Recovery and Rehabilitation after Mycocardial Infarction

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THE MANAGEMENT AND COST OF THE STUDY

1. This study has been undertaken within the rehabilitation research programme of the Health Services Research Unit. It has been directed by Professor Warren and under the day-to-day management of Mr. Lee. Mr. Lee has been the member of the research staff with the greatest involvement in the study; he has probably spent about one-third of his time between 1973 and mid-1978 on it. Between these years he has also worked on the Princess Mary's Hospital Study (H.S.R.U. Report No. 5), the simple fracture study, the fractured femur study, and other aspects of the H.S.R.U.'s programme generally.

2. The timetable of the coronary study has been as follows.

June 1972	Proposals for hospital follow-up study submitted to D.H.S.S. as part of 1972/73 research programme.
Jan. 1973 onwards	Discussion and design of hospital follow-up study. Initial literature review. Decision to focus first study on coronary patients.
Sept./Oct.	First and second drafts of interview schedules. Preparation for fieldwork.
Jan. 1974	Pilot interviews.
April 1974	Start of first interviews with main series of patients.
Feb. 1975	Decision to reduce number of patients to be included in the series.
July 1975	End of first interviews with patients.
July 1976	End of follow-up interviews with patients.
Sept. 1976 onwards	Data processing.
Jan. 1977 onwards	Data analysis. Detailed review of coronary rehabilitation literature.
July 1977	Outline and rough draft of report prepared.
Feb. 1978	Internal discussion draft of report prepared.
Sept. 1978	Final Report.

3. Because of the involvement of staff in different areas of work, it is difficult to produce an accurate, detailed statement of the cost of the study. It seems reasonable to estimate the cost of the study to D.H.S.S., at current prices, to be approximately as follows.

Year	Expenditure £
Oct.1972 - Sept.1973	1,660
Oct.1973 - Dec.1974	3,160
1975	3,300
1976	3,470
1977	3,070
1978	2,000
Total	16,660

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A research study and report of this kind is the result of the work and contributions of many people. To everybody that has helped I am very grateful. I owe particular thanks to a number of people.

Mrs. M.J.A. Russell helped to develop the study and undertook nearly all the interviews. She worked with a skill and sympathy without which the study could not have succeeded.

Other members of the Health Services Research Unit helped in many ways. Professor M.D. Warren provided the initial impetus for the study, and has guided and directed it throughout. He, and other members of the Unit, particularly Mr. J.M. Bevan, Dr. J.R. Butler, Dr. K.S. Dawes, Mrs. R.F. Dowie, Miss G.M. Dyche, Mrs. R. Knight and Miss M.A. Morgan, helped by commenting on the proposals, interview schedules and the report. Mrs. B. Wall undertook the coding and data processing. Mrs. E.V. Browne, Mrs. M. James, Mrs. T.Z. Pullinger and Mrs. S.M. Woodward typed interview schedules, the report and other documents with great speed and accuracy.

Members of the staff of the Kent and Canterbury Hospital helped in different ways. Particular thanks are due to Dr. D.J.E. Taylor who provided the initial cooperation and discussed the study at all its stages. Dr. J.M. Lipscomb, Dr. M.O. Rake and Dr. C.I. Roberts allowed us access to their patients. Dr. T. Habib contributed to the development of the study and provided much of the clinical data. Dr. C.V. McCormick and other members of the junior hospital medical staff also helped obtain the clinical data. Mr. A.M. Barson allowed us into the hospital to do the study. Many members of the nursing and clerical staff helped us to find the patients and work in their wards.

The Department of Health and Social Security financed the study as part of their continuing support of the Health Services Research Unit.

The respondents answered our questions. Without their willingness to cooperate, the study could not have taken place at all.

R.H. Lee

SUMMARY AND MAIN CONCLUSIONS

Introduction

In recent years there has been a growth in programmes of physical exercise in coronary rehabilitation and, to some extent, an increase in interest among doctors in educating patients about the implications of coronary heart disease for their daily lives. At the same time, increasing attention has been paid to the personal and social aspects of recovery after myocardial infarction, especially to the sufferers' psychological state and their work experience. But there is little evidence to show whether or not different methods of rehabilitation are effective in improving these broad personal and social aspects of recovery.

Aims and Methods of the Study

The present study was established to examine patients' needs for and use of rehabilitation and aftercare services after myocardial infarction. We have data about a consecutive series of 52 infarct patients, aged 59 or less, treated at the Kent and Canterbury Hospital. The main source of data was a series of five interviews held with each respondent at specified times during the year after the infarct. Examination of various medical and social characteristics suggested that the respondents were likely to be similar to other series of British hospital-treated infarct patients of the same age.

Findings

The main findings of the study were as follows.

(i) Work and income. One fifth of the series experienced unemployment associated with their illness. On average the present series of patients returned to work later than is considered desirable, although an acceptable proportion eventually returned. Two-thirds of the series reported they experienced problems with their work; they were concerned especially about their physical capacity to do their jobs. Half the series reported problems because of the effect of their illness on their income, at some time during the year after their infarct. This is a set of problems that is more varied and more frequent than is sometimes thought to occur after myocardial infarction.

(ii) Life at home. Nearly all the respondents reported restrictions in their domestic activities and recreation in the months after the acute infarct. Some restriction continued for much of the subsequent year. These difficulties have not previously been studied closely among infarct patients.

(iii) The level and nature of incapacity. The respondents were moderately incapacitated during the first weeks after their infarct. Most respondents experienced a small amount of incapacity for the whole of the year after their

infarct; the illness has more varied and longer-lasting effects than has sometimes been thought. The present study is the first to have made systematic comparisons of the effect of myocardial infarction on different aspects of the sufferers' daily lives. Work was the aspect most frequently and most significantly affected by the illness. Recreation, sexual activity and sleep were other aspects of the respondents' daily lives frequently and significantly affected by the illness, and many people also said that the illness caused them worry and physical discomfort.

(iv) Use of and needs for services. The main services received were routine medical care from hospital and general practitioners. Few respondents received much rehabilitation. A quarter of the respondents said they needed extra help in returning to work, but few said they needed any help from other rehabilitation services.

(v) Advice and information. Nearly all the respondents said they received advice from medical sources about exercise, rest, sex and, where appropriate, smoking; most said it was useful advice. No studies have previously examined infarct patients' needs for information and advice. Nearly all the respondents said they wanted more information or advice; about exercise, rest, sex, the nature of their illness, their treatment or recovery, or the effects of their illness on their work or life at home.

Conclusions and Recommendations

(i) The research conclusions. The personal and social after-effects of myocardial infarction are more widespread and persistent than has frequently been thought. This implies that coronary rehabilitation services should have the objectives of restoring patients to as full a state of health and well-being as possible, and returning them to as full a range of daily activities as possible. Physical rehabilitation is unlikely to achieve these objectives by itself, and should be part of a comprehensive programme of rehabilitation. Within the programme of comprehensive rehabilitation, more emphasis should be placed on the patients' own experience and knowledge of their illness, and on their performance of daily activities at work and at home.

(ii) Recommendations for the development of rehabilitation and aftercare services.

(a) Specific problems.

Work. There were a number of work-related problems - unemployment, delayed return, difficulties at work, - that could be solved more effectively, perhaps by therapeutic measures in medical rehabilitation to make the patients

more fit, or by routine vocational resettlement to help adjust patients' jobs or find them new ones.

Activities at home. Rehabilitation staff should pay more attention to patients' activities at home after discharge from hospital, in order to raise the level and improve the timing of recovery.

Information and advice. Health service staff should provide patients with more information and advice about the illness and its effects, both because patients desire this and because it might help improve other aspects of recovery.

Emotional distress. In order to relieve the high levels of emotional distress experienced by coronary patients, it may be most appropriate for health service staff to help the patients understand their illness better and orientate them more towards recovery and the resumption of daily activities.

(b) General implications for coronary rehabilitation.

Objectives. The objectives of coronary rehabilitation are often seen in terms of the restoration of physical fitness or functional capacity. Doctors and other rehabilitation staff should see the overall rehabilitation objectives in terms of patients' daily lives and circumstances.

Individualised services. The variety of problems and needs experienced by coronary patients means that rehabilitation and after-care should not simply be a standard programme of treatment in hospital or immediately afterwards. Instead rehabilitation should be based on assessments of the particular needs of individual patients, wherever they arise.

The doctor's role. Cardiologists and other physicians should be more deeply involved in the personal and social aspects of coronary rehabilitation. They could help patients understand their illness and its effects better, attempt to overcome more of the distress felt by patients, identify and take early action on possible employment problems, and encourage patients to undertake more activity at home during their recovery. This would mean that the specialist would be taking a broader view of recovery and rehabilitation than previously. It would involve him in new relationships with staff and agencies both inside and outside hospital, particularly general practitioners, social workers and employment staff.

(iii) Further research. Research is needed in four main areas: the nature and causes of particular problems experienced by coronary patients; the criteria different people use to assess the existence of needs for rehabilitation; the way in which rehabilitation and after-care services work

at present; and the effects and effectiveness of different methods of coronary rehabilitation in changing the personal and social aspects of patients' recovery.

CHAPTER 1 INTRODUCTION

1. MYOCARDIAL INFARCTION

Myocardial infarction is an acute episode of a serious illness that may result in physical disability and many personal and social problems for the sufferers. The main purpose of rehabilitation services for people with myocardial infarction is to eliminate this disability and to solve these problems. Although doctors and health services in Britain are orientated primarily towards the prevention and treatment of disease, they inevitably are concerned also to reduce the suffering and incapacity that results from disease. They contribute to these broad aspects of recovery both by specific medical and paramedical activities and by cooperating with other specialist rehabilitation and resettlement agencies. A major issue, that perennially faces the health service in relation to rehabilitation, is to identify the appropriate contributions of doctors, remedial professions and others involved in rehabilitation to the solution of problems that may contain physiological, psychological, economic and social components.

A myocardial infarction is an interruption of the blood supply to part of the heart muscle, through a blockage of a coronary artery. A variety of factors - including smoking, insufficient exercise, a high level of consumption of dairy products, and stress - may be contributory causes of the disease. Acute myocardial infarction is fatal in a substantial minority of cases. In one community-based study in East London, Pedoe et al (1975) reported a 35 per cent fatality rate among men by 28 days after the onset. In another community-based study, on Teesside, Colling et al (1976) reported a 51 per cent fatality rate by 28 days. The majority of survivors have a relatively uncomplicated course of recovery after the initial attack, but some of them experience complications affecting the electrical activity or haemodynamic performance of the heart, and some suffer a further infarction. Myocardial infarction is more frequent in men than in women, and is primarily a disease of middle-aged and elderly men. According to the Hospital In-patient Enquiry (D.H.S.S., 1977a) there were about 93,000 hospital discharges or deaths of people with acute myocardial infarction in England and Wales in 1973. Of these, about 43,000 were people aged less than 65 and were discharged alive - the group on whom rehabilitation has tended to focus.

There have been two developments in the hospital treatment of myocardial infarction, in recent years, that have had substantial implications for the subsequent rehabilitation of patients. The first has been the abandonment of prolonged rest as the standard form of treatment. Forty years ago medical textbooks advocated strict bed rest for six weeks after myocardial infarction and recommended that patients should avoid unnecessary exertion thereafter.

During the 1940s Levine (1944, 1951) came to question the value of bed rest in coronary heart disease and to point to the possible dangers. Since then, the amount of rest prescribed has fallen dramatically, and has been replaced by early mobilisation and active convalescence.

The second development has been the growth of cardiology as a distinct specialty during the last twenty years, and the associated growth of coronary care units. This has resulted in an increase in the expertise and resources devoted to the hospital-based diagnosis and treatment of acute myocardial infarction. This in turn may have produced a rise in the proportion of cases receiving hospital, as opposed to home, treatment, and a rise in the proportion of survivors. Both of these factors might increase the number of patients for whom hospital rehabilitation might be appropriate. A further consequence has been the development of specialist interest in myocardial infarction which was then extendable to rehabilitation.

2. LITERATURE REVIEW

The purpose of this literature review is to bring together in a single place what has been written about the personal and social aspects of recovery and rehabilitation after myocardial infarction. The Joint Working Party of the Royal College of Physicians and the British Cardiac Society (1975) and Doehrman (1977) have recently reviewed parts of this subject. The value of the present review lies in the attempt to relate what is known about different rehabilitation methods to different aspects of recovery. For the reader who prefers to go straight to the individual aspects of recovery and rehabilitation, some of the material from the literature is recapitulated in the later chapters of this report.

(a) Coronary Rehabilitation

(i) Definitions of Rehabilitation General notions of what constitutes rehabilitation in relation to coronary heart disease are vague and ill-defined. The Joint Working Party of the Royal College of Physicians and the British Cardiac Society (1975) quoted the definition of rehabilitation suggested by the World Health Organization Expert Committee on the Rehabilitation of Patients with Cardiovascular Disease in 1964. The W.H.O. committee defined the rehabilitation of coronary patients as "the sum of activity required to ensure them the best possible physical, mental and social conditions so that they may by their own efforts regain as normal as possible a place in the community and lead an active and productive life". Definitions are sometimes implicit rather than explicit; according to Semple (1970), "Rehabilitation of patients after acute

myocardial infarction extends from the first nursing and medical care until they are established in full-time employment or returned to maximum physical and mental activity advisable. Some would include the management of their future way of life and activities." And definitions are sometimes very wide-ranging, as in the statement of Groden et al (1971a), "The whole process to complete recovery, known by the rather unattractive term 'rehabilitation', is much more comprehensive than (diagnosis and drug therapy)."

A similar breadth of approach to the concept of rehabilitation is present when the word is used in relation to other kinds of disease and disability. According to the World Health Organization (1959), "As applied to disability, (rehabilitation) is the combined and co-ordinated use of medical, social, educational and vocational measures for training or re-training the individual to the highest possible level of functional ability." In the words of the Tunbridge Committee (D.H.S.S., 1972a), "The essential features of any rehabilitation programme are that in addition to restoring the individual patient to the highest level of functional activity, both mental and physical, in the shortest possible time it is necessary to consider the programme in terms of the individual's morale, motivation and relationship to the society in which he lives and to which he will return." According to Goble and Nichols (1971), "Rehabilitation in its widest sense signifies the whole process of restoring the disabled person to a condition in which he is able to resume an active life."

The main theme in these definitions is that rehabilitation is a service or form of treatment designed to restore patients to activity. This activity may be perceived or modified in various ways. Rehabilitation goals may be articulated in terms of previous levels of activity, maximum or optimum levels of activity, or normal activity. Emphasis may be placed on the capacity to undertake activities, on functional capacity in the abstract, or on the actual performance of different activities. Also the activities may be ranged along a spectrum from the physiological, through the individual, to the social. At the physiological end of the spectrum, one might be interested in restoring, for example, the functional capacity of the heart to pump blood around the body, or the range of movement in an arthritic hip. At the individual point on the spectrum one might be concerned to restore, for example, the ability of the individual to climb stairs. At the social end of the spectrum one might attempt to restore the individual's ability to climb particular flights of stairs (leading perhaps to his flat), or to return the individual to his job or to a particular kind of job. The characteristics of the physiological and individual range of the spectrum are that these are more or less physical activities, that are isolated from everyday social values and meanings, and may be capable of being observed in test conditions. It is at this end of the spectrum that the

medical contribution to rehabilitation is strongest. The characteristic of the social end of the spectrum is that these activities are undertaken in particular ways by specific individuals, not simply because of the individual's physiological capacity and biological drives, but because of a wide range of psychological and social influences. In this case, the restoration of physiological or functional capacity by doctors or paramedical staff may be a necessary but not a sufficient condition for the resumption of social activities. Furthermore the patient's feelings about or reaction to, the social activities at which rehabilitation is aiming may create an actual barrier to the restoration of functional capacity. In such circumstances, the contribution of doctors and paramedical staff to rehabilitation is not complete in itself, but has to be related to the contributions of other agencies. But, whether the medical contribution stands alone or is part of a larger whole, the essential starting point of medical rehabilitation is that it is an attempt to change the functioning of a particular body-system or of the individual as a whole, in order to raise his level of activity.

Around the central core of medical rehabilitation there are a variety of other treatments or services that may be quite closely related in different ways. The whole range of medical treatments to cure disease and relieve suffering may well have the effect of restoring patients to their previous levels of activity, without being designed primarily to do so. Conversely, some treatments that are designed at least in part to restore functional capacity may not conventionally be called "rehabilitation", arthroplasty of the hip in cases of osteoarthritis is an example. A third kind of service, the provision of aids or equipment, as aids to mobility or activities of daily living, are perhaps on the borderline of rehabilitation; they do not change the individual's physiological status but they do change his ability to undertake different social tasks. A fourth kind of service, of direct benefit to the individual, may or may not further rehabilitation aims; social work intervention to relieve distress after myocardial infarction may be seen as an end in itself or as an attempt to eliminate psychological barriers to the resumption of full activity; social security sickness benefits may make it easier for individuals to seek medical care that will return them to full health and capacity, or they may provide a disincentive to individuals to return to work. A fifth kind of service, which includes manipulation of the individual's environment by, for example, rehousing or social work intervention with the family, may or may not have direct implications for the level of activity that is achieved by the patient. In this context, rehabilitation is one service among many that range from the acute treatment of disease, through rehabilitation and resettlement, to care and aftercare. In each of these there may be a difference of emphasis and objectives that complicates relationships with the rehabilitation process.

(ii) Comprehensive Rehabilitation In accordance with this broad conception of the rehabilitation process, there have been a number of attempts to develop and describe comprehensive rehabilitation programmes. Much of the professional literature in this area consists of discussion or review papers. These papers contain a sometimes inextricable mixture of what does happen, of what is considered good professional practice, and of what the author thinks should happen. Much of the discussion literature on coronary rehabilitation is American, but a little is British. One theme in this literature is the growing specificity of the diseases which successive authors discuss; the trend is from cardiovascular disease, through cardiac and coronary disease, to myocardial infarction. Another theme is the variation through time in the specificity and the breadth of the rehabilitation programmes that are discussed.

One of the major features of the foreign - primarily American - professional literature of the last 25 years has been the persistence of the theme of comprehensive rehabilitation. Newman et al (1952) outlined a programme of physical medicine and rehabilitation in acute myocardial infarction. They included physiotherapy and occupational therapy as aids to mobilisation, advice and education as part of psychological rehabilitation, and vocational advice and guidance. In two papers, Benton and Rusk (1952, 1953) discussed mobilisation in hospital, and physical training and assessment in relation to future employment and housework. In a major paper, Hellerstein and Goldston (1954) emphasized strongly the themes of comprehensive rehabilitation and the team approach, that had been developed in the cardiac rehabilitation programmes at Cleveland, Ohio. They discussed clinical treatment, physical activation, emotional and psychological assessments, education about diet and activity, and vocational rehabilitation. A number of discussions over the next ten years or more in America contained a similar breadth of rehabilitation objectives, but emphasized a more limited range of rehabilitation methods and treatments (Newman et al, 1956; Hellerstein and Ford, 1957; Hellerstein, 1959; Hellerstein and Hornsten, 1966). Other authors reviewed broad rehabilitation programmes - concerned for example with smoking, diet, physical activity, work and family relationships - but without the vigour and specificity of detail of the early Hellerstein (Lee and Bryner, 1957; Lee, 1958; Kahn, 1958). A similar breadth of approach can sometimes be found in later discussions. Seldon (1969), in describing the work of a cardiac rehabilitation unit in Australia, highlighted the contributions of doctors, psychiatrists, social workers and occupational therapists in the restoration of patients to activity and work. Naughton et al (1969) and Naughton (1973) also treated rehabilitation broadly, reviewing mobilisation, exercise programmes, counselling, self-care at home, sexual adjustment and return to work. More recently Wenger (1975a, 1976) has

identified two major aspects of coronary rehabilitation: physical activity and patient and family education. All these discussions reveal variability of emphasis between different aspects of rehabilitation programmes, but each is concerned with comprehensive rehabilitation.

