in the literature impose standard models of quality of life and pre-selected domains on the individual. What differentiates health-related quality of life from other measures is the need to obtain and integrate the patient's values and perceptions into the assessment (Gill & Feinstein 1994). We understand quality of life from a variety of indicators, many of which tell us about life, but not about quality. A systematic review of cardiac rehabilitation undertaken by Brown et al. (2003) found few studies in which the improvement in health-related quality of life in the intervention groups exceeded that observed in the usual care control groups. Therefore, the question is raised as to, are we measuring the right things? Does an expert driven tool lead us to exclude aspects of an individual's quality of life, which they find important?

A review of health-related quality of life questionnaires in CHF published in 1999 found 41 studies using instruments published between 1990 and 1998 (Leidy et al. 1999). Most commonly, such questionnaires were used in conjunction with clinical trials that tested the effectiveness of new medications or treatments. HRQL related to many domains, including disease state, physical and social functioning, social interaction and emotional state. The review found that 30 of the 41 studies were trials evaluating the effectiveness of a medication. The remaining studies focused on physical exercise, positive airway pressure, nurse cases management and primary care related quality of life. In summary, no single general health-related quality of life measures dominated the area of CHF, and that three quarters of the studies were related to drug trials (Leidy et al. 1999).

I would argue that health-related quality of life can only be measured by determining the opinions of patients and using these in place of expert opinion. A patient's self-assessment can differ substantially from the judgment of the doctor or other healthcare staff (Slevin et al. 1988; Wilson et al. 2000). Physicians tend to dramatically underestimate overall social functioning, role functioning and pain (Wilson et al. 2000).

Discrepancies also exist between patient's measurements and patient narrative accounts (Campbell et al. 2003). There are substantial discrepancies between patient and physician scores on the more subjective quality of life domains (Wilson et al. 2000). Practitioners are often surprised at the low value patients attach to aspects of quality of life and the high value to others, which is at odds with the viewpoint of the practitioner (Williams 1988). Therefore, other factors are important in quality of life, which are not included in recognised measures. Research into the best ways of measuring quality of life should continue.

> *"The uncritical acceptance of "expert"-driven questionnaires into clinical trial protocols will only diminish the importance of the patient's perspective."* (1995)

The patient's perspective is as valid as the clinician's when it comes to evaluating outcomes (O'Boyle et al. 1994). Many health-related quality of life measures force an external value system on individuals rather than allowing them to describe their lives in ways that they themselves find important (O'Boyle et al. 1994). The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is a quality of life measure which is able to take account of the patient's assessment of his or her overall situation in relation to the chronic disease or intervention (O'Boyle et al. 1994). The Patient Generated Index (PGI), was also developed in response to the need for a measure of quality of life that had meaning and relevance in the context of patients' everyday lives (Garratt & Ruta 1999). Another example of a patient generated index, which is an outcome measure for primary care and for complementary treatment is the Measure Yourself Medical Outcome Profile

(MYMOP) (Paterson 1996). It has been shown to be more sensitive to change than the SF-36 and has the added bonus of improving patient-practitioner communication (Paterson 1996). The Measure Yourself Concerns & Wellbeing (MYCAW) was also developed as a patient-centred tool suitable for the routine evaluation of cancer support care that includes complementary therapies (Paterson et al. 2003). However, none of these individualised instruments have been validated for use in a heart disease population (Dempster et al. 2001). Dempster and colleagues suggest that further research should be undertaken focussing on the responsiveness of these instruments before firm recommendations can be made for their use in clinical practice (Dempster et al. 2001). Health-related quality of life tools in chronic heart failure do not measure quality of life in a reliable or valid fashion (Berry & McMurray 1999).

1.12.2 Qualitative approaches to the study of quality of life

A qualitative approach to understanding everyday quality of life has the potential to provide powerful and detailed information about the context and contradictions that people with chronic clinical conditions experience (Nicolson & Anderson 2003). Many of the tools for measuring health-related quality of life are based on a health status model that focuses mainly on objective measures and less attention is paid to subjective forms of assessment (Nicolson & Anderson 2003). For example, the phenomenological approach is a philosophy and a method of analysis for qualitative research. The founder of the approach was Edmund Husserl (1972). The phenomenological approach states that an important feature of being a person is that we have conscious awareness. This approach tries to study human awareness as we experience it. It particularly looks at what the subjective nature of experience is and how we conceptualise it, the most significant information is what people are feeling and experiencing. Rather than the objective study of human existence, it aims to discover a descriptive picture of human experience. Scientific assumptions are put aside, and experience itself as it occurs to the individual is investigated. The philosophy of phenomenology emphasises that social facts are characterised by their meaningfulness to individuals (Bowling 2002). Therefore, researchers should study the social meaning that the individual assigns to interactions, experiences and perceptions through internal forces. The researcher attempts to study every day experience as it is lived and to develop insights into the world of human experience. The researcher does not seek to validate his or her own theories.

Most of the widely used measures are not patient-centred and restrict a patient's choice, therefore these limitations will reduce the accuracy and usefulness of current health-related quality of life tools as they do not measure what the patient feels contributes to their quality of life. Previous work by Bosworth et al. (2004) also reported that both clinicians and standardised instruments used to assess the HRQL of patients with CHF focus primarily on physical symptoms rather than capturing the full range of psychosocial concerns. Patient-centred outcome instruments allow the respondents to choose for themselves the areas of their lives that matter (Paul & Sneed 2001). Assessing the patient's experience of chronic heart failure and its treatment is a central component of health care. Health-related quality of life measures capture the personal and social context of patients (Higginson & Carr 2001). Measures that have been developed for clinical research cannot be easily used in clinical practice. There is increasing interest in developing individualised tools which reflects the perception that quality of life is unique to individuals and cannot be adequately assessed using standardised measures (Higginson & Carr 2001). Asking patients meaningful questions and listening to them is the first step in developing a valid HRQL measure (Cheater 1998). Therefore, the author intends to develop a measure, which reflects the individual's health-related quality of life.

1.12.3 Thesis aims and objectives

The author has looked at the current literature and opinions otherwise held and found the current health-related quality of life measures are expert driven and there is no suitable patient-centred measure to assess HRQL in chronic heart failure (Dunderdale et al. 2005*). Most of the measures were designed for use in clinical research and are therefore not necessarily appropriate for clinical practice. Therefore, further research should be carried out to look at patient-led health-related quality of life measures in every day practical care in a chronic heart failure population.

The aim of this research is to develop a patient-centred health-related quality of life measure for use in a chronic heart failure population.

The objectives of this thesis are:

- To identify the main caveats in the literature (Chapter 1)
- To identify items to be included in a health-related quality of life measure from patients (Chapter 2)

- To develop a health-related quality of life measure, which is patient-centred in chronic heart failure (Chapter 3)
- To establish the reliability and practicality of the health-related quality of life measure in a chronic heart failure population (Chapter 4)
- To establish the validity of the measure in a chronic heart failure population (Chapter 5)
- To identify any additional HRQL domains and issues (Chapter 6)
- To discuss the findings and indicate recommendations for future research (Chapter 7).

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* Dunderdale et al 2005, Appendix 34

Chapter 2 – Qualitative study to generate insight and explore the patient's perspective of health-related quality of life

2.0 Introduction

This chapter describes a study investigating patients' perceptions of chronic heart failure (CHF) and quality of life. A qualitative method was employed using a semi-structured interview with patients discharged from hospital. The interview data was analysed using Framework Methodology (Ritchie & Spencer 1994). Themes identified from the analysis will inform the development of patient generated items for inclusion in a health-related quality of life measure. The development of a patient-centred health-related quality of life (HRQL) measure is important given the scarcity of such measures in Coronary Heart Disease (CHD). It is of particular importance in chronic heart failure given the lack of these measures (Dunderdale et al. 2005).

2.1 Background

The development of this measure will be based on a qualitative research approach, which will lead to a patient-centred health-related quality of life instrument. Thompson et al. (2002) developed the Myocardial Infarction Dimensional Assessment Scale (MIDAS), which is a disease-specific health status measure for individuals with myocardial infarction. The current research will be based on the principles used to develop the MIDAS.

Bowling (1995) reviewed the literature regarding what should be measured in the measurement of quality of life in cardiovascular disorders and suggested that it should encompass broader physical, social and psychological domains. Wenger et al. (1984) also stated that in addition to these components the following should be assessed: physical capability, emotional status, social interactions, intellectual functioning, economic status and self-perceived health status.

The purpose of a health-related quality of life measure is to assess the patient's views of the importance of aspects of health status and quality of life. Becoming a patient with heart failure is a process of searching for a meaning to this condition and a process of taking on a new identity and appropriate role behaviours. This process takes place over a period of time. This suggests that the formation of individual identities evolve as new information becomes available, as meanings are attached to the new circumstances, and as a process of negotiating new roles among family members takes place (Stull et al. 1999).

2.1.1 Aim

The aim of this study was to identify patients' perceptions about how chronic heart failure affects their health-related quality of life.

2.1.2 Research questions

- What are the patients' perceptions of their health and well-being following a diagnosis of chronic heart failure?
- How do patients perceive the concept and characteristics of health and illness?
- What factors influence a patient's perception of health and quality of life?

2.2 Method

2.2.1 Design

Semi-structured interviews to ascertain patient general views of their health-related quality of life were undertaken. Semi-structured interviews involve a series of open-ended questions based on the area being researched (Mathers et al. 1998). The advantage of semi-structured interviews are: interviewers can probe fully for clarity; more information of greater depth, can be obtained; rich quotable material can be obtained (Bowling 2002). This type of data collection allows the interviewees to express views and opinions more easily verbally than might be the case in writing. If the interviewee has difficulty answering a question or provides only a brief answer, the interviewer can prompt to encourage the interviewee to consider the question further (Mathers et al. 1998). Open-ended questions were used to enable respondents to give their opinions in full on complex topics (Bowling 2002). Open-ended questions are recommended for developing questionnaires and measurement scales (Bowling 2002).

Disadvantages of this design are: the interviewer needs to be skilled in interview techniques; the respondent may reply how he/she thinks they should do; the interviewer can bias the interview, even unwittingly by non-verbal cues; interviews are time consuming (Ogier 1995). The scope for introducing error and bias is large and can affect a number of stages of the interviewing process including asking the questions, interpreting the answers, recording the answers and coding the answers (Mathers et al. 1998). Interviewer bias can be problematic. The interviewer should avoid bringing their personal perspectives into the discussion. This can happen during the phrasing of questions, the use of prompts and selection of which responses to probe further. These biases were minimised by the interviewer spending more time on active listening and less time talking, the interview was less directive and there was less likelihood of bias being introduced (Mathers et al. 1998). A disadvantage of open-ended questions is that they can be time consuming and difficult to analyse and some of the data can be distorted by the coding process (Bowling 2002).

For this study a semi-structured interview was appropriate because it allowed detailed exploration of patients' health-related quality of life without restricting their views and opinions, in order to understand how patients define and perceive quality of life. In-depth interviews aim to analyse how people understand their social worlds and the meanings of events (Bowling 2002).

2.2.2 Sampling strategy

The sample consisted of patients admitted to a district general hospital with an objective diagnosis of chronic heart failure. The hospital in the study has 287 medical beds and a catchment population of between 180,000 – 200,000 people. A purposive sample of consecutive patients admitted with chronic heart failure over a four-month period was recruited. This sampling method was chosen because the author wanted a sample of subjects, which were easy to recruit, near at hand and likely to respond to the study. A random sample is not required at this stage in the research as the emphasis is on understanding the complex phenomena and to generate a hypothesis rather than apply the findings to a wider population (Bowling 2002). Timing of the interviews was seen as important to this study. The interviewer did not want to conduct interviews with patients who had not had time to come to terms with their diagnosis or who had not long left hospital and may not be able to focus on the interview questions (Hutchinson & Skodol-Wilson 1992).

2.2.2.1 Eligibility criteria

Patients were included in the study if they fit the following criteria:

- Diagnosed as suffering from chronic heart failure (ICD-9 code 428.0)
- Objective measurement of left ventricular function confirmed by echocardiography or angiography
- Discharged from hospital at least six weeks prior to the interview.

2.2.2.2 Exclusion criteria

Patients were excluded from the study if they fit the following criteria:

- Poor command of the English language
- Suffered from any disease or condition that may have impaired their ability to give informed consent
- Extensive reversible ischaemia precipitation heart failure
- Valvular heart disease amenable to surgical correction
- Had a terminal disease
- Home address outside the hospital's catchment area.

2.2.3 Sample size

Qualitative interviewing is usually based on small sample sizes (Bowling 2002). Sample sizes are small because of the complexity of the data and the aim is to provide rich insights rather than statistical information (Bowling 2002). These data are also expensive and time consuming to analyse. When no new stories, themes or issues emerge from analysis of qualitative data, it is generally accepted that a sufficient sample size has been reached. For qualitative studies this is between six-20 participants (Harris & Inayat 1997; Bowling 2002).

2.3 Resources

A data collection sheet was used to collect basic demographics of the individual, which was supplemented by details from a cardiac specialist nurse. A checklist was used to prompt the researcher for topics to cover rather than fixed questions (Appendix 1).

A tape recorder and audiotapes were used to enable the author to attend to the patient rather than manually recording all the responses. This aids in the elimination of researcher bias by reducing the ability of the researcher to selectively observe and record certain data at the expense of other data. The researcher could also concentrate on listening and responding to the interview and was not distracted by trying to write down what had been said. Each interview was transcribed prior to the commencement of the next interview. This was to enable the monitoring of interviewer nonverbal behaviour and responses for bias (Hutchinson & Skodol-Wilson 1992).

2.3.1 Ethical approval

Local Research Ethics Committee approval was given in October 2003.

2.3.2 Piloting

The data collection sheet and the interview schedule were piloted to evaluate the sequence of the interview, clarity of wording and questions. After this pilot the following were changed. Some of the questions contained medical jargon and were rephrased in plain and clearer language. Three of the interviewees raised issues of personality changes that were not included in the original interview schedule. This was therefore incorporated in the final schedule. The pilot also highlighted to the interviewer the need to be clear about the boundaries of being a clinician and being a researcher. This can raise a dilemma as to when to intervene with a patient (Jones 1975).

2.4 Procedure

The author identified patients who met the study entry criteria when they were discharged from hospital. Initially the author contacted patients by telephone after checking on the hospital computer system that the patient was not deceased. During the telephone call the researcher explained where their names were obtained, the purpose of the interview and what this would involve, why the study was being conducted and confidentially and anonymity of the information. It was made clear that participation was voluntary. Once prospective interviewees confirmed their willingness to participate, the date, time and place of the interview was arranged. All the interviews were carried out in the patient's own home by the author. This was a convenient place for the interviewee and the researcher found that there were fewer interruptions in the person's own environment compared to a hospital setting.

When the author met the patient the purpose of the interview was again explained to the patient, including the aim of the research and what would happen to the interview data. A patient information sheet was given to the patient. This also included an agreement to participate form (Appendix 2). Each interview was tape recorded and therefore verbal consent to tape the interview was obtained from the patient. All the interview tapes were transcribed in full (Appendix 3).

On commencing the interview the anonymity of each patient who participated was assured. The author, who tried to ensure that each interview was conducted in the same manner, so excluding any extraneous variables associated with interviewer bias, carried out all interviews.

2.4.1 Analysis of the data

Qualitative data analysis deals with the human experience and is based on analysis of words rather than numbers (Mathers et al. 1998). Qualitative researchers study things in their natural surroundings, attempting to interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln 1998). A full transcript of all tape recordings was undertaken. These were analysed using an iterative process in which emergent issues and analytical themes were identified using Framework methodology (Ritchie & Spencer 1994).

Framework methodology is a well-defined procedure, that allows the researcher to reconsider and rework ideas precisely because the analytical process has been documented and is therefore accessible (Ritchie & Spencer 1994). The method involves a systematic process of sifting, charting and sorting material according to key issues and themes (Ritchie & Spencer 1994).

A qualitative software package (Non-numerical Unstructured Data Indexing Searching and Theorising or NUD*IST) for data analysis was used (QSR International Pty Ltd 2002). NUD*IST allows manipulation of the coding system to accommodate emerging themes, it can search for significant words or phrases (Pateman 1998). The main advantage is the ability to go beyond indexing and retrieval and test out emerging theory in a procedure similar to grounded theory (Pateman 1998). There are disadvantages to using NUD*IST; it is time consuming to input and index the data before analysis can begin; the researcher must also have an understanding of how to use the software.

2.4.2 Validity and reliability checks of the data

Four criteria need to be considered, including internal validity, reliability, external validity (generalisability) and objectivity.

Internal validity was tackled in the analysis by checking the data with that participant from who it was derived (Mays & Pope 2000). Ten participants verified their interview transcripts as an accurate record of their interview. One transcript was not checked as the participant had deceased.

Inter-coder reliability refers to the degree to which two coders working separately agree on the same codes for the same block of data (Miles & Huberman 1994). Exact coding instructions enhanced the reliability of the analysis. Reliability of the codes was ascertained by a second researcher independently coding two interviews (19% of the sample), therefore ensuring that the findings were not simply based on the subjective judgements of one individual researcher (Pope et al. 2000). The level of concordance between the two coders was calculated using Cohen's Kappa. Construction of a confusion matrix demonstrated any agreement or disagreement between two coders (Appendix 4).

The formula for calculation of Cohen's Kappa (k) is given below:

$$K = \frac{\text{the proportion of agreement} - \text{the proportion expected by chance}}{1 - \text{the proportion expected by chance}}$$

In order to assess the significance of Kappa the following proportions have been suggested as significant:

A Kappa of 0.40 to 0.60 is fair, 0.60 to 0.75 is good and >0.75 is excellent (Robson 1995). The inter-coder reliability calculated with Cohen's Kappa for both transcripts was found to be very good (interview 1: Kappa = 0.78, agreement of 86 of 107 codes; interview 2: Kappa = 0.81, agreement of 47 of 57 codes).

Validity of a theme surmises that there is a relationship between the theory being investigated and the themes emerging from the data. A theme is externally valid if it can produce unbiased inferences regarding a target population (Last 2001). External validity was addressed by providing a detailed description of everything that a reader may need to know to understand the findings. This allows the reader to make parallels with their own situation in which they work or otherwise have knowledge about (Robson 1995). The reader should be able to apply the findings about one situation to a second one which is considered to be sufficiently similar to the first to warrant that generalisation (Robson 1995; Dunderdale et al. 2006*). The framework approach is systematic and designed so that the analytic process and interpretations can be viewed and assessed by people other than the primary analyst (Pope et al. 2000).

Objectivity refers to the ability of the reader to determine if the research itself is objective. The reader needs to be told enough about the study not only to judge the adequacy of the process, but also to assess whether the findings flow from the data (Robson 1995). Ultimately the reader is able to follow an audit trail which is comprehensible, useful and linked to the study in order to judge the trustworthiness of the study (Robson 1995). Since the methods used in research unavoidably influence the objects of inquiry a clear account of the process of data collection and analysis is important (Mays & Pope 2000). Tree nodes, analysed products, table of themes, definition and classification of themes, instrument development information have been included in the appendices 5-7.

2.5 Results

The findings are summarised by participant demographics, the themes of quality of life, coping, understanding and experience will be summarised with quotations from the participant interview transcripts. Eleven patients were interviewed; they were all conducted in the patients' homes. The interviews lasted between 40 and 55 minutes (mean 49 minutes). They were all audiotaped.

2.5.1 Demographics

The sample consisted of eleven participants: two women and nine men, the age range was 57-72 years (mean = 62 years). Most of the participants were working at the time of their diagnosis of heart failure, but this had changed for some at the time of the interview (Table 2.0).

Table 2.0 Frequency of participants' occupational status at the time of the interview.

Occupational Status at the time of interview	Number of participants
Retired	4
Retired on health grounds	3
Working in same job	1
Working in different job	1
Claiming benefits	2
Total	11

On echocardiogram the participants were found to have left ventricular dysfunction (of varying severity, as measured by ejection fraction) (Table 2.1).

Table 2.1 Severity of heart failure

Severity of heart failure	EF%	Number of participants
Mild	>50	0
Moderate	40-50	1
Moderate to Severe	20-40	8
Severe	<20	2

Functional status of the participants was assessed using the New York Heart Association classification system previously described in chapter 1 (Goldman et al. 1981). This is presented in Table 2.2.

Table 2.2 Functional status

NYHA Class	Number of participants
I	5
II	4
III	2
IV	0
Total	11

Six of the participants had previously never been admitted to hospital with any heart related problems; three participants had been admitted before and diagnosed to have heart failure; one participant had been admitted twice previously, and one had been admitted three times previously.

2.5.2 Framework methodology

The transcripts were analysed using an iterative process in which emergent issues and analytical themes were identified using Framework methodology, which is a systematic method of mapping and charting developing themes (Ritchie & Spencer 1994). The approach involves a systematic process of sifting, charting and sorting material according to key issues and themes (Ritchie & Spencer 1994). Five key stages to qualitative data analysis were involved: the researcher was familiar with the range and diversity of the material and able to gain an overview of the material (Familiarisation); the researcher whilst reviewing the material began a process of abstraction and conceptualisation (Identifying a thematic framework); the researcher applied a systematic index to the data in its textual form though annotation and numbering of themes (Indexing); the researcher took data from the text and rearranged it according to the appropriate thematic reference (Charting); finally the researcher pulled together key characteristics of the data by interpreting the data set as a whole (mapping and interpretation) (Ritchie & Spencer 1994). The number of codes per concept and per theme were identified and frequencies counted utilising the search facilities in NUD*IST. The ranking of themes, concepts and their overall classification is presented (Table 2.3).

The physical theme was ranked the highest (63 codes) by participants. The theme of emotion also ranked highly (60 codes), as did self-perception (50 codes).

Table 2.3 Themes ranked by frequency of participant response

Rank	Number of Concepts	Theme	Classification	Codes
1	22	Changes in physical ability	QoL	63
2	25	Emotional state	QoL	60
3	30	Self-awareness and self-perception	QoL	22 28
4	20	Changes in relationships	QoL	46
5	12	Symptoms	QoL	40
6	13	Coming to Terms with Illness	Management	37
7	20	Maintaining social/lifestyle status	QoL	33
8	12	Perception	Understanding CHF	25
9	12	Ability of Health Care Professionals	New experiences as a direct result of CHF	25
10	5	Support mechanisms	Management	19
11	8	Financial	New experiences as a direct result of CHF	17
12	6	Cognitive aspects	QoL	17
13	5	Advice & Experience	Understanding CHF	15
14	4	Information	Management	11

2.5.3 Description of themes about health-related quality of life

Seven themes on health-related quality of life were identified. These themes were primarily driven by the data but also reflect theoretically derived dimensions of quality of life described in other cardiovascular measures. Participants described changes in physical ability, emotional state, self-awareness and self-perception, changes in relationships, coping with symptoms, maintaining social/lifestyle status and cognitive aspects in respect to CHF. Three further themes were also identified which indirectly contributed to quality of life issues; these included management, understanding and experience.

2.5.3.1 Changes in physical ability

The topic on which all participants focused more than any other described changes in physical ability, which impacted on all areas of participant's lives. This aspect was discussed the most by all participants. This theme comprised categories on change of role, considering every activity, limiting activity levels, influence of symptoms and dependency. Three participants described how other people in their life were now helping them undertake tasks they would normally have done. This had led to changes in their roles. Each of these participants saw the changes as negative initially because they were stopped from doing physical tasks before they were ready to stop or that they felt they might be able to attempt. During the interviews it raised a degree of anger and annoyance from them.

> *"B (Wife) takes up the slack for anything I can't do. B will help me whenever. I've D next door he'll help me and G his wife will help me. I've also another couple of friends and I could ask them and they'd come straight away. I'm well covered, I do ask them. It took a long time. When you're stubbornly independent like we are you can't just give in like that, you think, I can do that and an hour later I wish I bloody hadn't."* Interview 7

> *"When I got my summerhouse and it was erected by the people that supplied it, that's the first time in my life that anybody has ever had to do anything for me totally."* Interview 1

> *"Some of the things I can't do any more, me husband does like cleaning windows, even pushing the hoover."* Interview 6

Six participants described how they consider everything they do, which was their way of dealing with the problems heart failure gave them. In some cases this was seen as negative but in other cases it was a means of self-preservation and reduced the onset of symptoms.

> *"I can't play squash [laugh], up 'till the end of last year I played squash two or three times a week and, I played squash competitively and I ran a squash club for fifteen years. A lot of my life has been round squash, err, I have to consider almost everything I do and what the implications are going to be, should I climb up a ladder and paint the guttering and when I paint the guttering and I feel silly should I get down, I get down the ladder, or do I think or I'll be alright. I have to consider everything physical, that I do."* Interview 1

> *" You don't bother with a trolley and it's a fair walk, and you stay close to the shelves, you don't go out into the middle where there's nothing to hang onto if you need it. But I mean, Asda, which I use most of all, always a trolley. Even if it's just for one thing, I would take a trolley because I've got to get back to the car as well."* Interview 3

> *"You have to stop and think before you do anything because again there's no point starting something and leaving it half finished."* Interview 11

Eight participants described how they limit activity levels. This was due to the onset of symptoms or the fear of inducing symptoms by doing too much.

> *"You get used to limiting yourself to the amount of time you're doing something, then you notice year by year that you're doing less."* Interview 11

2.5.3.2 Emotional changes

This theme includes expressions of emotions, including fear, frustration, worry, anger, guilt and panic. Some of the participants expressed their emotions as a result of the condition and as a result of the reaction of others towards them because of the condition. One participant felt angry and guilty when she was unable to carry out an important role with her dogs due to the effects of heart failure.

> *"Things like, I lost a litter of pups by bad husbandry on my part. I knew she was going have her pups, but I just couldn't keep awake long enough to help her and it was her first litter and they were born dead. In normal circumstances had I been all right that would never happen. Never happened."* Interview 6

Eight participants described feeling frightened as a result of either the symptoms they experienced or the thoughts evoked by past experience of acute symptoms.

> *"Frightened ye, frightened. When it [breathlessness] starts to happen, I think, I'm not going through it again, don't do it again."* Interview 10
>
> *"that as quality of life goes, there are certain things that I daren't attempt for fear of anything going wrong."* Interview 2
>
> *"The odd time I do go into town the walking bit terrifies me, some times you don't know whether you're going to make it."* Interview 3

Eight participants described feeling frustrated as a result of the reaction of other people towards them or because of how the symptoms limit their activity levels.

> *"I do get frustrated because I can't do what I did before, because L [Wife] stops me doing a lot."* Interview 2
>
> *"I walk to the paper shop every morning, it's a bit less than three hundred yards, but the last bit, I get to a slight incline and that takes nearly as long as walking from here to the end of the road. And again I have to stop three or four times, I either just stop and get me breath back or hang on somebody's fence. Then that is really frustrating, it's not bad at this time of year because I try and go when nobody else is about so that nobody can see."* Interview 3
>
> *"We usually share things. I get a little frightened but more I get angry and frustrated, because it's not my lifestyle to sit in a chair and do nothing. I find I get angry, if somebody says something to me just a bit wrong then up I go like a rocket. That's how it gets you, I don't mean to be."* Interview 7

Seven participants expressed feelings of worry. Worry by the participant was usually as a result of financial issues. Participants described how their partners were worried and the realisation of their own mortality.

> *"She's [Wife] frightened of everything that I do, and worries continually."* Interview 1
>
> *"She [Wife] worries that, she worries that I sometimes do too much. She's worried that I will do too much."* Interview 2
>
> *"S [granddaughter] helps me do all that kind of thing [Washing, dressing]. But S herself, this is what I worry about, S has a problem where she has no*

growth hormone, and she has just started working, but I worry that if anything happens to me there's nobody to look after her." Interview 6

"You know what's wrong with you, but you don't know what exactly is going to hit you. They did tell me at the present time I'm in no danger of a heart attack, they tell me its heart failure, where your heart will say enough's enough and just pack up. So it's always in the back of your mind, if you do too much, is it going to happen? So I suppose a lot of it's worry about what, whether you can let yourself go or you can't let yourself go." Interview 8

"It's always at the back of your mind is today the day or is tomorrow the day, but you haven't to worry about it. You live day by day and just hope it doesn't get any worse. This worry is always there but it's not there as much when you're alright as much as it is when you happen to be having a bad day. You never know when you're going to have a bad day." Interview 8

Three participants described a feeling of panic which was related to misconcepts of CHF.

"Because when you can't catch your breath it puts more strain on your heart. It gets worse when I get frightened, I panic, if I could just settle down, and relax more." Interview 11

"I would walk down the garden and I'd walk down the street, but I was that insecure I didn't want to leave the house, but gradually that went. I seem to panic if I'm away for too long." Interview 5

A number of participants discussed emotional consequences of physical aspects of dealing with heart failure, these included: feeling of failure, avoidance and struggling to do activities.

"That gets me, I used to go to school coaching football and in coaching them I used to play with them, run about with them and he [Doctor] said don't do that, don't do any jogging or anything like that, so I packed up. As far as I was concerned if I couldn't do it I didn't want to know. It's maybe a failing on my part, but if I can't do it, I don't want to know." Interview 2

"When I have to stop, don't forget I'm a diabetic as well, and when you have to stop for something to eat and the place is crowded and you can't get a

table, I'd rather stop here than go through all that. Because I know what I'm going to feel like." Interview 6

"Getting up in a morning isn't that bad at all just at the moment, sometimes I struggle in a morning because I'm not breathing very well." Interview 8

"I've walked into supermarkets before, taken one look and come straight out. I tend to go first thing in a morning when there's no one about." Interview 3

"find is, the greatest indicator is the garden. Since I've not worked, I've taken a great interest in the garden, because it was something to do. Now I can't bend, well I can but, after thirty seconds of bending, that's it. So I've tried to rearrange the garden, well I got other people to rearrange it for me so most of it can be done on my hands and knees and as long as it's, not over reaching I can do quite well." Interview 3

2.5.3.3 Self-awareness and self-perception

This theme includes the perception by the participant of the condition and how it affects them. It also includes awareness of themselves and their personality. Participants described their perception of the condition in terms of why had it happened to them, discrepancies between the mind and body and comparing themselves to others of a similar age. Three participants questioned why CHF had happened to them. These three participants had been diagnosed with CHF more recently than the other participants.

"Why does it [breathlessness] happen to me, what have I done wrong?" Interview 11

"L [Wife] *and I sat and thought well what causes it [Heart failure], why has it suddenly come on, why has it come on? During the last, I was gradually getting worse and worse, I can't understand in hindsight why I didn't realise it."* Interview 2

"Sometimes I feel if I went to see another specialist he'd say no there's nothing wrong with me. Obviously it isn't that way, but that's how it feels to me." Interview 2

Two participants described the discrepancies they felt between wanting to do something and not being able to.

> *"It's everything you want to do but can't and it makes me feel rotten. In your mind you feel capable of doing things but because of what's happening to you, you can't."* Interview 7

Two participants described how they compare themselves to people they know, which resulted in negative thoughts about CHF.

> *"D, brothers wife, she's ten years younger than me and she walks with a stick and in a wheelchair and I've seen her get up and rock and roll, she's no where near as bad as I am."* Interview 6

Participants described aspects that related to self-perception. This included self-awareness, reflection, self-preservation, not being perfect and coping.

> *"But when I woke up, or came back to earth after the second incident, the world was a different place. In terms of emotions, my emotions have changed dramatically; I am a lot more emotional in terms of soft hearted than I was prior to this happening. I'm much more conscious of simple things in life. A blue sky, a bird singing, when I was in the coronary care unit, every morning I would wake up and there was a bird singing in the tree outside that meant nothing to anyone else."* Interview 1

> *"I often think that I wouldn't wish what has happened to me to happen to my worse enemy, but I think that everybody would be better for suffering what I have suffered or something similar. The worlds a nicer place and people in it are nicer, without a doubt."* Interview 1

> *"Psychologically I feel better, I feel more alert in me self. It's easy in hindsight, but looking back, I was getting bogged down in life some how. Things upset me easily but now they don't, it's the same as I've said to you nothing bothers me now. Obviously, it's not the tablets that making me feel that way, it's attitude of mind that's doing that."* Interview 2

> *"And to suddenly find that I've got to take all these [Tablets] several times a day was a great blow to my self esteem I suppose, I'm not perfect anymore. And before that I thought I was."* Interview 1

Four participants described changes in personality due to CHF; these were seen as both positive and negative consequences.

> *"When it happened [heart failure] I changed, my personality changed which I have also explained the get up, come let's do it chaps, got up and went. And I tend not too be so, assertive, dynamic and I can't be bothered arguing."* Interview 1

> *"The biggest impact and it leads to a certain amount of frustration and I think that, that has changed my personality as well. I am not as cheerful as I was, definitely I'm not miserable but I'm not as cheerful. I know that, people keep telling me, miserable bugger."* Interview 3

A number of coping mechanisms were discussed by participants these included: compromise, changing how tasks were undertaken, thinking through activities before doing them, restricting activities, being careful and taking longer to perform tasks. These coping mechanisms were employed to reduce the symptoms which any physical activity would create.

> *"I've always been on my own, so I've always been used to looking after me self. So I've always kept the place clean. Where as now it's a case of the bits I use and if I see a bit, dust somewhere else can wait."* Interview 3

> *"But now far in away the very fact you think, I'll do so and so, no maybe I won't well lets think, does it need doing? Whereas before, I would potter about getting stuff ready and you would do it without thinking about it you didn't have to, you just went and did it."* Interview 3

> *"I'm sort of restricted really. Where as I used to enjoy the golf competitions, I daren't put my name down for a competition now because I don't know what the weather will be like in two weeks time and that particular day, and you tend to, that's all gone."* Interview 4

> *"If I want to do gardening, where as I used to take half an hour it takes me all day now, I can still get things done but it takes me an awful lot more time. But I do it."* Interview 5

> *"It's more when I want to go out. In here if I go dizzy or get breathless I can sit down straight away, but I don't find that it stops me doing anything, but I do things at a slower pace."* Interview 8

2.5.3.4 Changes in relationships

This theme includes the relationship the participant has with others around them, this is usually the spouse and family members. This theme also includes the reaction of others to them as a result of the condition. Six participants described their relationship with others.

> *"My partner has looked after me and she's been very good to me but she gets on my nerves, but that's because I'm here all the time."* Interview 11

> *"I've upset J [wife] a lot of times. The worst thing is you tend to bottle things up, you don't say things day by day which you maybe should do. And then all of a sudden it blows, you don't have a row but you say words about it. It has put a strain on our relationship; but you don't fall out over it. Not been about to do some of the things you used to does change you."* Interview 8

> *"I've always been a worker; I don't know how to do anything except work. I still do it but it will take me a lot longer to do it and some of the things I can't do any more, me husband does like cleaning windows, even pushing the hoover that makes me break out in a sweat."* Interview 6

> *"My relationship with A has changed because it has deteriorated a lot. Because we are in each other's pockets all the time. It's hard going so hopefully when I'm away or I've got a new job it will change. It will mean I'm not here all day."* Interview 9

Six participants felt that limitations in life had been imposed on them either by other people or by the condition.

> *"Other people tell me not to do it [country walking]. I could do it, I'm sure I could. I can maybe not do it as fast as I did before. I could walk a while and then stop, a while and then stop, whereas before I used to go straight up. But I'm sure I could do it, it's only that people have said no you don't and I think really it would be stupid to take no notice of what people in their professional capacity have told me to do. So I don't do it. It isn't, it isn't my choice."* Interview 2

"I haven't had the time to build up me confidence yet. I think physically my legs have got weaker because I'm not doing anything, same with the dogs I just throw them out, that there vehicle, they walk and I drive. I, the only thing I do is walk. I've got a disabled badge now, so I walk from the car park to Tescos round there, that's about all the exercise I'm doing." Interview 4

"I wouldn't walk from here up to the bus stop up there, no way. But it's even a hard job for me to get in the car now. Everything no matter what it is isn't the same as it used to be. Sometimes I get pain in me chest up here not all the time, and I stop and do nothing then until it goes." Interview 6

"Life going up fells and things like that, but I daren't do it. Possibly if I attempted but obviously I can't, I could do it, but I daren't do it and that is the only thing, that as quality of life goes, there are certain things that I daren't attempt for fear of anything going wrong." Interview 2

Eight participants described how other people tell them about the effects heart failure has on them and how this interaction has changed their relationship.

"My relationship is closer, for the better. N [husband] does everything now. I get up and do dinner and dusting; he won't let me do anything else. I was told to go up the stairs twice a day by the nurse for exercise, so I do that. I go up at night when I want me bath. That's embarrassing as well, when he's got to bath ye." Interview 10

"I get tired in the day and I have difficulty concentrating. I don't notice it other people notice it about me." Interview 6

"I think the fact that there are a lot of people like me neighbours would see me doing something, they will shout at me you shouldn't be doing that let me do it. And I found after a while I was really starting to gasp for a while after doing things, but it's taken a long time to come to terms with it." Interview 7

Seven participants described the reaction of others towards them since they have had heart failure.

"The way that people react to me is, in some ways very nice, but in some ways it's almost offensive." Interview 1

> *"Everybody around me, the guys at work for instance, know what's happened to me, don't do that I'll do that, it's alright you sit there I'll see to that, and, in a way it's nice that they care, but it makes me feel, not able to do the things I should be able to do and, not able to play my part as I would like to play it."* Interview 1

> *"People tend to, yes they're asking how you are and all that sort of stuff, ye, they know what's happened. I don't get asked to things, I put that down to them thinking he's not well enough, it doesn't bother me."* Interview 4

> *"She's [Wife] frightened of everything that I do, and worries continually."* Interview 11

Two male participants described how their sexual relationship had changed as a result of fear by their partners that symptoms would manifest during sexual intercourse.

> *"Bonking, [sexual intercourse] she's frightened of that as well, because she's had to sit and watch me in the state that I've been in while I've been ill and that must have been pretty rotten for her. She also thought that one of the incidents resulted from bonking. Which I don't, but that's bothered her."* Interview 1

> *"I worry about the physical side with L [wife] to be honest. Should I? I don't know. She's fifty five, we've always had a good physical relationship, but all of a sudden with all this it's, it's fear."* Interview 4

One participant described how their routine and relationship with others was affected by the emotions they felt.

> *"I go see football. I force myself not to get quite as involved and I can't stand all the way through a match. You don't get as excited because, years ago before it happened you get excited and you could feel your heart pumping away, but you can feel that far more so you don't let yourself go quite as far as you'd like to go, no jumping up and down. You tend to just stand there and just clap a bit instead of the cheering and jumping."* Interview 8

Three participants described consequences of dependency on others.

> *"I've got me brother who helps and he's never been married he's always lived with us and he's two years older than me, but he's on his last legs he shakes he's got mild Parkinson's, but I always thought I'd be looking after him but he's more or less looking after me."* Interview 6

Three participants described how they would have to rely on medication and how this concerned them.

> *"It's a worry, to think that for the rest of me life I'm likely to have to take all these pills - but that's a personal thing from me because I have never ever taken anything that is totally unavoidable, not even an aspirin, and to suddenly find that I've got to take all these several times a day."* Interview 1

One of these participants described how she not only relied on her medication but on her husband organising them for her.

> *"My husband gets them [medication] all sorted out for me, he has a list and he puts me night times ones out at night and puts me morning ones out and puts them on a saucer on top so that I can take them when I get up and then in an afternoon he will get me, me beta blocker when he comes back and two more frusemide. So if anything happened to him I'd be a bit lost."* Interview 6

2.5.3.5 Coping with symptoms

Participants described symptoms which included breathlessness, oedema, dizziness, tiredness, chest discomfort and feeling unwell. Breathlessness and tiredness were the most frequently mentioned symptoms and were a problem in relation to physical activity.

> *"We went on a trip on Sunday on a coach trip me sister and her daughter went, me, S [daughter] and me husband went. I had to sit down about twenty or thirty times, in fact I had to say to S [daughter] you go looking round and I'll sit here, I couldn't walk round me legs wouldn't let me, I couldn't get me breath. It makes me feel awful because what's the point in me going if I can't enjoy it. I don't enjoy it."* Interview 6

> *"What's different now basically is that I come home from work and I don't do anything in the evening. I would previously have come home from work in the evening and thought well tonight I'm going to do*

> *this. I just come home and that's it I'm tired. I tend not to do as much or get as much done at a weekend because I'm not physically able too, I get tired."* Interview 1.

Every participant mentioned feeling breathless. Most reported that these symptoms were associated with activities of daily living which did not necessarily mean they were exerting themselves before they became breathless and tired.

> *"We don't go to functions a lot in an evening where we would have done, I get tired, I went to a sixtieth birthday party last Monday and I was home at half past ten, where as I could have been one of the last ones there."* Interview 4.

> *"Household chores, well I've cut down to just doing dinner because doing the hoovering used to pull me around a bit. In doing so many different things trying to get dinner ready I start to get tired you can't think about what you're doing and there's been many a time I thought I haven't done any veg or any tatties, just silly things like that."* Interview 7.

> *"I can not move about like I used to be able to do, everything is hard to do. Getting dressed, I'm even out of breath getting dressed most times. I can't go shopping without stopping every few minutes. I can't carry me shopping."* Interview 6.

Three participants described feeling generally unwell; this was due to physical manifestations and psychological consequences of their symptoms.

> *"A big change one way or another, its everything you want to do but can't, and it makes me feel rotten. In your mind you feel capable of doing things but because of what's happening to you, you can't."* Interview 7

> *"Now putting the pieces together, it makes sense so over a period of time, that fluid has been building up but I never noticed. I was feeling drained and really awful. I was really breathless."* Interview 9

2.5.3.6 Maintaining social/lifestyle status

Ten participants described aspects related to lifestyle. This theme included social life, lifestyle, stress, missing out and not giving up. Some participants found that their social life had been reduced; where as some participants found it had been enhanced.

> *"We didn't go for drinks, we used to go out on the buses to C [town], we don't do that now."* Interview 10

> *"But the thing about Asda is it's almost like a social event. Sometimes it's the only time I get out, the girls on the check out are the only people I see, other than mother because I always go down to see mother."* Interview 3

One participant found his social activities had changed for him in a positive way. However, he no longer socialised with his spouse, but had found his own activities.

> *"It's [heart failure] stopped us going out. Sometimes we used to go out for a meal regularly and now I feel I don't want to do that. I go to chapel, I go there regular and that's a social thing as well as other things, you meet with people without it being strenuous work you know, so it's a thing that gets me out."* Interview 5

Four participants described how tiredness had affected their social life.

> *"It's mostly through tiredness. You try to do things and you're too tired too early."* Interview 5

> *"By the time its time to go out I'm too tired. But we go out now and again. I just go out earlier rather than later, I'm fine."* Interview 5

> *"He's [husband] a standard bearer for a reunion group and it's their dinner dance next week and he's asked me if he should get me a ticket, but I don't want to go. If I can't get up and dance I don't want to sit there and mope I'd rather him go on his own than me go with him like, things like that have altered."* Interview 6

Three participants described how heart failure had changed their lifestyle on a day-to-day basis.

> *"As a social comment, I drank a lot more, before, than I do now, I wouldn't say I drank to the extent of being drunk every night, but, I didn't consider, other than driving, the amount that I drank I might have a couple of glasses of wine or 4 or 5 pints of bitter, and now I consider it."* Interview 1

> *"For fifteen years, golfing holidays with the boys, drinking, enjoying everything, all of a sudden all that's gone."* Interview 4

Some participants described the importance of avoiding stress and how this had affected their quality of life.

> *"Yes I think it has, I think that how it changes you [heart failure]. I know that I can't get stressed, I know that I shouldn't get stressed, so I think looking to find the best in people stops you getting stressed. If there's any arguments I just walk away. There are, you tend to walk away. I would have been in the thick of it before; I always had to put my viewpoint in, but now I don't bother."* Interview 5

One participant described how stress was a cause for concern from his employer and how this caused financial worry for him.

> *"I couldn't go back to work, the people at work were so concerned that I didn't go back to a stress situation, that, I wasn't allowed to go back to work until my GP had actually written a report on me. Not just a, he's fit for work on this particular day, and then what could I do what couldn't I do, what hours could I work. If that hadn't happened I couldn't realistically have continued to do me job."* Interview 1

One participant described how the side effects of the medication were affecting his sex life with his partner. However, this was also related to emotional concerns on both their parts.

> *"She's fifty-five [wife], we've always had a good physical relationship, but all of a sudden with all this it's, it's fear, and I think the tablets affect you that way. It's from me. She's never pushed. If I do approach anything like that, I think I better take me spray, I do things like that."* Interview 4

Two participants described missing out on things in life due to changes in their lifestyle.

> *"And of course when you have these bouts you ended up having to miss something, like we had booked a holiday and we had to cancel it."* Interview 7

Although some participants felt they were missing out on things in life, some participants felt this gave them a new resolve to ensure they didn't give up.

> *"Once you start to lose your independence you're liable to start on a wave of just giving in but you can't afford to do that...Go to the limit, if you say well that's it, but if you push yourself you can always get another half an hour, but you feel better because you've done that, you don't feel that you're giving in to it. You're saying hang on a minute I work hard and get more out of you before I give in, sort of thing. That's how you've got to think."* Interview 7
>
> *"I won't give in and we are just planning a holiday and if you don't plan then you're giving in to my way of thinking."* Interview 8

2.5.3.7 Cognitive aspects

Eight of the participants described cognitive aspects of their life which were affected by the condition. These included changes in concentration, denial or forgetting they had the condition, forgetting to take medication and reliance on them and changes in sleep patterns. Three participants had problems with concentration and found that it affected their judgement and alertness.

> *"I also found the attention span is shortened dramatically. I could sit all day with a book, twenty minutes half an hour and you find your reading the same page again, 'oh I've read that. It can't be that good, but it's a good book'."* Interview 3
>
> *"We pack balloons for El [company]. This week we had to do some with a pump in, and I kept sealing the bags up and forgetting these pumps and S [granddaughter] will say grandma there's another one there without a pump. I can't concentrate like I did. I would never admit to that before."* Interview 6

Six participants described forgetting about the condition. Of these participants four were reminded of their condition by the acute onset of symptoms and two participants became aware of their condition by other people reminding them.

> *"It's like I go upstairs and I'm still forgetting that I've had this heart failure, and the worst hard time is when I'm getting up in the morning and I'm taking a cup of tea to L [wife], say and I'm flying up the stairs and all of a sudden woo, woo [breathless]."* Interview 4
>
> *"Because the other day, I don't know if you've noticed but in the front garden we have two big pots, full of soil with buxom plants in them, and L [wife] was*

> *away and I picked them up and carried them down the back me self. And she played hell up with me."* Interview 2

One participant described how he felt when he had forgotten to take his tablets.

> *"And I hadn't had any tablets and I was beginning to feel a bit tired. I think that's best way to explain it, tired and very, not panicky but a bit worried about having not taken them. And that's the only time that I thought I had but I hadn't had the tablets."* Interview 2

> *"I have no problem taking tablets. I've had side effects from them all. I just take them."* Interview 10

> *"I hate it. I think, although they do you a lot of good, I think they give you, the side effects, I think. Because the doctors keep changing them and the specialists keep changing them, so you know that they are doing you harm as well as good. I suppose its all trial and error that Eucarduric, I've been on six and gone up to twenty five, well going up to twenty five I couldn't handle, so that side of it I think you're always there to try and get stabilised on tablets and that's a problem. It's the same as being on warfarin you go regular to get your blood checked you can't understand why you're up and down so much and I still don't know the reason for that, but all in all they don't bother me."* Interview 5

Six participants described how they had difficulty sleeping or changes in their sleep patterns. This was due to a number of psychological consequences.

> *"I get to the point where I get so tired that I get a really good nights sleep and then mostly it's half past twelve, quarter past one and I wake up and I get up and I go to toilet. You get to the point that you get so tired that you would give anything for a good nights sleep."* Interview 7

> *"I couldn't sleep, I used to prop me self up at forty five degrees in bed to go to sleep, because if I laid down I kept feeling as though I'd stop breathing."* Interview 2

> *"I wouldn't let me self sleep because of this breathlessness. I was concerned about the breathing. You think you're not going to wake up."* Interview 9

2.5.4 Description of other themes

Three other themes were also described by participants, which related to coping, understanding and experience. These will be discussed in the following section.

2.5.4.1 Management

Participants described three aspects related to managing their condition. These included information, support mechanisms and coming to terms with the illness. Three participants described the medical assistance they were given and how this reassured them and led them to understand when to seek medical help.

> *"I say to the nurses even though I'm out on a limb here [lives in a rural area] and people are always criticising the NHS, I can have an ambulance in this drive way in twenty minutes, so that's not bad."* Interview 4
>
> *"Leave me to get on. I don't get frightened, I would always call for an ambulance, I've learnt that."* Interview 8

One participant didn't think he had been given enough information and this led to him becoming very anxious and stressed about his condition.

> *"I don't think I've been given enough information. I want practical information, I don't like people telling me what to do."* Interview 9

Six participants described how they rely on others to help them and do tasks for them that they would previously have undertaken. This feeling of dependency was described in section 3.2.1.4 and section 3.2.1.7. However, some of the participants felt that relying on others was a positive support mechanism and helped them to live with chronic heart failure.

> *"I used to climb up and down ladders and I used to do all the decorating, now N [husband] does it all."* Interview 10
>
> *"Well ye, I've always cut the grass, done that sort of thing and now somebody else does it."* Interview 4
>
> *"The things that you can do, that you could do that you can't do now. The main one is me job, cause I'm a coach driver and automatically this is me PSV license so I can't do that. I can't go up and down stairs like I used to be able to do. I can't lift things, carry things, ye all the time relying on somebody else to do things for you."* Interview 8

Five participants identified how the support of health care professionals and family and friends was a reassurance to them.

> *"I think it's nice to know that someone else shares what you've got. They can't have what you've got but I think your selves [Health care professionals] understand what we've got. It makes, it nice when someone understands what you've got."* Interview 5

> *"You've got to do it, but there again if you've got good family, good partner, good people like yourself and the doctor, it's all a big help. When they say 'let's finely tune you,' you feel they are helping you."* Interview 7

> *"It's not just me it affects it affects your wife as well. B [wife] worried just as much as I did about it. It takes it toll on you. But you manage, but if you have somebody who will support you like I have, I'm fortunate. But those who haven't are in deep trouble."* Interview 7

All the participants described how they had or how they were coming to terms with their illness. This was expressed in discussions about planning for the future, not wanting to do things and therefore their expectations were not high. Their attitude to the condition and acceptance of it led to them using coping strategies and learning what to do and what not to do which ultimately led to planning a certain amount of things in life. Two participants described planning for the future. This relates to planning to ensure that family members would be taken care of when they were no longer able to.

> *"In spite of my life expectancy, I've made plans that should leave P [wife] and the family comfortable, so there isn't anything else that I want to plan. I only plan things in the future in terms of not expecting to be alive. I set up my pensions according to what I felt was likely."* Interview 1

> *"I am planning for S [granddaughter], it has been going on for a couple of years, as soon as I knew about my heart I started planning for her."*
> Interview 6

Seven participants described not wanting to do things either because they were concerned about aggravating symptoms or because they didn't expect to do things and therefore were not bothered.

> *"I'm retired. I think that takes a lot of pressure off. Because if I've something to do and I don't feel like doing it, I don't do it."* Interview 2
>
> *"So what's the point of rushing in the first place? But basically I like everything out of the way by lunch time, I don't want to have to do anything in an afternoon, because, I was just nodding off in the chair when you knocked."* Interview 3

Three participants describe how their attitude to chronic heart failure has helped them cope and come to terms with the illness.

> *"It's the same as I've said to you nothing bothers me now. Obviously, its not the tablets that make me feel that way, it's an attitude of mind that's doing that."* Interview 2
>
> *"I sometimes get sad about it, but life's life and it depends how you look at life."* Interview 11

Five participants described how they had accepted and come to terms with having chronic heart failure.

> *"You have to accept the way you are because it's not going to change. So you put up with what ever's there".* Interview 3
>
> *"I just have to accept what I can do and I'm grateful for what people do for me."* Interview 5

Strategies for coping with chronic heart failure were discussed by six of the participants. These strategies were practical ways to deal with the problems they had experienced with their illness, rather than sitting down and allowing other people to do everything for them.

> *"Again, a silly thing, it sounds disgusting, but it's practical. I pee in a bottle, which I keep under the sink a big two-litre Comfort bottle. And then, when it's eventually full I go up the stairs and empty it down the toilet. But that's one trip instead of five or six. If you drop stuff, and you don't need it, it stays dropped, until, you go round shove everything together and get it all in one fell swoop."* Interview 3

> *"When I think its coming on [breathlessness] and then I find what I have to do is start counting. And then I'm thinking I'm not short of breath it's panic. It stops me sort of [pants]."* Interview 4

2.5.4.2 Understanding chronic heart failure

This theme included two aspects related to understanding. These included advice, experience and perception. Seven participants described how their experiences had increased their understanding of the nature of chronic heart failure and how to deal with any problems that arose.

> *"I think that I know all about it now from my point of view. I know what I have to do, the things that concern me are, when the ambulance eventually gets here are they going to be able to put a cannula in me, you go cold. Your hands and feet go cold, and will they be here in time to get it in because they won't drive the ambulance away until they have and on one occasion I was outside in the ambulance for about 20 minutes. It was absolutely terrible, and then because we were able to respond more quickly to the situation the ambulance arrived sooner and my veins hadn't shut down or what ever they do, and they were able to get the cannula in to start with."* Interview 1

> *"Like mowing the lawn, I have an electric mower and I have a push mower. If I'm feeling alright I use the push mower. I feel better doing that and then I feel I've done something, but the rest I just learnt I can't do what I did."* Interview 5

> *"You think I can do that and an hour later I wish I bloody hadn't. I've learnt though experience, but it took me a long, long while though."* Interview 7

Some of the participants had found out about chronic heart failure either through reading books or using the internet. They did this because they needed to know more about the condition in order to understand how to deal with the problems it gave them.

> *"I went to see me GP to ask him what was causing this build up of fluid, he said it was because of the erratic heart beat it was causing the build up and having heart failure it's not clearing the backlog. Now putting the pieces together, it makes sense so over a period of time, that fluid has been building up but I never noticed."* Interview 9

> *"I would say a lot of the information I have gleaned is because I have gone out and asked people, I am more aware of what's going on now. I understand all the situations, I'm checking me weight, watching me legs."* Interview 11

Eight of the participants described how they had thought about death and dying as a result of either their symptoms, or understanding the illness much better than they had before.

> *"I look around and I'm going to a few more funerals than I used to and I'm still around, so ye, so what ever way I can enjoy me self I will. Because who knows this time next year or the year after I might not be here. You can't live for next year, but unfortunately there are restrictions so it doesn't work out any where near as good as it sounds."* Interview 3
>
> *"Just wonder especially when I'm told I only have one artery that's pumping blood to the heart and you panic that if ever that one blocks, that's the end of me. What can you do about it, not a lot? The other thing that worries ye, is you don't know how much time you've got left."* Interview 4
>
> *"I'm not afraid to die, probably people in normal circumstances would. But I've never had a fear of death, so I just, I would be really fearful if I thought I was going to end up where somebody was going to have to look after me totally hundred percent of the time. But while I can still do things, if I have palpitation and drop dead, I drop dead. It's not me that will feel anything it's people I've left behind in that respect."* Interview 6
>
> *"It's always at the back of your mind is today the day or is tomorrow the day, but you haven't to worry about it. You live day by day and just hope it doesn't get any worse."* Interview 8

One participant described how unpredictable the illness was. He found it difficult to know how he was going to be and this had implications for his daily activities and routine.

> *"I never know when you're going to have a bad day. You get up in a morning and you're alright and as the day goes on you get bad, sometimes just for half an hour."* Interview 8

2.5.4.3 New experiences as a direct result of chronic heart failure

This theme was discussed by participants and includes issues regarding the ability of health care professionals and financial implications. Three participants described issues they had relating to the incompetence of the medical profession and how this had led to a loss of confidence and trust in the health care system and therefore reluctance to believe what they were being told.

> *"The major failing in the way that I've been treated that's led to all these worries is incompetence on the part of several people, and the inadequate control system at the hospital which just destroyed all yer confidence and hers (wife), and that's why she worries. The person that I believe is Dr K. He's the only guy that I've got 100% confidence in, in terms of the way forward, he's the only guy that can discuss things with me in a matter of fact way, so that, I can understand what's happening, I can make my decisions, I can explain my problems, all the other people that I've dealt with in terms of doctors and systems have let me down. It's worry, it's a big worry, because I don't know who to believe. It's frightening I could have died in there while, everybody was fannying about, saying "oh yes this great Dr D is going to come and see yer," and he was a myth, he just didn't appear and didn't appear."* Interview 1

> *"I didn't think that the doctors gave me a good deal at all. Because even the doctors and the nurses didn't tell me much they just pushed me into the ward and I hadn't got a clue what was going on, I didn't understand what my heart problem was. I wouldn't have had a lot of the problems I've had since especially with the medication, if I'd have had people around me explaining and I've found the worse people are the doctors. But I needed to know from practical experience rather than talking, so no one gave me any information at all. Even when I asked specific questions, nothing at all, his point from a medical point of view he didn't give me advice on where I should be looking, it would have been nice to have some facts. I'm an engineer and I need the information so I can look at it all and assess."* Interview 9

However, some participants had positive experiences of the health care professionals and were grateful for the involvement of the doctors and nurses.

> *"But there again if you've got good family, good partner, good people like yourself and the doctor, it's all a big help. When they say let's finely tune you, you feel they are helping you."* Interview 7

Most of the participants were working at the time of their admission with chronic heart failure. However, this had changed for some at the time of the interview. Seven of the participants described how having heart failure and being off work and the uncertainty of knowing if and when, they would return to work affected their financial position and caused them some degree of anxiety. One participant discussed how he had paid privately for therapy in order to expedite his treatment so he could return to a better quality of life and work.

> *"If I'd not paid privately for the treatment I've had, I would be out of work now, I wouldn't be able to pay me mortgage, I'd be out of me house, and they're the things that get home to you."* Interview 1

Most of the participants who were working had not given any thought to the long term future of their finances until they were diagnosed with heart failure and their earning potential was severely reduced.

> *"Ye, seventy two pounds fifty a week. I was on eight hundred and fifty pound a week. Yes it's a slight difference. Again it all happened at the wrong time, I'd been spending, spending and spending, I knew the job I was on was going to last. And it would have set me up totally, even I couldn't spend it. And bang it comes right out of the blue and it's amazing how much money you can get by on. Ok, I had some savings but they went, well a lot of it went."* Interview 3

> *"You know how much you're bringing home and when someone says that's it your working days are over all of a sudden it's like somebody hit you over the head with a piece of four be two. Then your problems start."* Interview 7

> *"I would definitely still be at work, other than one or two days sickness, I've never been one for not working. I'm sixty this year and people don't want to know you after thirty, thirty fine as far as finding another job. But I would still have been at work, the job I had was a good job. One that I would have been at until I was sixty five without a doubt."* Interview 8

Two participants were forced to apply for state benefits which they found a very negative experience.

> *"Every single penny I'm receiving we've had to fight tooth and nail for. I have to cut me cloth to suit because I'm hundreds of pounds down. All your plans are all out the window you have to rethink your life. It's not just me it affects, it affects your wife as well."* Interview 7

> *"I've never been on social security or disability or anything like that. I wouldn't say its degrading but I would sooner be at work, you always feel that you're claiming money that you shouldn't really be doing. The process is murder, they want to know all the ins and outs, some of the things they want to know are out of this world."* Interview 8

2.6 Discussion

This study aimed to explore HRQL from the perspective of patients with CHF, and to identify themes for inclusion in a patient-generated instrument. Themes were driven by the data and theory, with the results of the framework methodology providing quantitative data to illustrate the most relevant themes to aid item-generation for the health-related quality of life measure. The participants described a number of factors that affected their perceptions of how CHF impacted upon them, bringing to light new information regarding HRQL measures.

Data collected through qualitative methods is invariably unstructured and unwieldy. Framework methodology provided a coherent and structured way to deal with a cumbersome data set whilst retaining hold of the original accounts. This process relied on the researchers' creativity and conceptual ability to determine meaning, salience and links amongst the data. This process required analytical thinking in order to reconsider and rework ideas precisely. Central to this method is ensuring the quality of the research through reflexivity. Reflexivity enables the researcher to state how their personal values and beliefs may affect the conduct and interpretation of the data. This reflective practice is fostered through framework methodology to ensure that the research findings have been performed in good faith and not overtly influenced by the personal values of the researcher.

Important dimensions of health-related quality of life, as perceived by participants were identified in physical, emotional, self-perception, relationships, symptoms, lifestyle, medication and cognitive consequences of chronic heart failure. Other consequences included coping, understanding and experience. Some participants reported coping with CHF and accepting it whereas others were still coming to terms with the condition.

The participants described a number of factors that affected their perceptions of how CHF impacted upon them, including their values and beliefs, misconceptions, attitudes to health and illness and what they understood about their illness. Similar findings regarding people with other forms of coronary heart disease have been described in the literature (Bowling 1996; Petrie & Weinman 1997; Furze et al. 2001; Roebuck et al. 2001).

In this study all participants described the negative effects of having CHF, which reflects the findings in other studies (Stull et al. 1999; Juenger et al. 2002; Bennett et al. 2003; Johansson et al. 2004). The limiting of activities described, may be due to behavioural avoidance as a coping strategy, even though this has been linked to higher mortality in this group of people (Denollet & Brutsaert 1998; Murberg et al. 2001; Murberg et al. 2004). The participants rated the ability to perform tasks and physical activities as the most important aspect of health-related quality of life which is also identified in the literature (Wenger et al. 1984; Fitzpatrick et al. 1992; Berry & McMurray 1999).

The participants in this study expressed many negative emotions, including fear, frustration, worry, anger, guilt and panic. Anxiety and fear are commonly reported by people with heart disease, and as early as 1967 Wynn reported that unwarranted fear was found in 50% of people post-myocardial infarction. Lee et al. (2005) found that psychological status was the most prominent, suggesting that a high level of anxiety and depression was most detrimental to HRQL in CHF patients. A link between extreme health anxiety and physical limitation among people with CHF has been reported (Murberg et al. 1997; Murberg 1999; Doering et al. 2004), which suggests that fear and anxiety may promote behavioural avoidance and reduce physical functioning due to a sense of inadequacy in performing activities of daily living (Franks et al. 1992). Negative emotions have been associated with increased mortality and morbidity both in patients with coronary heart disease (Kawachi et al. 1994; Frasure-Smith et al. 1995; Moser & Dracup 1996; Rozanski et al. 1999; Kubzansky & Kawachi 2000; Doering et al. 2004) and in patients with heart failure (Konstam et al. 1996; Denollet & Brutsaert 1998).

The finding that relatives and friends encourage behavioural avoidance is not new. It has been reported in studies of post-myocardial infarction and among people with angina that relatives may encourage unnecessary limitation of activity because of their fears for the patient (Ebbesen et al. 1990; Petrie & Weinman 1997; Bennett & Connell 1999; Furze et al. 2001; Roebuck et al. 2001). However, some of the participants described how support from family and friends helped them to cope with the illness. The family had a significant effect on the emotional aspects of the participant, depending on how much they felt supported. These positive and negative effects of support have been found in previous research (Martensson et al. 1997; Martensson et al. 1998).

The participants in this study expressed changes in their personality due to chronic heart failure. This has been reported by Murberg (1998) and has been linked to neuroticism and depression.

In this study all the participants described symptoms that limited them on a daily basis; these included breathlessness, tiredness, oedema, chest discomfort and feeling unwell. It is well documented in cancer patients and chronic obstructive pulmonary disease that breathlessness has a major negative impact on patients' physical and social functioning and is also associated with anxiety (Skilbeck et al. 1998; O'Driscoll et al. 1999; Stull et al. 1999; Silvester et al. 2000). It has been found that symptoms and activity levels can have a negative effect on HRQL in CHF patients (Johansson et al. 2006). More recently it has been reported that heart failure patients' descriptions of breathlessness are distinct from medical terminology and more clearly related to physical adaptations to breathlessness (Edmonds et al. 2005).

Some of the participants in this study described cognitive aspects of their life that were affected by CHF, including changes in concentration, denial of the condition and changes in sleep pattern. Cognitive function is a broad term used to describe thinking, learning, memory, attention and problem solving skills (Lezak 2004). Cognitive dysfunction has been found to be prevalent in this group (Zuccala et al. 2005). An abnormal prevalence of cognitive dysfunction ranging from 35% to over 50% has been described among patients with CHF (Almeida & Flicker 2001; Lang & Mancini 2006). Early reports indicated that patients with CHF display deficits in memory and other intellectual abilities, although the clinical relevance of these findings remains unclear (Almeida & Flicker 2001; Wolfe et al. 2006). Sleep disturbances are very common in patients with CHF (Bradley & Floras 1996; Brostrom et al. 2001). Research has shown that patients' sleep is affected by their daily activities, the disease itself and cardiac symptoms. Sleep disturbances produce effects such as fatigue, listlessness, loss of concentration and loss of temper. These effects led to a need for daytime sleep, seclusion, counselling and information (Brostrom et al. 2001). Sleep disturbances are prevalent among the elderly, especially among those with chronic heart failure (CHF) and can affect all dimensions of quality of life negatively (Brostrom & Johansson 2005). Sleep disturbances in patients with CHF are related with different causes such as sleep breathing disorders, occurring in about 50% of the heart failure population and/or depression as well as from heart failure symptoms such as dyspnoea and dysrhythmia (Johansson et al. 2006). Effective treatment of sleep problems may contribute to improvement in quality of life (Redeker & Hilkert 2005).

Participants in this study reported forgetting about their condition and trying to perform physical activities. This aspect of quality of life was important because participants were soon reminded of their illness by symptoms which prevented them carrying on and was also paralleled with an awareness of their own mortality. This has been identified in studies of patients' understanding and perceptions of quality of life in chronic heart failure (Rogers et al. 2000; Paul & Sneed 2001).

Searches of the relevant literature did not identify instances of changes in relationships, maintaining social/lifestyle status and medication being identified previously. These topics have not been identified by current health-related quality of life measures. This suggests that quality of life research among this patient group to date has not been able to fully report the subjective experience from the patient, highlighting the importance of producing such measures from the patient perspective. The development of a health-related quality of life measure derived from patient perspective might help to remedy this deficit.

A minority of participants in this study described poor experiences of the health care process. This demonstrated a clear picture that these participants were not being treated as individuals. These bad experiences were as a result of poor doctor-patient relationships. Recent literature shows a high prevalence of conflict between CHF patients and their physicians (Zickmund et al. 2006). This study found major problems included the providers' poor communication skills, trust in the physicians' competence, and insufficient medical information. Patients identified care outside the tertiary referral hospital and inadequate communication between physicians as additional sources of difficulty. These results support the experiences discussed by the participants in this current study.