Within the overall framework of comprehensive rehabilitation programmes, a number of changing emphases and trends can be detected. In the first place, mobilisation and physical exercise took an increasingly important place in discussions of the overall rehabilitation programme during the 1950s and 1960s. The growing emphasis on exercise and the measurement of cardiac capacity is most apparent in the work of Hellerstein (Hellerstein and Ford, 1957; Hellerstein, 1959; Hellerstein and Hornsten, 1966), but can be seen elsewhere, (Newman et al, 1956; Weeda, 1971). During the late 1960s and early 1970s there was an emphasis, in a number of discussions, on exercise and vocational rehabilitation as equal components of the whole (World Health Organization, 1969a; Naughton et al, 1969; Harris, 1970; Morgan, 1973; Goldberg, 1973). A particular interest in psychological aspects of rehabilitation developed during the late 1960s, although it had been mentioned earlier (Hellerstein and Goldston, 1954; Seldon, 1969; Naughton et al, 1969; Weeda, 1971. Morgan, 1973). During the 1970s, there has been a particular emphasis on counselling, education and advice as part of the rehabilitation process, although, again, there were forerunners (Hellerstein and Goldston, 1954; Jefferson, 1966; Naughton, 1973; Borgman, 1975; Wenger 1975a, 1976).

Recent British discussions of comprehensive cardiac rehabilitation can be set against this background. Semple (1970) emphasised physical exercise as the major part of the rehabilitation programme, but also developed the argument that doctors, with the increased knowledge about the safety of exercise, should communicate more effectively with patients to reduce anxiety and invalidism. Groden et al (1971a) discussed rehabilitation in terms of mobilisation and convalescence, vocational rehabilitation and secondary prevention, but not in terms of exercise programmes. The Joint Working Party of the Royal College of Physicians and the British Cardiac Society (1975) emphasized exercise and exercise testing, and vocational rehabilitation. They paid some attention to psychological factors and to education and advice, as subsidiary features. In editorials after the Joint Working Party report, The Lancet (1975) and the British Medical Journal (1975) both endorsed the report's cautious support for exercise programmes. The B.M.J. also criticized the report's failure to consider what advice doctors should give to patients about driving and sexual activity after myocardial infarction. Groden et al (1971b) commented that British cardiologists had been less active than their foreign colleagues in exploring the field of cardiac rehabilitation. The thinking of the Joint

Working Party reflects a great deal of earlier American exploration. British discussions of comprehensive rehabilitation do not contain the breadth of approach of some American ones.

There has not been a great deal of empirical research examining comprehensive cardiac rehabilitation programmes. A number of studies describe the different components of the rehabilitation programme and the characteristics of the patients at the start and the end of the programme. Torkelson (1964) described a programme, consisting of exercise, physiotherapy, occupational therapy and art therapy in mobilisation, and observed several clinical and functional parameters in a small number of patients. Askansas et al (1973) examined a comprehensive psychic, somatic, occupational and social rehabilitation programme in three Polish sanatoria, and made subjective clinical and functional assessments of the patients' subsequent condition. Stijns et al (1975) described a not very extensive programme of mobilisation, exercise and convalescence, and observed various aspects of patients' return to work. Naso(1975) described a programme of mobilisation in activities of daily living and occupational therapy and physiotherapy, and assessed outcome in terms of timing of progress through the programme and of complications. Monzigo and Medina (1976) described an exercise and advice programme, and assessed the patients in relation to exercise tolerance and cardiovascular function. In none of these studies were there any controls. Although the patients in each study tended to show improvement in their condition and otherwise satisfactory levels of outcome, it is impossible to say how far these improvements were due to the rehabilitation programmes, or how far they were due to a natural process of recovery that would have occurred anyhow.

There have been very few studies that have examined rehabilitation programmes consisting of several methods of treatment, and that have used controls to facilitate evaluation of the programme. Singh et al (1970), in a study of Indian armed forces personnel, showed that a higher proportion of those rehabilitated by a comprehensive programme than of those rehabilitated by advice only returned to high grades of fitness for duty. Kavanagh et al (1970) compared the effects of exercise and hypnotherapy on a small number of patients, but were unable to attribute improvements to the effects of the therapy. Thockloth et al (1973) undertook a randomised control trial of rehabilitation after acute myocardial infarction. The treatment group of patients received regular assessment and treatment from an occupational therapist, a social worker, an employment adviser and the rehabilitation physician. The control group received social work or occupational therapy only if their physicians referred them. Thockloth et al found that the treatment group returned to work at the same time, on average, as the control group (12 to 13 weeks), but

that they were much more closely bunched in the timing. They also found that patients in the treatment group subjectively felt better than did those in the control group. These studies suggest that there are benefits to be gained from a comprehensive rehabilitation programme, but do not tell us a great deal about how much benefit might be expected from a comprehensive programme, as opposed to a single programme of advice or exercise.

(iii) Programmes of Physical Exercise The most prominent development in rehabilitation after myocardial infarction in recent years has been the introduction of programmes of physical exercise. These developed out of progressively organised programmes of mobilisation and activities of daily living, such as those described by Newman et al (1956) and Cain et al (1961). The major impetus to narrow the focus on to exercise was the development of techniques of measuring cardiac capacity and reserve (Hellerstein and Ford, 1957). The initial development of exercise programmes appears to have been undertaken by Hellerstein and his colleagues at Cleveland, Ohio, in the early 1960s (Hellerstein and Hornsten, 1966). The main idea of restoring patients' physical fitness and physical work capacity was widely accepted quite rapidly, and in 1968 the World Health Organization outlined suitable exercise programmes for patients with myocardial infarction. During the late 1960s and early 1970s, a large number of papers discussing and advocating exercise programmes were published, mainly in North American medical journals (Brunner, 1968; Tobis, 1969; Wenger, 1969; Wenger et al, 1970; Enselberg, 1970; Cohen and Grant, 1971; Kavanagh and Shephard, 1973; Wenger, 1973). Groden et al (1971b) reported that very few hospitals in Britain at that time possessed exercise programmes for myocardial infarction patients. There have been some developments since then (Carson et al, 1973), and the report of the Joint Working Party (1975) has stimulated the introduction of others.

At the same time, there was an enormous growth in the number of published American papers reporting empirical research into the effects of exercise programmes. The exercise programmes studied ranged from those concerned with mobilisation in a coronary care unit, through those aiming to reactivate patients and restore them to physical fitness during the weeks or first few months after the initial infarction, to those concerned with long-term maintenance of function and secondary prevention for months or years after the initial infarction. The studies varied in the definition of the patients included in the research: some including only those with myocardial infarction and some including coronary heart disease more broadly; some taking general hospital series of patients and some taking those referred for rehabilitation. A variety of parameters of recovery have been studied, including the physiological, the clinical, the functional, the psychological and the socio-economic. The

number of subjects included in studies has ranged between four, in one pioneering effort, and 300 or more. There has been no standard practice concerning the inclusion or adequacy of controls.

The general conclusion of these studies has been that patients, who undertake a programme of physical exercise after myocardial infarction, experience improvement in several different aspects of their recovery. According to the Joint Working Party (1975) " ..... it is believed that the benefits of (physical conditioning) for cardiac patients depend largely on the effects on the peripheral circulation and muscles rather than on the heart itself." Some studies have found that patients who have undertaken exercise programmes after myocardial infarction experience improvement in various aspects of cardiac function at specified levels of physical activity (Rechnitzer et al, 1965; Kellerman et al, 1967; Hellerstein, 1968, 1973; Clausen et al, 1969; Sanne, 1973). It has been claimed (Hellerstein et al, 1967; Hellerstein, 1968) that electrocardiographic abnormalities improve in the course of an exercise programme, but Barry et al (1966) reported no overall changes. A number of authors have reported improvement in clinical features, particularly angina, during exercise programmes after myocardial infarction (Heller, 1967, 1969b; Clausen et al, 1969; Rigner and Wilhelmsson, 1970), and others have reported no increase in complications among those undertaking exercise (DeBusk et al, 1971; Carson et al, 1973). The main thrust of the research has shown increases in exercise tolerance, physical fitness and physical work performance among those who have completed exercise programmes (Rechnitzer et al, 1965; Naughton et al, 1966; Heller, 1967, 1968, 1969a, 1969b; Kellerman et al, 1967; Clausen et al, 1969; Rigner and Wilhelmsson, 1970; Bjorntop et al, 1972; Kellerman, 1973). One study by Kavanagh et al (1973) found that around half the patients in the programme did not benefit from it in terms of increased physical fitness. Various authors have found that patients, who have undertaken a programme of physical exercise after myocardial infarction, achieve satisfactory levels of return to work (Naughton et al, 1966; Kellerman et al, 1967; Kellerman, 1973; Tobis and Zohman, 1968; Jackson, 1973; Carson et al, 1973). And various authors have shown that these patients also experience improvements in mood, well-being and confidence (Hellerstein et al, 1967; Heller, 1969b; Rigner and Wilhelmsson, 1970; Carson et al, 1973; Sanne, 1973).

The evidence available from studies using controls shows that many of these improvements in the condition of patients are associated with or caused by the physical exercise programmes. Naughton et al (1968) and Ressl et al (1975) found improvements in cardiovascular function among fairly small numbers of post-coronary patients who undertook exercise programmes, but no

such improvements among groups who did not. Two studies have found reductions in complications and angina associated with exercise programmes (Heller, 1969a; Brunner and Meshulam, 1969). One has reported that exercise is associated with a reduction in the number of subsequent infarcts (Brunner and Meshulam, 1969), and one with a reduction in mortality (Gottheiner, 1968). Several studies have reported increases in fitness and physical work capacity associated with exercise programmes (Rechnitzer et al, 1967; Grant and Cohen, 1973; Kellerman, 1973; Kirchheiner and Pedersen-Bjergaard, 1973; Ressl et al, 1975). There have been no studies that demonstrate the effect of programmes of physical exercise on patients' ability to return to work. One study (McPherson et al, 1967) has found an exercise programme to be associated with improvements in patients' psychological status, but other studies (Rechnitzer et al, 1967; Naughton et al, 1968) have not found a statistically significant association.

In summary, there is good evidence that programmes of physical exercise increase the degree of physical fitness achieved by patients after myocardial infarction. But, in the words of the Joint Working Party (1975), "..... the information that has emerged neither strongly supports nor denies a beneficial effect on morbidity and mortality." Nor is there much evidence one way or the other about the effect on patients' psychological status or socioeconomic functioning. The Joint Working Party cautiously concluded that "..... even although proof is lacking, we feel that there are adequate grounds, based on physiological and collateral evidence, for advising physical conditioning." The evidence reviewed here suggests that such conditioning would improve physical fitness but would be unlikely to solve all the personal and social problems experienced by patients after myocardial infarction.

(iv) Early Mobilisation and Discharge Associated with the change from rest to exercise in the treatment of myocardial infarction has been an increase in the popularity of early mobilisation and discharge from hospital. British doctors have taken more of a lead in exploring this area. Data from the Hospital In-patient Enquiry show that the average length of stay in hospitals in England and Wales for patients under 65 with acute myocardial infarction fell from 23 days in 1968 to 15 days in 1973 (D.H.S.S., 1972b, 1977a). The following table reveals something of the variations in clinical policies between different centres at different times. The table shows the number of days after admission, at which discharge was planned, in studies of early and late mobilisation and discharge.

Author	Discharge: Days after Admission	
	Early	Late
Groden et al (1967)	22	36
Harpur et al (1971)	15	28
Medical Division, Royal Infirmary, Glasgow (1973)	21	28
Hayes et al (1974)	9	16

The speed of change in outlook a few years ago may be illustrated by two editorials from The Lancet. In the first (1969) three weeks bed rest was regarded as the optimum; in the second (1971a) the likelihood of increasingly widespread acceptance of periods as short as eight days in bed and of discharge at 15 days was noted. The current belief is that a total length of stay in hospital of just over one week is safe for patients with uncomplicated myocardial infarction and may be all that is needed for them.

The empirical research has consistently shown that early mobilisation and discharge after myocardial infarction is as safe as more extended hospital care. In an early study without controls, Brummer et al (1956) in Finland examined mortality, complications and recurrences and concluded that there were no immediate hazards to patients mobilised after 16 days in bed. Subsequent British studies without controls, but with shorter periods of bed rest and hospitalisation, have examined similar parameters and have also concluded that early discharge is not harmful (Royston, 1972; Boyle et al, 1972; Tucker et al, 1973). Furthermore, a number of foreign studies (Brummer et al, 1966; Takkunen et al, 1970; Lamers et al, 1973) and British ones (Groden et al, 1967; Harpur et al, 1971; Medical Division, Royal Infirmary, Glasgow, 1973; Hayes et al, 1974) have examined mortality, complications, recurrence and return to work in controlled studies of early and late mobilisation, and have found no significant differences between patients mobilised early and those mobilised late. One study (Groden and Brown, 1970, 1971) found a lower level of neuroticism at the time of discharge among those mobilised early than among those mobilised late, but also found that this difference had disappeared one year later.

This evidence has shown that early mobilisation and discharge is safe. Other pressures, such as the risks of bed rest and the demand for hospital beds, have reduced the length of stay in hospital after myocardial infarction. The longer-term implication for the rehabilitation of these patients is that reconditioning should be aimed less now than formerly at overcoming the debilitating effects of prolonged inactivity and the psychological consequences of extended dependency.

To what extent this change reduces all needs for rehabilitation has not been examined in the literature.

(v) Vocational Rehabilitation Although achieving satisfactory levels of return to work after myocardial infarction is one of the major goals of coronary rehabilitation, there is relatively little discussion of or research into vocational rehabilitation in the literature.

The particular problems of vocational rehabilitation for heart patients have received more attention in the United States than elsewhere, largely at the initiative of the American Heart Association. The A.H.A. sponsored the development of Cardiac Work Evaluation Units in the 1940s and 1950s. About 50 such units were in existence by the late 1960s. Much of the professional literature analysed their functions (assessment, physical retraining, placement) and discussed their advantages (Jezer and Hochhauser, 1954; Clark and Altman, 1960; Pinner and Altman, 1966; Whitehouse, 1966; Jezer, 1966). Originally these Units were largely concerned with chronic heart disease, but by the late 1960s the changing pattern of heart disease and the increase in the incidence of myocardial infarction was causing uncertainty about the future of the Units (Hellmuth, 1969). In addition to discussion of Cardiac Work Evaluation Units, there has been some literature stressing the importance of occupational health nurses and rehabilitation counsellors in the rehabilitation of cardiac patients (Bissonnette, 1966; Nichols, 1966).

In Britain, the Joint Working Party (1975) reviewed the provision of vocational rehabilitation. They said that return to work was an important milestone in recovery and emphasised the need to avoid unduly prolonged invalidism. They continued: "Despite the size of the problem and the need for improvement, it seems that our national return to work record is no worse, and often better, than that of the other countries. This might suggest that the more laissez-faire attitude of British physicians is not wholly detrimental." They made a variety of suggestions about doctors encouraging positive attitudes towards work, about the early identification of problems, about the need for instituting rehabilitation and cooperation, and about the importance of reviewing continued sickness absence. Although the Joint Working Party did not emphasize this area particularly strongly, it is in the performance of these tasks that consultants and general practitioners make their major contributions to the vocational rehabilitation of most patients with myocardial infarction. The Joint Working Party then reviewed the facilities available in Britain for late rehabilitation: work assessment teams, disablement resettlement officers, the Employment Medical Advisory Services, industrial rehabilitation units, the disabled persons' register, and the occupational medical services. They expressed no strong views about the value of these services and did not advocate particularly strongly their development in one way or another.

A small amount of empirical research has examined some aspects of vocational rehabilitation of cardiac patients in different countries. The studies have simply described the patients in different kinds of rehabilitation units and what has happened to the patients subsequently. They include studies of an industrial rehabilitation unit in England (Wilkinson and Mattingly, 1973), of separate cardiac rehabilitation units in Australia and the United States (Seldon, 1963; Seldon et al, 1966; Aldes et al, 1968), and of hospital rehabilitation clinics in the United States and Scotland (Tobis and Zohman, 1970; Groden and Cheyne, 1972). Because these studies included no data on untreated patients, it is impossible to assess the value of the vocational rehabilitation. The only general conclusions that might possibly be drawn from these studies is that if the rehabilitation unit deliberately seeks out problem cases, very few patients return to work (Aldes et al); if it is a separate rehabilitation unit accepting referrals from elsewhere, almost two-thirds of the patients return to work (Seldon); if it is a hospital-based clinic, over two-thirds of the patients return to work (Groden and Cheyne).

A second group of research studies about vocational rehabilitation have examined employers' policies towards cardiac cases. Several American surveys, mainly in the 1950s, found that employers generally retained existing employees who developed cardiac disease, but were reluctant to hire new employees with existing cardiac disease (Kline, 1954; Olshansky et al, 1955; Lee et al 1957; Reeder, 1965). The two main kinds of reasons for their reluctance, given by employers, were, on the one hand, their lack of suitable jobs and their need for physically versatile employees, and, on the other hand, the importance of minimising the possible costs to the company of workmen's compensation and of company financed benefits. There appears to have been no comparable research in Britain.

(vi) Psycho-social Aspects of Rehabilitation An increasing amount of attention has been paid in recent years to psycho-social aspects of rehabilitation after myocardial infarction. A considerable number of people have emphasized the importance of counselling, educating and advising coronary patients and their families. The professional discussions of these aspects of rehabilitation often treat them as parts of a single spectrum, but the research literature handles them more distinctly.

Most of the professional discussions advocate better and more effective communication with patients. They cover a wide range of things to do with the illness and its effects. They exhort health service staff to advise or educate patients about the causes and nature of the illness, about their work and their pattern of daily living, about anxiety, and about exercise, diet, smoking, sex, alcohol and travel (de la Chapelle and Connor, 1964; Sibley, 1965; Parsons, 1974; Cohen et al, 1976). Other discussions emphasize not so much the contents of the

advice, but the staff who provide the therapy or rehabilitation. Some emphasize the doctors' contribution (Harrison and Reeves, 1965; Parsons, 1974), some the nurses' (Morgan, 1976; Stockwell and Tada, 1976), and some the social workers' (Jefferson, 1966). Other discussions emphasize the method, whether this is based on hypnotherapy(Nuland, 1968) the honesty of discussion (Harrison and Reeves, 1965) or explicit educational principles (Wenger, 1975b).

The empirical research has been somewhat less varied than this. Three exploratory studies, in which patients were interviewed while in hospital and at home afterwards, concluded that there was a need for a programme of education and advice about a variety of aspects of the illness and the patient's life (Toone, 1972; Mullen, 1973; Mayou et al, 1976a). Two social work projects and one group psychotherapy project were designed (implicitly) as action research, in which a therapeutic service was delivered and the contents of sessions were noted (McGrath and Robinson, 1973; Clarke, 1974; Adsett and Bruhn, 1968). In these studies the main emphasis was on the relief of anxiety. In another set of studies controls were used in order to evaluate the therapy or advice. Rahe et al (1975) found that patients treated in group therapy sessions had less complications, and knew slightly more about the nature of coronary heart disease and psychological factors in it, than did patients who were not so treated. In a small-scale British study, Shaw and McNiven (1974) found that a higher proportion of patients, who received frequent follow-up visits and advice, than of controls returned to work by three months and stopped smoking cigarettes. In another small-scale study, Woodwark and Gauthier (1972) reported that a programme of education by the nurse and family physician increased patients' knowledge of the illness and compliance with treatment, and lowered their post-coronary disability. In a larger-scale study, Burt et al (1974) found that a much higher proportion of patients given intensive advice about smoking, than those given conventional advice, stopped smoking after their myocardial infarct. These studies suggest that programmes of education and advice may be effective in changing quite a wide range of behaviour and events after myocardial infarction. They do not indicate how much benefit might be expected, or whether advice should complement or replace exercise as a form of rehabilitation.

(vii) Discussion During the last 25 years there have been many impulses to the development of coronary rehabilitation. These impulses have occurred in different places at different times, and have not been part of a planned strategic development. They have led to different kinds of rehabilitation service, whose relationships to each other have rarely been examined. No single pattern of coronary rehabilitation has been authoritatively established. New forms of treatment, aimed at solving sifferent aspects of patients' problems continue to be developed and discussed.

On the whole, there is very little evidence that shows that the different kinds of rehabilitation are effective in solving patients' problems. The best evidence relates to programmes of physical exercise. Exercise has been shown to be associated with improvements in patients' cardiovascular function, clinical condition and physical fitness. It is believed to be associated with improvements in patients' mood and with satisfactory work performance, but this has not been adequately demonstrated. Programmes of education and advice appear to affect patients' knowledge and everyday activities, but this has been demonstrated adequately only in relation to smoking. Comprehensive rehabilitation programmes may affect a variety of aspects of patients' recovery, but so little research has been done that it is impossible to be certain. Programmes of vocational rehabilitation and of psychological or social therapy, have not been evaluated adaquately at all.

On the basis of this evidence, it is impossible to be certain that any of these forms of rehabilitation would improve infarct patients' performance of their everyday activities or solve their personal and social problems. It is with these activities and problems that we are most concerned in this study. With the exception of physical incapacity, the identification of particular difficulties or problems should not lead to automatic recommendations for the development of particular rehabilitation services. Not enough is known about the effectiveness of rehabilitation to allow us to specify needs for rehabilitation with certainty.

(b) Recovery after Myocardial Infarction

(i) Concepts of Recovery In these research and discussion papers about rehabilitation, a great deal has been said about those aspects of the patient's recovery to which rehabilitation relates. Notions of, and data about, recovery are handled in many different ways. Authors may be more or less explicit in the way they view recovery, and in the extent to which they identify the promotion of particular aspects of recovery as the actual or proper goals of rehabilitation services. Some authors have emphasized the need to take a holistic view of chronic disabling illness (Feldman, 1974) - that is, to pay attention to "the whole man". Groden et al (1971a) discussed "the whole process of recovery". The attempt to handle recovery in such broad terms leads, however, to difficulties. It may lead to vagueness, or to the selection of a single easily measured indicator of recovery such as timing of return to work, that unduly narrows the focus of attention. In a major review article ten years ago, Croog et al (1968) discussed various medical, psychological, social and professional influences on recovery, but tended to treat recovery itself as a single undifferentiated process. In a recent review, Doehrman (1977) has distinguished more clearly between psychological, social and vocational aspects of recovery. Hellerstein and Goldston (1954) identified the physical, mental, social, vocational and economic

usefulness of cardiac patients as aspects of their recovery that are important in rehabilitation. Stated in these terms, it is obvious that recovery can be seen as a multifaceted process. It is possible to study either several aspects of recovery simultaneously, or individual aspects singly.

(ii) Physical Capacity The primary purpose of medical rehabilitation, and particularly of exercise programmes, after myocardial infarction is the restoration of patients' physical capacity. At one level, attention has been focussed on the effects of exercise on the heart itself (Hellerstein, 1968; Merriman, 1970). Exercise programmes for cardiac patients are believed to increase the patients' maximum oxygen intake and improve their exercise tolerance, with lesser increases in heart rate, respiratory rate and systolic blood pressure (Joint Working Party, 1975). These are aspects of recovery of great significance to cardiologists. Cardiac impairment and performance are not the only contributors to physical fitness. Research has examined the effects of exercise programmes on broader aspects of physical functioning. In the words of the Joint Working Party, "The main emphasis in these investigations has been placed on training the oxygen transport system, and it is believed that the benefits of such training for cardiac patients depend largely on the effects on the peripheral circulation and muscles rather than on the heart itself .....". The restoration of physiological performance and physical capacity is the end towards which much medical rehabilitation is devoted. This may be a major factor influencing personal, social and vocational aspects of recovery. On the other hand, many patients may return to work, for example, without having achieved complete physical fitness. Similarly, restoration of physical fitness is not a sufficient condition to ensure that patients return to work. It is necessary, therefore, to examine each aspect of recovery separately, to weigh their importance and to consider their interrelationships.

(iii) Return to Work Patients' return to work after myocardial infarction is often felt to be the most important aspect of their recovery; it is certainly the most studied. The Joint Working Party (1975) expressed the view that, "For many patients after myocardial infarction, successful return to work will be the crowning achievement, signifying restoration to independence and integration in the life of the community. With few exceptions the doctor should present this concept from the start of the illness as the prime target." There have been substantial changes in emphasis and achievement during the last 40 years. In the 1930s, "..... it was generally believed that the great majority of persons who had coronary heart disease with myocardial infarction were no longer able to work and could expect a drastic curtailment of their activities." (Crain et al, 1950). Much of the professional and research literature of 30 to 40 years ago was concerned to establish that coronary heart disease did not necessarily lead to permanent disability among survivors (White, 1939; Master and Dack, 1940;

Master et al, 1954). As data have accumulated it has become widely expected that the large majority of survivors achieve a substantial degree of recovery. The report of the Joint Working Party (1975), for example, reviews a series of British studies that show that 80 per cent of survivors of myocardial infarction eventually return to work without special rehabilitation measures. The report then identifies delay in return to work as the problem to be overcome: "These studies show that the proportion returning to work by three months is variable, but commonly this is only 50 to 60 per cent and it appears that there is a considerable amount of unnecessary and unduly prolonged invalidism following infarction." The change has been from acceptance of high levels of permanent disability, through attempts to reduce the level of permanent disability, to concern to reduce the length of time of sickness absence from work.

Details of the proportion of patients returning to work after myocardial infarction, and the proportions returning by different times after the acute episode, have been reported in numerous studies. Vuopala (1972) reviewed quite a lot of the earlier literature. In 14 studies, with publication dates between 1930 and 1959, from which he extracted data, the proportion of survivors who had returned to work by various follow-up times ranged between 50 and 90 per cent. In nine studies, with publication dates in the 1960s, the proportion of survivors who had returned to work by various follow-up times was grouped much more consistently between 80 and 90 per cent. In a review of 11 more recent studies, with publication dates between 1967 and 1973, Doehrman (1977) concluded that 85% of patients, who survived a myocardial infarction and who had been previously employed, returned to work by one year. As noted, the Joint Working Party (1975) said that British studies showed 80 per cent of survivors returned to work eventually, without special help. The following table shows the proportions of patients reported in different studies to have returned to work by the specified follow-up dates. These figures are based on the total number of patients, who were employed before admission to hospital, and who were discharged live (or survived to follow up). The first part of the table includes recent foreign studies not covered by Doehrman's review. The second part includes a longer series of British studies.

Study	% Returned to Work	Follow-up interval
Wigle et al (1971) Ontario	89	c. 2½ yr
Stijns et al (1975) Leuven	59	not stated
Kjoller (1976) Copenhagen	80	average 26 mnth
Wilhelmsson et al (1976) Goteburg	69	not stated
Stern et al (1976) Washington D.C.	83	1 yr
Sharland (1964) London	86	1 yr
Wincott & Caird (1966) Oxford	88	1 yr
Groden (1967) Glasgow	75	1 yr
Harpur et al (1971) Chelmsford	82	7½ mnth
Royston (1972) Barnet	90	6 mnth
Cay et al (1973) Edinburgh	78	1 yr
Shaw & McNiven (1974) Glasgow	79	9 mnth
Kushnir et al (1975b) Hull	73	10 mnth
Finlayson & McEwen (1977) Dundee	72	1 yr

The impression that emerges from this table is that statements of 80 to 90 per cent return to work are a little too optimistic. In Britain, at least, anything between 70 per cent and 90 per cent should be expected.

Good data are also available that show the proportions of patients who have returned to work at different times after their infarct. As a fairly stable total figure has been reached, the attention of the rehabilitation services has turned to minimising the duration of incapacity and avoiding unnecessary delays in return to work. Table 1.1 shows the proportions of patients found, in nine different British studies, to have returned to work by various intervals after their myocardial infarction. These proportions are shown graphically in Figure 1. A very high proportion of Royston's (1972) series returned unusually early to work. The other eight studies may indicate the normal British pattern in the timing of return to work. In Figure 1, the possible boundaries of this pattern have been drawn in. These boundaries indicate the ranges in the proportions of patients we might normally expect to have returned to work at different times after their admission to hospital. These proportions are shown in the following table.

Months after Admission to Hospital	Proportion of Patients Returned to Work	
	Low %	High %
1	0	5
2	10	50
3	35	65
4	50	80
5	60	65
6	65	85
7	70	90

The greatest differences between series occurred when patients first started returning to work at about the second month. From the table we can see that the Joint Working Party's statement that "only 50 to 60 per cent" return by three months is too high; in fact, anything between 40 and 60 per cent seems to be the usual figure. Between three and six months, the differences between the studies gradually narrow. The proportion of patients who had returned to work did not increase substantially in any of the series after seven months.

A number of studies have examined patients' work experience in more detail than the simple fact of returning to work. Doehrman (1977) suggested that "perhaps 20% of all work returners either change jobs or reduce their hours". Some British studies have focussed on the hours worked. Sharland (1964) found

that 20 per cent of all patients were working part-time three months after their infarct, and that this figure fell to nine per cent at six months and two per cent at one year. This picture was confirmed by Royston (1972), who found seven per cent of patients working part-time at six months, and by Wincott and Caird (1966), who found that 18 per cent of patients worked part-time when they first returned. Recently, however, Kushnir et al (1975b) found that 19 per cent of patients were working less than 90 per cent of their pre-morbid hours at both four months and ten months after their infarct. Finlayson and McEwen (1977) found that 36 per cent of patients were working less hours at six months than before their infarct. These figures suggest that it is important to look at the total number of hours worked, rather than simply at full-time or part-time work, to assess the impact of the infarct. It seems likely that the hours of work of between one quarter and one half of patients may be affected by the infarct at some time in the subsequent months.

A certain amount of British data is also available to show changes in employment or in the type of work after myocardial infarction. Some people change jobs after their infarct. Sharland (1964) found that seven per cent of his series were employed in jobs that were not their usual ones three months after their infarct; this figure had risen to 16 per cent by six months and 19 per cent by one year. Finlayson and McEwen (1977) found that five per cent of their series were working at six months in employment different from that which they held before their infarct. Royston (1972) found that three per cent of his series had returned to different work by six months. A certain proportion of these changes is presumably related to the infarct, but there is no way of telling how much, directly from the statistics quoted.

Some indication of the kinds of changes produced by the infarct is given by studies that show alterations in the nature of patients' work. Wincott and Caird (1966) reported that 19 per cent of their series returned to work via light work. Royston (1972) reported that 15 per cent of his series had returned to modified work at six months. Cay et al (1973) reported that 24 per cent of their patients were not fully active on their previous, or a comparable, job at four months, and that five per cent had moved to a less demanding job. Kushnir et al (1975b) reported that 27 per cent of their series were undertaking less than 90 per cent of their previous physical load four months after their infarct and that this figure had risen to 37 per cent by 10 months. These studies suggest a fairly consistent picture of about one-quarter to one-third of patients undertaking reduced levels of activity at work at some time during the year after their infarct.

As Doehrman (1977) noted, there is little empirical information available about the more subjective aspects of patients' experience of work after myocardial

infarction. Two British studies contain data about patients' expectations, about their future work and about their actual difficulties. Cay et al (1972) reported that 30 per cent of their coronary heart disease series would have employment problems facing them on discharge from hospital. Finlayson and McEwen (1977) reported that 35 per cent of their series of myocardial infarction patients in hospital anticipated specific difficulties in relation to employment (concerned with physical inability to manage their work, discontent with their work, or difficulty with their fellow-workers); they also reported that 15 per cent experienced general anxiety about their return to work. These two studies are in broad agreement that about one-third of hospital patients anticipate problems in relation to their work.

Their findings about difficulties actually experienced at work are less easy to compare. Cay et al (1973) reported that seven per cent of patients followed-up at four months had some problems in returning to work or finding a new job, and 28 per cent had serious problems; they also found at one year that six per cent and 28 per cent had some problems and severe problems, respectively. In other words, they found, on each occasion, that about 35 per cent of patients had (or had had) problems. Finlayson and McEwen (1977) followed up patients at six months. They found that 41 per cent of patients experienced difficulties when they first returned to work, and that most were not serious. They also found that a further 13 per cent of patients had continuing but intermittent difficulties, and that five per cent had had difficulties leading to them giving up work. In reporting about 40 per cent of patients to have initial difficulties only and a further 30 per cent of patients to have longer-term difficulties, Finlayson and McEwen found more frequent problems than Cay et al. In neither study, however, was the nature of the difficulties reported in much detail.

(iv) Personal and Social Aspects of Recovery Although patients' work experience after myocardial infarction has been much studied, it is not the only kind of activity that is important. In recent years some attention has been paid to a variety of personal and social consequences of coronary heart disease. These include the impact on recreation, family life, sexual activity and driving. Attention has been paid not simply to the activities involved, but also to the social relationships based upon them. The involvement in these areas stems, perhaps, from concern with the problems of the severely disabled and the old, for whom paid employment may not be a feasible rehabilitation objective (Goble and Nichols, 1971; Office of Population Censuses and Surveys, 1971a and b) and from changes in the perception of the nature of coronary patients' needs.

There has been little professional discussion of these personal and social activities. Master (1961) concentrated on the importance of work rehabilitation,

because of the boredom and dangers of inactivity and excessive leisure. In contrast, Thompson (1966) emphasized the potential of recreational activities in rebuilding the patient's life, and discussed in some detail the kinds of activities that were suitable and the resources available. Williams and White (1961) discussed the implications of cardiac disease not only for work, physical activity and personal adjustment, but also for smoking habits, diet and sexual activity; they stressed the importance of the physician-patient relationship, organised rehabilitation, and education in secondary prevention. A number of authors have discussed problems of sexual activity, both from the physiological and personal points of view. They have usually emphasized the safety of sexual activity after myocardial infarction and the need for better communication between doctors and patients about sex. (Naughton, 1973; Kent, 1975; Green, 1975).

More research data relate to sexual activity than to other aspects of daily living after myocardial infarction. A variety of definitions and measures have been used. Although the broad direction of the findings is clear, there are considerable differences between studies. In some studies (Finlayson and McEwen, 1977), the data are suspect, because of low response rates for the questions about sexual activity. The following table shows the proportion of each series who were sexually inactive before the infarct. It also shows the patients, who were sexually active before the infarct and who returned to full or reduced levels of activity, as proportions of the total patients in each series.

Study and Follow-up Interval	Proportion of Patients Inactive Pre M.I.	Level of Activity Post M.I.		Total
		Reduced	Full/More	
Skelton and Dominian (1973) 12 months	37	26	37	100
Kushnir et al (1975b) 10 months	10	35	55	100
Bloch et al (1975) 11 months	15	62	23	100
Stern et al (1976) 12 months	19	25	56	100

The general conclusions to be drawn from this table are that perhaps one-quarter to one-half of the patients have reduced levels of sexual activity one year after their infarct, and that perhaps one-quarter to one-half have returned to their pre-infarct levels. Stern et al (1976) reported that the vast majority of those who returned to normal did so between six and 12 weeks after their infarct. Kushnir et al (1975b) found that there was no increase in the proportion returning to full activity between four and 10 months. The pattern of recovery seems therefore to be established by four months after the infarct.

In these studies, there is no way of distinguishing between the effects of the infarct and the effects of ageing. Hellerstein and Friedman (1970) attempted to isolate the effects of the illness. They found that in a series of men with arteriosclerotic heart disease the average number of orgasms per week fell from 2.1 one year before the first coronary event to 1.6 one year after it, and that, in a series of coronary-prone controls, the average number of orgasms per week increased from 1.9 to 2.0 after participation in a programme of physical conditioning. They also concluded that over 80 per cent of post-coronary patients can fulfil the physiological demands of sexual activity without symptoms or evidence of significant strain. Although the broad picture of a reduction in the level of sexual activity after myocardial infarction is clear enough, more research would be needed to establish the exact level and the causes.

It would be expected that myocardial infarction would have a substantial effect on family life. Cay et al (1972) found that 20 per cent of all coronary heart disease patients had family or marital problems, when interviewed nine days after admission to hospital. Finlayson and McEwen (1977) found, 12 months after the infarction, that the responsibilities of 47 per cent of the patients' wives had increased substantially, and that 62 per cent of the wives had taken over their husband's household tasks. Skelton and Dominian (1973) found the infarct had an emotional impact on all patients' wives, and that it had a considerable effect on family life.

There is some evidence that myocardial infarction is also associated with financial problems. Hay and Turbott (1970a) found in New Zealand that 3 per cent of their patients were no longer earning a living when followed up, that the income of 10 per cent of the patients was reduced to less than half its previous level, and that the income of 12 per cent was reduced but was still more than half its previous level. Cay et al (1972) in Scotland found that 12 per cent of infarct patients had financial problems nine days after admission to hospital. Finlayson and McEwen (1977) found, at 12 months, that money was a major problem for 25 per cent of their series and a problem of intermediate severity for 20 per cent. The definition of what is accounted a problem presumably varies between studies, and affects the proportion of patients recorded as having financial problems.

It has been suggested that recreational activities are an important part of the daily life of post-infarct patients, but there are very few research data in this area. Martin (1967) reported that the outcome at three months of leisure rehabilitation was a failure in 48 per cent of patients; failure was assessed in terms of not resuming or not suitably modifying previous activities, or not finding alternative activities. Hay and Turbott (1970a) found that, at 14 months, 36 per cent of their series were gardening, 38 per cent had one or more outdoor interests, and that 26 per cent had no outdoor interests.

Finlayson and McEwen (1977) found that, at six months, 15 per cent of their series were undertaking more physical activity in their spare time than before their infarct (generally walking and golf), that 44 per cent were undertaking the same amount, and that 41 per cent were undertaking less (sport, household repairs and decoration, gardening). They also found that three per cent of their series were undertaking more social activities than before the infarct, 60 per cent the same amount, and 37 per cent less. Kushnir et al (1975b) found that 18 per cent of their series were undertaking reduced levels of private driving four months after their infarct and 12 per cent reduced levels at 10 months. From these data, it seems reasonable to suggest that the recreational activity of at least half the myocardial infarction patients is affected by their illness in the months after the acute event. There are no data to show the changing pattern over time. As with the effect of the illness on family life, the impact on recreation is more important than suggested by these studies, because of the large number of people over retirement age who have a myocardial infarct, and because of the long-term tendencies to reduce the age of retirement and to reduce the length of the working week. In these circumstances, activities other than work will be increasingly important aspects of recovery after myocardial infarction.

One other activity that has been quite closely studied is smoking, though this is of more concern in prevention than in rehabilitation. Several studies have produced quite detailed data on patients' smoking habits after myocardial infarction, as shown in the following table.

Study and Follow-up Interval	% of Series Non-Smokers	% of Smokers					
		Stopped	Re-duced	Changed	Same	More	Total
Hay and Turbott(1970b) 6-24 months	28	40	35	5	21	0	100
Shaw and McNiven (1974) 9 months	29	40	30	0	20	10	100
Burt et al (1974) 12 months plus	22	63	18	3	15	0	100
Finlayson and McEwen (1977) 6 months	5	34	46	0	14	6	100

This suggests that about one-half the smokers stop smoking after their infarct, and that a further third reduce the amount that they smoke. It is also known that a substantial number of smokers stop smoking temporarily at the time of their infarct, but resume again later. Hay and Turbott (1970b) found the proportion of smokers who stopped and then restarted was 44 per cent. Finlayson and McEwen (1977) found it was 29 per cent.

(v) Psychological Aspects of Recovery Personal and psychological aspects of recovery after myocardial infarction have received a considerable amount of attention in the literature, both in professional discussion papers and in reports of empirical research. One line of approach has been to view the psychological factors as an influence on recovery, as measured in terms of resumption of physical activity or return to work. Frequently, psychological factors have been seen by doctors as barriers to successful recovery (World Health Organization, 1969b; Wishnie et al, 1971; Lancet, 1971b; Joint Working Party, 1975; Dellipiani et al, 1976). Within this general approach, some authors (Klein et al, 1965; Wynn, 1967) have attempted to identify patients with unwarranted invalidism - patients who fail to resume normal activity in the absence of any detectable physiological incapacity.