The strengths of this study were the one to one interviews with participants which provided rich detailed data on the concepts of HRQL and illness perceptions. Areas of uncertainty and vagueness were clarified with participants avoiding any misunderstandings. This ensured that the research was rigorous. Most of the data analysis in this study was driven by the data itself. Previous research (Wenger et al. 1984), informed the thematic framework for analysis.

The limitations of this study were that the interviews were conducted after the participant had been discharged from hospital and therefore does not address those individuals who have chronic heart failure and are diagnosed and treated by their general practitioners (McMurray & Cleland 2000). There was a potential for respondent bias because the participants may have tried to tell the interviewer what they think the researcher wants to hear (Bowling 2002). Respondent bias was minimised by asking the questions in such a way as to avoid a right or wrong answer. The sample contained mostly men with only two women interviewed, although figures from the British Heart Foundation show that the incidence of heart failure is more common in men than women (Petersen et al. 2002). The average age of the participants was considerably lower than the typical patient with CHF. Involving an interpreter would have permitted the inclusion of participants from the ethnic minorities, but this was beyond the financial constraints of the study. A purposive sample technique was used to ensure that the sample selected possessed the characteristics needed for the study. With a qualitative descriptive design, it is not possible to obtain a representative sample in a statistical sense. Eleven interviews were conducted, an adequate number to allow different conceptions to be constructed. Saturation of themes was reached after ten interviews, which increases the concordance of the findings. A greater number of interviews could have resulted in an even wider range of subcategories. However, with more informants, there is a risk that the data analysis becomes superficial. It would also have been beneficial to explore the impact of chronic heart failure on the quality of life of family members. The interviews revealed not just the impact on the individual concerned, but also the impact on the whole family. By identifying spouses' experiences, health care professionals can assess which kind of specific interventions should be used to improve the life situation of the patient with heart failure and their spouse (Martensson et al. 2001). A truly patient centred quality of life measure should take this extended impact into account, however this issue was not addressed in this study.

Chronic heart failure, understandably, significantly impairs health-related quality of life, causes emotional distress, adversely affects daily life activities and routines (Juenger et al. 2002; Johansson et al. 2004) and imposes a heavy burden of symptoms (Dargie & McMurray 1994). The importance of measuring HRQL in this patient population is being increasingly recognised (Deyo 1991; Wilson & Cleary 1995: Fallowfield 1996). However, the majority of clinical research has used inappropriate or poorly developed quality of life measures (Mayou & Bryant 1993). Most clinical interest and research in cardiology has focused on myocardial infarction and comparatively little on chronic heart failure. However, despite an increasing familiarity with the concept of quality of life, its measurement is often poorly understood and applied inappropriately (Jenkinson & McGee 1998).

2.7 Summary

This study identifies a variety of dimensions that adversely affect health-related quality of life for an individual with chronic heart failure (Dunderdale et al. 2006*). There is increasing interest in developing individualised tools which reflect the perception that quality of life is unique to individuals and cannot be adequately assessed using standardised measures (Higginson & Carr 2001). No instrument has measured quality of life in heart failure trials in a reliable or valid way, and therefore an obvious need exists for the development of valid and reliable instruments (Berry & McMurray 1999). The current knowledge base in the area of patient-centred quality of life measures in chronic heart failure is lacking and there is a lack of consensus as to which measurers are appropriate for research and clinical practice. To date little data exists which attempts to assess HRQL from the patient's perspective. Most of the scales are not derived from a patient's perspective, instead they rely on the perspective of professionals, and it may be the case that medical professionals view different aspects of function as important to quality of life (Paul & Sneed 2001).

Findings from this study will contribute to the development of a patient-led health-related quality of life measure for use in everyday practical care in a chronic heart failure population. Psychometric properties of the new measure will be established in subsequent research.

* Dunderdale et al 2006, Appendix 35

Chapter 3 Part I – Development of the health-related quality of life measure

3.0 Introduction

This Chapter is presented in two parts (Chapter 3 & Chapter 4): Part one (Chapter 3) describes the development of the Health-Related Quality of Life (HRQL) measure, known as the CHFQoL (Chronic Heart Failure Quality of Life) questionnaire. Part two (Chapter 4) describes the establishment of the psychometric properties of the CHFQoL questionnaire. This questionnaire has been developed from the item pool identified in Chapter 2 and the literature and theory reviewed in Chapter 1. A qualitative method was employed in part one to test the face validity of the measure by utilising focus groups and expert opinion. A quantitative method was employed in part two to test the internal reliability and the correlation of items by utilising a prospective survey of individuals who were discharged from hospital with a diagnosis of chronic heart failure. The implications for the future reliability and validity of the measure will be discussed.

3.1 Background

Increasingly there is a move towards measuring HRQL in medical care rather than relying on negative aspects of health outcome, such as, mortality or objective outcome indicators (Jenkinson 1994). Subjective measures of HRQL can complement objective measures, but need to be useful in the clinical setting, practical, easy to use and interpret; they must also be acceptable to patients and health care professionals (Greenhalgh et al. 1998).

3.1.1 Aim

The aim of this study is to develop the CHFQoL questionnaire by establishing face validity through focus groups and expert opinion.

3.1.2 Objectives

- To identify items for inclusion in the questionnaire
- To determine the acceptability of this measure
- To determine the practicality of this measure.

3.2 Method

3.2.1 Design

The study employed two different qualitative methods 1) focus groups, 2) face-to-face interviews. Facilitation of two focus groups and face-to-face interviews with experts were undertaken to devise the questionnaire items from the exploratory interviews conducted in Chapter 2. The first stage employed a focus group method. Focus groups are unstructured interviews with small groups of people who interact with each other and the group leader (Bowling 2002). The group process helped individuals explore their views and generate questions in ways that they would find more difficult in face to face interviews (Bowling 2002). Focus groups were chosen because they provide a rich source of insight and interpretations from participants (Polgar & Thomas 1998). Group discussion was deemed appropriate, as the researcher had wished to encourage participating patients and partners to explore the pilot questionnaire and generate constructive criticism. Disadvantages of focus groups include compromising on confidentiality of the research session and the articulation of group norms may silence individuals (Kitzinger 1996). Group dynamics can affect who speaks and what a person says, it is also difficult to follow up the views of individuals (Robson 1995).

The second stage employed a face-to-face interview method with clinicians to describe the factors clinicians identified as important in the measure. This method was chosen because the researcher wanted to ascertain the clinicians' views of the questionnaire by asking a series of open-ended questions. It was also more convenient for the clinicians to be interviewed individually rather than as a group.

3.2.2 Sampling strategy

3.2.2.1 Focus group

The purposive sample for the focus groups consisted of two groups of eight individuals; comprising four patients and their partners. Focus groups generally comprise four - ten participants (Kitzinger 1996). A Heart Failure Nurse identified patients retrospectively, when the patient was stable on medication for chronic heart failure. Purposive sampling relies on the researcher's judgement as to typicality or interest, and enabled the researcher to satisfy the specific needs of the project (Robson 1995).

3.2.2.2 Expert opinion

A purposive sample of four clinicians representing clinical experts within the field of cardiology and heart failure were chosen as the experts. This group was made up of four individuals; a Consultant Physician, a Consultant Cardiologist, a Heart Failure Nurse and a member of the Research Advisory Group (RAG). The researcher identified the individuals that were the experts.

3.2.3 Questionnaire design

The design of a questionnaire is important as it affects response rate. The two most important procedures at the outset of constructing a questionnaire are the planning and piloting (Bowling 2002). The CHFQoL questionnaire was designed to evaluate HRQL outcomes in adults with chronic heart failure.

3.2.4 Construction of questions and response type

Following the recommendations of Robson (1995), the questionnaire was designed to look easy to fill in, with plenty of space for questions and answers. The following factors were addressed when designing the CHFQoL questionnaire; appearance, clarity, ambiguity, response formats and question order. The appearance of a questionnaire is vital. It is essential that terms or expressions used in the questions are easily understood by the respondents (Jackson & Furnham 2000). Ambiguity of question wording and responses was avoided by ensuring that double barrelled questions, one question is asked with two answers leading the respondent in a dilemma as to which answer to give, were not used (Moser & Kalton 1996; Oppenheim 2001). If a vague word is used different people will understand the question differently and will in effect be answering different questions (Moser & Kalton 1996). Questions which have a double negative were also avoided, that is a negative question with a disagree response, as this can cause difficulty for the respondent who may want to give a positive response (Oppenheim 2001). Jargon, idioms, acronyms and metaphors were avoided in order to communicate with respondents as nearly as possible in their own language (Moser & Kalton 1996; Oppenheim 2001). Leading questions were also avoided, which by their content, structure or wording lead the respondent in the direction of a certain answer (Moser & Kalton 1996). Clarity of the items was ensured by asking the questions appropriate to a readability score for the minimum for plain English (Flesch 1949). The Flesch Reading Ease score rates text on a 100-point scale; the higher the score, the easier it is to understand the document. Most standard documents aim for a score of approximately 60 to 70. The readability scores of the CHFQoL questionnaire were tested. The results revealed acceptable reading ease and reading grade statistics (70.4% and 6.5) (Flesch 1949).

The questionnaire used structured, pre-coded formats (Bowling 2002). Consideration was given to question types. Closed questions are usually preferable to open questions (Robson 1995). It is almost impossible to undertake factor analysis on open questions. However, a small number of open questions were used to allow respondents to give further comments to questions. Consideration was also given to the ordering of questions in the questionnaire because this can affect response and bias results. The CHFQoL questionnaire adopted a funnel approach to the question order (Bowling 2002). The funnel approach starts off the items with a very broad question and then progressively narrows down the scope of the questions until it comes to some very specific points (Robson 1995). The questionnaire starts with easy and non-threatening questions in order to attempt to gain rapport. Socio-demographic data was asked at the end of the questionnaire so avoiding any objections by the respondent to personal questions at the outset (Bowling 2002).

The CHFQoL questionnaire asks respondents to consider their health in relation to the past two weeks. This was to reduce the instance of recall bias, which is possible in questions asking about the past (Bowling 2002). Using shorter time periods and asking questions about more recent events obtains the most reliable information. Quality of life measures usually ask respondents to rate themselves in relation to the past week (Bowling 2002).

The most commonly used scale for measuring responses is the rating scale in the Likert format (Likert 1932; Bowling 2002). Some health status questionnaires use a combination of Likert scales and visual analogue scales (Bowling 2002). Likert scales contain a series of opinion statements about an issue that the person agrees or disagrees with, usually on a five-point scale (Bowling 2002). A visual analogue scale is a scale in the Likert style (Bowling 2002). The respondent places a mark on a defined line which best answers the question being asked (Bowling 2002). A Likert scale and visual-analogue scale were selected because they are easier to construct, administer and interpret than other scales (Robson 1995). Reliability of Likert scales is good which is due in part to the greater range of answers permitted to respondents (Oppenheim 2001). Therefore the pattern of responses becomes more interesting than the total score (Oppenheim 2001). A further criticism has been that since the scale offers no metric or interval measures and lacks a neutral point, it is not possible to know where scores in the middle ranges change from mildly positive to mildly negative (McColl et al. 2001). Many respondents will take a middle response category and prefer to avoid a decision at either end of response scales (Oppenheim 2001; Bowling 2002). Too many scales can be boring for people, words may be conceptually easier to understand than numbers, although there is no consistent evidence for this and alternative answers and statements on response scales should be balanced (Bowling 2002). The rating scales used in the CHFQoL questionnaire were placed on separate pages to minimise the halo effect (Oppenheim 2001). The halo effect expresses itself in a response set. If the scales are arranged one underneath the other with the socially desirable end on the left and the opposite end on the right, then the respondents, having once made up their minds that they are favourably disposed toward the object of the rating may run down the page with out actually reading the items or giving each of them separate thought (Oppenheim 2001).

3.2.5 Improving response rates

Attention to the appearance of the questionnaire, including its length and layout were considered. Appearance of the questionnaire can influence the respondent at several stages, including the prompting of interest to complete the questionnaire, evaluation of the task involving perceptions of time and effort required to complete the questionnaire. The questionnaire was printed clearly and professionally and is visually easy to read and comprehend. Lower case letters, rather than capitals were used for text. Consideration was given to the font and font size. There is conflicting evidence regarding the length of questionnaires influencing response rates (Iglesias & Torgerson 2000; Edwards et al. 2002). However, increasing the length of a questionnaire from five to seven pages reduces response rates and seems to affect the quality of responses to questions near the front of the questionnaire (Iglesias & Torgerson 2000). Making questionnaires and covering letters personal and using stamped return envelopes increases response rates (Bowling 2002; Edwards et al. 2002). There is no universal accepted response rate since it depends upon so many factors (Jackson & Furnham 2000). However, a response rate of less than 35% might be considered unacceptable (Jackson & Furnham 2000).

3.2.6 Item generation

The main themes elicited from in-depth interviews of patient data included: physical, emotional, self-perception, relationships, symptoms, lifestyle and cognitive aspects of chronic heart failure (Chapter 2). Items were developed to reflect the participants' beliefs about how chronic heart failure affected their health-related quality of life. Items were worded so that participants compared themselves to other healthy adults of the same age as themselves. Using the words *'in comparison with other healthy adults of the same age as you'* as a frame of reference for respondents aimed to minimise misunderstanding, avoid ratings diverging more than they might have done and to facilitate interpretation as recommended by Oppenheim (2001).

3.2.6.1 Demographic items

Questionnaires utilised in the Office of National Statistics were reviewed in order to develop demographic items for inclusion in the questionnaire. Items developed from this review included; gender, age, ethnic origin, marital status, employment status and change in employment. Further items were developed based upon a review of other HRQL measures and suggestions from the RAG members. These were past medical history, date of first diagnosis with chronic heart failure, NYHA, ejection fraction and degree of left ventricular dysfunction. These are important because patients with CHF are by definition functionally impaired (Molloy et al. 2005).

3.3 Resources

The CHFQoL questionnaire was developed with reference to literature on the development of HRQL measures in coronary heart disease described in Chapter 1, participants' beliefs about how chronic heart failure affected their health-related quality of life and the empirical data described in Chapter 2. Patients were given an information sheet about the focus groups when they saw the heart failure nurse in the clinic (Appendix 8).

3.3.1 Ethical approval

Local Research Ethics Committee approval was given in November 2004 to undertake the focus groups and seek expert opinion.

3.4 Procedure

3.4.1 Sampling

The researcher independently devised the questionnaire items from the exploratory interviews in Chapter 2, which were then discussed, scrutinised for repetition and ambiguity with the experts. A final set of items were agreed. This led to a final pool of 51 items.

A Heart Failure nurse identified a total of eight patients who met the study entry criteria when they were seen in clinic. Initially, the author contacted patients by telephone after checking on the hospital computer system that the patient was not deceased. During the telephone call the researcher explained where their names were obtained, the purpose of the focus group and what this would involve, why the study was being conducted and confidentially and anonymity of the information. It was made clear that participation was voluntary. Once prospective interviewees confirmed their willingness to participate the date, time and place of the focus group was arranged.

When the author met the patients and their relative the purpose of the focus group was again explained to the patient and their partner, including the aim of the research and what would happen to the data obtained during the group discussion. A patient information sheet was given to the patient (Appendix 8). Two focus groups were facilitated with a total of four patients and four partners in each group.

On commencing the focus group the anonymity of each patient who participated was assured. The author, who tried to ensure that each focus group was conducted in the same manner, so excluding any extraneous variables associated with interviewer bias, carried out the focus group facilitation.

Each clinician was contacted by telephone and invited to participate in an interview. The interviews were arranged according to the clinician's availability. Face-to-face interviews were conducted so the researcher could give the questionnaire and discuss any constructive criticism of the format and content. Face-to-face interviews have the advantage of allowing areas of uncertainty and ambiguity to be clarified, thus avoiding misinterpretations.

3.4.2 Materials

In the focus groups each patient and their partner were given a copy of the CHFQoL questionnaire in its pilot format (Appendix 9). Participants were asked to complete the questionnaire. Participants were asked open-ended questions regarding the appearance, response format and question order. In addition they were asked open-ended questions regarding clarity of questions, ambiguity and relevance of questions. The experts were asked the same questions regarding the appropriateness of the questions, clarity of questions and their impression of the format of the questionnaire.

3.4.3 Analysis of the data

The design of the CHFQoL questionnaire was an iterative process performed in consultation with clinicians and research colleagues from the RAG and focus groups.

3.4.3.1 Practicality

A 5-point scale within the pilot questionnaire asking the respondent to rate how easy they found the questionnaire to complete assessed the practicality of the CHFQoL questionnaire. The 5-point scale ranged from "very easy" to "difficult". Participants were also asked to time themselves when completing the questionnaire to assess practicality. Descriptive statistics summarise the practicality of the CHFQoL questionnaire (section 3.5.1).

3.5 Results

3.5.1 Practicality

Most participants found the questionnaire "quite easy" to complete (Table 3.0).

Table 3.0 Participant questionnaire evaluation (Phase 2)

Ease of completion of questionnaire	Frequency (%) (n=16)
Very easy	6 (37.5%)
Quite easy	8 (50.0%)
Neither easy nor difficult	2 (12.5%)
Quite difficult	0
Difficult	0
Total	16 (100%)

Participants were instructed to time how long it took to complete the questionnaire; these times were 15-30 minutes (mean 23 minutes).

3.5.2 Demographics of focus group members

The sample composition of the focus groups and the experts are summarised (Table 3.1 and table 3.2).

Table 3.1 Sample composition of focus groups

	Male	Female
Gender	8	8
Number of patients	5	3
Number of partners	3	5
Age range of patients	58-69	36-62
Age range of partners	37-66	51-66

Table 3.2 Sample composition of face-to-face interviews

Type of health care professional	Place of work
Consultant Physician	District General Hospital
Consultant Cardiologist	District General Hospital
Heart Failure Nurse	District General Hospital
Research Fellow	University

3.5.3 Focus groups

The focus groups lasted 1.5 hours. Findings from the focus groups revealed that some modifications were required to aid questionnaire clarity and improve comprehensiveness. The layout of questions with tick boxes were amended by moving the box next to the item it represented, so reducing the confusion as to which response box to tick. The list of Likert scales which formed question 17 were reduced and three items were removed. These items were removed as members of the focus groups did not understand their relevance and struggled to give an answer. These items were statements regarding; *"I find the way people react to me is nice," "I don't feel I play my part in life"* and *"I find the way people react to me offensive".* Question 18 was moved in front of question 17 therefore changing the number order to improve the format of the questionnaire and reduce the number of sides within the questionnaire.

The introduction was revised as some individuals had not recently been in hospital and therefore felt that the questionnaire was inappropriate for them to complete. Where as, those who had recently left hospital found some of the items difficult to complete within "the past two weeks". This was amended to "a diagnosis of heart failure" rather than "a recent admission," therefore including all patients identified as eligible for inclusion.

3.5.4 Expert opinion

Interviews were conducted from 5 December – 21 December 2004, four clinicians were interviewed. The experts identified similar areas for improvement as the focus group participants. In particular there was confusion as to which box to tick on the questionnaire.

3.5.5 Face validity

A further attempt to establish face validity was undertaken by asking experts to review the questionnaire; a Cardiac Specialist Nurse, a Heart Failure Nurse, a Consultant Cardiologist and a service user. Generally the comments were positive about the questionnaire design and content and no further changes were made to the questionnaire at this point.

The revised questionnaire was posted to individuals with chronic heart failure who met the inclusion criteria. The results of which are reported in the next chapter (Chapter 4).

3.6 Summary

This study identified improvements needed to enhance the CHFQoL questionnaire for use in a chronic heart failure population. Findings from this study will contribute to research to establish the psychometric properties of the CHFQoL questionnaire described in part two of this chapter.

Chapter 4 Part II – Establishing the psychometric properties of the health-related quality of life measure.

4.0 Introduction

This Chapter describes part two of a study (Phase 2 of the research) to establish the psychometric properties of the CHFQoL (Chronic Heart Failure Quality of Life) questionnaire.

4.1 Background

In order to develop a measure, items were generated from a variety of sources. For example; patients, clinical observation, research and expert opinion (Streiner & Norman 2003). It was anticipated that the scale would have more items than would be in the final scale, a number of statistical techniques were used to select the best items for the measure.

The main areas identified from the participants in relation to HRQL, identified in Chapter 2, were: changes in physical ability; emotional state; self-awareness and self-perception; changes in relationships; symptoms; maintaining social/lifestyle status and cognitive aspects. Similar aspects have been identified in the literature review in Chapter 1.

4.1.1 Aim

The aim of the study reported in this Chapter is to refine the CHFQoL questionnaire using statistical techniques.

4.1.2 Objectives

- To identify those items that are redundant
- To identify sub-scales of the instrument that address different dimensions of chronic heart failure.

4.2 Method

4.2.1 Design

A cross-sectional survey design was used to test the CHFQoL questionnaire. The questionnaire was administered to patients by post.

For this study a survey design was appropriate because it involves collecting the same standardised data from an undifferentiated group of respondents over a short period of time (Robson 1995; Creswell 2003), in order to collect simple and straightforward data about attitudes, values, beliefs and motives (Robson 1995). A major advantage of surveys is that they are performed in natural surroundings (Bowling 2002). This will allow statistical inferences to be made in relation to the broader population of interest and therefore allows for generalisations to be made (Bowling 2002). Surveys also have the advantage of being efficient at providing large amounts of data, at relatively low cost, in a short period of time (Robson 1995; Creswell 2003). There are also disadvantages to surveys, including data being affected by the characteristics of the respondents. HRQL is known to be affected by psychological and functional status, health perceptions and educational level (Lee et al. 2005). Therefore, respondents would not necessarily report their beliefs and/or attitudes accurately. There is also potential for a social desirability response bias because people respond in a way that shows them in a good light (Robson 1995). For example, individuals with chronic heart failure may not wish to admit that they are unable to function as an effective member of a family or group.

Postal administration of the questionnaire was chosen to reach a wide audience and reduce the cost of data collection. This questionnaire will be used in the future as a postal questionnaire. This method also reduces interview bias and aids anonymity of the respondent (Oppenheim 2001); the author has extensive experience of working with individuals with chronic heart failure and has been involved in the medical care of some of the participants.

Disadvantages to postal questionnaires are the general low response rates and consequent bias (Moser & Kalton 1996; Oppenheim 2001). One problem which may occur is due to the individuals failure to understand the relevance of the questionnaire, particularly if they do not understand their diagnosis. This was addressed by sending this disease-specific questionnaire to those patients who had been given a diagnosis of chronic heart failure by a medical professional. Questionnaires can only be considered when the questions are sufficiently simple and straightforward to be understood with the help of printed instructions and definitions and therefore will be unsuitable for respondents of poor literacy (Moser & Kalton 1996; Oppenheim 2001). This was minimised by providing a respondent information sheet and covering letter with the questionnaire and the contact details for the researcher, should the respondents have any queries regarding the completion of the questionnaire. There is no opportunity to correct misunderstandings or to probe the respondent; there is no control over the order in which questions are answered; there is no check on incomplete questionnaires or the passing on of questionnaires to others and no opportunity to collect ratings or assessments based on observations (Moser & Kalton 1996; Oppenheim 2001).

The main problem with postal questionnaires is that of getting an adequate response rate (Moser & Kalton 1996). However, the problem is not with the loss of sample numbers but that the non-respondents may differ significantly from the respondents, so that estimates based on the latter are biased (Moser & Kalton 1996; Oppenheim 2001). When data are collected by self-report questionnaire, it is natural to speculate whether missingness is caused by the phenomena being measured, especially if the items are of a personal or sensitive nature. If an item pertains to non-normative behavior, some participants exhibiting that behavior may indeed leave it blank in order to mask their true values, despite repeated assurances of confidentiality. On the other hand, some who do not exhibit that behavior may also skip the item, thinking that the question cannot possibly apply to them. Reasons for non-response vary from one person to another. Many of these reasons could be correlated with the item itself, but probably not to the same degree, and perhaps not even in the same direction (Schafer & Graham 2002). Non-response bias was minimised by considering how to increase response rates prior to the questionnaires being mailed out. Researchers using postal questionnaires can improve the quality of their research by using strategies shown to be effective (Edwards et al. 2002).

4.2.2 Sampling strategy

The sample consisted of patients admitted to an Acute Trust, which consists of two district general hospitals and a smaller satellite hospital, with an objective diagnosis of chronic heart failure. Participants were identified retrospectively from discharge coding information, referral from the Cardiac Specialist Nurses and a locally held database of CHF patients. The sample was as diverse as possible in order to ensure that factor analysis was more meaningful and useful.

4.2.2.1 Eligibility criteria

Patients were included in the study if they fit the following criteria:

- Diagnosed as suffering from chronic heart failure (ICD-9 code 428.0)
- Objective measurement of left ventricular function confirmed by echocardiography or angiography.

4.2.2.2 Exclusion criteria

Patients were excluded from the study if they fit the following criteria:

- Poor command of the English language, due to evaluation being via questionnaire
- Suffered from any disease or condition that may have impaired their ability to give informed consent
- Had a terminal disease requiring palliation e.g. cancer.

4.2.3 Sample size calculation

The sample size calculation was based on evidence in the literature on successful scale generation in adults with coronary heart disease, where samples of 100-200 participants were recruited to test HRQL items for reduction (Oldridge et al. 1991; Avis et al. 1996; Ni et al. 2000; Furze et al. 2002; Bennett et al. 2003). The sample size was also determined by practical limitations such as time and cost (Oppenheim 2001). Rating scales were used in the questionnaire and therefore the sample size did not need to be larger than a few hundred (Oppenheim 2001). In this study the ideal sample size would be two hundred. Samples must be of sufficient size to produce reliable factors (Kline 1996). Factor analysis is usually applied to matrices of correlations. Correlations become reliable when a sample size of 100 or more is acheived (Kline 1996). However, there is very little agreement regarding sample size. It has been suggested that at least 10 to 15 subjects per initial item are required for factor analysis, although the number of participants available may restrict that (Pett et al. 2003). A variable to subject ratio of 1:10 has been suggested as sufficient (Ferguson & Cox 1993; Watson 1998). However, over the years, several rules of thumb have been proposed. In reality there is no rule of thumb that applies to all situations. The sample size needed for a study depends on many factors including the size of the model, distribution of the variables, amount of missing data, reliability of the variables, and strength of the relationships among the variables (Muthen & Muthen 2002). The sample size used in this study was 345.

4.3 Resources

The CHFQoL questionnaire was developed with reference to the literature in Chapter 1, in-depth interviews with patients with chronic heart failure in Chapter 2 and by generating items for inclusion in the measure in Chapter 3. A data collection sheet was used to collect basic demographics of the individual, which was supplemented by details from a Cardiac Specialist Nurse (Appendix 11). A covering letter was sent with the CHFQoL questionnaire along with an information sheet, which identified the researcher, the purpose and significance of the study and assured anonymity. A pre-paid envelope for the reply was also included (Appendix 12-13).

4.3.1 Ethical approval

Local Research Ethics Committee approval was given in November 2004 to undertake the postal survey.

4.4 Procedure

4.4.1 Sample

Hospital computer records were checked and individuals' General Practitioners were contacted to ensure the person was alive prior to the letter and questionnaire being posted. The author identified patients who met the study entry criteria when they were discharged from hospital. Participants were identified retrospectively from discharge coding information, referral from the cardiac specialist nurses and a locally held heart failure database. No post event time limit exclusion criteria were used, in order to recruit a broad cross-section of respondents.

4.4.2 Materials

Prospective participants received a study information sheet, covering letter, questionnaire and pre-paid envelope. Consent was inferred by return of the questionnaire. Those participants who did not return the questionnaire within two weeks were re-mailed on a second occasion, which improved the response rate. If a response was not given after the second attempt this was classed as a non-response.

Anonymity of each participant was assured by using a unique study number on each questionnaire. This allowed the researcher to match the data collection sheet to the questionnaire. Only the researcher was able to identify the respective participant and questionnaire. Data regarding participant information and their unique study number were stored using an Excel spreadsheet.

4.4.3 Analysis of the data

Data were entered into an Excel spreadsheet and imported into a statistical computer package SPSS version 12.0.1 (2003). The pilot sample from the focus groups, Chapter 3, was included in the main sample for data analysis.

A sample of 10% of the entered data was cross-referenced with the original questionnaires. Confidence in the final results was assured by checking for omissions and consistencies in missing data and consistency of responses. The analytic methods used will be presented as: demographics; item reduction; factor analysis of the measure and internal consistency and homogeneity of the measure.

4.4.4 Demographics

Descriptive statistics were used to identify frequency distributions, cumulative frequency distributions, central tendency, and dispersion of scores expressed as the range and standard deviation.

4.4.5 Item reduction

Response alternatives, item-total correlations and factor analysis were the statistical techniques chosen to select items for inclusion in the CHFQoL questionnaire. Items were included in the CHFQoL questionnaire if they met the inclusion criteria for endorsement. Response alternatives were calculated by computing the percentage of people responding to each response alternative.

4.4.6 Factor analysis of the measure

Factor analysis was used in order to explore the structure and concepts (dimensions) that make up the measure, and to describe how the items grouped together in order that they form a more manageable set of variables in order to develop the questionnaire (Bowling 2002). Factor analysis is a method for simplifying complex sets of data (Kline 1996).

There are two types of factor analysis; exploratory and confirmatory. Exploratory factor analysis (EFA) was used for this research. EFA was chosen because it is a method of discovering the number and nature of latent variables that explain the variation and co variation in a set of measured variables (Preacher & MacCallum 2003). It is best used when the researcher does not know how many factors are necessary to explain the inter-relationships among a set of items (Pedhazur & Schmelkin 1991; Tabachnick & Fidell 2001). Confirmatory factor analysis (CFA) was not attempted in this study because it is primarily concerned with testing specific hypotheses about relationships between variables that underlie the data tested (Field 2005).

There are many different types of factor analysis extraction technique; principal component analysis (PCA) and common factor analysis or principal axis factoring (PAF) are two such techniques. PCA is a commonly used extraction technique in factor analysis (Pett et al. 2003). PAF and PCA have different goals (Thomson 1951). Principal component analysis represents the original variables in a mathematically efficient manner by reduced dimensionality. It is most appropriate for data reduction making it possible to represent the data in a minimal number of dimensions (de Vet et al. 2005). PAF provides valuable insight into the multivariate structure of an instrument (Widaman 2005). It aims to identify a set of more general factors that explain the covariance among the measured variables (Floyd & Widaman 1995).

PCA provides a succinct set of uncorrelated components that extract variance in descending order, effectively summarising the data set (Pett et al. 2003). However, it does not separate out errors of measurement from shared variance. The extracted components tend to overestimate the linear patterns of relationships among sets of variables (Pett et al. 2003). The retention of components with eigenvalues greater than 1.0, and varimax rotation of these components is shown to have potentially serious negative consequences, such as invalid or distorted results that may confuse the researcher or mislead readers (Preacher & MacCallum 2003). Principal axis factoring approach, on the other hand, claims that factors should be extracted only from the variances that items share in common (Kline 1996; Pett et al. 2003). PAF analysis can estimate the underlying factors and relies on various assumptions for these estimates to be accurate. This was the method used in this study. Once factors had been extracted oblique rotation was used to discriminate between factors. Oblique rotation was used because the underlying theory of this study suggests that the factors might correlate.

4.4.7 Internal consistency and homogeneity of the measure

Tests for internal consistency and homogeneity were conducted to determine the extent to which the items relating to a particular dimension, tapped only that dimension and no other (Bowling 2002). Item-total correlations were calculated. Cronbach's alpha is based on the average correlations among the items and the number of items in the instrument (Bowling 2002). The alpha statistic should be above 0.7 to ensure the items are tapping the same underlying area of interest. Those which are below 0.1 have a low correlation and can be considered for removal (Nunnally & Bernstein 1994; Bowling 2002; Field 2005). Cronbach's alpha statistic gives an indication of the internal consistency or reliability of a measure. Where it is indicated on analysis that removing an item will result in substantially greater values of alpha then this item may need to be deleted from the scale to improve its reliability (Field 2005).

4.5 Results

4.5.1 Non-Responders

There were 112 non-responders to the questionnaire. Differences of responders and non-responders by age, gender and severity of heart failure were compared using t-tests and chi-square (Tables 4.0–4.1).

Table 4.0 T-test of age and left ventricular function in responders and non-responders (Phase 2)

					t-test	
	Group	N	Mean	SD	95% Confidence Interval of the Difference	Sig
Age	Responders	223	69.46	10.841	(-2.130, +2.920)	.365
	Non-responders	112	69.06	11.548		
Left ventricular function	Responders	223	3.49	1.287	(+.395, +1.020)	.082
	Non-responders	112	2.79	1.527		

Table 4.1 Chi-square test of gender and left ventricular function in responders and non-responders (Phase 2)

	Pearson Chi-Square		
	Value	df	Asymp. Sig. (2-sided)
Gender	.001	1	.980
Left ventricular function	56.716	4	<.001

No statistically significant differences were found between the age and gender of responders or non-responders. Therefore, the two groups were similar in age and gender. There was a significant difference in the severity of heart failure between the responders and non-responders. The responders had overall a more severe reduction in their left ventricular function.

4.5.2 Response rates

Utilising the inclusion criteria of admission to hospital with an objective diagnosis of CHF, 892 patients were identified from discharge coding information; referral from the Cardiac Specialist Nurses and a locally held database of CHF patients. However, this figure was reduced for a number of reasons (Table 4.2).

Table 4.2 Reason for exclusion

Reason for exclusion	Frequency (%) (n=892)
Deceased prior to questionnaire being sent	204 (22.9%)
Duplicate entry	8 (0.9%)
Missing data	9 (1.0%)
Unable to verify diagnosis	300 (33.6%)
Moved out of the area	3 (0.3%)
Unable to give informed consent	23 (2.6%)

Following the above exclusions, 345 questionnaires were sent to participants, (January 2005 – April 2005), 232 were returned (67% response rate). Four respondents deceased after the questionnaire had been sent to them. Three respondents sent back uncompleted questionnaires with explanation letters as to reasons why they felt the questionnaire was inappropriate for them to fill in. Two relatives complained about the inappropriateness of the questionnaire, 223 questionnaires were therefore analysed.

4.5.3 Demographics of respondents

All of the respondents were white; the majority were married males (Tables 4.3-4.4).

Table 4.3 Respondents gender (Phase 2)

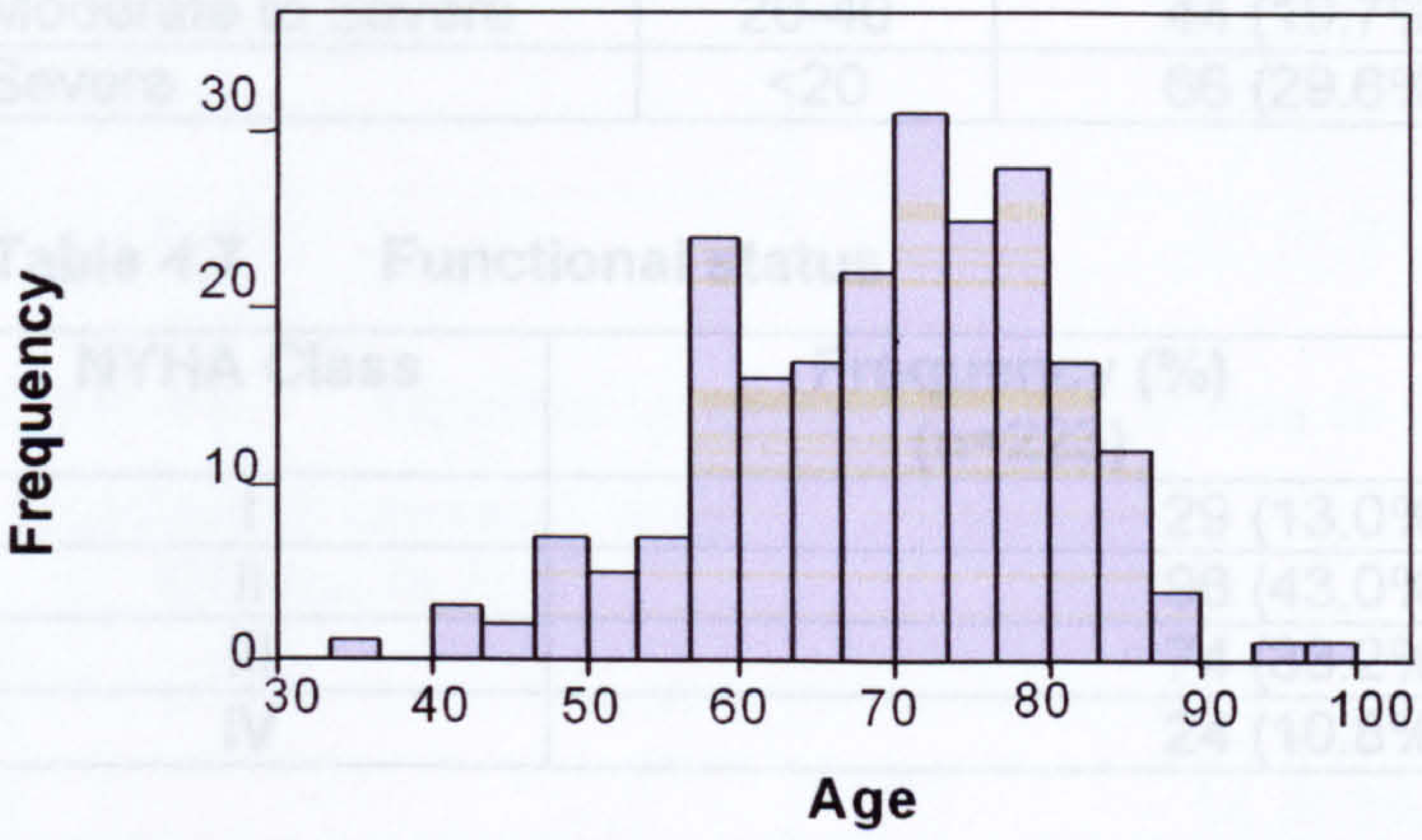
Gender of respondent	Frequency (%) (n=223)
Male	155 (69.5%)
Female	68 (30.5%)

Table 4.4 Respondents marital status (Phase 2)

Marital status of respondent	Frequency (%) (n=223)
Single	14 (6.3%)
Married	143 (64.1%)
Living together as a couple	10 (4.5%)
Widowed	47 (21.1%)
Divorced or separated	9 (4.0%)

The mean age of participants was 69.5years (SD 10.84 years; range 35-99 years). (Figure 4.0).

Figure 4.0 **Histogram of respondent age in years (Phase 2)**



Most of the respondents had changed their work status since they were diagnosed with heart failure due to a number of reasons (Table 4.5). Thirty-nine participants no longer worked as a direct result of having heart failure. This was due to being physically incapable of working because of symptoms of breathlessness and tiredness. Emotional factors were also an issue as individuals were frightened to work in case they were ill.

Table 4.5 **Respondents employment status (Phase 2)**

Employment status of respondent	Frequency (%) (n=223)
Now works part-time	1 (0.5%)
Work in a different job	6 (2.7%)
Work in same job	33 (14.8%)
Retired on health grounds	8 (3.6%)
No longer work due to CHF	39 (17.5%)
Already retired	136 (60.9%)

Severity of heart failure was assessed objectively by echocardiography and subjectively by NYHA; approximately 40% of participants had moderate heart failure (Table 4.6-4.7).

Table 4.6 Severity of heart failure on echocardiogram

Severity of heart failure on echocardiogram	EF%	Total (%) (n=223)
Mild	>50	24 (10.8%)
Moderate	40-50	89 (39.9%)
Moderate to Severe	20-40	44 (19.7%)
Severe	<20	66 (29.6%)

Table 4.7 Functional status

NYHA Class	Frequency (%) (n=223)
I	29 (13.0%)
II	96 (43.0%)
III	74 (33.2%)
IV	24 (10.8%)

Thirty-one respondents (13.9%) had no documented previous medical history of any medical condition within the secondary care setting. However, the remaining 192 respondents (86.1%) either reported a past medical condition when they filled in the questionnaire or evaluation of the individual's medical notes revealed a previous medical condition (Appendix 14). One hundred and twenty four respondents (55.6%) were reported to have ischaemic heart disease; this included previous myocardial infarction and angina. Other categories of past medical history were: cardiac surgery, including coronary artery bypass surgery and valvular surgery (7.2%); diabetes (15.7%); respiratory disease, including Chronic Obstructive Pulmonary Disease, asthma and bronchitis (6.3%); musculoskeletal problems, including arthritis and knee problems (3.6%); cardiomyopathy (4.5%); and other medical conditions including arrhythmias (mainly atrial fibrillation), stroke, renal failure and hypertension (35.0%).

Most participants had been admitted to hospital prior to their last admission on one to five occasions or more (Table 4.8). Only 23 respondents (10.3%) had not been admitted to hospital previously. The main reason for admission was due to heart failure, 106 (47.5%), and 94 (42.2%) respondents were admitted for other illnesses. One hundred and sixty seven (74.9%) respondents had not visited or called their GP because of heart failure prior to this admission. (This does not include visits for prescriptions) (Table 4.9).

Table 4.8 Number of previous hospital admissions

Number of previous hospital admissions	Frequency (%) (n=223)
0	23 (10.3%)
1	83 (37.2%)
2	46 (20.6%)
3	28 (12.6%)
4	14 (6.3%)
5	7 (3.1%)
More than 5	22 (9.9%)

Table 4.9 Number of visits/calls to GP due to CHF

Number of contacts with GP due to CHF	Frequency (%) (n=223)
0	167 (74.9%)
1	28 (12.6%)
2	14 (6.3%)
3	6 (2.7%)
4	5 (2.2%)
5	2 (0.9%)
More than 5	1 (0.4%)

A cross tabulation of NYHA class and number of admissions to hospital show that those participants with NYHA class II and III had the most admissions to hospital (Table 4.10 & Figure 4.1). Further analysis of the data in which the admissions are collapsed to less than or equal to one or above one admission reveals a statistically significant difference (Table 4.11 & table 4.12).

Table 4.10 Cross tabulation of NYHA class and number of admissions to hospital with heart failure.

	NYHA Class Frequency (%)				Total
Number of admissions to hospital with heart failure	I	II	III	IV	
0	4 (17.4%)	11 (47.8%)	6 (26.1%)	2 (8.7%)	23 (100%)
1	13 (15.7%)	38 (45.8%)	25 (30.1%)	7 (8.4%)	83 (100%)
2	2 (4.3%)	20 (43.5%)	21 (45.7%)	3 (6.5%)	46 (100%)
3	5 (17.9%)	9 (32.1%)	8 (28.6%)	6 (21.4%)	28 (100%)
4	2 (14.3%)	5 (35.7%)	4 (28.6%)	3 (21.4%)	14 (100%)
5	0 (0%)	5 (71.4%)	2 (28.6%)	0 (0%)	7 (100%)
> 5	3 (13.6%)	8 (36.4%)	8 (36.4%)	3 (13.6%)	22 (100%)
Total	29 (13.0%)	96 (43.0%)	74 (33.2%)	24 (10.8%)	223 (100%)

The admissions were all to hospital for heart failure

Figure 4.1 Number of admissions to hospital with heart failure categorised by NYHA class

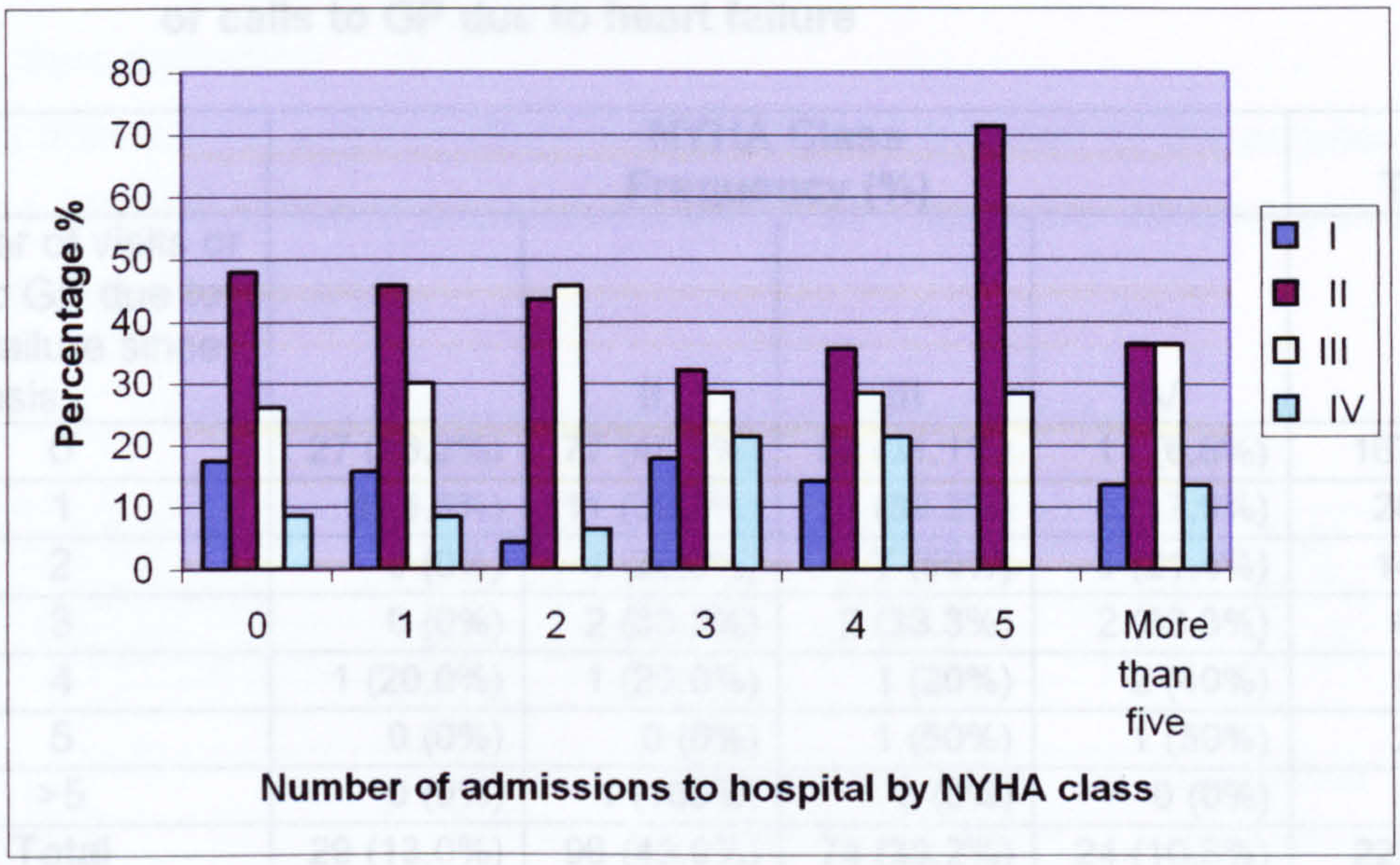


Table 4.11 Number of admissions to hospital categorised by NYHA Class collapsed down.

		NYHA Class Frequency (%)				Total
		I	II	III	IV	
Number of admissions to hospital	<1	17 (16.5%)	49 (47.6%)	29 (28.2%)	8 (7.8%)	103 (100%)
	>1	12 (10.0%)	47 (39.2%)	45 (37.5%)	16 (13.3%)	120 (100%)
Total		29 (13.0%)	96 (43.0%)	74 (33.2%)	24 (10.8%)	223 (100%)

Table 4.12 Spearman correlation of NYHA class and number of admissions to hospital with heart failure.

		NYHA Class
Number of admissions to hospital	Correlation Coefficient	.161
	Sig. (2-tailed)	.016

The Spearman correlation shows that there is a significant relationship between NYHA class and the number of hospital admissions which is significant at the 0.05 level.

A cross tabulation of NYHA class and number of contacts with GP shows the majority of participants do not visit or call their GP and of those who do are in class

II and III (Table 4.13 & Figure 4.2), but the differences were not statistically different (Table 4.14).

Table 4.13 Cross tabulation of NYHA class and number of visits or calls to GP due to heart failure

	NYHA Class Frequency (%)				Total
Number of visits or calls to GP due to heart failure since diagnosis	I	II	III	IV	
0	27 (16.2%)	77 (46.1%)	52 (31.1%)	11 (6.6%)	167 (100%)
1	1 (3.6%)	11 (39.3%)	11 (39.3%)	5 (17.9%)	28 (100%)
2	0 (0%)	4 (28.6%)	7 (50%)	3 (21.4%)	14 (100%)
3	0 (0%)	2 (33.3%)	2 (33.3%)	2 (33.3%)	6 (100%)
4	1 (20.0%)	1 (20.0%)	1 (20%)	2 (40%)	5 (100%)
5	0 (0%)	0 (0%)	1 (50%)	1 (50%)	2 (100%)
>5	0 (0%)	1 (100%)	0 (0%)	0 (0%)	1 (100%)
Total	29 (13.0%)	96 (43.0%)	74 (33.2%)	24 (10.8%)	223 (100%)

Figure 4.2 Number of visits or calls to GP due to heart failure categorised by NYHA Class

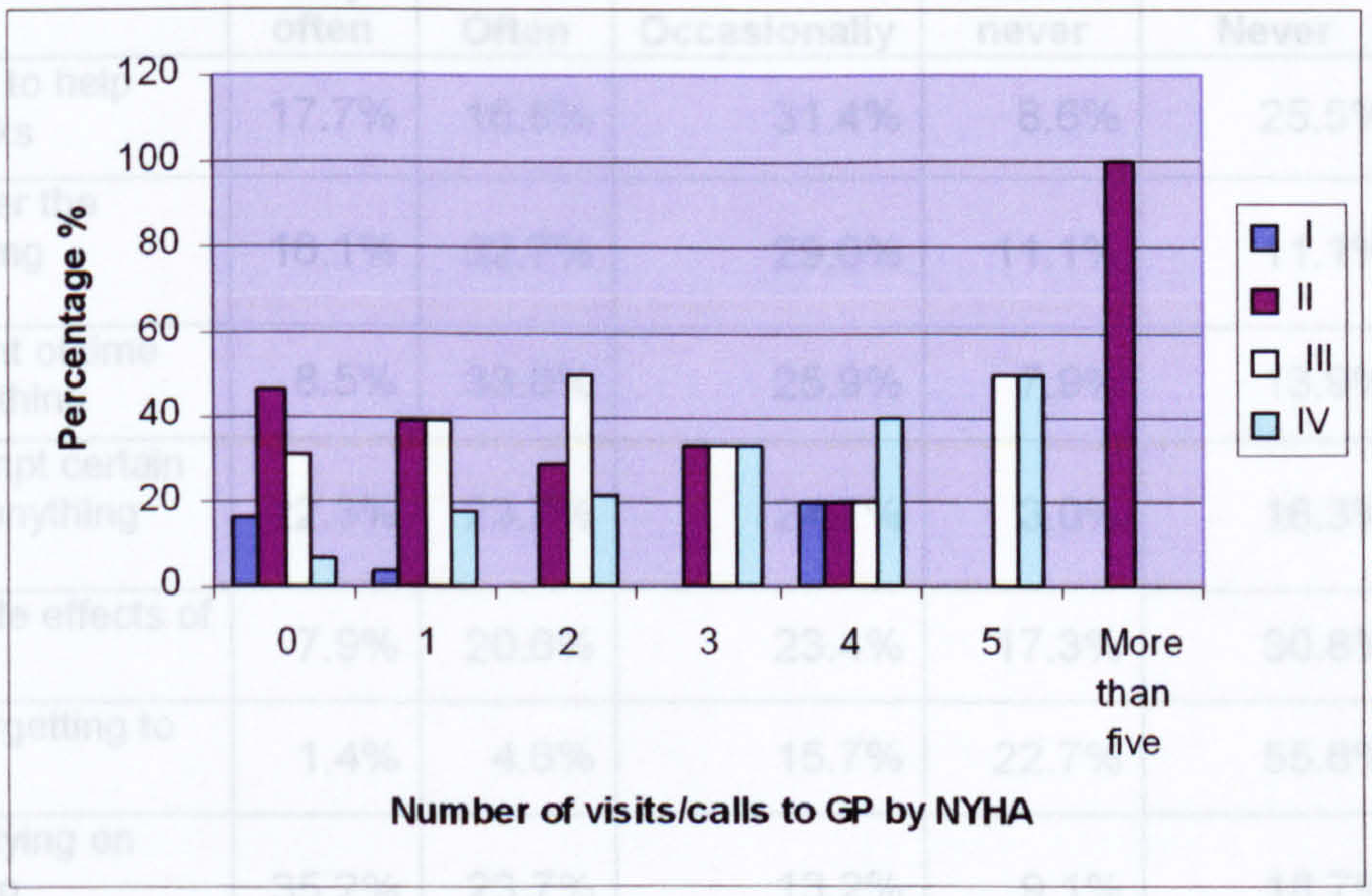


Table 4.14 Spearman correlation of NYHA and number of visits or calls to GP due to heart failure.

		Value	Approx. Sig.
Ordinal by Ordinal	Spearman Correlation	.271	<.001
N of Valid Cases		223	

The Spearman correlation shows that there is a statistically significant association between the samples at <0.001, but the correlation is <.3 so it is not really meaningful.

4.5.4 Item reduction

Results from the focus group interviews have been integrated for the purpose of this analysis. The proportion of respondents who gave a response alternative to an item was calculated (table 4.15).

Table 4.15 Frequencies for response alternatives (Phase 2)

Question 1 & 7	Excellent	Very Good	Good	Fair	Poor
Describe your health	2.2%	8.5%	26.9%	45.7%	16.6%
Describe breathing now	4.1%	11.4%	34.2%	38.4%	11.9%

Question 2	Much better	Somewhat better	The same	Somewhat worse	Much worse
Health compared to last admission	24.2%	33.2%	25.1%	14.3%	3.1%

Question 3 & 4	Very often	Often	Occasionally	Almost never	Never
Needed someone to help with chores or tasks	17.7%	16.8%	31.4%	8.6%	25.5%
Needed to consider the implications of doing something	16.1%	32.7%	29.0%	11.1%	11.1%
Limited the amount of time spent doing something	8.5%	33.8%	25.9%	7.9%	13.9%
Not dared to attempt certain things for fear of anything going wrong	22.3%	23.7%	24.7%	3.0%	16.3%
Concern about side effects of medication	7.9%	20.6%	23.4%	17.3%	30.8%
Concern about forgetting to take medication	1.4%	4.6%	15.7%	22.7%	55.6%
Concern about relying on medication to keep symptoms under control	35.2%	23.7%	13.2%	9.1%	18.7%
Concern about relying on others to organise medication	13.3%	8.7%	6.0%	9.6%	62.4%

Table 4.15 Frequencies for response alternatives (Phase 2) (continued)

Question 5	Much less than other adults	Somewhat less than other adults	About the same as other adults	Somewhat more than other adults	Much more than other adults
Think through activities before doing them	1.5%	3.5%	20.8%	38.6%	35.6%
Restricted in what activities can be done	2.9%	5.3%	14.8%	35.4%	41.6%
Careful in what activities are done	3.3%	3.8%	15.6%	38.4%	38.9%
Take longer to perform activities	1.9%	2.4%	16.5%	33.5%	45.8%
Often feel a failure	5.8%	7.5%	29.5%	28.9%	28.3%
Avoid doing certain activities	2.5%	5.4%	15.8%	33.5%	42.9%
Struggle to do certain activities	3.9%	3.4%	19.0%	28.8%	44.9%
Symptoms influence what activities can be done	2.5%	3.9%	12.8%	36.5%	44.3%

Table 4.15 Frequencies for response alternatives (Phase 2) (continued)

Question 6, 9, 10, 12, 14, 15	Very often	Often	Occasionally	Almost never	Never
Felt breathless/puffed out	24.7%	14.2%	29.7%	20.5%	11.0%
Breathless/puffed out when still or inactive	4.5%	11.4%	29.5%	25.0%	29.5%
Breathless/puffed out when active	24.8%	20.6%	26.6%	17.9%	10.1%
Felt unduly tired	23.2%	31.4%	29.1%	11.4%	5.0%
Symptoms have interrupted everyday family activities	2.3%	10.2%	24.1%	23.6%	9.8%
Going out of the house is stopped due to symptoms	11.9%	14.2%	24.3%	16.5%	33.0%
Symptoms have caused cancellation or change of plans at the last minute	6.1%	10.3%	26.3%	16.4%	40.8%
Symptoms have caused tension or arguments in the home	5.1%	8.8%	19.4%	15.2%	51.6%
Worried about symptoms	14.6%	15.5%	33.8%	17.8%	18.3%

Question 8	0	1	2	3	4	5	6	7	8	9	10
How much feeling breathless/puffed out made life difficult	13.5%	10.7%	9.8%	7.9%	7.4%	11.6%	9.8%	13.0%	7.0%	5.6%	3.7%

Question 11	Not limited at all	Sometimes limited	Often limited	Always limited
Eating/drinking limited due to breathlessness	68.5%	23.2%	4.9%	3.4%
Walking around limited due to breathlessness	27.7%	31.0%	25.4%	16.0%
Sleeping limited due to breathlessness	61.5%	26.3%	8.3%	3.9%
Talking limited due to breathlessness	57.0%	26.6%	12.1%	4.3%

Table 4.15 Frequencies for response alternatives (Phase 2) (continued)

Question 13	Yes	No
Other symptoms	49.8%	50.2%

Question 16	Yes	No	Don't know
Personality changed	37.4%	44.6%	18.0%

Question 17	Not limited at all	Sometimes limited	Often limited	Always limited	Not applicable
Going out for drink/meal	34.7%	21.3%	8.3%	11.6%	24.1%
Going shopping	32.1%	27.6%	15.4%	16.7%	8.1%
Hobbies	29.5%	11.4%	17.1%	17.1%	24.8%
Socialising	34.7%	21.6%	11.7%	15.0%	16.9%
Work	9.6%	9.6%	1.4%	10.0%	69.4%
Holidays	21.0%	11.2%	8.4%	17.3%	42.1%
Sexual relationship	10.7%	5.1%	9.3%	20.1%	54.7%

Table 4.15 Frequencies for response alternatives (Phase 2) (continued)

Question 18	0	1	2	3	4	5	6	7	8	9	10
Frightened about things	30.2%	14.9%	10.7%	7.0%	7.0%	5.1%	7.0%	7.4%	4.2%	2.3%	4.2%
Frustrated with myself	**15.1%**	**7.3%**	**6.9%**	**6.4%**	**6.9%**	**10.6%**	**9.2%**	**8.7%**	**10.6%**	**6.4%**	**11.9%**
Annoyed/angry with people	35.0%	10.6%	11.1%	6.5%	7.8%	5.5%	4.6%	5.5%	4.6%	2.3%	6.5%
Often wonder "Why me"	41.9%	9.2%	6.9%	4.1%	5.1%	6.5%	.5%	1.8%	7.4%	4.1%	12.4%
Feel dependent on other people	23.9%	6.9%	9.6%	6.0%	6.4%	11.0%	5.0%	7.3%	6.4%	4.6%	12.8%
If I saw another specialist they would say there is nothing wrong with me	62.9%	13.1%	1.9%	1.9%	2.8%	3.8%		1.9%	4.2%	.9%	6.6%
Difficulty concentrating	28.4%	8.7%	8.7%	8.3%	6.4%	8.7%	4.1%	6.9%	8.3%	6.9%	4.6%
Sleeping habits have changed	24.7%	7.4%	8.4%	5.6%	5.6%	8.8%	4.2%	9.8%	9.8%	6.0%	9.8%
Family/partner worry	12.8%	3.8%	3.8%	5.2%	4.7%	7.1%	4.7%	7.1%	10.0%	11.8%	28.9%
I feel capable of doing things but I can't	**10.6%**	**6.0%**	**7.4%**	**2.8%**	**3.2%**	**11.1%**	**6.9%**	**8.8%**	**14.7%**	**12.0%**	**16.6%**
More conscious of the simple things in life	**17.1%**	**2.4%**	**5.2%**	**6.6%**	**6.6%**	**9.5%**	**7.1%**	**8.5%**	**15.6%**	**9.5%**	**11.8%**
Anxious about dying	43.0%	12.6%	7.9%	4.7%	5.1%	5.1%	1.9%	3.3%	2.8%	4.7%	8.9%
Other people stop me doing certain things even though I think I could manage	27.8%	6.9%	6.0%	8.8%	7.4%	11.1%	6.5%	6.0%	8.8%	5.6%	5.1%
Forget I have heart failure and try to do things like I used to do	20.7%	7.4%	4.1%	7.8%	4.6%	12.0%	8.3%	6.9%	9.2%	4.6%	14.3%

Items were included in the CHFQoL questionnaire when at least one response alternative was between 0.20 and 0.80 (Streiner & Norman 2003). The majority of items fell within this range with the exception of 4 items: Questions 8 a Likert scale which states "how much during the past 2 weeks has feeling breathless/puffed out made life difficult", 18b a Likert scale which states "I get frustrated with myself", 18j a Likert scale which states "In my mind I feel capable of doing things but I can't" and 18k a Likert scale which states "I am more conscious of the simple things in life". These items were removed from the analysis. Demographic items (Additional information about you and your family) and question 2 which compared health now with health before last admission to hospital were not included in the analysis.

4.5.5 Factor analysis of the CHFQoL measure

Factor analysis represents a complex array of structure analysing procedures used to identify the interrelationships among a large set of observed variables and then, through data reduction, to group a smaller set of these variables into factors that have common characteristics (Nunnally & Bernstein 1994; Watson 1998). Factor analysis of the items was conducted on the data (n=223). Principal axis factoring (PAF) was undertaken using SPSS 12.0.1 for windows on 51 items. A sample size of 223 could be argued, is not enough for the number of items. Therefore, the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) was calculated; the data value was .886. Values of .6 and above are required for good factor analysis (Tabachnick & Fidell 2001). Bartlett's test of sphericity tests the null hypothesis that there is no relationship among the items (Pett et al. 2003), this test was significant, indicating there are some relationships between the items to be included in the analysis.

Initial analysis of the data to establish the factor extraction was determined by retaining all factors with eigenvalues greater than 1. This identified 11 potential factors. Before extraction, 51 items within the data set were identified (Appendix 15).

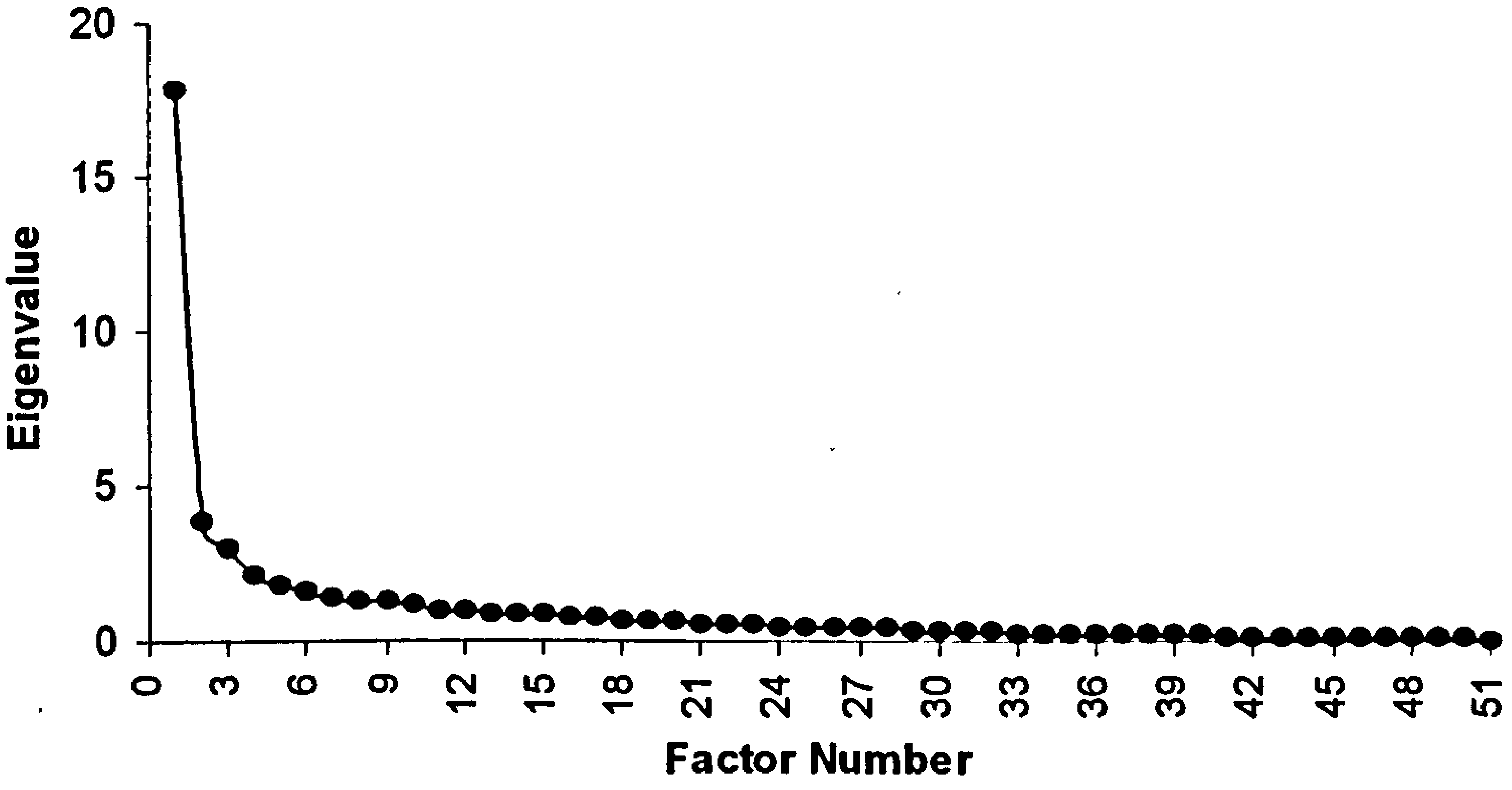
Graphing of the eigenvalues shows the relative importance of each factor. Using the point of inflexion of the curve as a cut off point for selection of factors, the scree plot suggests there are four factors (Figure 4.3) (Cattell 1966; Cattell & Vogelmann 1977; Child 1990; Preacher & MacCallum 2003). However, it could be argued that the scree plot (figure 4.3), clearly suggests there are two factors. Factor analysis specifying the extraction of two factors was undertaken. The results of this analysis were uninterpretable and did not show any relationship (Appendix 16). However, the data does appear to load well on one factor. This factor could be quality of life and therefore suggests that the tool is measuring quality of life. Table 4.16 shows the analysis.

Table 4.16 Factor analysis of one factor (Phase 2)

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings(a)
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	17.131	37.242	37.242	16.648	36.190	36.190	16.002
2	3.661	7.959	45.201	3.316	7.208	43.399	8.774

Factor one explains 36.19% of the variance.