The second main approach to psychological aspects of recovery has been to treat them, not as influences on physical recovery, but as ends in themselves. Such factors as anxiety and depression have been seen and studied as part of patients' overall personality or well-being, and have been made the objectives of intervention. A number of people have discussed the psychologically-defined impact of the illness, such as dependency, depression, anxiety, regression and neuroticism (Whitehouse, 1960; Braceland, 1966; Josten, 1970; Hackett et al, 1973). Others have discussed psychological strategies for coping with the illness, such as denial and vacillation (Sullivan and Hackett, 1963; Josten, 1970). Some authors have concentrated not so much on purely psychological reactions, but on the meaning of the illness for the sufferer. They have usually seen the myocardial infarct as a threat to the sufferer's integrity, body-image or self-esteem (Braceland, 1966; Smith, 1972; Cook, 1976). Many of these authors have urged the development of the caring or therapeutic services, in order to improve these psychological or personal aspects of recovery.

The empirical research into psychological aspects of recovery may be divided into four main groups. First, there are studies that have attempted to make a fairly general assessment of patients' well-being or morale. Theckloth et al (1973) made subjective assessments of patients' sense of well-being with a variable follow-up interval between three and 18 months; they reported that 31 per cent of patients felt better than previously, 21 per cent felt the same, 33 per cent felt less well and 15 per cent were not sure. Garrity (1973) found that patients' employment, level of activity and (especially) health perception were related to morale six months after the infarct; but he did not report the overall level of morale achieved.

A considerable amount of research has focussed on emotional distress, particularly anxiety and depression, after myocardial infarction. The studies

have used a variety of definitions and measures, and, not surprisingly, have produced a variety of results. In none of the studies has there been any attempt to distinguish between distress caused by the infarct and anxiety that was part of the patient's pre-morbid personality. In addition, it should be noted that the much quoted study by Wynn (1967) was based on a cardiac work-evaluation centre, to which patients were referred from hospitals and elsewhere; the proportion of patients found in Wynn's study to be experiencing distress or other problems is likely to have been higher than the proportions in hospital-based series. The table below is an attempt to present systematically the findings of five studies of series of hospital patients. It shows the proportion of each series experiencing various kinds of emotional or psychological problems at the specified times after the infarct.

Study	Time after Admission	Proportion of Patients	Problem	Assessor
Cay et al (1972)	9 days	32% 26%	Anxiety Depression	Psychiatrist
McGrath and Robinson (1973)	In hospital	100%	Anxious Secondary (inappropriate) anxiety	Medical Social Worker
		31%	Depressed	
Wishnie et al (1971)	During 1st month after discharge	88%	Anxious or distressed	Patients
Martin (1967)	3 months	54%	Not successfully accepted or adjusted to illness and its effects	Medical Social Worker
Finlayson and McEwen (1977)	Before 6 months	$> \frac{1}{2}$	Difficult to adapt, feelings of uncertainty, fear or frustration	Patients
McGrath and Robinson (1973)	6 months	27%	Secondary (inappropriate) anxiety	Medical Social Worker
		40%	Depressed	
Finlayson and McEwen (1977)	6 months	Nearly 1/3	Fears about recurrence or ability to cope in future	Patients
Martin (1967)	6 months	52%	Not successfully accepted or adjusted to illness and its effects	Medical Social Worker
Finlayson and McEwen (1977)	12 months	62%	Lasting changes in personality, increased irritability, dependency or bottling things up	Wives

The impression from this table is of a considerable variety of personal problems. These problems are experienced by nearly all patients during the first weeks after their infarct. They seem to persist among about half the patients for the rest of the first year after the infarct.

Following the work of Cassem and Hackett (1971) attention has been paid to the changing pattern of distress through time. Dellipiani et al (1976) found that patients' anxiety scores fell substantially following the first few days after the infarct. They also found some variation in anxiety levels over the next few weeks, but that fairly low levels of anxiety had been achieved by three or four months. Doehrman (1977) says that the literature shows a decline with time in the proportion of patients experiencing distress, from 88 per cent at two months, to 69 per cent at six months and 20 per cent at two years. In fact, the 20 per cent he quotes is not the proportion of patients experiencing distress at two years, but the proportion of patients in which delayed rehabilitation was thought (at a two-year assessment) to be attributable to anxiety (Hinohara, 1970). The best single set of data about the changing prevalence of anxiety and depression during the year after myocardial infarction is presented by Stern et al (1976) from Washington, D.C.

Time after Admission	Proportion of patients with	
	Anxiety %	Depression %
6 days	42	29
6 weeks	30	15
3 months	18	12
6 months	22	10
1 year	17	13

Stern et al made use of psychiatric rating scales in their study. Their findings are close to those of Cay et al (1972) and McGrath and Robinson (1973) for anxiety and depression in hospital. They are also close to McGrath and Robinson for anxiety at six months, but much lower than them for depression. They found quite high levels of anxiety and depression in hospital, and that these fell during the first three months but not subsequently. Allowing for some overlap, it seems that about 50 per cent of patients experience psychiatrically identifiable anxiety or depression in the first few days after myocardial infarction, that this falls to about 25 per cent by three months, and persists at that level for the next nine months. This pattern is consistent with the suggestion, made in the previous paragraph, that nearly all patients

experience broadly defined personal or emotional problems in the initial stages after their infarct and that one half continue to do so during the rest of the first year.

A third set of studies has employed a more technically psychological approach, using standard personality inventories. In Britain, Groden and Brown (1971) used the Eysenck Personality Inventory to assess psychological changes in patients treated by early mobilisation and in controls; Cay et al (1972) used a Symptom Sign Inventory to assess patients' psychiatric status about 9 days after admission. Doehrman (1977) says that the published studies show that post-hospital infarct patients differ from controls or the published norms particularly in the neurotic triad (hypochondriasis, depression and hysteria) and also in anxiety.

A fourth set of studies has focussed not so much on purely psychological variables as on the contents of patients' personal beliefs or perceptions. Cowie (1976) explored the way in which patients engage in retrospective construction of their own biographies, and in comparison of themselves with other people, in order to help themselves understand and typify their heart attack. Cowie focused on the acute episode. In an unpublished paper, McMullen (1976) examined patients' comparisons of themselves with others and perceptions of their progress through time, to help themselves understand the process of their own recovery. In an American study, Croog and Levine (1972) found no changes in men's religious behaviour or outlook after a myocardial infarction. In reporting a series of therapeutic group discussions, Adsett and Bruhn (1968) outlined the themes which engaged the group; these included the expression of emotions, relations with others, dependency, sexual activity, and personal problems, among others. Clearly, empirical research has hardly begun to scratch the surface of the contents of the beliefs and ideas of patients during their recovery after myocardial infarction.

(vi) Discussion The research literature allows us to assemble a fairly clear picture of some of the restrictions and problems experienced by survivors of myocardial infarction. We can make quite good assessments of the changes during the months after the infarct in the proportions of people with certain difficulties. The proportion of people who are off work falls from 100 per cent one month after the intial attack to about 20 per cent seven months after it. Most people experience restriction in sexual activity immediately after the infarct and perhaps about 30 per cent do so four months after it. Nearly everyone experiences broadly defined emotional distress in the first weeks after the infarct; perhaps 50 per cent do so six months and one year after it. The proportion of people experiencing these difficulties declines substantially during the months after the infarct.

For other difficulties and problems, we have less complete data. In some instances we can only establish the frequency with which difficulties occur at particular points in time; there are not sufficient data for us to establish the changes through time in the frequency with which they occur. Thus, we know that about 30 per cent of hospital patients anticipate problems in returning to their work, and that about 40 per cent have reduced leisure activities six months after the infarct. In other instances, such as the actual experience of problems at work, within the family, or in money matters, the data are not adequate for us to get a clear idea even of the frequency of the problems at particular points in time.

Consideration of these different aspects of recovery raise issues relevant to further research.

(i) In some aspects of people's lives after myocardial infarction, e.g. difficulties at work, family relationships, the literature suggests that there may be certain unresolved difficulties or problems; but these are not clearly identified, nor is the frequency with which they occur firmly established.

(ii) Even when the overall frequency with which problems occur is known, we do not know whether it is the same people or different people who experience them at any one point in time. It is important to know whether many people experience one or two problems each or whether a few people experience multiple problems. An assessment of the overall impact of the infarct in this way has implications for the delivery of rehabilitation services. If many people experience a single problem each, then services may operate successfully on their own; if individuals experience multiple problems, then services will need to be coordinated closely around the individual patients.

(iii) Even when the changing frequency with which problems occur is known, we do not always know whether it is the same people or different people who experience them at different points in time. Again there are implications for the delivery of rehabilitation services. If it is the same people experiencing problems at different points in time, then intervention by the services may eliminate the problems completely. If it is different people, then the implication may be that the problems resolve themselves and intervention is unnecessary; or it may be that even successful intervention at one point in time would not remove the need for more intervention later with different patients.

Examination of these issues would require the repeated collection of data about a single series of infarct patients at specified times after the acute infarct.

There are no established criteria for translating the difficulties which patients experience into needs for rehabilitation. This review has shown that sufferers from myocardial infarction subsequently may experience a variety of personal or social problems. These may include delayed return to work, limitations or difficulties at work, restrictions in recreation or sexual activity, family problems, financial loss, and anxiety or depression. Although many of these problems are obviously associated with and caused by the infarct or other aspects of the disease, in some cases they may be the result of external factors to do with the patient's previous life or circumstances. There is a large practical and academic literature analysing the notion of needs. An explicit analysis of the needs to which the problems of coronary patients give rise would involve many things: an examination of the causes, nature and severity of the problems, and of who defines them as problems; a study of the appropriateness and effectiveness of different services in solving the problems; and an assessment of the costs of providing different quantities of services and the benefits of doing so (Forder 1974; Culyer 1976). The difficulty of undertaking all this in a single piece of research is obvious. A first step in the right direction consists of the identification of particular problems and the consideration of what services may be appropriate to their solution.

3. AIMS OF THE STUDY

This study was established with the overall aim of exploring patients' needs for rehabilitation after myocardial infarction. Within this broad area a number of more specific objectives were articulated. They were:

(i) to explore patients' needs for and use of rehabilitation and aftercare services;

(ii) to examine how far the organisation and delivery of the services are appropriate to the needs to be met;

(iii) to examine staff recommendations about patients' use of services; and

(iv) to test the value of certain "predictors" of outcome.

The aims of this study were established, and the fieldwork carried out, before the detailed review of the literature was undertaken. The study was established in the context of uncertainty about the direction of the future development of the rehabilitation services, around the time of the publication of the Tunbridge Report (D.H.S.S., 1972a). It was based on broader examples of hospital follow-up studies (e.g. Ferguson and McPhail, 1954; McKenzie et al, 1962), on a broad conception of the possible effects of ill-health on the sufferer (e.g. Grogono and Woodgate, 1971), and on discussions based on

personal and clinical experience about possible areas of interest. Therefore the aims of the study have a certain breadth, but the design of the study was not as specific as it might have been. Instead the literature review has been used to guide the analysis of the data and the writing of the report, with the aim of firmly relating the findings and conclusions to current knowledge and issues.

The study has concentrated primarily on the first and second of the objectives. We have collected data about the personal and social aspects of patients' recovery and problems and about patients' use of rehabilitation services. These data allow us to make some assessment of the appropriateness of the services, and to indicate where improvements may be needed. The objective relating to staff recommendations was based on the idea that health service staff might know what services patients needed, but be unable to obtain them. In the event, data about what staff recommended were only obtained through interviews with patients and have not proved particularly productive. The objective relating to predictors of outcome was based on work showing that the severity of infarct is related to subsequent mortality (Peel et al, 1962; Norris et al, 1969; Chapman and Gray, 1973). It was hypothesized that clinically assessed severity would also be related to outcome measured in social terms. Data relating to this objective have been collected, and are examined later. A further review of the literature and analysis of the data would be needed to examine fully factors that might explain or predict variations in recovery.

This study is one of a series, within the Health Services Research Unit, that are examining needs for rehabilitation among hospital patients. It is complemented by a study undertaken with the wives of some of the men in this series, which is designed to explore the wives' views of the impact of the illness on their husbands and the family. It is also related to two parallel studies of patients' needs for rehabilitation. A study of patients treated on an outpatient basis for fractures is focussing largely on the shorter-term problems of return to work among younger patients than those covered in this study. Another study, of old people with fractures of the neck of femur, is examining the factors that cause the high levels of disability and dependency experienced by those patients. In these studies, we are developing our understanding of the variety of rehabilitation problems faced by hospital patients. This knowledge is relevant both to future involvement of different medical specialties in rehabilitation and to the development of comprehensive rehabilitation departments in general hospitals (D.H.S.S., 1972a; Lee, 1975).

As this was established as an exploratory study, some terms were not defined as narrowly in the preparatory stages of the research as they might

otherwise have been. We have seen earlier in this chapter the breadth and variability that pertains to definitions of "rehabilitation". In this report we will continue to use the word with all its breadth and variety to refer to the whole range of services and treatments that are used to return patients to activity and well-being after their illness. We will also use the word "recovery" in a very broad sense, relating it not only to improvements in patients' physical condition after myocardial infarction, but also to improvements in the broad range of personal, social and economic problems they experience. A similar approach is taken towards the word "needs". As we saw in the previous section, technical analyses of the nature of needs may be very complicated. But again, these imply an excessive sophistication for an exploratory study. What we have produced is a broad ranging study that explores several different aspects of patients' recovery and attempts to identify where unsolved problems exist. This is the essential first step in any specification of the services that are needed.

4. METHODS

This study has been designed as a simple follow-up study of patients during the year after their myocardial infarction. Five interviews were held with each patient, at specified times during the year. This design allowed us to trace the natural history of the personal and social aspects of patients' recovery in the year after their infarct, in considerably more detail than has been done before. It has allowed us to compare different aspects of the patients' recovery at any one point in time. And it has allowed us to draw a systematic picture of the changing pattern of recovery through time. Both these elements are necessary, if practical conclusions are to be drawn and recommendations made about the areas in which rehabilitation services are most needed.

The patients admitted to the study were defined in respect of several characteristics. It was a study of a consecutive series of patients, who:

(i) were admitted to the Kent and Canterbury Hospital,

(ii) with proven diagnosis of myocardial infarction, using the criteria of Norris et al (1969),

(iii) who were aged 59 or less on admission,

(iv) and who were said by the responsible clinician to be fit for interview.

It was thought that very few, if any, patients under 60 in the hospital's catchment area, who survived long enough after their infarct, would not be admitted to the hospital. An age limit of 59 was chosen in order to focus

on patients who would be expected to return to work, and to avoid those who would be more likely to retire. There were no deaths in the series between the first interview in hospital and discharge from hospital.

There were no systematic exclusions from the series as defined. Two patients were deliberately excluded. One was excluded because he was known to the research staff because of his job at the University. The other was excluded because the consultant physician considered that the patient's problems would be exacerbated by contact with another agency. There were also a number of accidential omissions and non-respondents, described below.

The original intention was to take 200 patients into the series. It was realised, however, after fieldwork had begun, that the number of persons under 60, admitted to the Kent and Canterbury Hospital with myocardial infarction, was much lower than had been expected. It would have taken an impracticably long time to collect the full series. It was decided to reduce the number of patients to about 50 to 60. This meant that the scope for cross-tabulations and explaining variations in recovery has been much more limited than was originally intended.

Five other patients are known to have been omitted from the series. One refused to participate in the study. One moved away from Canterbury immediately after discharge from hospital. Three patients should have been included in the series, but difficulties of communication between the hospital and research staff meant that the interviewer was unable to contact them in time for the first interview. These omissions have meant that the final number of patients in the series, for whom data are available and who are included in the analyses, is 52.

The main source of data in this study was a series of five interviews with each patient. Interviews were intended to be held one week after admission to hospital, and again at five weeks, three months, six months and one year. The first interview was relatively short and intended in part to gain the respondent's cooperation. The second interview was the longest of the series, covering the respondent's life both before and after the infarction. Five weeks was chosen for the time of the second interview, because this would be fairly close to the outpatient attendance for most patients, thus allowing the clinicians to relate the research findings to their impressions of patients' progress at that time. Three months, six months and one year were chosen, in order to concentrate attention in the early part of the year when most changes in the patients' circumstances would be taking place, and because these were follow-up intervals used quite frequently in the research literature. One of the most important features of this

study is that systematic observations of a wide range of personal and social events were made on five occasions after the infarct, so that we are able to provide a more detailed picture of the changing pattern of recovery than has been available before.

The data were collected by means of structured interviews. One experienced and trained interviewer undertook nearly all the interviews. The interview schedule contained the precise form of words to be used in each question. Many of the questions were closed and precoded. Some of the questions - particularly those concerned with the nature of respondents' personal or social problems and those asking for their reasons for a particular statement or comments about a service - were open-ended, with the interviewer being required to probe extensively. The main topics covered in each interview were the respondent's general health, use of and comments about health and rehabilitation services, advice received about various activities of daily living, and the effect of the illness on a range of different aspects of personal life, with particular detail about spare-time activities, home life, work and money. In this way, we hoped both to cover a wide range of material systematically and to obtain as much as possible of the respondents' own views about the problems they faced.

Clinical data, about the patient's medical condition in hospital, were recorded for the study on a specially designed form. The forms were filled in by senior house officers in the hospital with specific responsibilities relating to the research. The data covered the presence of pre-existing heart disease and other disease, the severity of infarction and the occurrence of complications, and various items about skinfold thickness and smoking habits. Written instructions were provided in order to standardise these data as far as possible. These instructions were based on published work and covered the criteria for diagnosis and the various classifications that were used. Two items required that the doctors use their judgement in recording them; they were whether any pre-existing non-coronary disease or any complications were likely to affect the patient's rehabilitation.

The series of patients was collected for this study between April 1974 and June 1975. This meant, with a one-year follow-up, that the fieldwork continued until June 1976.

As has been mentioned, 52 respondents have been included in the series for the purpose of analysing the data. For a variety of reasons, a complete set of data (consisting of five interviews and a clinical data form) is not available for each of these 52 respondents. The total number of respondents, for whom each item of data is available, is shown in the following table.

Item	No. of Respondents for Whom Item is Available
First interview	52
Second interview	52
Third interview	48
Fourth interview	47
Fifth interview	48
Clinical data	45

These figures represent the total number of respondents at each interview, on whom the results contained in this report are based. The reasons for the non-availability of interview data are as follows: one respondent died after the second interview; one respondent moved away after the second interview; for one respondent the second interview was so late (on the general practitioner's requirement) that the third interview was omitted; two interview schedules relating to one respondent were lost during the data processing; four respondents were either not contacted or not available at particular interviews. The gaps in the clinical data appear to have been due to uncertainties and misinterpretations, when junior hospital doctors were on leave or when new appointments were being made.

There was some variation in the time at which each set of interviews was actually held. The first interviews were planned for about one week after admission. In fact, they were held between four days and 23 days after admission. Half the interviews were held between seven and nine days, with the mean at 10 days. They will be referred to in this report as taking place at 10 days. The second interviews were planned for five weeks after admission. They were held between four weeks and nine weeks. Half the interviews were held at five weeks, with the mean at six weeks. They will be referred to as taking place at six weeks. The third interviews were planned for three months after admission. They were held between 12 weeks and 19 weeks. Half the interviews were held between 13 and 14 weeks, with the mean at 14 weeks. They will be referred to in this report as taking place at three months. The fourth interviews were planned for six months after admission. They were held between 26 weeks and 35 weeks. Just under half the interviews were held between 27 and 28 weeks, with the mean at 29 weeks. They will be referred to in this report as taking place at seven months. The fifth interviews were planned for one year after admission. They were held between 51 weeks and 73 weeks. The interviews were more widely spread than the others, with half being held between 53 and 57 weeks. The mean was 57 weeks. They are referred to in this report as taking place at one year; in making detailed comparisons with other studies the reader should remember

that the average time of interview was 13 months, and that many interviews took place in the following weeks. This information is summarised in the following table.

Interview	Time of Interview after Admission	
	Planned	Average Time Actually Held
First	1 week	10 days
Second	5 weeks	6 weeks
Third	3 months	3 months
Fourth	6 months	7 months
Fifth	1 year	13 months

Because of the small number of respondents in this study, the results are usually presented as whole numbers or as fractions of the total. Percentages are only used when direct comparison with the findings of other studies is desired. Where tests of statistical significance have not been used, these percentages should not be taken as implying precision; they are presented only to facilitate comparison.

CHAPTER 2 THE RESPONDENTS

This chapter presents some introductory medical and social data about the respondents and some data about the services they used. It has two purposes. The first is to provide the reader with a background to the following chapters, that focus more specifically on recovery and rehabilitation. The second is to compare the patients included in this study with those included in other studies. If the patients in this study appear to be similar to those in other series, in relation to those characteristics for which comparisons can be made, then conclusions and recommendations based on this study can be treated as more generally applicable than would otherwise be possible.

1. PERSONAL AND SOCIAL CHARACTERISTICS

The demographic characteristics of respondents are easily reported and compared to those of patients in other studies. In this study 47 respondents were men and five were women. As shown in Table 2.1, 16 respondents were aged between 40 and 49, and 35 between 50 and 59. This age distribution is very similar to that shown for survivors by Norris et al (1969) and Finlayson and McEwen (1977).

Some of the social characteristics of the respondents may be sketched in briefly. The distributions of respondents' family and household circumstances appear to be similar to those of the general population of about the same age in Kent. In the present study 50 of the 52 respondents were married. One was single and one was widowed. In Kent as a whole 86 per cent of the population between the ages of 40 and 59 in 1971 were married (O.P.C.S., 1973a). In the present study 20 respondents lived with a spouse only and 27 lived with a spouse plus children, as shown in Table 2.2. Table 2.3 shows the relationship between house-ownership and type of house among the respondents. The majority of respondents were owner occupiers, which corresponds to the general situation in Kent (O.P.C.S., 1973b) but differs from that among Finlayson and McEwen's (1977) series of patients. The majority lived in semi-detached houses, terraced houses or bungalows. This distribution contains more semi-detached houses and bungalows than are found in the outer south-east region generally (O.P.C.S., 1973c), but is perhaps typical of the locality in which the study was based. In all of these respects the respondents seem reasonably typical of the area in which they live.

Data about the respondents' educational background and socioeconomic status have been obtained from interviews. Respondents were asked in the second interview about the age at which they left school, and about their educational or occupational qualifications. Table 2.4 shows that two-thirds of the

respondents left school at the minimum school-leaving age. Table 2.5 shows that the majority had no formal educational or occupational qualifications, but that one third did have a craft or technical qualification. Table 2.6 shows the social class distribution of respondents, making use of the Registrar General's Classification of Occupations (O.P.C.S., 1970). Unemployed men were classified according to their previous job and women according to their husband's job. The respondents were distributed mainly among the managerial, skilled and partly-skilled classes. This is less of a bunching in the skilled manual class than is found among male heads of household of working age in Britain as a whole (O.P.C.S., 1976). A higher proportion of respondents was in the higher social classes, and a lower proportion in the lower classes, than was found in two recent Scottish studies with comparable data (Cay et al, 1973; Finlayson and McEwen, 1977). As a greater proportion of patients in the lower social classes, than of those in the higher classes, experience difficulty in returning to work after myocardial infarction (Finlayson and McEwen), it seems likely that the socioeconomic composition of the present series would mean that the series experienced no more work-adjustment problems than would be found among infarct patients in Britain as a whole.

Data about respondents' economic position at the time of the infarct have been obtained from the second interview. Table 2.7 shows that, at the time of the infarct, 47 of the 52 respondents were employees or self-employed, two were housewives, and three were not employed. Those not employed constitute six per cent of the total; this is the same level of unemployment as found in other British studies of myocardial infarction. Cay et al (1973) found eight per cent of their series to be unemployed before admission; Finlayson and McEwen (1977) found six per cent of their series to be unemployed.

2. MEDICAL CONDITION

(a) Previous Illness

In the present study, data have been obtained about respondents' medical condition before the acute infarct, from the clinical data form and from interviews. Data about the existence of heart disease prior to the onset of the myocardial infarction have been obtained from the clinical data forms. Ten of the 45 respondents, for whom clinical data are available, were reported to have had ischaemic heart disease prior to the onset of the acute myocardial infarction. One of these was classified as New York Heart Association Grade III, as having marked limitation of physical activity and experiencing symptoms with mild levels of activity. One was classified as Grade II, as having slight limitation of physical activity and experiencing symptoms only with the more

strenuous grades of ordinary activity. None of the others were reported to have limitations of physical activity or to experience symptoms on undertaking activity. Clinically identifiable ischaemic heart disease was reported in almost one-quarter of the respondents, but very little disability resulted from it.

In the first interview, respondents were asked whether, in the four weeks before their admission to hospital, they were suffering from any illnesses or disabilities. Sixteen of the 52 respondents replied that they were, and identified symptoms or an illness that related to their heart. These reports varied from hypertension, shortness of breath and tiredness, to pains in the chest, angina and the after-effects of a previous infarct. In addition, another two respondents said, in reply to a later question that they had seen their general practitioners in connection with their heart. This makes a total of just over one-third of the respondents reporting symptoms or illnesses before the onset of the infarct, that may be associated, retrospectively by the research worker, with the heart. Finlayson and McEwen (1977) found that 17 per cent of their series had had symptoms that were recongnised at that time by the respondent as evidence of heart disease. In view of the minor nature of many of the symptoms that often precede myocardial infarction, and in view of the process of normalisation of symptoms (as discussed by Finlayson and McEwen), there is a moderately close degree of similarity between the findings of the two studies.

Data were also collected in the present study about the presence of other pre-existing disease. Ten of the 45 respondents, for whom clinical data are available, were reported to have such pre-existing disease. Four respondents were reported to have hypertension, two diabetes, and four other diseases. In only two cases - one of asthma and one of duodenal ulcer - was the condition said to be likely to affect the respondent's rehabilitation. Again, we have a picture of just under a quarter of the respondents suffering from clinically identifiable illness, but of very little incapacity or disability resulting from it.

In reply to the question in the first interview, about illness or disability in the month before admission to hospital, 19 of the 52 respondents identified an illness that did not appear to be related to the heart. Six of these mentioned minor illnesses, such as a cold or 'flu. Others mentioned a variety of conditions, such as bronchitis, hernias, diabetes, varicose veins, arthritis or diarrhoea. In addition, a further five respondants said that they had seen their general practitioners about some illness in the preceding month. In total, therefore, almost one half of the respondents identified some kind of illness, not directly related to their heart, from which they

suffered before their infarct. Much of this illness appeared to be minor, and would not have a significant impact on the patient's subsequent recovery or rehabilitation.

There was only a small amount of overlap between different kinds of pre-existing disease in the present series of patients. Of the 45 respondents, for whom clinical data are available, 10 were reported to have ischaemic heart disease and 10 other diseases. Only one respondent fell into both categories, so that 19 of the 45 (two-fifths of the total) were reported to have had a disease prior to the onset of their infarction. Four of these respondents were reported to have experienced significant disability or to have a disease likely to affect their rehabilitation. Of the 52 respondents who were interviewed, 18 identified symptoms related to their heart (many of them associated with the onset of the infarction), and 24 identified other symptoms or illnesses. Four respondents fell into both categories, so that 38 of the 52 (three-quarters of the total) identified some symptom or illness in the month before their admission to hospital. The overall picture is one of a considerable amount of minor illness, or symptoms associated with the onset of the infarct, a fairly small amount of more serious illness, and a very small amount of illness that might affect subsequent recovery or rehabilitation.

(b) Severity of Infarct

Data are available that show the severity of the infarct in the present series of patients. The method of measuring severity is that developed by Norris et al (1969). Norris et al identified and weighted five factors, that they found to be related to mortality in a hospital series of infarct patients. The five factors were age, position of infarct, systolic blood-pressure on admission, heart size, pulmonary congestion, and the existence of previous ischaemia. The scoring system was such that any one patient might have a score between 1.62 and 21.9 points. About 70 per cent of their patients scored between four and 10 points. Reading off from the graphs in the Norris et al paper, it is possible to estimate the proportion of survivors with each score. This is shown in Table 2.8. The distribution in Table 2.8. will be weighted towards the higher scores compared to the present series, because two-thirds of the Norris et al series were aged 60 or more, and therefore automatically attracted higher scores.

In the present study, data for measuring the severity of infarct were recorded on the clinical data forms of 44 subjects. Table 2.9 shows that 16 had a score of less than four points, and that 18 had a score of between four and 5.99 points. It is clear that the present series contains few patients with relatively severe infarcts, as measured by the Norris Coronary Prognostic Index.

The distribution of scores contains more subjects with low scores than there were among the survivors in the Norris et al series. The difference between the two series would be explained in part by the exclusion of older patients from the present study, given the association between age and mortality found by Norris. The comparability of the series might be increasedby extracting the age-component from the Norris Index. This would necessitate re-running Noris's discriminant analysis to obtain new values for each of the factors contributing to the Index, and then applying the reconstructed index to the present series of patients. Given the complexity of this, it seems worth examining the predictive capacity of the unadjusted Norris Index in relation to the personal and social parameters of recovery included in the present study. This will be done later.

(e) Symptoms and Illnesses after the Infarct

Data were collected in the present study about the complications patients experienced while in hospital. Eleven of the 45 subjects (one-quarter of the total), for whom clinical data are available, were reported to have experienced one complication, and three of them experienced two complications. Four subjects experienced cardiac failure, three pericarditis and the others a variety of different complications.

Only one person in the series died between discharge from hospital and the one year follow up. She was a 42 year old woman, who had a Coronary Prognostic Index score of 5.58 when first admitted to hospital. She died about two months after her first infarct.

Some of the main features of the respondents' medical condition after discharge from hospital may be identified from interview data. Respondents were asked in each of the follow-up interviews whether they had had a recurrence of their illness, and whether they had had anything else wrong with them, since the last interview. Information contained in the replies has been classified into three broad groups. Symptoms or illnesses, ranging from heart attacks, angina and palpitations to breathlessness,tiredness and weakness, have been classified as directly connected with the heart. A variety of conditions such as giddiness, blackouts, depression, anxiety and thrombi have been classified as related to the heart or treatment. Other conditions, including colds, sore throats, headaches and a variety of other, usually minor, ailments, have been classified as "other". The items identified are obviously not as detailed or complete as those that would be reported by a doctor making a comprehensive clinical examination. They probably represent those medical events of most significance to the respondents.

Tables 2.10 to 2.13 show the number of respondents who reported different illnesses or symptoms. Between half and three-quarters of the respondents at each interview identified some illness or symptom. Three-quarters of the

respondents identified symptoms that appeared to be directly connected with their heart condition, at some time during the follow-up period. These included pains in the chest, breathlessness, tiredness and a variety of other more or less serious events. Just over a third of the respondents identified problems that may have been related to their heart condition or treatment, such as giddiness or blackouts, or heavy or aching legs. And two-thirds of the respondents identified other illnesses, ranging from colds, 'flu and sore throats to such things as rheumatism, pneumonia and colitis. Overall, these data suggest a fairly high level of illness during the months after the acute infarct. We have no way of assessing from the interviews the clinical importance of the episodes reported. Presumably some of them were significant enough to have an impact on the overall level of the respondent's wellbeing and activities, but others were not.

In addition to data about specific symptoms and events, the interviews yielded information about the respondents' feelings about their progress more generally. At the beginning of each interview, the respondents were asked "In general, how do you feel you are coming along now?" The question has two aspects: it asked about the respondents' feelings, and it asked about their progress. Garrity (1973) found that patients' perceptions of their health were strongly related to their morale after a heart attack. It is likely that the responses given in this study reflect both morale and medical progress. The answers to the questions in this study were written down by the interviewer who then coded the reply as "well", "average", or "poor". Clearly, these are broad categories for classifying the replies to a multifaceted question.

Table 2.14 shows that, at each interview, half the respondents or more were coded as feeling that they were making good progress. Between one-tenth and one-third of the respondents at each interview were coded as feeling they were making poor progress. The number making poor progress increased appreciably between the time of discharge from hospital and the third interview at three months. There was a positive association between respondents' identification of specific symptoms or events directly connected with their heart and their being coded as making average or poor progress. In general, there was no consistent pattern of recovery through time, with some people improving at one interview and deteriorating again subsequently. About half the respondents experienced symptoms directly related to their heart, and appeared to be making less than good progress in their recovery, six months or more after their acute infarct.

3. USE OF SERVICES

A variety of data have been obtained in the present study that show respondents' use of health services around the time of their infarct. These data are important as the baseline of current practice, in the light of which

respondents'problems and needs for other services have to be assessed. They are also important because, in describing the nature and amount of rehabilitation and after-care services used by respondents at the time of the study, they will allow those with experience of working in this field the opportunity of comparing the services available in different places and at different times, and of relating these differences to variations in outcome and in unmet needs.

Respondents were asked, in the first interview, whether, in the four weeks before their admission to hospital, they had had any contact with a variety of health or personal social services for any reason. They were also asked the reason for contact with each service. Table 2.15 shows the number of respondents who had contact with the different services, and the reason for the contact. Six respondents had been hospital outpatients, mainly for illnesses other than their heart. Twenty-four (almost half the total) had seen their general practitioner; 11 of them for something to do with their heart and 13 of them for other illnesses. The proportion who had seen their general practitioner is slightly higher than that found by Finlayson and McEwen (1977), who reported that 31 per cent of their series had been attending their general practitioner in the few weeks prior to the infarction. In the present series, three respondents reported contact with other community health services.

Information obtained in the interviews allow us to build up a picture of respondents' movements around hospital, the time of their discharge and their subsequent movements. Fifty of the 52 respondents were admitted straight to the Coronary Care Unit of the Kent and Canterbury hospital. The mean length of stay in the Unit was six days. The range was from one day to 20 days. After transfer out of the Coronary Care Unit to other medical wards in the hospital, 44 of the respondents were discharged home. Six respondents were readmitted to the C.C.U. Half the respondents stayed in hospital between 13 and 16 days, but a few stayed for four weeks or more as shown in Table 2.16. The average length of stay of 16 days was very close to the national figure for patients under 65 with acute myocardial infarction (D.H.S.S., 1977a). The time of discharge in the present series is as early as that reported in some studies of early discharge (Harpur et al, 1971; Royston, 1972) but not as early as that in others (Boyle et al, 1972; Tucker et al, 1973; Hayes et al, 1974).

In each of the follow-up interviews, the respondents were asked about their contacts with the health and rehabilitation services since the previous interview. Tables 2.17 to 2.19 show that the pattern of health care after discharge from hospital was mainly one of contacts with general practitioners and visits to hospital out-patient clinics. Nearly all the respondents saw their G.P.s about their heart in the early weeks after discharge, and two-thirds continued to do so subsequently.

Somewhat fewer respondents continued to have hospital out-patient appointments during the year after their infarct. There was less contact with other rehabilitation or resettlement services. At the time of the study in 1974/5 there was no exercise programme for cardiac patients at the Kent and Canterbury Hospital; the early contacts with physiotherapists were mainly for breathing exercises. One quarter of the respondents said that they had contact with a social worker at some time during the year after their infarct, and a quarter had contact with the employment services or works' doctor about returning to work. In total, two-fifths of the respondents were in contact with either a social worker or the employment services, or with both, at some time during the year after their infarct. Nevertheless, hospital doctors and nurses, and general practitioners, were the main professional sources of advice and aftercare.

4. DISCUSSION

In concluding this chapter, it may be useful to review the material, by which the comparability of this series of myocardial infaction patients with other series may be assessed. A number of factors suggest that the present series is similar to other series. They include the age distribution of respondents, the number reporting heart symptoms before the onset of the infarct, the number reporting contact with their G.P. before the infarct, the pattern of hospital use and the pattern of aftercare. Two factors suggest that the present series might have experienced less frequent or less severe problems after their infarct than other series. These are the high socioeconomic status of the present series and, apparently, the relative mild infarct they suffered. One factor - the lack of a rehabilitative programme of physical exercise - suggests that the present series may have experienced a greater number of residual problems than patients successfully completing such a programme. On balance, it seems likely that the present series would be fairly similar to other series of hospital-treated myocardial infarction patients of the same age. There are no obvious reasons for assuming that they differ greatly.

CHAPTER 3 WORK AND INCOME AFTER MYOCARDIAL INFARCTION

"After discharge from hospital, return to work is the most important milestone on the patient's way to full recovery. Not only does he thereby become economically independent but, in most cases, he resumes his accustomed pattern of life and role in society." (Joint Working Party, 1975). In this statement, the Joint Working Party made three points: the importance of return to work; its implications for economic independence; and its implications for normality. In this chapter, we shall throw light on each of these matters, by presenting findings about respondents' return to work, about their experiences and problems related to their work, and about their income.

In Chapter Two, we presented some background material about the respondents' social and economic status at the time of the infarct. Two-thirds of the respondents left school at the minimum school-leaving age, and the majority had no formal educational or occupational qualifications. The respondents were fairly evenly distributed among the managerial, skilled and partly-skilled social classes. The relatively high proportion of respondents in the higher social classes might have tended to reduce the frequency of work adjustment problems experienced by the present series of respondents. Nine-tenths of the respondents were employees or self-employed at the time of the infarct; the remainder being housewives or not employed.

1. EMPLOYMENT AND UNEMPLOYMENT

Although much attention has been paid to the timing of return to work after myocardial infarction, there are prior questions about whether people are employed or unemployed. There appear to be no detailed data on this subject in the British literature. Table 3.1 shows the number of respondents in the present study who were employed or not employed. There was a decline in the proportion of respondents who were self-employed or employees, from nine-tenths of the total at the time of the infarct to four-fifths at the fourth and fifth interviews. There was a corresponding rise in the proportions who were retired or not employed. One quarter of the respondents were not employed at some time during the year after their infarct. Myocardial infarction appears to be associated with an appreciable increase in the chances of moving out of employment.

Table 3.2 shows the work position of the respondents at each interview. None of the respondents had returned to work at the time of the second interview, and the number at work rose slowly during the subsequent weeks. Correspondingly, the number of people on sick leave fell slowly. Eventually most respondents

returned to work. Of those who did not, more became unemployed or retired than continued on sick leave.

Changes in the economic position of individuals, particularly the unemployed, during the year after their infarct were more complex than shown in Table 3.1. Three men were unemployed at the time of their infarct; only one of them subsequently returned to work. Another three were employees at the time of their infarct, spent some time off sick, and then were unemployed for the rest of the follow-up period. Four were unemployed temporarily after their infarct, but had found work again by the fifth interview. And three returned to work after their infarct, but subsequently became unemployed. There was no uniform pattern of unemployment during the year after the infarct.

In 10 cases, the unemployment appeared to be related to the respondent's heart condition. One man was unemployed, when he entered this study, because of a previous infarct. Five men became unemployed after their infarct, without having returned to work. They had been employed in heavy manual jobs such as pipelaying or labouring on building sites. Three of them said in interviews that they wanted lighter work. The other two said they were made redundant by their employers because of their health. One person, a salesman, became temporarily unemployed because he had given in his notice just before his infarct and was delayed in starting his new job. Three men - two of them in heavy manual jobs - returned to their previous work, but became unemployed after a renewal of their illness: two suffered further heart attacks and one severe angina. In all of these cases the illness appeared to be a significant cause of the unemployment, particularly when associated with heavy manual work.

In only three instances did unemployment appear not to be associated with the respondent's heart condition. Two were men unemployed before their infarct. The other was a man who lost his job when the family business closed. There is no way of knowing whether these people would have found work if it had not been for their infarcts.

The unemployed respondents were asked in each interview what were the main problems that not having a job was making for them. Table 3.3 shows that all of them identified one or more problems. Table 3.4 shows that all of them said that their lack of money was a problem. Some of them simply said they had financial problems; others elaborated a little. In some cases, domestic and recreational spending had been reduced or debts had begun to accumulate. In other cases the lack of money was a definite source of worry. In total, three-quarters of the unemployed people identified some kind of mental distress - worry, frustration, depression or boredom - as a

problem. In the words of a man who had been a painter and decorator until his first heart attack:

> "Not having a job at all is problematic. You can't earn enough money to advance your standard of living. It's soul destroying just sitting here not able to do things that you are capable of."

Similar financial and emotional problems are frequent among all kinds of unemployed people, not just those who have been ill. But frequently the unemployment and resulting difficulties stemmed directly from the respondents' heart conditions, adding substantially to the physical and medical problems they faced.