Figure 4.3 Scree plot of PAF (Phase 2)



Replication of the analysis specifying the extraction of four factors was undertaken (Table 4.17).

Table 4.17 Factor analysis specifying four factors (Phase 2)

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings(a)
Factor	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	**17.792**	**34.886**	**34.886**	**17.361**	**34.042**	**34.042**	**15.565**
2	**3.833**	**7.516**	**42.402**	**3.518**	**6.898**	**40.940**	**9.913**
3	**2.960**	**5.805**	**48.207**	**2.371**	**4.649**	**45.589**	**5.129**
4	**2.173**	**4.261**	**52.468**	**1.658**	**3.250**	**48.839**	**5.163**
5	1.808	3.545	56.013				
6	1.543	3.026	59.039				
7	1.419	2.782	61.821				
8	1.277	2.504	64.325				
9	1.236	2.423	66.749				
10	1.183	2.320	69.068				
11	1.010	1.981	71.050				
12	.974	1.910	72.960				
13	.904	1.772	74.732				
14	.840	1.646	76.378				
15	.806	1.581	77.959				
16	.772	1.514	79.473				

48.84% of the total variance was explained by four factors.

Factor rotation using oblique rotation was used because there was good reason to suppose that the underlying factors could be related in theoretical terms (Preacher & MacCallum 2003; Field 2005). Rotation of factors improves the interpretability of factors by maximizing the loading of each variable on one of the extracted factors whilst minimizing the loading on all other factors (Preacher & MacCallum 2003). A factor loading cut-off of 0.1 was used in the analysis. A factor loading cut off of 0.3 was used in the interpretation. The analysis grouped items on factors by size of loading to facilitate interpretation in PAF four-factor solution (direct oblimin) rotation. The pattern matrix (Appendix 17) revealed three items, which did not load; "Other people stop me doing certain things even though I think I could manage," "Concern about forgetting to take medication," "Forget I have heart failure and try to do things like I used to do." These were removed at this point. Subsequent EFA of the data (Appendix 18) revealed two items, which did not load well on several factors. These were "Often feel a failure" and "Concerned about relying on others to organise medication." These two items were removed. Exploratory factor analysis was undertaken again on 46 items (Appendix 19). 51.24% of the total variance was now explained by four factors. Table 4.18 shows the pattern matrix with all five items removed.

Table 4.18 PAF (four-factor solution) pattern matrix (Phase 2)

	Factor			
	Symptoms	Activity levels	Psychosocial	Emotions
Q10 Breathless/puffed out when active	.921			
Q6 Felt breathless/puffed out	.827			
Q9 Breathless/puffed out when still or inactive	.824	-.126		
Q11b Walking around limited due to breathlessness	.789		.110	
Q14a Symptoms have interrupted everyday family activities	.786			
Q14c Symptoms have caused cancellation or change of plans at the last minute	.771			
Q3a Needed someone to help with chores or tasks	-.741			.150
Q7 Describe breathing now	.737			
Q11a Eating/drinking limited due to breathlessness	.708	-.126		
Q12 Felt unduly tired	.704			
Q3c Limited the amount of time spent doing something	.658	.280		-.155
Q14b Going out of the house is stopped due to symptoms	.646		.236	
Q11d Talking limited due to breathlessness	.642			-.116
Q3b Needed to consider the implications of doing something	.612	.277		-.114
Q11c Sleeping limited due to breathlessness	.576			.129
a Frightened about things	.553			.401
Q3d Not dared to attempt certain things for fear of anything going wrong	.523	.284		
Q15 Worried about symptoms	.521		.135	.336
Q1 Describe your health	.438		.362	
Q4c Concern about relying on medication to keep symptoms under control	.418	.129		
I Anxious about dying	.409			.363
h Sleeping habits have changed	.406	.101		.305
I Family/partner worry	.392	.202		.167
Q17b Going shopping	.382	.109	.375	.112
e Feel dependent on other people	.370	.227	.133	.160
Q4a Concern about effects of medication	.357	.131		.104
Q13 Other symptoms	.317	.116	.106	

Table 4.18 PAF (four-factor solution) pattern matrix (Phase 2) (continued)

Q5h Symptoms influence what activities can be done		.879		
Q5c Careful in what activities are done		.871		-.133
Q5b Restricted in what activities can be done		.810		
Q5d Take longer to perform activities		.810		
Q5a Think through activities before doing them		.800		
Q5g Struggle to do certain activities		.769	.138	
Q5f Avoid doing certain activities		.768	.161	
Q16 Personality changed		.313		.283
Q17d Socialising			.765	.181
Q17a Going out for drink/meal		-.132	.690	.100
Q17c Hobbies	.143		.628	
Q17f Holidays			.582	
Q17g Sexual relationship		.105	.558	-.167
Q17e Work			.429	
c Annoyed/angry with people	.177	.214		.636
Q14d Symptoms have caused tension or arguments in the home	.211	.165		.510
d Often wonder "Why me"	.142	.161	.114	.392
f If I saw another specialist they would say there is nothing wrong with me		-.184		.390
g Difficulty concentrating	.263	.105	.221	.365

The pattern matrix revealed four factors: Factor 1 seems to represent symptoms, factor 2 seems to represent activity levels, factor 3 seems to represent psychosocial aspects and factor 4 seems to represent negative emotions. The structure matrix confirms the representation of the four factors. It is more complex to interpret but identifies the interrelationship between the four factors (Appendix 20). Analysis of the structure matrix reveals the correlation of each of the factors.

The correlation matrix (Table 4.19) shows the correlation coefficients between the factors.

Table 4.19 Factor correlation matrix (Phase 2)

Factor	Symptoms 1	Activity Levels 2	Psychosocial 3	Negative Emotions 4
Symptoms 1	1.000	.450	.432	.295
Activity Levels 2	.450	1.000	.276	.179
Psychosocial 3	.432	.276	1.000	.026
Negative Emotions 4	.295	.179	.026	1.000

As predicted from the structure and pattern matrix all the factors are interrelated to some degree. Factor 1 (Symptoms) seems to relate to factor 2 (activity levels) and factor 3 (psychosocial), and to a lesser extent to factor 4 (emotions). Factor 2 has a relationship with factor 3 and a lower correlation to negative emotions. However, factor 3 does not seem to correlate with factor 4, who have low correlation coefficients indicating little or no relationship. Evidence of the relationship between symptoms and activity levels has been shown in Chapter 2. Where participants described feeling frustrated as a result of the reaction of other people towards them or because of how the symptoms limited their activity levels.

Expectedly, symptoms are reported as highly correlated to physical function. The low correlation between psychosocial factors and negative emotions is surprising. However, this may be partly explained by the participants ability to view changes in psychosocial factors as an opportunity to develop coping mechanisms which in turn allow the individual to live with CHF. This is echoed in a study by Bosworth (2004) which found changes in patients' lives attributed to CHF were not always considered deficiencies; rather, methods of coping with CHF were identified as important attributes representing possible opportunities for personal growth. Evidence of this was reported in Chapter 2, where participants described changes in physical ability, which impacted on all areas of their life. A number of coping mechanisms were discussed by participants, which were employed to reduce the symptoms, which any physical activity would create. A number of participants in Chapter 2 discussed emotional consequences of physical aspects of dealing with heart failure including; avoidance and struggling to do activities. During the analysis of the transcripts of Phase 1, some participants described aspects related to lifestyle. They found that their social life had been reduced; where as others found it had been enhanced.

4.5.6 Internal consistency and homogeneity of the CHFQoL measure

Item-total correlations describe the extent to which each of the items within a domain are correlated and the extent to which each item within a domain correlates with the total score for that domain (Bowling 2002). Item-total correlations were calculated using Spearman's rank correlation; rho or Pearson's product-moment correlation coefficient. Item-total correlations of below 0.3 are usually rejected in the development of measurement scales (Bowling 2002).

Item-total correlations were calculated. Items below the value 0.3 have not been deleted because they do not substantially increase the overall alpha. Discussion with members of the RAG decided that no further items should be removed therefore, adding to the content validity of the measure.

Internal consistency was calculated using Cronbach's alpha. Reverse-phased items were transformed to ensure they were scored appropriately during reliability analysis (Appendix 21 shows the item-total statistics). Cronbach's alpha was calculated for each factor, this is shown in Table 4.20.

Table 4.20 Reliability analysis – Phase 2

	Factor 1	**Factor 2**	**Factor 3**	**Factor 4**
Cronbach's alpha	.932	.917	.860	.844

The overall alpha for each factor is above 0.8, which indicates excellent reliability, which is recommended by Bland & Altman (1997) for clinical scales.

Cronbach's alpha was also calculated for the overall scale, this is shown in table 4.21.

Table 4.21 Reliability analysis of complete measure (Phase 2)

Cronbach's Alpha	N of Items
.925	46

The overall alpha for the entire measure indicates excellent reliability which indicates the CHFQoL tool is measuring quality of life.

4.6 Discussion

4.6.1 Part I

The purpose of the study in part one was to identify patients, partners and experts' opinion regarding the acceptability and practicality of the CHFQoL questionnaire. This resulted in modifications to the layout and questions, to make the questionnaire easier to understand and complete.

The CHFQoL questionnaire was designed with mostly closed questions and open-ended questions used minimally. General questions were asked initially followed by specific questions. Demographic questions were included at the end of the questionnaire. Participant evaluation of the questionnaire illustrated that most individuals found the questionnaire was "very easy" or "quite easy" to complete.

The methodology utilised in this phase enabled the research objectives to be met, namely the identification of any misunderstandings in item wording through piloting of the CHFQoL questionnaire; to determine the acceptability and practicality of this measure.

4.6.2 Part II

The study in part two aimed to develop the CHFQoL questionnaire and investigate the item selection/reduction, homogeneity and factor analysis of the measure in a population of patients admitted to hospital with chronic heart failure.

Response alternatives and item-total correlations were used to select items. The majority of items had at least one response alternative within the accepted range (0.2-0.8), with the exception of four items. These items were removed from future questionnaires. The internal consistency of the items and the overall measure was high with Cronbach's alpha being excellent (above 0.8).

Exploratory factor analysis of the items (n=46) revealed four factors: symptoms, activity levels, psychosocial and negative emotions. Factor 1 describes symptoms (breathlessness, puffed out, breathless when active, breathless when inactive, tiredness, fear), these seem to have a large influence on other factors and appear to be warning signs when activity levels (Factor 2), are limited, struggle to be undertaken or restricted. Previous studies have found that patients experience various frequencies and intensity of symptoms (Rector 2005). Their symptoms can affect their ability or willingness to do various physical, mental, social or role functions (Rector 2005). Symptoms and functional limitations may lead to negative psychological reactions (Rector 2005). The intention to undertake activities seems to lead to issues associated with negative emotions (Factor 4; fear, anger, tension, concern, anxiety), and re-enforces the effect of warning signs. Psychosocial aspects (Factor 3; limited ability to undertake shopping, work, holidays and social events) seem to be an issue when they are influenced by the other factors. Five items were removed on the basis of the factor analysis at this phase.

Factor analysis also revealed that there was one factor which seemed to load well for each item. This describes quality of life which is the underlying assessment of the measure.

Psychological and functional status, and health perception have been found to be significant factors associated with HRQL in CHF patients (Lee et al. 2005). Previous research has found that preserved or improved physical function is important for patients with CHF, because remaining independent and active plays an important part in their life (Winters 1999; Bosworth et al. 2004). Patients experience varying frequency and intensity of symptoms of CHF (Friedman 1997; Bennett et al. 2000; Moser & Worster 2000; Rector 2005). Patients with heart failure face unacceptably high numbers of symptoms and significant symptom burden. Symptom prevalence and symptom burden have been found to be the greatest predictors of diminished HRQL (Zambroski et al. 2005). Symptoms affect the individual's ability and willingness to undertake various physical, mental, social and role functions (Rector 2005). Assessment of the effects of symptoms, functional limitations, and psychological distress on a patient's health-related quality of life determines the clinical significance from the patient's perspective (Rector 2005). Symptoms are important for the interpretation and understanding of patients with CHF. They reflect either the disease itself or the patient's perception of the illness (Ekman et al. 2005).

In this study most of the respondents had changed their work status since being diagnosed with CHF. This was mainly due to physical incapacity due to symptoms of breathlessness and tiredness and the associated negative emotional aspects of fear and worry. These findings are in accordance with the literature (Zambroski et al. 2005

The methodology utilised in the phase enabled the research objectives to be met, namely the selection of items to include within the measure. Piloting of the CHFQoL questionnaire allowed for the identification of any misunderstandings in item wording. Utilising a prospective sample enhanced the sample size and reduced bias owing to recall and memory distortions.

4.7 Summary

This study established the item reduction, internal consistency, factor analysis and homogeneity of the CHFQoL questionnaire in a chronic heart failure population. The CHFQoL questionnaire for testing in the next phase (Phase 3) therefore comprised of 46 items and demographic evaluation items.

Chapter 5 – Validation of the CHFQoL measure in a chronic heart failure population

5.0 Introduction

This Chapter describes a quantitative study (Phase 3 of the research) to test the psychometric properties of the CHFQoL questionnaire presented in Chapter 3, in a chronic heart failure population. The face validity was found to be acceptable (Chapter 3). In order to further validate the measure, criterion validity, convergent validity, and discriminant validity need to be assessed. The research in this Chapter aimed to assess the reliability and validity of the CHFQoL measure.

5.1 Background

As discussed previously in Chapter 1, there has been a growth in the measurement of health-related quality of life as an indicator of health outcome (Fallowfield 1996; Wilson & Cleary 1995). Chronic heart failure (CHF) has been no exception to this, where the goal of treatment is not only to prolong life, but also to relieve symptoms and improve physical and psychological function.

Most of the widely used measures are not patient-centred - this is a result of the development process. Many questionnaires restrict a patient's choice and do not capture the full range of psychosocial concerns which individual's feel contribute to their quality of life (Bosworth et al. 2004). These limitations will reduce the accuracy and usefulness of expert driven health-related quality of life tools because they do not measure what the patient thinks or feels contributes to their quality of life. Therefore, the purpose of this research is to develop a measure which reflects the individual's health-related quality of life (HRQL).

Evidence in the literature suggests that CHF significantly impairs HRQL, causes emotional distress, adversely affects daily life activities and routines (Juenger et al. 2002; Johansson et al. 2004) and imposes a heavy burden of symptoms (Dargie & McMurray 1994). Individuals with CHF describe the negative effects of having CHF (Johansson et al. 2004; Stull et al. 1999; Juenger et al. 2002; Bennett et al. 2003). The limiting of activities may be due to behavioural avoidance as a coping strategy, even though this has been linked to higher mortality in this group of people (Denollet & Brutsaert 1998; Murberg et al. 2001; Murberg et al. 2004). A link between extreme health anxiety and physical limitation among people with CHF has been reported (Murberg et al. 1997; Doering et al. 2004) which suggests that fear and anxiety may promote behavioural avoidance and reduce physical functioning due to a sense of inadequacy in performing activities of daily living (Franks et al. 1992). Relatively little is known about the effect of gender on HRQL as few women enrol in heart failure studies. Epidemiologic and clinical studies have suggested gender related differences in the incidence and the prognosis of CHF (Galvao et al. 2006). Some gender specific studies have found that women with CHF report worse HRQL. Therefore, men and women may have different values regarding which factors are important to perceive a good HRQL (Johansson et al. 2006). Men have a higher incidence of heart failure, but the overall prevalence rate is similar in both sexes, since women survive longer after the onset of heart failure (Stromberg & Martensson 2003). Women tend to be older when diagnosed with heart failure and more often have diastolic dysfunction than men (Stromberg & Martensson 2003).

However, at all ages heart failure is more common in men than women (Cowie et al. 1999). Older, frailer CHF patients might have more impairment of HRQL than their younger, and otherwise fitter counterparts; there are few studies that directly examine this (Weir et al. 2006). A small study of women with CHF found that age alone does not affect HRQL (Varvaro et al. 1999). It is estimated that there are approximately 350,000 men aged 45 years and over living in the UK with CHF and approximately 300,000 women (Petersen et al. 2002). The prevalence of heart failure also varies with deprivation (Ellis et al. 2001).

Chapter 2 of this thesis involved exploratory in-depth interviews which were carried out with patients with chronic heart failure in order to generate a large number of candidate questionnaire items.

This study is the third phase of a three-stage piece of research to develop and validate a chronic heart failure specific health-related quality of life measure. In this study validity of the measure was undertaken by testing the validity of the measure with other recognised HRQL measures (SF-36 & MLHFQ). There is no gold standard measure in this area however; the SF-36 was identified as the best available gold standard measure and the MLHFQ was identified as the best measure developed for use in a CHF population, for the assessment of criterion validity of the CHFQoL questionnaire. There are several limitations of these measures as previously described (Chapter 1).

5.1.1 Validity

Validity of a measure is the extent to which a test measures what it is intended to measure (Streiner & Norman 2003).

5.1.1.1 Criterion validity

The assessment of criterion validity refers to the ability of a measure to correspond with other measures seen to be gold standards (Jenkinson & McGee 1998). In reality, very few studies can claim to have evaluated criterion validity; gold standard measures are hard to find in this area of research. However, the SF-36 is the most widely and extensively used generic measure due to its reliability and validity across numerous population samples (McHorney et al. 1993; McHorney et al. 1994; Berry & McMurray 1999; Dunderdale et al. 2005). Criterion validity is usually divided into two types: concurrent validity and predictive validity (Streiner & Norman 2003). Concurrent validity is found when the results from two measures administered at the same time are compared (Streiner & Norman 2003). Predictive validity is when the results of a measure predict a future event or outcome (Jenkinson & McGee 1998). Concurrent validity was assessed in this study by administering the CHFQoL questionnaire, SF-36 and MLHFQ (Rector et al. 1987).

5.1.1.2 Construct validity

Without a true "gold standard" measure, construct validity was also assessed. Construct validity is a way of assessing validity by investigating if the measure really is measuring the theoretical construct it is supposed to be measuring. A measure is valid for measuring an attribute if the attribute exists and variations in the attribute causally produce variation in the measurement outcomes (Borsboom et al. 2004). It is concerned with the patterns of relations of an HRQL measure with other more established measures (Cronbach & Meehl 1955; Fitzpatrick et al. 1992). Many measures of health are designed to tap some aspect of a hypothetical construct (Streiner & Norman 2003). Hypotheses are generated and questionnaires are tested to determine if they actually reflected these prior hypotheses (Jenkinson & McGee 1998). If the expected relationship is found, then the hypothesis and the measure are sound (Streiner & Norman 2003).

Construct validity can be broken down into two sub-categories: Convergent validity and discriminant validity. Convergent validity is the actual general agreement among ratings, gathered independently of one another, where measures should be theoretically related. For convergent validity to exist, the results from a measure would be related to other variables and measures of the same construct.

> *"Discriminant validity is the lack of a relationship among measures which theoretically should not be related."* (Jenkinson & McGee 1998).

Discriminant validity assumes that the results will not be related when the questionnaire data are compared to other data measuring distinct and unrelated concepts (Jenkinson & McGee 1998).

> *"To understand whether a piece of research has construct validity, three steps should be followed. First, the theoretical relationships must be specified. Second, the empirical relationships between the measures of the concepts must be examined. Third, the empirical evidence must be interpreted in terms of how it clarifies the construct validity of the particular measure being tested."* (Carmines & Zeller 1991).

Construct validity was tested in this study by exploring the statistical relationship between physical function, symptoms, psychosocial and emotions and CHFQoL scores. The hypothesis was theoretically driven as it was informed by the analysis of patient data in Phase 2 (Chapter 4). The factor analysis in Chapter 4 identified four factors of physical function, symptoms, psychosocial and emotion aspects. The hypotheses were generated from evidence in the literature on HRQL in CHF presented in Chapter 1.

Construct validity was also tested in this study by administering the angina diary (Lewin et al. 1995; Lewin et al. 2002) with the CHFQoL questionnaire. Correlations were made between those respondents with angina and those without angina.

5.1.1.3 Reliability

Reliability of a measure is its ability to produce the same results under the same conditions. It can be examined by test re-test reliability. Reliability is often assessed by examining internal reliability and inter-rater reliability for interview based assessments. The homogeneity of a scale is assessed through item-total correlations; items should be moderately correlated with each other. Internal consistency and homogeneity were the forms of reliability evaluated in this study. Test re-test reliability was not evaluated in this study as this population has a high mortality rate and it was not possible to give a substantial number of respondents a second questionnaire.

5.1.1.4 Hypotheses

Epidemiological literature suggests that there is no single sociodemographic profile that predicts the burden of CHF.

The following hypotheses were tested to determine if the CHFQoL measure made a synthesis that had not been found before:

- Gender and social class will not be significant predictors of symptoms
- Gender and social class will not be significant predictors of activity levels
- Gender and social class will not be significant predictors of psychosocial aspects
- Gender and social class will not be significant predictors of emotion.

It was hypothesised that the CHFQoL questionnaire would correlate with the MLHFQ and SF-36.

Not only should the CHFQoL questionnaire correlate with related variables, it should not correlate with dissimilar, unrelated ones (Streiner & Norman 2003). It was hypothesised that:

- The CHFQoL questionnaire is independent of angina pain.

5.2 Method

5.2.1 Design

A cross-sectional survey design was used to test the psychometric properties of the CHFQoL questionnaire. The questionnaire was administered to patients by a Heart Failure Nurse working in each of the recruitment centres, when they attended an appointment with the nurse. A retrospective approach was chosen because of the advantage of speed within the limited timescales and to allow for the results of the study to be available as soon as the data is collected and analysed (Moser & Kalton 1996). A disadvantage of this approach includes memory bias. Employing a prospective design may have minimised this. To achieve a larger sample size for this study may have taken several months to complete prospectively and was not feasible within the study time constraints.

Face-to-face administration of the questionnaire was chosen to ensure that the Heart Failure Nurse could give out the questionnaire and discuss any concerns the participants had prior to completing and returning the questionnaires. The Heart Failure Nurse could also encourage the participants to take part in the study.

The questionnaires were self-administered as this is less costly than interviews and allows for a larger sample over a wider geographical area to be targeted (Robson 1995). Self-administration of the questionnaires in this study also allowed respondents to have more time to think carefully about their answers, and data collection and analysis was relatively quick (Robson 1995; Russell 2002).

5.2.2 Sampling strategy

The sample for the questionnaire consisted of individuals with chronic heart failure discharged from; Northern Lincolnshire & Goole Hospitals NHS Trust, which consists of Scunthorpe General Hospital, Goole District Hospital and Diana Princess of Wales Hospital Grimsby; Doncaster East Primary Care Trust; and United Lincolnshire Hospitals NHS Trust of which Lincoln County Hospital collaborated. Recruitment took place over six months. Participants were identified retrospectively from discharge coding information, referral from the Cardiac Specialist Nurses/Heart Failure Nurse. No post event time limit exclusion criteria were used, in order to recruit a broad cross-section of respondents.

5.2.2.1 Eligibility criteria

Patients were included in the study if they fit the following criteria:

- Diagnosed as suffering from chronic heart failure (ICD-9 code 428.0)
- Objective measurement of left ventricular function confirmed by echocardiography or angiography.

5.2.2.2 Exclusion criteria

Patients were excluded from the study if they fit the following criteria:

- Poor command of the English language, due to evaluation being via questionnaire
- Suffered from any disease or condition that may have impaired their ability to give informed consent
- Had a terminal disease requiring palliation i.e. cancer.

5.2.3 Sample size calculation

The primary objective of this study was to validate the measure rather than estimate values or compare groups using the measure. For this reason a sample size calculation was based on the expectation that 100 patients will be recruited. The main analysis was to calculate correlation coefficients to examine the level of agreement between measures. A sample size of 100 provided 80% power (alpha = 0.05, 2 tailed) to detect a population correlation (rho) of 0.28.

5.2.4 Resources

SF-36 (Ware & Sherbourne 1992) (Appendix 22): is a valid and reliable generic health-related questionnaire that measures the full range of health domains, including well-being and personal evaluations of health. It is the most widely and extensively used generic measure, which has been found to be reliable and valid across numerous population samples.

MLHFQ (Rector et al. 1987) (Appendix 23): is a 21-item disease-specific health-related questionnaire that measures the effect heart failure has on the domains of emotional and physical health. The MLHFQ has been extensively used in clinical trials and has excellent psychometric properties. MLHFQ is freely available.

The angina diary has been used in research to elicit frequency and severity of angina in cardiac patients (Lewin et al. 1995; Lewin et al. 2002), (Appendix 24). Permission to use the Angina Diary from the original authors was granted.

A patient information sheet (Appendix 25) was sent with the postal questionnaires to explain the purpose of the study, along with a covering letter (Appendix 26) and a pre-paid envelope.

The CHFQoL questionnaire (Appendix 27): was developed in phase one of this research, (Chapter 3) and is the intellectual property of the author.

5.2.5 Ethical approval

Multi-centre Research Ethics Committee approval was given in November 2005 to undertake the postal survey. Permission to use the MLHFQ was given in July 2005. Permission from the authors of the Angina Diary was given in July 2005. Permission to use the SF-36 was given in August 2005. Research Governance approval was granted for each site between December 2005 and January 2006.

Anonymity of each participant was assured by using a unique study number for each individual. Only the researcher was able to identify the respective participant and questionnaire. Data regarding participant information and their unique study number was stored using an Excel spreadsheet.

5.3 Procedure

5.3.1 Sample

The Heart Failure Nurses working in each of the recruitment centres identified the patients that met the study entry criteria when they saw them at their next follow up appointment. No post event time limit exclusion criteria were used, in order to recruit a broad cross-section of respondents. A total sample of CHF patients admitted to hospital with decompensation of heart failure, being seen by a Heart Failure Nurse was selected to be representative of this population.

5.3.2 Materials

Prospective participants received a study information sheet, covering letter, a battery of questionnaires (CHFQoL, MLHFQ, SF-36), Angina diary and a pre-paid envelope. Consent was inferred by return of the questionnaires. If a response was not given within two weeks this was classed as a non-response.

Further items were developed based upon suggestions from the Multi-centre Research Ethics Committee and RAG members. These concerned Part 2 – "Extra information about you and your family". The following were added to the questionnaire in order to explore any correlation with social class and HRQL; Question 5 occupational status, the questionnaire utilised the socio-economic classification for the 2001 census (Rose & Pevalin 2001), Question 6 – postcode. Data was also collected regarding the length of time the individual had been aware of a diagnosis of heart failure, (Question 7).

5.4 Analysis of the data

Data were entered into an Excel spreadsheet and imported into a statistical computer package SPSS version 12.0.1 (SPSS Inc. 2003). A sample of 10% of the data was checked with the original questionnaires. The analytic method used will be presented as demographics; item analysis and scale analysis.

The relationships between the scales were examined using correlation together and calculating correlation statistics - (Pearson product moment where the assumptions are satisfied, Spearman's Rho where not). A moderate to high correlation was expected because the CHFQoL questionnaire, MLHFQ and SF-36 have similar items regarding HRQL. The correlation of items with their scale totals and the internal consistency (Cronbach's alpha) reliability of scales was also determined.

Correlations do not provide any information about the predictive power of variables (Field 2005). Regression analysis fits a predictive model to the data and uses that model to predict values of the dependent variable from one or more independent variables. Simple regression was used to predict an outcome from a single predictor variable and multiple regression was used to predict an outcome from several variables (Tabachnick & Fidell 2001; Field 2005).

5.4.1 Demographics

Descriptive statistics will be used to identify frequency distributions, cumulative frequency distributions, central tendency, and dispersion of scores expressed as the range and standard deviation.

5.4.2 Missing data

The data were explored for patterns of missing values. Missing data was substituted by the mean value for other items. Mean values were used if less then 50% of the items were missing. This decision was taken based on discussion with RAG members, observations of the distribution of responses and prior knowledge of the author (Tabachnick & Fidell 2001). Data analysis was repeated using complete cases to compare the analysis of cases with estimated missing values to identify any differences.

5.4.3 Item reduction

The frequency of endorsement was calculated using the same condition applied in Chapter 4. Only items with endorsement rates for response alternatives between 0.20 – 0.80 were used (Streiner & Norman 2003). No items were removed at this stage based on these criteria. (Appendix 28) shows the frequency of response alternatives).

5.4.4 Reliability

The internal consistency of the CHFQoL questionnaire was assessed using Cronbach's alpha.

5.5 Results

5.5.1 Accuracy of the data

Accuracy of the data was agreed by calculating double data entry on a 10% random sample of people who had completed the CHFQoL questionnaire and the SF-36 questionnaire (n=7) using the following formula:

$$\frac{\text{Number of agreements}}{\text{Number of agreements + Number of disagreements}}$$

(Robson 1995)

The proportion of agreement is shown in table 5.0. There were four errors in the CHFQoL questionnaire data entry, which was resolved by double-checking the data entry to find the wrong data.

Table 5.0 Accuracy of data entry (Phase 3)

Questionnaire	Proportion of agreement
CHFQoL	0.998
SF-36	1.00

5.5.2 Demographics

Sixty-eight patients responded to the battery of questionnaires: 58 male and 10 female, the age range was 36 – 87 years (mean 70 years) (Figure 5.0). All the respondents were white and most of them were married or living with someone (Table 5.1).

Figure 5.0 Histogram of respondent's age in years (Phase 3)

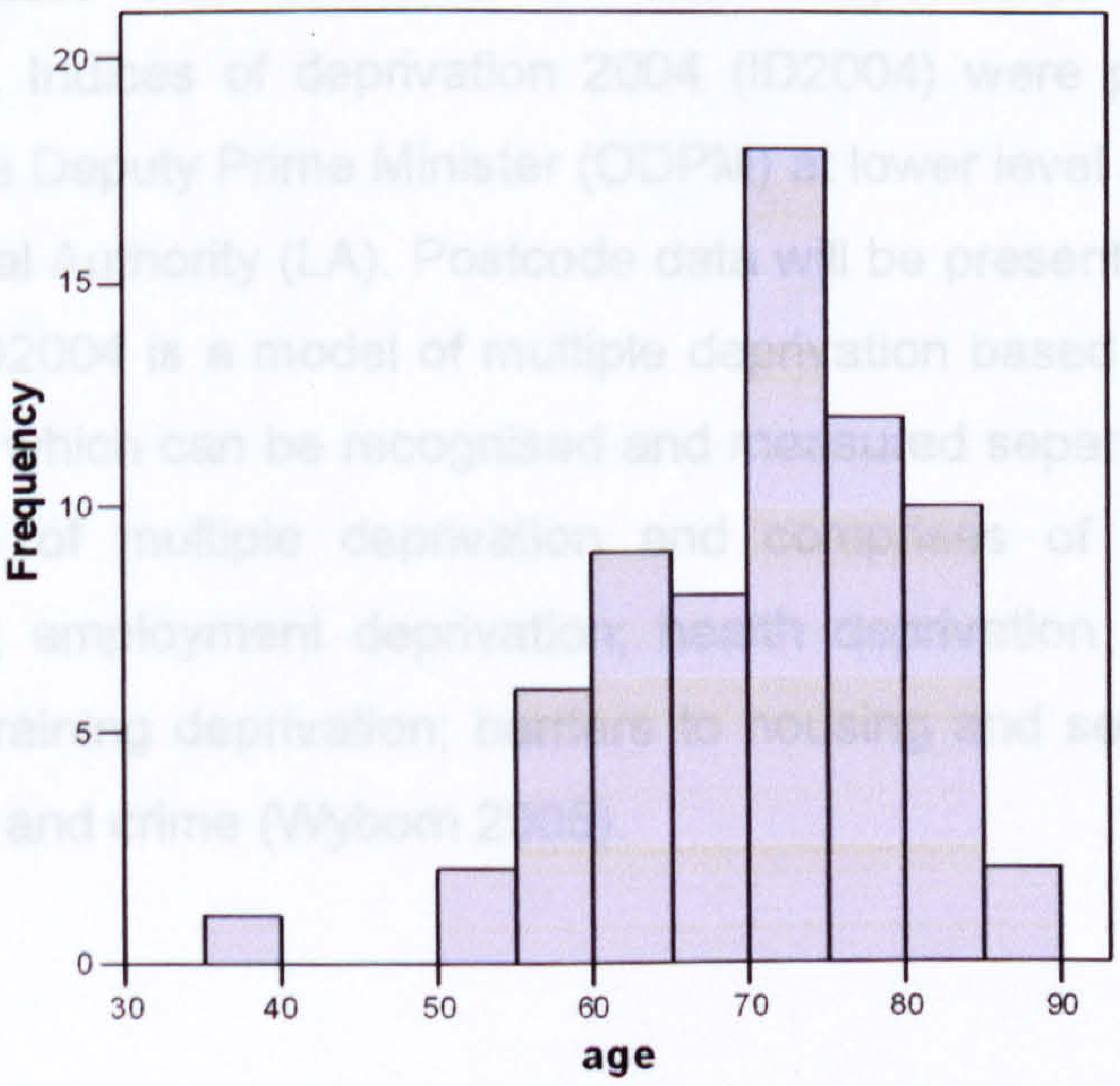


Table 5.1 Respondent's marital status

Marital status of respondent	n (%)
Single	1 (1.5%)
Married	52 (76.5%)
Living together as a couple	4 (5.9%)
Widowed	7 (10.3%)
Divorced or separated	4 (5.9%)
Total	68 (100%)

Social class of the respondents was assessed using the Socio-Economic Classification (SEC) for the 2001 census. Most respondents were from social class 3 & 7 (skilled manual & routine occupations) (Table 5.2).

Table 5.2 Respondent's occupational status

Occupation (social class)	n (%)
Professional (1)	10 (14.7%)
Junior managers in smaller organisations (2)	7 (10.3%)
Skilled manual and clerical (3)	21 (30.9%)
Smaller employer with fewer than 25 employees, plus the self-employed (4)	3 (4.4%)
Supervisor of those in routine and semi-routine occupations (5)	6 (8.8%)
Semi-routine occupations (6)	0
Routine occupations (7)	14 (20.6%)
Never worked or long-term unemployed (8)	7 (10.3%)
Total	68 (100%)

Postcode data was collected on each respondent to determine indices of deprivation. Indices of deprivation 2004 (ID2004) were published in 2004 by the Office of the Deputy Prime Minister (ODPM) at lower level Super Output Area (SOA) and by Local Authority (LA). Postcode data will be presented by electoral ward. The model of ID2004 is a model of multiple deprivation based on distinct dimensions of deprivation which can be recognised and measured separately. The overall index is a measure of multiple deprivation and comprises of seven domains: Income deprivation; employment deprivation; health deprivation and disability; education, skills and training deprivation; barriers to housing and services; living environment deprivation and crime (Wyborn 2005).

Figure 5.1 Map of Local Authorities

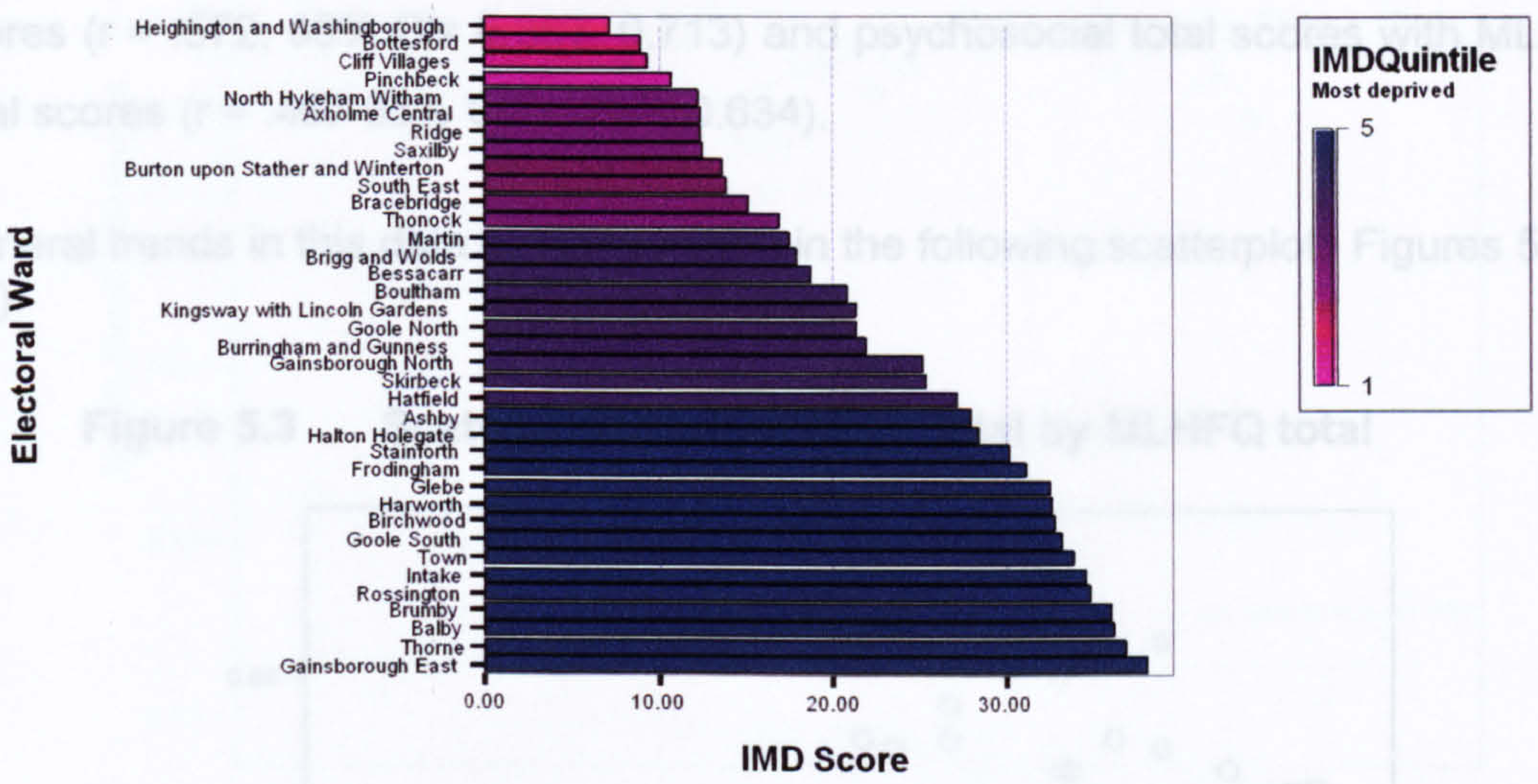
Data regarding overall IMD scores are presented by electoral ward and national quintile (Figure 5.2). The domains of education, employment, health and income are illustrated in Appendix 29.

Table 5.3 shows the Local Authorities and electoral ward in which the respondents reside.

Table 5.3 Local Authority and Electoral Ward

Local Authority	Electoral Ward
Bassetlaw	Harworth
Boston	Skirbeck
Doncaster	Balby Bessacarr Hatfield Intake Rossington South East Stainforth Thorne
East Lindsey	Halton Holegate
East Riding of Yorkshire	Goole North Goole South
Lincoln	Birchwood Boultham Bracebridge Glebe
North Kesteven	Cliff Villages Heighington and Washingborough Martin North Hykeham Witham
North Lincolnshire	Ashby Axholme Central Bottesford Brigg and Wolds Brumby Burringham and Gunness Burton upon Stather and Winterton Frodingham Kingsway with Lincoln Gardens Ridge Town
South Holland	Pinchbeck
West Lindsey	Gainsborough East Gainsborough North Saxilby Thonock

Figure 5.2 IMD 2004 score by electoral ward by national quintile



The Index of multiple deprivation 2004 is an overall index which combines the seven domain scores. The overall IMD 2004 score and the individual domain scores follow a similar pattern of deprivation. The majority of deprived electoral wards tend to be located in Doncaster. The most deprived electoral wards are Gainsborough East, Thorne, Balby, Brumby and Rossington. The least deprived electoral wards are Heighington and Washingborough. With the exception of Heighington and Washingborough, Bottesford, Cliff Villages and Pinchbeck the other electoral wards fall within the most deprived areas in England.

5.5.3 Reliability

Internal consistency of the CHFQoL questionnaire was measured using Cronbach's alpha statistic.

The alpha for the questions relating to symptoms (alpha = 0.850), activity levels (alpha = 0.950), and psychosocial (alpha = 0.786) were above 0.7, which indicates excellent reliability (Kline 1999). However, the alpha for emotion questions was low (0.578).

5.5.4 Criterion validity

The CHFQoL questionnaire, MLHFQ questionnaire and SF-36 have similar items regarding, general health, symptoms, activity levels, psychosocial aspects and emotion. Results revealed significant correlations in all aspects of the CHFQoL questionnaire and MLHFQ. The MLHFQ total scores are significantly correlated with symptoms, r = .734, (95% CIs 0.601, 0.827), emotion r =.691 (95% CIs 0.542, 0.797) and activity levels r =.600 (95% CIs 0.422, 0.733), (all *p* <0.01). There were also significant relationships between general health scores and MLHFQ total scores (r = .572, 95% CIs 0.387, 0.713) and psychosocial total scores with MLHFQ total scores (r = .467 95% CIs 0.258, 0.634).

General trends in this data can been seen in the following scatterplots Figures 5.3-5.6).

Figure 5.3 Scatterplot of symptoms total by MLHFQ total

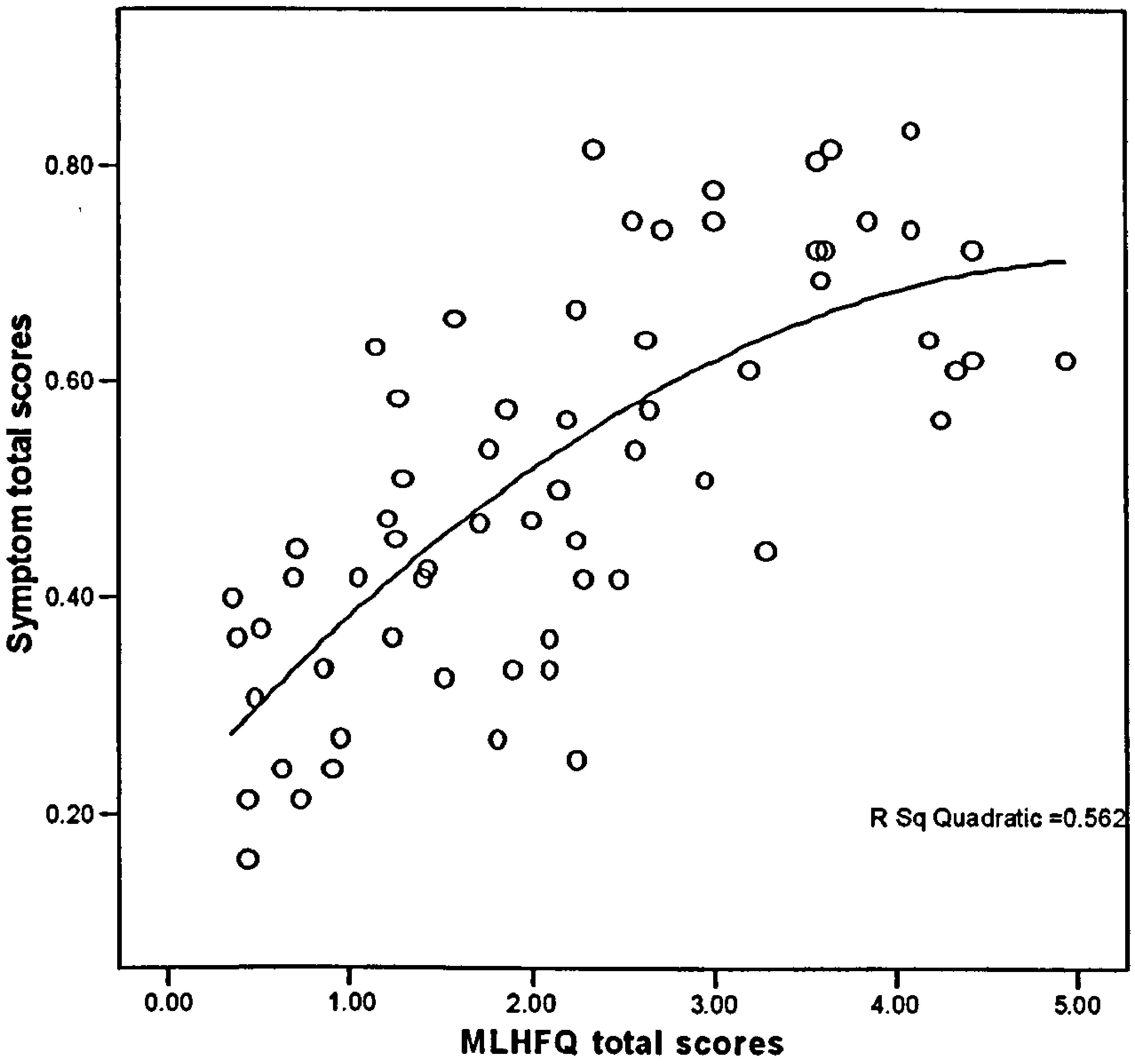


Figure 5.3 shows there is a positive relationship between worsening symptoms and high scores on the MLHFQ. High scores on the MLHFQ indicate worsening CHF.

Figure 5.4 Scatterplot of activity level total by MLHFQ total

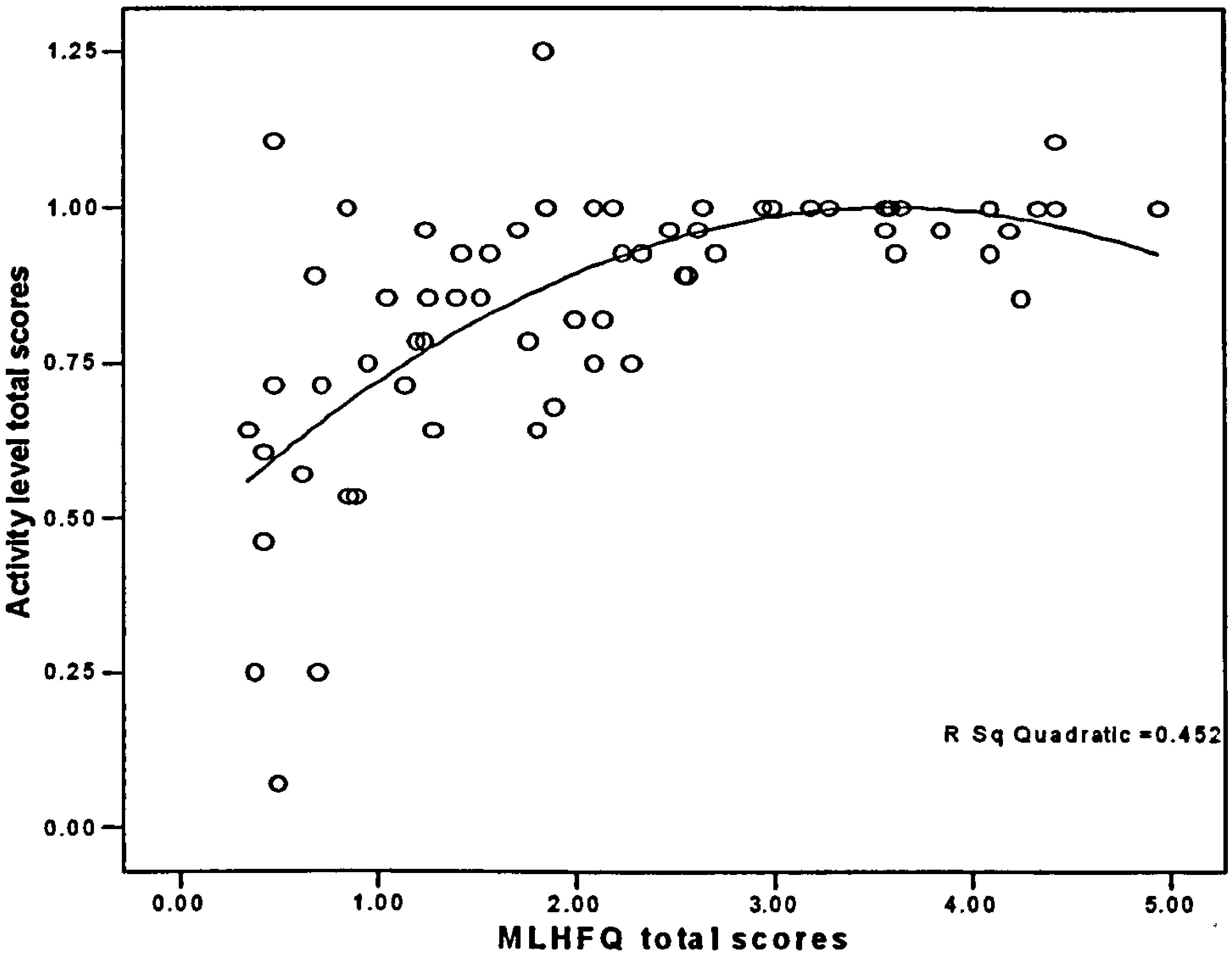


Figure 5.4 shows there is a relationship between activity level totals and the MLHFQ total score; as activity level total scores increase (indicating reduced activity levels) the MLHFQ total score increases (indicating worse heart failure). There are no cases having low activity level totals and high MLHFQ total scores. The data in this scatterplot also indicates two trends that should be taken note of. First, there is a non-linear relationship between the two variables. Second, there appears to be a heteroscedastic relationship between the measures, suggesting that a further factor may be altering the relationship (Miles et al. 1999).

Figure 5.5 Scatterplot of psychosocial total by MLHF total

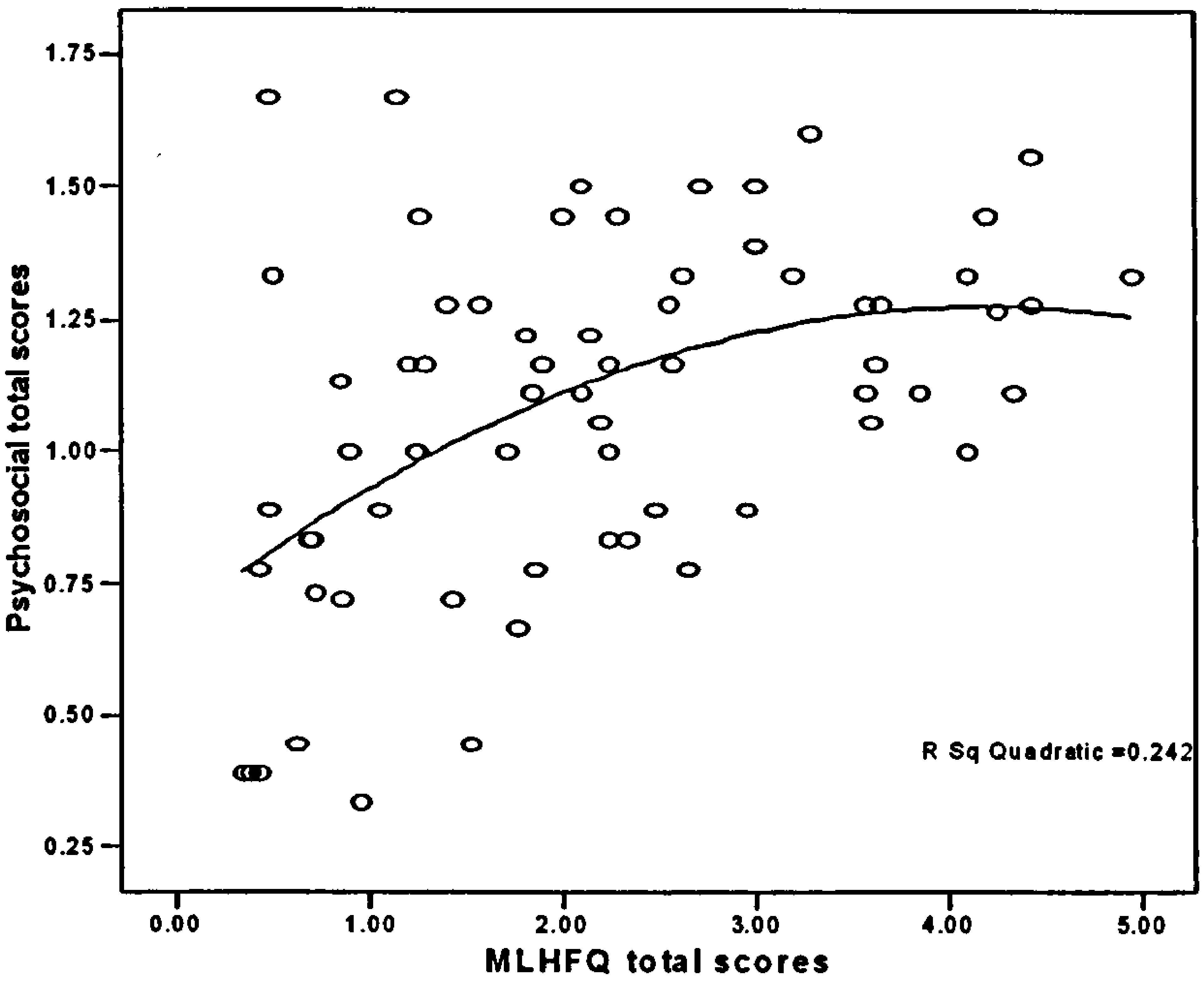
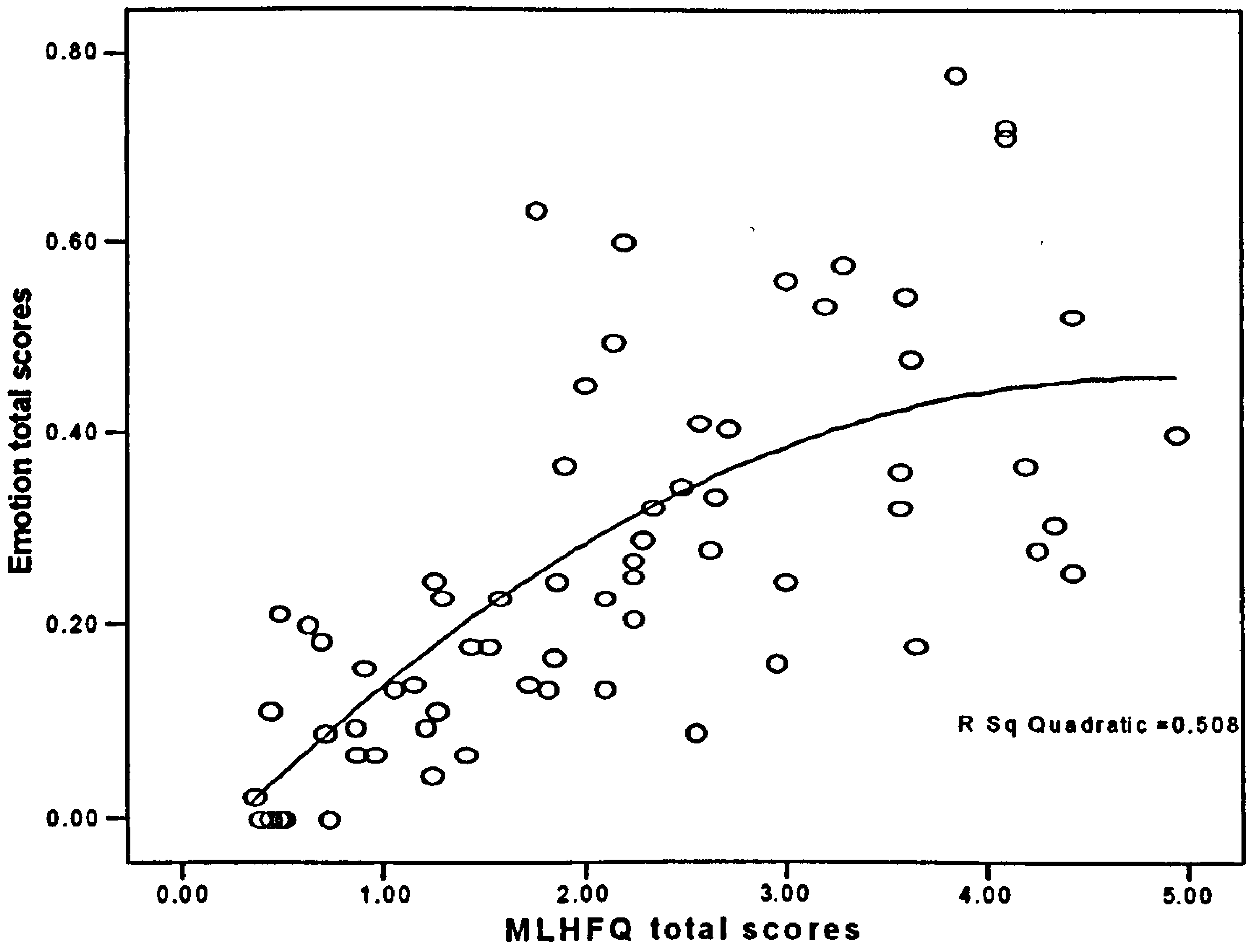


Figure 5.5 shows a positive relationship between increasing psychosocial total scores and an increase in the MLHFQ total scores indicating that individuals who score high on the MLHFQ questionnaire have found that their heart failure has interfered with their ability to carry out psychosocial aspects of their life. This relationship is also heteroscedastic.

Figure 5.6 Scatterplot of emotion total by MLHFQ total



Finally figure 5.6 also shows a relationship between increasing MLHFQ total scores and increases in emotion total scores. There is a non-linear relationship between the two variables and there appears to be a heteroscedastic relationship between the measures.

Results from the CHFQoL questionnaire and the SF-36 revealed significant correlations in each of the SF-36 domains and the CHFQoL questionnaire (Table 5.4). Correlation statistics for the CHFQoL questionnaire general health domain were analysed with question one of the SF-36 (general health domain), (Table 5.4). The remaining general health items from the SF-36 were analysed separately due to the items on the CHFQoL questionnaire having reversed phrased questions which produce negative correlations (Appendix 30). Negative correlations in each of the domains were due to reverse phrased questions.

Table 5.4 Correlation statistics of CHFQoL scale scores and their corresponding SF-36 scale scores (Phase 3)

		CHFQoL General Health (Q1)	CHFQoL Symptom total score	CHFQoL Activity Level total score	CHFQoL Psychosocial total score	CHFQoL Emotion total score
General Health SF-36	Pearson Correlation	**.791****	-.439**	.321**	.355**	.300*
Vitality SF-36	Pearson Correlation	-.008	**-.321***	.322**	.051	.118
Bodily Pain SF-36	Pearson Correlation	.949	**.553****	.358**	-.286*	-.240
Physical Functioning SF-36	Pearson Correlation	-.506**	.694**	**-.531****	-.610**	-.320*
Role Physical SF-36	Pearson Correlation	-.597**	.576**	**-.416****	-.438**	-.364**
Role Emotion SF-36	Pearson Correlation	-.371**	.401**	-.162	**-.321***	-.454**
Social Functioning SF-36	Pearson Correlation	-.517**	.567**	-.366**	**-.435****	-.395**
Mental Health SF-36	Pearson Correlation	.498**	-.658**	.428**	.260*	**.295***

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

The inter-correlations between the CHFQoL total scores reveal each item is significantly correlated (Table 5.5). Symptom total scores correlate well with all other scores. Psychosocial total scores and emotion total scores do not correlate highly. This was found in chapter 4.

Table 5.5 Inter-correlation of CHFQoL scale scores (Phase 3)

		CHFQoL general health score (Q1)	Symptom total score	Activity level total score	Psychosocial total score
Symptom total score	Pearson Correlation	.516**			
Activity level total score	Pearson Correlation	.321**	.548**		
Psychosocial total score	Pearson Correlation	.344**	.442**	.363**	
Emotion total score	Pearson Correlation	.390**	.538**	.312**	.276*

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

5.5.5 Regression analysis

The data analysis thus far has measured the strength of the association between two measured quantitative variables (Kinnear & Gray 2000). Non-linearity was analysed using simple regression analysis, the dependent variable was activity level total scores and the independent variable was MLHFQ total scores using SPSS.

The scatterplot analysis (figure 5.4) shows non-linearity and heterscedasticity, therefore the non-linear effect was added to the simple regression analysis by computing a new variable which is the square of MLHFQ total score (Table 5.6).

Table 5.6 Overall fit of model with non-linear effect

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.600(a)	.360	.350	.168	.360	36.599	1	65	<.001
2	.672(b)	.452	.435	.157	.092	10.699	1	64	.002

a Predictors: (Constant), MLHFQ Total score.
b Predictors: (Constant), MLHFQ total score squared.

This regression model demonstrates a significant prediction of activity level. Therefore, the non-linearity effect is significant. There is clearly an interaction occurring within the data, which has not been measured. Regression analysis of gender, social class and marital status do not account for the variation (Appendix 31). Table 5.7 shows the parameter estimates which indicate the contribution of

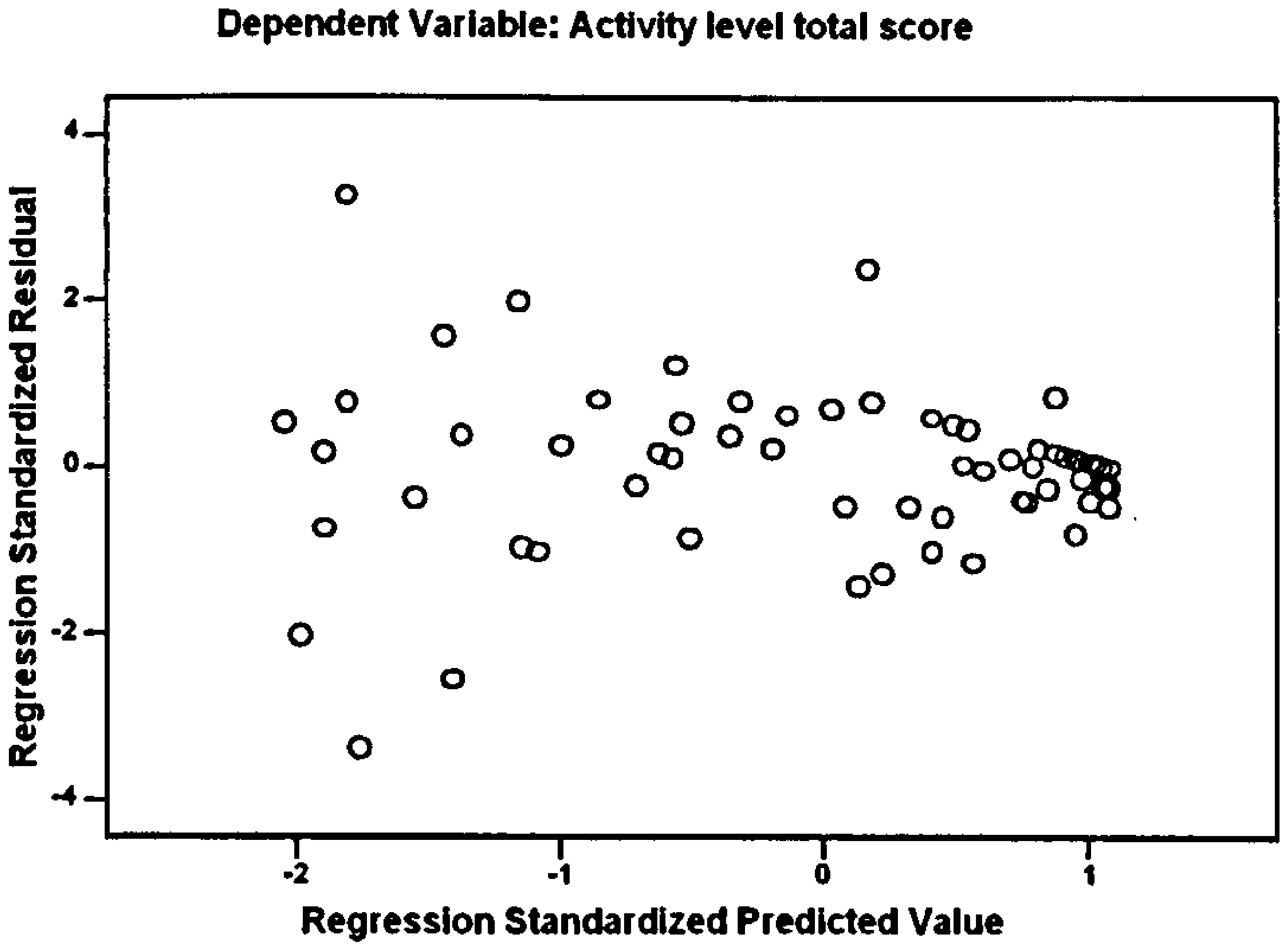
MLHFQ to the regression model. The MLHFQ total scores have made a significant contribution to predicting the outcome. Figure 5.7 checks the assumptions of the model by illustrating heteroscedasticity. The points form a funnel so they become less spread out across the graph. This indicates a decrease in the variance across the residuals.

Table 5.7 Coefficients table

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	.632	.041		15.291	<.001
	MLHFQ total score	.101	.017	.600	6.050	<.001
2	(Constant)	.460	.065		7.053	<.001
	MLHFQ total score	.300	.063	1.787	4.772	<.001
	MLHFQ total scores squared	-.042	.013	-1.225	-3.271	.002

Dependent Variable: activity level total score.

Figure 5.7 Regression plot



Regression analysis of MLHFQ total scores with each of the CHFQoL total scores did not reveal any further variations in the relationships (Appendix 32).

5.5.6 Construct validity

Construct validity was tested by the hypotheses in section 5.1.1.4. The hypothesis states that there will be no relationship between gender and social class with physical function, symptoms, psychosocial and emotional aspects. Comparisons were made for gender on scores for each domain using t-test (Table 5.8 & table 5.10).

Table 5.8 Mean CHFQoL scores by gender (Phase 3)

	Mean scores by CHFQoL domain (SD)			
Gender	Symptom total	Activity level total	Psychosocial total	Emotion total
Male	26.4 (4.0)	23.1 (6.3)	19.0 (6.0)	14.5 (6.9)
Female	24.8 (4.4)	24.9 (7.6)	20.7 (4.8)	15.2 (9.5)

On average women appear more restricted in the psychosocial aspects of their life than were men. Men had more symptoms than women, but seem to be marginally more active than women. There is also a small difference in emotion between men and women, in that women express more emotion than men. Independent samples t-test was calculated which determined no significant difference in these findings (Table 5.9).

Table 5.9 Independent samples t-test of CHFQoL total scores and gender

	Levene's Test for Equality of Variances		t-test for Equality of Means				
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Symptom total score	.145	.704	1.146	61	.256	1.667	1.454
Activity total score	.105	.747	-.790	66	.432	-1.762	2.229
Psychosocial total score	.631	.430	-.778	61	.439	-1.648	2.118
Emotion total score	2.784	.100	-.224	9.432	.828	-.740	3.308

Table 5.10 Mean CHFQoL score by occupation (social class) Phase 3

	Mean scores by CHFQoL domain (SD)			
Occupation (social class)	Symptom total	Activity level total	Psychosocial total	Emotion total
Professional (1)	27.3 (4.2)	22.8 (5.5)	17.5 (6.5)	13.0 (4.6)
Junior managers in smaller organisations (2)	27.0 (4.6)	25.0 (2.6)	19.5 (4.5)	12.7 (4.6)
Skilled manual and clerical (3)	25.8 (4.5)	22.1 (8.7)	19.9 (6.4)	14.3 (7.1)
Small employer with fewer than 25 employees, plus the self-employed (4)	27.7 (2.9)	25.0 (4.4)	18.0 (5.3)	13.0 (6.3)
Supervisor of those in routine and semi-routine occupations (5)	24.7 (2.9)	24.3 (3.6)	22.3 (2.9)	15.5 (5.8)
Routine occupations (7)	26.7 (3.6)	24.0 (3.5)	18.0 (6.8)	12.5 (7.2)
Never worked or long-term unemployed (8)	24.4 (4.6)	24.0 (10.4)	20.0 (4.9)	25.0 (9.9)

All the occupations appear to score equally well on each of the domains of the CHFQoL questionnaire. Interestingly, there appears to be a difference in emotion total scores of never worked or long-term unemployed compared to the other occupational classes.

A one-way ANOVA of occupation with physical function, symptoms, psychosocial and emotional aspects revealed no significant differences in mean scores except for the domain of emotion total (Table 5.11). Post hoc test using Scheffe revealed a significant difference in emotion scores between routine occupations and never worked or long term unemployed (Appendix 33).

Table 5.11 One-way ANOVA of occupation with CHFQoL scores

		Sum of Squares	df	Mean Square	F	Sig.
Symptom total	Between Groups	59.151	6	9.858	.577	.747
	Within Groups	957.167	56	17.092		
	Total	1016.317	62			
Activity level total	Between Groups	80.394	6	13.399	.298	.936
	Within Groups	2743.886	61	44.982		
	Total	2824.279	67			
Psychosocial total	Between Groups	125.653	6	20.942	.585	.741
	Within Groups	2006.283	56	35.826		
	Total	2131.937	62			
Emotion total	Between Groups	773.875	6	128.979	2.836	.017
	Within Groups	2637.909	58	45.481		
	Total	3411.785	64			

All hypotheses were confirmed in the expected direction.

5.5.7 Discriminant & convergent validity

This was assessed by observing the relationship between those respondents who reported angina pain with those who did not report any angina, using the angina diary to measure symptoms of angina. Independent t-tests were performed which revealed significant differences between those individuals who had angina compared to those who did not have angina in terms of symptoms, activity levels and emotion (Table 5.12). There was no significant difference in psychosocial aspects. Therefore discriminant validity of the CHFQoL questionnaire was established with the psychosocial scale. These results revealed that the CHFQoL scale scores of symptoms, activity levels and emotion established convergent validity of the CHFQoL questionnaire.

Table 5.12 **Independent samples t-test**

		t-test for equality of means			
	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Symptom total	3.989	65	<.001	.2020	.0506
Activity level total	3.757	61	<.001	.1489	.0396
Psychosocial total	.484	66	.630	.0487	.1008
Emotion total	2.123	66	.038	.1243	.0586

5.6 Discussion

This study explored the reliability (internal consistency) and validity (criterion and construct) of the CHFQoL questionnaire in a chronic heart failure population.

Strict procedures were followed in conducting item reduction for the CHFQoL questionnaire by calculating frequency of response alternatives as was performed in the previous Phase of research. Response alternatives were within the acceptable range and no items were removed from the CHFQoL questionnaire.

The internal consistency of the CHFQoL questionnaire was high ($\propto = 0.950 - 0.786$) for activity levels, symptoms and psychosocial aspects. The internal consistency for emotion was low ($\propto = 0.578$). However, these results should be interpreted with caution, alpha depends on the number of items on the scale. It is possible to get large values because there are a lot of items on the scale and this scale is small (Cortina 1993; Field 2005).

Imputed data was used when 50% of the items were missing. It is recognised that substitution by the mean will reduce the variance of the variable and can bias the correlation downward or, if the same cases are missing for two variables and means are substituted, correlations can be inflated. Imputation results in the sample size being over-estimated with the variance and standard errors being underestimated. However, analysis of complete cases with cases of estimated missing values did not identify any substantial differences.

Test re-test reliability was not attempted on this group because the population is not stable. A number of respondents with chronic heart failure had deceased over the time period of the research which made it impossible to undertake test re-test in those cases. In future research more then one questionnaire would be sent to the patient initially so that they could return both within a short time frame.

The adverse impact of socioeconomic deprivation on health, and particularly cardiovascular health, is well recognised. Socioeconomic deprivation is associated with higher rates of admission to hospital and fatality in heart failure, but the mechanisms are unclear (McAlister et al. 2001). Evidence in the literature shows that compared with affluent patients, socio-economically deprived patients are 44% more likely to develop heart failure (McAlister et al. 2004). Data in this study shows the majority of electoral wards from which the participants were drawn fall within the most deprived in England.

Criterion validity was used to determine whether the CHFQoL questionnaire was measuring what it was intended to measure. Although no gold standard for HRQL exists, the SF-36 was used as the gold standard in this case. The MLHFQ was also used as it was specifically designed for use in heart failure (Dunderdale et al. 2005). When no gold standards exists, other validation strategies were used, such as construct validity (Guyatt et al. 1993).

In the assessment of criterion validity the results revealed significant correlations between the CHFQoL questionnaire domains and SF-36 subscales (general health, symptoms, activity level, psychosocial and emotion). Similar significant correlations were found between CHFQoL questionnaire and MLHFQ. This suggests that the criterion validity of the CHFQoL questionnaire was established and favourable against the best available gold standard measure.

In the assessment of construct validity all the hypotheses were confirmed. Gender and social class are not significant predictors of symptoms, activity levels, psychosocial aspects and emotion. The life situations for men and women with heart failure are not significantly different.

Discriminant and convergent validity were assessed by comparing individuals with and without angina. It has been shown that the CHFQoL questionnaire demonstrated discriminant validity on the psychosocial domain. The CHFQoL questionnaire also demonstrated convergent validity due to the significant differences between the CHFQoL scores and the angina diary scores. This may be because angina also affects psychological and social functioning and therefore had a similar effect on HRQL. Psychosocial factors that may have an independent role in angina include anxiety, depression and lack of social support (Hemingway & Marmot 1999). Many patients with severe disabling angina even opt to withdraw from daily life, becoming physically inactive, socially isolated and increasing dependant on carers and health providers (Moore et al. 2005), which is similar to that of individuals with CHF.

5.6.1 Strengths of the study

The survey design in this study (Phase 3) met the research objectives of evaluation of the psychometric properties of the new HRQL measure. The evaluation of reliability and validity addressed two of the four essential requirements in the development of a new measure (Streiner & Norman 2003); Practicality of the CHFQoL measure was addressed in Chapter 4. A retrospective approach enabled data to be collected quickly within the timescale.

Self-administered questionnaires were presented to the respondents by the Heart Failure Nurse to increase the response rate. Further advantages of this method of data collection are minimum interviewer bias and accurate sampling (Oppenheim 2001). The closed response format in the CHFQoL questionnaire had the benefit of being structured, allowing responses to be easily coded and analysed and for less time to be taken collecting responses (Polgar & Thomas 1998). Due to limited funds and time constraint, self-administered questionnaires were an appropriate approach to target this population.

Response rates to the survey were excellent (68%). A prospective study design may have minimised any recall bias, as patients would have more recent experience of their condition. However, evidence from the interviews in Phase 1 clearly revealed that patients could recall their experiences in great detail.

5.6.2 Limitations of the study

The sample did not include any respondents from ethnic minorities. The primary aim of the study was to evaluate the psychometric properties of the CHFQoL questionnaire, and not to explore differences between variables according to ethnicity. However, differences in HRQL perceptions would be valuable to investigate in the future.

The extent to which the results can be generalised to other samples or situations is limited. The research setting may not be representative of other Secondary care establishments or Primary care circumstances across the UK. Other district general hospitals admit patients with CHF as in this study. However, their demographics may differ, such as age variation, gender variation and social class variations. Furthermore, the treatment and management of this group of patients by other medical and nursing experts may vary. It could also be argued that a regional sample is not representative of all the UK because patients might vary by region in their understanding of a question, in their behaviour or their beliefs about health and illness.

This sample does not take into account the many individuals who are being treated for CHF by their GP who have not been admitted to hospital and may have a different experience of CHF.

The use of questionnaires has several disadvantages including; the pre-coding of response alternatives which may not be sufficiently comprehensive and force some respondents to choose inappropriate responses which may not fully represent their views (Bowling 2002). In order to minimise this, five-point response items were used in the CHFQoL questionnaire. The CHFQoL questionnaire was previously piloted in Phase 2 (chapter 3) of this research.

Self-administered questionnaires rely on 100% literacy and a common language. They are inflexible as responses cannot be clarified and they are inappropriate where spontaneous answers are wanted. The researcher can not be sure that the right person completed the questionnaire and there is no opportunity to supplement the respondent's answers with observational data which adds useful background material (Moser & Kalton 1996).

Central tendency bias is the reluctance of some respondents to use extreme categories of a scale. Using statements such as "almost never" instead of "never" can minimize this. However, this was not undertaken in this survey because the researcher wanted to encourage respondents to reply with absolutes if they wanted to (Streiner & Norman 2003).

Inter-observer reliability was not assessed in this study. Testing inter-observer reliability of the CHFQoL questionnaire with clinicians may have enhanced the reliability. However, evidence suggests that clinician assessments of an individual's HRQL differ in certain domains (Williams 1988; Wilson et al. 2000; Paul & Sneed 2001).

5.6.3 Advantages of the CHFQoL questionnaire over the SF-36 & MLHFQ

The CHFQoL questionnaire has several advantages over the SF-36 & MLHFQ measures in the assessment of HRQL in CHF patients. These advantages relate mainly to how the measure was developed. The CHFQoL questionnaire was developed with the intended users of the measure that is individuals with CHF. Thus the CHFQoL questionnaire comprises important dimensions of HRQL as identified by patients in the population under study.

The CHFQoL questionnaire comprises items that may be classified as generic items and items that are disease-specific. Generic HRQL measures, such as the SF-36, are not exhaustive in their assessment of HRQL and additional disease-specific information is required in certain conditions. The advantages and disadvantages of both generic and disease-specific measures were discussed previously (Chapter 1).

The CHFQoL questionnaire was designed to evaluate HRQL in individuals with CHF. The measure was also designed to evaluate changes in HRQL in this group, therefore indirectly evaluating the effectiveness of treatment. It is recognised that further research is needed to determine whether any changes in score represents a small, moderate or large improvement or deterioration.

5.7 Conclusion

The survey conducted in this Phase established the internal consistency, criterion validity, convergent validity and discriminant validity of the CHFQoL questionnaire in a CHF population. Statistical findings were within acceptable ranges for establishing reliability and validity, although some responses to the CHFQoL scores were non-linear and heteroscedastic. Therefore, although the correlation with the SF-36 and MLHFQ was high, the CHFQoL questionnaire covered components of CHF not tapped by existing questionnaires. Further research is needed to test the validity of the CHFQoL questionnaire in a larger CHF population.

Chapter 6 – Perceptions and experiences of chronic heart failure patients

6.0 Introduction

This Chapter describes a study of respondent's perceptions generated during the research performed in Phase 2 (Chapter 2) and Phase 3 (Chapter 5) of this thesis. A qualitative method was employed using a self-administered CHFQoL questionnaire in a Chronic Heart Failure (CHF) population. The data was analysed using Framework methodology (Ritchie & Spencer 1994) described in Chapter 2.

6.1 Background

In order to fully investigate individuals' perceptions of health-related quality of life (HRQL) in CHF, free text comments were sought during the research described in Chapter 2 and Chapter 5 to elicit further experiences or beliefs about CHF. The purpose of HRQL measures is to assess the individual's views of the importance of aspects of health status and quality of life. HRQL measures should allow the individual to describe their lives in ways that they find important (O'Boyle et al. 1994). Qualitative research can explore attitudes and interactions that quantitative research cannot by developing concepts which increase knowledge regarding social phenomena and provide understanding to meanings, experience and views of all the participants (Creswell 2003; Mays & Pope 1996). Qualitative research also allows exploration of ideas to seek new insight, assess phenomena in a new light and to obtain rich data on complex issues (Robson 1995; Bowling 2002).

6.1.1 Aim

The aim of this study is to identify individual's views of how CHF affects their HRQL.

6.1.2 Objectives

- To identify any additional HRQL domains to those described
- To identify any new HRQL issues.

6.2 Method

6.2.1 Design

A qualitative design was employed using the CHFQoL questionnaires administered during Phase 2 and Phase 3 as a way of exploring any new areas or perceptions of health and HRQL. Qualitative methods are essential in the initial stages of questionnaire design and allow the exploration of areas not amenable to quantitative research (Mays & Pope 1996).

6.2.2 Sampling strategy

The sample consisted of respondents from Phase 2 and Phase 3, who had returned completed CHFQoL questionnaires.

6.2.3 Resources

The CHFQoL questionnaire, which was developed and validated as part of this thesis, was analysed.

6.2.4 Procedure

Three questions in the CHFQoL questionnaire asked for comments from the respondent. During Phase 2 (Appendix 9) these were Question 12 *"Do you have any other symptoms other than breathlessness or tiredness – If yes, please state what these other symptoms are."* Question 15 *"Since you were told by a doctor, that you have heart failure has your personality changed? – If yes, please state how your personality has changed."* Part 3 – *"If you have any comments about this questionnaire or your care in general, write them in the space provided below."* The CHFQoL questionnaire developed for Phase 3 (Appendix 27) had the same questions, however these were question numbers 10 and 13, not 12 and 15. This version of the questionnaire asked for "Comments" at the end.

6.3 Analysis of data

Framework methodology was used to systematically map and chart developing themes in the data. This method allows the researcher to test theoretical issues to improve understanding of the data.

A qualitative software package (Non-numerical Unstructured Data Indexing Searching and Theorising or NUD*IST) for data analysis was used (QSR International Pty Ltd 2002); this was described in Chapter 2. This software package allows the management of data, creation of ideas and management of categories and allows the building of theories about the data.

6.4 Results

The findings are summarised by symptom comments and personality comments. CHFQoL questionnaires from Chapter 3, 4 and 5 were included in the analysis.

Three hundred and seven questionnaires were analysed. Table 6.0 shows the breakdown of questionnaires from the different phases of the research.

Table 6.0 Composition of questionnaires within the research

Phase of research (Chapter)	Number of questionnaires
2 (3)	16
2 (4)	223
3 (5)	68

6.4.1 Demographics

Of those respondents who answered, "yes" to having further symptoms (n=144), 36% were male, 11% were female. Table 6.1 shows co-morbidity of the respondents. Some of the cohort experienced more than one co-morbidity.

Table 6.1 Co-morbidity

	Frequency N=144
No past medical history	18
Past history of IHD	68
Past history of cardiac surgery	10
Past history of diabetes	18
Past history of respiratory disease	11
Past history of muscular problems	3
Past history of cardiomyopathy	5
Any other past medical history	42

Of this group of respondents, 48% were NYHA class III or IV. Of those respondents who answered, "yes" to having changes in their personality (n=94), 74% were male, 26% were female. Of this group of respondents, 70% were NYHA class II or III.

6.4.2 Symptoms

During the semi-structured interviews presented in Chapter 2 and the questionnaires returned in Phase 3 (Chapter 5), individuals described a number of symptoms. These included; breathlessness, oedema, dizziness, tiredness, chest discomfort and feeling unwell. Breathlessness and tiredness were the most frequently mentioned symptoms. Every participant mentioned feeling breathless, and most reported that these symptoms were associated with activities of daily living including activities which involved minimal exertion. Respondents also stated that they experienced other symptoms. These other symptoms are presented as medical diagnosis and descriptive symptoms (Table 6.2). Respondents described their symptom frequency and severity in a number of different ways from occasional to frequent, from slight/uncomfortable to severe.

Table 6.2 Other symptoms

Medical diagnosis	Diabetes, Arthritis, Gout, Angina, Chest Infections.
Descriptive symptom	Lack of strength in legs/aching legs & feet, dizziness, chest pain, memory loss, lethargic/fatigue, cough, nausea, oedema, headache, back pain, dry/sore mouth, bad chest, confusion, irritable, tiredness, aching body, cold feet, weakness, stressed, uncomfortable, loss of balance, skin irritation, stomach pain, loss of concentration, vision impaired, depressed, live day by day, running nose, bloated, muscles ache, cramp, loss of appetite, palpitations, sweat, panic attacks, sleeplessness, cold hands and feet, lack of libido, weight gain, mood swings, hot flushes.

The most commonly reported symptoms were; dizziness, lack of strength in legs, chest pain, memory loss, lethargy, cough, gout, nausea, and oedema. Respondents also reported that diabetes and arthritis were a problem but grouped this response with other symptoms described in table 6.2.

Fifty six percent of these respondents described their general health as "fair", (Table 6.3)

Table 6.3 General health

	Frequency (%) (n=144)
Very Good	3 (2%)
Good	22 (15%)
Fair	80 (56%)
Poor	39 (27%)
Total	144 (100%)

The majority of respondents felt that their symptoms influenced how much activity they could perform, "much more than other adults" (Table 6.4), which adversely affected their activity level. They also felt that their symptoms often or occasionally interrupted their family activities (Table 6.5).

Table 6.4 Influence of symptoms on activity

Symptoms influence activity levels	Frequency (%) (n=144)
Much less than other adults	1 (1%)
Somewhat less than other adults	3 (2%)
About the same as other adults	7 (5%)
Somewhat more than other adults	39 (27%)
Much more than other adults	84 (58%)
Not applicable	10 (7%)
Total	144(100%)

Table 6.5 Interruption of activities by symptoms

	Frequency (%) n=141
Very often	25 (18%)
Often	32 (23%)
Occasionally	50 (35%)
Almost never	24 (17%)
Never	10 (7%)
Total	141(100%)

6.4.3 Personality

During the interviews documented in Chapter 2, a number of interviewees described changes in their personality due to CHF. These changes were seen as both positive and negative. A large number of respondents to the questionnaires stated that their personality had changed and commented on how it had changed. Table 6.6 presents the positive and negative comments respondents made.

Table 6.6 Personality comments

Positive changes to personality	Don't take things for granted, live for today, enjoy what you have, appreciate things more, change for the better, not as miserable and moody, resigned to life, take one day at a time, live each day to the full.
Negative changes to personality	Frustration, can't do things, a lot quieter, always question myself, slowed down, don't like to rely on others, bad mood/moody, tired, introspective, depressed, bad/short tempered, argumentative, no patience, can't forget about CHF, lack interest in things, not tolerant, forgetful, irritable, worry, grumpy, tearful, feel life is over, snap, no fun left, don't care, withdrawn, less/not confident, no zest for life, no determination, angry, easily upset, subdued, can't be bothered, frightened, confused, conscious of every ache and pain, stopped socialising, serious, feel useless, can't concentrate, inactive, no strength or energy, nasty, unhappy, insecure, failure.

The most commonly described changes were; depression, frustration at not being able to do things, bad tempered, irritable, worry and less/no confidence.

Forty nine percent of respondents described their general health as "fair" and 29% described their general health as "poor" (Table 6.7).

Table 6.7 General health

Description of health	Frequency (%)
Excellent	2 (2%)
Very Good	1 (1%)
Good	18 (19%)
Fair	46 (49%)
Poor	27 (29%)
Total	94 (100%)

6.4.4 Further comments

Respondents were asked for any further "comments" at the end of the questionnaires. Of those respondents who wrote comments these were a mix of comments which were directed towards the quality of care they had received; how they felt about their heart condition; difficulties they were experiencing and the health care process as they saw it.

Most of the respondent's comments on how the care given by a Heart Failure Nurse was very supportive and helpful and they would have struggled without this contact.

> *"I have been encouraged by the advice and care given to me by my visiting Cardiac Nurse."*
>
> *"I feel scared at times but everybody who is involved with my illness have gave me the best possible care and I feel safe with their treatment they are giving me and I trust them all 100%."*
>
> *"My health is far greater improved than I thought possible a year ago due to care and medication received from the hospital and cardiac teams."*
>
> *"Since attending the cardiac clinic I have become more aware of the effects of certain drugs and their side effects relative to their main purpose."*

Some respondents were pleased to have been sent the CHFQoL questionnaire because they felt is showed someone was interested in them.

> *"I wish to thank you very much for taking interest in me, it makes me feel secure in myself. Thank you very much. Please don't forget me."*

A number of respondents commented about how they felt about their heart condition and the difficulties they experienced.

> *"Because I look healthy many people I meet think I'm putting it on (even some friends) – this leads to great frustration - I no longer mention my illness - if asked I may say 'Fine, just getting over a cold!'."*
>
> *"Recently I have had a severe cold, which I think has made my symptoms appear worse then they normally are."*
>
> *"I personally feel fit and well and think why do I have to carry on with all the drugs I am taking, I also think I should have other heart scans to see how my heart is working, which may reduce my medication."*

> *"The last five years I feel that I have no purpose in my life, all I do is sit in the chair all day because I am frightened of anything happening and I have not got the energy or the breath to do anything."*

> *"My health isn't just my heart I have other problems too. But I take life as it comes each day, and I don't worry one bit. Life is too short to worry."*

> *"I feel if I could stop feeling sick I could live a better life, even though I would still be restricted in many ways."*

6.5 Discussion

This analysis aimed to describe any additional HRQL domains to those described in previous chapters. Important dimensions of HRQL were identified by respondents regarding symptoms, personality changes, cognitive impairment and interventions aimed at CHF.

6.5.1 Co-morbidity

Respondents in this study reported other co-morbidity which may have affected the other symptoms they described. HRQL may be dependent on co-morbidity particularly in the older population (Weir et al. 2006). Co-morbidity is usually related to an underlying cardiac problem or its cause (for example, angina, hypertension, diabetes, smoking-related lung disease) and age (osteoarthritis), as well as a consequence of heart failure (arrhythmias) and its treatment (gout from diuretics) (McMurray & Pfeffer 2005). Some common co-morbidities have many causes (renal dysfunction), whereas others are not fully explained (anaemia, depression, disorders of breathing, and cachexia) (McMurray & Pfeffer 2005). Older patients with heart failure have relatively good HRQL in spite of significant functional limitations, however, they are at risk for worsening HRQL with further decline in functional status (Masoudi et al. 2004). The majority of elderly CHF patients have three to five other conditions (Weir et al. 2006). For example, diabetes and chronic obstructive pulmonary disease, which leads to increases in length of hospital stay and the number of readmissions (Jaarsma & Dracup 2001). Co-morbidity often means more medication resulting in increased risk of side effects. Having diabetes with other metabolic conditions, and particularly with heart disease, substantially elevates the risk of adverse outcomes such as health service utilisation, HRQL deficits, and mortality in both middle and older age adults (Oldridge et al. 2001). In a study by

Braunstein et al (2003), arthritis is one of the top 10 non-cardiac co-morbidities in CHF and its treatment influences heart failure status.

6.5.2 Symptoms

It has been reported in the literature that patients face a wide variety of symptoms which are multidimensional in nature (Friedman 1997; Moser & Worster 2000; Bennett et al. 2000). Individuals not only experience breathlessness they also complain of dizziness and fatigue as a common symptom (Stull et al. 1999; Dunderdale et al. 2006). These symptoms impose a huge burden on the individual and impact on their quality of life (Zambroski et al. 2005). Symptoms commonly experienced by patients with heart failure explained a substantial proportion of the variation in the effects of heart failure on patients' quality of life (Rector et al. 2006).

Symptoms can be a cry for help, reflecting not only the physical aspects of the disease but the associated impact on lifestyle, anxiety, depression and expectations of the patient. For these reasons, symptoms will vary markedly amongst patients and within the same patient from one time to another (Ekman et al. 2005). Breathlessness and fatigue are the classic symptoms of heart failure (Lynn et al. 1997; Nordgren & Sorensen 2003). As many as 23 symptoms have been reported by patients during their last six months of life (Nordgren & Sorensen 2003). Symptoms such as difficulty concentrating and bodily pain are common (Zambroski et al. 2005).

6.5.3 Depression

Clinical depression is a disorder of mood, consisting of a combination of elements that interfere with a person's ability to perform his or her day-to-day functioning (Konstam et al. 2005). Depression is often associated with heart failure due to declining physical health, role changes, financial insecurity and social isolation. The diagnosis of depression is important because of its association with mortality, quality of life, and functional status in patients with heart failure independent of somatic parameters (Westlake et al. 2005). Depression and its symptoms have been shown to increase mortality in patients with CHF (Sullivan et al. 2004). Most of the respondents did not report any depression but of those who did it was related to both physical and psychosocial aspects of their life. This is in keeping with the literature (Westlake et al. 2005; Pihl et al. 2005). People with heart failure frequently report depression and sleep disturbances. A study by Brostrom et al. (2004) found that those patients suffering from insomnia had a poorer HRQL compared to heart failure patients without insomnia. Both depression and/or a sleep disturbance may be suspected when patients with CHF express themselves as being fatigued (Johansson et al. 2006). Fatigue is a core symptom of CHF as well as a symptom of depression, but fatigue can also easily be interchanged with daytime sleepiness, a principal symptom of sleep disturbances. Moreover, sleep disturbances are also a symptom of depression (Johansson et al. 2006). Clinicians should intervene to decrease these symptoms because they impact on prognosis and HRQL (Johansson et al. 2006). Interventions that improve patient functional status may result in decreased depression and improved HRQL on the part of both patients and spouses (Martensson et al. 2003).

Stull et al (1999) found that patients with CHF went through a process of adjustment which promoted coping or made coping and adjustment difficult. Some patients found purpose and meaning, maintained social roles, were content with life now and past life and have a sense of support when they were coping. Whereas others had feelings of abandonment, sense of limitations, were physically restricted, socially isolated and felt powerless when they were struggling to adjust.

6.5.4 Cognitive impairment

There is increasing evidence that CHF is independently associated with impairment in cognitive function (Trojano et al. 2003; Bennett & Sauvre 2003). A recent systematic literature review indicated that CHF is associated with a pattern of cognitive impairment that includes memory, attention, mental flexibility and global cognitive deficits (Vogels et al. 2006). Research into the cognitive capacity of CHF patients is limited. It is possible that cognitive impairment affects patients' understanding of CHF as well as limiting their functional capacity and ability to implement treatment options (Wolfe et al. 2006). Cognitive impairment is prevalent among patients with CHF and is independently associated with disability and mortality (Zuccala et al. 2005). Cognitive aspects were highlighted in this research and discussed in Chapter 2.

6.5.5 Chronic heart failure interventions

High rates of depression have been found in patients who are hospitalised with CHF (Koenig 2006). Increased symptoms severity and functional impairment in patients with CHF and depression may be a reason for high health care utilisation (Sullivan et al. 2004). Medications can improve the functioning and HRQL of patients with CHF and reduce morbidity, mortality, and costs of treatment. However, patients may not adhere to therapy (Murray et al. 2003). It is well documented that specialist nurse led heart failure interventions which are multi-disciplinary in nature are effective in improving health outcomes (Rich et al. 1995; McAlister et al. 2001; Thompson et al. 2005; Jaarsma et al. 2006). Specialist nurse led multi-disciplinary interventions have the potential to significantly improve health outcomes in individuals with CHF. Recent literature has found that nurse led interventions significantly reduce readmission rates and length of stay which leads to an improvement in a patient's quality of life (Stewart et al. 2002). Evaluation of a Heart Failure Nurse led service found that patients and carers valued the nurse service which provided them with many benefits; patients were reassured by regular monitoring, having a key nurse with whom they could build a relationship who provided continuity of care and who was easily accessible and carers welcomed having the nurse with whom they could share responsibility for the patient (Pattenden et al. 2004). The relationship health care professionals have with their patients is very important. An effective relationship has been associated with an increase in patient satisfaction, adherence to treatment recommendations, lower hospital readmission, and better quality of life in patients with CHF (Zickmund et al. 2006).

6.6 Summary

This study identified a variety of additional symptoms and personality changes experienced by respondents to the CHFQoL questionnaire. Similar findings have been found in the literature. However, no additional HRQL dimensions were found. The CHFQoL questionnaire allowed respondents to report beliefs in addition to responding to questionnaire based methods (French et al. 2002). Research has shown that using different methods to assess causal beliefs can result in different aspects being assessed (Gudmundsdottir et al. 2001; French et al. 2002). This study produced similarities to the previous studies (Phase 2 & Phase 3), which support the view that these beliefs exist and can be assessed (French et al. 2002). Research by Gudmundsdottir et al. (2001) found that the method of obtaining attributions does not appear to affect the attributions made but affects their numbers. This research has identified HRQL through completion of scales and also by allowing the respondent to describe further symptoms and experiences through free text options within the questionnaire.

Chapter 7 – Discussion & recommendations

7.0 Introduction

This chapter summarises the findings of this research and discusses how the thesis contributes to existing knowledge. The research findings are interpreted in the context of the measurement of health outcomes in CHF, with a description of methods to enhance the psychometric properties and generalisability of the CHFQoL measure. Recommendations for the future use of the CHFQoL measure in the context of clinical practice and research are also presented.

7.1 Main findings of the thesis

There are a number of stages in the development of a HRQL measure. These include: devising items; selecting items and testing the psychometric properties of the measure (Streiner & Norman 2003). Furthermore, Fitzpatrick (2000) also describes the properties of precision, acceptability, interpretability and feasibility. There are two reasons for wanting to develop such an instrument: the construct is a new one, and no scale exists which measures it; or we are dissatisfied with the existing tools, and feel that they omit some key aspect of the construct (Streiner & Norman 2003).

This thesis demonstrates how a literature review (Dunderdale et al. 2005) and patients' interviews (Dunderdale et al. 2006) generated items to develop a new HRQL measure; and how the psychometric properties of the HRQL measure were tested.

7.1.1 Summary of the literature review

The literature review demonstrated that no HRQL measures are available which are patient-centred for use in the CHF setting (Chapter 1). A new HRQL measure was indicated for the population under study (Dunderdale et al. 2005). None of the measures reviewed were suitable owing to their poor psychometric properties in CHF populations or a lack of patient involvement in their development. The exception being the MLHFQ which is the most commonly used measure in heart failure and SF-36, which was selected as the best available gold standard measure. Although, both of these measures have limitations which were highlighted and discussed in Chapter 1.

The use of a generic HRQL measure in a CHF population may not be responsive to HRQL changes in the population following treatment. The CHFQoL questionnaire was designed to be an evaluative HRQL measure for use in a CHF population. The measure was designed to evaluate changes in HRQL in this group thus evaluating the effectiveness of treatment. However, it is recognised that further research is needed to define whether a change in score represents a small, moderate or large improvement or deterioration, or whether there is a correlation between change in HRQL and a change in status.

The literature review was updated in 2006, following the completion of the final phase of the research programme. The Seattle Heart Failure Model was identified as a new measure (Levy et al. 2006). This is a multivariate risk model to predict one year, two year, and three year survival in heart failure patients with the use of easily obtainable characteristics relating to clinical status, therapy, and laboratory parameters. As part of the Euro Cardio-QoL Project, the HeartQoL study is designed to develop a single reliable and valid core coronary heart disease-specific, HRQL questionnaire, in order to compare outcomes with the same or across different treatments among pure or mixed populations of patients with myocardial infarction, angina pectoris, and/or heart failure (Oldridge et al. 2005) The MacNew Heart Disease HRQL questionnaire (MacNew) is a self-administered modification of the original Quality of Life in Myocardial Infarction instrument (Lim et al. 1993). The MacNew heart disease questionnaire addresses three major HRQL domains, the Emotional, Physical, and Social domains which can be combined to give a Global HRQL score (Hofer et al. 2004). The MacNew may be a valuable tool for assessing and evaluating HRQL in patients with heart disease (Hofer et al. 2004).

7.1.2 Item generation for the CHFQoL measure

A measure of HRQL in CHF should focus on dimensions that are relevant to the individual's perceptions of well-being, be sensitive to change over time, be sensitive to small changes in health status, measure various health problems and be simple enough to administer quickly and effectively to adults from a wide age range.

The views of patients and clinicians were elicited to develop and complete the measure (Streiner & Norman 2003). Only individuals with objective evidence of CHF completed the CHFQoL questionnaire in this study (Chapter 4-6). Assessment by clinicians was not performed. However, clinicians contributed to the development of items to strengthen the clinical utility and feasibility of the CHFQoL measure

(Chapter 3). Satisfaction and practicality of the CHFQoL measure amongst health care professionals are recommended for future research.

Patients described the concept of health and quality of life as being multidimensional and possessing similar dimensions. These dimensions included physical, behavioural, emotional and social characteristics (Chapter 2). These dimensions have been described in patient-based outcome measures which include physical function; symptoms; global judgements of health; psychological well-being; cognitive functioning; role activities; personal constructs and satisfaction with care (Black et al. 1998). Patients perceived the difference between health and quality of life as health forming a part of their quality of life. Patients perceived physical aspects as the most important attribute of health and emotion as the most important attribute in quality of life (Dunderdale et al. 2006). Assessment of the effects of symptoms, functional limitations, and psychological distress on a patient's health-related quality of life determines the clinical significance from the patient's perspective (Rector 2005).

7.1.3 The CHFQoL measure response scales

The CHFQoL questionnaire was developed to reflect all the dimensions of health described in the literature (Chapter 1) and those described by patients (Chapter 2). The questionnaire contained one summary item asking respondents to rate their overall health. Summary items have the advantage of brevity and validity. The disadvantages include an inability to reveal contradictory trends in different dimensions of health (Fitzpatrick et al. 1998). Summary items were not used in isolation in the HRQL measure, detailed information on a respondent's health and HRQL was also obtained.

The CHFQoL questionnaire contained six transition items which asked respondent's to compare their overall health, breathing, symptoms and medication with a specific point in time, namely over the last two weeks. Transition items have good validity by producing scores consistent with independent evidence of the direction of change in health experienced by respondents between separate assessments (Fitzpatrick et al. 1998). A disadvantage to this approach is that respondents may be unduly influenced by their current health state when asked to compare current with past health (Fitzpatrick et al. 1998).

Most scale developers choose a seven-point scale in an evaluative HRQL measure to allow for sufficient graduations to register change (Guyatt et al. 1993). A five-point response scale was utilised for most of the items in the CHFQoL questionnaire. The use of five categories can reduce final reliability by about 12% (Streiner & Norman 2003). The minimum number of categories used by respondents should be in the region of five to seven. However, there is good evidence to suggest that in a wide variety of tasks people are unable to discriminate much beyond seven levels (Streiner & Norman 2003).

Nine items were developed using phrase completion scales. Phrase completion scales were designed to provide enhanced psychometrics compared to Likert scales (Hodge & Gillespie 2004) Each scale consists of a phrase followed by an 11-point response scale. The response scale represents the underlying theoretical continuum. Zero indicates the absence of the construct where as ten indicates the theorized maximum amount of the construct (Hodge & Gillespie 2005). The advantages of phrase completion scales may be particularly pronounced when measuring attitudes that fall at all points along the underlying continuum (Hodge & Gillespie 2004).

7.1.4 Item selection of the CHFQoL measure

The redundancy of items within the CHFQoL questionnaire was determined by one of two criteria: a response alternative which fell within the range 0.2-0.8 and item-total correlations above 0.3 (Streiner & Norman 2003). Most items met one of these criteria; any item which did not meet the criteria was removed after discussion with the RAG. Factor analysis was also applied to the items. Exploratory factor analysis was utilised in Phase 2 to assess the dimensionality of the measure by grouping together variables that correlated and to identify redundant items. The final CHFQoL measure tested in Phase 3 comprised 46 HRQL items with additional demographic items, and comments.

A scree plot was utilised to determine the number of factors. Oblique rotation was used in the analysis to discriminate between factors. Using this method it is less likely that factors will be forced to be unrelated (Tabachnick & Fidell 2001). Items which correlated less then 0.3 with a factor were not considered (Field 2005).

Exploratory factor analysis was utilised to identify relationships between the various items examined without determining the extent to which the results fitted a particular model (Preacher & MacCallum 2003; Bryman & Cramer 2005). The impact method was also used to select items on the basis of the importance to patients of their ratings and frequency of items (Fitzpatrick 2000). Aspects of life considered important by patients were evaluated and included the relative value of the different aspects as determined by them (Jenkinson & McGee 1998).

7.2 Psychometric properties of the CHFQoL measure

7.2.1 Reliability

Reliability refers to the reproducibility and consistency of the measure (Bowling 2002). The CHFQoL questionnaire in this study is an evaluative one and therefore internal consistency and item-response statistics have been described as an appropriate approach to test the reliability of this evaluative measure (Bowling 2002). Cronbach's alpha statistic and item-total correlations were used to calculate the internal consistency of the CHFQoL measure by identifying the extent to which items on a scale were tapping a single underlying construct (Field 2005). Cronbach's alpha ranged from 0.844 – 0.932 (Phase 2) and 0.578 – 0.950 (Phase 3) for CHFQoL items suggesting high internal reliability. However, some alpha's were above the recommended range of 0.9, in particular activity level items in Phase 3 (Bland & Altman 1997). If alpha coefficients are too high, it may suggest that some items are unnecessary and the content validity may be poor (Streiner & Norman 2003). No items had alpha coefficients that were low.

7.2.2 Validity

Validity refers to the assessment of whether an instrument measures what it aims to measure. It should have face, content, criterion, construct and predictive validity (Bowling 2002). Face validity refers to the subjective assessment of the presentation and relevance of the questionnaire (Bowling 2002). Face validity of the CHFQoL questionnaire was established with patients, carers and clinicians assessing CHFQoL items were appropriate to the measurement of HRQL in CHF and the items were understandable (Oppenheim 2001). Content validity refers to judgements about the extent to which the content of the measure appears logically to examine and comprehensively include the full scope of the characteristic or domain it is intended to measure (Bowling 2002). Content validity was established with the involvement of patients and carers in the generation of CHFQoL items, ensuring that the measure encompassed all relevant concepts of HRQL.

If a measure has high content validity broad inferences can be made about the person under a variety of conditions and different situations (Streiner & Norman

2003). Difficulties can occur when assessing a behaviour, disorder or trait that is heterogeneous, as in the case of CHF. It is possible that the measure will have low internal consistency because not all patients with one symptom will exhibit other similar symptoms (Streiner & Norman 2003). Internal consistency can be increased by removing items which are not highly correlated with each other. However, the resulting measure would only assess one aspect of CHF, giving rise to low content validity. In these circumstances it is better to have content validity than internal consistency because the ultimate aim of the CHFQoL measure is to make inferences (Streiner & Norman 2003). High content validity was guaranteed by including aspects of HRQL identified by patients which were described in the literature in addition to symptom specific consequences of breathlessness, impact on physical activity levels, emotion specific consequences of these symptoms on the individual's psychosocial life.

Criterion validity was assessed using the SF-36 and MLHFQ. Significant correlations at the 0.01 level were found between the SF-36 and MLHFQ.

Construct validity refers to a conceptual definition of a topic or construct to be measured which is expressed as hypothesis. Assessing the construct validity of the CHFQoL measure was tested by exploring the statistical relationship between gender and social class with CHFQoL scores of physical function, symptoms, psychosocial and emotional aspects. Construct validity confirmed all "a priori" hypothesis in the expected direction. Discriminant validity was assessed. This form of validity tests whether the CHFQoL measure should not correlate with dissimilar, unrelated variables (Streiner & Norman 2003). Discriminant validity was tested using the angina diary to observe any relationship between respondents with CHF and angina with those with CHF and no angina. There were significant differences between the two groups in the psychosocial domain indicating that the CHFQoL questionnaire is discriminant in that scale Discriminant validity is difficult to test in quality of life as there are numerous variables. Therefore convergent validity was also tested. The CHFQoL questionnaire demonstrated convergent validity due to the significant differences between the CHFQoL scores and the angina diary scores

7.2.3 Sensitivity

Evaluative measures need to be able to detect change and that level of change needs to be interpretable in some way. The sensitivity to change of a measure is a very important criterion to consider when selecting measures (Jenkinson & McGee

1998). Measures may be insensitive to change in HRQL for several reasons; generic measures may include items not relevant to a particular disease or treatment group (this was discussed in Chapter 1); measures may include items that assess areas that are relatively static or not a feasible target of the health care intervention; measures may be subject to ceiling and floor effects (Fitzpatrick et al. 1992).

The distribution of scores revealed no CHFQoL score with a minimum or maximum value (floor or ceiling effect), with the exception of one; the activity level total score with MLHFQ total score, suggesting that there may be scope for an improvement or deterioration in scores over time. The assessment of the sensitivity to change of the CHFQoL questionnaire is recommended for future research.

7.2.4 Practicality

One of the essential criteria of a HRQL measure is its practicality (Streiner & Norman 2003). Measures of HRQL are most practical for use in clinical trials and formal evaluations, where they are used alongside other information about patients, treatments and outcomes to address precise questions (Fletcher et al. 1992).

The practicality of the CHFQoL questionnaire was assessed by including an item on ease of completion. Thirty seven percent (n=16) found the questionnaire *"very easy"* to complete, 50% (n=16) found the questionnaire *"quite easy"* to complete (Phase 2). The mean time to complete the questionnaire was 23 minutes (range 15 – 30 minutes). This suggests good practicality of the measure. Practicality was also assessed by the survey response rates in Phase 2 and Phase 3; these were 67% and 68% respectively. Measures of HRQL also need to be appropriate to the target population and setting (Oppenheim 2001). The CHFQoL questionnaire scores highly for appropriateness as it has been designed in association with patients who have experienced CHF (Chapter 2). The CHFQoL questionnaire has also been tested in the target population selected for this research, namely individuals with CHF.

7.2.5 Generalisability

Generalisability in qualitative research should not be assumed and in this case was not aimed for. Streiner & Norman (2003) state that the assumptions that generalisability theory makes about items and tests are relatively weak. Item and scale statistics only apply to those individuals that take the test. Should the CHFQoL measure be administered to people who are different in some way it may be necessary to re-establish its psychometric properties.

Classic test theory has underpinned most test construction and theory since it was introduced (Streiner & Norman 2003). The aim of classic test theory is to understand and improve the reliability of psychological tests (Allen & Yen 2002). Concern with classic test theory is that the scores on a measure depend on how much of the trait the individuals in the sample have. How much they have depends on the norms of the scale. Therefore, the measures characteristics change as different groups are tested and the groups' characteristics change as different tests are used (Streiner & Norman 2003). Item response theory has been developed in response to the inflexibility of classic theory. One of the major contributions of item response theory is the extension of the concept of reliability. Traditionally, reliability refers to the precision of measurement (Hambleton et al. 1991). Traditionally, it is measured using a single index, such as the ratio of true and observed score variance. This index is helpful in characterising a test's average reliability (Hambleton et al. 1991). Item response theory makes it clear that precision is not uniform across the entire range of test scores (Hambleton et al. 1991). Item response theory assumes that the data are unidimensional and the probability of answering any item in a positive direction is unrelated to the probability of answering any other item positively for people with the same trait (Streiner & Norman 2003). Item characteristic curves can be calculated to describe the relationship between a person's performance on any item and the underlying trait using one of three models, the simplest being the one-parameter model or Rasch model (Streiner & Norman 2003). Classic test theory underpins this research because the aim was to understand how HRQL affects a population with CHF by developing a patient centred measure. However, item response theory deserves further investigation in this research.

7.2.6 Interpretability

Interpretability has only recently emerged as an important issue in HRQL. It raises the question of how meaningful scores of HRQL really are (Fitzpatrick 2000). HRQL measures should be able to provide clinically relevant information. A major barrier to the use of HRQL measures in evaluative research is that they lack the intuitive meaning and familiarity to clinicians that are obtained with conventional empirical measures such as blood pressure and temperature (Deyo 1991; Fitzpatrick 2000). Studies with traditional outcomes have usually a consensus on what constitutes a meaningful clinical effect. However, there is no similar direct interpretation of HRQL scores (Fletcher et al. 1992).

One approach described by Guyatt (1993), is to examine the changes in scores in two groups of patients who showed improvement and those who did not. Another approach is to identify minimal clinically important differences in score that might realistically be perceived as important by the patient or lead to change of management (Juniper et al. 1994). Other methods for interpreting change scores are statistical in nature. One method of interpretation that can be adopted for generic HRQL measures is the comparison of results before and after treatment with norms for the general population (Jenkinson & McGee 1998). While it is possible to find a statistically significant difference in scores on a questionnaire before and after treatment it may not be clear, and the difference may not mean much either to clinicians or patients (Jenkinson & McGee 1998).

A classification system needs to be developed for the CHFQoL measure to aid interpretation of the scores. It may be helpful to clinicians to have a high or low score. A high CHFQoL score for the general health dimension may therefore reflect the patient's belief that their health is poor and likely to deteriorate. Whereas a low score may reflect the belief that their health and HRQL is excellent. This may assist clinicians in identifying those patients whose HRQL outcomes have changed over time.

7.2.7 Acceptability or patient-centeredness

Measures should be acceptable to patients, if measures are not acceptable there is concern that response rates and rates of missing responses are increased and so endanger the interpretation of HRQL measures in relation to interventions and therefore the potential to introduce bias (Greenhalgh et al. 1998). One method to improving the appropriateness of HRQL measures is to use measures that let patients select the domains of most concern. Therefore, the HRQL scores will vary from patient to patient and scores can be assessed over time (Fitzpatrick et al. 1992). Acceptability should be examined at the design stage with the most direct and simple evidence being the length of the questionnaire and the response rates of questionnaires. Patients were interviewed in Phase 1 (Chapter 2) to identify items for inclusion in the CHFQoL questionnaire. Patients, carers and clinicians were asked in Phase 2 (Chapter 3) to comment on the CHFQoL questionnaire design, including content relevance.

7.2.8 Feasibility or clinical utility

Feasibility refers to the fact that HRQL measures may disrupt clinical care and impose burdens on staff (Fitzpatrick 2000). HRQL measures used in clinical trials are invariably completed by patients during routine care. Methods of assessing HRQL that are more time-consuming and require more effort and training to collect and process may be less likely to be successfully integrated into many clinical trials, thus endangering trial conduct and disrupting clinical care (Fitzpatrick et al. 1998). Some measures have been shortened to increase their acceptability and feasibility, for example, the SF-12. The validity and responsiveness of shorter measures needs to be studied and may be a consideration for future research with the CHFQoL questionnaire.

Time to train staff to administer a measure should be considered. The CHFQoL questionnaire is designed to be self-administered and it is thus anticipated that staff would need minimal training to administer the CHFQoL questionnaire. The CHFQoL questionnaire can be administered face to face or by post, therefore minimising staff effort and time.

7.3 Health policy and CHFQoL measure

Heart failure is the leading cause of hospitalisation for patients over the age of 65 years in most industrialised countries (Cowie et al. 1997). HRQL deteriorates with increasing severity of heart failure. This is associated with increased visits to General Practitioners, drug prescriptions and hospitalisation (McMurray & Stewart 2001). HRQL is increasingly seen as an important end-point in trials of pharmacological and non-pharmacological treatments (McMurray & Stewart 2001). Rather than measuring survival, studies are being designed to assess quality of life in order to determine if longevity equates to poor HRQL before an inevitable death (McMurray & Stewart 2001).

Evidence in the literature has shown that an estimated 8% of all patients discharged with a diagnosis of heart failure will be readmitted within three months (Jaarsma & Dracup 2001). Good systematic care with appropriate specialist intervention to ensure optimal treatment and good symptom control can significantly improve HRQL for these people (The Department of Health Heart Team 2003). Understanding the patient's perspective, by understanding what affects their HRQL can provide an evaluation of the quality of medical care, estimation of the health care needs of a population and an understanding of the causes and consequences of the differences in health. As better outcomes of care emerge health policy debates regarding the cost effectiveness of treatments and procedures and the policy decisions which result are likely to change. Priorities within the NHS have changed with the emergence of the NSF for CHD. Heart failure is now being focused on with local strategies being drawn up to reflect the level of services required to care for those individuals with CHF. Individual characteristics such as age, gender, and ethnicity may influence people's self reported HRQL and interventions should be adapted to each individual (Johansson et al. 2006). The extent of gender differences in treatment, hospital cost and quality of care can partly be explained by age differences (Stromberg & Martensson 2003). The known gender differences in patients with heart failure need to be highlighted in guidelines as well as implemented in standard care (Stromberg & Martensson 2003). Recent literature quantifying the economic burden of CHF found heart failure imposes a significant direct economic burden on the UK (Lacey & Tabberer 2005).

This thesis has reported the development and validation of the CHFQoL questionnaire for individuals with CHF. The use of HRQL outcomes are advocated to measure the benefits of health care expenditures and to assess structure and process of health care delivery (Drummond et al. 2001). Improvements in HRQL is one of the main economic benefits of treatment and it needs to be incorporated in economic evaluation (Drummond et al. 2001). Cost-effectiveness analyses compare the relative cost of treatment with the relative consequences. HRQL measures may also be useful in cost-utility analysis (Drummond et al. 2001). Generic HRQL measures can inform policies across different levels in the healthcare setting. Health-related quality of life must then be considered an integral component of the evaluation of service effectiveness (Oldridge 1996).

The CHFQoL measure developed in this thesis may inform healthcare policy in a number of ways. It can provide policy relevant information on the effectiveness of treatment by comparing outcomes in clinical trials, assessing the outcome of new treatments and evaluating interventions and methods to improve care. The CHFQoL measure may also provide information to inform patients regarding treatment choices and their likely impact on outcomes.

7.4 Research design and methods

The advantages and disadvantages of the overall research design and methods used are presented in detail in each chapter. The data collection approach was driven by the research purpose, practical considerations as well as by concerns about data quality (Mays & Pope 1996).

7.4.1 Alternative methods

This research used a combination of quantitative and qualitative research methods to develop and validate the CHFQoL measure. The design may have been improved by using standard physical, psychological tests to measure patient ability that are important aspects of quality of life. Several tests are available for CHF populations such as tests to assess cognitive function, depression, physical functioning, and degree of impairment. These may have complemented HRQL information obtained from the CHFQoL questionnaire and contributed to the assessment of validity of the CHFQoL measure.

The interviews undertaken with patients and carers (Phase 1) and the postal survey (Phase 2 & 3) were retrospective of the individual's episode of admission and therefore recall bias might have been a problem with some patients finding it difficult to recall past experience. A time frame of "in the past two weeks" was used for questions relating to current health and wellbeing to minimise problems with recall.

Patient diaries may have been a useful complementary method of HRQL assessment in this research by asking patients to describe aspects of their HRQL.

Using a different method to assess causal beliefs may result in different aspects of quality of life being elicited from individuals and how this relates to HRQL.

Financial and time restraints limited the literature review. Articles from other languages other than English may have enhanced the methodological quality.

7.4.2 Alternative sample

Patients who were not English speaking were not sampled in this research. This may have led to this research not being applicable to minority groups. Using an interpreter and translator was beyond the financial resources available. The use of the CHFQoL questionnaire in ethnic minorities is a consideration for future research.

The sample size and response rate could have been enhanced in Phase 1 and Phase 3, by recruiting patients from other Primary Care and Secondary Care Trusts.

However, this would have impacted on the cost of the research in terms of time and financial resources.

The sample for each of the Phases of research was derived from a Secondary Care environment. Therefore, those individuals who are cared for by their General Practitioner were not incorporated in the analysis.

The average age of the respondents is considerably lower than the typical patient with CHF and there were also more men in the samples than women. HRQL is likely to be influenced by different things in the post-retirement population than in the working population and is very likely to be different in men than women, and this raises the question of the generalisability of the findings.

The literature shows that psychological and physical health of spouses of chronically ill elderly people is negatively affected, especially in female spouses (Luttik et al. 2005). Several studies on the impact of Myocardial Infarction (MI) on the family describe severe consequences for example: high levels of physical and emotional distress in partners of MI patients were found (Moser & Dracup 2004). Quality of life of partners seems to be affected by caring for a patient with CHF and it is apparent that our knowledge about this group is insufficient. In our attempts to improve outcome in patients with CHF we cannot ignore the possible burden of the care giving partner (Luttik et al. 2005).

7.4.3 Additional analysis

The CHFQoL questionnaire was tested in a CHF population but reliability of administration and analysing the questionnaire in routine clinical practice were not formally evaluated.

Confirmatory factor analysis of the CHFQoL questionnaire (Chapter 3) would have been interesting to perform because it may have strengthened the construct validity of the measure. This was not attempted as a different sample would have been required.

There was a clear interaction between CHFQoL activity level total scores and the MLHF total scores which needs to be investigated further to determine what may be leading to this interaction.

7.5 Recommendations for future research

Future recommendations have been described in this chapter and therefore the following research is suggested.

7.5.1 Specific recommendations

- Development of the reliability and validity of the CHFQoL in other languages will enhance the quality of the measure
- Determine the responsiveness of the CHFQoL questionnaire by comparing the mean change in CHFQoL scores with a stable group of CHF individuals with a group of unstable patients
- Further test the responsiveness of the CHFQoL questionnaire by comparing the mean change in CHFQoL scores for a group of individuals treated in Primary Care and a group of individuals who are treated in Secondary Care.
- Confirmatory factor analysis of the CHFQoL questionnaire to test the hypothesised structure
- Further testing of the CHFQoL questionnaire on a wider age range of individuals with CHF to enhance the generalisability of the measure
- Further testing of the CHFQoL questionnaire on both men and women with CHF to enhance the generalisability of the measure.

7.5.2 Non-specific recommendations

- A further literature review incorporating all evidence which fits the search criteria to ensure the quality of the data
- Evaluation of the carer burden in a CHF population as carers raised issues which were briefly discussed in Chapter 2
- Dissemination of the thesis findings to relevant audiences to promote the use of the CHFQoL questionnaire, both nationally and internationally
- Further testing of the CHFQoL questionnaire to provide a global interpretation.

7.6 Conclusion

The evaluation of HRQL outcomes in individuals with CHF is a national priority for research. Treatment for CHF may be assessed by its ability to improve symptoms and prolong life but patients are interested in how the treatment will improve quality of life. This thesis has contributed to research in this field by creating and interpreting new knowledge through original research. Two important contributions have been made to the evidence base for outcome measurement in CHF.

Firstly, a published literature review (Dunderdale et al. 2005), of HRQL measures in CHF and a synthesis of the evidence relating to the development (Dunderdale et al. 2006), psychometric properties, practicality and feasibility of a patient-generated HRQL measure in a CHF population.

Secondly, the development and testing of a disease-specific HRQL measure (CHFQoL questionnaire), for future use in the evaluation of the effectiveness of treatment in the UK through the monitoring of HRQL outcomes over time from the patient's perspective.

The importance of using aspects of health-related quality of life that are important to those with chronic heart failure, as opposed to those who diagnose, manage or care for such people is increasingly recognised. This work is one small step in moving from professionally derived HRQL measures to ones that might more appropriately reflect the concerns and values of patients. If we are better able to define HRQL in CHF then we will be able to adjust and focus our efforts in different ways which are to the benefit of both the patient and carer and the health care professionals.

Appendix 1

Quality of Life in Chronic Heart Failure
Data Collection Sheet

Study No: ☐☐☐ Patient Initials.............. Age..................

Gender:

Male☐	Female☐

Marital Status:

Single	☐
Married	☐
Living together as a couple	☐
Widowed	☐
Divorced or separated	☐

Occupation:	
Retired	☐
Working - employed	☐
Working – self-employed	☐
Claiming benefits	☐

Ethnic origin:

White	☐
Pakistani	☐
Bangladeshi	☐
Other Asian background	☐
Caribbean	☐
African	☐
Chinese	☐
Any other ethnic group	☐
Not stated	☐

Medical history:

Date of admission	
Date of Discharge	
When was a diagnosis given of heart failure to the person	
Has the patient had an outpatient follow up appointment since discharge	

Appendix 1 (continued)

Left Ventricular Function:

☐	☐	☐	☐	☐
Mild	Mild to moderate	Moderate	Moderate to severe	Severe

Date of the interview	
Time interview commenced	
Time interview terminated	

Interview Guide *(Discussed)*	Yes	No
What does the phrase "Quality of life" mean to you?		
How does your heart failure affect the following? Physical capabilities (Housework, hobbies, getting about)		
Emotional Status (Worries/Anxieties, health, heart)		
Social interactions (family relationships, personal life, cosseting, sexual relationships)		
Intellectual functioning (lethargy, concentration, mood, sleep)		
Economic status (money, employment)		
Self-perceived health status (symptom management, medicine, lifestyle changes)		
Other (any other topics discussed)		

Appendix 2

Quality of Life in Chronic Heart Failure

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. If there is anything that is not clear, or if you would like more information, please ask us. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

What is the purpose of the study?

To develop a patient led Quality of Life assessment tool that can be used in clinical practice, for measuring the quality of life in a chronic heart failure population, and develop a patient led definition of Quality of Life.

Why have I been chosen?

You have been invited to take part because you have been diagnosed with heart failure and a number of people (twenty in total), such as yourself who are admitted to Scunthorpe General Hospital over the next four months will be asked if they wish to take part.

Do I have to take part?

No, the choice to take part is entirely yours. If you do decide to take part, you will be given this information sheet to keep and be asked to sign the agreement to participate at the end of this information. If you do decide to take part in the study you are able to withdraw your consent at any time if you feel you no longer wish to participate. This will not affect your treatment or care in any way. If you decide not to take part in this study, this will also not affect your normal treatment and / or care.

What will happen to me if I take part?

If you decide to take part, you will be interviewed by the researcher. The interview will be tape recorded. Once all interviews have taken place, the researcher will transcribe the interviews (put in writing what has been said on the tape recording).

Appendix 2 (continued)

What are the advantages / disadvantages of participating in this study?

Whilst there are no guarantees that you will benefit from taking part in this study, the results will be used to develop a way in which the quality of life for patients with heart failure can be measured. This will hopefully ensure that we provide optimum care for this group of patients.

Will my taking part in the study be kept confidential?

If you agree to take part in this study, you will be known only by your initials and a study number. Only the researchers involved with the study will see the information that is collected. All information will be treated in the strictest confidence.

What will happen to the results of the study?

This study will identify the patient's perception of quality of life. These perceptions will be used to develop a patient led assessment tool, which will complement the tools currently in use at the hospital.

Ethical considerations

This study has been approved by our Local Ethic Committee, which has not objected to the study taking place. All records of you taking part in the study will be kept confidential. All data is anonymised.

If you wish to discuss this further please contact Karen Dunderdale on 01724 290093.

I am happy to take part and be interviewed. Name................................

Signature:..Date........./......./........

I am not happy to take part and be interviewed. Name.........................

Signature:..Date......../......./..........

Appendix 3

29/10/03

Interview 1

I If I say quality of life what does it mean to you? If we're talking about quality of life what does it mean?

P The freedom and where with all.... to.... do the things in life you want to do.

I Would you say your quality of life has been inhibited?

P Undoubtedly

I So how would you say that heart failure has affected the activities you can do in your life?

P Enormously, I can't play squash (laugh), up till the end of last year I played squash two or three times a week and....I played squash competitively and I ran a squash club for fifteen years. A lot of my life has been round squash, err, I have to consider almost everything I do and what the implications are going to be, emm, should I climb up a ladder and paint the guttering and when I paint the guttering and I feel silly should I get down, I get down the ladder or do I think or I'll be alright, it's like the sword of Damocles' hanging over you. Em, I have to consider everything physical, that I do. Err.

As a social comment, I drank a lot more, before, than I do now, I wouldn't say I drank to the extent of being drunk every night, but emm, I didn't consider, other than driving emm, the amount that I drank I might have a couple of glasses of wine or 4 or 5 pints of bitter, emm, and now I consider it, now I have to plan what I'm going to eat...emm.

I Do you have to plan everything?

P Yes, yes. I even have to think about me pills. Sometimes I think, gosh have I taken me pills (laugh). Emm, and that, that really is emm, it's not a bind it's a worry, to think that for the rest of me life I'm likely to have to take all these pills. Emm, but that's a personal thing from me because I have never ever taken anything that is totally unavoidable. Emm not even an aspirin. Emm and to suddenly find that I've got to take all these several times a day was a great blow to my self esteem I suppose, I'm not perfect anymore. And before that I thought I was. Emm, The way that people react to me, is, in some ways very nice, erm, but in some ways it's almost offensive.

I What do you mean people?

P ever body around me, the guys at work for instance, know what's happened to me, don't do that I'll do that, it's alright you sit there I'll see to that. And, in a way it's nice that they care erm, but erm, it makes me feel, erm, not able to do the things I should be able to do and, not able to, play my part as I would like to play it, I've always been, I'm the one at the front, come on chaps this is what we do. Erm, and I can't do that any more, I don't want to do it I would add, but I can't.

I What about at home with family is it different or is it the same in comparison to being at work? You've just said that your work people make you sit down.

P No it's not the same because Pat (wife) worries all the time, the kids worry if they ring up and I'm not here, Pats not here, Pats not at Jenny's, were very close, our families before she died have been, we've known each other since before we were married. Erm, they then think oh crikey what's happened. Every time they see an ambulance they think is that dad, is that dad? It affects them a lot and in fact Pats been affected really badly with it, the worry of it all. She's been really quite distraught.

I How does that make you feel?

P Pretty awful. (Silence) but, I don't feel I can do anything to change that. Err nor do I think that anybody in the medical world could do anything to change it, your so called wizards. Erm, the, major failing erm, in the way that I've been treated that's led to all these worries is incompetence on the part of several people, erm, and the inadequate control system at the hospital which just destroyed all yer confidence and hers, and that's why she worries. The person that I believe is Dr K. he's the only guy that I've got 100% confidence in. Erm, in terms of the way forward erm, he's the only guy that can discuss things with me in a matter of fact way err, so that err, I can understand what's happening, I can make my decisions, I can explain my problems

Err, all the other people that I've dealt with in terms of doctors and systems have let me down. Erm.

I Do you think that has contributed to how heart failure has?

P Yes it's a worry, it's a big worry, because I don't know who to believe. Pat doesn't, and I'll be quite blunt with you and again I don't know if its (tape recorder) running or not and I don't really care, she rang our solicitor when I was taken ill, emm and was all set to sue, because of the way I've been treated, and the issue at A of Dr D not being available for 4 days, I don't care whose fault it was it's crass, and that's worrying, it's frightening I could have died in there while, everybody was fannying about, saying oh yes this great Dr D is going to come and see yer, and he was a myth, he just didn't appear and didn't appear.

I That affects how you deal with your heart failure as well then?

P Well yes it does because I just don't believe people.

I What about from the point of view, if you were to become ill again, how would it affect that? Would it have any bearing on it?

P Yes it would be a great worry to me. I've had a lot of private treatment and, if I could afford it I would go privately all the time, for the sake of that reassurance, and I would feel a lot happier for it, but I don't have private insurance I have to pay me self for what I do have, and it's bloody expensive for minor things. This operation I'm going to have to repair me valve, I couldn't contemplate paying for that me self, and I know if it was done on the national health it would be a cock up, they would say, well the waiting lists only 6 months, but the waiting list isn't 6 months effectively its probably a year, and when it gets to 6 months before yer can be dealt with, you then you go onto a waiting list, and then at the end of that for my sort of operation if somebody else has something that's life threatening, they'll simply take the place and I'll have to wait, further, so I just don't believe it, and in the interim I could die. If I'd not paid privately for the treatment I've had, I would be out of work now, I wouldn't be able to pay me mortgage, I'd be out of me house emm, and there the things that get home to you at home.

I Did it have potentially any financial implication?

P Potentially, I could have lost me job. Emm, I was off for 3 months. Emm and that stage a decision had to be made at work, how long can everybody else cope and cover? Emm, I couldn't go back to work, the people at work were so concerned that I didn't go back to a stress situation, that erm, I wasn't allowed to go back to work until my GP had actually written a report on me. Not just a, he's fit for work on this particular day, and then what could I do what couldn't I do, what hours could I work. If that hadn't happened I couldn't realistically have continued to do me job. So loose me job, I won't get another job or I wouldn't have got another job with the sort of salary that would allow me to keep paying me mortgage. And so erm, ok, I could probably sell next door, but before its complete, sell next door and then what? So it would have been absolutely disastrous, erm, and that was a great worry and a great worry to Pat.

I Would you say now that worry isn't as much in the fore as it was? Is it still there?

P It's not there for the moment, because I'm back at work, but who knows what's going to happen next month, and the sort of things that happen at the level that I've got too, I simply can't afford to pay, and I do not trust the National Health Service because of the incompetence of the people within it and the untruthfulness of the people sometimes.

I Work aside, how has your heart failure affected your normal day to day activities?

P When I got my summerhouse and it was erected by the people that supplied it, that's the first time in my life that anybody has ever had to do anything for me totally. Everything else from building, central heating, plumbing, car maintenance, gardening, what ever it be I've done me self. Err, when I was not as well as I am now, erm, I had to get the builder in, and talk about what we could do and what we couldn't do and had actually agreed with him that I would teach him to do the things he couldn't do and he would do the donkey work and I'd sort of do the planning and explain how to do things if he couldn't. So it makes it a lot more expensive.

I So you've had to compromise, where as before you would never have done that?

P Yes

I What about the more mundane, chore things around the house in your day-to-day life, has any of that changed?

P Well, when I was eleven or twelve, I had a medical at school and I was told I had a heart abnormality. My father died, I'll say a heart attack, I don't know, but it was heart related erm, death. My mum died of a heart related death and because I was told that when I was young, I was determined I was going to live life to the full and also did a highly stressed job. I fully expected to die by the time I was forty. And therefore put into my life everything that I could before then. When I didn't die when I was forty and then I became fifty I started to become concerned because, I scrambled motorbikes, I played squash, I played badminton, I rode bicycles everything was physical and hard work and it occurred to me, I wasn't dead and really I ought to think about the time when I couldn't do these things, and so I took up clock repairs and renovations, specifically with that in mind, because I was able to exercise my engineering ability erm if needs be I could make money at it, it needn't be stressful, so that was fine.

Erm, purely by accident because I was off work for so long, I started to cook. Prior to that I found that, I'm the man at the barbecue. Erm and I do a lot of cooking now, its not bacon and egg cooking, it's nice stuff, coupled with my need to have a more controlled diet. Where as I would never ever dream of cooking, I've probably in the last 3 weeks, I've probably done two thirds of the cooking, erm, which I didn't do before. Er I've always been interested in reading, music, play the flute, erm those things have not changed and I've started to do. The odd jobs around the house that need doing. Which I didn't do whilst I was ill.

I So what's different now then between when you were ill and now. When now you are starting to do the odd jobs?