The work of housewives was affected by their illness. There were two women in the series who were housewives before their infarct. One married woman gave up her part-time job as a shop assistant because of her infarct and became a full-time housewife. She was the person who subsequently died. The housewives were asked at each interview whether they were doing all their normal housework again yet. One started doing it all before the second interview at six weeks, and the other two between six weeks and three months. They were also asked whether they had any problems with their housework because of their illness. One woman said on three occasions that she had problems; she found difficulty with specific tasks, such as cleaning, cooking and bedmaking.

None of the respondents was retired at the time of their infarct. Two people retired subsequently, between three months and seven months after their infarct, because of their illness. One was a man of 58, who had previously commuted each day from East Kent to his administrative job in London. The other was a college lecturer of 53,who had had a previous infarct, and who made a slow physical recovery during the follow-up period. The opportunity for giving up work altogether seemed to be greater for these people than it did for the manual workers who experienced periods of unemployment.

2. TIMING OF RETURN TO WORK

Much of the medico-social research into rehabilitation after myocardial infarction has focused on the timing of return to work. We saw in Chapter One that the majority of British studies reported between 15 and 46 per cent of patients returned to work by two months after the infarct, and that between 70 and 86 per cent returned by six months. These studies have tended to concentrate upon the proportion of 'eligible' respondents, i.e. those who were in employment and at work before the infarct. In the present study, 45 respondents have been included in a return-to-work subseries; that is the

whole series minus five people who were housewives or unemployed before the infarct, and minus two people for whom the relevant data were not available. The date of return to work was established by detailed questioning in the interview immediately following the first return. This gives us a set of data comparable to that contained in the tables on pages 17 and 18. Table 3.5 shows that 31 per cent of the eligible respondents had returned to work three months after their infarct and 69 per cent by six months. The average time of return to work was 20 weeks - four and a half months. The numbers in this series are small, and too much reliance should not be placed on the percentages. At three months and six months, the proportions of the present series who had returned to work were lower than in other series, and considerably lower than the targets advocated by the Joint Working Party. By nine months and one year the proportions who had returned were more in line with other series. The timing of return to work in the first few months after the infarct was later among the present series of patients than it has been among other British series.

The Joint Working Party (1975) reviewed several factors that they considered might be associated with delays in returning to work after myocardial infarction. The most important, they thought, was psychological: "Fear of reinfarction and sudden death on the part of the patient, his relatives, family doctor and employers, encourages overprotection and is still the main stumbling block to early return to work." They considered that the physical condition of a small number of patients, and the risky or arduous nature of the work of a small number, might also result in later returns. They also considered that a variety of social and economic factors, associated particularly with the adverse trends in social classes IV and V, might be significant. These included difficulties in rearranging duties, small differences between sick pay and normal earnings, high unemployment and the absence of occupational medical officers.

In the present study, several factors were related to variations in the timing of return to work. The first was the respondents' assessments of the physical demands of their jobs. Three men, who had previously held physically heavy jobs and who were temporarily unemployed after their infarct, returned to work on average 51 weeks after the infarct. Another six men with physically heavy jobs returned on average 24 weeks after their infarct. The 29 respondents who said they had medium or light jobs, returned on average 17 weeks after their infarct. A second factor that may have been related to variations in the timing of return to work was the respondents' medical condition. Among those people who had not returned to work at the time of their third interview,

those who identified some symptom or event directly connected with their heart returned to work on average seven weeks later than those who did not. However, this relationship is complicated by the fact that more people with physically heavy jobs than with other jobs reported heart symptoms at this time. A third factor was the respondents' attitude towards their jobs. After completing the Grogono Index of Health (see Chapter Five), the respondents were asked which item was the most important to them. The 24 people, who said at the second interview that their work was most important, returned on average 17 weeks after their infarct, the others returned 23 weeks after it. Furthermore, among the people who thought their work most important, those who expressed a positive interest or involvement in it returned earlier than those who simply identified money as the important feature. These findings suggest that the physical nature of patients' jobs, and patients' attitudes towards their work, may be more important than the Joint Working Party considered.

Several other factors were examined, but were not found to be related to variations in the timing of return to work. These included the level of disability from ischaemic heart disease before the infarct and the presence of medical conditions thought likely to affect rehabilitation, as recorded on the clinical data form. The severity of the acute infarct, as measured by the Norris Coronary Prognostic Index, was not related to the timing of return to work. Nor were the socio-economic factors examined: social class, respondents' being engaged in manual or non-manual work, or the difference between their pre-infarct earnings and their income while off work. Nor did respondents' feelings of worry or unhappiness, in so far as these were expressed in general terms or in relation to death, recurrence or prognosis, appear to be related to timing of return to work. Although this study did not set out to examine causes of variations in the timing of recovery, it appears that respondents' fears of reinfarction may not be the most important stumbling block to early return to work, as the Joint Working Party suggested they were.

Data were collected in the present study on the respondents' views about their return to work. At each interview, all respondents on sick leave were asked whether they felt they were ready to go back to work at that time. Those who said that they did feel ready were asked why they had not gone back. Table 3.6 shows that about one-third of those on sick leave at the time of each interview said that they were ready to go back to work. Table 3.7 shows that the large majority of those, who said they were ready to go back to work, said that the reason they had not done so was that the doctor had said not to. A number of questions of interpretation surround these findings. The respondents' assessments of their readiness may have been unrealistic. Few of them identified the doctor involved. It is not clear whether the statements are an accurate reflection of events as they happened, or whether they represent a rationalisation

after the event. Further research would be needed to resolve these questions. In any event, it is clear that, for a substantial minority of the respondents on sick leave between six weeks and three months after the infarct, the doctor was seen as cautioning against return to work rather than positively encouraging it.

In the interview immediately following their first return to work, respondents were asked whether they felt they had returned to work earlier than they should have done, at about the right time, or later than they need have done. Table 3.8 shows that, of the 40 respondents who returned to work at some time during the follow-up period, 30 felt that they had done so at about the right time. Seven of the remaining 10 felt that they had returned earlier than they should have done; most of these were identified in the third or fourth interview. Only three respondents said that they returned to work later than they need have done. Although respondents who were off sick may have felt ready to return to work, once they had returned to work they did not feel that they should have gone back earlier than they actually did. The experience of working may have presented more difficulties than had been anticipated.

3. CHANGES AND DIFFICULTIES AT WORK

The research literature reviewed in Chapter One revealed a variety of alterations and difficulties associated with work after myocardial infarction, in addition to the simple fact of the timing of return to work. Various British studies have found that between five and 20 per cent of patients are working part-time at different points in time after the infarct (Sharland, 1964; Wincott and Caird, 1966; Royston, 1972). Others have found that between 20 and 40 per cent work significantly fewer hours after their infarct than before it (Kushnir et al, 1975b; Finlayson and McEwen, 1977). In the present study, respondents were asked how many hours per week they were working just before admission to hospital with their infarct, and how many hours they were working at the time of each of the follow-up interviews. Before the infarct, the majority of respondents were working between 35 and 50 hours per week; five were working less hours, and 10 more. Table 3.9 shows the number of respondents working different proportions of their pre-infarct hours at the time of each of the follow-up interviews. The table shows that, although appreciable numbers were not at work at the time of each interview, relatively few were working substantially reduced hours. Just over one-tenth of the respondents at the fourth and fifth interviews were working less than 90 per cent of their premorbid hours. This is less reduction in working hours than reported in other studies. Very few respondents worked appreciably longer hours after their infarct than before it.

Previous studies have found that aspects of patients' work, besides the hours, are frequently modified after myocardial infarction. Perhaps one-fifth of the sufferers return initially to a modified job (Wincott and Caird, 1966; Royston, 1972). At any one point in time, between four months and one year after the infarct, perhaps one-quarter to one-third of sufferers undertake less physical activity in their work than before the infarct (Cay et al, 1973; Kushnir et al, 1975b). In the present study, those respondents who were at work at the time of each interview were asked whether their job had been altered in any way because of their illness, since the previous interview. Those who said it had been altered were then asked whether it was still altered or had returned to normal. Table 3.10 shows the number of respondents who said their job had been altered since the previous interview. Just under one-fifth of the respondents at the third and subsequent interviews said that their job had been altered and was still altered. Several more said it had been altered, but was now back to normal. These figures may well underrepresent the true total of alterations at the fourth and fifth interview. At those interviews, respondents whose jobs had been altered before the preceding interview and were still altered, should properly have answered that there had been no alterations since the preceding interview. The respondents identified a variety of alterations, including physicial lightening of their work, less responsibility, changed pace of work, shorter hours, and other people helping them. In making these replies the respondents identified as changes both the formal alterations in the work that was expected of them, and the changes in their own behaviour within the job. More specific questioning about informal adaptations within the job might have elucidated a greater number of the latter kinds of change.

Two British research studies have reported data on more subjective aspects of patients' experiences of returning to work after myocardial infarction. They were in broad agreement that about one-third of hospital patients anticipate problems in relation to their return to work. The problems were both general anxiety and specific concerns with, for example, physical capacity to manage the job, their dislike of the job, or their relationship with their fellow-workers (Cay et al, 1972; Finlayson and McEwen, 1977). In the longer term, Cay et al found that about 35 per cent of their series experienced problems at one year, most of them serious. Finlayson and McEwen found that 30 per cent of their series had continuing problems, and again most of them were serious. In the present study, those respondents who were in employment were asked in each of the follow-up interviews whether they had any problems with their job because of their illness. Those who said yes were asked what the problems were. From the replies it has been possible to ascertain whether the contents of the problem related to the time of the interview or to some future time, e.g. a problem that would have to be faced after the respondent had returned to work.

Table 3.11 shows that half the respondents on sick leave said that they had problems with their jobs. Most of these related to the future, in the sense for example of people worrying whether they would be able to cope with their job when they got back to it. But some were of more immediate concern, as with people who were worried about losing their jobs because of their illness. Table 3.12 shows the variety of problems experienced or anticipated by people who were off sick. Nine or ten people, at each of the second and third interviews, said they would have problems with lifting or heavy work. For example, one shop assistant and delivery man, when asked whether he had any problems with his job, said:

> "Not now, but I will do. I won't be able to lift and carry things. And I do deliveries, which means lifting."

Slightly smaller numbers of people who were off sick feared that they would not be able to do their job or that they might lose it. Often this was related to the physical demands of the job. For example, the manager of an off-licence said at his third interview:

> "I can't go back to that job. The doctors have told me that. The work is far too heavy."

At the second interview several people identified a variety of other problems: some were worried about travelling to work, especially commuting every day to London; others with the stress and the strain of their work, which they felt they would not be able to stand again.

The problems identified by the people who were off work sick are important, not only for the immediate distress they caused, but also because of their relationship to future events. Of the 14 respondents, who said at the second or third interview that they anticipated problems in relation to their work, and for whom a complete set of interview data is available, 12 said at a subsequent interview, that they were actually experiencing some problem. Of these 12, three were still off sick but were facing more urgent problems about what they would be able to do; four had returned to work, but were having difficulties performing particular tasks; and five had become unemployed. Nearly everyone, who was off sick and anticipated problems in relation to their work, experienced them subsequently.

Table 3.13 shows that a quarter of the respondents who were at work said at one of the follow-up interviews that they had problems with their jobs. The number with problems increased from two at the third interview to nine at the fifth. Table 3.14 shows that a few respondents who were at work at the time of the fourth or fifth interviews said that they had problems with lifting or other physically heavy tasks. One man, who was a farmworker in an orchard, said:

> "I can't do the jobs that I would normally have done, like digging and planting. The boss won't send me on those jobs."

A few people said, in general terms, that they were unable to do their job. The only clearly identifiable group of problems experienced by those at work were expressed in psychological terms. Five people mentioned worry, stress or irritability at work. For example, a foreman mains layer, who had returned to work four months after his infarct, said at the fifth interview:

> "I get a bit fed up when something goes wrong. It gets on top of me and I fly off again. I don't seem to have the patience with the job now. Everything seems too much trouble. I'm just not interested anymore - I just go there."

With these exceptions few problems were identified by the respondents who had actually returned to work.

4. THE OVERALL LEVEL OF WORK PROBLEMS

By relating the data about the unemployed, the sick and those at work, we may reach an assessment of the overall level of problems experienced by the present series of coronary patients. Table 3.15 shows that 37 of the 52 respondents (over two-thirds of the total) said at some stage during the follow-up period that they had a problem with their job or employment. About half the respondents said they had a problem, at the second interview six weeks after the infarct. This is a somewhat higher level of work-related problems than reported by Cay et al(1972) and Finlayson and McEwen (1977) in their hospital based studies. This might be expected as life and death problems recede in the patient's mind and work problems emerge, during recovery. The table also shows that just over one-third of the respondents at each of the subsequent interviews said that they had a work-related problem. This figure is practically identical with that reported by Cay et al for one year after the infarct, and by Finlayson and McEwen for "continuing problems".

The present study provides clearer data about the nature of infarct patients' work problems than has been reported in the British literature. More people who were off sick than who had returned to work said they had, or would have, a problem. Altogether 18 respondents (one-third of the total) identified a problem with their work, because of the physical demands of their job, because it was a heavy job, or because of the lifting involved. Twelve respondents (one-quarter of the total) expressed a fear that they would not be able to do their job or that they would lose their job because of their illness. And six people were concerned about the mental stress and distress they experienced in their jobs. In addition to these problems of sickness absence and work, 13 respondents (one-quarter of the total) experienced

unemployment at some time after their infarct. In 10 cases, the unemployment appeared to be caused by their illness. These people experienced financial problems and suffered from mental distress in a way that is known to occur among the unemployed, but which has not been documented previously among infarct patients.

We have shown in Table 3.15 that there is quite a high frequency of work related problems at each point in time after the original infarct. But the table does not make it clear whether it is the same people who experienced problems at each point in time, or whether it is different people at each point in time. In order to examine this question more closely, it is necessary to study those 45 respondents for whom a complete set of five interviews is available. Table 3.16 shows the number of respondents who identified work-related problems at different interviews and combinations of interviews. The first impression that emerges from this table is one of variety and differences between individuals. Ten respondents reported problems at one interview only, but seven reported them at all four interviews. Fifteen respondents reported problems at consecutive sequences of interviews, but eight reported them at two or three separate interviews. It is clear that there is no uniform pattern in the time at which individuals experience work related problems after myocardial infarction. The second main point to be learnt from the table is that 20 of the 24 respondents who identified problems at the third or fourth interview had previously done so at the second. For these people an early vocational assessment should be feasible. The third point is that, although most of the people who identified a problem at the fifth interview had previously done so, there was no consistency in the time at which this had occurred. From all this material it may be concluded that early vocational assessment might detect most work-related problems in coronary patients, but that it would not detect them all. This study has raised questions about the variations in the time at which individuals experience problems, but more research would be needed to clarify the picture further and explain those variations.

5. INCOME

In each of the follow-up interviews, the respondents were asked about the effects of their illness on their income. This appears to be the first time that such data have been reported from a British study. In each interview, the respondents were asked what their own income, after deducting tax and national insurance, was at that time. Table 3.17 shows that just under half the respondents at each of the interviews had incomes of between £20 and £40 per week. The number of people with low incomes fell slightly between the infarct and the second interview. Most of this fall was regained by the fifth interview,

at one year, but not earlier. Table 3.18 paints a more detailed picture. More than a third of the respondents at the second and third interviews had incomes which were less than 90 per cent of their pre-infarct level. Nineteen respondents (one third of the total) reported incomes that were less than 70 per cent of their pre-infarct level, at some stage during the follow up period. At the fourth and fifth interviews a substantial number of people reported higher incomes than they had earned before their infarct. Most of these appeared to be wage increases paid at a time of high inflation.

Unemployment was the factor most clearly related to reductions in income. Eight of the nineteen people with substantially reduced incomes were unemployed at the time. In each of these eight, their heart condition appeared to be the cause of their unemployment and thus of their loss of income. Six of them had incomes of less than half their pre-infarct level, sometimes reduced to around £10 per week, near the basic rate of unemployment benefit. Four of the unemployed men did not experience reduced levels of income after their infarct; three of them because they had been unemployed previously, and one because his income had been only £11 per week. Unemployment after myocardial infarction was almost invariably associated with low or reduced incomes.

Dependence on national insurance sickness benefit, in the absence of an occupational sick pay scheme, was the second factor that was related to reductions in income. At the second interview, for example, the income of employees receiving sick pay from their employers was on average 90 per cent of its pre-infarct level. The income of those not receiving sick pay was 66 per cent of its pre-infarct level. Twenty-four of the 28 employees receiving occupational sick pay at the second interview had incomes of 70 per cent or more of their pre-infarct level; five of the eight not receiving such sick pay had incomes of less than 70 per cent of their pre-infact level. A few people receiving sick pay from their employer has substantially reduced incomes, and a few not receiving it maintained their income. For the majority the presence or absence of an occupational sick pay scheme was the decisive factor in determining whether or not their income during their sickness absence stayed at its pre-infarct level or not.

After being asked the amount of their income, the respondents were asked in each interview whether they had any problems or difficulties because of the effect of their illness on their income. Table 3.19 shows that half the respondents said at one of the interviews that they currently had a problem of this kind, and that several more said they would have in the future. About one quarter of the respondents said at each interview that they currently had a problem or difficulty because of the effect of the illness on their income. This is a substantial number of people.

Several factors were related to the presence of current problems with income. The most important was the relationship between the respondents' pre-infarct income and their income at the time of the interview. For example, six of the eleven people, whose income at the third interview was less than 70 per cent of its pre-infarct level, said they had problems. Four of the 28 people, whose income at the third interview was 90 per cent or more of its pre-infarct level, said they had problems. Half of the 18 people whose income was substantially reduced at any point in time said they had problems at that time. Four-fifths of the people, whose income was 90 per cent or more of its previous level, said that they did not have a problem. Reductions in income, themselves related to unemployment and the absence of occupational sickness benefit schemes, accounted for many of the respondents' financial difficulties and problems.

A number of respondents had substantially reduced incomes at particular interviews, but said that they did not currently have any difficulties or problems. Fourteen people had incomes of less than 70 per cent of their pre-infarct level at some time during the follow-up period but no current problems. This appeared largely to be a question of timing. Eight of them either said that they would have problems in the future, or actually said at a subsequent interview that they did have problems. Two people identified problems they had experienced previously. Three-quarters of the respondents with substantially reduced incomes, therefore, identified difficulties or problems, caused by the effect of their illness on their income, either at or around the time at which they reported the reduction in their income.

Four other respondents reported substantially reduced incomes but said they did not have any difficulties because of this. Three of these people reported reduced incomes at the second interview only. It may be, therefore, that the impact of the reduction in income for a few weeks after the acute infarct was not great enough to cause any problems.

Fourteen respondents said at some time during the follow-up period that they did have problems, because of the effect of the illness on their incomes, although

their incomes at the time were 90 per cent or more of their pre-infarct level. Several factors appeared to be related to the existence of problems in the absence of a reduction in income. Three people reported a reduction in their own income at an interview held earlier or later than that which they said they had difficulties. Unemployment, and particularly, a low level of income before the infarct seemed to be factors that predisposed respondents to identify problems subsequently. Eight of the 13 respondents with pre-infarct net incomes of less than £30 per week subsequently said they had problems although their own incomes had not been reduced. Three respondents' wives had stopped work, apparently to look after their husbands, causing a drop in the household income. Three respondents felt they had problems, in comparing their income to something other than the immediate pre-infarct level; two referred to their incomes before they became ill at all, and one to what he would have been earning if he had not had to give up his previous job. Two respondents felt they had problems because they had increased expenses because of their illness, and two simply because their incomes were not great enough to meet all their requirements. We can see therefore that, although most people's financial difficulties were caused by a straightforward reduction in their income, in some cases there existed a more complex relationship between the total level of income, changes in it, expectations and expenditure, that caused the respondents to experience problems.