P Well what's different now basically is that I come home from work and I don't do anything in the evening. Erm... I would previously have come home from work in the evening and thought well tonight I'm going to do this. It might have been recreate a window or something next door, painting decorating but I don't do it now. I just come home and that's it I'm tired. I tend not to do as much or get as much done at a weekend because I'm not physically able too, I get tired.

I Would you say it's tiredness that is the main problem?

P Yes, I think so.

I Have you had any changes in your emotions, mood, concentration?

P When it happened I changed, my personality changed which I have also explained the also get up, come let's do it chaps, got up and went. And, I tend, not too.... be so... erm assertive, dynamic and I can't be bothered arguing.

I Why do you think that is?

P I've got no idea, whether its some sort of self preservation thing from when I was ill, I really don't know. But when I woke up, or came back to earth after the second incident erm the world was a different place. In terms of emotions... my emotions have changed dramatically, I am a lot more emotional in terms of soft hearted than I was prior to this happening. Erm and I'm much more conscious of simple things in life. A blue sky, a bird singing, when I was in the coronary care unit, every morning I would wake up and there was a bird singing in the tree outside that meant nothing to anyone else. And then just before I came home I had a couple of days in the Lindsey suite. No birds or trees there, I would much rather have gone back to the coronary care unit and been able to open the window and hear the bird singing. It sounds daft. And in fact an issue tonight when on Sunday I had more strength than I should have, and the ladies in there were mocking me tonight because you're sat there and said how nice it is to be able to sit here in this nice warm room, we had the log fire going and the family were there. And I just sat and thought this is grand and because I sat there and said it was, they didn't understand. And those sort of things mean a lot more too me.

I Do you have conflict, you said they didn't understand what you meant does that cause you conflict? Do you get frustrated at that?

P Not really because I've been there before, I feel sorry. Erm for, people who don't realise that. And in fact there an issue when we have finished this that I want to discuss with you about Pat. Erm and my retort at that time was if she goes on the

way she's going and her life goes bang and her life falls down around her shoulders, she'll understand then exactly what I mean.

I Would you say that, that's a good thing, that out of all this?

P I do. I often think that I wouldn't wish what has happened to me to happen to my worse enemy, but I think that every body would be better for suffering what I have suffered or something similar. The world's a nicer place and people in it are nicer, without a doubt.

I Talking about your relationship with Pat, how has that changed at all now that you've got heart failure?

P Yes.

I In what way has that changed?

P She frightened of everything that I do, erm and worries continually.

I Does that happen in reverse?

P No, no. I've never been a ringer up. If I drive to the other end of the country I wouldn't dream of ringing up to say I'm here. When I was little I used to go out on me push bike and I'm talking about 11 or 12, and I'd go off to Scarborough, likely, Skipton places like that, at a weekend. And never ever think about it, my mum never worried about me so long as I had a little piece of paper saying who I was, erm I've never bothered about those sorts of things, but a lot of people today do worry about them. If we come home and we go to see her mum, she rings up as soon as we get in, "were home alright" Erm, and I've never done that.

I You mentioned that she gets frightened, is there anything else that changed in your relationship?

P No I don't think so.

I What about physical issues?

P Bonking? Erm, she frightened of that as well

I Has that changed at all since we spoke?

P Erm the other thing about that, is that also, she is hormonally unstable and has been for.... a while and that affects her as well and that will also be contributory to those problems. For a number of reasons. So part of it is her state of health and part of it is mine, but ye it frightens her and I do think she makes excuses, to put it crudely, rather than say I'm frightened I don't want to do it.

I How do you feel

P Well it's frustrating, I'm not at all frightened

I Why do you think there is the difference between you?

P Because she's had to sit and watch me in the state that I've been in while I've been ill and that must have been pretty rotten for her. She also thought that one of the incidents resulted from bonking. Which I don't but that's bothered her.

I What symptoms do you get that have necessitated you coming into hospital? Tell me, describe what happens

P Well you must remember before that, I was hospitalised I often couldn't sleep in bed, I could only sleep sitting up and that went on for about 6 months because no one seemed to believe what I was saying, that I was having difficulties and it was only when I became so concerned that my health was deteriorating at such a rate that if something wasn't done about it in another 6 months I didn't expect to be alive, and that when I went off to see Dr K and put it too him in those terms. Erm, but the events leading up to the incidence the first signs something was going to happen, that I didn't know for the first couple of times. Was a strange sort of crackly noise that was coming from deep inside. A bit like if you've got a cold and you can't quite clear your throat, I were to breath out as much as I could... the last little bit would be this crackle. Erm, and about 20 minutes after that I couldn't breathe. I've learnt now the difference between short of breath and breathlessness. And I became rapidly and increasingly short of breath erm to describe that, if you imagine you are lying on the floor and there was a weight coming down on your chest that was supported so that each time you breathed out it would go down but wouldn't go back up again, so that gradually each breath became progressively shorter. To in my mind it would only be a matter of time before I couldn't breath at all. I am claustrophobic which doesn't help that situation, I have to say the first couple of times I panicked which didn't help. Erm and then it was a case of wanting the ambulance people to do there bit.

I Did you get chest pain or any aches?

P I've never had any chest pain in my life, I've never knowingly had palpitations. Erm people have described them to me and I can't relate to that at all.

I So if you were to get anything this crackle or breathlessness what would you do?

P I would squirt the fly spray down my throat, take a couple of Frusemide and ring for an ambulance.

I Would it frighten you?

P Yes. The other thing that happens you gets hot and start sweating. Before the breathlessness really get hold of you, or me I don't know how it affects other people. I get very hot and sweat like hell.

I Have you had any of these symptoms when you have been say up your ladder, or anything around the house, or at work?

P I could do it now, if, if stood up and looked up at the light I won't go dizzy but I would feel light-headed and a sort of achy

I What's the difference between that and what would bring you into hospital?

P There's no crackles and no shortness of breath.

I Would you say your now in a position to know what you need to be concerned about?

P I think that I know all about it know from my point of view. Answer your question I know what I have to do the things that concern me are one am I going to die, which I don't think I will do now. 2 when the ambulance eventually gets here are they going to be able to put a cannula in me, you go cold. Your hands and feet go cold. Erm and will they be here in time to get it in because they won't drive the ambulance away until they have and on one occasion I was outside in the ambulance for about 20 minutes. It was absolutely terrible, And then because we were able to respond more quickly to the situation the ambulance arrived sooner and my veins hadn't shut down or what ever they do, and they were able to get the cannula in to start with. And give me, I think it was Frusemide they gave me, they also gave me something else which made me sick. Erm, which was an inhaler thing, and that is really all I can do. In my heart I will be very surprised when this happens again, in my heart, I believe that, the issue was caused totally by fibrillation, that was there all the time and the fact that the condition of my heart has improved makes me very sure that that's the issue. And if that doesn't come back then I don't expect that I shall have to call an ambulance again. If I can go ahead and have this valve repaired I expect to feel better than I ever have to be quite honest with you because I believe I've had this leaky valve all me life. And I think that what they told me when I was at school but because so much wasn't know then about hearts, what ever was wrong with you, oh he's had heart attack and 6 months later, do you remember that guy that had a heart attack, well he's died now, and there it ended, there wasn't any understanding or discussion, or the response that you have today or the service you give. Erm, that is without doubt the most reassuring and helpful part of the whole exercise. But going back to what do I understand about it, that in a nutshell is what I believe and believe firmly. Erm. And I also believe that had the doctors that I saw believed what I was telling them and responded to it, rather than use their own prejudices and preconceptions that I don't think I would have been in the state I was in. And I feel very strongly about that but I'm not going to blame anyone because I've decided not to do that. If I'd wanted to take issue I would have done and I've persuaded Pat that we shouldn't the last thing I want to be doing is taking on some National Health Service barrister, in my condition and I didn't think that she was able to without my help and so I let it go.

I It's a shame you have to let something go like that because of your heart failure, is what it boils down to

P If this guy and I don't care if this is taped, because I've told Dr K and I'll tell you. If I ever see him again I shall punch him, I'm quite serious, he was ignorant, bigoted and conceited to a degree that's almost incredible.

I So you if you realise it or not your heart failure is stopping you from doing something, but previously had this not been related to a health issue you would have gone full steam ahead and dealt with it?

P Yes, oh yes, yes, yes.

I Let's talk about the future then. Obviously there is a major event happening next year (wedding). How do you see things in terms of the future, are you somebody who looks to the future and plan and is that different now?

P I only plan things in the future in terms of not expecting to be alive. I set up my pensions according to what I felt was likely. In my motor biking days I suffered a severe injury to my knee, which stopped my motor biking and ironically enough started me playing squash, because I was so frustrated by it I thought I would either live life or knacker it completely and something would be done about it. And that was my approach and I anticipated if anything that I would not be able to work because of this injury to me knee. I never considered really when I got to 40 or 50 the heart issue, I thought well I'm living on borrowed time and still think that. And so no I don't look forward. My looking forward is tomorrow I could drop down dead. So there isn't a future for me. And yes it'll be interesting this exercise next year if it goes ahead.

And until someone sends me a letter and says come in were going to do this on such and such a date, that's the national health, I can't afford that. Then I won't believe it. Even though Dr K pushing he's up against a useless system. If and when that happens it holds no fear for me what so ever because tomorrow I might be dead anyway.

I Getting away from medical sorts of things, do you look to the future in other aspects of your life? Social, family, work?

P For work I've had to look at the issues, for family things there is the impending wedding. It sounds really hard to say it, but if I'm there and there and if I'm not I'm not. That has to be planned it has to go ahead. Erm... at work, my absence rather than my illness has caused a lot of things to come to light. That are weakness in the system and reflect on my realisation on problems beforehand. As I've said to you I was very much a right come on let's get on with this, if something need to be done I would get on and do it. This has led to a number of failings in that there are lots of things that nobody can do because I've not written down the procedures, I've just gone and done them. The worst of which sounds absolutely ridiculous to sit here and say it is that in 1999 I designed and built a mill to grind things like salt into very fine salt, not an engineering mill to run under liquid nitrogen, it's quite a complex piece of equipment, and we set it up and we've done all sorts of trials, and now we are to date half way through the first big job for it. But I've never shown anybody to set the temperature that it should run at, because, why I don't know. And now I have to think forward that I might not be there. Every little detail I have to write down and train people. Even if it's a minor issue I think, shit nobody knows how to do that so I type a little memo saying this is how you do it. I have to think ever so closely about mundane things at work and there are so many and I am really, really surprised.
My home life, no I think that it runs along and will continue to run alone until I don't. in spite of my life expectancy, I've made plans that should leave Pat and the family comfortable, so there isn't anything else that I want to plan.

I Is there anything else that we haven't talked about that having this heart problem affects your quality of life?

P There is yes, and that is still my day to day finances. I am absolutely terrified that the bank will find out that I have had heart failure, because I said I would live life to the limit and I have both financially and physically and I've been in a few spots in my life, not desperate, but I've always had the confidence of the people around me. The people around me are people not numbers and the financial world people tend to be rude and change specifically to stop them becoming friendly with their customers or clients. And there is an increasing moving to telephone banking. That means to me that I don't mean anything to anybody at the HSBC. And who ever looks at the annual review knowing that I've had heart failure will see my affairs differently and it bothers me.

I Why does that bother you?

P In case they decide to squeeze me so that they don't loose anything. Obviously I've had card cover and I thought this is nonsense. And I thought this is stupid and so I cancelled them all. I then thought that might have been silly. So a month later I put it back, but it means nothing because my condition predates the start of it. I can't change pensions or my job, well I can't change my job now because my career's over. There the sorts of areas were there are other things

I So what you've got your stuck with?

P Yes. Other than that life's fine and full of wonderful people.

Appendix 3

12/11/03

Interview 2

I I am interested in how heart failure affects your life.

P To me, I've been reading up on heart failure and it seems to be a non-entity subject to me at the moment. Because when I was in hospital I said what's caused it. Nobody could really say what's caused it. They only found it out accidentally that I had this heart failure problem by going for the scan. Because to all intents and purposes I was in there with oedema, and I said to Dr B well what causes it and he said I don't know. You could have had it all your life. He says you could have had a small heart attack because he asked me to relay it back, think back to any time I've had chest pain or anything like that and it's just that Lynda and I sat and thought well what causes it, why has it suddenly come on, why has it come on? But in hind sight when I was at work, I had quite a stressful job in that I was in charge of a lot of blokes and there were a lot of problems with them ringing me up at quarter past one in the morning saying could they have the day off, but that's by and by. But I was on shifts for quite a while for twenty odd years and towards the end of that I was noticing that when I was walking, I wasn't getting short of breath but I was getting I was getting a queer feeling here, like a bit of a sicky feeling, and that's the only symptoms I had, and this is what puzzles me about this heart failure, because it's a joke because people say how are you, so I keep saying I feel fine, its those at the hospital that say there's something matter with me. And that's how it feels to me. Sometimes I feel if I went to see another specialist he'd say no there's nothing wrong with him. Obviously it isn't that way, but that's how it feels to me.

I Do you think its because you can't see it?

P It might be, the only way it does affect me, I think is that, I can't, when I used to be on shift work, I used to be up at quarter past four to start the six o'clock. I'm not one that can get up and sit about. I used to get up and get on. I was always at work at ten past five anyway. I just can't seem to do that now, I don't think that it's, I can't do it, it's that I don't want to do it. I feel better if I sit down. Ye see I've taken some of those tablets this morning, I take them and then I sit down for half and hour, then I feel as right as rain. I sat down, I had me tablets, in fact I had a kip for half an hour on the settee, just sat down watching television and then we went off walking and that lot you know. I feels as right as rain, I just don't feel I can do that now.

I Is that a problem to you, do you find you get frustrated because you can't do what you did before?

P I do get frustrated because I can't do what I did before, because Lynda stops me doing a lot. Because the other day, I don't know if you've noticed but in the front garden we have two big pots, full of soil with buxom plants in them, and Lynda was away and I picked them up and carried them down the back me self. And she played hell up with me. Then I think to me self well may be it is a bit silly. But things like that do frustrate me because I, I can't do what I used to do. Maybe I could if I really tried, but I think I would be putting me self under unnecessary pressure. But there again, I don't like this feeling of maybe mollycoddling me self. They tell me Dr B told me, Dr G told me, Dr A told me, I can't climb up hills, I can't go up hills now what, I was walking in the Lake District and did 8 miles, it didn't bother me at all. I go up the shop it doesn't bother me, I think to me self I could still go up, now that does frustrate me because, I feel fitter now than I have done for 5 years. Me weights better now than it has been for 5 years, and the one thing that I used to like doing, going up there, I can't do it and I feel I'm in a fitter condition to do it.

I Is it that you physically can't do it or is it that other people are telling you not to do it?

P Other people tell me not to do it. I could do it, I'm sure I could. I can maybe not do it as fast as I did before. I could walk a while and then stop, a while and then stop, where as before I used to go straight up. But I'm sure I could do it, it's only that people have said no you don't and I think really it would be stupid to take no notice of what people in their professional capacity have told me to do. So I don't do it

I It's not a choice you've made then?

P It isn't, it isn't my choice. I spoke to Dr A last time I was talking to him about it and he said you probably could go up and you would get up there and feel great and then you would probably get up there and few who, feel a bit tired. He says then when you start to come down you maybe feel queer then you are putting your own life in jeopardy, your putting the people with you at jeopardy and then they'll have to send someone out to get you at jeopardy. He said make no mistake about it, it could happen irrelevant of how you feel. So would be foolish not to take notice of it wouldn't I? That gets me, I used to go to school coaching football and in coaching them I used to play with them, run about with them and he said don't do that, don't do any jogging or anything like that, so I packed up. As far as I was concerned if I couldn't do it I didn't want to know. It's maybe a failing on my part, but if I can't do it, I don't want to know.

I Suppose in that situation there is no compromise?

P They've been on to me about going back to school now, are you coming back? Lynda says no. I don't know I might do later on it depends how things are going, if someone says referee the odd match should be ok, then I would do, I certainly would do. And is really the only thing that affects me.

I What does quality of life mean to you?

P What now?

I If I ask about quality of your life, what would you take that to mean?

P How much I can enjoy living, virtually.

I In terms of how you are now and how you have been since you were told you had heart failure, how has your quality of life been affected?

P It's improved actually, it's improved. That might sound silly to you but it has.

I Tell me why it's improved

P During the last, I was gradually getting worse and worse, I can't understand in hindsight why I didn't realise it. Dr B said that this is what oedema does, it affects your reasoning. He said you wouldn't realise how ill you were. But still to this day, even when I'm talking I don't realise how ill I was. But gradually I slowed down and I

mean dramatically slowed down. Even if I was going up stairs it was a matter of going up one step, feel it pulling, it sounds silly i know, but this is how it had got. I couldn't sleep, I used to prop me self up at forty five degrees in bed to go to sleep, because if I laid down I kept feeling as though I'd stop breathing.

I What did you think was the reason for that at the time?

P I just thought it was, well I'd put quite a bit of weight on because I had this oedema in the legs and all that lot. I didn't really know. To be honest I didn't really know, I didn't realise how bad it was. I just thought, I thought I'd just got some fluid on me knees and legs and it just felt like fluid. Just before I went into hospital I realised, I'd been leaning on me knee and as I took the hand away, nothing happened, there was a big indent there where my hand had been. But it didn't come back up, it just stayed as a big indent there and I thought well that's a bit queer. But I honestly did not realise how bad it was.

I Were you seriously compromised then without realising it?

P That's right, it got worse, I got to the stage where I used to sit down and I couldn't get up, it's laughable now but I couldn't get up. My son he's 28 and before he went to bed at night he used to pull me up out of there and sit me on a straight chair where I could get up and everything was getting so that it was pulling on me I used to stop and take some really deep breaths. Everything was governed by breathing deep before I dare think of doing anything. If I walk from the back door to the gate I was exhausted when I got to the gate. My heart felt as though, I used to stand and feel me pulse and my heart was going bum, bum, bum, bum, like that, there's something the matter, but there can't be. Til it got to the stage where I just broke down in tears because I couldn't do anything. Dr B came to see me, he said you've got oedema bad, in fact it's the worse case I ever seen. So I said in the course of time what would have happened if I hadn't of said something. Well within a fortnight you could be dead. They did find some liquid in me lungs, it had gone up to me lungs, me ankles up to here were just solid. I had a poor quality of life up to then.

I What is it like now?

P It's absolutely fantastic, I feel one hundred and ten percent. I do honestly; I often sit and think to me self, why do I feel so well in fact I used to say this to Dr G. He used to say, you well Mr W and I used to say why do I feel so well cause I feel wonderful, he said good. So, but, I still get, the only thing I have is this bit of frustration that I think I can do more than I should than I do, I think I could, like going up fells and things like that, but I daren't do it. Possibly if I attempted but obviously I can't, I could do it, but I daren't do it and that is the only thing, that as quality of life goes, there are certain things that I daren't attempt for fear of anything going wrong.

I Is it the fear, because people have told you that?

P I would be foolish not to take notice, wouldn't I?

I You thought you were bad because of all the extra fluid do you think it was a weight thing and because you have lost that weight that is why you feel so good now?

P No, I don't I think it's more than that.

I What else do you think?

P It's psychological as well. Psychologically I feel better, I feel more alert in me self. It's easy in hindsight, but looking back, I was getting bogged down in life some how. Things upset me easily but now they don't. It's the same as I've said to you nothing bothers me now. Obviously, it's not the tablets that making me feel that way, it's an attitude of mind that's doing that.

I Do you think the tablets have any bearing at all on why you feel so good? If you stopped taking your tablets would it make any difference?

P I don't know. The only thing I do know is that one day I forgot to take them for some reason, I cant remember what it is, oh I do know what it was, it was early on, it was when I had to go to another hospital they were supposed to be sending an ambulance car for me, I had rung up and asked if Lynda could come with me and they had said yes. And at the time it was supposed to come it was an ambulance

that drew up and they came down the drive with a pushchair because they thought I was a walking wounded. They got it all wrong. They said to Lynda were you thinking of coming and he said sorry there isn't room. So she stopped at home, and I was taking the tablets with me and she had the tablets. So by the time we'd gone through all this lot and got home it was two o'clock. And I hadn't had any tablets and I was beginning to feel a bit tired. I think that's best way to explain it, tired and very, not panicky but a bit worried about having not taken them. And that's the only time that I thought I had but I hadn't had the tablets. I've said to Lynda I wonder what would happen if I didn't take the tablets for a couple of days. I would never attempt that.

I Why not? What keeps you taking the tablets if your not sure if they are making a difference?

P Because they've been prescribed for me to me to protect me. This is what Dr A said to me when he wanted to put me on beta-blockers. I said why do I need to go on beta-blockers? He said well to be honest with you to stop you having a sudden death. So I was a bit taken back. What do you mean? Well fifty percent of heart failure patients die suddenly for no reason at all and these beta-blockers help prevent that. So I said right, that good enough for me, I'll have some of them. He said he wants to get me up to a maximum strength five or ten, I can't remember, as soon as possible, I said I'll start taking the full strength one now, he said you wont. We have to build it up and I said fair enough. That's as good as a thing as you need to be told that. So, its just the fact that, I've always been a person that if I want some joinery doing I get a joiner if I want some brick work doing I get a bricklayer to do it. Because I always believe that in the end the profession is the thing that counts. So if a professional person like yourself says you need these tablets then as far as I'm concerned I need them and I take them.

I Do you ever have any times when you are concerned or worried about anything in relation to your heart?

P No

I Do you think that's because you feel good?

P I don't have anything that worries me at all. Going through to basics, Lynda and I have been married forty odd years. We've never been apart we've lived in each others pockets and all the time whenever we've never had separate holidays we've always been together. Whatever I've done Lynda's come or whatever she's wanted to do with J we've done together and our two kids both of them have done well there never given us five minutes anxiety in their lives. And K nearly forty and I is twenty-eight the basics of life are very good. My daughters married she's got a good house, a good job she's ok. L works at Chorus he's in construction, so everything, nothing to worry me really. Consequently now they've grown up nothing worries me. Consciously nothing worries me. As far as I'm concerned if anything crops up it would have to wait, it would wait until, I could deal with it in my own way. Because that's the only difference now, as what I intend to do is. I'm in the fortunate position with having heart failure problems; I'm in the fortunate position that I'm retired. I think that takes a lot of pressure off. Because if I've something to do and I don't feel like it doing it, I don't do it. If you work shifts and something wants doing you wait till your two days off and pack it into those two days. You find out your working seven shifts on and when it comes to your days off you've got to pack in more in two days than when you are at work. So you're under more pressure on your days off than when you're at work.

I Is that how you were?

P Yes, ye. At one stage when I was on days there were four hundred odd blokes, I was in charge of four hundred odd blokes. And I used to get phone calls at quarter past one in the morning; I can't come to work in the morning. You go back to bed and you think, what am I going to do, I'm going to be some men short. You don't really get any quality sleep. That's the other thing I've noticed since I came out of hospital. I sleep not one or two percent. Me, I go to bed and I don't hear a thing. The only time I hear anything is if Lynda gets up to go to the loo. That's the only time I wake. I don't take any tablets after lunch at all. I take one frusemide, losartan and beta-blockers in a morning and then I take another frusemide at eleven or twelve o'clock and that's it. I don't take anymore we don't have supper at all. We maybe have a cup of tea or a glass of ginger ale stuff, that's all.

I So were you retired when you had your heart problem or were you still working?

P I was retired. I worked on British Steel all my life. The job was fairly stressful there was a lot of work to do and it was all down to pounds, shillings and pence in the end. And it's worse since I've left. I felt all right when I was at work; I used to get very tired. I used to come home and I was supposed to work when I was on days eight to four and I was always there for ten past seven in a morning and some times it was five when I got home sometimes it was six, sometimes it was half past. It was never four o'clock unfortunately, but I used to love me job and I used to put a lot more into it, Lynda used say I was carrying the people I was with, maybe I did. I don't know but I didn't notice it at the time. But I did notice that I used to get very tired.

I What about now, do you find you get tired now?

P No, its unreal, health wise this is the best thing that's happened to me. You see Dr B said it could have been with me from birth, it could be a heart defect from birth. He said you could have had a heart attack. I told him I used to be a part time professional footballer, and he said it seems strange this having been a professional footballer that you've got this problem. You see, do you think it could have been related in any way. So I couldn't think of any. Then over a period of time I used to think about it, I used to think when I was playing football I used to train Tuesday nights, Wednesday nights, Thursday nights and maybe playing up at Newcastle or Sunderland on the Saturday getting home at nine o'clock at night and I was out. We never used to train on a Monday. Come the Monday it was a detox day where you never ate anything at all you just drunk liquids that's all. But on that day I really did feel tired. I used to find it an effort to go training on a Tuesday night. And then I'd think to me self; if I had this problem it was maybe showing up when I was training hard. It may have affected me training. I don't know it might not have done.

I How long ago was that, what age were you?

P When I started professional when I was seventeen up to twenty seven.

I A number of years ago and there certainly wasn't the ways of investigating things like now

P No, going back to what you said initially my quality of life now is absolutely great.

I Have you had to make any changes in your life style?

P I do watch me diet a lot more I see the dietician at the hospital. Off me own back I decided to go see him. And he said do you think it fluid or do you think it's fat? I think it's fat, cause been on holiday and eating and all that. I do watch me diet a lot I don't eat fat at all. In fact the dietician said I don't eat enough variety. I said I was getting fed up I was starting to eat a few biscuits, things like that, he said why because mainly difference in taste. So he said to Lynda, do you bake plumb bread, she said well no we stopped since he's done this, he said no let him eat a couple of slices of plumb bread because the sugars that your getting are natural sugars. So I maybe a slice a week I eat low fat ice cream so I do watch what I eat.

I So that is different to be for is it?

P Yes, I used to love food, I've cut down on potatoes, I was at the dietician a fortnight ago and I said I want to lose some more weight. So he said what will do is start knocking carbohydrates on the head and reduce your carbohydrate load because he said what he thought was happening because I was getting that fed up I was binging out on carbohydrates. I'm one of those unfortunate people I only have to look at food and I put weight on. So I consciously have cut down on carbohydrate intake.

I If somebody was to say to you a couple of years ago you will be seeing a dietician and you would be enjoying what you're eating what would you have said?

P Rubbish. I would really; the thing that kicked me hard was going into hospital. Because for breakfast we used to have a weetabix and a slice of wholemeal bread. I was famished absolutely famished when I first went in and come lunch I'd get potatoes well it was stuff like smash and I couldn't eat that anyway and I used to have the steak or what ever it was with it and then tea time, I said to Lynda oh I'll have some fresh fruit and I got an apple. Eight o'clock the girl used to come with a cup of tea and I used to get a couple of biscuit off her. Then we'd wait for the drug squad at ten o'clock and they used to make us a cup of tea and I used to have another two biscuits. Then come breakfast time me tongue was hanging out for something to eat. But that did the trick in that it brought me down into relatively small portions of food. We maybe have a curry once a fortnight but before it was twice a week, and fish and chips we have maybe once a fortnight but I only have half a dozen chips. The dietician said it doesn't do you any harm provided your not doing it on a regular basis. It has educated me a lot.

I Is there anything else from a life style point of view that's changed either for the better or worse?

P I think I'm a lot more tolerant of people. I always been a good listener but I could segregated what I was listening to some things went like that and some things went like that.

I Why do you think that is?

P It because I've got time. One of the things that I have to do is, when this problem I've got, that people tell me I've got, I don't think I should have a sedentary lifestyle. But because I've got the time to do what I want when I want, I don't feel I could sit back and ignore it. But I am aware, it's religion to me that I go walking every day, some days you can't. Normally were walking from half post eight in a morning.

I Is walking something new to you, since your heart failure?

P We did it before, we've been going to the Lake District for twenty odd years. But not on a regular basis. We used to go walking; we spent more time up at Bridlington in winter than anywhere else. But not on a regular basis like we do now. I'm maybe paranoid about walking on a daily basis. But Lynda enjoys it and it does her good.

I What makes you walk religiously on a daily basis? Have you chosen to do that or have you been told to do it?

P No I chose to do it. Dr B said when I was coming out, make sure that you do some walking. Quite a bit of walking, so I said ok I go walking every day. He said if you do, that will be fine, but I'm not saying every day. And then when I used to go back to out patients Dr G used to say are you walking regularly and I said yes, he said good. He said how many miles, well first time I went back, I used to walk a mile in a morning, so he said up it, up it. Now we go out and we walk, well in the Lake District, we walked eight miles and six of those we did in two hours and it's not on roads, it's on the Lake Derwent shore line. Before if it was raining like this morning I wouldn't have gone, I'd of said sod that. But this morning we went. We had a good walk. Then we had a drink and then I went for me flu jab, I pottered about in the garden, then we had some lunch. Yesterday we didn't go because we didn't leave the hospital till half past five. The fact that we didn't go walking yesterday you just walk a bit further today or faster. If the weather is bad we walker faster. So that's what we do. I feel wonderfully fit I feel fitter now than I have done for years and years. It must be the type of lifestyle I lead now, it might sound silly but if we have a day when we don't get walking we feel you know we could have done with a walk today. Sometimes we both said after tea we'll go for a walk and we have gone round the streets. I might be paranoid about it I don't know, but if it keeps me ticker going ok I aren't bothered. That's paramount to me and its paramount to Lynda and the family?

I What difference do you think your heart failures had on your family?

P She worries that, she worries that I sometimes do too much. She's worried that I will do too much. Sometimes when I walk, walking and talking I go where's Lynda, when I look behind, she's behind, she says just slow down your going too fast. I say what for you or for me. No you're walking to fast. Actually she's good for me because she makes me stop and think before I do things, which before I wouldn't have done, you know. I would have gone up a ladder and cleaned guttering, now it's me not doing that. Both the kids, they like to see me ok. If I was to sit there tonight and L was here and I didn't say anything for twenty minutes he'd ask me if I was ok. It still worries them, I worry Lynda. I keep saying I feel ok. She says are you sure you do and I keep saying ye I feel ok. The fact I feel ok and I can do things and it doesn't bother me, like going up stairs and I'm ok, I don't think about it, I don't think about it. I don't know whether it subconscious putting it into the background or not, I think if you want to do it, do it. If it's safe to do it, do it.

I Do you think if you were getting symptoms like before you'd be more concerned?

P If I had any symptoms at all I'd ring the nurse. I just feel great. If someone said to me we've got I wrong you haven't got a heart problem, I could believe it. That's how well I feel, maybe a good sign, it maybe isn't. I do feel sometimes, Lynda will say you're not doing that and I say why not leave me alone and then I think she's maybe right. Sometimes we take L dog for a walk and he's run off and I say to Lynda I'll hide and I just run off behind a bush and she says you shouldn't be doing that you know, but I do it as a matter of fact because I just feel as though I could and you know everything is ok. I don't get a feeling of molly coddling me self, because as far as I'm concerned I'm not ill. It's you lot that tell me there's something the matter with me. I don't know that there isn't, it's you people that tell me there is. That's about weights it up. I wish I could have felt like this ten years ago.

Appendix 3

26/11/03

Interview 3

I What does the phrase quality of life mean to you?

P What you can do and what you can't do. Is it worthwhile? There are a lot of things I can't do any longer, some of those bother me some of them don't. You have to accept the way you are because it's not going to change. So you put up with what ever's there.

I How does heart failure affect your day to day life?

P There's nothing positive at all. It's been a gradually thing. What you find is, the greatest indicator is the garden. Since I've not worked, I've taken a great interest in the garden, because it was something to do. Now I can't bend, well I can but, after thirty seconds of bending, that's it. So I've tried to rearrange the garden, well I got other people to rearrange it for me so most of it can be done on my hands and knees and as long as its, not over reaching I can do quite well. But I've noticed year by year it's got more and more difficult and I can't do as much and basically I only do, you limit yourself to a maximum of about fifteen minutes and then you come inside and sit down for half an hour, read the paper get your nose into a book, listen to the radio or a cup of coffee or what ever and then back out for another fifteen minutes. It's the same if your doing anything around the house, fifteen minutes maximum otherwise all of a sudden, the chest tightens up, you're out of breath and if you ignore that you start going dizzy and that's it. You get used to limiting yourself to the amount of time you're doing something. Then you notice year by year that you're doing less. And this last year, well the gardens a disgrace, but I don't give a monkeys because there's nothing I can do about it right here and now. Probably come February if we get some decent weather that'll be the time to get gloved up and go out maybe ten minutes, fifteen minutes and then back in again just to clear everything away.

I Is there anything in particular, indoors that you struggle with?

P Oh ye, I have somebody come in. They come in once a fortnight, I could do with them once a week but I can't afford that. She does all the hovering, changes the bedding because it's a quilt. I think the last time I tried it three or four month ago, ooh, I was on the bedding, the quilt was on the floor and I was fast asleep and I didn't give a monkeys. Anything that's reaching, stretching, lifting, it's not much of a thing. The hovers upstairs, I'd be struggling to get it downstairs, I could do it but I couldn't use it for about an hour afterwards. I flick a duster around if it's obvious but basically it can go a fortnight. The bits I use are clean, the bits I don't use, why should I dust them? Because they'll get done once a fortnight.

I Is this a compromise for you?

P I've always been on my own, so I've always been used to looking after me self. So I've always kept the place clean. Where as now, it's a case of the bits I use and if I see a bit, dust somewhere else can wait.

I Does that frustrate You?

P Sometimes. But where you do get frustrated is, like when I go to town, finding somewhere to park. And then you've got to walk. And again the walking gets less and less and less. I'm all right on the flat, but if you go to town, nearly everywhere there's a slight incline. That's, it seems laughable because its so slight but it does. It may be all right going down but coming back up. I try, I walk to the paper shop every morning, it's a bit less than three hundred yards, but the last bit, I get to a slight incline and that takes nearly as long as walking form here to the end of the road. And again I have to stop three or four times, I either just stop and get me breath back or hang on some bodies' fence. Then that is really frustrating, its not bad at this time of year because I try and go when nobody else about so that nobody can see you. Because you don't want nobody else to see you, hanging on to things and trying to get your breath. Although that has improved since I came out of hospital and got rid of the water on me lungs.

I Why does it bother you about people seeing you?

P You don't really want it. I'm fifty-seven and people say well you look well. Hem, and I do, look reasonably well, but you see some of the other poor soles. Quite a lot of the time I feel a bit of a fraud because I start to do something, but I'm always fine until I do something. Mondays I put that board up for the dogs because she's got another dog that won't get on with her sisters dogs so there round here quite a lot, so I leave the back door open so they can go in and out but they won't go over the board. But of course on Monday that board has got to be move to get the dustbin out. Again I can do that but I don't move the dustbin up to the gate for up to an hour after that. And I don't go out when it's windy. I don't go round to the paper shop on foot when it's windy, I go in the car. Basically on windy days summer or winter I don't go out unless I've got to.

I Have you learnt that through experience?

P Oh ye. It just takes your breath away, and your struggling to get your breath all the time and you sort of get into a cycle where your trying to catch up. When it first started, you think, I said earlier you give your self fifteen minutes in the garden well it would probably only take another five minutes to finish this little bit, if I get this done know, it's, it's like your short of petrol and you need to get to a filling station so you go faster to get there quicker, and your using more fuel and the chances are your not going to make it there. And that's just what it's like on windy days, it's, it's a no, no. In fact I can get breathless listening to it. Stairs, stairs tend to get better during the day until, probably four, five o'clock and then they seem to get harder again. I probably have to stop at least once climbing the stairs and if I've forgotten something and I've been up stairs and come down again, it stays forgotten. Until I feel like going up again. Again, a silly thing, it sounds disgusting, but it's practical. I pee in a bottle, which I keep under the sink a big two litre Comfort bottle. And then, when it's eventually full I go up the stairs and empty it down the toilet. But that's one trip instead of five or six. If you drop stuff, and you don't need it, it stays dropped, until, you go round shove everything together and get all in one fail swoop. I keep meaning to get one of those sticks, like the park keepers got, to pick things up, I keep meaning to get one of those. I never get round to it.

I What are your main symptoms?

P To be quiet honest I've not had that many symptoms, in the early days I used to, you feel a tightening in the chest, and if you didn't sit down and stop what you were doing then you would start to go dizzy and there was a chance of you going over.

I've not had that for a long time, basically because I don't let it get to that stage. When I went into hospital I passed out and I came too on the bed in the middle of the night, the only reason I knew there was something wrong was because I'd tried to batter my head through the carpet, went to the doctors, ambulance and straight in. This last time, I went along to see me doctor because I'd put four inches on around me waist in no fine flat, me ankles had swollen and I was struggling to get me breath. The breathing thing had been coming on for three months I think, but not the rest of the swelling and I told that the lungs were starting to fill up with fluid. And that was making things much more difficult getting in and out of the car. And again I'd taken to parking the car on the street, cause it hasn't got power steering and to try and get out, when other people park, I thought sod it, I've as much right as every one else, although I don't like leaving it on the street. It's one of those things, it's easier, so that's what happens now. Prior to going into hospital last time I'd get into the car and sit there for two or three minutes because I was out of breath. But that's changed round dramatically, that a mega plus since coming out.

I Has your medication changed?

P Oh ye, drastically. I was on one water tablet, I'm now on four, plus they've thrown another one in, Digoxin, beta blockers, too many. Again I'm a bit concerned about the water tablets because quite often I feel like I've been squeezed by a Sumo wrestler. Whether it's the kidneys or what I don't know. But sometimes, it was more so in hospital when I was getting rid of the water. But sometimes now it comes back a bit. It just feels as though someone has really squeezed you hard. But, no the whole thing has been going on that long I don't really notice a lot any more. Sunday, I woke up on Sunday morning and I was conscious of my heart and I knew something was wrong, don't ask me what it was because I couldn't tell you. I was conscious of my heart all day Sunday. I was a little bit frightened as well. Monday fine. I am falling asleep quite a lot, but that's been an intermittent thing ever since I've been off. In 2000 they diagnosed me as having diabetes and put me on metformin, that a total difference. I wasn't falling asleep all the time, or I seemed to have a lot more energy, but that, the effects of that seem to have tailed off. Again, in 1996 or 1997 before they gave me the electric shocks, no it was ninety six, the only way I can describe it is, it seems as though the previous six months I'd been living under water, it was so much different, it was that bit easier to move, oh so much freer and that lasted about a week and away it went again. So I had to have it done again and it didn't work a second time around. Erm, but now I'm less inclined to do things any way, erm, I think sod it I'll do it tomorrow, and tomorrow you don't want to do it. I've bought two coat hangers down because there's two shirts in there want ironing, but whether they'll get ironed I don't know. But I've now got the coat hangers downstairs, to do it.

I You mentioned on Sunday that you had this feeling in your heart but you didn't know what it was, but you were frightened.

P I was frightened later on in the day because it had been that long, and it was, it had moved, from a bit of indigestion to a feeling of unease all round, and then pins and needles in my arm, I slept most of Sunday in the chair. I got a meal ready on Sunday night, because A (Wife) gets a joint (Meat); her bother in law is a butcher and I cook the meat and she comes around and eats it, which is fair enough. I'd cooked it, but I ate about half of mine didn't want the rest and if she hadn't have washed up it would still have been there the next morning.

I Do you have any other times when you get anxious or frightened?

P No not really, erm, you get the odd twinge, but I think everybody gets that. If your not careful you can but too much on things so if anything you tend to discount things rather than dwell on them. Maybe that's a good thing maybe that's a bad thing, I'm not really sure. But ye you can't keep crying wolf every time you get a bit of a twinge or anything like that. I think its been going on that long now, I mean this is the first time it's actually been called heart failure. But it's been going on that long, that I wouldn't know what it's like to do things that I was used to. I changed my library books, Friday, and, no it wasn't it was yesterday, before I came to hospital. I parked near the Pig and Whistle pub, went into the market to get two pork steaks and again coming back up its on a hill so I was huffing and puffing. Then went round by the Crosby up onto Frodingham Road and I thought at one stage I would have walked this without even thinking about it. And even if I just wanted to go to the Crosby or Woolworth's or somewhere like that I would still have taken the car and tried to find some where to park. The odd time I do go into town the walking bit terrifies me, some times you don't know whether your going to make it. Supermarkets aren't too bad, although I will not go into supermarkets, I've walked into supermarkets before taken one look and come straight out. I tend to go first thing in a morning when there's no one about and the other thing is I've always got the trolley to hang on too. And that makes all the difference in the world. Tesco, I get their oat cakes, which are wonderful, especially the bacon mayonnaise and salad. And sometimes that's all I want. Now you can't take, well I suppose you could, but, you don't bother with a trolley and it's a fair walk, and you stay close to the shelves, you don't go out into the middle where there's nothing to hang onto if you need it. But I mean, Asda, which I use most of all, always a trolley. Even if it's just for one thing, I would take a trolley because I've got to get back to the car as well.

I Do you find yourself planning what you are going to do?

P You do plan, you think well what do I need, do I need it today or will it do tomorrow, but the thing about Asda is it's almost like a social event. Sometimes it's the only time I get out, the girls on the check out are the only people I see, other than mother because I always go down to see mother. I do most of her shopping for her as well. But you think about what you need and will it do tomorrow or will it do Friday or what ever. If towns involved at all, I mean the markets not too bad on Fridays and Saturdays because you can park outside until nine o'clock. So as long as your relatively early you can get in and out before the crowds appear. Plus there's no hassle parking, but town itself I couldn't say the last time I was actually in town as such.

I Do your problems relate to people and your relationship with others?

P Oh ye, I'm becoming more and more a loner, I've always been a loner, I've always lived on my own but I've always been a loner as well. But oh ye I don't want to go out, and sometimes I resent people trying to get me out.

I What about your family?

P There's only mother, she's eighty eight. I had to take her to get a medical today to get a car sticker. Although it turned out all right, we've got sort of a love hate relationship, as I'm getting older, I'm getting more short tempered and she's getting dafter, I'd swear blind she takes thick tablets sometimes just to annoy me. But she does really well for eighty eight, she's had her left hip done, which was not very successful, I think they put it in twisted, she's had her right knee done which that is a success, except she's got no feeling left there at all, so she's got two sticks, and her spines crumbling and she's riddled with arthritis and, but she still does her own garden after a fashion. And that does make me feel guilty, I can't do anything for her, I can't do me own, never mind hers. Now she's eighty-eight still doing the garden. I get down to see her most days. As I say it's difficult to quantify cause its been around that long, its been a gradual process, that certain things I do I take for granted and consider them normal. Which three or four years ago I certainly wouldn't.

I Are you on disability because of this problem with your heart ?

P Ye

I What was your job? What did you do?

P I was in construction. I was a material controller, so that covers a multitude of sins, so in at the planning stage, making sure the right material and equipment is ordered and actually on the sites making sure the right people get it. And that I loved because you never knew from one year to the next where you were gunner be. And you got good jobs and not so good jobs, and you knew, that when you went on them, you thought oh no, this is going to be a bad one. It's only a year, and then you'd go on a good job you see for twelve months again. And that was, you were constantly leading a double life really I suppose. I used to come home a lot but not necessarily every weekend it depended on the job and where it was. Up north in Scotland it was difficult to get home, it's a waste of time every weekend and Wales as well and down in Pembroke. I worked for the underground I was at the Kings Cross fire, in fact I was on the underground for over two years, I was living on a barge, a fifty foot Dutch barge, on Grand Union Canal in Brentford almost opposite Kew Gardens. In fact my friend and I we used to have it out on the Thames at weekends, brilliant. I rented a little cottage down in Pembroke, it was a case of where do you live, oh I've got a stone cottage on the edge of the Pennines and weekend semi in Scunthorpe. You never knew from one year to the next where you were going to be, so it was a variety and constant change, which was great. It was the opposite to what I do know, I don't go anywhere. Well no I went to a funeral last week. But I don't particularly want to go anywhere. I could go anywhere I wanted but I don't, I don't like crowds.

I Has that always been the case?

P No not in the same way. I feel hemmed in I feel slightly frightened. A friend of mine got tickets to see Bob Dillon at Sheffield Arena, somebody dropped out, of course it was right at the top, I kept thinking I was going to fall, I just couldn't hack all the people. So I avoid crowds were ever possible. If I'm shopping and it's early, to avoid people, well not people, to avoid the rush. The thought of being in London, I've always loved London, I think its exciting, brilliant, as long as your not stuck there, as long as you can get out of it and get away from it. I always liked London, now I couldn't do it.

I Has this made a big impact on you from a financial point?

P Ye, seventy two pounds fifty a week. I was on eight hundred and fifty pound a week. Yes it's a slight difference. Again it all happened at the wrong time, I'd been spending, spending and spending. I knew the job I was on was going to last, well I'd been on it nearly twelve months when I had to pack in, but I would have got another three years out of that one, I knew that, because there was more work following on from what we had and it would have set me up totally, even I couldn't spend it. And bang it comes right out of the blue and it's amazing how much money you can get by on. Ok I had some savings but they went, well a lot of it went. I'd been paying into, well it turned out it wasn't a pension but I do get an annuity of it. A pension I was paying into, which I hadn't been paying into for very long I get thirty pounds for money. The other one I get fifteen hundred, but it all came ten years too soon. So I've got to get by on one hundred and ten pounds a week, well the very fact I don't do anything, or go anywhere that helps, and I've got lump sums in drips and drabs. So I've had the kitchen done since I've been off, because that really was getting to me. The bathrooms desperate to be done. I got a WC, I've got the hand basin and the taps, and I last spoken to the plumber before Easter and I don't want him now till after Christmas, but the bathroom has got to be done.

I Is this something you would have done yourself or would you have paid someone?

P No I would normally get somebody in, but I would have been working and could have paid for it no problem. But now all that's gone. You get frustrated, you think oh nice summers day, I'll go somewhere, it's alright you get there, but what can you do when you get there? You know, you get out of the car you walk a short distance and then you look for somewhere to sit down and get your breath again. So sit in the garden instead. I do an awful lot of reading; I listen to the radio quite a lot. I don't watch that much television, unless there's something I particularly want to watch I won't just stick it on for the sake of having it on. I also found the attention span is shortened dramatically. I could sit all day with a book, twenty minutes half an hour and you find your reading the same page again, oh I've read that. It can't be that good, but it's a good book. Put it down, put it down. So one-way round that, sometimes I'll read two or three at the same time. Have three on the go at the same time and that way you tend not to get stall and not so quite bogged down.

I Do you have problems in remembering things as well, or is it around concentration?

P I think it around concentration more than anything. But I forget the names and days of the week, but there again I think I've always done that. I think I've always done it. Ye maybe the memory isn't quite as good as it was, oh God not Alzheimer's as well. Short-term memory has gone. (Laugh4). No memory not that bad actually, in fact I've got pretty good recall. But again what helps there is with the working away, I always relate things to where I was working at the time and I can work back, since 1981 and tell you exactly where I was and prior to that I was three years in Iraq, and a year in Algeria plus I worked in Belgium. The other thing about that, is you never knew who you were going to be working with. So you've got to be adaptable. But they always knew you. Cause construction is a very small industry really and if you don't know somebody, you know somebody that does or you know somebody who knows somebody who's worked with them, so you've always got the low-down on somebody before they get there.

I Would you say your as adaptable now?

P No

I Why is that?

P Well again, part of the thing, the way I used to get by was I would create a routine for me self. First thing is you've got to find somewhere to live, and unless it was very, very short term or it was somewhere like London, where it was very expensive, I always wanted somewhere of my own. Whether it be a flat, a bed sit or whatever or even a caravan. And then it's a case of the area you are staying in, and again I would like to be a reasonable distance from work so you weren't living on top of work and you weren't living with the people from work, so that when you left, you left it behind you. And then the area you where staying in, you would wonder around the pubs and the clubs or what ever and you would pick a particular pub out, it might not be the one you like the best, but you knew you would get more social life out that one or more contacts and you would be accepted quicker in the area. And then you would go back to the one you did like but you had to, there was always one pub that you had to use, to get yourself known in the area or find out what was going on. And then you would be away on another job, and again you would get yourself a routine. It might be completely different to the last one you had, but you get a routine and you did things at a certain time, you shopped at certain places, because that's easiest. I'm in a routine here, hospital threw it out a bit, but I've got be down there early, I've got to, I've got to, because I don't want the crowds, but the odd times I've not been down there early the things you can buy on the oops are wonderful. Sometimes but not all, so does that compensate for the crowds? The answer is no, because again, I'm starting to wind me self up again. I must be up early so I can get down get things finished get down to see me mother and then the rest of the day is mine and what do you do, sit down and sleep. So what's the point of rushing in the first place? But basically I like everything out of the way be lunch time, I don't want to have to do anything in an afternoon, because I was just nodding off in the chair when you knocked.

I What is the one thing in your life that has changed the most, whether from what we have discussed so far or from anything we haven't talked about?

Appendix 3 (continued)

P It's physically not being able to do things, that far in a way the biggest impact and it leads to a certain amount of frustration and I think that that has changed my personality as well. I not as cheerful as I was, definitely I'm not miserable but I'm not as cheerful. I know that people keep telling me, miserable bugger. But now far in away the very fact you think I'll do so and so, no maybe I won't well let's think, does it need doing, where as before I would potter about getting stuff ready and you would do it without thinking about it you didn't have to you just went and did it. If somebody wanted a hand you went out and gave them a hand. Not now. I'm having to call people around to do things for me. I don't like that. I look around and I'm going to a few more funerals than I used to and I'm still around, so ye, so what ever way I can enjoy me self I will. Because who knows this time next year or the year after I might not be here. You can't live for next year, but unfortunately there are restrictions so it doesn't work out any where near as good as it sounds. That the overriding thing, that fact that physically you can't do a lot of things. You have to stop and think before you do anything because again there's no point starting something and leaving it half finished. At night, I tend to eat quite late, but there again that's a throw back to when I was working, I'm a fairly good cook although I don't particularly enjoy it. I like me food and I can't afford to eat out. But the washing up gets put in soak and the next morning you tip all the water out and put hot back in again, so at least it's all soaked off and it's just a case of wiping it then. I put it on the draining board and it's there till mid afternoon. I think no it can stay until I need that space and then I'll put it away. I was never like that before things were washed and put away straight away. I'm saying I've ever been particularly tidy but I've always been organised and fairly efficient and that I'm not any longer.

I Why do you think that is?

P It could be priority, the main thing of the day is what am I going to eat at night. That is the overriding thing and that the first thing I decide or that's the first thing that has to be decided each morning. So I know what I'm going out to buy, if I'm going out or I need to go out. That another thing since is started these tablets, I'm burping all the time it's terrible. But now it's basically it's difficult to say as it's been going on for that long and I can't remember what its like to be alright. It sounds silly that but its true. You just forget. There are two things that stick out the first thing was the set of electric shocks that I felt so differently, it was wonderful, then the second occasion was when they put me on these metformin tablets and in a very short space of time I couldn't get over how much energy I had, how many more things I could do I wasn't falling asleep every time I sat down. That seems to have gone into a bit of a reverse, even in the summer. That's about it.

Appendix 3

Interview 4

I If I was to say the phrase quality of life, what does that mean to you?

P Healthy lifestyle so that you can enjoy your leisure periods where now I'm sort or restricted really. Where as I used to enjoy the golf competitions, I daren't put my name down for a competition now because I don't know what the weather will be like in two weeks time and that particular day, and you tend to, that's all gone.

I Would you say you wouldn't plan anything ahead?

P Yes, I'm very apprehensive about travelling abroad

I Why is that?

P Medical reasons, I suppose, I spoke to Dr D about it he said short of no problems, just make sure what ever country you go to just make sure they have a good reputation for medical and the rest of it. But it's just me it's the apprehension I have, and I suppose I've just go to get used to it. It's just at home I know I'm ok in certain temperatures, but in the summer when it was very, very hot I needed a fan, if I go to a hotel somewhere am I going to get these facilities? Air conditioning and things like that. So you begin to?

I Do you have problems in winter with cold?

P Yes

I What sort of problems do you get?

P Shortness of breath basically and obviously I still get panic attacks, when I think it's coming on and then I find what I have to do is start counting and then I'm thinking I'm not short of breath it's panic, it stops me sort of (pants)

I How often does that happen?

P Less now than obviously after it had happened. Whether the temperature is helping me a bit as well. Because when I came out it was very, very hot and I was struggling at that time. I can go three or four days now and feel fine, then all of a sudden, you have a warmer evening for some reason, and you have to open a window and then all of a sudden I wake up, it soon goes away.

I Do you wake up short of breath?

P short of breath, well I think I am and then I start counting and realise I'm not as bad as I thought, and then the panic sets in. Night times the worse time, I get up and have a cup of tea and walk around a bit, maybe it is all in my head, I don't know.

I Let's think about how your heart affects you on day to day basis, how does it affect you?

P I don't actually walk the dogs now, I tend to throw them out the vehicle, where as I used to walk them a couple of miles and every day I would go along the river bank, I don't go now because I'm on my own. You just wonder especially when I'm told I only have one artery that's pumping blood to the heart and you panic that if ever that one blocks, that's the end of me.

I If you had somebody with you would it make a difference.?

P You feel more comfortable, ye you do

I Do you think you would do more, if there was another person with you?

P Yes, I would, yes, I mean I wouldn't want to be say two miles away on that river bank even with a mobile phone if something happened. Its just there, I'm, very careful where I go. What I must try and do is calm down, because I tend to do is everything on the run. It's like I go upstairs and I'm still forgetting that I've had this hear failure, and the worst hard time is when I'm getting up in the morning and I'm taking a cup of tea to L, say and I'm flying up the stairs and all of a sudden woo, woo (breathlessness), where as I've never had that see, I don't lift things generally I have someone cutting the lawn, gardening, what ever.

Appendix 3 (continued)

I Has that changed?

P Well ye, I've always cut the grass, done that sort of thing and now somebody else does it.

I These things that you don't do, how do you know not to do them?

P It's me saying don't do them, or haven't had the nerve to have a go at it I suppose. I just don't want the attacks to come on. I've got to learn to calm down, if there's any problems over there (work), I've been one that's jumped in with both feet and now I've got to learn to walk away from it a bit. My wife's always worked with me and we've never had a nine to five job in away, so you work at home as well. So what I've go to try and do sometimes, we were doing paper work last night, to try and calm down and forget about it, things like that have got to change.

I How does that make you feel?

P Oh frustrated, ye, ye I do. What can you do about it, not a lot. The other thing that worries ye, is you don't know how much time you've got left. Ye.

I Do you think that's any different from before?

P Ye I do really, it's just that I had a by pass you see and no problem for fifteen years, golfing holidays with the boys, drinking, enjoying everything, all of a sudden all that's gone. So you do get frustrated, I don't go to functions a lot in an evening where we would have done, I get tired, I went to a sixteenth birthday party last Monday and I was home at half past ten, where as I could have been one of the last ones there, it's little things like that, I find I need my sleep, I can't survive, where as I could have survived on four hours, I can't do that anymore.

I Do you find you sleep during the day as well?

P No, I can get tired by teatime. But I put that down to age anyway. Is any of this making sense?

I Do you find that other people cause you any problems?

P Ye, they tend to, yes there asking how you are and all that sort of stuff, ye, they know what's happened. I don't get asked to things, I put that down to them thinking he's not well enough, it doesn't bother me.

I You talked about getting frustrated, do you find you get any other emotions?

P Not really, no. I get fearful of having another heart attack. I'm not too bad that way. What I wouldn't do as well is go to the golf course and go on the golf course on my own. Where as I would do in the past. Say today for instance, I've nothing on this afternoon I'd go to the golf course and if there was nobody to play with I'd still go and play nine holes, and I wouldn't do that now. If I'm three miles out on the golf course and I do have an attack how's anybody going to get to me. I often say to the nurses even though I'm out on a limb here and people are always criticising the NHS, I can have an ambulance in this drive way in twenty minutes, so that's not bad. And that way it makes you wonder if you went abroad would you have to look for that, before you could settle down and enjoy me self abroad so you tend not to bother.

I Would you consider a holiday in this country?

P There again it's back to this facilities. If I stay with my daughter in London and stay there two nights, I'm worn out. You can't open a window there's no air conditioning, I'd worry how I'd go on in the evenings so I tend not to bother so it has made a difference. I wasn't as worried when I had the stents done but when they tell you you've just got one artery, its different.

I Why is it different?

P Well if that blocks you've gone haven't you? There's no blood getting there. If I didn't know that it would make a difference. When we talk about planning I mean I've always tended to get out there, I come back and start ringing round because they told me I can't have a heart transplant in the future. But I ignore that and I start ringing round.

I find that I could have an operation in Washington DC, I've contacted Papworth on my own initiative, in case the day I need to do something like that. I know I have damage and I didn't realise that the damage is from sixty to eighty percent not hundred so I've still got thirty percent so I came away feeling quiet buoyant.

I You mentioned you get tired, would you say you have any other problems which relate to that?

P No, I can concentrate.

I You have obviously had some big changes in your life in what you choose to do and in what you can and can't do, has that made any difference either to your personality or mood?

P No I don't think so. I always tended to be a bit sort, snappy, I don't suffer fools very well. No I don't think it has really. I've never been a serious person not that way, no I don't think so.

I What about your family, what would they say?

P I suppose its made a difference to L, physically as well as everything, because that's not the same, my daughters, no I don't think it had because I've always had a joky time. No we get on well. I worry about the physical side with L to be honest. Should I, I don't know, she's fifty five, we've always had a good physical relationship, but all of a sudden with all this it's, it's fear, and I think the tablets affect you that way. But I think it's the stairs as well. It's from me. She's never pushed. If I don't approach anything like that. I think I better take me spray, I do things like that. It's been such a short period of time I haven't had the time to build up me confidence yet. I think physically my legs have got weaker because I'm not doing anything, same with the dogs I just throw them out, that there vehicle, they walk and I drive. I, the only thing I do is walk. I've got a disabled badge now, so I walk from the car park to Tescos round there, that's about all the exercise I'm doing.

I When your in Tescos do you have any problems?

Appendix 3 (continued)

P I do sometimes when it's warm, when I've gone from cold to warm, a lot of clothing on. That's a thing, because you feel the cold you've got your winter clothes on and then you get in Tescos and it's hot.

I What symptoms do you get? You've mentioned breathlessness.

P I always tend to know when it's coming on. I was told to take that GTN spray, before I do something and I've been waiting until the pain was coming and I take that.

I When would you use your spray?

P For breathlessness, I get an ache then breathlessness, I'm starting to learn what happens and what to do. I have noticed that when I've taken those tablets that within ten minutes quarter of an hour I feel great. So first thing in the morning before my tablets is the worse bit of the day.

I How do you feel about taking medication?

P I just take them. I never forget to take it, I've been an hour or two late.

I Is there any other changes that you want to tell me about?

P No, no. it's been an over night change. I mean I had my stents put in and I just carried on as I had done before, when I had my by pass I was forty seven and when you listened to the people in the ward they were packing in work, but I didn't do a thing to me I came out and carried on. If I got up every day, what would I do? Part of the problem that I've got at the moment is that L is working so hard, we rarely have time.

I Is there anything else that we haven't spoken about?

P No that's it basically. I think when I look back I wouldn't have worked so hard, I don't know.

Appendix 3

Interview 5

I What does the phrase quality of life mean to you?

P Something I don't have, there's something missing that I can't do now that I used to do. It's mostly through tiredness. You try to do things and you are too tired to early.

I Would you say tiredness is the main problem?

P It is with me, ye, lack of energy.

I Let's talk about your life on a day to day basis, how is it affected?

P If I want to do gardening, where as I used to take half an hour it takes me all day now, I can still get things done but it takes me an awful lot more time. But I do it. There are things like the heavy work that I don't do anymore. I've quite a big garden, we do it between us and it gets done. Like mowing the lawn, I have an electric mower and I have a push mower. If I'm feeling alright I use the push mower. I feel better doing that and then I feel I've done something. But the rest I just learnt I can't do what I did.

I Is it how you would like it to be?

P No, no. I can't do anything about it.

I Have you learnt through experience

P Oh ye, because I know that I will get into trouble health wise if I don't. There's no sense in making my self ill, so I try and keep to a level where I can handle it, I do that.

I You said you can make yourself ill, what sort of problems do you get?

P I get dizzy and I get short of breath and I know that's not a good thing. I look at it that I might have another heart attack and I don't want that. I try to keep on that level. I still go walking which I can but that's not the amount that it used to be. I get on ok.

I So other than your gardening is there any other things that you have changed?

P Not really, no. I have a job going up and down stairs which can be a bit of a problem but I had a hand rail fitted and that helps a lot. Getting in and out of the bath, I can't do it how I used to do but I manage. I'm thinking that I may go down and buy on of those things that you put across the bath to help you in and out, I think that might help. It's maybe a silly thing to say but I used to play football, cricket and golf and I've had to stop doing that. I can still do golf now and again. So I took up indoor bowls and I can just about cope. It gets me out, it gets me amongst people.

I Over time you seem to have cut down what you do. Have you found your fearful of anything?

P No.

I Do you have any worries or anxieties related to your heart?

P Every now and again I hear it, especially when I'm laid in bed and that something I didn't used to. I wouldn't say it's frightening but it makes you think that all's not well. No more than that.

I How do you think your heart failures affected your relationship with other people?

P I've had more support than I thought I would have. I think they've been good. No it hasn't really. It's stopped us going out. Sometimes we used to go out for a meal regularly and now I feel I don't want to do that. By the time it's time to go out I'm too tired. But we go out now and again. I just go out earlier rather than later, I'm fine.

I You mentioned both of you do the gardening now, has that always been the case?

Appendix 3 (continued)

P She has to do more, she likes gardening, but I still want to mow the lawn and do a bit. I think that good therapy being out there and I have a fish pond down there. I have to plan what to do, I used to do in half an hour and I can't do that now.

I Do you plan a lot of things?

P I tend to find I plan things I needn't. If I want to go shopping I plan where to go first so I don't have to go up town. I'm better now than what I was because I have a disabled thing for me car and I can get to places I couldn't get to go I couldn't get from the market to the car park but now I can park at the back. We don't go to town together because she likes shopping and I don't. I get what I want for me self, I use the printers a lot for me calligraphy I can park outside now.

I Has the role your wife takes changed?

P Do you mean does she do more? Then yes, ye, she's always done a lot. Even when she was working she was always busy so it might seem that she's not doing more than she did but I appreciate what she does more now than I maybe did then. Sometimes you think, sometimes you feel inadequate, not very often; I used to think it more than I do now. I just have to accept what I can do and I'm grateful for what people do for me. But what I do for my self I try to do as much as I can.

I How long do you think its taken for you to come to terms with it?

P These last five years have been better, initially you still have your ego, you want to do things and when your ill you can't. It's the same old thing, why me? So I don't know, I go down and have a game of bowls. If I go to chapel, I go there regular and that's a social thing as well as other things, you meet with people without it being strenuous work you know, so it's a thing that gets me out.

I Have you always been a chapel goer?

P Ye, always helped out at chapel even from being in the forces. It's something I like and I'm happy to do. Now I do the posters for them and you feel happy being able to do something like that. I can't go down and decorate for them so I do other things to make up for it.

I You said you have problems getting tired, so you find this causes any other problems?

P I don't fight it usually unless I'm doing something I'm in bed by nine o'clock. I do enough in the day and when I go to bed usually I can fall asleep four or five hours like that, I'm not saying I sleep all night but I'm that tired I go to sleep straight away. I don't think I lack sleep and I have a telly upstairs so if I wake up in the night and I put telly on and if I'm not well J (Wife) in the other room so I don't disturb anybody.

I Do you think having your heart problem has changed you?

P Ye I think it probably has, your more grateful. I think you wake up and say thank God were here. I'm happy enough, I don't think I get morbid about things I get upset, I get a bit emotional sometimes, whether it's the tablets or whether it's me or the condition I don't know, but I never used to get like that, but I tend to do now. I don't like talking about it.

I What sort of symptoms would you normally get, we have already talked about the tiredness?

P My ankles swell up quiet a bit, I would stop. I notice that a lot. I come in here and put me feet up. I take me frusemide

I You mentioned frusemide, you must be taking some tablets, do you have any problems with taking tablets?

P Ye, I hate it. I think, although they do you a lot of good, I think they give you, the side effects, I think. Because the doctors keep changing them and the specialists keep changing them, so you know that they are doing you harm as well as good. I suppose it's all trial and error that eucarduric, I've been on six and gone up to twenty five, well going up to twenty five I couldn't handle, so that side of it I think your always there to try and get stabilised on tablets and that's a problem. It's the same as being on warfarin you go regular to get your blood checked you can't understand why you're up and down so much and I still don't know the reason for that, but all in all the don't bother me. I think the things that most is having to take frusemide, you're at the loo more times when you're in the house. You're got to, if you go to chapel, you can't take one in a morning you've got to wait until you come home. But no, you know one thing balances another. If I didn't take tablets I wouldn't be here. So that's the way you're got to look at it. I've had good help from doctors and the hospital and that's appreciated.

I Why do you think that makes a difference?

P I think it's nice to know that some else shares what you've got. They can't have what you've got but I think yourselves understand what we've got. It makes, it's nice when someone understands what you've got.

I Do you know anybody else that's got the same heart problem as you?

P Not really, I used to I used to keep in touch with one or two from the hospital but over the years you loose track, but actually me brothers probably worse, he's had a triple by pass and he's also got a stoma bag. I relate to me brother and me dad died early of heart failure and me sister died early, so we've got bad hearts running through the family, it's hereditary I think it is. I could never understand and I still don't understand, I was playing good football, high level football for a good team, local until I was fifty, and never felt a thing, and never, never knew I had nothing and first thing I knew I had a heart, I was at work and I had this pain come and shoot through me and that I was the first I knew about it. I never felt tired playing cricket, I used to bowl and that was a tiring job. All through me life I've played all sort of sport and I never, never had inkling that I had anything wrong. But obviously it must have been there through a lot of me life you know. That's hard to understand that it didn't show up when I exerted when I was younger, I had three years in the forces, nothing was ever shown there, you get rigorous examinations in there.

I Do you think that your heart failure has affected you in any other ways at all?

P I don't think so, as I've got older I would have kerbed a lot of things, had this happened when I was thirty and I was fifty now it would have been different, but been seventy now I accept I wouldn't have been doing all these things if I'd had a good heart. I would have been doing a little bit more but I wouldn't have expected to play football. So I would have had to slow down anyway so really even though I've got what I've got I'm lucky that I've been fit enough to counter it by getting up and doing things, I think it's my fitness through life that's helped me through it. That's why now I won't give in and sit here, not more than I need. I think it's that that keeps you going and people.

I How do people make a difference?

P Well because I think you need people you can't live on your own, no matter how good you are or how clever you think you are, you need people. Not just for this but for everything, but I think when you've got this you realise how much people are important, I don't think you're selfish, I'm not as selfish as I was I don't think, I do realise I do need people now more than ever.

I How does J (wife) see things ?

I I think she cares that much she's happy. Every bodies different and you learn to pick the good out, there's good in everybody. You don't look for the bad you look for the good because that helps you and so by doing that you don't have the quarrels you don't have the pettiness that you probably would have had. You try to avoid that, so that does you good by not getting stressed up.

I Do you think that's different to before?

P Yes.

I Do you think that it's your heart failure that's changed you?

P Yes I think it has, I think that how it changes you. I know that I can't get stressed I know that I shouldn't get stressed so I think looking to find the best in people stops you getting stressed. If there's any arguments I just walk away. There are, you tend to walk away. I would have been in the thick of it before, I always had to put my view point in, but now I don't bother.

I Is it you that's made the decision to walk the other way or does you wife?

P No, we don't get out together a lot I like bowling she doesn't, we do separate things. We used to go away on holidays and that's what I miss because I never feel like going. I don't feel, I feel safe at home. I always let me daughter and granddaughter with Jean go away. I feel safer here. I don't know why I just do. I remember when I first came out I wouldn't leave the sight of the house for at least six months. I would walk down the garden and I'd walk down the street, but I was that insecure I didn't want to leave the house, but gradually that went. I seem to panic if I'm away for too long.

I When you developed your heart problem did it affect you financially?

P I left a good salary but I got a good pension and Jean was working full time. But I worked part time doing book keeping for small firms, so we kept going, we got the mortgage paid and there was nothing we needed. We always saved a bit so. I never thought I'd missed out due to ill health.

I Do you think there is anything else?

P I used to do all my own decorating and I can't do that now, but it doesn't bother me any more, it did. That was the biggest thing that hit me, but when you learn that you can't and accept it then I think you feel a bit better and my outlook seems a bit better. There are a lot of people in the grave yard at my age.

Appendix 3

Interview 6

I If I say the phrase quality of life, what does that mean to you?

P It means I don't have the quality of life I used to have.

I Why is that?

P Because I can't move about like I used to be able to do. Everything is hard to do. Getting dressed I'm even out of breath getting dressed most times. I can't go shopping without stopping every few minutes. I don't carry me shopping, I can't, if I sit in that chair where you are now, nine times out of ten I'd drop off to sleep. That's what I call, I haven't got any quality of life, when you think five years ago I was running around the agility coarse with the dogs. I've got no quality of life compared to that.

I So what are your symptoms?

P I'm short of breath, tired, can't walk, well I don't know if it's heart, but me legs are like lead sometimes I have difficulty in moving, in fact I've bought a walking stick because I'm not as mobile as I used to be. Everything's a hassle, even to try to cook. I used to love cooking and that, but it's a hassle to open the cupboard doors to bend down to get the pans out. I've no quality of life like I had, everything is now hard work.

I In your normal day to day routine, how does your heart affect you?

P It, I'm S carer and she cares for me now. Like I said if we walk. I wouldn't walk from here up to that bus stop up there, no way. But it's even a hard job for me to get in the car now. Everything no matter what it is isn't the same as it used to be, sometimes I get pain in me chest up here not all the time, and I stop and do nothing then until it goes sometimes it goes quickly sometimes it's there quite a while. I have had, I used to get palpitations, I haven't had palpitations for a couple of months I don't know whether that's because I'm on these beta blockers or not?

I So if you did something and you got your symptoms what would you do?

Appendix 3 (continued)

P There's nothing you can do except sit down

I Would you carry on at anytime?

P Yes I still get on, but I can't, at one time of day say like five years ago I would be going out. I've always been a worker, I don't know how to do anything except work. I still do it but it will take me a lot longer to do it and some of the things I can't do any more, me husband does like cleaning windows, even pushing the hover that makes me break out in sweat. Lots of things I can't do.

I Have you learnt this?

P Yes I've learnt from experience

I When you get these symptoms how does it make you feel?

P It makes me feel frustrated for a start off because I can't do it. I've even cried about it thinking you sad thing. Because I don't like to have to rely on anyone else. I don't get fearful. I'm not afraid to die, probably people in normal circumstances would. But I've never had a fear of death, so I just, I would be really fearful if I thought I was going to end up where somebody was going to have to look after me totally hundred percent of the time. But while I can still do things. If I have a palpitation and drop dead, I drop dead. It's not me that will feel anything it's the people I've left behind in that respect I don't fear.

I Do you find that your personality has changed?

P Oh a lot. I'm more withdrawn I don't like going out the house. I go out because I have too. I don't like going out. I've got some dogs of me own, there at the bottom of the garden I go down once a week, me brother does them for me now. Before I would be up and down all day long seeing to them. Things like I lost a litter of pups by bad husbandry on my part. I knew she was going to have her pups, but I just couldn't keep awake long enough to help her and it was her first litter and they were born dead. In normal circumstances had I been alright that would never happen. Never happened. So I cannot do anything like I use to, nothing.

Appendix 3 (continued)

I What is it that keeps you around your house?

P because of the hassle I have. My husband and my granddaughter come with me and they have to put their arms in mine and they have to carry the bags and if I get in a crowd of people I start, even getting worse in a crowd of people. When I have to stop, don't forget I'm a diabetic as well, and when you have to stop for something to eat and the place is crowded and you can't get a table, I'd rather stop here than go through all that. Because I know what I'm going to feel like. We went on a trip on Sunday on a coach trip me sister and her daughter went, me, S and me husband went. I had to sit down about twenty or thirty, in fact I had to say to S you go looking around and I'll sit here I couldn't walk around me legs wouldn't let me, I couldn't get me breath. It makes me feel awful because what's the point in me going if I can't enjoy it. I don't enjoy it.

I You have made many changes in your life, has it made any difference to your relationships with other people?

P I don't think so, I don't know if they are aware of the seriousness of my condition or not. My husband does more. He's a standard bearer for a reunion group and it's their dinner dance next week and he asked me if he should get me a ticket, but I don't what to go. If I can't get up and dance I don't want to sit there and mope I'd rather him go on his own than me go with him like, things like that have altered. He still thinks I should go so I've said no don't get me a ticket I'm not going. I sometimes get sad about it, but life's life and it depends how you look at life.

I How do you look at life?

P Well, I look at life as it's hard, it's hard for everybody. Financially we're secure, I'm a pensioner but we're not living on the bread line or anything like that. And I feel lucky I've got S and I've got me brother who helps and he's never been married he's always lived with us and he's two years older than me, but he's on his last legs he shakes he's got mild Parkinson's, but I always thought I'd be looking after him but he's more or less looking after me. And another thing I never used to go to bed until midnight gone and now I'm in bed sometimes at eight o'clock I just can't sit up anymore. I get tired in the day and I have difficulty concentrating, I don't notice it other people notice it about me. We do, we pack balloons for Everett international. This week we had to do some with a pump in, and I kept sealing the bags up and forgetting these pumps and S will say grandma there's another one there without a pump. I can't concentrate like I did. I would never admit to that before.

I Has your heart problem made any difference to you financially?

P No, no because of the family, if I was on me own then ye it definitely would. I wouldn't be able to do anything much.

I How do you deal with having to take medication for your heart problem?

P My husband gets them all sorted out for me, he has a list and he puts me night times ones out at night and puts me morning ones out and puts them on a saucer on top so that I can take them when I get up and then in an afternoon he will get me, em beta blockers when he comes back and two more frusemide. So if anything happened to him I'd be a bit lost. I rely on people around me, I'm comfortable with it but I don't like having to do it. I don't get any, I've never asked about disability or mobility I've never done anything about it. I would think about it if I'm going to get worse then would think about it.

I Do you think about what might happen in the future?

P Yes, I think about it a lot I think about it for S for a start of. S sees to me all the time. I can't wash me feet any more, she washes me feet, my husband doesn't do that he'd just put a flannel over the top and that would be that. I can't lift me leg to put me knickers or anything on. S helps me do all that kind of thing. But S herself, this is what I worry about , S has a problem where she has no growth hormone, and she only started on them last week. We've had to go back and forth to Sheffield with S, which that nearly killed me. She's got no pituitary gland so she hasn't grown. She had mobility allowance and I get carers allowance for looking after her. She's thirty one and she's beginning to grow up a bit more than she was, she's been like a child. She hasn't got a job, she can't do a job or anything like that but she's very kind to me and she's intelligent. She's only just started her periods, her ovaries have just stared working, but I worry that if anything happens to me there's nobody to look after her. That's why I'm trying, they tell me these hormones will make her grow up more and make her more independent and be able to do things. I don't worry about my husband because I'm sure he'll cope without me.

I Do you plan for the future?

P I am planning for S, it has been going on for a couple of years, as soon as I knew about my heart I started planning for her. S does a lot of the cooking now, she's not brilliant, but between us we manage, but before I wouldn't have even wanted her in the kitchen. I don't plan things because I don't go out much.

I Is there anything else we haven't discussed that's changed?

P I don't think so, I don't feel ill, I just feel like is it worth it, it's an effort to do this and that, and that's how I feel . I can't say it's through something because I don't smoke, I can't say it's through drinking because well I drink to be sociable. So I don't know why we get like this why are we chosen. Why was I chosen to have diabetes. I don't know why we are? You just have to look at it I don't give up I'm not a giver inner.

I What's the one thing that makes you cope with it all?

P Because I'm, me because that's my nature, that's who I am, if I've been knocked down I've got up and started again, it's just me, managing to cope. D brothers wife, she's ten years younger than me and she walks with a stick and in a wheelchair and I've seen her get up and rock and roll, she's no where near as bad as I am. She's really sorry for herself, I don't moan what's matter with me. We know here but I don't say anything. My husband knows when I'm, not right he'll say go to bed. That's my life now, I do the best I can.

Appendix 3

Interview 7

I What does the term quality of life mean to you?

P Enjoy me self or me family, everything I do.

I Would you say your quality of life has changed since you have had a heart problem?

P Well it's maybe in your mind, but I can't go for walks and that like I used to do. We went every day and never missed, 4 mile round the block here, and I can't do that now.

I On a day to day basis what sort of things do you have difficulty with because of your heart?

P I don't feel the same, so I, sort of reject, if that's the word, going out. It's a funny feeling, you feel as if you want to sit down and when you go out for a walk I do sit on a wall or anywhere I can. It's maybe in your mind, but I don't feel, how can I say, ill or, I don't feel as though I want to do, do what I used to do like.

I What stops you from doing things?

P I feel as though I want to sit down, I get these terrible pains in my shoulder. I can stand a little but I feel myself, as though I want to sit down, so I said to G (wife) I'll go for a cup of tea. When I'm at the market I go to the café. Well I turned away from her, because I could feel me self going, so I grabbed hold of something with my hand and the next minute, I let go and I went down, I knew I was going down, so I lowered me self down and the market nurse, she come to me. She got the ambulance. I didn't go unconscious, I knew what was happening. The doctor said it was a good job I didn't sit in the house because one more minute she couldn't have done anything for me and I would have been gone. So when I'm out this always goes through me mind and it's frightening. I thought then, is this the end of me life. It's always in me mind. It makes me feel a bit awful in a way. It's hard to tell you, it's er, you think I'll have a sit down and I'll be OK. You sit for a moment and you feel yourself, yourself clear and then your off.

Appendix 3 (continued)

I Have you found you stop doing things?

P I was a workaholic, I've never had a day off like, hard work, mixing to put posts in, for the Council. It's stopped what I can do I didn't want it to happen again. It's a simple thing; you don't want another heart thing. I've eased off I can tell you that. For instance cutting the lawn. I go up and down with me mower and I wonder will I be alright. It's always in the back of me mind. You don't get any pains or anything, and your thinking that's enough for a minute, this is it. You can't explain it. I get anxious and frightened. Your always thinking, you're sort of waiting, waiting for it to happen. So I think I'll have a sit down and I'll be alright. The doctor said it's in your mind you know, they said they can get me better but it's up to me to get me mind better. Does it make any sense?

I How has your relationship with your family changed?

P No I don't think so, I'm still the same as I was, I don't think it's changed. I think you do get, you fall out a bit more. I don't mean fall out in a way that's nasty, but I think it does cause you to argue, because, I don't know why. We've just had our golden wedding and I was wrong for about 4 months, I wasn't my usual self. Me wife kept saying go to the doctors and get a check up, this is it ye see. I said things to G (wife) that I would normally not say. I was awful to her like. I had very big changes in my mood. Now I know what is wrong we only occasionally argue, we have always been happy go lucky people, this has affected us, we used to ride about five or six mile and walk three mile, we were always doing something you know. I think to me self, I'm a crock like. She'll (wife) will say shut up I hate that phase. She says your not a crock, but I can't do now't. I get very frustrated because I feel as though I can do it. I think I'll go and cut that lawn, and I go do it but I'm not happy at it.

I What do you feel happy doing?

P Watching the cricket. I like cleaning me fish out. I like sitting on that seat out there watching the fish. I like them because I'm not thinking, when I'm sat on that seat there, like this and I'm thinking ah come on your OK. You seem to just ease off. Your head seems to accept what ever it is, and you think I'm a lot better. So you'll sit there and you'll come in, then you think. I'm not really, but I won't. So when I'm watching cricket you see something is occupying my mind. I think that's a big factor, your minds not the same, it's relaxed. When I fainted in the market the doctor said did you know you were going down? I said ye, I lowered me self. In a way I was in control of me self. The paramedics said my heartbeat was very slow, the doctors thought it was the medication.

I How do you manage with your tablets?

P We have a paper with them all on, it tells me when to take them and how many. I sort them out me self now, G (wife) was doing it. I have no more appointments with the nurse now but I can ring if I get stuck.

I Do you have any other problems?

P I struggle to go to sleep, but I can nod during the day like. But I think it's getting better. I often sit here and I've gone off, and I come back and there's two wickets gone. I am still a relaxed type of man because in my mind every things better. At one time I asked the nurse if I was off mad because every thing was coming to me, when I went in hospital they put me in this ward and I thought it was going to drive me mad, I started panicking and was better when I got home. You know if you don't get some sleep that every thing is awful.

But I can't go shopping, we tend to get everything and straight home, we've done in two hours. I can't stand the noise, yap, yap, yap, you look at folk and think belt up a bit. It didn't bother me before I was always joking. I go to bingo, I love me bingo, I don't mind that.

The biggest change is I can't go through that gate and go round the block on me own. I haven't the confidence, confidence is a lot. No confidence is a big thing for anyone in my condition. But I'm not really sure what my condition is, I've been told by the doctors, but what is it really? I'd love to be able to get on me bike and we want to go to Bridlington for a holiday but I daren't go now if anything happened to me, it's always in your mind. We went with the bingo club, we took a wheelchair in the bus, we never used it although I pushed it. They wanted to push me around and I said no I don't feel as though I want to be pushed and I took it and when G (wife) wanted to go in a shop I sat in it outside which I was comfortable then, I didn't mind doing that. I think a lot of it's in the mind it's not the actual heart. We don't go a long way off, we're frightened to because if we go we have to come back. And me daughter is worrying and doesn't relax until we're back.

Appendix 3

Interview 8

I What does the phrase quality of life mean to you?

P At times not very good. No energy, no get up and go. Low ebb until everything passes and you pick yourself up and mentally as well how long your going to be down there.

I Have you had a change in your quality of life since having this heart problem?

P A big change one way or another, it's everything you want to do but can't and it makes me feel rotten. In your mind you feel capable of doing things but because of what's happening to you, you can't. I been used to being so independent all your life and then you have to rely on other people to ask them to do it, it goes against the grain a bit.

I When you have to rely on other people and ask them, how does that make you feel?

P Not very good, it's as if your loosing your independence. That's something you don't want. Once you start to loose your independence your liable to start on a wave of just giving in but you can't afford to do that. Each time it happens to you it's a harder struggle to lift yourself up again. You've got to do it, but there again if you've got good family, good partner, good people like yourself and the doctor, it's all a big help. When they say let's finely tune you, you feel they are helping you.

I Thinking about what you do on a day to day basis, what has changed?

P I can't walk as much as I would like to do, on the flat you're not so bad but when you start getting to hills, stairs, slopes then it starts taking its toll because you haven't got the puff and the energy to do it. And regards to anything else everything you have to do you have to do in moderation after that. I like wood working but I can only do so much at a time, so when you start to use a plane and you start pulling across your chest, you soon run out of puff so you have to do everything in moderation. I do things a lot slower, I take a break when I have too. I go to the limit, if you say well that's yet, but if you push yourself you can always get another half an hour but you feel better because you've done that, you don't feel that your giving in to it. Your saying hang on a minute I work hard and get more out of you before I give in sort of thing. That's how you've got to think.

I What about more mundane things in life, how has that changed?

P Getting up in a morning isn't that bad at all just at the moment, sometimes I struggle in a morning because I'm not breathing very well. Household chores well I've cut down to just doing dinner because doing the hovering used to pull me around a bit. In doing so many different things trying to get dinner ready I start to get tired you can't think about what your doing and there's been many a time I thought I haven't done any veg. or any tatties, just silly things like that. I struggle to concentrate, I really concentrate some times. It's because I get so tired. I've told Dr B and he says it's because I get so tired and that's why I get so light-headed and I can't concentrate to do more than one job at a time if you like.

I Do you sleep well at night?

P I get to the point where I get so tired that I get a really good nights sleep and then mostly it's half past twelve, quarter past one and I wake up and I get up and I go to toilet. You get to the point that you get so tired that you would give anything for a good nights sleep. I have got sleeping tablets but I don't want to rely on tablets I'm taking too many as it is. I used to sleep very well.

I Has there been any change in your mood or personality?

I Oh ye a big change. I've no patience. All I want to do is do things right. Like if I do a dinner I want to do it right for her. Things just don't go right I just loose it. I soon loose me rag. It's not a personality I like and it's not one B likes either. It's every now and again. If things don't go right I soon fly off the handle. And that's not me. I've always been a bit hot tempered but not like I have been since this happened.

I Has your relationship with other people changed?

P I don't think so. It's just things at home that if they go wrong. Where as if I'm outside just talking to people I'm fine. I like to mix with other people. B takes up the slack for what I can't do. My daughter lives down south but anything that up with me she's here in a flash. My lads in a world of his own. It's not that he doesn't care. But ask him to do anything and it's when he is ready. Where as B will help me whenever, I've D next door he'll help me and G his wife will help me. I've also another couple of friends and I could ask them and they'd come straight away. I'm well covered, I do ask them. It took a long time. When you're stubbornly independent like we are you can't just give in like that, you think I can do that and an hour later I wish I bloody hadn't. I've learnt though experience, but I took me a long, long while though.

I What has helped you accept your heart problem?

P I think the fact that there are a lot of people like me neighbours would see me doing something. They will shout at me you shouldn't be doing that let me do it. And I found after a while I was really starting to gasp for a while after doing things, but it's taken a long time to come to terms with it. I think since B has finished work I have coped with it, because before I felt guilty because I thought I'm at home all day I'm only doing a meal, B at work all the time, she's coming home doing the hovering and the washing and every thing else, Everything we've done in our working lives we've just pulled together and having to put in the little bit of money I'm getting I didn't feel I was pulling me weight even though she kept assuring me not to worry about it, that's me that's how I think,

I Do you find you become anxious or fearful due to your heart problems?

P No I don't think so, I don't think about what's wrong with me, I try not, I don't make that an excuse for anything. I won't play on it and I won't say anything to anybody to make them feel sorry for me. The only way anybody would know is if I'm having a bad day and struggling to breath or something like that then maybe they'd notice, that sort of thing but apart from that no.

I What sort of symptoms do you experience?

P Its very difficult. When you get tired you get very light headed as though you're floating, you don't have the energy, no energy, tops of your arms ache, not hurting. Chest feels like some bodies sat on it and when you get water you undo tops of your trousers, and I'm taking tablets which give me gout so one thing leads to another. I just sit around and relax and watch somebody else do everything for you. When I'm bad B has to wash me hair and your knackered like Steptoe's horse. I don't have the energy, your just dragging your feet and not getting anywhere.

I What sorts of things really get you down?

P I think if it goes on any length of time. It can go on for about a week or so and you feel like a zombie I suppose, you can't just get up, you can't do what you want, be time I've walked from here to that toilet, I've had enough. Or if I've got to go upstairs I've got to crawl up stairs. It's not, it's not something that I've been used to and it's something I've go to get used to and having to rely on B doing everything for me, getting in and out the bath, washing me hair, having to traipse up and down stairs, it puts a lot more work on B which I don't like to do. We usually share things. I get a little frightened but more I get angry and frustrated, because it's not my lifestyle to sit in a chair and do nothing. I find I get angry, if somebody says something to me just a bit wrong then up I go like a rocket. That is how it gets you, I don't mean to be. And of course when you have these bouts you ended up having to miss something, like we had booked a holiday and we had to cancel it. It's not me I'm bothered about but B ends up missing out. It very frustrating when there is something that you've really looked forward to it and then you can't do it. It's not me it's B. it makes me feel bad because it's happening but B must feel twice as bad because she has been watching me doing every thing for me looking forward to this holiday and then all of a sudden it's gone. She just says it's one of those things but any other woman would probably say sod you pal, she doesn't.

I Has your heart problem had financial implications for you?

P Ye because, you know how much your bringing home and when someone says that's it your working days are over all of a sudden it like somebody hit you over the head with a piece of four be two. Then your problems start. Your allowed mobility but you try and claim it, you can't I went to the tribunal and the following day I ended up back in hospital for three or four days, with the stress. When I came out my lad thought I was going to have a bad do. Every single penny I'm receiving we've had to fight tooth and nail for. I have to cut me cloth to suit because I'm hundreds of pounds down. All your plans are all out the window you have to rethink your life. It's not just me it affects it affects your wife as well. B worried just as much as I did about it. It takes it's toll on you. But you manage. But if you have somebody who will support you like I have, I'm fortunate. But those who haven't are in deep trouble.

I Do you have any problems with your medication.

P We organise them between us. They don't bother me I wish I wasn't taking all those tablets. The amount I'm taking they can't do me a lot of good in other ways. My weight for instance, I don't eat a lot because I can't if I eat too much I end up gasping. I don't loose weight, it must affect me metabolism. Me taste, I can't taste me food. Me water tablets affect what I do. I do me water tablets as me day is. I won't be tired down by me water tablets. I regulate me tablets as to how much water I have.

I How has your lifestyle altered since you've had this heart problem?

P I don't think it has altered in those great amounts. I take every day as it comes. We plan ahead not in months like we used to do. Now we do things last minute. I don't drive that much, I don't have the same amount of confidence. B does most of the driving now. You have to make the best of a bad job. My confidence has taken a knock. I do something and then I can't so I throw everything down, slam the garage door shut and think well what's the point.

I If there is one thing that has changed what would it be?

P Doing things for yourself, like I used to do. Not been able to do things that you want to be able to do, you have to wait for the right day or somebody to help you to do them.

I Is there anything else?

Appendix 3 (continued)

P If you feel good do it, if you don't feel as good do a bit of it, if you feel crap don't do owt. Take every day as it comes but don't get into the routine of not doing things because once you start to give in you may as well go and dig your own hole and jump in. and I've no intension of doing that. What you've got you've got there is no good grousing because no body can change anything. It's an excuse to some people.

Appendix 3

Interview 9

I What does the phrase quality of life mean to you?

P Getting the best out of life that you can.

I Has your quality of life changed since you were told you have heart failure?

P Oh yes it has.

I What sort of things have changed?

P The things you can do, that you could do, that you can't do now. The main one is me job. I'm a coach driver and automatically this has done me PSV license, so I can't do that. I can't go up and down stairs like I used to be able to do; I can't lift things, carry things. You're all the time relying on somebody else to them for you.

I Is this because you were told not to do things or for another reason?

P I was told not to do things for a start. The doctor told me not to do any heavy lifting. I get out of breath very, very quick. But, yes I was told not too. But I've adapted to it now, but I just don't do it automatically now. I have had a go at things, before I came to moving here. I had a go. It really does hurt, you really can hurt yourself. If you try to lift something, you get away with it so far, then you start to get a pain across the bottom of your chest. I always said it tells me when I start to do something I shouldn't it always tells you. I get a shortage of breath and basically not much more than that, it's enough to stop me.

I When you get those sorts of symptoms how does it make you feel?

P I sometimes go very dizzy, I'm not sure whether that's something to do with the anaemia I had before I was diagnosed with this heart problem. I get a bit of dizziness, I've got to sit down. I used to get frightened when it first happened. But not so much frightened now because I've got used to it happening. It still makes you wonder sometimes. The pain is sometimes worse than another. But basically that's it.

I What makes these symptoms go away?

P Sitting down and resting more than anything, it takes it off gradually. Well it always has done with me. But not a great lot has changed. I get up in the morning, I still, I've no problems getting a cup of tea and making some breakfast. It's more when you come to wanting to go out. I'm quite alright in here because if I happen to go a bit dizzy or something I can just sit down straight away. But I don't find that it stops me doing anything but I do it at a lot slower pace than what I would do it. I think I would like it to be better, but I have to make myself comfortable with it. But I get annoyed and curse a bit and blow off steam a little. It's more when you want to walk somewhere, I, you get half way there and you have to stop and prop yourself on wall or sit on a wall or something. It gets very frustrating, you want to pick something up but know full well if you do it's going to hurt so you don't do it. It can be very embarrassing if there's nowhere for you to sit down. I've had comments made to me before about it. One time in particular, two women said that so and so is drunk. You can't explain yourself you have to stand and prop yourself up. I try to avoid some situations to stop it happening, but if you did that all the time you would never go out anywhere. You've got to force yourself to go out. It's not something that happens every day. Just now and again if you've walked a bit further than what you should have done. It's just odd times it can be embarrassing.

I Have your family or friends changed towards you?

P Not really. I get all the support and help I want from any of them. They are all really good to me. My wife did have to do some things. We sold our house to come here and I was a very, very keen gardener and I used to love me garden. One of the reasons that we left the house was that I couldn't manage the gardening and J (wife) was doing a lot of it. It was all up and down stairs and it was putting on her. I would still be at work if I hadn't had this heart problem I never had any sickness. And we would still be in that house. I'm 60 this year. The job I had was a good job, I would have worked til 65 without a doubt. We are living on social security and disability. I wouldn't say its degrading but I would sooner be at work. You always feel your claiming money that you shouldn't really be doing. It s murder, it really is trying to get anything, they want to know all the ins and outs, some things they want to know is out of this world.

I Has any of this made any difference to you as a person?

P you get very depressed when you want to do things and you can't and of course the person you take it out on is the one you don't really want to take it out on. But its one of those things you adapt too as best you can. You certainly do say things as you get frustrated and you say things that you don't mean. I've upset J (wife) a lot of times but your worse thing is, you tend to bottle things up, you don't say things day by day and may be you should do, you bottle things up and all of a sudden you blow up. I wouldn't say you have a good row but you certainly have words about it. Its put a strain on our relationship but it doesn't, you don't actually fall out over it or anything like that. It puts a strain on some of the things you do and say. I wouldn't say I'm a different person, but with not been able to do some of the things that you used to do it certainly changes you. It's hard to say how I've changed. Just the fact that you can't do things it's frustrating. As far as I know I haven't changed much J (wife) will probably tell you different.

I How do you find dealing with the doctors and treating your heart failure?

P As far taking tablets goes the biggest job is remembering to take them. I only take them in the morning and afternoon. I have no trouble taking tablets its just remembering to take them at the right time. As I say I've never had any trouble taking tablets. Two of them are water tablets which cause problems in a morning if you do want to go out. But other than that I don't have any problems. I take it in my stride. We have a car and J (wife) always takes me to the hospital in the car. I know I have to go to the hospital to be seen but I don't have any problems, I know in my own mind that I'm going for my own good.

I Has your social life been affected?

P I don't drink or anything like that, we visit the kids it's never stopped us doing anything like that before. I like going to the football. I like fishing. I still go fishing. J (wife) and I go out together, we go for short walks down town and things like that. It's never really stopped us doing anything, only walking to the town is as far as we go now. I like to go to the football I watch S (Local team). I force me self not to get so involved. I can't stand all the way through a match. I don't like the seating part. I've always liked the same part of the ground and I still go there but at half time I'm well ready for a sit down for quarter of an hour and then I get back up. But we always have a sit for ten minutes quarter of an hour before we go back to the car. You don't get as excited because years ago before it ever happened you used to get really excited and into it, you could feel your heart pumping away when things were going right and things were going wrong, but you can feel that far more so you don't let yourself go quite as far as you would like to go, jumping up and down, you tend to stand there and just clap about rather than cheering and jumping up and down, you still enjoy it though. I think you are always bothered that your going to make yourself go too far and something happen. Worry probably that you don't want to cause yourself unnecessary problems and then, you know what's wrong with you but you don't know exactly what's going to hit you. They did tell me that at the present time I'm in no danger of a heart attack, they tell me its heart failure, that your heart will say I've had enough and pack up so its always in the back of your mind that if you do too much is it going to happen. So I suppose a lot of its worry whether you can let yourself go or you can't let yourself go. I know that if you start getting out of breath and bit dizzy you stand there and prop yourself up. It's at the back of your mind. Is it going to come off or isn't it. Yes, I suppose its always at the back of your mind is today the day or is tomorrow the day. But you haven't to worry about it, you have to life day by day and just hope it never gets any worse. It doesn't bother me as much when if feel alright as much as it does when I'm not alright. I don't really know if I'm going to have a bad day. I can get up in the morning and be alright and then just for some unknown reason it will just, sometimes it can last half an hour sometimes it can last a couple of hours. I thing the worse thing is when you feel your heart miss a beat, it's a sort of feeling that you can't really explain to anybody, its as if for that split second everything stops. I think that's the worst sensation of it all. It makes your mind go round just for that split second you think all sorts of things. I tend to but a brave face on with me friends, but me family only have to look in your eyes to know there is something wrong. They are watching you, they leave me to get on with it. In my case they know I'm not silly, if there is anything wrong I would say something. J (wife) a couple of times, I felt like it for a start, I always know when it gets to the stage when I'll need some help. I've learnt that. It used to be embarrassing but we've got used to it now and I'll hold her arm. She can tell in me face that it's a bad day.

I is there anything else that we haven't discussed that you want to say?

P No I don't think there is. I don't sit down and wished this had never happened, I just take it as a fact of life that things happen to people. I've never sat and really thought about why this has happened to me. I know I'm over weight. We are planning a holiday just now and I see it, that if you don't plan then you are giving in. That's my way of thinking. Come and take me when you want I'm not bothered, no I still plan I'm not going to give up. I'm very careful when we plan things to make sure I'm going to finish it. I live as normal as possible. I wouldn't go far on my own I tend to be with other people for security, for my security. I feel most secure at home, but my family is good and I like to go to them. The street is the worst place on your own. That's the time you feel most vulnerable. I have a mobile phone and that helps we can just ring each other. If something is going to happen its going to happen, it won't matter whether I'm sat here or outside.

Appendix 3

Interview 10

I What does the term quality of life mean to you?

P What quality? I haven't got half I use to have. I can't do, same as cleaning for a start. I used to do all the decorating N (husband) does it now I just do the pasting now. Its me heart. I used to climb up and down ladders. I haven't had much trouble with me heart until two months ago, I was in with fluid on me lungs. I got over that after eight days in hospital. I was home a month and I went back in again. And now I've been home a few weeks.

I Tell me what happened

P It gradually came on. In the morning I was a bit breathless, real ruttley, I had a sniff or two of oxygen cause now I have oxygen. I went to bed and I had the oxygen bottle for quarter of an hour in bed. The next morning I was alright. I had to go hospital that morning for me blood and me toe, and, so I went for me blood. I said I can't breath, they got me oxygen, I went to see the cardiac nurse and that's when they took me in. It was fluid on the lungs, it was. They told me they can't cure that.

I When you get breathless how does it make you feel?

P I get frightened, I'm not frightened all the time, it's just when it happens when it starts to happen. I think I'm not going through this again, surely not. Don't start again. Why does it happened to me what have I done wrong. I get frightened of having another heart attack, because when you can't get your breath it puts more strain on your heart. Other than that I'm alright. When I get frightened it makes it worse. If I could just settle down and relax more. I do relax, nothing worries me, I haven't a care in the world, I don't let anything worry me, same as him (husband), everything worries him. But, as I say I don't let anything worry me, whatever happens in the street happens. I'm not bothered. If I don't get this done today, I'm not bothered it will wait til another day. I used to worry, I'm not joking didn't I N (husband), I used to worry. But since I had me heart attack, I've changed.

I What else do you thing has changed about you?

P I wouldn't say anything else has changed. We used to go here, there and everywhere, relations and that, they never used to come to us, they never come to us. Now I reckon, no I'm not going there, they don't come to us. So I'm not going, I've got while, I would never of thought about doing that before, we used to go. My sister, we used to go every time, she never dreams of coming here, because I've got now, I've got to the stage where I think I'm not going. She rings and thinks a phone call is as good as a visit. My daughter and son lives away, my relations don't come. I don't worry now. Me and N (husband), we are closer, for the better. He does everything, he does it all, I'll get up and peel the tatties and that. After dinner I do the dusting, but he won't let me do anything else. Washing up, I do. Otherwise, I do. I can't walk very far, I do, I go sit in the greenhouse and do all me seeds and the gardening but I don't do that now. I've lost interest in most things, I don't know why. The cardiac nurse told me to climb the stairs at least once a day for exercise which I do at night. Sometimes twice a day if I have a bath, that's embarrassing as well. N (husband) has to bath me, there's no privacy. N (husband) tries to get me out the bath, I don't like it, I'm too heavy for him. I don't like the bath lift. You can't get a proper bath. My daughter is a brick. She lives in Stevenage; if I want her she's here. She comes at least one weekend a month. They're a lot more loving, every night they phone use. My son was a seaman in the Navy; he likes to boss everyone about. He's loving in his way. He's very bossy. The grand kids, that's another thing, I don't see me grand banes. They're all growing up and up. My grand daughter is 16, 17. We had a blessing on 28 December there was everyone.

I Do you have any problems with taking the treatment given?

P I have no problems, I've had side effects. My tablets have been changed recently. I've had side effects with them all.

I Your on quite a list of tablets (shows interviewer a list)

P I don't bother about taking them. N (husband) organises my tablets. Every night he gets my tablets ready, and every morning. He keeps me organised. He has all the records of everything, hospital, doctors and that. I've had a cold nose, cough, dry cough, I've had that for ages, and ages but that seems to be fizzling out now. I would manage with out N (husband) but it would be a struggle. I can get me pills but as for the housework I couldn't do a quarter of what he does.

I Do you go anywhere?

P We go off to do our shopping. We always plan a holiday, my friends from Sheffield always plan it and we go with them. I always bear in mind the, just in case. You can only go so far, we have planned a holiday, it's only a two hour journey. It means I can go anywhere I want to go but I can get back if I'm poorly. I also have to think about me equipment, oxygen; I get portables and then there's the doctor. I'm registered with the doctor down there. It's near my daughter. I feel safe at home and my daughters. I don't feel comfortable at me sons'. I feel safe at home. The doctors is near and the hospital is just round the corner.

I Has anything else changed that we haven't talked about?

P no I don't think so. I'm a wreck. I think about the future. I would like to live a lot longer than I do. Were having a conservatory built at the back. We were going to move house, we changed our mind. The conservatory would be nice, my daughter has one and I sit there all day. We play cards every night and we could sit in there and play cards. We used to go for a drink now and again. We used to go to Cleethorpes, we use to go out, its hard for him (husband). We used to go on the train. Now we are dependant on them fetching us. We don't rely on anybody. He does what I can't do. I prefer it that way. I feel disappointed that I can't do things anymore. I used to like oil painting I can't concentrate on it. I read a lot and listen to tapes. I afraid my quality of life has dropped a bit, a little bit. Otherwise I've got my brasses to clean (laugh). He hates them, he won't clean the brass. Now all of its gone, other than a few bits and treasured pieces. I'm happy as I am now, so long as I can keep like how I am now. I've got me husband and I've got me daughter and me son. No I'm happy enough.

Appendix 3

Interview 11

I What does the term quality of life mean to you?

P I've had a chance to assess my quality of life and my quality of life hasn't changed, I think its about to change. I think they are about to get rid of people at work and I think they might pay me off, I don't know. My quality of life hasn't changed a lot, I can still do all the things, meals and so on. The only thing is I'm at home now, which I don't like. I hate been stuck inside. I used to work all over the country and I do detest been in one place for a long time. A (partner) has looked after me and been really good to me and I feel really terrible saying it, but she gets on my bloody nerves to be honest, but that's because I'm here all the time. My quality of life isn't what I would expect it to be at the moment but I'm still on the sick. If I went back to work or working from home, I can only basis it on my thought about how it would be. That is going in and doing a certain amount of work and build a work pattern. I now how I feel health wise. Do you want to know about that?

I Yes tell me about that

P well, that's changed in as much as, that changed about three years ago when I was diagnosed as having heart failure and I'll be blunt about this, but I consider the doctors, I didn't feel I got a good deal off them at all, perhaps its because I'm a scouser and the accent and I don't come over very well at all. All they did was see me and then push me into the world, I didn't have a clue what was going on I didn't understand what my heart problem was, after 3 months of working with a guy and I told him how upsetting it was. The GP said things, nobody gave me information, and I had to start doing things to find my parameters. Nothing bothered me much and I still did everything. I even joined the company's five a side football to push me self. But I needed to know by practical experience rather than someone explaining to me, so no one gave me any information at all. Even when I asked, I asked the doctor, absolutely nothing was said. They didn't give me any advice. I saw the cardiac nurse and she finally helped me make decisions. I'm an engineer and I need to be talked about. I have been left to my own devices. I've also had a small stroke. I lost my eye sight and after ten minutes it came back and I didn't bother. But if I'd known more about it initially I would have probably gone to the doctor to get something done about it. A lot of the information I have gleaned I've gone around and asked people the questions, I really don't feel, it would have been more helpful to talk and ask questions. If I could have asked I probably wouldn't have had some of the problems I've had since. It seems like each medical person is very good at the particular job they do, this is here, this is here but they can't pull it together. They're only experts in their area and they don't know about other things and they don't bother to find out. I think the doctors should be working together to sort us all out. Stress is my biggest problem; I was never given the information that stress can course some of my problems. I don't think in answer to your question that I have been given enough information. The cardiac nurse has been talking about getting me on an exercise course at the hospital, I need that, I need to be tired down. It would give me something to do. I asked about this six months ago. I like practical solutions. I feel let down that not a lot of information is available. I asked me GP what causes all this and he more or less said that my erratic heartbeat isn't allowing me heart to clear the fluid, and of course that makes sense. Over a period of time it's gone a little bit, and a little bit. I've been taking drugs to make me better, and each day I got better. I was so breathless. I have water retention and I take tablets for that but if I'd been told be careful, look for this. Bits have added up over the last three years that have changed what I can do, I don't play football anymore (laugh). I'm more aware of things and what's going on now. I check me weight, for water building up. I've had to change things all along the line because as things have come up I've had to make guesses. I guess at what is wrong with me. I've been frightened by the symptoms I've had the loss of eyesight and the breathlessness. I push it to the back of my mind. The breathlessness crept up on me and it was strange. I would go to bed at night and keep me self awake, I couldn't sleep because of the breathlessness. I sleep now, I am a lot more happy. I thought it was because I wasn't going to wake up or I was going to wake up with something wrong. I want to go back to work now but my doctor won't let me and the work I do I will need to retrain I am thinking of changing who I work for and seeing if I can work from home. I love me job, I like working and getting involved in what I'm doing. I don't think they will let me go back to what I was doing. I've more or less resigned my self to that. Being at home hasn't changed things people have been pretty good. I talk a lot more on the phone to my family. My relationship with A (partner) has changed, were in each other's pockets, we squabble, its hard going. Hopefully if I get work sorted out it should help.

Appendix 3 (continued)

I How do you feel about taking the treatment?

P I don't have a problem, the only thing is I don't remember the names A (partner) tried to organise me but I don't let her. I can organise the tablets no problem at all. I know what I should be taking and what there are all for.

I Is there anything else we haven't discussed that you want to say?

P No I don't think so. I've got rid of this fluid, I could play football, I'm not going too. I feel so much better now a days. I want to do the exercises at the hospital because there will be someone qualified on site and then if anything goes wrong they will get stuck in. I will be able to push me self and I will feel confident that I can do it. Then I might go back to going swimming and other things. Once I'm happy with my exercises I will go off and do things. But other than that I'm doing alright and I have the cardiac nurse to contact should I need to ask anything.

Appendix 4

Interview 1

	emotion	sympt	Self-p	medic	relation	cogn	routine	lifestyle	Inform	Support mech	Coming to terms	Advice /experie	percept	Ability HCP	finance	total
Emotion	9		1								1			1		12
Symptom	1	8	1			1						1				12
Self-p	2		6		1											9
Medicat				1												1
Relation	2				14		1									17
Cogn						0										0
Routine			1				9						1		1	12
Lifesty								7								7
Inform									1							1
Support										1						1
Coming to terms		1	1								11				1	14
Ad/ex												6				6
Perce			1										2			3
Ability hcp											1			6		7
Finance															5	5
total	14	9	11	1	15	1	10	7	1	1	13	7	3	7	7	107

$$K= \frac{Po-Pc}{1-Po} \qquad K= \frac{0.804-0.112}{1-0.112} \qquad \mathbf{K= 0.78}$$

Appendix 4 (continued)

Interview 3

	emotion	sympt	Self-p	medic	relation	cogn	routine	lifestyle	Inform	Support mech	Coming to terms	Advice/experie	percept	Ability HCP	finance	total
Emotion	5				1		1	1								8
Symptom		4	1				1									6
Self-p		1	7													9
Medicat				1							1					1
Relation					2											2
Cogn						2										2
Routine					2		11									13
Lifesty					1			6								7
Inform									0							0
Support										1						1
Coming to terms											5					5
Ad/ex												0				0
Perce													1			1
Ab hcp														0		0
Fin															2	2
total	5	5	8	1	6	2	13	7	0	1	6	0	1	0	2	57

$K= \frac{Po-Pc}{1-Po}$ $K= \frac{0.824-0.041}{1-0.041}$ **$K= 0.81$**

Appendix 5

```
QSR N6 Full version, revision 6.0.
Licensee: Karen Dunderdale.

PROJECT: phase 1, User Karen Dunderdale, 10:15 pm, Jul 19, 2004.

REPORT ON NODES FROM Tree Nodes '~/'
Depth: ALL
Restriction on coding data: NONE

(1)        /Quality of Life
(1 1)      /Quality of Life/Emotional
(1 1 1)     /Quality of Life/Emotional/worry
(1 1 2)     /Quality of Life/Emotional/angry
(1 1 3)     /Quality of Life/Emotional/frightened
(1 1 4)     /Quality of Life/Emotional/Frustration
(1 1 5)     /Quality of Life/Emotional/Enjoyment
(1 1 6)     /Quality of Life/Emotional/guilty
(1 1 7)     /Quality of Life/Emotional/apprehensive
(1 1 8)     /Quality of Life/Emotional/Inadequate
(1 1 9)     /Quality of Life/Emotional/grateful
(1 1 10)     /Quality of Life/Emotional/upset
(1 1 11)     /Quality of Life/Emotional/don't like going out
(1 1 12)     /Quality of Life/Emotional/whats the point
(1 1 13)     /Quality of Life/Emotional/sad
(1 1 14)     /Quality of Life/Emotional/tears
(1 1 15)     /Quality of Life/Emotional/mood swings
(1 1 16)     /Quality of Life/Emotional/lack of confidence
(1 1 17)     /Quality of Life/Emotional/annoyed
(1 1 18)     /Quality of Life/Emotional/depressed
(1 1 19)     /Quality of Life/Emotional/secure
(1 1 20)     /Quality of Life/Emotional/vulnerable
(1 1 21)     /Quality of Life/Emotional/panic
(1 1 22)     /Quality of Life/Emotional/embarrassed
(1 1 23)     /Quality of Life/Emotional/disappointed
(1 1 24)     /Quality of Life/Emotional/happy
(1 1 25)    /Quality of Life/Emotional/feel a failure
(1 2)      /Quality of Life/symptoms
(1 2 1)     /Quality of Life/symptoms/tired
(1 2 2)     /Quality of Life/symptoms/breathlessness
(1 2 3)     /Quality of Life/symptoms/oedema
(1 2 4)     /Quality of Life/symptoms/dizzy
(1 2 5)     /Quality of Life/symptoms/lack of energy
(1 2 6)     /Quality of Life/symptoms/chest discomfort
(1 2 7)     /Quality of Life/symptoms/palpitations
(1 2 8)     /Quality of Life/symptoms/feel awful
(1 2 9)     /Quality of Life/symptoms/light headed
(1 2 10)     /Quality of Life/symptoms/gout
(1 2 11)     /Quality of Life/symptoms/loss of taste
(1 2 12)     /Quality of Life/symptoms/bloated stomach
```

Appendix 5 (continued)

(1 3) /Quality of Life/Self perception
(1 3 1) /Quality of Life/Self perception/condition
(1 3 1 1) /Quality of Life/Self perception/condition/sword of Damocles
(1 3 1 2) /Quality of Life/Self perception/condition/concerns
(1 3 1 3) /Quality of Life/Self perception/condition/Why?
(1 3 1 4) /Quality of Life/Self perception/condition/climate effects
(1 3 1 5) /Quality of Life/Self perception/condition/hereditary
(1 3 1 6) /Quality of Life/Self perception/condition/compare to others of same age
(1 3 1 7) /Quality of Life/Self perception/condition/diabetic
(1 3 1 8) /Quality of Life/Self perception/condition/worthless
(1 3 1 9) /Quality of Life/Self perception/condition/low ebb
(1 3 1 10) /Quality of Life/Self perception/condition/discrepancy between mind & body
(1 3 1 11) /Quality of Life/Self perception/condition/brave face
(1 3 1 12) /Quality of Life/Self perception/condition/determined
(1 3 1 13) /Quality of Life/Self perception/condition/understand
(1 3 1 14) Quality of Life/Self perception/condition/strain on the heart
(1 3 2) /Quality of Life/Self perception/wonderful
(1 3 3) /Quality of Life/Self perception/best of life
(1 3 4) /Quality of Life/Self perception/role in life
(1 3 5) /Quality of Life/Self perception/not perfect
(1 3 6) /Quality of Life/Self perception/reassurance
(1 3 7) /Quality of Life/Self perception/personality changes
(1 3 8) /Quality of Life/Self perception/self preservation
(1 3 9) /Quality of Life/Self perception/self awareness
(1 3 10) /Quality of Life/Self perception/nothing positive
(1 3 11) /Quality of Life/Self perception/regret
(1 3 12) /Quality of Life/Self perception/positive outcome
(1 3 13) /Quality of Life/Self perception/ego
(1 3 14) /Quality of Life/Self perception/withdrawn
(1 3 15) /Quality of Life/Self perception/goes against grain
(1 3 16) /Quality of Life/Self perception/no patience
(1 3 17) /Quality of Life/Self perception/thankful
(1 4) /Quality of Life/Relationships
(1 4 1) /Quality of Life/Relationships/think forward
(1 4 2) /Quality of Life/Relationships/reaction of others
(1 4 3) /Quality of Life/Relationships/sexual relationship
(1 4 5) /Quality of Life/Relationships/other people telling
(1 4 6) /Quality of Life/Relationships/imposed
(1 4 7) /Quality of Life/Relationships/relationship with others
(1 4 8) /Quality of Life/Relationships/calm down
(1 4 9) /Quality of Life/Relationships/appreciate
(1 4 10) /Quality of Life/Relationships/company
(1 4 11) /Quality of Life/Relationships/walk away
(1 4 12) /Quality of Life/Relationships/crowds
(1 4 13) /Quality of Life/Relationships/expectation of others
(1 4 14) /Quality of Life/Relationships/reluctant
(1 4 15) /Quality of Life/Relationships/loss of independence
(1 4 16) /Quality of Life/Relationships/help
(1 4 17) /Quality of Life/Relationships/strain

Appendix 5 (continued)

(1 4 18)	/Quality of Life/Relationships/relationship deteriorated
(1 4 19)	/Quality of Life/Relationships/independent
(1 4 20)	/Quality of Life/Relationships/closer
(1 4 21)	/Quality of Life/Relationships/hard
(1 4 22)	/Quality of life/Relationships/medication reliance
(1 5)	/Quality of Life/Cognitive
(1 5 1)	/Quality of Life/Cognitive/sleep pattern
(1 5 2)	/Quality of Life/Cognitive/denial
(1 5 3)	/Quality of Life/Cognitive/concentration
(1 5 4)	/Quality of Life/Cognitive/forget
(1 5 5)	/Quality of Life/Cognitive/lost interest
(1 5 6)	/Quality of Life/Cognitive/forgetting to take tablets
(1 6)	/Quality of Life/Routine/physical
(1 6 1)	/Quality of Life/Routine/physical/routine
(1 6 2)	/Quality of Life/Routine/physical/not able
(1 6 3)	/Quality of Life/Routine/physical/done by someone else
(1 6 4)	/Quality of Life/Routine/physical/consider everything
(1 6 5)	/Quality of Life/Routine/physical/physical activity
(1 6 6)	/Quality of Life/Routine/physical/compromise
(1 6 7)	/Quality of Life/Routine/physical/failings
(1 6 8)	/Quality of Life/Routine/physical/limit activity level
(1 6 9)	/Quality of Life/Routine/physical/think through activity
(1 6 10)	/Quality of Life/Routine/physical/restricted
(1 6 11)	/Quality of Life/Routine/physical/careful
(1 6 12)	/Quality of Life/Routine/physical/takes longer
(1 6 13)	/Quality of Life/Routine/physical/avoid
(1 6 14)	/Quality of Life/Routine/physical/sit down
(1 6 15)	/Quality of Life/Routine/physical/change of roles
(1 6 16)	/Quality of Life/Routine/physical/giving up
(1 6 17)	/Quality of Life/Routine/physical/moderation
(1 6 18)	/Quality of Life/Routine/physical/struggle
(1 6 19)	/Quality of Life/Routine/physical/cut down
(1 6 20)	/Quality of Life/Routine/physical/forced
(1 6 21)	/Quality of Life/Routine/physical/more difficult
(1 7)	/Quality of Life/Lifestyle
(1 7 1)	/Quality of Life/Lifestyle/freedom
(1 7 2)	/Quality of Life/Lifestyle/sport
(1 7 3)	/Quality of Life/Lifestyle/social life
(1 7 4)	/Quality of Life/Lifestyle/life style
(1 7 5)	/Quality of Life/Lifestyle/stress
(1 7 6)	/Quality of Life/Lifestyle/hobbies
(1 7 7)	/Quality of Life/Lifestyle/manage
(1 7 8)	/Quality of Life/Lifestyle/meet people
(1 7 9)	/Quality of Life/Lifestyle/get out
(1 7 10)	/Quality of Life/Lifestyle/factors in life
(1 7 11)	/Quality of Life/Lifestyle/hassle
(1 7 12)	/Quality of Life/Lifestyle/not the same
(1 7 13)	/Quality of Life/Lifestyle/don't give up
(1 7 14)	/Quality of Life/Lifestyle/missing out

Appendix 5 (continued)

(1 7 15)	/Quality of Life/Lifestyle/stuck
(1 7 16)	/Quality of Life/Lifestyle/medication
(1 7 17)	/Quality of Life/Lifestyle/inconvenience of medication
(1 7 16)	/Quality of Life/Lifestyle/amongst people
(1 7 17)	/Quality of Life/Lifestyle/implications
(1 7 18)	/Quality of Life/Lifestyle/driving
(2)	/Coping
(2 1)	/Coping/Information
(2 1 1)	/Coping/Information/assistance
(2 1 2)	/Coping/Information/medical help
(2 1 3)	/Coping/Information/alternative treatment
(2 1 4)	/Coping/Information/information
(2 2)	/Coping/Support Mechanisms
(2 2 1)	/Coping/Support Mechanisms/rely on others
(2 2 2)	/Coping/Support Mechanisms/facilities available
(2 2 3)	/Coping/Support Mechanisms/support
(2 2 4)	/Coping/Support Mechanisms/family support
(2 2 5)	/Coping/Support Mechanisms/future
(2 3)	/Coping/Coming to terms with illness
(2 3 1)	/Coping/Coming to terms with illness/plan for future
(2 3 2)	/Coping/Coming to terms with illness/expectations
(2 3 3)	/Coping/Coming to terms with illness/don't want to do things
(2 3 4)	/Coping/Coming to terms with illness/attitude
(2 3 5)	/Coping/Coming to terms with illness/acceptance
(2 3 6)	/Coping/Coming to terms with illness/coping strategies
(2 3 7)	/Coping/Coming to terms with illness/learn what to do
(2 3 8)	/Coping/Coming to terms with illness/plan
(2 3 9)	/Coping/Coming to terms with illness/selfish
(2 3 10)	/Coping/Coming to terms with illness/hard life
(2 3 11)	/Coping/Coming to terms with illness/last minute
(2 3 12)	/Coping/Coming to terms with illness/cautious
(2 3 13)	/Coping/Coming to terms with illness/parameters
(3)	/Understanding
(3 1)	/Understanding/Advice & experience
(3 1 1)	/Understanding/Advice & experience/experience
(3 1 2)	/Understanding/Advice & experience/educated
(3 1 3)	/Understanding/Advice & experience/foolish
(3 1 4)	/Understanding/Advice & experience/asked for information
(3 1 5)	/Understanding/Advice & experience/aware
(3 2)	/Understanding/Perception
(3 2 1)	/Understanding/Perception/family history
(3 2 2)	/Understanding/Perception/family concern
(3 2 3)	/Understanding/Perception/death
(3 2 4)	/Understanding/Perception/permission
(3 2 5)	/Understanding/Perception/joke
(3 2 6)	/Understanding/Perception/psychological
(3 2 7)	/Understanding/Perception/understanding
(3 2 8)	/Understanding/Perception/do the best
(3 2 9)	/Understanding/Perception/life expectancy

Appendix 5 (continued)

(3 2 10)	/Understanding/Perception/unpredictable
(3 2 11)	/Understanding/Perception/wish
(3 2 12)	/Understanding/Perception/too late
(4)	/Experience
(4 1)	/Experience/Ability of Health Care Professionals
(4 1 1)	/Experience/Ability of Health Care Professionals/believe
(4 1 2)	/Experience/Ability of Health Care Professionals/make decisions
(4 1 3)	/Experience/Ability of Health Care Professionals/incompetence
(4 1 4)	/Experience/Ability of Health Care Professionals/loss of confidence
(4 1 5)	/Experience/Ability of Health Care Professionals/let down
(4 1 6)	/Experience/Ability of Health Care Professionals/loss of trust
(4 1 7)	/Experience/Ability of Health Care Professionals/hope
(4 1 8)	/Experience/Ability of Health Care Professionals/not told
(4 1 9)	/Experience/Ability of Health Care Professionals/didn't understand
(4 1 10)	/Experience/Ability of Health Care Professionals/practical experience
(4 1 11)	/Experience/Ability of Health Care Professionals/lack of medical advice
(4 1 12)	/Experience/Ability of Health Care Professionals/left to own devices
(4 2)	/Experience/Financial
(4 2 1)	/Experience/Financial/expensive
(4 2 2)	/Experience/Financial/alternative income
(4 2 3)	/Experience/Financial/private
(4 2 4)	/Experience/Financial/financial
(4 2 5)	/Experience/Financial/work
(4 2 6)	/Experience/Financial/benefits
(4 2 7)	/Experience/Financial/tooth and nail
(4 2 8)	/Experience/Financial/cut your cloth

Appendix 6

Table of Themes

Rank	Themes	Codes	Title	Description
1	22	63	Physical	Routine, consider everything, compromise, avoid, change of role, struggle, physical activity, limit activity level, failings, restricted, careful, think through, take longer
2	25	60	Emotional	Frightened, frustration, worry, angry, guilty, secure, panic
3	30	22 28	Self-perception – condition – self	Why?, concerns, compare to others, mind & body, brave face, self perception, personality change, self awareness, not perfect, reassurance, positive outcome
4	22	46	Relationships	Other people telling, reaction to others, relationship with others, sexual relationship, imposed, hard, independent
5	12	40	Symptoms	Breathlessness, oedema, dizzy, tired, chest discomfort, feel awful
6	20	33	Lifestyle	Social life, stress, don't give up, lifestyle, missing out, side effect of medication
7	6	17	Cognitive	Sleep pattern, denial, concentration, forget

Appendix 7

Definition of classifications and themes (Phase 1)			
NUD*IST Code	**Classification**	**Theme**	**Definition of theme**
0	**Medical History (Participants medical history taken from medical case notes)**	1 Gender	1 Gender of each participant
		2 Age of participant	2 Age of participant at the time of the interview
		3 Occupational status	3 Participant's occupational status at the time of interview
		4 Severity of heart failure	4 Number of participant's with a categorised description of the severity of heart failure e.g. mild, moderate, moderate to severe, severe.
		5 Ejection fraction	5 Number of participant's with echocardiographic measurement of severity of heart failure expressed as a percentage.
		6 NYHA Class	6 Number of participant's with a specific functional status.
		7 Previous hospital admissions	7 Number of participant's hospital admissions prior to interview.
1	**Quality of Life (Factors participants perceived to have been caused by CHF)**	1 Changes in physical ability	1 Changes in ability to perform physical tasks e.g. limiting activity levels, change of roles, considering every activity, influence of symptoms on physical ability, dependency on others.
		2 Emotional state	2 Emotional characteristics expressed by participants e.g. fear, frustration, worry, anger, guilt, panic.
		3 Self-awareness	3 Perception by the participant of the condition and how it affects them e.g. why had this happened to them, comparing themselves to others of a similar age.
		4 Self-perception	4 Participants awareness of themselves and their personality e.g. self-awareness, reflection, self-preservation.
		5 Changes in relationships	5 The relationship the participant now has with others around them and the reaction of others to them as a result of CHF.
		6 Symptoms	6 chronic heart failure symptoms e.g. breathlessness, oedema, dizziness, tiredness, chest discomfort and feeling unwell.
		7 Maintaining social/lifestyle status	7 Participants experience of changes in their social life and lifestyle.
		8 Medication	8 Participants experience of taking medication for CHF e.g. side effects, forgetting to take tablets and reliance on the medication.
		9 Cognitive aspects	9 Participants experience of changes in cognitive characteristics e.g. concentration, forgetting about CHF, changes in sleep patterns.

Appendix 7 (continued)

Definition of classifications and themes (Phase 1)			
NUD*IST Code	**Classification**	**Theme**	**Definition of theme**
2	**Management**	1 Coming to terms with illness 2 Support mechanisms 3 Information	1 How participants planned for the future, used coping strategies and how this affected their expectations of life. 2 Support of others helps the participant live with CHF. 3 Information given to participant from Health care professionals.
3	**Understanding CHF**	1 Perceptions 2 Advice and experience	1 How the participant perceived death and dying since having CHF 2 Participants experiences had increased their understanding of CHF and how to deal with any problems.
4	**New experiences as a result of CHF**	1 Ability of health care professionals 2 Financial	1 Attitude and ability of health care staff e.g. incompetence, loss of confidence, reluctance to believe, grateful for involvement of staff. 2 Participants experience of how changes in work affected them financially

Appendix 8

Quality of Life in Chronic Heart Failure: Development of the CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. If there is anything that is not clear, or if you would like more information, please ask us. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this information.

What is the purpose of the study?

To develop a questionnaire that can be used by Doctors and Nurses in their clinical practice for measuring the quality of life (the things you do and how easy or difficult it is for you to do them) of patients who have chronic heart failure.

Why have I been chosen?

You have been invited to take part because you have been diagnosed with chronic heart failure and a number of people (8 patients), such as yourself who are admitted to Northern Lincolnshire & Goole Hospitals NHS Trust will be asked if they wish to take part.

As some patient's partners accompany them to the clinic, we will be inviting 8 partners to join in.

Do I have to take part?

No, the choice to take part is entirely yours. If you decide not to complete the questionnaire or join in a focus group this will not affect your treatment or care in any way.

What will happen to me if I take part?

The Cardiac Specialist Nurse will explain the study to you whilst you are at the clinic, and that you will be contacted by the researcher to take part in a focus group (Group discussion). If your partner usually accompanies you to the clinic, he/she will also be invited to take part in a focus group, this will take place on the same day as your next clinic visit.

Appendix 8 (continued)

If you and your partner are willing to take part in the focus group you will be asked to stay for about 30 minutes after your clinic visit. If you decide to stay for the focus group, we will regard this as your and your partners consent to taking part.

What are the advantages / disadvantages of participating in this study?

Whilst there are no guarantees that you will benefit from taking part in this study, the results will be used to develop a way in which the quality of life for patients with chronic heart failure can be measured. This will hopefully ensure that we provide the best possible care for these patients.

Will my taking part in the study be kept confidential?

If you agree to take part in this study, you will not be identified, but will only be known by a study number. Only the researchers involved with the study will see the information that is collected. All information will be treated in the strictest confidence. At the beginning of the focus group meeting everyone involved will be asked to keep what is discussed confidential.

What will happen to the results of the study?

This study will identify how chronic heart failure affects a person's quality of life, and will complement the measures the hospital already uses. It is also probable that the results from this study will be published in appropriate medical journals. No individual patient will be identified in any published article.

Ethical considerations

This study has been reviewed by our Local Research Ethics Committee, which gave a favourable opinion for the study to take place. All records of you taking part in the study will be kept confidential. All data is anonymised.

If you wish to discuss this further please contact Karen Dunderdale on:
Tel: 01724 290093.

'Original in colour'

Appendix 9

CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

We would like your help to improve care for people with heart failure and their families. All you need to do is fill in this questionnaire.

You have recently been in hospital with heart failure. We would like to know about your health and wellbeing since you were discharged.
Please answer each question, your opinions are very important. Some questions may look alike, but each one is asking for different information. Any information will be treated in the strictest confidence.

Please return your questionnaire to Karen Dunderdale in the stamped-addressed envelope provided. If you wish to discuss this study further please contact Karen Dunderdale on 01724 290093.

Please time yourself filling in this questionnaire

Part 1 – About You & Your Heart Failure

1 At the moment, how would you describe your health?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2 Compare your health now with your health before your last admission to hospital by choosing one of the following:

My health is ***much better now*** than before my last admission ☐
My health is ***somewhat better now*** than before my last admission ☐
My health is ***the same now*** as before my last admission ☐
My health is ***somewhat worse now*** than before my last admission ☐
My health is ***much worse now*** than before my last admission ☐

3 Please tick one box for each statement and indicate how often during the past two weeks:

	Very often	Often	Occasionally	Almost Never	Never
Has someone else needed to help you undertake or complete a chore/task	☐	☐	☐	☐	☐
Have you needed to consider what you do and what the implications are going to be?	☐	☐	☐	☐	☐
Have you limited the amount of time you spent doing something?	☐	☐	☐	☐	☐
Have you not dared to attempt certain things for fear of anything going wrong?	☐	☐	☐	☐	☐

4 Here is a list of questions asking you to think about your everyday activities (e.g. washing/dressing/cooking/gardening etc.) in the past two weeks. Specify how true each statement is in comparison to other healthy adults of the same age as you, by circling one response only for each statement.

	Much less than other adults	Somewhat less than other adults	About the same as other adults	Somewhat more than other adults	Much more than other adults	
I think through activities before doing them	0	1	2	3	4	N/A
I am restricted in what activities I can do	0	1	2	3	4	N/A
I am careful in what activities I do	0	1	2	3	4	N/A
I take longer to perform activities	0	1	2	3	4	N/A
I often feel a failure	0	1	2	3	4	N/A
I avoid doing certain activities	0	1	2	3	4	N/A
I struggle to do certain activities	0	1	2	3	4	N/A
My symptoms influence what activities I can do	0	1	2	3	4	N/A
I am dependant on other people	0	1	2	3	4	N/A

5 How often during the past two weeks have you felt breathless/puffed out?

Very often ☐
Often ☐
Occasionally ☐
Almost Never ☐
Never ☐

6 How would you describe your breathing now?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

7 How much during the past two weeks did feeling breathless/puffed out make life difficult for you? (Please indicate by drawing a cross on the line below marked from 1 to 10).

0 1 2 3 4 5 6 7 8 9 10

Not at all Difficult — Really difficult

8 How often during the past two weeks have you felt breathless/puffed out when you were still or inactive and resting?

Very often ☐
Often ☐
Occasionally ☐
Almost Never ☐
Never ☐

9 How often during the past two weeks have you felt breathless/puffed out when active? (e.g. walking, washing, dressing, cleaning).

Very often ☐
Often ☐
Occasionally ☐
Almost Never ☐
Never ☐

10 Have you been limited in any of the following everyday activities because of feeling breathless/puffed out during the past two weeks.

	Not Limited at all	Sometimes limited	Often limited	Always limited
Eating/drinking	☐	☐	☐	☐
Walking around	☐	☐	☐	☐
Sleeping	☐	☐	☐	☐
Talking	☐	☐	☐	☐

11 How often during the past two weeks have you felt tired?

Very often	☐
Often	☐
Occasionally	☐
Almost Never	☐
Never	☐

12 Do you have any other symptoms other than breathlessness or tiredness?

Yes ☐ No ☐

If **Yes**, please state what these other symptoms are

....

....

13 Please tick one box to indicate how often during the past two weeks your symptoms have:

	Very Often	Often	Occasionally	Almost never	Never
Interrupted everyday family activities (E.g. mealtimes)	☐	☐	☐	☐	☐
Stopped you from going out of the house?	☐	☐	☐	☐	☐
Caused you to cancel or change plans at the last minute at home or work?	☐	☐	☐	☐	☐
Caused tension or arguments in the home?	☐	☐	☐	☐	☐

14 During the past two weeks how much have you been worried about your symptoms?

- Very often ☐
- Often ☐
- Occasionally ☐
- Almost Never ☐
- Never ☐

15 Since you were told by a doctor, that you have heart failure has your personality changed?

Yes ☐ No ☐

If **Yes**, please state how your personality has changed

………

………

16 Please look at the following statements and put a cross on the scale which best describes the following: (Please draw a cross on the line below marked from 1 to 10).

I get frightened about things

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I get frustrated with myself

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I get annoyed/angry with people around me

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I often wonder "why me?"

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I feel dependant on other people

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I think if I saw another specialist they would say there is nothing wrong with me

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I have difficulty concentrating

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

My sleeping habits have changed

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

My family/partner worry about me

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

In my mind I feel capable of doing things but I can't

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I am more conscious of the simple things in life

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I feel anxious about dying

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I think is today the day or will it be tomorrow

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

Other people stop me from doing certain things even though I think I could manage

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I find the way people react to me is nice

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I don't feel I play my part in life

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I forget I have heart failure and try to do things like I used to

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

I find the way people react to me offensive

All of the time 0 1 2 3 4 5 6 7 8 9 10 None of the time

17 Please tick one box to indicate if you have been limited in any of the following activities during the past two weeks?