Table 3.20 shows the difficulties or problems identified by those respondents who though that they would experience them in the future. Some of these were rather general or vague statements, saying, for example, that the person did not have problems now but might have if the illness went on much longer. One small group of people thought that they would have problems because they had used up or were using up their savings. A few people mentioned other items, such as the prospect of reduced sick pay, or difficulty with particular bills. Of the 14 respondents at the second or third interview who identified a problem that might arise in the future, six said at some later interview that they had a current problem. Although we may not have identified all the people who did actually experience financial difficulties, this suggests that some respondents may have felt concern that did not materialise in the form of practical difficulties.

Table 3.21 shows the current difficulties or problems identified by respondents at each interview. Many respondents identified more than one item. In comparison with those who anticipated problems in the future, those who were experiencing them at the time of the interview focused not so much on their reduced income and resources as on their reduced expenditure and consumption. More than one third of the respondents made general comments about the kinds of difficulties they were experiencing: that they were finding it difficult to manage or that they had had to reduce their standard of living. In the

words of one unemployed man, whose wife worked part-time:

> "It's a strain, but we are not destitute yet. Things are tight. We just about manage."

Or in the words of another man, who had been a heavy goods vehicle driver and was unable to return to his job:

> "The money is insufficient. You can't live on it. The earnings related has finished. I had that while I was off sick ... There's not enough to live on, we have to draw on our savings. They don't give you enough. With rising costs you just can't manage."

More than a quarter of the respondents were more specific, and identified particular areas of expenditure that had been affected: cars, social activities and normal household bills. One man, who had been off work for nine months and had returned to his low-paid job in an off-license, said at the fifth interview:

> "We don't eat as we'd like to. We have to wear old shoes instead of buying new ones. No new clothes - we have to make do with what we've got. Jumble sales come in useful, you just don't have to be proud. All the bills have to be kept to a minimum. We use the minimum of electricity and we can't use coal on the fire yet."

And another man, who had become unemployed and suffered a severe reduction in income after his heart attack, commented:

> "The T.V. and 'phone are cut off. We can't pay the bills. I can't pay for my life insurances, but I can't cancel them either, because after this attack I'd never get any firm to give me another one. Generally everything. We can't use the car very often."

Before he returned to work he had cancelled his life insurance. Besides these reductions in expenditure a few respondents identified difficulties caused by the fact that they were incurring greater expenses than previously. Some of these expenses were associated with changes in diet, others with rising recreational expenditure during convalescence before return to work. None of this range of problems appeared to be so severe as to constitute destitution. Rather the reductions of income and expenditure interfered with well-established and accepted patterns of living. In this sense they added to the personal or emotional problems of a few respondents, and were felt to be an unpleasant consequence of the illness by about half of the whole series.

We saw in Table 3.19 that about one quarter of the respondents at each interview said that they currently had a problem because of the effect of their illness on their income. This does not tell us whether it is the same or

different individuals at each interview reporting problems. The simplest pattern that might possibly underlie the distribution of Table 3.19 is that each of the respondents who reported a problem did so at two interviews. In fact, as Table 3.22 shows, there was no clear pattern in the number or distribution of interviews at which individuals reported problems. The variety of factors, to do with the illness, employment, income and expenditure, that result in financial difficulties, seemsto be so complicated that the problems do not occur in a uniform or regular pattern through time.

6. CONCLUSIONS

The findings presented in this chapter consolidate and extend those from other studies. The data about timing of return to work and alterations at work are broadly consistent with those of other British studies. But data, about unemployment, problems connected with work, and income, have not been reported previously in this detail. In addition the importance of the findings lies in the fact that they bring together data about a variety of different aspects of patients' work experience after myocardial infarction. Previous studies have usually focused only on one or two aspects. The importance also lies in the fact that we have been able to present data that relate systematically to different points in time after the infarct. This allows us to identify the changing nature of patients' experience and problems.

Some of the findings of the present study illustrated ways in which the respondents' experience after myocardial infarction appeared to be reasonably satisfactory. Over four-fifths of the eligible respondents had returned to work by one year. This is in line with the findings of other studies and with the recommendations of the Joint Working Party. When they were interviewed after their return to work, the large majority of respondents felt that they had returned at about the right time. Once they had returned to work, about one-fifth of the respondents at each interview were working less than 90 per cent of their pre-infarct hours. This is in the middle of the range of findings of British studies on this matter. Similarly, just under one-fifth of the respondents at each of the third and subsequent interviews, held between three months and one year, said that their jobs had been altered because of their illness. Although the data are not directly comparable, this is perhaps a lower proportion than that found in other British studies. These data suggest that the majority of respondents returned satisfactorily to work.

In other ways, the findings of the present study reveal unresolved problems. Much of the emphasis in recent medical discussions has been on the timing of return to work after myocardial infarction. In the present series a substantially lower proportion of the eligible respondents had returned

to work three months after the infarct than has been reported in any other recent British study; this is also lower than the proportion advocated by the Joint Working Party. A slightly lower proportion had returned to work by six months, than found in most other studies. About one-third of the respondents who were on sick leave at the time of the six weeks and three months interviews said that they were ready to go back to work. Nearly all said that the doctor's advice was the reason they had not done so. Nevertheless, most of these people said later that they felt they had returned to work at about the right time. It seems likely that a substantial proportion of the present series could have returned to work eariler than they did. Medical attitudes and advice would be an important factor in influencing earlier return to work.

A second area of unresolved difficulties concerns the respondents' subjective experience of problems connected with work. Over two-thirds of the respondents reported such problems at some time after their infarct. In the eariler interviews these were mostly people who were off sick, many of them anticipating difficulties in the future. In these interviews respondents were mainly concerned with their physical incapacity to do their jobs, although a number also mentioned mental problems or the fear of losing their jobs altogether. In the later interviews respondents at work reported problems with the physical demands of their jobs or arising from mental stress. As most of the respondents who anticipated that they would have problems did experience them later, the issue is not simply one of initial anxiety provoked by the illness. In many cases, the appropriate course of action would appear to consist of both a programme of activity to restore physical capacity, and an assessment of the demands of the patient's job followed, if necessary, by vocational readjustment measures. These would not necessarily consist of a whole programme of retraining and resettlement, as might be needed for a severely disabled person. Instead, it is a question of restoring the individual to as full a degree of fitness as may be attained and ensuring that the tasks he undertakes match his capacity.

A third area of unresolved difficulties was unemployment. One quarter of the present series were unemployed at some time during the year after their infarct. Most of them became unemployed because of their illness and the physically heavy demands of their jobs. The financial problems and the loss of self-esteem experienced by these people makes them a high priority for further attention from the health and employment services. There would not seem to be any great barrier to the early identification of the possibility of unemployment. Earlier active job-seeking might prevent the drift into unemployment at the end of the initial period of sickness.

A fourth area of difficulty was money. One third of the respondents in the present series reported that their income was less than 70 per cent of its pre-infarct level at some time during the year after the infarct. Half the series reported that they had current problems because of the effect of the illness on their income. Some of these problems appeared not to be very serious; they were difficulties of adjusting to reduced income and expenditure. In some cases of substantially reduced income or of persistently low income - particularly when associated with unemployment or low levels of sickness benefit - the problems were more serious. They led to substantial reductions in standards of living or increased the levels of emotional and social distress experienced by the respondents. Financial difficulties added to the medical rehabilitation problems experienced by the present series of patients.

The research that has been reviewed in this chapter and the findings of the present study provide a fairly consistent picture of patients' work-experience after myocardial infarction. Statistical data about the frequency and timing of return to work are well established. To a somewhat lesser extent, so too are data about the frequency of changes in the hours worked and of changes in the tasks performed. Similarly, one begins to see a consistent picture emerging about the frequency of subjectively experienced difficulties and problems. All these aspects of work would obviously be subject to variations due to local circumstances, but the broad picture in Britain seems clear enough.

Further research is needed in two related areas. First more research is needed into the causes of variations in the pattern of work experience and into the causes of problems. Why do some people return to work earlier than others? Why do some people become unemployed or retire, but not others? Why do some people anticipate problems in returning to work but not others? These causes may range from physiological, through the psychological, to the social and economic; or they may be a mixture of them all. When the causes of difficulties and problems are understood more fully, then it will be possible to specify and plan developments in the treatments and services more rationally. Secondly, more research is needed into the appropriateness and effectiveness of particular treatments and services in the solution of these various problems. At present much of the development of services is based only on the intuition of practitioners. As we saw in Chapter One, there has been virtually no research that has demonstrated the effectiveness of rehabilitation programmes on patients' work experience after myocardial infarction. Research of both kinds, into the causes and solution of problems, is required in order to promote the more effective planning and development of rehabilitation services.

CHAPTER 4 LIFE AT HOME AFTER MYOCARDIAL INFARCTION

This chapter examines the pattern of respondents' lives at home after the myocardial infarction. It presents data about the respondents' expectations while in hospital of what they would be able to do at home, and then examines the actual activities undertaken and difficulties experienced at home. It examines in more detail the impact of the illness on the respondents' spare time activities. And it then widens the perspective a little from the respondents themselves, to describe the impact of the illness on their family and friends. In all of this material we shall be concerned to describe the effect of the illness on the respondents' day-to-day life at home, to identify the difficulties and unresolved problems they experienced, and to begin to specify their unmet needs for services.

By way of introduction, we may recapitulate briefly some of the data, presented in Chapter Two, about respondents' domestic circumstances at the time of their heart attack. Forty-seven of the respondents were men and five women. All but one were aged between 40 and 59. Forty-seven were employees or self-employed, two were housewives and three were not employed. At home, 20 lived with their spouse only and 27 lived with their spouse and children. Nearly all of the respondents lived in owner-occupied or local authority rented houses or bungalows. The majority of respondents were middle-aged men, living at home with their families in Canterbury or the surrounding area, and going out to work each day.

1. DOMESTIC ACTIVITY

During the last twenty years or more, there has been a steady growth of medical interest in early mobilisation and progressive re-activisation after myocardial infarction. The authors of numerous British studies have concluded that early mobilisation is both safe and desirable. Similarly, a considerable amount of research and professional discussion has stressed the advantages of active exercise as a method of rehabilitating patients. In this context there has been a certain amount of research examining the amount of different kinds of activities that patients undertake after infarction, but very little about patients' expectations about what they will do or should do. Patients' expectations are important, because it may be that medical staff and therapists believe in the value of exercise and an active life, and that patients believe that there are dangers attached to doing too much and that they should therefore do little.

Although the respondents in the present study were not questioned systematically about their beliefs about the advantages or disadvantages of exercise, they were asked in the first interview, what they expected to do when they first left hospital. This was an open-ended question; many respondents mentioned more than one item. The overwhelming majority of respondents gave replies that included a mention of a minimum activity. Forty-six of the fifty-two respondents mentioned such things as "Do nothing","Sit about", "Rest" or "Take it easy". These people were not orientated towards reactivation. A number of respondents also mentioned specific activities that they expected to undertake. These are shown in Table 4.1. Eleven respondents mentioned jobs around the house; most of them said they would be doing only a little of such activity. Sixteen respondents mentioned exercise; again the large majority indicated that it would only be a little. Five respondents mentioned physical recreation and eight other kinds of recreation; in these instances the majority envisaged that they would be doing quite a lot of the activities mentioned. Seventeen respondents said that what they would do at home would depend on the advice they were given by the doctors or other staff. From these data we can see that many respondents did not have very clear expectations about what they would be able to do at home and many expected to do very little. Among those who did have expectations of doing things, more were orientated towards doing a little work around the house or a little exercise than a lot. More were orientated towards doing quite a lot of recreational activities than a little. This suggests that recreational activities may be a useful point around which to build reactivation at home after myocardial infarction. Doctors and others may be able to encourage patients to look forward to and resume pleasurable recreational activities, which could form part of a programme of progressive reactivation.

It is to be expected that many people would experience substantial restrictions on their daily activities at home after myocardial infarction. Although there has been no research that has examined the frequency or nature of difficulties that are experienced, the level of incapacity that has been reported in relation to work, recreation and sexual activity indicates that many other activities would also be affected. In each of the follow-up interviews, the respondents were asked whether they had difficulty doing things round the house because of their illness. Table 4.2 shows that nearly all the respondents said that they had difficulty at some time after their infarct. At least half the respondents at each interview said they had some difficulty. In addition, a quarter of the respondents at the second interview said they had no difficulties around the house because they were not doing anything yet. For many people the effects of their illness lasted a long time after the initial infarct.

Although just over half the respondents at the third and subsequent interviews said they had difficulty around the house, it was not always the same people at each interview who had difficulty. Table 4.3 shows that 14 respondents reported difficulties, or that they were not doing anything around the house, at all four follow-up interviews. Four people reported difficulties at no interviews at all and six at the first interview only. Otherwise there was great variability in the pattern of interviews at which difficulties were reported, with respondents reporting difficulties at different times both early and late in the follow-up period.

Those respondents, who said that they did have difficulty doing things around the house because of their illness, were asked to identify the activities they found difficult. Some people may not have identified particular activities as difficult because they were not undertaking them at all. This question followed one about recreational activities, which may explain the fact that very few people identified recreation in this question. Table 4.4 shows that almost half the respondents said they had difficulty with everything. The activities most frequently identified were house repairs and decoration, outdoor activities such as gardening, lifting things, and other physical activities such as bending, stretching or climbing steps. From the data, two points may be noted. The first is the variety of activities identified as difficult. These were identified both in functional terms - lifting, climbing, bending - and in terms of activities of daily living - making beds, digging the garden. The second is the absence of a very clear pattern in the number of respondents reporting difficulties in each activity in each interview: for some activities the numbers fell with time, for some they rose, and for some they were variable.

After being asked in general terms about their difficulties around the house, the respondents were asked specifically whether they had difficulty going up stairs. Those who replied that they did have difficulty were then asked what problems this caused. In considering the answers to these questions it should be noted that 16 of the respondents lived in bungalows and two in other accommodation without stairs. Table 4.5 shows that about one-quarter of the respondents at each interview said that they did have difficulty with stairs. Only a few of these respondents said, when asked, that their difficulty with stairs caused any problems. Of those who did have problems, each mentioned two or three things, such as physical distress, emotional upset, restriction of activities or disruption of the family routine. Although an appreciable number of respondents reported difficulty with going upstairs, many had found ways of coping with the stairs or with the difficulties.

Table 4.6 shows the number of respondents who, when asked whether they had difficulty with stairs, made spontaneous comments about how they coped with them. The most frequently mentioned method was that of going slowly, but several people said that they did not use the stairs as much as previously, especially during the day. In summary, it can be seen that half the respondents reported difficulty with stairs at some time during the follow-up period and that most had found ways of coping with this difficulty. For a few people, however, the difficulties with stairs were associated with a variety of personal problems.

2. RECREATION

There has, in recent years, been a certain amount of interest in recreational aspects of recovery and rehabilitation after myocardial infarction. Although there has been a movement among occupational therapists away from the view that they should provide diversional therapy, some individuals have emphasized the importance of recreational activities, both as a means of rehabilitation and as an end towards which rehabilitation should be aimed (Thompson, 1966). Research studies have found that the recreational activities of perhaps one half of the survivors of myocardial infarction are affected at any one point in time several months after the infarct (Martin, 1967; Finlayson and McEwen, 1977). The only information in the research literature about the kinds of recreational activities affected was presented by Finlayson and McEwen, who found that 41 per cent of their series were undertaking less physical activity at six months than before their infarct, and that 37 per cent were undertaking less social activity.

In the second interview, the respondents were asked what hobbies and spare-time activities they did before they became ill, and what they were doing at the time of the interview. In each of the subsequent interviews, they were asked again what they were doing currently. These were open-ended questions, and presumably resulted in some variability between respondents in the nature and amount of information they produced. The respondents varied considerably in the number of activities they mentioned and in what they identified as distinct activities. One person might have mentioned for example, cricket and tennis, while another might simply have mentioned sport, but be playing the same amount of the same two games. This has caused difficulties in comparing the replies of different respondents. The solution adopted was as follows. The replies of a sample of respondents were scrutinised, and all the individual items listed. These items were then classified into 24 fairly distinct activities or groups of activities (as shown in Table 4.9). In the data processing, six variables were allocated to each respondent. In each variable, any one of the

24 activities could be coded. Each activity could only be recorded once for any one respondent, even though two items (e.g. cricket and tennis) might have been mentioned. If any respondent identified more than six activities, only the first six were recorded. In the data analysis, the six variables were combined, to produce a consolidated list of the number of respondents who mentioned each activity. The activities were also grouped together, according to whether they took place in the home, around the home or away from the home. We are therefore able to count the total number of spare time activities undertaken by respondents at different times, and to identify those activities.

Table 4.7 shows the number of respondents who identified different numbers of spare-time activities at different times. The modal number of activities reported as being undertaken prior to the infarct was three. Before the infarct there was a considerable variation in the number of activities undertaken; six respondents undertook one activity only and six undertook six or more. At the time of the second interview there was an appreciable reduction in the overall number of activities. By the time of the third interview, the number of activities had returned to the pre-infarct level, but it showed another decline in the fourth and fifth interviews. It seems possible that this rise and subsequent fall is associated with a resumption of activity at about three months, before returning to work, and with a subsequent reduction in the amount of time available for spare-time activities after returning to work.

Table 4.8 shows the number of respondents who identified different numbers of spare-time activities that they undertook inside their homes, around their homes and away from their homes. The number of activities in the home rose between the time before the illness and the time of the second interview, and it fell again between the third and the fifth interview. The number of activities undertaken in the immediate vicinity of the home fell appreciably between the time before the illness and the second interview, and it returned to its previous level by the fourth interview. The number of activities undertaken away from the home fell very substantially between the time before the illness and the time of the second interview, and it increased again a little at the third and fourth interviews, but never to the previous level. The overall picture, therefore is one of an increase in the number of spare-time activities within the home during the first three months after the infarct, with a subsequent reduction to just above the pre-infarct level; of an initial reduction in the number of spare-time activities around the home, that had returned almost to the pre-infarct level by six months; and of a substantial reduction in the number of activities away from home, that had not returned to its pre-infarct level one year later.

Table 4.9 shows the number of respondents who said at each interview that they were undertaking different spare-time activities. Even within the home or around the home, different activities were taken up or relinquished by different numbers of people at different times. Within the home, there was a group of activities, which were undertaken by very few people before the infarct, by an increased number at the time of the infarct, and a gradually reduced number subsequently. These activities included reading (which was the most frequently mentioned single activity), listening to music or watching television, letter-writing or telephoning, and playing games. All of these require little physical exertion. Within the home, the number of people undertaking do-it-yourself activities, such as home repairs or decorations, showed systematic variations. The number of people undertaking these more strenuous activities fell between the time of the illness and the time of the second interview, and then rose again, but not to the previous level. The activities undertaken around the home varied in similar ways. The number of people undertaking do-it-yourself activities, such as car maintenance and outside house repairs, and gardening fell substantially between the time before the illness and the second interview and then rose again. The number of people taking walks, however, rose up to the time of the third interview and fell subsequently; in this, walks were an activity of convalescence. Away from home, the numbers of people undertaking each activity fell between the time before the illness and the time of the second interview. The numbers rose again subsequently, but never to their pre-infarct level.

It is not so much the number of spare-time activities that are affected by myocardial infarction as their nature. The effect of the illness was to reduce the amount of physically strenuous activity in and around the home and of all activity away from the home, in the months immediately following the infarct. These activities were replaced, during convalescence, by less demanding ones, such as reading or listening to music. From the third month onwards, there was a gradual resumption of the more strenuous activities and a relinquishing of the less strenuous ones.

A further understanding of the activity of convalescence can be obtained from a variety of unsolicited comments made by the respondents in reply to the questions about their spare-time activities. Table 4.10 shows the number of respondents who made various comments that reflected the level or nature of their spare-time activities. The main feature of this table is the fairly high number of people, who said that they were doing nothing at the time of the follow-up interviews. A comparison with Table 4.9 shows that most of these people also identified one or more spare-time activity. Presumably, therefore,

these replies should be interpreted as meaning that the respondents did not have a great deal to do in their spare time. If we added the number of those who said they were doing nothing to those who reported that their activities were restricted or that they were not doing much, we find that between one-quarter and two-fifths of the respondents at each interview made comments indicating diminished activities. Furthermore, the table shows that a number of respondents (11 in the second interview, diminishing to four in the fifth) identified relaxing or just sitting among their spare-time activities. Clearly, many people saw the months after the infarct as a time of substantial diminution of activity.