	Not Limited at all	Sometimes limited	Often limited	Always limited	N/A
Going out for drink/meal	☐	☐	☐	☐	☐
Going shopping	☐	☐	☐	☐	☐
Hobbies	☐	☐	☐	☐	☐
Socialising	☐	☐	☐	☐	☐
Work	☐	☐	☐	☐	☐
Holiday	☐	☐	☐	☐	☐
Sexual relationship	☐	☐	☐	☐	☐

18 Please tick one box to indicate how often during the past two weeks you have been concerned about:

	Very Often	Often	Occasionally	Almost never	Never
The side effects of your medication	☐	☐	☐	☐	☐
Forgetting to take your medication	☐	☐	☐	☐	☐
Relying on medication to keep your symptoms under control	☐	☐	☐	☐	☐
Rely on others Organising your medication for you	☐	☐	☐	☐	☐

Part 2 - Extra Information about You and Your Family

1 Are you?

Male ☐ Female ☐

2 What is your date of birth?

☐☐ / ☐☐ / ☐☐

Day Month Year

3 Which one of the following best describes your marital status?

Single ☐
Married ☐
Living together as a couple ☐
Widowed ☐
Divorced or separated ☐

4 Which one of the following best describes your ethnic origin?

☐ White
☐ Caribbean
☐ African
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other ethnic group (Please specify)…………………………

5 Has your work status changed since you were diagnosed with heart failure?

Yes ☐ No ☐

If **Yes**, please state how it has changed. (E.g. I now work part-time/ I now work in a different job/ I now no longer work due to my heart failure)

………………………………………………………………………………………………

………………………………………………………………………………………………

'Original in colour'

6 How many times have you been admitted to hospital as an in-patient before this last admission?

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ More than five

7 If you were admitted to hospital as an in-patient before your last admission, what was the main reason for this?

☐ Heart Failure ☐ Other illness (*Please specify*……………….) ☐ Not applicable

8 How many times during the last month have you visited or called out your GP because of your heart problem?

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ More than five

Part 3 - This Questionnaire

1 How many minutes did it take you to complete this questionnaire? (Approximately)

☐☐ minutes

2 What is today's date?

☐☐ / ☐☐ / ☐☐
Day Month Year

3 How easy did you find it to complete this questionnaire?

Very easy ☐
Quite easy ☐
Neither easy nor difficult ☐
Quite difficult ☐
Difficult ☐

If you have any comments about this questionnaire or your care in general, write them in the space provided below:

Comments:

Please return your completed questionnaire to:
Karen Dunderdale, Cardiac Rehabilitation, Scunthorpe General Hospital, Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7BH

Thank you for your participation

Appendix 10

Chronic Heart Failure Quality of Life (CHFQoL) Questionnaire
Data Collection Sheet

Study No: ☐☐☐

Gender:

Male☐ Female☐

Date of Birth: ☐☐ / ☐☐ / ☐☐

Day Month Year

Marital Status:

Single	☐
Married	☐
Living together as a couple	☐
Widowed	☐
Divorced or separated	☐

Past Medical History:

Date first diagnosed with chronic heart failure:

☐☐ / ☐☐ / ☐☐

Day Month Year

NYHA:

☐	☐	☐	☐
I	II	III	IV

Ejection fraction%:

Left Ventricular Function:

☐	☐	☐	☐	☐
Mild	Mild to moderate	Moderate	Moderate to severe	Severe

Appendix 11

Tel: 01724 290093

13 April 2005

Mrs NAME
ADDRESS

Dear Mrs

My name is Karen Dunderdale and I am a cardiac specialist nurse at Scunthorpe General Hospital. I am currently undertaking a piece of research for a post-graduate degree.

I have written to you to ask for your assistance in this research because you are currently under the care of Dr XXX. Contained in this envelope is an information sheet about the research, a questionnaire and a pre-paid envelope.

If you are willing to take part, please can you complete the enclosed questionnaire and post it back to me in the pre-paid envelope.

If you have any queries you can contact me on the above number.

Thank you in anticipation of your assistance

Yours faithfully

Karen Dunderdale
Cardiac Specialist Nurse

Appendix 12

Quality of Life in Chronic Heart Failure: Development of the CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. If there is anything that is not clear, or if you would like more information, please ask us. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this information.

What is the purpose of the study?

To develop a questionnaire that can be used by Doctors and Nurses in their clinical practice for measuring the quality of life (the things you do and how easy or difficult it is for you to do them) of patients who have chronic heart failure.

Why have I been chosen?

You have been invited to take part because you have been diagnosed with chronic heart failure and a number of people (800 patients), such as yourself who are admitted to Northern Lincolnshire & Goole Hospitals NHS Trust will be asked if they wish to take part.

Do I have to take part?

No, the choice to take part is entirely yours. If you decide not to complete the questionnaire this will not affect your treatment or care in any way.

What will happen to me if I take part?

You have been sent a questionnaire to complete at home and asked to return it in the pre-paid envelope provided. If you complete and return the questionnaire, we will regard this as your consent. If you do not wish to take part, then do not complete or return the questionnaire.

What are the advantages / disadvantages of participating in this study?

Whilst there are no guarantees that you will benefit from taking part in this study, the results will be used to develop a way in which the quality of life for patients with chronic heart failure can be measured. This will hopefully ensure that we provide the best possible care for these patients.

Will my taking part in the study be kept confidential?

If you agree to take part in this study, you will not be identified, but will only be known by a study number. Only the researchers involved with the study will see the information that is collected. All information will be treated in the strictest confidence.

What will happen to the results of the study?

This study will identify how chronic heart failure affects a person's quality of life, and will complement the measures the hospital already uses. It is also probable that the results from this study will be published in appropriate medical journals. No individual patient will be identified in any published article.

Ethical considerations

This study has been reviewed by our Local Research Ethics Committee, which gave a favourable opinion for the study to take place. All records of you taking part in the study will be kept confidential. All data is anonymised.

If you wish to discuss this further please contact Karen Dunderdale on: Tel: 01724 290093

Appendix 13

Study No: ☐☐☐

CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

We would like your help to improve care for people with heart failure and their families. All you need to do is fill in this questionnaire.

You have been given a diagnosis of heart failure and we would like to know about your health and wellbeing since you were told this.

Please answer each question, your opinions are very important. Some questions may look alike, but each one is asking for different information. Any information will be treated in the strictest confidence.

Please return your questionnaire to Karen Dunderdale in the stamped-addressed envelope provided. If you wish to discuss this study further please contact Karen Dunderdale on 01724 290093.

Part 1 – About You & Your Heart Failure

1 At the moment, how would you describe your health?

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

2 Compare your health now with your health before your last admission to hospital by choosing one of the following:

My health is ***much better now*** than before my last admission ☐
My health is ***somewhat better now*** than before my last admission ☐
My health is ***the same now*** as before my last admission ☐
My health is ***somewhat worse now*** than before my last admission ☐
My health is ***much worse now*** than before my last admission ☐

3 Each question below is about how you have been in the <u>past two weeks</u>.

Please tick one box for each statement.

	Very often	Often	Occasionally	Almost never	Never
I have needed someone to help me with chores or tasks because of my heart failure.	☐	☐	☐	☐	☐
I need to consider the implications of doing something because of my heart failure.	☐	☐	☐	☐	☐
I have limited the amount of time I spend doing something because of my heart failure.	☐	☐	☐	☐	☐
I have <u>not</u> dared to attempt certain things for fear of anything going wrong because of my heart failure.	☐	☐	☐	☐	☐

4 Please tick one box to indicate how often during the <u>past two weeks</u> you have been concerned about:

	Very often	Often	Occasionally	Almost never	Never
The side effects of your medication.	☐	☐	☐	☐	☐
Forgetting to take your medication.	☐	☐	☐	☐	☐
Relying on medication to keep your symptoms under control.	☐	☐	☐	☐	☐
Rely on others organising your medication for you.	☐	☐	☐	☐	☐

5 Here is a list of questions asking you to think about your everyday activities (e.g. washing/dressing/cooking/gardening etc.) in the <u>past two weeks</u>. Specify how true each statement is when you think about how your heart failure limits you in comparison to other healthy adults of the same age as you, by circling one response only for each statement.

	Much less than other adults	Somewhat less than other adults	About the same as other adults	Somewhat more than other adults	Much more than other adults	Not applicable
I have to think through activities before doing them.	0	1	2	3	4	N/A
I am restricted in what activities I can do.	0	1	2	3	4	N/A
I am careful in what activities I do.	0	1	2	3	4	N/A
I take longer to perform activities.	0	1	2	3	4	N/A
I often feel a failure.	0	1	2	3	4	N/A
I avoid doing certain activities.	0	1	2	3	4	N/A
I struggle to do certain activities.	0	1	2	3	4	N/A
My symptoms influence what activities I can do.	0	1	2	3	4	N/A

6 How often during the past two weeks have you felt breathless/puffed out?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

7 How would you describe your breathing now?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

8 How much during the past two weeks did feeling breathless/puffed out make life difficult for you? (Please indicate by drawing a cross on the line below marked from 1 to 10).

0 1 2 3 4 5 6 7 8 9 10

Not at all Difficult

Really difficult

9 How often during the past two weeks have you felt breathless/puffed out when you were still or inactive and resting?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

10 How often during the past two weeks have you felt breathless/puffed out when active? (e.g. walking, washing, dressing, cleaning).

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

11 Have you been limited in any of the following everyday activities because of feeling breathless/puffed out during the past two weeks?

	Not limited at all	Sometimes limited	Often limited	Always limited
Eating/drinking	☐	☐	☐	☐
Walking around	☐	☐	☐	☐
Sleeping	☐	☐	☐	☐
Talking	☐	☐	☐	☐

12 How often during the past two weeks have you felt unduly tired?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

13 Do you have any other symptoms other than breathlessness or tiredness?

Yes ☐ No ☐

If **Yes**, please state what these other symptoms are

....

....

14 Please tick one box to indicate how often during the past two weeks your symptoms have:

	Very often	Often	Occasionally	Almost never	Never
Interrupted everyday family activities? (E.g. mealtimes)	☐	☐	☐	☐	☐
Stopped you from going out of the house?	☐	☐	☐	☐	☐
Caused you to cancel or change plans at the last minute at home or work?	☐	☐	☐	☐	☐
Caused tension or arguments in the home?	☐	☐	☐	☐	☐

15 During the past two weeks how much have you been worried about your symptoms?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

16 Since you were told by a doctor that you have heart failure, has your personality changed?

Yes ☐ No ☐ Don't know ☐

If **Yes**, please state how your personality has changed

………………………………………………………………………………………………

………………………………………………………………………………………………

17 Please tick one box to indicate if you have been limited in any of the following activities during the past two weeks?

	Not limited at all	Sometimes limited	Often limited	Always limited	Not applicable
Going out for drink/meal	☐	☐	☐	☐	☐
Going shopping	☐	☐	☐	☐	☐
Hobbies	☐	☐	☐	☐	☐
Socialising	☐	☐	☐	☐	☐
Work	☐	☐	☐	☐	☐
Holiday	☐	☐	☐	☐	☐
Sexual relationship	☐	☐	☐	☐	☐

18 Please look at the following statements and put a cross on the scale which best describes the following: (Please draw a cross on the line below marked from 1 to 10).

a) I get frightened about things

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

---

b) I get frustrated with myself

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

---

c) I get annoyed/angry with people around me

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

---

d) I often wonder "why me?"

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

---

e) I feel dependant on other people

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

---

f) I think if I saw another specialist they would say there is nothing wrong with me

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

g) **I have difficulty concentrating**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

h) **My sleeping habits have changed**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

i) **My family/partner worry about me**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

j) **In my mind I feel capable of doing things but I can't**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

k) **I am more conscious of the simple things in life**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

l) **I feel anxious about dying**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

m) **Other people stop me from doing certain things even though I think I could manage**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

n) **I forget I have heart failure and try to do things like I used to**

0 1 2 3 4 5 6 7 8 9 10

None of the time All the time

Part 2 - Extra Information about You and Your Family

1 Are you?

Male ☐ Female ☐

2 What is your date of birth?

☐☐ / ☐☐ / ☐☐

Day Month Year

3 Which one of the following best describes your marital status?

Single ☐
Married ☐
Living together as a couple ☐
Widowed ☐
Divorced or separated ☐

4 Which one of the following best describes your ethnic origin?

White ☐
Caribbean ☐
African ☐
Indian ☐
Pakistani ☐
Bangladeshi ☐
Chinese ☐
Any other ethnic group ☐

(Please specify)……………………………………

'Original in Colour'

5 Has your work status changed since you were diagnosed with heart failure?

Yes ☐ No ☐ Not applicable ☐

If **Yes**, please state how it has changed. (E.g. I now work part-time/ I now work in a different job/ I now no longer work due to my heart failure)

…………………………………………………………………………………………

…………………………………………………………………………………………

6 How many times have you been admitted to hospital as an in-patient with heart failure?

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ More than five

7 If you were admitted to hospital as an in-patient before your last admission, what was the main reason for this?

Heart failure ☐ Other illness ☐ Not applicable ☐

(Please specify……………………………………………)

8 How many times during the last month have you visited or called out your GP because of your heart problem?

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ More than five

Comments:

Please return your completed questionnaire to:
Karen Dunderdale, Cardiac Rehabilitation, Scunthorpe General Hospital
Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7BH

Thank you for your participation

Appendix 14

Frequency of respondents past medical history (Phase 2)

No past medical history

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	31	13.9	13.9	13.9
	No	192	86.1	86.1	100.0
	Total	223	100.0	100.0	

Past history of IHD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	124	55.6	55.6	55.6
	No	99	44.4	44.4	100.0
	Total	223	100.0	100.0	

Past history of cardiac surgery

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	16	7.2	7.2	7.2
	No	207	92.8	92.8	100.0
	Total	223	100.0	100.0	

Past history of diabetes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	35	15.7	15.7	15.7
	No	188	84.3	84.3	100.0
	Total	223	100.0	100.0	

Past history of respiratory disease

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	14	6.3	6.3	6.3
	No	209	93.7	93.7	100.0
	Total	223	100.0	100.0	

Appendix 14 (continued)

Past history of muscular problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	8	3.6	3.6	3.6
	No	215	96.4	96.4	100.0
	Total	223	100.0	100.0	

Past history of cardiomyopathy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	10	4.5	4.5	4.5
	No	213	95.5	95.5	100.0
	Total	223	100.0	100.0	

Any other past medical history

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	78	35.0	35.0	35.0
	No	145	65.0	65.0	100.0
	Total	223	100.0	100.0	

Appendix 15

Initial Exploratory Factor analysis of the data retaining all factors with eigenvalues greater than 1.

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	17.792	34.886	34.886	17.476	34.267	34.267
2	3.833	7.516	42.402	3.581	7.021	41.288
3	2.960	5.805	48.207	2.524	4.950	46.238
4	2.173	4.261	52.468	1.781	3.492	49.730
5	1.808	3.545	56.013	1.391	2.727	52.457
6	1.543	3.026	59.039	1.124	2.204	54.660
7	1.419	2.782	61.821	.997	1.954	56.614
8	1.277	2.504	64.325	.874	1.713	58.327
9	1.236	2.423	66.749	.784	1.538	59.865
10	1.183	2.320	69.068	.751	1.472	61.337
11	1.010	1.981	71.050	.641	1.256	62.593
12	.974	1.910	72.960			
13	.904	1.772	74.732			
14	.840	1.646	76.378			
15	.806	1.581	77.959			
16	.772	1.514	79.473			
17	.716	1.403	80.876			
18	.689	1.351	82.227			
19	.625	1.226	83.453			
20	.598	1.173	84.626			
21	.558	1.095	85.721			
22	.542	1.062	86.783			
23	.508	.996	87.779			
24	.465	.912	88.690			
25	.452	.885	89.576			
26	.420	.824	90.400			
27	.404	.793	91.193			
28	.396	.777	91.970			
29	.366	.719	92.688			
30	.339	.665	93.354			
31	.285	.559	93.913			
32	.272	.533	94.446			
33	.261	.512	94.957			
34	.255	.501	95.458			
35	.235	.462	95.920			
36	.223	.437	96.356			
37	.218	.428	96.784			
38	.194	.380	97.164			
39	.181	.354	97.518			

Appendix 15 (continued)

40	.163	.319	97.837			
41	.156	.306	98.143			
42	.143	.280	98.422			
43	.132	.259	98.681			
44	.125	.244	98.925			
45	.107	.210	99.136			
46	.102	.201	99.337			
47	.092	.180	99.517			
48	.077	.152	99.668			
49	.064	.126	99.794			
50	.064	.125	99.919			
51	.041	.081	100.000			

Extraction Method: Principal Axis Factoring.

Appendix 16

Pattern Matrix

	Factor	
	1	2
Breathless/puffed out when active	.867	
Walking around limited due to breathlessness	.851	
Breathless/puffed out when still or inactive	.801	-.114
Going out of the house is stopped due to symptoms	.791	
Felt breathless/puffed out	.786	
Frightened about things	.771	
Symptoms have caused cancellation or change of plans at the last minute	.769	
Felt unduly tired	.764	
Symptoms have interrupted everyday family activities	.764	-.152
Worried about symptoms	.738	
Needed someone to help with chores or tasks	.728	
Eating/drinking limited due to breathlessness	.697	-.146
Describe breathing now	.696	
Going shopping	.683	
Sleeping limited due to breathlessness	.676	-.100
Needed to consider the implications of doing something	.676	.221
Limited the amount of time spent doing something	.628	.188
Sleeping habits have changed	.607	
Health compared to last admission	.599	
Not dared to attempt certain things for fear of anything going wrong	.586	.202

Appendix 16 (continued)		
Talking limited due to breathlessness	.585	
Anxious about dying	.557	
Feel dependent on other people	.517	.206
Hobbies	.516	.123
Difficulty concentrating	.503	
Family/partner worry	.500	.127
Annoyed/angry with people	.475	.152
Concern about relying on medication to keep symptoms under control	.454	
Going out for drink/meal	.450	
Socialising	.435	.158
Often feel a failure	.404	.305
Symptoms have caused tension or arguments in the home	.398	
Often wonder "why me?"	.383	.132
Concern about side effects of medication	.371	
Other people stop me doing certain things even though I think I could manage	.309	
Concern about relying on others to organise medication	.304	
Concern about forgetting to take medication	.273	
Holidays	.257	.102
Work	.197	
Forget I have heart failure and try to do things like I used to do	.171	
Sexual relationship	.148	.131
Symptoms influence what activities can be done		.848
Take longer to perform activities	.132	.841
		.832

Appendix 16 (continued)		
Careful in what activities are done	.103	.807
Restricted in what activities can be done	.179	.771
Struggle to do certain activities	.126	.767
Avoid doing certain activities	.158	.764
Think through activities before doing them		.277
Personality changed		-.168
If I saw another specialist they would say there is nothing wrong with me		

Appendix 17

Pattern matrix which reveals blank items

	Factor			
	1	2	3	4
Breathless/puffed out when active	-.913			
Breathless/puffed out when still or inactive	-.796			
Walking around limited due to breathlessness	.789			
Felt breathless/puffed out	-.785			
Symptoms have caused cancellation or change of plans at the last minute	-.780			
Symptoms have interrupted everyday family activities	-.766			
Needed someone to help with chores or tasks	-.760			
Limited the amount of time spent doing something	-.743			
Describe breathing now	.710			
Felt unduly tired	-.710			
Needed to consider the implications of doing something	-.687			
Eating/drinking limited due to breathlessness	.687			
Going out of the house is stopped due to symptoms	-.644			
Talking limited due to breathlessness	.633			
Not dared to attempt certain things for fear of anything going wrong	-.599			
Sleeping limited due to breathlessness	.575			
Frightened about things	.544			.371
Worried about symptoms	-.525			
Describe your health	.483		.348	
Going shopping	.448		.328	
Concern about relying on medication to keep symptoms under control	-.436			
Anxious about dying	.435			.308
Family/partner worry	.411			
Sleeping habits have changed	.387			.320
Concern about side effects of medication	-.369			
Other symptoms	-.331			
Feel dependent on other people	.330			
Other people stop me doing certain things even though I think I could manage				
Concern about forgetting to take medication				

Appendix 17 (continued)

Symptoms influence what activities can be done		.893		
Take longer to perform activities		.876		
Careful in what activities are done		.871		
Restricted in what activities can be done		.837		
Struggle to do certain activities		.805		
Think through activities before doing them		.801		
Avoid doing certain activities		.796		
Often feel a failure		.325		
Socialising			.706	
Going out for drink/meal			.646	
Hobbies			.621	
Holidays			.521	
Work			.508	
Sexual relationship			.486	
Annoyed/angry with people				.688
Symptoms have caused tension or arguments in the home				-.610
Difficulty concentrating				.422
Often wonder "Why me?"				.414
Concern about relying on others to organise medication				-.376
If I saw another specialist they would say there is nothing wrong with me				.346
Personality changed		-.311		-.332
Forget I have heart failure and try to do things like I used to do				

Appendix 18

Exploratory Factor Analysis with blank items removed which reveals 2 low loading items.

Pattern Matrix

	Factor			
	1	2	3	4
Breathless/puffed out when active	.916			
Symptoms have caused cancellation or change of plans at the last minute	.804		.107	
Walking around limited due to breathlessness	.792		-.104	
Breathless/puffed out when still or inactive	.790	-.124		
Symptoms have interrupted everyday family activities	.787	-.106		
Felt breathless/puffed out	.783			
Needed someone to help with chores or tasks	-.747		.132	.169
Limited the amount of time spent doing something	.744	.240		-.212
Describe breathing now	.708			
Felt unduly tired	.708		-.105	
Eating/drinking limited due to breathlessness	.686	-.141		
Needed to consider the implications of doing something	.674	.267		-.146
Going out of the house is stopped due to symptoms	.647		-.230	.110
Talking limited due to breathlessness	.637			-.101
Not dared to attempt certain things for fear of anything going wrong	.598	.244		
Sleeping limited due to breathlessness	.573			.148
Frightened about things	.568			.399
Worried about symptoms	.544		-.103	.296
Anxious about dying	.467		.125	.327
Describe your health	.467		-.334	
Concern about relying on medication to keep symptoms under control	.439	.135		
Going shopping	.425		-.358	.145
Family/partner worry	.411	.161		.171
Sleeping habits have changed	.409			.329

Appendix 18 (continued)

Concern about effects of medication	.380	.115		
Feel dependent on other people	.330	.227	-.146	.196
Other symptoms	.330	.103		
Symptoms influence what activities can be done		.882		
Take longer to perform activities		.869		
Careful in what activities are done		.860		-.143
Restricted in what activities can be done		.830		
Think through activities before doing them		.792		
Struggle to do certain activities		.792	-.117	
Avoid doing certain activities		.782	-.131	
Personality changed		.345	.105	.292
Often feel a failure	**.200**	**.311**	**-.188**	**.206**
Socialising		.119	-.697	.199
Going out for drink/meal	.135	-.157	-.628	.113
Hobbies	.204		-.613	
Holidays			-.594	
Work			-.560	
Sexual relationship			-.557	-.132
Annoyed/angry with people	.159	.213		.669
Symptoms have caused tension or arguments in the home	.171	.173	.135	.538
Difficulty concentrating	.199		-.213	.435
Often wonder "Why me?"	.141	.150		.404
If I saw another specialist they would say there is nothing wrong with me	-.115	-.164		.384
Concern about relying on others to organise medication			**-.105**	**.290**

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.
a Rotation converged in 9 iterations.

Appendix 19

Exploratory Factor Analysis on 46 items, specifying four factors

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings(a)
Factor	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	17.131	37.242	37.242	16.704	36.312	36.312	15.013
2	3.661	7.959	45.201	3.336	7.253	43.565	9.560
3	2.627	5.712	50.913	2.063	4.485	48.050	6.703
4	1.974	4.291	55.204	1.469	3.193	51.242	3.902
5	1.506	3.274	58.478				
6	1.319	2.867	61.345				
7	1.253	2.724	64.069				
8	1.106	2.405	66.473				
9	1.016	2.209	68.682				
10	.960	2.087	70.769				
11	.886	1.926	72.696				
12	.816	1.774	74.470				
13	.781	1.697	76.166				
14	.742	1.613	77.780				
15	.712	1.548	79.327				
16	.709	1.542	80.869				
17	.671	1.458	82.327				
18	.634	1.379	83.706				
19	.577	1.255	84.961				
20	.535	1.163	86.124				
21	.528	1.148	87.272				
22	.459	.998	88.270				
23	.444	.966	89.236				
24	.410	.890	90.126				
25	.398	.865	90.991				
26	.347	.754	91.745				
27	.331	.719	92.464				
28	.309	.671	93.135				
29	.289	.629	93.764				
30	.280	.609	94.373				
31	.272	.591	94.964				
32	.251	.545	95.510				
33	.241	.525	96.034				
34	.229	.499	96.533				
35	.199	.432	96.965				
36	.190	.412	97.377				
37	.183	.397	97.775				
38	.162	.352	98.127				
39	.143	.311	98.438				
40	.138	.300	98.738				
41	.131	.285	99.023				
42	.114	.249	99.272				

Appendix 19 (continued)

43	.102	.222	99.494				
44	.094	.204	99.698				
45	.077	.167	99.865				
46	.062	.135	100.000				

Extraction Method: Principal Axis Factoring.

a When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.

Appendix 20

Structure Matrix

	Factor			
	1	2	3	4
Q10 Breathless/puffed out when active	.869	.352	.374	
Q11b Walking around limited due to breathlessness	.846	.406	.456	
Q6 Felt breathless/puffed out	.824	.388	.366	
Q9 Breathless/puffed out when still or inactive	.774		.341	
Q14b Going out of the house is stopped due to symptoms	.773	.367	.516	
Q14c Symptoms have caused cancellation or change of plans at the last minute	.761	.331		
Q3a Needed someone to help with chores or tasks	-.755	-.373	-.419	
Q14a Symptoms have interrupted everyday family activities	.743			
Q3b Needed to consider the implications of doing something	.742	.556	.427	
Q12 Felt unduly tired	.732		.383	
Q3c Limited the amount of time spent doing something	.729	.543	.336	
Q15 Worried about symptoms	.719	.422	.394	.510
Q7 Describe breathing now	.718		.337	
a Frightened about things	.686	.319		.563
Q11a Eating/drinking limited due to breathlessness	.668		.322	
Q3d Not dared to attempt certain things for fear of anything going wrong	.653	.521	.347	
Q11d Talking limited due to breathlessness	.648	.340	.318	
Q1 Describe your health	.644	.368	.569	
Q17b Going shopping	.626	.404	.573	
Q11c Sleeping limited due to breathlessness	.612			
e Feel dependent on other people	.577	.459	.360	.313

Appendix 20 (continued)

h Sleeping habits have changed	.563	.352		.444
g Difficulty concentrating	.513	.350	.373	.467
I Family/partner worry	.500	.388		.317
I Anxious about dying	.498			.487
Q4c Concern about relying on medication to keep symptoms under control	.446			
Q4a Concern about effects of medication	.428			
Q13 Other symptoms	.412			
Q5h symptoms influence what activities can be done	.396	.883		
Q5c Careful in what activities are done	.390	.863		
Q5d Take longer to perform activities	.463	.856	.314	
Q5b Restricted in what activities can be done	.449	.853	.341	
Q5a Think through activities before doing them	.453	.844		
Q5g Struggle to do certain activities	.456	.832	.368	
Q5f Avoid doing certain activities	.397	.805	.362	
Q17d Socialising	.387	.321	.779	
Q17c Hobbies	.469	.322	.711	
Q17a Going out for drink/meal	.311		.675	
Q17f Holidays			.592	
Q17g Sexual relationship			.553	
Q17e Work			.433	
c Annoyed/angry with people	.445	.397		.725
Q14d Symptoms have caused tension or arguments in the home	.403	.330		.600
d Often wonder "Why me?"	.379	.326		.466
f If I saw another specialist they would say there is nothing wrong with me				.330
Q16 Personality changed		.304		.309

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.

Appendix 21

Corrected Item-total Correlation

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Q1 Describe your health	142.97	1470.685	.645	.718	.923
Q3a Needed someone to help with chores or tasks	143.69	1586.326	-.663	.735	.931
Q3b Needed to consider the implications of doing something	143.23	1458.569	.707	.808	.922
Q3c Limited the amount of time spent doing something	143.19	1460.200	.652	.776	.922
Q3d Not dared to attempt certain things for fear of anything going wrong	143.31	1452.328	.643	.789	.922
Q4a Concern about effects of medication	143.99	1474.441	.423	.457	.923
Q4c Concern about relying on medication to keep symptoms under control	143.24	1467.668	.412	.440	.923
Q5a Think through activities before doing them	142.56	1474.597	.590	.789	.923
Q5b Restricted in what activities can be done	142.53	1472.964	.568	.799	.923
Q5c Careful in what activities are done	142.48	1482.433	.503	.821	.923
Q5d Take longer to perform activities	142.38	1476.406	.589	.792	.923
Q5f Avoid doing certain activities	142.53	1476.768	.547	.752	.923
Q5g Struggle to do certain activities	142.52	1469.440	.607	.817	.923
Q5h symptoms influence what activities can be done	142.45	1475.914	.559	.853	.923
Q6 Felt breathless/puffed out	143.33	1446.797	.706	.884	.922
Q7 Describe breathing now	143.22	1472.608	.596	.755	.923
Q9 Breathless/puffed out when still or inactive	144.26	1460.500	.644	.759	.922
Q10 Breathless/puffed out when active	143.23	1448.164	.711	.881	.922

Appendix 21 (continued)

Q11a Eating/drinking limited due to breathlessness	145.23	1486.597	.550	.654	.923
Q11b Walking around limited due to breathlessness	144.35	1455.195	.756	.805	.922
Q11c Sleeping limited due to breathlessness	145.12	1482.399	.571	.569	.923
Q11d Talking limited due to breathlessness	145.05	1483.949	.550	.588	.923
Q12 Felt unduly tired	143.05	1460.956	.654	.689	.922
Q13 Other symptoms	145.15	1502.046	.379	.583	.924
Q14a Symptoms have interrupted everyday family activities	144.50	1463.944	.627	.731	.922
Q14b Going out of the house is stopped due to symptoms	144.04	1440.977	.728	.799	.921
Q14c Symptoms have caused cancellation or change of plans at the last minute	144.40	1455.011	.653	.757	.922
Q14d Symptoms have caused tension or arguments in the home	144.63	1468.920	.510	.630	.923
Q15 Worried about symptoms	143.65	1442.174	.768	.727	.921
Q16 Personality changed	**144.47**	**1504.097**	**.216**	**.388**	**.925**
Q17a Going out for drink/meal	144.07	1471.911	.362	.561	.924
Q17b Going shopping	144.30	1455.148	.662	.629	.922
Q17c Hobbies	143.80	1454.470	.537	.636	.922
Q17d Socialising	144.24	1462.489	.508	.660	.923
Q17e Work	**142.36**	**1495.449**	**.209**	**.433**	**.925**
Q17f Holidays	143.06	1476.584	.321	.497	.924
Q17g Sexual relationship	**142.70**	**1493.036**	**.216**	**.460**	**.925**
a Frightened about things	143.72	1353.016	.722	.761	.920
c Annoyed/angry with people	143.41	1370.146	.578	.730	.922
d Often wonder "Why me?"	143.32	1366.541	.497	.532	.925
e Feel dependent on other people	142.22	1350.296	.629	.637	.922
f If I saw another specialist they would say there is nothing wrong with me	**145.03**	**1508.313**	**-.001**	**.321**	**.931**
g Difficulty concentrating	142.59	1356.313	.619	.627	.922

Appendix 21 (continued)

h Sleeping habits have changed	142.12	1353.210	.596	.564	.922
I Family/partner worry	139.92	1376.371	.531	.583	.923
I Anxious about dying	144.06	1378.702	.532	.593	.923

Appendix 22

Trial Reference Number:
Date:

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. ***Thank you for completing this survey!***

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5

2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5

Appendix 22

3. **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
c	Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
d	Climbing several flights of stairs	☐ 1	☐ 2	☐ 3
e	Climbing one flight of stairs	☐ 1	☐ 2	☐ 3
f	Bending, kneeling, or stooping	☐ 1	☐ 2	☐ 3
g	Walking more than a mile	☐ 1	☐ 2	☐ 3
h	Walking several hundred yards	☐ 1	☐ 2	☐ 3
i	Walking one hundred yards	☐ 1	☐ 2	☐ 3
j	Bathing or dressing yourself	☐ 1	☐ 2	☐ 3

4. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
C	Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	Had difficulty performing the the work or other activities (for example, it took extra effort)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Appendix 22

5. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
		▼	▼	▼	▼	▼
a	Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
C	Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5

7. **How much bodily pain have you had during the past 4 weeks?**

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5	☐6

Appendix 22

8. **During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5

9. **These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time <u>during the past 4 weeks</u>...**

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
		▼	▼	▼	▼	▼
a	Did you feel full of life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Have you been very nervous?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	Have you felt so down in the dumps that nothing could cheer you up?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e	Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f	Have you felt downhearted and low?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g	Did you feel worn out?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h	Have you been happy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
i	Did you feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

10. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
☐1	☐2	☐3	☐4	☐5

11. How TRUE or FALSE is <u>each</u> of the following statements for you?

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
		▼	▼	▼	▼	▼
a	I seem to get ill more easily than other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	I am as healthy as anybody I know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c	I expect my health to get worse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d	My health is excellent	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

Appendix 23

MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -	**No**	**Very Little**				**Very Much**
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

Appendix 24

Angina diary. Study Number...........Date started................

Please fill in this diary every day for the next 7 days. It would be best if you could carry it with you and fill it in every time you get any angina or tightness in the chest, pain in the arm or throat etc. If that is not possible please try to fill it in a the same time each day, convenient times might be; on getting up - at lunch time or around midday - at tea time or after 6 o'clock - and on going to bed.

Please put how many minutes the angina lasted.

Please give a score out of 100 as to how bad the pain or tightness was, 100 would be "worst possible pain" and 1 would be "so slight hardly noticed it".

Please put down the number of pills or puffs of spray you needed to take to get rid of it. If you sometimes take a pill or spray before you get pain or tightness please put that down as well. Don't put down the other pills you may have to take each day on a regular basis. If you need extra space please use more paper.

This record is very important, thanks for your help.

1. Day.....................

Midnight to 7 O'clock in the morning

How long	How bad 100 = worst
10 minutes	60

Example

Number of pills [illegible] taken...........

7 am to 12 O'clock Midday

How long	How bad 100=worst

Number of pills / puffs taken...............

12 Midday to 6 O'clock in the afternoon

How long	How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long	How bad 100=worst

Number of pills / puffs taken...............

2. Day.....................

Midnight to 7 O'clock in the morning

How long	How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long	How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long	How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long	How bad 100=worst

Number of pills / puffs taken...............

3. Day.....................

Midnight to 7 O'clock in the morning

How long	How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long	How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long	How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long	How bad 100=worst

Number of pills / puffs taken...............

4. Day....................

Midnight to 7 O'clock in the morning

How long | How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long | How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long | How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long | How bad 100=worst

Number of pills / puffs taken...............

5. Day....................

Midnight to 7 O'clock in the morning

How long | How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long | How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long | How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long | How bad 100=worst

Number of pills / puffs taken...............

6. Day....................

Midnight to 7 O'clock in the morning

How long | How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long | How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long | How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long | How bad 100=worst

Number of pills / puffs taken...............

7. Day....................

Midnight to 7 O'clock in the morning

How long | How bad 100 = worst

Number of pills / puffs taken..........

12 Midday to 6 O'clock in the afternoon

How long | How bad 100=worst

Number of pills / puffs taken...............

7 am to 12 O'clock Midday

How long | How bad 100=worst

Number of pills / puffs taken...............

6pm to 12 Midnight

How long | How bad 100=worst

Number of pills / puffs taken...............

Appendix 25

Quality of Life in Chronic Heart Failure: Development of the CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. If there is anything that is not clear, or if you would like more information, please ask us. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

What is the purpose of the study?

To develop a questionnaire that can be used in clinical practice, for measuring the quality of life in a chronic heart failure population.

Why have I been chosen?

You have been invited to take part because you have been diagnosed with heart failure (reduced pumping of the heart muscle) and a number of people (One hundred in total), such as yourself who are admitted to (NAME OF HOSPITAL) have been asked if they wish to take part.

Do I have to take part?

No, the choice to take part is entirely yours. If you decide not to complete the questionnaire this will not affect your treatment or care in any way.

What will happen to me if I take part?

If you decide to take part, please complete the three questionnaires and the Angina Diary you have been sent and return them in the pre-paid envelope. If you do not suffer from angina (Angina is an uncomfortable feeling or pain in the chest. It usually feels like a heaviness or tightness in the centre of the chest, which may spread to the arms, neck and jaw. You may have been given a GTN Spry or tablets for this), please return the diary indicating you have had no problems. The questionnaires should take approximately 20 minutes to complete in total. The angina diary is to be completed over one week.

What are the advantages / disadvantages of participating in this study?

Whilst there are no guarantees that you will benefit from taking part in this study, the results will be used to develop a way in which the quality of life for patients with heart failure can be measured. This will hopefully ensure that we provide optimum care for this group of patients.

Will my taking part in the study be kept confidential?

If you agree to take part in this study, you will be known only by a study number. Only the researchers involved with the study will see the information that is collected. All information will be treated in the strictest confidence.

What will happen to the results of the study?

This study will identify how heart failure affects a person's quality of life.

Ethical considerations

This study has been approved by our Local Ethic Committee, which has not objected to the study taking place. All records of you taking part in the study will be kept confidential. All data is anonymised.

If you wish to discuss this further please contact Karen Dunderdale on:
Tel: 01724 290093

Appendix 26

Tel: 01724 290093

Date:

Dear Sir/Madam

My name is Karen Dunderdale and I am a cardiac specialist nurse at Scunthorpe General Hospital. I am currently undertaking a piece of research for a post-graduate degree in conjunction with the University of York.

This piece of research is looking at how heart failure affects an individual's quality of life. I have written to you to ask for your assistance in this research because you have been diagnosed with heart failure (reduced pumping of the heart muscle). Contained in this envelope is an information sheet about the research, a set of 3 questionnaires, an angina diary sheet, and a pre-paid envelope.

If you are willing to take part, please can you complete the enclosed questionnaires and the angina diary and post them back to me in the pre-paid envelope.

If you have any queries you can contact me on the above number.

Thank you in anticipation of your assistance

Yours faithfully

Karen Dunderdale
Cardiac Specialist Nurse

Appendix 27

Study No: ☐☐☐

CHFQoL (Chronic Heart Failure Quality of Life) Questionnaire

We would like your help to improve care for people with heart failure and their families. All you need to do is fill in this questionnaire.

You have been given a diagnosis of heart failure (reduced pumping of the heart muscle) and we would like to know about your health and wellbeing since you were told this.

Please answer each question, your opinions are very important. Some questions may look alike, but each one is asking for different information. Any information will be treated in the strictest confidence.

Please return your questionnaire to Karen Dunderdale in the stamped-addressed envelope provided. If you wish to discuss this study further please contact Karen Dunderdale on 01724 290093.

Part 1 – About You & Your Heart Failure

1 At the moment, how would you describe your health?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2 Please tick one box to indicate how often during the <u>past two weeks</u> you have been concerned about:

	Very often	Often	Occasionally	Almost never	Never
The side effects of your medication.	☐	☐	☐	☐	☐
Relying on medication to keep your symptoms under control.	☐	☐	☐	☐	☐

Please check that you have answered **each question** before going on to the next page

3 Here is a list of questions asking you to think about your everyday activities (e.g. washing/dressing/cooking/gardening etc.) in the past two weeks. Specify how true each statement is when you think about how your heart failure limits you in comparison to other healthy adults of the same age as you, by circling one response only for each statement.

	Much less than other adults	Somewhat less than other adults	About the same as other adults	Somewhat more than other adults	Much more than other adults	Not applicable
I have to think through activities before doing them.	0	1	2	3	4	N/A
I am restricted in what activities I can do.	0	1	2	3	4	N/A
I am careful in what activities I do.	0	1	2	3	4	N/A
I take longer to perform activities.	0	1	2	3	4	N/A
I avoid doing certain activities.	0	1	2	3	4	N/A
I struggle to do certain activities.	0	1	2	3	4	N/A
My symptoms influence what activities I can do.	0	1	2	3	4	N/A

4 How often during the past two weeks have you felt breathless/puffed out?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

5 How would you describe your breathing now?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

Please check that you have answered **each question** before going on to the next page

6 How often during the past two weeks have you felt breathless/puffed out when you were still or inactive and resting?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

7 How often during the past two weeks have you felt breathless/puffed out when active? (e.g. walking, washing, dressing, cleaning).

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

8 Have you been limited in any of the following everyday activities because of feeling breathless/puffed out during the past two weeks?

	Not limited at all	Sometimes limited	Often limited	Always limited
Eating/drinking	☐	☐	☐	☐
Walking around	☐	☐	☐	☐
Sleeping	☐	☐	☐	☐
Talking	☐	☐	☐	☐

9 How often during the past two weeks have you felt unduly tired?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

10 Do you have any other symptoms other than breathlessness or tiredness?

Yes ☐ No ☐

If **Yes**, please state what these other symptoms are

…………………………………………………………………………………………

…………………………………………………………………………………………

11 Please tick one box to indicate how often during the past two weeks your symptoms have:

	Very often	Often	Occasionally	Almost never	Never
Interrupted everyday family activities? (E.g. mealtimes)	☐	☐	☐	☐	☐
Stopped you from going out of the house?	☐	☐	☐	☐	☐
Caused you to cancel or change plans at the last minute at home or work?	☐	☐	☐	☐	☐
Caused tension or arguments in the home?	☐	☐	☐	☐	☐

Please check that you have answered **each question** before going on to the next page

12 During the past two weeks how much have you been worried about your symptoms?

Very often ☐ Often ☐ Occasionally ☐ Almost never ☐ Never ☐

13 Since you were told by a doctor that you have heart failure, has your personality changed?

Yes ☐ No ☐ Don't know ☐

If **Yes**, please state how your personality has changed

………………………………………………………………………………………………

………………………………………………………………………………………………

14 Please tick one box to indicate if you have been limited in any of the following activities during the past two weeks?

	Not limited at all	Sometimes limited	Often limited	Always limited	Not applicable
Going out for drink/meal	☐	☐	☐	☐	☐
Going shopping	☐	☐	☐	☐	☐
Hobbies	☐	☐	☐	☐	☐
Socialising	☐	☐	☐	☐	☐
Work	☐	☐	☐	☐	☐
Holiday	☐	☐	☐	☐	☐
Sexual relationship	☐	☐	☐	☐	☐

15 Please look at the following statements and put a cross on the scale which best describes the following: (Please draw a cross on the line below marked from 1 to 10).

a) I get frightened about things

0 1 2 3 4 5 6 7 8 9 10

None of the time — All of the time

---

b) I get annoyed/angry with people around me

0 1 2 3 4 5 6 7 8 9 10

None of the time — All of the time

Please check that you have answered **each question** before going on to the next page

Please look at the following statements and put a cross on the scale which best describes the following: (Please draw a cross on the line below marked from 1 to 10).

c) **I often wonder "why me?"**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

d) **I feel dependant on other people**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

e) **I think if I saw another specialist they would say there is nothing wrong with me**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

f) **I have difficulty concentrating**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

g) **My sleeping habits have changed**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

h) **My family/partner worry about me**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

i) **I feel anxious about dying**

0 1 2 3 4 5 6 7 8 9 10

None of the time All of the time

Please check that you have answered **each question** before going on to the next page

‘Original in colour’

Part 2 - Extra Information about You and Your Family

1 Are you?

Male ☐ Female ☐

2 What is your date of birth?

☐☐ / ☐☐ / ☐☐

Day Month Year

3 Which one of the following best describes your marital status?

Single ☐
Married ☐
Living together as a couple ☐
Widowed ☐
Divorced or separated ☐

4 Which one of the following best describes your ethnic origin?

White ☐
Caribbean ☐
African ☐
Indian ☐
Pakistani ☐
Bangladeshi ☐
Chinese ☐
Any other ethnic group ☐

(Please specify)……………………………………

Please check that you have answered **each question** before going on to the next page

‘Original in colour’

5 Which of the following best describes your occupation? (If you are retired, which best describes your occupation before you were retired?)

Professional (teacher, social worker, business executive, entrepreneur) ☐

Junior managers in smaller organisations (policemen, hospital nurse, journalist, market researcher) ☐

Skilled manual and clerical (telephone engineer, secretary, dental nurse) ☐

Small employer with fewer than 25 employees, plus the self-employed ☐

Supervisor of those in routine and semi-routine occupations ☐

Semi-routine occupations (sales assistant, factory worker, drivers) ☐

Routine occupations (domestic worker, labourer) ☐

Never worked or long-term unemployed ☐

6 What is your postcode?

☐☐☐☐ ☐☐☐

7 When were you told you have heart failure?

☐☐/☐☐/☐☐

Day Month Year

Comments:

Please return your completed questionnaire to:
Karen Dunderdale, Cardiac Rehabilitation, Scunthorpe General Hospital
Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7BH

Thank you for your participation

Appendix 28

Frequency of response alternatives (Phase 3)

Question 1 & 5		Excellent	Very Good	Good	Fair	Poor
At the moment, how would you describe your health	Count	1	2	20	34	11
	%	1.5%	2.9%	29.4%	50.0%	16.2%
How would you describe your breathing now?	Count	1	6	21	32	7
	%	1.5%	9.0%	31.3%	47.8%	10.4%

Question 8		Not limited at all	Sometimes limited	Often limited	Aways limited
Have you been limited in any of the following everyday activities because of feeling breathless/puffed out during the past two weeks?	Count	35	21	6	1
	%	55.6%	33.3%	9.5%	1.6%
Walking around	Count	8	33	18	8
	%	11.9%	49.3%	26.9%	11.9%
Sleeping	Count	35	21	7	2
	%	53.8%	32.3%	10.8%	3.1%
Talking	Count	36	20	9	
	%	55.4%	30.8%	13.8%	

Appendix 28 (continued)

Question 2, 6, 7, 11 & 12		Very Often	Often	Occasionally	Almost Never	Never
The side effects of your medication.	Count	6	14	22	15	11
	%	8.8%	20.6%	32.4%	22.1%	16.2%
Relying on medication to keep your symptoms under control.	Count	17	17	16	9	8
	%	25.4%	25.4%	23.9%	13.4%	11.9%
How often during the past two weeks have you felt breathless/puffed out?	Count	16	15	25	8	3
	%	23.9%	22.4%	37.3%	11.9%	4.5%
How often during the past two weeks have you felt breathless/puffed out when you were still or inactive and resting?	Count	3	11	21	15	17
	%	4.5%	16.4%	31.3%	22.4%	25.4%
How often during the past two weeks have you felt breathless/puffed out when active? (e.g. walking, washing, dressing, cleaning).	Count	16	13	28	5	5
	%	23.9%	19.4%	41.8%	7.5%	7.5%
Symptoms Interrupted everyday family activities? (E.g. mealtimes)	Count	1	8	21	11	25
	%	1.5%	12.1%	31.8%	16.7%	37.9%
Symptoms Stopped you from going out of the house?	Count	1	11	25	11	18
	%	1.5%	16.7%	37.9%	16.7%	27.3%
Symptoms Caused you to cancel or change plans at the last minute at home or work?	Count	2	6	14	21	24
	%	3.0%	9.0%	20.9%	31.3%	35.8%
Symptoms Caused tension or arguments in the home?	Count	2	1	15	15	32
	%	3.1%	1.5%	23.1%	23.1%	49.2%
During the past two weeks how much have you been worried about your symptoms?	Count	7	13	30	8	10
	%	10.3%	19.1%	44.1%	11.8%	14.7%

Appendix 28 (continued)

Question 3		Much less than other adults	Somewhat less than other adults	About the same as other adults	Somewhat more than other adults	Much more than other adults	Not applicable
I have to think through activities before doing them.	Count	2	4	8	25	26	3
	%	2.9%	5.9%	11.8%	36.8%	38.2%	4.4%
I am restricted in what activities I can do.	Count	2	7	4	15	39	1
	%	2.9%	10.3%	5.9%	22.1%	57.4%	1.5%
I am careful in what activities I do.	Count	2	4	5	18	38	1
	%	2.9%	5.9%	7.4%	26.5%	55.9%	1.5%
I take longer to perform activities.	Count	2	3	6	13	43	1
	%	2.9%	4.4%	8.8%	19.1%	63.2%	1.5%
I avoid doing certain activities.	Count	3	4		17	40	4
	%	4.4%	5.9%		25.0%	58.8%	5.9%
I struggle to do certain activities.	Count	1	3	6	20	34	4
	%	1.5%	4.4%	8.8%	29.4%	50.0%	5.9%
My symptoms influence what activities I can do.	Count	1	3	4	19	39	2
	%	1.5%	4.4%	5.9%	27.9%	57.4%	2.9%

Appendix 28 (continued)

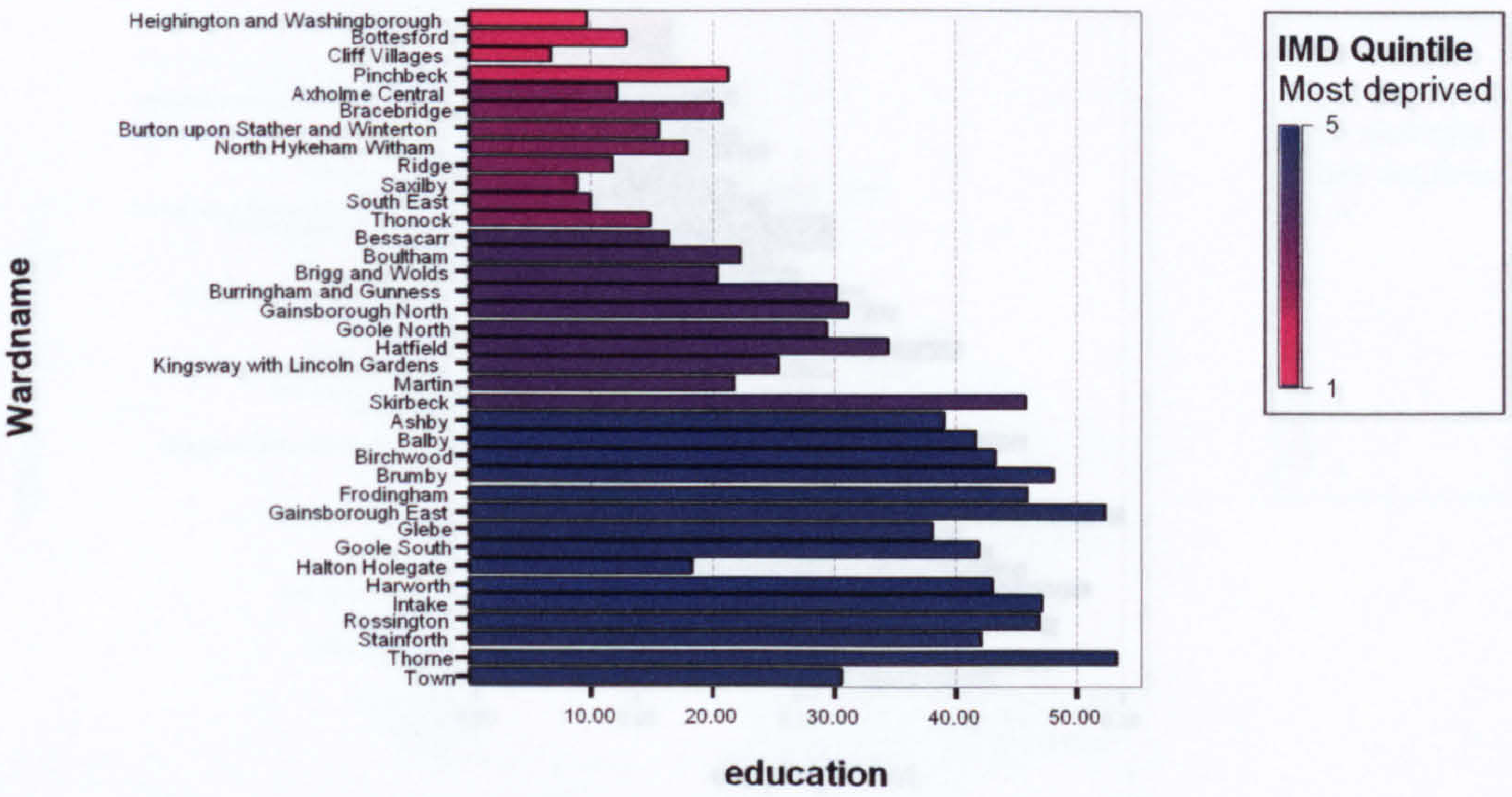
Question 14		Not limited at all	Sometimes limited	Often limited	Always limited	Not Applicable
Going out for drink/meal	Count	20	17	8	11	11
	%	29.9%	25.4%	11.9%	16.4%	16.4%
Going shopping	Count	17	27	12	8	3
	%	25.4%	40.3%	17.9%	11.9%	4.5%
Hobbies	Count	18	15	15	14	6
	%	26.5%	22.1%	22.1%	20.6%	8.8%
Socialising	Count	22	16	15	8	6
	%	32.8%	23.9%	22.4%	11.9%	9.0%
Work	Count	4	6	1	7	49
	%	6.0%	9.0%	1.5%	10.4%	73.1%
Holidays	Count	12	13	4	12	26
	%	17.9%	19.4%	6.0%	17.9%	38.8%
Sexual relationship	Count	6	7	5	13	36
	%	9.0%	10.4%	7.5%	19.4%	53.7%

Question 15		0	1	2	3	4	5	6	7	8	9	10
I get frightened about things	Count	20	9	8	6	7	3	4	4	5	1	1
	%	29.4%	13.2%	11.8%	8.8%	10.3%	4.4%	5.9%	5.9%	7.4%	1.5%	1.5%
I get annoyed/angry with people around me	Count	14	16	5	10	4	4	6	3	4	1	1
	%	20.6%	23.5%	7.4%	14.7%	5.9%	5.9%	8.8%	4.4%	5.9%	1.5%	1.5%
I often wonder "why me"	Count	26	10	3	8	3	8	3	1	1	3	2
	%	38.2%	14.7%	4.4%	11.8%	4.4%	11.8%	4.4%	1.5%	1.5%	4.4%	2.9%
I feel dependant on other people	Count	8	5	8	6	10	8	3	3	7	5	5
	%	11.8%	7.4%	11.8%	8.8%	14.7%	11.8%	4.4%	4.4%	10.3%	7.4%	7.4%
I think if I saw another specialist they would say there is nothing wrong with me	Count	51	2	2	2	1			3	1	2	4
	%	75.0%	2.9%	2.9%	2.9%	1.5%			4.4%	1.5%	2.9%	5.9%
I have difficulty concentrating	Count	19	8	11	5	1	4	4	5	4	5	2
	%	27.9%	11.8%	16.2%	7.4%	1.5%	5.9%	5.9%	7.4%	5.9%	7.4%	2.9%
My sleeping habits have changed	Count	15	3	9	7	3	7	4	5	2	9	4
	%	22.1%	4.4%	13.2%	10.3%	4.4%	10.3%	5.9%	7.4%	2.9%	13.2%	5.9%
My family/partner worry about me	Count	8	1	2	1	7	6	2	5	7	12	17
	%	11.8%	1.5%	2.9%	1.5%	10.3%	8.8%	2.9%	7.4%	10.3%	17.6%	25.0%
I feel anxious about dying	Count	29	12	4	2	2	6	2	4	3	2	2
	%	42.6%	17.6%	5.9%	2.9%	2.9%	8.8%	2.9%	5.9%	4.4%	2.9%	2.9%

Appendix 29

Indices of deprivation

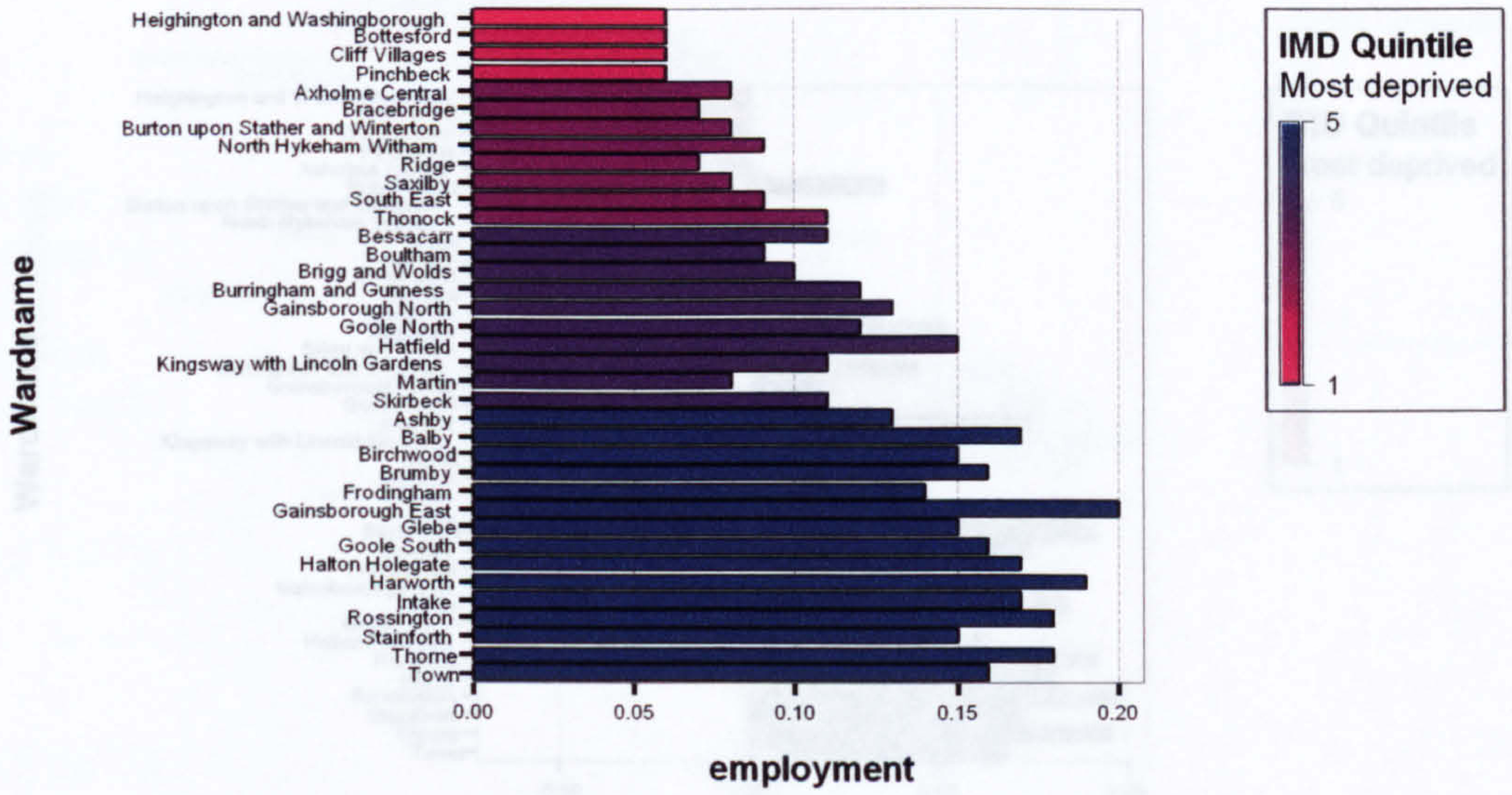
Education, skills and training domain by electoral ward by national quintile



This domain measures deprivation in terms of education, skills and training in a local area (Wyborn 2005).

Appendix 29 (continued)

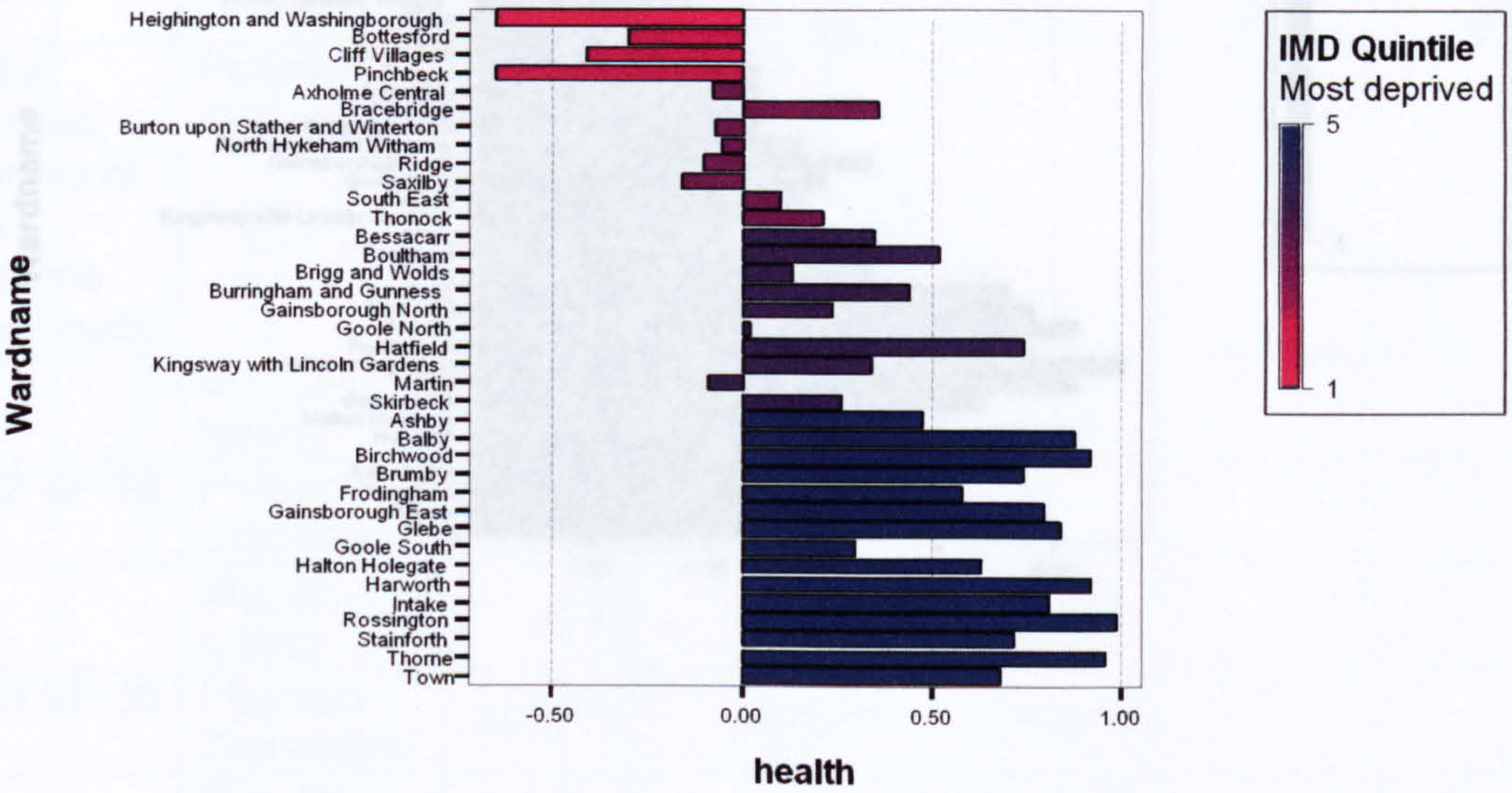
Employment deprivation domain score by electoral ward by national quintile



This domain measures employment deprivation in terms of involuntary exclusion of the working age population from the world of work (Wyborn 2005).

Appendix 29 (continued)

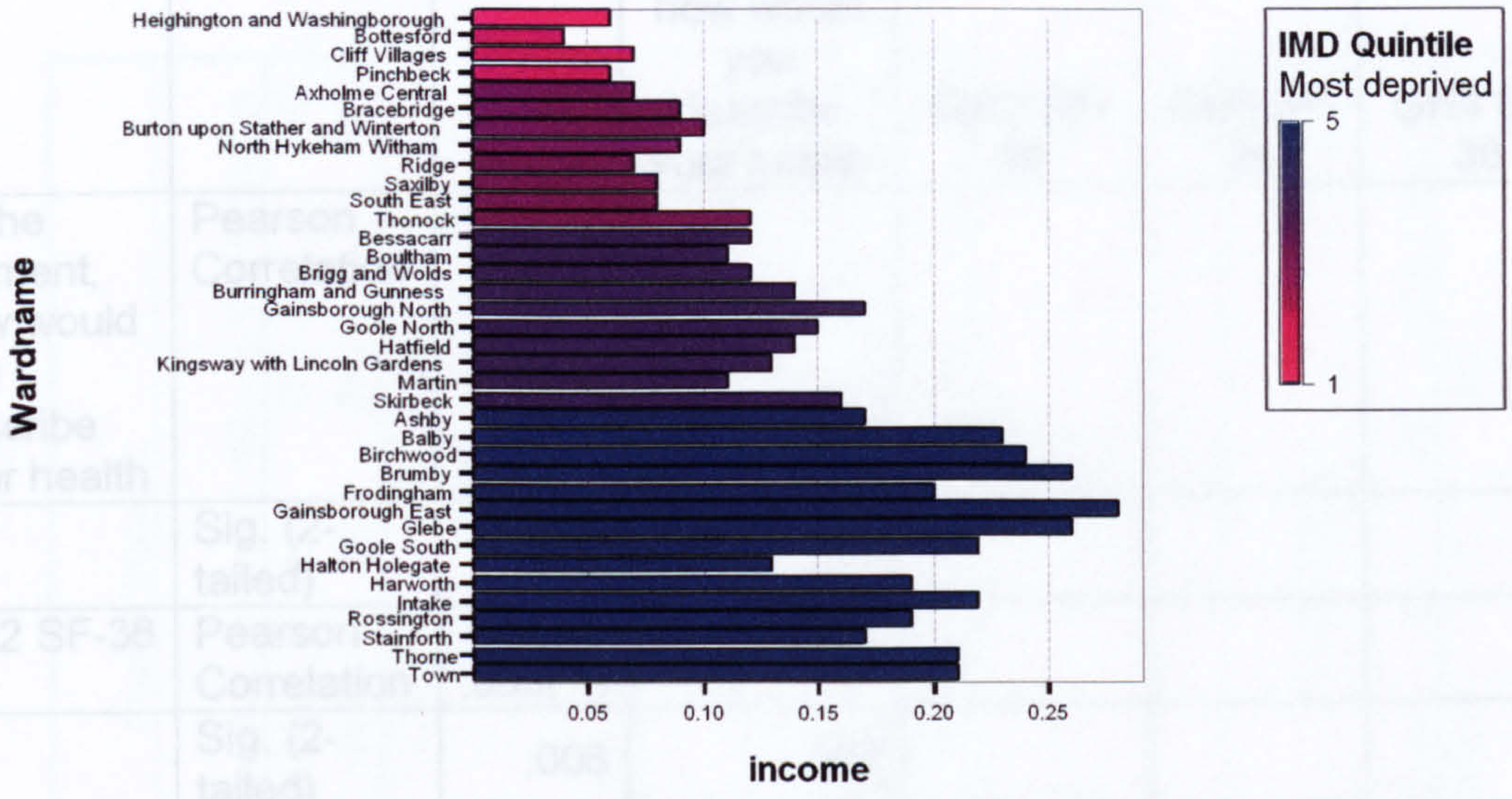
Health deprivation and disability domain score by electoral ward by national quintile



This domain measures health deprivation by areas with relatively high rates of people who die prematurely or whose quality of life is impaired by poor health or who are disabled, across the whole population (Wyborn 2005).

Appendix 29 (continued)

Income deprivation domain score by electoral ward by national quintile



This domain measures the proportion of the population experiencing income deprivation in an area (Wyborn 2005).

Appendix 30

Correlation statistics of CHFQoL questionnaire general health scores and SF-36 general health scores (Phase 3)

		GH1 SF-36	At the moment, how would you describe your health	GH2 SF-36	GH3 SF-36	GH4 SF-36
At the moment, how would you describe your health	Pearson Correlation	.791(**)				
	Sig. (2-tailed)	.000				
GH2 SF-36	Pearson Correlation	-.339(**)	-.379(**)			
	Sig. (2-tailed)	.006	.002			
GH3 SF-36	Pearson Correlation	.477(**)	.476(**)	-.402(**)		
	Sig. (2-tailed)	.000	.000	.001		
GH4 SF-36	Pearson Correlation	-.392(**)	-.303(*)	.244(*)	-.306(*)	
	Sig. (2-tailed)	.001	.013	.049	.012	
GH5 SF-36	Pearson Correlation	.645(**)	.590(**)	-.398(**)	.677(**)	-.482(**)
	Sig. (2-tailed)	.000	.000	.001	.000	.000

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Appendix 31

Regression analysis of gender, occupation and marital status

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.600(a)	.360	.350	.16877	.360	36.599	1	65	.000
2	.601(b)	.361	.341	.17002	.000	.041	1	64	.840

a Predictors: (Constant), Minnesota total
b Predictors: (Constant), Minnesota .total, Gender
c Dependent Variable: activity level total

Model Summary(c)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.600(a)	.360	.350	.16877	.360	36.599	1	65	.000
2	.603(b)	.363	.343	.16967	.003	.308	1	64	.581

a Predictors: (Constant), Minnesota total
b Predictors: (Constant), Minnesota .total, occupation
c Dependent Variable: activity level total

Model Summary(c)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.600(a)	.360	.350	.16877	.360	36.599	1	65	.000
2	.601(b)	.361	.341	.16994	.001	.105	1	64	.747

a Predictors: (Constant), Minnesota total
b Predictors: (Constant), Minnesota .total, marital status
c Dependent Variable: activity level total

Appendix 32

Multiple regression analysis

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.734(a)	.538	.531	.86074	.538	74.608	1	64	.000
2	.785(b)	.617	.605	.79046	.078	12.888	1	63	.001
3	.792(c)	.627	.609	.78637	.010	1.656	1	62	.203
4	.835(d)	.696	.677	.71483	.070	14.032	1	61	.000

a Predictors: (Constant), symptom total
b Predictors: (Constant), symptom total, activity level total
c Predictors: (Constant), symptom total, activity level total, psychosocial total
d Predictors: (Constant), symptom total, activity level total, psychosocial total, emotion total

Appendix 33

Post hoc test using Scheffe

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Symptom total	Professional	Junior managers in smaller organisations	.300	2.037	1.000	-7.21	7.811
		Skilled manual and clerical	1.500	1.60120	.989	-4.403	7.403
		Small employer with fewer than 25 employees, plus the self-employed	-.367	2.721	1.000	-10.400	9.667
		Supervisor of those in routine and semi-routine occupations	2.633	2.134	.956	-5.238	10.504
		Routine occupations	.633	1.770	1.000	-5.8932	7.159
		Never worked or long-term unemployed	2.900	2.264	.947	-5.448	11.248
	Junior managers in smaller organisations	Professional	-.300	2.037	1.000	-7.811	7.211
		Skilled manual and clerical	1.200	1.815	.998	-5.493	7.893
		Small employer with fewer than 25 employees, plus the self-employed	-.666	2.852	1.000	-11.185	9.851
		Supervisor of those in routine and semi-routine occupations	2.333	2.300	.983	-6.147	10.813
		Routine occupations	.333	1.966	1.000	-6.916	7.582
		Never worked or long-term unemployed	2.600	2.420	.978	-6.325	11.525
	Skilled manual and clerical	Professional	-1.500	1.601	.989	-7.403	4.403
		Junior managers in smaller organisations	-1.200	1.815	.998	-7.893	5.493
		Small employer with fewer than 25 employees, plus the self-e	-1.866	2.559	.997	-11.304	7.570
		Supervisor of those in routine and semi-routine occupations	1.133	1.924	.999	-5.961	8.228
		Routine occupations	-.866	1.509	.999	-6.432	4.699
		Never worked or long-term unemployed	1.400	2.067	.998	-6.221	9.021
	Small employer with fewer than 25 employees, plus the self-employed	Professional	.366	2.721	1.000	-9.667	10.400
		Junior managers in smaller organisations	.666	2.852	1.000	-9.851	11.185
		Skilled manual and clerical	1.866	2.559	.997	-7.570	11.304
		Supervisor of those in routine and semi-routine occupations	3.00	2.923	.982	-7.778	13.778
		Routine occupations	1.00000	2.66867	1.000	-8.8392	10.8392

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
		Never worked or long-term unemployed	3.26667	3.01925	.977	-7.8651	14.3984
	Supervisor of those in routine and semi-routine occupations	Professional	-2.63333	2.13493	.956	-10.5047	5.2380
		Junior managers in smaller organisations	-2.33333	2.30010	.983	-10.8136	6.1470
		Skilled manual and clerical	-1.13333	1.92440	.999	-8.2285	5.9618
		Small employer with fewer than 25 employees, plus the self-employed	-3.00000	2.92338	.982	-13.7783	7.7783
		Routine occupations	-2.00000	2.06714	.987	-9.6214	5.6214
		Never worked or long-term unemployed	.26667	2.50343	1.000	-8.9633	9.4966
	Routine occupations	Professional	-.63333	1.77019	1.000	-7.1599	5.8932
		Junior managers in smaller organisations	-.33333	1.96624	1.000	-7.5827	6.9160
		Skilled manual and clerical	.86667	1.50963	.999	-4.6992	6.4325
		Small employer with fewer than 25 employees, plus the self-employed	-1.00000	2.66867	1.000	-10.8392	8.8392
		Supervisor of those in routine and semi-routine occupations	2.00000	2.06714	.987	-5.6214	9.6214
		Never worked or long-term unemployed	2.26667	2.20064	.982	-5.8469	10.3803
	Never worked or long-term unemployed	Professional	-2.90000	2.26444	.947	-11.2488	5.4488
		Junior managers in smaller organisations	-2.60000	2.42079	.978	-11.5253	6.3253
		Skilled manual and clerical	-1.40000	2.06714	.998	-9.0214	6.2214
		Small employer with fewer than 25 employees, plus the self-employed	-3.26667	3.01925	.977	-14.3984	7.8651
		Supervisor of those in routine and semi-routine occupations	-.26667	2.50343	1.000	-9.4966	8.9633
		Routine occupations	-2.26667	2.20064	.982	-10.3803	5.8469
Activity level total	Professional	Junior managers in smaller organisations	-2.20000	3.30517	.998	-14.3478	9.9478
		Skilled manual and clerical	.75238	2.57685	1.000	-8.7186	10.2233
		Small employer with fewer than 25 employees, plus the self-employed	-2.20000	4.41498	1.000	-18.4268	14.0268
		Supervisor of those in routine and semi-routine occupations	-1.53333	3.46340	1.000	-14.2627	11.1960
		Routine occupations	-1.20000	2.77690	1.000	-11.4062	9.0062
		Never worked or long-term unemployed	-1.20000	3.30517	1.000	-13.3478	10.9478
	Junior managers in smaller organisations	Professional	2.20000	3.30517	.998	-9.9478	14.3478
		Skilled manual and clerical	2.95238	2.92711	.984	-7.8059	13.7106

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
		Small employer with fewer than 25 employees, plus the self-employed	.00000	4.62816	1.000	-17.0103	17.0103
		Supervisor of those in routine and semi-routine occupations	.66667	3.73134	1.000	-13.0475	14.3808
		Routine occupations	1.00000	3.10466	1.000	-10.4109	12.4109
		Never worked or long-term unemployed	1.00000	3.58496	1.000	-12.1761	14.1761
	Skilled manual and clerical	Professional	-.75238	2.57685	1.000	-10.2233	8.7186
		Junior managers in smaller organisations	-2.95238	2.92711	.984	-13.7106	7.8059
		Small employer with fewer than 25 employees, plus the self-employed	-2.95238	4.13955	.998	-18.1669	12.2621
		Supervisor of those in routine and semi-routine occupations	-2.28571	3.10466	.997	-13.6966	9.1251
		Routine occupations	-1.95238	2.31408	.994	-10.4575	6.5528
		Never worked or long-term unemployed	-1.95238	2.92711	.998	-12.7106	8.8059
	Small employer with fewer than 25 employees, plus the self-employed	Professional	2.20000	4.41498	1.000	-14.0268	18.4268
		Junior managers in smaller organisations	.00000	4.62816	1.000	-17.0103	17.0103
		Skilled manual and clerical	2.95238	4.13955	.998	-12.2621	18.1669
		Supervisor of those in routine and semi-routine occupations	.66667	4.74245	1.000	-16.7637	18.0970
		Routine occupations	1.00000	4.26695	1.000	-14.6827	16.6827
		Never worked or long-term unemployed	1.00000	4.62816	1.000	-16.0103	18.0103
	Supervisor of those in routine and semi-routine occupations	Professional	1.53333	3.46340	1.000	-11.1960	14.2627
		Junior managers in smaller organisations	-.66667	3.73134	1.000	-14.3808	13.0475
		Skilled manual and clerical	2.28571	3.10466	.997	-9.1251	13.6966
		Small employer with fewer than 25 employees, plus the self-employed	-.66667	4.74245	1.000	-18.0970	16.7637
		Routine occupations	.33333	3.27260	1.000	-11.6948	12.3614
		Never worked or long-term unemployed	.33333	3.73134	1.000	-13.3808	14.0475
	Routine occupations	Professional	1.20000	2.77690	1.000	-9.0062	11.4062
		Junior managers in smaller organisations	-1.00000	3.10466	1.000	-12.4109	10.4109
		Skilled manual and clerical	1.95238	2.31408	.994	-6.5528	10.4575
		Small employer with fewer than 25 employees, plus the self-employed	-1.00000	4.26695	1.000	-16.6827	14.6827

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
		Supervisor of those in routine and semi-routine occupations	-.33333	3.27260	1.000	-12.3614	11.6948
		Never worked or long-term unemployed	.00000	3.10466	1.000	-11.4109	11.4109
	Never worked or long-term unemployed	Professional	1.20000	3.30517	1.000	-10.9478	13.3478
		Junior managers in smaller organisations	-1.00000	3.58496	1.000	-14.1761	12.1761
		Skilled manual and clerical	1.95238	2.92711	.998	-8.8059	12.7106
		Small employer with fewer than 25 employees, plus the self-employed	-1.00000	4.62816	1.000	-18.0103	16.0103
		Supervisor of those in routine and semi-routine occupations	-.33333	3.73134	1.000	-14.0475	13.3808
		Routine occupations	.00000	3.10466	1.000	-11.4109	11.4109
Psychosocial total	Professional	Junior managers in smaller organisations	-2.00000	3.09091	.999	-13.3960	9.3960
		Skilled manual and clerical	-2.45000	2.31818	.980	-10.9970	6.0970
		Small employer with fewer than 25 employees, plus the self-employed	-.50000	3.94015	1.000	-15.0270	14.0270
		Supervisor of those in routine and semi-routine occupations	-4.83333	3.09091	.871	-16.2293	6.5626
		Routine occupations	-.50000	2.51764	1.000	-9.7824	8.7824
		Never worked or long-term unemployed	-2.50000	3.27841	.996	-14.5872	9.5872
	Junior managers in smaller organisations	Professional	2.00000	3.09091	.999	-9.3960	13.3960
		Skilled manual and clerical	-.45000	2.78611	1.000	-10.7222	9.8222
		Small employer with fewer than 25 employees, plus the self-employed	1.50000	4.23240	1.000	-14.1045	17.1045
		Supervisor of those in routine and semi-routine occupations	-2.83333	3.45574	.995	-15.5744	9.9077
		Routine occupations	1.50000	2.95414	1.000	-9.3917	12.3917
		Never worked or long-term unemployed	-.50000	3.62441	1.000	-13.8629	12.8629
	Skilled manual and clerical	Professional	2.45000	2.31818	.980	-6.0970	10.9970
		Junior managers in smaller organisations	.45000	2.78611	1.000	-9.8222	10.7222
		Small employer with fewer than 25 employees, plus the self-employed	1.95000	3.70587	1.000	-11.7133	15.6133
		Supervisor of those in routine and semi-routine occupations	-2.38333	2.78611	.993	-12.6555	7.8888
		Routine occupations	1.95000	2.13242	.990	-5.9121	9.8121
		Never worked or long-term unemployed	-.05000	2.99276	1.000	-11.0841	10.9841

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
	Small employer with fewer than 25 employees, plus the self-employed	Professional	.50000	3.94015	1.000	-14.0270	15.0270
		Junior managers in smaller organisations	-1.50000	4.23240	1.000	-17.1045	14.1045
		Skilled manual and clerical	-1.95000	3.70587	1.000	-15.6133	11.7133
		Supervisor of those in routine and semi-routine occupations	-4.33333	4.23240	.983	-19.9379	11.2712
		Routine occupations	.00000	3.83380	1.000	-14.1349	14.1349
		Never worked or long-term unemployed	-2.00000	4.37121	1.000	-18.1163	14.1163
	Supervisor of those in routine and semi-routine occupations	Professional	4.83333	3.09091	.871	-6.5626	16.2293
		Junior managers in smaller organisations	2.83333	3.45574	.995	-9.9077	15.5744
		Skilled manual and clerical	2.38333	2.78611	.993	-7.8888	12.6555
		Small employer with fewer than 25 employees, plus the self-employed	4.33333	4.23240	.983	-11.2712	19.9379
		Routine occupations	4.33333	2.95414	.902	-6.5584	15.2250
		Never worked or long-term unemployed	2.33333	3.62441	.999	-11.0296	15.6963
	Routine occupations	Professional	.50000	2.51764	1.000	-8.7824	9.7824
		Junior managers in smaller organisations	-1.50000	2.95414	1.000	-12.3917	9.3917
		Skilled manual and clerical	-1.95000	2.13242	.990	-9.8121	5.9121
		Small employer with fewer than 25 employees, plus the self-employed	.00000	3.83380	1.000	-14.1349	14.1349
		Supervisor of those in routine and semi-routine occupations	-4.33333	2.95414	.902	-15.2250	6.5584
		Never worked or long-term unemployed	-2.00000	3.14979	.999	-13.6130	9.6130
	Never worked or long-term unemployed	Professional	2.50000	3.27841	.996	-9.5872	14.5872
		Junior managers in smaller organisations	.50000	3.62441	1.000	-12.8629	13.8629
		Skilled manual and clerical	.05000	2.99276	1.000	-10.9841	11.0841
		Small employer with fewer than 25 employees, plus the self-employed	2.00000	4.37121	1.000	-14.1163	18.1163
		Supervisor of those in routine and semi-routine occupations	-2.33333	3.62441	.999	-15.6963	11.0296
		Routine occupations	2.00000	3.14979	.999	-9.6130	13.6130
Emotion total	Professional	Junior managers in smaller organisations	.28571	3.32347	1.000	-11.9515	12.5229

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
		Skilled manual and clerical	-1.25000	2.61193	1.000	-10.8673	8.3673
		Small employer with fewer than 25 employees, plus the self-employed	.00000	4.43943	1.000	-16.3463	16.3463
		Supervisor of those in routine and semi-routine occupations	-2.50000	3.48257	.997	-15.3231	10.3231
		Routine occupations	.53846	2.83667	1.000	-9.9063	10.9833
		Never worked or long-term unemployed	-12.00000	3.48257	.083	-24.8231	.8231
	Junior managers in smaller organisations	Professional	-.28571	3.32347	1.000	-12.5229	11.9515
		Skilled manual and clerical	-1.53571	2.96165	1.000	-12.4407	9.3693
		Small employer with fewer than 25 employees, plus the self-employed	-.28571	4.65378	1.000	-17.4213	16.8498
		Supervisor of those in routine and semi-routine occupations	-2.78571	3.75200	.997	-16.6008	11.0294
		Routine occupations	.25275	3.16162	1.000	-11.3886	11.8941
		Never worked or long-term unemployed	-12.28571	3.75200	.118	-26.1008	1.5294
	Skilled manual and clerical	Professional	1.25000	2.61193	1.000	-8.3673	10.8673
		Junior managers in smaller organisations	1.53571	2.96165	1.000	-9.3693	12.4407
		Small employer with fewer than 25 employees, plus the self-employed	1.25000	4.17546	1.000	-14.1243	16.6243
		Supervisor of those in routine and semi-routine occupations	-1.25000	3.13915	1.000	-12.8086	10.3086
		Routine occupations	1.78846	2.40263	.997	-7.0582	10.6351
		Never worked or long-term unemployed	-10.75000	3.13915	.087	-22.3086	.8086
	Small employer with fewer than 25 employees, plus the self-employed	Professional	.00000	4.43943	1.000	-16.3463	16.3463
		Junior managers in smaller organisations	.28571	4.65378	1.000	-16.8498	17.4213
		Skilled manual and clerical	-1.25000	4.17546	1.000	-16.6243	14.1243
		Supervisor of those in routine and semi-routine occupations	-2.50000	4.76871	1.000	-20.0587	15.0587
		Routine occupations	.53846	4.31960	1.000	-15.3666	16.4435
		Never worked or long-term unemployed	-12.00000	4.76871	.400	-29.5587	5.5587
	Supervisor of those in routine and semi-routine occupations	Professional	2.50000	3.48257	.997	-10.3231	15.3231
		Junior managers in smaller organisations	2.78571	3.75200	.997	-11.0294	16.6008
		Skilled manual and clerical	1.25000	3.13915	1.000	-10.3086	12.8086
		Small employer with fewer than 25 employees, plus the self-employed	2.50000	4.76871	1.000	-15.0587	20.0587

Appendix 33 (continued)

Dependent Variable	(I) occupation	(J) occupation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
		Routine occupations	3.03846	3.32848	.990	-9.2172	15.2941
		Never worked or long-term unemployed	-9.50000	3.89364	.439	-23.8366	4.8366
	Routine occupations	Professional	-.53846	2.83667	1.000	-10.9833	9.9063
		Junior managers in smaller organisations	-.25275	3.16162	1.000	-11.8941	11.3886
		Skilled manual and clerical	-1.78846	2.40263	.997	-10.6351	7.0582
		Small employer with fewer than 25 employees, plus the self-employed	-.53846	4.31960	1.000	-16.4435	15.3666
		Supervisor of those in routine and semi-routine occupations	-3.03846	3.32848	.990	-15.2941	9.2172
		Never worked or long-term unemployed	-12.53846(*)	3.32848	.041	-24.7941	-.2828
	Never worked or long-term unemployed	Professional	12.00000	3.48257	.083	-.8231	24.8231
		Junior managers in smaller organisations	12.28571	3.75200	.118	-1.5294	26.1008
		Skilled manual and clerical	10.75000	3.13915	.087	-.8086	22.3086
		Small employer with fewer than 25 employees, plus the self-employed	12.00000	4.76871	.400	-5.5587	29.5587
		Supervisor of those in routine and semi-routine occupations	9.50000	3.89364	.439	-4.8366	23.8366
		Routine occupations	12.53846(*)	3.32848	.041	.2828	24.7941

* The mean difference is significant at the .05 level.

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Review

Quality-of-life measurement in chronic heart failure: do we take account of the patient perspective?

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Abstract

The modern management of chronic heart failure has led to improved life expectancy, functioning and health-related quality of life (HRQL). HRQL measures the effects of an illness or a treatment from the patient's perspective. It is now recognised that the patient's perspective is as legitimate and valid as the clinician's in monitoring health care outcomes. Although there are a number of quality-of-life measures, which can be separated into two types—generic and disease specific—many have been developed, with little or no account being taken of the patient's perspective. Because most of the widely used measures are not patient centred, they may lack sensitivity and specificity in determining those aspects of HRQL important to individual patients.

This paper reviews the use of quality-of-life assessment tools in the evaluation of patients with heart failure.

Keywords: Health-related quality of life; Chronic heart failure; Patient centred

Contents

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1. Introduction

Coronary heart disease (CHD) is a major contributor to morbidity and mortality in Western societies [1]. Both the longevity of the population and advances in treatment have led to an increase in the prevalence of CHD in the population in developing countries [2]. Major advances in terms of prevention, treatment and rehabilitation have improved prognosis. As a result of these interventions, there is a population which is both older and more susceptible to morbidity due to advanced CHD. Modern management has led to improved survival, which is leaving more patients with a significantly damaged heart that is likely to fail at some time in the future [2].

2. Outcome of chronic heart failure

The diagnosis of heart failure has a comparable mortality rate to that of a diagnosis of cancer. Comparison with the West Midlands Regional Cancer Registry showed that 1-year survival rates for patients diagnosed with heart failure are worse than the 1-year survival rates for those diagnosed with breast, prostate and bladder cancer [3]. These findings support those of Stewart et al. [4] who studied the prognostic impact of heart failure relative to that of 'high-profile' disease states, such as cancer. They identified all patients with a first admission to any hospital in Scotland during 1991 for heart failure, myocardial infarction or the four most common types of cancer specific to men and women. Five-year survival rates and associated loss of expected life-years were compared. Their data showed that patients admitted to hospital with a diagnosis of cancer often survived longer than those with a diagnosis of heart failure. They concluded that, with the notable exception of lung cancer, which is worse, heart failure is as 'malignant' as many common types of cancer and is associated with a comparable number of expected life-years lost [4]. Heart failure is associated with poor health-related quality of life (HRQL; [5]) and increasing dependency [6] and may result in prolonged and frequent hospital admissions [7,8].

3. Effect of chronic heart failure on quality of life

In recent years, medical care has become increasingly concerned with the management of chronic diseases. In these cases, the aim of a medical management plan is to optimise the patients' quality of life. Over the past decade, there has been a growth in the use of quality-of-life measurements as an indicator of health outcome [9,10]. Chronic heart failure (CHF) is no exception to this, where the goal of treatment is not only to prolong life, but also to relieve symptoms and improve function. Improving quality of life is an important goal of medical therapy; it is increasingly being seen as an important outcome to be measured in clinical research [11]. The medical profession has been slow and, perhaps, reluctant to quantify such subjective, personal and human characteristics, preferring to rely on laboratory tests, objective measures or population statistics for information [11]. Quality of life reflects the way a person's mental and physical well-being is evident in their everyday life [12]. HRQL measures the effects of an illness or a treatment from the patient's perspective. Although health care professionals may be more interested in changes in objective physical measures, patients tend to be more interested in changes in symptoms, physical function and social roles [13]. These HRQL measures are particularly useful and important supplements to traditional physiological measures of health status because they describe or characterise what the patient has experienced as a result of health care [11].

The main clinical symptoms in CHF patients that limit activities of daily living and lead to exercise intolerance are dyspnoea, tiredness and fatigue. The fundamental issue to patients is how these symptoms hinder their life. Individuals with CHF experience impairment of physical and functional capacity, which imposes limitations on their life [6]. Quality of life in CHF may be impaired by physical symptoms, psychological problems, adverse treatment effects and social limitations [14]. These factors may lead to individuals withdrawing from activities and previous social contacts and losing their social relations and social support [15]. Rifts caused by family members struggling to meet illness-related demands and the inability of family and friends to cope with the deterioration of a close friend lead to withdrawal of contact with the CHF patient [15]. The increasing severity of CHF leads to the individual being aware of their own mortality; this also leads to depression, sleep disturbances and anxiety [14]. Personal relationships, eating, sexual activity and the ability to work are all limited and are paralleled by an increasing dependence on others [14]. Quality of life is an opinion formed by a person's interpretation of their own health status in comparison with what they might hope to be able to achieve [14]. Reduction in quality of life is an inherent problem to the individual with chronic heart failure.

4. Health-related quality-of-life measures in chronic heart failure

Two approaches to measuring HRQL are available: generic and specific instruments [16]. Generic instruments measure a wide variety of patients and usually cover a wide range of HRQL domains, including, e.g., functional capacity, disability and distress. Specific instruments concentrate on particular areas of relevance to the patient group. The choice of which instrument to use is vital, because the content must be related to the nature of the medical condition being treated, as well as to the effect of the treatment under assessment [17]. Therefore, a questionnaire suitable for the assessment of hypertensive therapy may not be suitable for evaluating the impact of cardiac surgery [18]. Most of the research that refers to HRQL has led to the development of measures that describe health status, which is not the same as quality of life. Quality-of-life research does share a number of similar fields to health status research, but it should be concerned with the individual rather than the group. Researchers have tended to use the terms "quality of life", "health status" and "health-related quality of life" interchangeably [19].

4.1. Generic measures

There are a number of generic measures available that measure quality of life. Examples are the Nottingham Health Profile (NHP; [20]), the Sickness Impact Profile (SIP; [21]) and the Medical Outcomes Study 36-item Short Form Health Survey (SF-36; [22]). These are applicable for a wide range of groups and cover a wide range of quality-of-life domains (Table 1).

4.1.1. Nottingham Health Profile (NHP)

The Nottingham Health Profile [20] is a measure of perceived distress relating to severe disabling diseases. Originally developed using public perceptions of health status to assess factors which predict the need for health care [23], it provides a description of how people feel during ill health. The main aim of the measure is that it should reflect the individual's rather than the professional's definition of health. The NHP is a short scale and, thus, can be self-administered and is suitable for use in postal questionnaires; however, its short length means that it does not provide a comprehensive assessment. Extensive testing has found the NHP to be reliable and valid [24–27]. However, it has been used in a number of clinical trials in heart failure and produced variable results [28–31]. This may have been due to its lack of sensitivity to symptoms experienced by patients with CHF. It may also be caused by its inability to detect minor illness, and therefore, minor improvements over time are not detected [32]. The assessment of pain is important in the NHP. This symptom is uncommon in CHF, and therefore, the content validity in relation to CHF is reduced. More studies are required on the validity and use of this measure in CHF.

4.1.2. Sickness Impact Profile (SIP)

The Sickness Impact Profile [21] is a generic measure which is widely used in angina. This was developed as a measure of perceived health status for use across a wide range of health problems. Sickness is measured in its relation to behaviour. The emphasis is on the impact of sickness on daily activities rather than feelings. It can be administered by interview, self-administered and by postal questionnaire. High scores for validity and reliability have been shown [24,33–36]. However, it is lengthy, and this can be a disadvantage. When the SIP has been used in interventional trials in CHF, it has shown variable results in improvements of quality of life in the intervention groups [37,38]. This may be due to its lack of sensitivity to HRQL changes in patients with CHF. Results in one study suggest that the SIP does not discriminate adequately between different severities of CHF [39].

4.1.3. Medical outcomes study 36-item short form health survey (SF-36)

The SF-36 [22] was developed to gather information about the individuals' multidimensional health concepts and a measurement of the full range of health domains, including well-being and personal evaluations of health. It was developed for a health insurance study by the RAND corporation [22] and is the most widely and extensively used generic measure [24,40]. This is due to the fact that it is short and has been tested for reliability and validity and found to be reliable and valid across numerous population samples [24,40–45]. However, there are reports of ceiling and floor effects in its use in chronic diseases [46]. It has been found to be more sensitive to small degrees of impairment in quality of life compared with that of the NHP. However, the SF-36 proved to be too long for inclusion in some large-scale health measurement and monitoring studies [47].

The SF-36 is suitable for use in heart failure trials and it can and should be used in conjunction with disease-specific questionnaires [48]. However, the incidence and prevalence of heart failure in the elderly population is high [3,7,49–51], and when this is taken into account, the usefulness of the SF-36 is doubtful. A study of older adults found that there were missing responses associated with the questions on work and vigorous activity,

Table 1
Properties of generic quality-of-life measures

Measure	Nottingham Health Profile [20]		Sickness Impact Profile [21]		The 36-item short form health survey (SF-36) [22]	
Description	Measure of broad health status among patients with angina. Developed in UK based on lay perceptions of health status.		Measure of perceived health status that would provide a descriptive profile of changes in a persons' behaviour due to sickness. Developed in the United States.		Measure of function and well-being. Used in a wide variety of circumstances.	
Acceptability and appropriateness	Short, simple, inexpensive, self-administered, postal administered. Designed for use as a population survey.	Does not provide comprehensive assessment. High nonreturn rate if high number of zero scores focuses on negative experience. Does not detect minor illness and minor improvements over time not detected [32]. Large numbers of relatively fit members of the population survey would gain low NHP scores.	Self-administered, postal and interview administered. Wide application used in chronic and acute illness. Adapted for UK population	Lengthy, repetition of items, major commitment to interviewer training	Short, inexpensive Self-administered, postal and interview administered. Becoming the generic measure of choice. Widely used as a proxy measure. Multidimensional Response rates are high. Covers a wide range of areas affected by ill health.	Too long for some trials [47] High degree of missing responses in the elderly. Fails to address some areas of function, e.g., sleep.
Validity	Established in the development method where items were drawn from lay experience. Numerous applications in clinical and community settings. Successful outcome measure with heart transplant patients in UK [25,26]	Content validity is reduced, as pain is an important item; this symptom is uncommon in CHF.	Validity trials compared SIP with subjective ratings made by respondents with clinical assessment and functional assessment instruments [21,35].	May not discriminate adequately between different severities of CHF [39]	High degree of validity in a number of populations [40,42,43]	Reported ceiling and floor effects in chronic diseases [46]
Reliability	Test–retest technique reported as high [20] Sensitive to change [27]	May lack sensitivity to symptoms experienced by patients with CHF [28–31].	Test–retest technique is high [21]. Interview administrated score better than self-completed and postal version. Sensitive to change in clinical trials [21,36].	May lack sensitivity in CHF due to HRQL changes in these patients	Test–retest technique and internal consistency is high in physical and mental health domains [40,44,45]. More sensitive to small degrees of disability than the NHP.	Insensitive to small clinical change which may be due to influences of comorbidity [56]
Comments	Limited measure of function; some disabilities are not assessed. Requires supplementation if used as a broad measure of health-related quality of life. People who score zero cannot show improvement over time.		People need to be regarded or regard themselves as ill.			

frequently regarded as not applicable by elderly people [52]. Hayes et al. [52] surmised that people under 75 years old could usually complete the SF-36 without difficulty, but those older than 75 years may need assistance, especially if they have poor physical and mental health. It has been suggested that administration by interview may be the best way to use the SF-36 in the elderly population [53]. O'Mahony et al. [54] found that there was a high response rate to the SF-36 in older stroke patients when it was administered as a postal questionnaire. However, the poor completion rates in older stroke patients and consequent inability to compute scores for a large proportion of responders in certain scales raises concerns about the perceived relevance of these sections [54]. When data quality indicators were examined, it appeared that postal administration of the SF-36 is not appropriate for assessing quality of life in older stroke patients [54]. The use of an interviewer improves response, but factors which influence health status, such as physical and cognitive dysfunction, have a significant effect on response rates. Therefore, the usefulness of the SF-36 in a predominantly elderly heart failure population is questionable [55]. Comorbidity associated with elderly patients may also cause insensitivity to small clinical change [56].

An advantage of generic instruments is that they make it possible to compare outcomes across disease groups and different types of intervention. Health economists frequently employ these measures, as they can be used to guide resource allocation. However, these general measures are likely to be insensitive to change that is related to CHF.

4.2. Disease-specific measures

Researchers started to use specific measures of quality of life to increase the responsiveness of the measures to the patients being studied [16,57]. There are a number of types of specific measures: disease-specific, function-specific and informal measures. These can be used on their own or grouped together and used as batteries. Disease-specific instruments have been developed to be suitable to the problems associated with a specific medical condition, although they may have a narrow range of application [58]. A review of quality of life in cardiovascular disorders concluded that there are doubts about current concepts and measures [59]. HRQL measures have been poorly developed in relation to cardiovascular disease. CHD patients usually have other comorbid conditions, which generic instruments may not detect [56]. If only generic instruments such as the SF-36 are used to assess differences in, or changes to, HRQL in CHD patients, then the probability of making an incorrect conclusion is altered, in an unpredictable manner [56]. The majority of cardiology research has used inadequate HRQL measures [60], and until recently, very little work has been undertaken in CHF.

A comprehensive review of quality-of-life evaluations in CHF found there were important differences between different quality-of-life questionnaires [14]. This paper reviewed the design and validation of both generic and disease-specific quality-of-life questionnaires, which have been used in clinical trials of CHF. The aim of the review was to consider the impairment in quality of life that may occur in a patient with CHF. First, the authors reviewed the characteristics of a quality-of-life questionnaire, which would make it a useful instrument to evaluate quality of life in chronic heart failure. Second, they evaluated the performance of both generic and disease-specific quality-of-life questionnaires when used in clinical trials in CHF. They argue that quality of life is an opinion formed by a person's interpretation of their own health status in comparison to what they might hope to be able to achieve. This review concluded by saying that no instrument has measured quality of life in heart failure trials in a reliable or valid way, and therefore, an obvious need exists for the development of valid and reliable instruments [14].

There is no unified approach to the measurement of quality of life, and little agreement has been found on what it means [61]. There is no clear theoretical basis for quality-of-life measures, and this has created confusion and misunderstandings amongst researchers and practitioners with regard to which tool to use in research [62]. This has been echoed by a number of researchers who have studied quality of life and acknowledge that the conceptual ambiguity, doubtful validity and reliability, inappropriate methods and the weak statistical analyses of the data have restricted the use of quality-of-life measures [9,63].

Researchers have been encouraged to select a measure that is reported as being reliable, valid and easy to complete. However, they are faced with a substantial number of instruments to choose from in some areas and a famine of tools in other areas. It would seem that researchers are guided towards instruments more by fashion than efficacy; instruments are used indiscriminately by researchers because so many others have used them before [64]. However, generic instruments are generalisable to a large patient population, and these instruments will be used repeatedly in different studies to allow for comparability of the client population.

The choice of quality-of-life instrument should be based on issues relating to the ability to demonstrate reliability and validity to change over time or the psychometric properties of the measure [65]. Reliability is assessed in two ways: test–retest reliability and internal consistency. The former requires the administration of an instrument on two separate occasions to the same population. The correlation of scores provides an estimate of the reliability of the measure. It is usually determined using Pearson's correlation [66]. Internal consistency involves testing for homogeneity of the items contained in the questionnaire and is usually determined by Cronbach's alpha [66,67]; however, item homogeneity is often mistakenly believed to be equivalent to unidimensionality by researchers [68].

The validity of an instrument refers to its ability to measure what it is supposed to measure. There are four main forms of validity. Face validity refers to the researchers subjective assessment of the presentation and relevance of the questionnaire [66]. Content validity refers to the appropriateness of the content of the instrument to measure what it is intended to. Criterion validity is the correlation of the measure with another measure, which is valid. Construct validity refers to the ability of the instrument to measure the underlying concept it claims to measure [66].

Reliability and validity are not fixed qualities of an instrument—the fact that the reliability and validity of an instrument have been established in one population does not mean that it will be valid and reliable in other populations. Once the reliability and validity of a measure have been shown in one population, it must be reestablished in other populations [69–71].

Traditionally, in CHF, the New York Heart Association (NYHA) classification system has been used to assess functional status [72]. This scale assesses a combination of physical symptoms and limitations. The NYHA is the most widely used system, but it has been shown to be unresponsive to change, has a high degree of interobserver variability and the perspective is that of the doctor rather than of the patient [73].

4.3. Disease-specific measures in chronic heart failure

Disease-specific questionnaires are designed to obtain information about quality of life in patients with heart failure. There are several tools in this area, including the Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF; [74]), the Chronic Heart Failure Questionnaire (CHQ; [30]), the Kansas City Cardiomyopathy Questionnaire (KCCQ; [73]), the Left Ventricular Dysfunction Questionnaire (LVD-36; [75]) and the Minnesota Living with Heart failure Questionnaire (MLHFQ; [37,76]). According to the literature, the three most commonly used are the QLQ-SHF, CHQ and MLHFQ ([77,78]; Table 2).

4.3.1. Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF)

The QLQ-SHF [74] is a 26-item questionnaire which uses a Likert scale to quantify physical activities and a visual analogue scale to assess life satisfaction, social and emotional factors [14]. The higher the score, the greater the impairment of quality of life. The QLQ-SHF has been used in a number of clinical trials [79], and its validity was determined by correlations of the results from the questionnaire with those from comparable domains of the SIP. The construct validity is acceptable for the domains of psychological symptoms and life satisfaction. However, it is weak for the domains of somatic symptoms and physical limitations [14]. Results from these trials have shown that it is moderately sensitive to small changes in quality of life in patients with CHF [14]. However, there is no evidence to suggest that this questionnaire is able to distinguish between patients with different severities of CHF, and therefore, this questionnaire needs to be explored and tested further in chronic heart failure [57].

4.3.2. Chronic Heart Failure Questionnaire (CHQ)

The CHQ [30] is a 20-item questionnaire, which was developed for use in CHF [14]. It is a complex questionnaire to administer. The questionnaire is administered by interview. It has three categories: dyspnoea, fatigue and emotional function. An increase in score shows an improvement in quality of life. This questionnaire was validated in a randomised, placebo-controlled trial of digoxin in CHF [80]. It was found to be most responsive to changes in dyspnoea and fatigue. The CHQ appears to be sensitive to patients with different severities of CHF.

4.3.3. Minnesota Living with Heart Failure Questionnaire (MLHFQ)

The MLHFQ [37] was designed specifically for use in heart failure. It assesses the patients' perception of the effects of CHF on the physical, socioeconomic and psychological aspects of their life. Patients respond to 21 items using a six-point Likert scale (0–5). It is also possible to obtain subscale scores for physical and emotional domains. The questionnaire is easy to administer, short and easily understood. It can be administered by interview, self-administered or by postal questionnaire. The measure has been found to be valid in comparison with other health outcome scales [14,81]. It has been shown to discriminate between patients with CHF and those with symptomatic left ventricular dysfunction. However, it does not distinguish well between different severities of CHF [14]. Test-retest technique found that initial low scores tended to increase and initial high scores tended to decrease. This suggests that regression to the mean is operating [82].

Concerns have been raised about the MLHFQ in terms of the patients ability to separate symptoms and impairments related to heart failure from other comorbidities [83]. The MLHFQ subscales may be less useful in quality-of-life assessment than the total score is [83]. Although the MLHFQ is the most popular measure, it should be noted that it was designed to be a patient self-assessment measure for use in clinical trials to assess the effects of drugs or devices, [83] and not as a complete quality-of-life assessment, thus, it is of value for some purposes, but not for others [37]. A recent study found the MLHFQ does not measure the concept that it is intended to measure [78].

5. Limitations of quality-of-life measures

Quality-of-life instruments have always been seen as long, time consuming and unresponsive assessment tools;

Table 2
Properties of disease-specific quality-of-life measures

Measure	Quality of Life in Severe Heart Failure Questionnaire [74]		Chronic Heart Failure Questionnaire [30]		Minnesota Living with Heart Failure Questionnaire [37]	
Description	Measure of HRQL in patients with severe heart failure. Items were derived from existing scales and literature.		Measure of subjective health status in people with heart failure		Measures patients' perceptions of the effects of CHF on their daily lives.	
Acceptability and appropriateness	Short. Self-administered. The scale's domains are summed to form an overall score. The higher the score the worse the patients.		Interview administered. Personal information is obtained from the participant in three categories of dyspnoea, fatigue and emotional function.	Lengthy. Well-trained interviewer. Complex to administer	Short, inexpensive, simple. Self-administered designed specifically for heart failure.	Respondents must be instructed on how to complete it. Designed specifically for use in clinical trials.
Validity	Determined by correlation of the results with those from comparable domains of the SIP. Construct validity is acceptable for the domains of psychological symptoms and life satisfaction. Internal consistency is satisfactory [74].	Lack of a gold standard. Needs to be compared with other well-validated questionnaires. Construct validity is weak for domains of somatic symptoms and physical limitations.	Able to distinguish between patients who improved with those who did not in an RCT of Digoxin in CHF [80].	Small-scale trial, needs further investigation.	Correlation has been reported with NYHA and patients self-rating [37]. Internal consistency has been found to be good [81].	Does not distinguish well between different severities of CHF.
Reliability	Test–retest technique is reported as high [74]. Trial of metoprolol detected improvements in the treatment group [79].	Unable to distinguish between different severities of heart failure.	The authors report reproducibility with 25 patients. Sensitive to different severities of CHF.	Small numbers, needs confirmation.	Test-retest technique reported no bias. Sensitivity to effects of medication.	Regression to the mean has been found with scores [37].
Comments	Trial results suggest that the measure is moderately sensitive to small changes in quality of life in patients with CHF [14]. Needs to be used and tested further in CHF research [57]		Most sensitive to changes in dyspnoea and physical function.		Patients' ability to separate symptoms of heart failure and comorbidities may affect the usefulness of this measure.	

but, since the introduction and availability of shorter, easier to understand and administer tools, there has been an increase in their use in clinical trials [22,41,46,84–88]. This reflects increasing interest in the need to know how the patient feels and how satisfied they are with their treatment. Although it has been recognised that these tools are reliable, they may not be relevant to individual patients; therefore, their validity may be suspect if they do not measure components of quality of life that are important to the patient. Many instruments are not derived from patient populations but from an expert medical viewpoint; yet, there is no guarantee that medical professionals understand patients' quality of life. Quality-of-life measures usually comprise a number of items to which patients respond. To maximise the relevance of these items, they should be derived, wherever possible, from a patient population. Many scales, e.g., the generic and disease-specific measures already described, were not derived from a patients' perspective. Instead, they relied on the perspective of professionals, and it may be the case that medical professionals may have a different view of the aspects of function that are important to quality of life [89].

A review of health-related quality of life questionnaires in CHF published in 1999 found 41 studies using instruments published between 1990 and 1998 [90]. Most commonly, such questionnaires were used in conjunction with clinical trials that tested the effectiveness of new medications or treatments. HRQL related to many domains, including disease state, physical and social functioning, social interaction and emotional state. The review found that 30 of the 41 studies were trials evaluating the effectiveness of a medication. The remaining studies focused on physical exercise, positive airway pressure, nurse case management and primary-care-related quality of life. In summary, no single general quality-of-life measure dominated the area of CHF, and three quarters of the studies were related to drug trials [90].

We would argue that quality of life can only be measured by determining the opinions of patients and using these in place of expert opinion. There may be factors that influence a patient's perception of quality of life that are individualised and cannot be expressed in a standard tool [89]. The individualised view of HRQL is not recognised or assessed by generic and disease-specific measures [91]. A qualitative approach to understanding everyday quality of life has the potential to provide powerful and detailed information about the context and contradictions that people with chronic clinical conditions experience [12]. A patient's self-assessment can differ substantially from the judgment of the doctor or of other healthcare staff [92,93]. Physicians tend to dramatically underestimate overall social functioning, role functioning and pain [93]. Discrepancies also exist between patients' measurements and patient narrative accounts [94], and in general, there are substantial discrepancies between patient and physician scores on the more subjective quality-of-life domains [93]. Practitioners are often surprised at the low value that patients attach to some aspects of quality of life and the high value to others, which is at odds with the viewpoint of the practitioner [95]. Therefore, other factors are important in quality of life, which are not included in recognised measures. Most of the widely used measures are not patient centred and restrict a patient's choice; therefore, these limitations will reduce the accuracy and usefulness of expert-driven quality-of-life tools, as they do not measure what the patients feel contributes to their quality of life. Patient-centred outcome instruments allow the respondents to choose for themselves the areas of their lives that matter [89]. Many of the tools for measuring quality of life are based on a health status model that focuses mainly on objective measures, and less attention has been paid to subjective forms of assessment [12]. Quality-of-life tools in CHF do not measure quality of life in a reliable or valid fashion [14].

6. Rationale for a new approach

Quality-of-life measures are not aimed at the correct target, unless an opportunity to express patients opinions and reactions is provided [61]. Quality of life is a personal perception, which shows the way an individual feels about their health and/or the nonmedical aspects of their lives [61]. Most measures of quality of life in the literature impose standard models of quality of life and preselected domains on the individual. Many of the measures force an external value system on individuals rather than allowing them to describe their lives in ways that they themselves find important [63]. What differentiates quality of life from other measures is the need to obtain and integrate the patients' values and perceptions into the assessment [61]. We understand quality of life from a variety of indicators, many of which tell us about life, but not about quality.

Assessing the patients' experience of CHF and its treatment is a central component of health care. Quality-of-life measures capture the personal and social context of patients [96]. Measures that have been developed for clinical research cannot be easily used in clinical practice. There is increasing interest in developing individualised tools that reflect the perception that quality of life is unique to individuals and cannot be adequately assessed using standardised measures [96].

7. Conclusion

A valid measure of quality of life should be defined in individual terms; therefore, there is a caveat to current quality-of-life measures for use in CHF, as their meaning and relevance to the target population are suspect. Generic measures produce an overall representation of a patients' assessment of their quality of life. The imprecise nature of these measures may cover a particular aspect that may be of major importance to the patient, therefore limiting their use.

The measure must focus less on functional disability and include aspects of life that give it meaning and purpose. Physiological measurements of health status describe only limited aspects of the individuals' life and may not have meaning and relevance in the context of that life [97]. The subjective and individualistic nature of quality of life has been defined as "the extent to which our hope and ambitions are matched by experience" [97].

Most of the measures were designed for use in clinical research and are therefore not necessarily appropriate for clinical practice. It is not the intention of this review to provide a solution to this limitation. However, further research is required to look at patient-led quality-of-life measures in everyday practical care in a chronic heart failure population.

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Appendix 35

Health-related quality of life from the perspective of patients with chronic heart failure.

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Abstract

Background

The aims of treatment in chronic heart failure are to reduce symptoms, improve function and prolong life. Currently there is no patient-centred health-related quality of life measure in chronic heart failure. The aim of this study was to explore health-related quality of life from the perspective of patients with chronic heart failure and to identify themes for inclusion in a patient-generated instrument.

Methods

Semi-structured interviewing of patients with an objective diagnosis of chronic heart failure was undertaken. The transcripts were analyzed using an iterative process in which emergent issues and analytical themes were identified using Framework methodology.

Results

Analysis of the transcripts identified seven themes on health-related quality of life. These were; changes in physical ability, emotional state, self-awareness and self-perception, changes in relationships, symptoms, maintaining social/lifestyle status and cognitive aspects.

Conclusions

This study provides a description of how health-related quality of life is affected by chronic heart failure from patients' perspectives. Findings from this study will contribute to the development of a patient-led health-related quality of life measure for use in everyday practical care in a chronic heart failure population.

Keywords: Health-related quality of life, chronic heart failure, qualitative

Key messages:

- Patients' beliefs about how chronic heart failure affects their health-related quality of life are identified.
- Emotional dimensions of health are more important than the physical dimensions.
- The development of a patient centred health-related quality of life measure is important given the scarcity of such measures in coronary heart disease.

Introduction

Recently the focus of medical care has shifted towards management of chronic diseases, with the aim of optimising quantity and quality of life (1), (2), (3). Chronic heart failure (CHF) has been no exception to this, where the goal of treatment is not only to prolong life, but also to relieve symptoms and improve function.

Quality of life is a reflection of a person's mental and physical well-being in their everyday life (4). Health-related quality of life (HRQL) measures the effects of an illness or a treatment from the patient's perspective. HRQL measures are particularly useful and important supplements to traditional physiological measures of health status because they describe or characterise what the patient has experienced as a result of health care (1).

The main clinical symptoms in CHF are dyspnoea, tiredness and fatigue, which affect quality of life through their limiting effect on physical functioning, (5) but may also give rise to psychological problems, adverse treatment effects and social limitations (3), (6). These factors may lead to individuals withdrawing from activities and social contact, experiencing a loss of social relationships and social support (7). Increasing severity of CHF leads to the individual being aware of their own mortality, which contributes to depression, sleep disturbances and anxiety (6). Personal relationships, eating, sexual activity and the ability to work are all limited whilst paralleled by an increasing dependence on others (6).

In the past, HRQL instruments have been seen as time-consuming and unresponsive assessment tools, but since the introduction of shorter, easier to understand and administer tools there has been an increase in their use in clinical trials (8), (9), (10). Although these tools are reliable, their validity may be suspect if they do not measure components of HRQL important to the patient. Many instruments are not derived from patient populations but from an expert, medical viewpoint, yet there is no guarantee that medical professionals understand patients' HRQL. To maximise the relevance of these items in HRQL measures they should be derived, wherever possible, from a patient population.

We have shown that all HRQL measures in CHF currently available are expert driven; there is no suitable patient-derived measure to assess HRQL in CHF (11). This is a weakness and justifies efforts to devise a truly patient-centred measure. We would hope that the eventual development of this tool would enable its use alongside more conventional physiological measures of health status in CHF.

Materials & Methods

The aim of this qualitative study was to explore HRQL from the perspectives of people with CHF.

The sample consisted of eleven patients admitted to a district general hospital with an objective medical diagnosis of CHF between October 2003 and February 2004

The participants were two women and nine men aged between 57 and 72 years (mean of 62 years). All were found to have left ventricular dysfunction (of varying severity, as measured by ejection fraction).

Semi-structured interviews were undertaken to ascertain how people with heart failure viewed their HRQL using a topic guide drawn from the literature, and which had been piloted to evaluate the sequence of the interview, clarity of wording and questions.

Local Research Ethics Committee approval was obtained. Patients meeting the study entry criteria were identified when they were discharged from hospital and given information about the study. Interviews of those consenting to take part were carried out in the patients' own home by the first author. Each interview was audio tape-recorded and transcribed in full.

The transcripts were analysed using an iterative process in which emergent issues and analytical themes were identified using Framework methodology, which is a systematic method of mapping and charting developing themes (12). Reliability of the codes was ascertained by a second researcher independently coding two interviews (19% of the sample), ensuring that the findings were not simply based on the subjective judgments of one individual researcher (13). The level of concordance between the two coders was calculated using Cohen's Kappa, and was found to be highly satisfactory (interview 1: Kappa = 0.78, agreement of 86 of 107 codes; interview 2: Kappa = 0.81, agreement of 47 of 57 codes).

Results

Seven themes on HRQL were identified. Table 1 shows the definition of classifications and themes. These themes were primarily driven by the data but also reflect theoretically derived dimensions of HRQL described in other cardiovascular measures.

Insert table 1 about here

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1 Changes in physical ability

The commonest topic described changes in physical ability, which impacted on all areas of participant's lives. This theme comprised categories on change of role, considering every activity, limiting activity levels, influence of symptoms and dependency. Participants described how other people in their life were now helping them undertake tasks they would normally have done, which had led to changes in the participants' roles. Each of these participants saw the changes as negative initially, because they were made to curtail physical tasks before they were ready, or prevented from doing those that they felt they might be able to attempt. Participants expressed a degree of anger and annoyance about this. Most reported that they now thought carefully about undertaking physical exertion due to fear of inducing symptoms, with a resulting limitation in activity levels.

2 Emotional state

The majority of participants expressed negative emotions, including fear, frustration, worry, anger, guilt and panic. These emotions may arise due to the condition or as a result of the reaction of others towards them because of the condition, or were caused by social issues such as reduced finances. A small number described a feeling of panic that was related to misconceptions of CHF.

3 Self-awareness and self-perception

This theme includes the perception by the interviewee of the condition and how it affects them. Participants described their perception of the condition in terms of why had it happened to them, discrepancies between the mind and body and comparing themselves to others of a similar age. Participants described aspects that related to self-perception. This included self-awareness, reflection, self-preservation, coping and not being perfect. Coping mechanisms were discussed by participants which included: compromise, changing how tasks were undertaken, thinking through activities before doing them, restricting activities, being careful and taking longer to perform tasks. These were employed to reduce the symptoms which any physical activity would create.

4 Changes in relationships

This theme includes the relationships the participant has with others around them, particularly the spouse and family members, and includes the reaction of others to them as a result of the condition. Participants felt that limitations in life had been imposed on them either by other people or by the condition, including limitations on sexual relationships as a result of fear by their partners that symptoms would manifest during sexual intercourse.

5 Symptoms

Interviewees described breathlessness, oedema, dizziness, tiredness, chest discomfort and feeling unwell. Breathlessness and tiredness were the most frequently mentioned symptoms and were a problem in relation to physical activity. Every participant mentioned feeling breathless, and most reported that these symptoms were associated with activities of daily living including activities which involved minimal exertion.

6 Maintaining social/lifestyle status

Nearly all participants described the impact that CHF had on their lifestyle. This theme included social life, lifestyle, stress, side effects of medication, missing out on life and not giving up. Some participants found that their social life had been reduced, whereas in some it had been enhanced. These changes were often due to tiredness, while some participants described the importance of avoiding stress and how this had affected their HRQL. Although some participants felt they were missing out on things in life, some participants felt this gave them a new resolve to ensure they didn't give up.

7 Cognitive Aspects

Most of the participants described cognitive aspects of their life which were affected by the condition. These included changes in concentration, denial or forgetting they had the condition, forgetting to take medication and changes in sleep patterns. In those who described forgetting about the condition, they were reminded by the acute onset of symptoms or by other people reminding them. Several participants described how they had difficulty sleeping or change in their sleep patterns, perhaps caused by the emotional concerns described earlier.

Discussion

This study aimed to explore HRQL from the perspective of patients with CHF, and to identify themes for inclusion in a patient-generated instrument. The participants described a number of factors that affected their perceptions of how CHF impacted upon them, bringing to light new information regarding HRQL measures.

Topics not included in current HRQL measures, but which were identified by this study included: themes of changes in relationships, maintaining social/lifestyle status, forgetting about the condition and medication issues. This finding suggests that HRQL research among this patient group to date has not been able to fully report their subjective experience, highlighting the importance of producing such measures from the patient perspective. The development of a patient-derived HRQL measure might help to remedy this deficit.

All participants described the negative effects of having CHF, which reflects the findings in other studies (3), (14), (15), (16). The limiting of activities may be due to behavioural avoidance as a coping strategy, even though this has been linked to higher mortality in this group of people (17), (18), (19). The participants rated the ability to perform tasks and physical activities as the most important aspect of HRQL which is echoed in the literature (6), (20), (21).

The participants in this study expressed many negative emotions. Anxiety and fear are commonly reported by people with heart disease, and as early as 1967 Wynn (22) reported that unwarranted fear was found in 50% of people post myocardial infarction. Lee et al (23) found that psychological status was the most prominent factor associated with CHF, suggesting that high levels of anxiety and/or depression would have more severe effects on HRQL in CHF patients.

A link between extreme health anxiety and physical limitation among people with CHF has been reported (24), (25) which suggests that fear and anxiety may promote behavioural avoidance and reduce physical functioning due to a sense of inadequacy in performing activities of daily living (26).

The finding that relatives and friends encourage behavioural avoidance is not new. It has been reported in studies of both post-myocardial infarction and angina that relatives may discourage activity because of their fears for the patient (27), (28), (29). However, family support had significant effects on participants' emotional states, which reflects findings from previous research (30), (31).

In this study all the participants described symptoms that limited them on a daily basis. It is well documented in cancer and chronic obstructive pulmonary disease that breathlessness has a major negative impact on patients' physical and social functioning and is associated with anxiety (32), (33), (34).

Some of the participants in this study described cognitive aspects of their life that were affected by CHF. Cognitive dysfunction has been found to be prevalent in this group (35). Reports indicate that patients with CHF display deficits in memory and other intellectual abilities, with unclear clinical relevance (36). Sleep disturbances are very common in patients with CHF (37), (38).

This study had a number of limitations. There were a small number of participants. The interviews were conducted after the participant had been discharged from hospital and therefore does not address those individuals who have CHF and are diagnosed and treated by their general practitioners (39). The sample contained mostly men with only two women interviewed, although it is accepted that the incidence of heart failure is more common in men than women (40). The average age of the participants was considerably lower than the typical patient with CHF. A truly patient centred HRQL measure should take account of the impact of CHF on the HRQL of family members; this extended impact was not addressed in this study.

This study provides a description of how HRQL is affected by CHF from patients' perspectives. Themes identified in this study will inform the development of patient-generated items for inclusion in a HRQL measure. This type of HRQL measure is sorely needed, as most scales are derived from the viewpoint of health professionals, who may hold different views of which factors are important to HRQL (41). Psychometric properties of the new measure will be established in subsequent research.

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Chapter 9 – Glossary

Angina – pain in the centre of the chest, which is induced by exercise and relieved by rest and may spread to the jaws and arms. Angina occurs when the demand for blood by the heart exceeds the supply of the coronary arteries.

Anonymity – the protection of the identity of research subjects such that even the researcher cannot identify the respondent to the questionnaire. Anonymity should not be confused with confidentiality where individuals can be identified by the researcher.

Appropriateness – a measure that is appropriate to the target population and setting.

Beta-Blocker – a drug which prevents stimulation of the beta-adrenergic receptors of the nerves of the sympathetic nervous system and therefore decreases the activity of the heart.

Bias - is a derivation of the results from the truth. This can either be due to random error or, more likely, due to systematic error. The latter could be caused by sampling or poor questionnaire design.

Ceiling and floor effects – the response range and the method of scoring a measure. A measure applied to a random sample of the population which is not sensitive to the lower levels of ill health and that is scored from 0 (good health) to 100 (poor health) would be said to manifest a floor effect, as most respondents would score0. If the measure were scored from 0 (poor health) to 100 (good health) this would be referred to as a ceiling effect, as most respondents would score 100. Floor and ceiling effects are likely to be found in measures with small numbers of items.

Chronic heart failure – a condition in which the pumping action of the ventricle of the heart is inadequate. This results in back pressure of blood, with congestion of the lungs and liver, and oedema.

Closed question – one where the possible answers have been defined in advance and so the respondents' answers will be restricted to pre-coded responses offered. A pilot study should be carried out to decide on the correct pre-codes.

Coding – the process by which responses to questionnaires or other data is assigned a numerical value or code in order that the data can be transferred to a computer for data analysis.

Co Morbidity – In a study looking at treatment for one disease or condition, some of the individuals with that disease will also have other diseases or conditions that could be affecting their outcomes.

Confidentiality – the protection of the identity of research subjects so that identities cannot be revealed in the research findings and the only person who can link a respondent's completed information to a name and address is the researcher. This should not be confused with anonymity, where not even the researcher can identify the subjects.

Construct – phenomenon that exists theoretically but that cannot be measured directly and is defined or operationalised in terms of other observable indicators. It can be thought of as a mini theory to explain the relationship among various behaviours or attitudes.

Construct Validity – the extent to which the measurement corresponds to the theoretical concepts (constructs) concerning the object of the study. There are two kinds of construct validity: convergent and divergent.

Content analysis – the systematic examination of text or conversational transcripts to identify and group common themes, and to develop categories for analysis.

Content Validity – a set of operations or measures that together operationalise all aspects of a concept.

Convergent validity – the actual general agreement among ratings, gathered independently of one another, where measures should be theoretically related.

Cost-utility analysis – a form of economic cost-effectiveness analysis where the effects of health care interventions are assessed according to the quality-adjusted life-years gained or lost.

Criterion validity – the extent to which measurement correlates with an external indicator of the phenomenon. There are two types of criterion validity: concurrent and predictive.

Cronbach's alpha – a statistic that is an indication of the internal consistency of a measure. It assesses the degree to which all the items in a questionnaire measure the same underlying construct.

Deduction – a process of data gathering to test predefined theory or hypotheses.

Dimensions of health – theoretically or empirically distinct aspects of health.

Disease-specific measures – questionnaires designed for use with a particular patient group e.g. the Minnesota Living with Heart Failure questionnaire was designed for specific use in individuals with heart failure.

Domains – different aspects of quality of life that might be included in a questionnaire.

Error – can be due to two sources: random error and systematic error. Random error is due to chance, whilst systematic error is due to an identifiable source such as sampling bias or response bias.

External validity – the extent to which the findings from the study can be generalised (from the sample) to a wider population (and be claimed to be representative).

Face Validity – the extent that the measure or instrument being used appears to measure what it is supposed to.

Factor analysis – a group of statistical techniques whose purpose is to reduce a large number of variables to a smaller number of latent variables – variables that can be measured directly.

Focus group – a method of collecting qualitative data from a group of people. It takes the form of a group discussion, ideally with 6-8 respondents. A facilitator directs the group discussion.

Functional status – an individual's ability to perform normal activities to meet basic needs, fulfil usual roles and maintain health and wellbeing.

Generalisability - the extent to which you can come to conclusions about one thing (often a population) based on information about another (often a sample).

Generic measure – a measure designed for use with any illness groups or populations samples, as opposed to those intended for specific illness groups.

Grey literature – documents written for a restricted audience that are outside of traditional bibliographical controls and are not readily available via conventional channels and are therefore difficult to find.

Health – The World Health Organisation define health as a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity.

Health-related quality of life (HRQL) – an individual's level of health-related wellbeing: measurement of HRQoL addresses various dimensions of health and is often multidimensional.

Heterogeneity - If a set of studies on the same subject have varied or conflicting results, the results of the group of studies are heterogeneous. Examining and explaining this heterogeneity is an important part of reviewing the research on a particular subject. (It is the opposite of homogeneous.)

Homogeneity - When results are similar and consistent from one study to another, then the results are said to be homogeneous. (It is the opposite of heterogenous.)

Hypertension – high blood pressure.

Hypothesis – a statement about the relationship between the outcome and the treatment or intervention to be studied.

ID 2004 – Indices of deprivation 2004. A set of indices, comprising seven domains that measure different dimensions of deprivation at a small area level for England.

IMD 2004 – Index of Multiple Deprivation 2004. This overall index is a combination of the seven domain scores used in the ID 2004.

Incidence - The number of occurrences of something in a population over a particular period of time, such as the number of cases of a disease in a country over one year.

Induction – a process of moving from data towards generalisations, hypotheses or theory.

Internal validity – the validity of the study itself, including both the design and the instruments used.

Inter-coder reliability – the consistency of coding when applied by different researchers. The Kappa statistic calculates a coefficient of agreement to assess whether differences were due to agreement or chance.

Internal consistency – the degree to which the items in a questionnaire measure the same attribute.

Left ventricular dysfunction – Inability of the left ventricle to pump blood around the body to meet the bodies demands.

Likert scale – a response scale in which respondents select from a range of options which are placed on a continuum, such as "Excellent", "Very good", "Good", "Fair" and "Poor".

Morbidity – the state of being diseased. The reported incidence of sickness per 1,000 of the population.

Mortality rate – the incidence of death in the population.

Myocardial infarction – death of a segment of heart muscle, which follows interruption of its blood supply.

Oedema – excessive accumulation of fluid in the body tissues.

Open-ended question – one which allows the respondent the freedom to give their own answer to a question, rather than forcing them to select one from a limited choice.

Orthopnea – breathlessness which prevents the patient from lying down, so that he has to sleep propped up in bed or sitting in a chair.

Palpitations – an awareness of the heart beat.

Paroxysmal nocturnal dyspnoea – attacks of breathlessness that occur during the night.

Pharmacotherapy – Treatment of disease through the use of drugs

Population – a term used in research which refers to all the potential subjects or units of interest who share the same characteristics which would make them eligible for entry into a study.

Predictive validity – the ability of a measure to predict some other measure of outcome.

Prevalence - The proportion of a population having a particular condition or characteristic, for example the percentage of people in a city with a particular disease, or who smoke.

Primary prevention – prevention of disease occurrence.

Prognosis – an assessment of the future course and outcome of a patient's disease.

Psychometrics – the sciences of measuring mental and subjective phenomena.

Publication bias – bias caused by the results of a trial being more likely to be published if a statistically significant benefit of treatment is found.

Purposive sample – deliberate choice of respondents or settings.

Qualitative research – the human experience, *which is based on analysis of word* rather than numbers. Qualitative research methods seek to explore rich information usually collected from a fairly small sample.

Quality of life (QoL) – a multidimensional construct encompassing several dimensions, including physical status and functional abilities, psychological status and wellbeing, social interactions, economic and/or vocational status and factors, and religious and/or spiritual status. It differs from the term health-related quality of life which is the impact of disease, illness or injury, medical treatment or health care policy on an individual; often it excludes income, freedom, and quality of the environment, that do not directly affect health issues.

Quality-adjusted-life-year (QALY) – a generic measure of health benefit which attempts to represent the relative value attached by society to different improvements in health, enabling systematic comparison between a variety of health care interventions. Comparisons between treatment programmes are expressed in QALYs. With a measure of both the life-years gained form a particular intervention and the quality of life in each of those years it is possible to calculate the number of QALYs obtained. An index of quality of life multiplied by the number of years in each health state equals the number of QALYs.

Random sample – a sample in which each individual in the given population has an equal chance of selection into the sample.

Recall bias - Arises from mistakes in recollecting events, both because of failures of memory, and looking at things 'with hindsight' and possibly changed views. People's reports of what is happening to them currently, therefore, can be more accurate than their recall of events or feelings from some time ago.

Reliability – the degree to which the results obtained by a measurement, procedure can be replicated.

Response rate – the proportion of people who have participated in a study or completed a question. It is calculated by dividing the total number of people who have participated by those who were approached or asked to participate.

Retrospective - the outcomes of a group of people are examined in hindsight ('after the event'). Retrospective studies are generally more limited in the data available for analysis, as the data have rarely been collected with the needs of that particular study in mind. This kind of limitation means that a retrospective study is usually less reliable than a prospective study.

Revascularisation – a surgical procedure for the provision of a new, augmented, or restored blood supply to a body part or organ.

Secondary prevention – the avoidance or alleviation of the serious consequences of disease by early detection.

Sensitivity – (Also known as responsiveness), the ability of the questionnaire to detect meaningful change.

Survey - A research design in which a sample of subjects is drawn from a population and studied (usually interviewed) to make inferences about the population. This design is often contrasted with the true experiment in which subjects are randomly assigned to conditions or treatments.

Test-retest reliability – the administration of a measure on two separate occasions to the same population; the correlation between score provides an estimate of the reliability of the measure. The two occasions need to be far enough apart so the at the previous responses cannot be remembered but close enough in time so that change in the true score is minimal.

Utility – the preference for or desirability of a particular outcome in terms of health status.

Validity – the degree to which a measurement measures what it purports to measure.

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