Table 4.11 shows the number of respondents who made comments that revealed something of their attitude towards or their view of their spare-time activities. Overall, only a few respondents made such comments. At the second interview, five respondents revealed boredom or dislike of their spare time, and three said that they were unable to concentrate on their spare-time activities. At each of the third and subsequent interviews, a few respondents commented that they could not do much, because of their illness, or that they avoided strenuous activities. These comments, which were unsolicited responses to a specific question, suggest that recreation poses a significant personal problem for a fairly small minority of patients after myocardial infarction. Although the infarct appreciably affected the nature and amount of spare-time activities of a majority of respondents, and although the majority said that this was important to them, the evidence as to whether this constituted an important problem is incomplete.

3. EFFECT ON THE FAMILY

The final aspect of the pattern of life at home to be examined in this chapter concerns the effect of the infarct on other people. Logically, this topic might be divided into two parts: the effect of the respondent's illness on other people, and what other people did in order to adapt to the illness or help the respondent. In this study we report both of these subjects together, as the data were obtained in a single set of questions in the follow-up interviews. The emphasis here is on the practical arrangements made by the family and other people. More detailed data, from the spouse's point of view, about the personal and psycho-social effects of the illness, are available in the complementary study of the wives of some of the men in this study.

In each interview the respondents were asked a series of questions about the effect of the illness on their family or other people: whether anyone had

come to stay; whether anyone had been coming in to help; whether anyone had been staying off work or going out to work, who would not otherwise have been doing so; and whether they had made any other alterations or rearrangements because of the illness. Table 4.12 shows the number of respondents who identified various domestic alterations or rearrangements that had been made at home because of their illness. The most frequent effect was someone - usually the wife - staying off work or rearranging their work, because of the illness. A number of people said that there had been alterations to the household's domestic arrangements, either people coming to stay or coming in to help, or moving a bed downstairs. Nearly all these changes and alterations were reported at the first or second interviews. A substantial minority of respondents identified changes at home that occurred because of their illness; these changes were concentrated around the time of the respondents' return home after discharge from hospital.

After being asked about the alterations that had been made, the respondents were asked in each follow-up interview whether there were any alterations or rearrangements that needed to be made at home because of their illness. Table 4.13 shows that very few respondents identified such needs. The only distinctive items were concerned with stairs or access to toilet facilities, which were mentioned by two or three respondents in each interview. There did not appear to be a high level of unmet needs for practical domestic arrangements.

4. CONCLUSIONS

Myocardial infarction caused substantial restrictions of activity among the respondents; these restrictions persisted for many respondents for much of the subsequent year. More than half the respondents at each interview reported difficulty with household activities, and a wide variety of activities were implicated. There were substantial reductions in the numbers of people undertaking the more strenuous spare-time activities in and around the home, and in the numbers undertaking all kinds of spare time activities away from home. There was only a gradual and incomplete resumption of these activities during the year after the infarct. Corresponding with the inactivity, a substantial minority of respondents identified alterations or changes in their family's routine that were caused by the illness, mainly around the time of discharge from hospital.

Although we have evidence about the extent of respondents' incapacity, we have less data to show that this incapacity constitutes problems severe enough to warrant attention from the health or social services. Although about a

quarter of the respondents said they had difficulty with stairs, most had developed ways of coping with this (by going slowly or avoiding using them), and very few stated that the difficulty caused them problems. Although more than half the respondents at each interview said they had difficulty in various activities around the house, very few identified any alterations or rearrangements that were needed. The data therefore do not constitute an immediate case for the development of services to improve the domestic circumstances of patients with myocardial infarction.

Argument in favour of the further development of services in this area might be based on one or more of four considerations. First, it might be thought that more systematic investigation of the personal and emotional problems associated with incapacity and inactivity at home might reveal unmet needs felt by the respondents themselves. Second, it might be argued that an increase in the domestic and recreational activity of patients would in itself contribute to an increase in their welfare, even though they themselves might not realise that such an increase was feasible. Third, it might be argued the rehabilitation process is an indivisible whole, and that an increase in the level of patients' activity at home would have beneficial effects on their medical condition, their morale and their working capabilities. Fourth, evidence may become available to show that, although incapacity may not cause severe personal problems for the incapacitated individual, it does cause appreciable problems and costs for other people, whether they be family members, relatives or friends. The health and rehabilitation services are not closely involved in patients' daily life at home after his heart attack. Further study might show that a closer involvement might produce substantial benefits to patients during their recovery.

CHAPTER 5 THE LEVEL OF INCAPACITY

This chapter examines the overall level and the changing pattern of the respondents' personal incapacity during the year after their infarct. The first section reports an attempt to measure systematically the effects of the illness at different times after the infarct. This is the first time this kind of systematic measurement has been undertaken in relation to infarct patients. The intention is to obtain an indicator of the extent and severity of incapacity, that is broader than the usual return-to-work data, and that shows where problems may exist and where intervention may be needed. The second section of this chapter examines in more detail the individual items of incapacity identified by the respondents. This will allow us to focus on different kinds of problems in turn, and to discuss what kind of rehabilitation and aftercare services, if any, may be appropriate. Most of the material on incapacity that is included in this chapter has been drawn from a single set of questions in each interview. It will set the specific data on work, income and life at home in a broader context than was possible in the last two chapters.

1. THE OVERALL LEVEL OF INCAPACITY

In Chapter One we reviewed the literature on recovery after myocardial infarction. Although a certain amount of emphasis has been placed on the importance of comprehensive rehabilitation (Hellerstein and Goldston, 1954; Groden et al, 1971a; Naughton, 1973), virtually no empirical research has made use of correspondingly comprehensive measures of recovery. Spelman and Ley (1966) measured recovery in terms of the level of activity revealed in patients' accounts of a usual day in their lives. They found that 61 per cent of their subjects had returned to 90 per cent or more of their pre-infarct level of activity six months after their infarct. This seems to be the only study that has examined the effect of the infarct on a combined set of patients' activities. There have not been any observations of the changes in the pattern of recovery, as measured in this way, through time.

Many studies have examined the impact of myocardial infarction on one or more individual aspects of patients' activities. These studies allow us to predict something of the pattern of overall incapacity. The Joint Working Party (1975) suggested that return to work is the best available indicator of recovery. On page 18 of this report we saw that most British studies had found that between 10 and 50 per cent of infarct patients had returned to work by two months, between 35 and 45 per cent by three months, and between 65 and 85 per cent by six months. There tends to be a small decline in the proportion

subsequently at work at any one time. This suggests something of the total pattern of returning capacity that might be expected. Other factors suggest that a somewhat flatter curve would be found for total capacity than for return to work. Return to work is the resumption of a single activity and incapacity scales are based on numerous different activities. Therefore, it is to be expected that patients will have resumed some activities before they have returned to work. Similarly, many people who have returned to work will not have resumed all their activities and will be still affected by the illness in many ways. Many examples can be given, from the literature reviewed in Chapter One. Kushnir et al (1975b) found that 19 per cent of their series were working shorter hours at ten months than before the infarct, and Cay et al (1973) found that 34 per cent of their series had problems at work at one year. Three of the four studies mentioned on page 21 found that between 25 and 35 per cent of patients had reduced levels of sexual activity at about one year. Finlayson and McEwen (1977) found at one year that there had been long-term alterations in the family responsibilities of 50 per cent of their series. And it was suggested, on page 26, that about one half of myocardial infarction patients experience emotional distress for most of the first year after the infarct. All this evidence suggests that the simplicity of the return to work figures may be misleading, and that we should expect the infarct to have an appreciable and varied impact on many aspects of many patients' lives for at least one year after the infarct.

There has been a substantial amount of research literature in recent years that has reported attempts to measure the impact of illness on sick people's activities and well-being. These have included the assessment of motor impairment (Jefferys et al, 1969), of disability in activities of daily living (Katz et al, 1963; Garrad and Bennett, 1971; O.P.C.S., 1971a), and of the comprehensive pattern of daily life (Grogono and Woodgate, 1971). In the present study it was decided to use the last-mentioned of these scales - the Grogono Index - to provide data about patients' incapacity. This was one of the broadest-based scales, that had been published at that time, covering such items as physical suffering, mental suffering and communication, as well as the more frequently studied activities of daily living. The Grogono Index was included in the study, both for the sake of the substantive information that it would provide and to assess its potential usefulness in evaluating rehabilitation services. The decision to include it was particularly valuable, in the light of the subsequent statement by the Joint Working Party (1975) of the difficulty of finding a suitable measure of rehabilitation outcome other than return to work.

The Grogono Index originated in an attempt by Grogono and Woodgate to find an index for measuring health. The index they published was concerned not so

much with health as with the impact of ill health upon the sufferer. They identified ten aspects of daily life, which they thought were comprehensive but without obvious redundancy. These were work, recreation, physical suffering, communication, mental suffering,/sleep, dependency on others, feeding, excretion and sexual activity. Each patient received a score for each item, according to whether his illness had a substantial or partial (harmful) impact. The total score for each patient could then be calculated by simple addition. Grogono and Woodgate argued that the index could be used to assess priorities for treatment or to examine the efficacy of treatment.

The scale has been used with very little modification in the present study. The main change was that the items in the scale were completed in writing by the respondents during each interview, rather than by the patient's doctor. This should have reduced inaccuracies due to lack of information, but may have increased variability due to differences of interpretation. Two other changes stemmed from the first. One related to the classification of each item. Grogono and Woodgate based their system on whether the patient was incapacitated, impaired or normal; in the present study we asked whether the illness or anything to do with it interfered completely, slightly or not at all with each activity. The second change related to the wording: malaise, micturition and defaecation were phrased in everyday language. A further change related to the arithmetical manipulation of each respondent's score. Grogono and Woodgate scored each item 0, ½ or 1, added the total, and divided by 10 to give each patient a score of between 0 and 1. In the present study we have scored each item 0, 1 or 2, and added the total, to give each respondent a score of between 0 and 20. Despite these minor changes, the contents of the scale and the handling of the data are basically the same as in the original publication.

The opportunity has been taken to add certain features to the scale, to help assess its value and to increase its usefulness. Grogono and Woodgate felt that the scale covered the main aspects and activities of daily living, while avoiding the difficulties of trying to make use of the all-encompassing World Health Organisation definition of health, as a state of complete physical, mental and social well-being. From the social scientist's point of view, however, the scale is inclined towards the performance of personal activities and biological functions, and away from such areas as family activities, social relationships and finance, on all of which illness and disability may have a major impact (Blaxter, 1976; Cunningham, 1977; Finlayson and McEwen, 1977). In the present study, after completing the scale, respondents were asked whether there was anything else about their illness that was particularly important to them or worried them. The answers to this question, and others in the interview, allow us to make some assessment of the claim to comprehensiveness and to consider whether other items should be included in the scale.

The second major addition to the scale has been an attempt to weight the different items according to their importance. As Culyer (1976) has pointed out, the scoring procedure devised by Grogono and Woodgate allocates an equal score for incapacity in each item. Yet it may be that a person's work is far more important than his recreation, or vice versa. In the present study, one step has been taken towards establishing whether the system of equal weights is a defect and, if so, towards remedying it. Respondents were asked whether their illness interfered with each item in the scale. Those who said that it did interfere, for any particular item, were then asked how important it was to them. This question was deliberately phrased so that the respondent did not have to make a fine distinction as to whether it was the item (e.g. work) or the interference of the illness with the item, that was important. Those who said it was very important have had two points added to their score for that item, those who said it was important have had one point added, and those who said it was not important have had no points added. This leads to a second scale, ranging from nought to 40 points, which can be compared to the original. A further addition, relevant to the weighting of the scale, was a question, immediately after it had been completed, which asked the respondent which of the things about the illness was most important. This information could be used to provide an additional weighting for different items; in the present report it is used to provide supplementary rather than modificatory information.

Table 5.1 shows respondents' scores on the Grogono Index at each interview. These scores take account only of the amount of interference with each activity, and not of the respondents' assessments of the importance of each item. The scores could range from no points, indicating no incapacity, to 20 points, indicating complete incapacity. The scores have been grouped into classes for ease of presentation, and the classes labelled "no incapacity", "little incapacity", "moderate incapacity", "severe incapacity", and "very severe incapacity". The mean score at the first and second interviews was eight points - moderate incapacity. At the third interview, the mean score was six points, and, at each of the subsequent ones, it was five points - on the borderline between light and moderate incapacity. The scores of the respondents were fairly closely distributed around the mean. Most people experienced moderate, but not very severe, effects of their illness at the time of the first interview 10 days after their infarct. The effects diminished gradually and slightly over the following weeks. Seven months after admission most respondents experienced little or no incapacity, but about one-third experienced a moderate amount. One year after admission the level of incapacity of a few respondents had risen again, so that the average level was slightly higher than it had been at seven months. The illness had more long-term effects than would be shown by the simple use of return-to-work as indicator of incapacity. The findings are consistent with the continued

problems and restrictions of activity at work and at home, that we examined in the previous two chapters. In many cases, some effects of the illness persist for many months after the acute infarct.

There appeared to be very little relationship between respondents' medical condition and their score on the Grogono Index. There was no relationship at all between the severity of the infarct, as measured by the Norris Coronary Prognostic Index, and the scores on the Grogono Index at any of the five interviews. The severity of the initial infarct was not related to the later personal and social effects of the illness. There was very little relationship between medical symptoms or events, connected with or related to the heart, which the respondents reported as having occurred since the previous interview, and the scores on the Grogono Index at each follow-up interview. The only exception to this was that the majority of those with a score of 11 or more points on the Grogono Index reported symptoms or events directly connected with their heart; only a minority of people with such symptoms were severely incapacitated. We have no data to show a clear positive relationship between the respondents' medical condition and the broader effects of their illness.

The Joint Working Party (1975) asserted its belief in the importance of returning to work as a milestone on the way to full recovery. By comparing the respondents' work position with their scores on the Grogono Index, we can see whether return to work is closely related to other aspects of recovery. Table 5.2 shows that those people at work had, on average, lower scores than people who were off sick. To some extent, therefore, return to work is a good indicator of broader aspects of recovery. It is, however, an incomplete indicator. At each of the interviews, more than a quarter of the respondents at work had scores of six or more - moderate incapacity. And at the first and second interviews about a quarter of the respondents who were off sick had scores of less than six points - little incapacity. Some people have substantially recovered before they return to work; others continue to feel the effects of their illness after they have returned to work. This is enough to show that it is not a single, clear-cut group of people who experience all the problems at any one time after myocardial infarction. No single indicator of recovery will identify all the problems and other effects of the illness.

Table 5.1 shows that, on average, the respondents' level of incapacity tended to improve with time. This masks variations in the pattern of individuals' recovery. In fact, 21 of the 45 respondents, for whom a complete set of interview data is available, showed a straightforward pattern of improvement between the interviews. They reported, for example, moderate levels of incapacity at the first two interviews, and little incapacity subsequently. Another eight

respondents stayed at about the same level of incapacity at all five interviews; they showed little improvement or deterioration during the follow-up period. Six respondents showed a deterioration between the first and second interviews, and a subsequent improvement. This suggests that they may have made an unrealistically low evaluation of the effects of their illness while they were in hospital. Four respondents improved between the first and fourth interviews, but deteriorated again by the fifth interview, one year after their infarct. And a further six people deteriorated at one other, or at more than one, of the follow-up interviews, for example at the third or at the fourth and fifth interviews. We can see, therefore, that the condition of two-thirds of the respondents improved or stayed the same during the follow-up period. And the condition of one-fifth of the respondents deteriorated at some point in time after the second interview at six weeks.

This far, we have been considering the scores on the Grogono Index, unweighted for the importance that the respondents attributed to each item. Table 5.3 shows the effect of adding in scores for respondents' assessments of the importance of each item. For each item where the illness was said to have some impact, respondents scored two points if they said it was very important, one point if they said it was important, and no points if they said it was not important. This gives a theoretically possible range of scores from nought to 40 points. These scores have been grouped in the same way as previously, indicating no, little, moderate, severe or very severe incapacity. Table 5.3 shows that there was very little modification to the overall distribution of incapacity scores, resulting from the introduction of weighting for importance. The only differences were a slight lowering of scores in the first two interviews and a slight raising of scores in the third and fourth interviews. This suggests that, when the Index is being used to assess the overall level of incapacity among a series of patients, it may not be worth allocating different weights to the separate items in the scale.

2. THE INDIVIDUAL ACTIVITIES AND ITEMS OF INCAPACITY

The respondents experienced a considerable amount of ill health and incapacity during the year after their infarct. The illness affected the work, income, recreation and life at home, and resulted in moderately severe levels of incapacity for many people. This section of the chapter will use the information collected systematically in the Grogono Index to examine the individual items of incapacity identified by the respondents, and to discuss their relative importance. This will allow us to focus on the different kinds of problems experienced, and so to consider the nature of any unmet needs for rehabilitation or aftercare.

The research literature reviewed in Chapter One of this report gives us some indications of the personal activities that are most frequently affected by myocardial infarction. The most obvious activity is work. The British studies quoted on page 18 (Sharland, 1964; Wincott and Caird, 1966; Groden, 1967; Harpur et al, 1971; Cay et al, 1973; Shaw and McNiven, 1974; Kushnir et al, 1975a; Finlayson and McEwen, 1977) suggested that about half the eligible patients have not returned to work three months after their infarct, and that one quarter have not returned six months after it. Studies quoted on page 19 showed that some patients who had returned to work were undertaking reduced levels of activity at different times. Cay et al (1973) found that 29 per cent were undertaking reduced levels of activity at six months; Kushnir et al (1975b) found that 37 per cent were undertaking reduced levels of activity at 10 months. The studies quoted on page 20 suggested that a substantial minority of patients experienced problems at work: Cay et al (1973) reported a figure of 35 per cent for six months and for one year; Finlayson and McEwen (1977) found that 40 per cent had experienced continuing difficulties when followed up at six months. Adding these figures together, and making some allowances for overlap, we might expect to find that the work of three-quarters or more of infarct patients would be affected by their illness three months after the infarct, that the work of two-thirds would be affected at six months, and that the work of half would be affected at one year.

The research data about the effect of the illness on other activities is much less complete. The recreation of a substantial number of patients is affected. Martin (1967) reported that the outcome at three months of leisure rehabilitation was a failure in 48 per cent of patients. Finlayson and McEwen (1977) found that 41 per cent of their series said that they were undertaking less physical activity at six months than before their infarct, and that 37 per cent were undertaking less social activity. The sexual activity of a minority of patients is affected. Studies quoted on page 21 (Skelton and Dominian, 1973; Kushnir et al 1975b; Stern et al 1976) suggest that between 25 and 35 per cent of patients have reduced levels of sexual activity about one year after the infarct. The studies quoted on page 22 indicated that patients' family and financial circumstances are affected by the illness, but the proportion of patients so affected varied considerably between the studies. The emotional and psychological condition of a large number of patients may be affected by the infarct. Studies quoted on pages 25 and 26 (McGrath and Robinson, 1973; Wishnie et al, 1971; Martin, 1967; Finlayson and McEwen, 1977) suggested that all patients experienced some broadly-defined emotional distress in the period immediately after the infarct, and that about half the patients experienced distress at any one point in time between three months and one year. Similarly, it was suggested (Cay et al, 1972; McGrath and Robinson, 1973; Stern et al, 1976)

that perhaps half the patients experienced more narrowly-defined anxiety or depression in the period immediately after the infarct, and that perhaps one quarter experienced anxiety or depression at any point in time after three months. Taking all these data together, we might expect to find that work and emotional distress are the aspects of personal life most frequently affected by the infarct, that recreation and psychological status are the next most frequently affected, and that family life, sexual activity and finance are less frequently affected.

Table 5.4 shows the effect of the infarct on the various aspects and activities of daily life that were included in the Grogono Index. The respondents were asked whether their illnesses or anything to do with it interfered with the different activities, or caused dependence or physical or mental suffering. They were asked whether the effect was one of complete, slight or no interference. A small number of respondents, who identified an effect as being more than none, or less than complete, have been coded as "slight". The table shows that the work and recreation of the large majority of respondents were affected by their illness for the year after their infarct. Many people's sexual activity was affected to some extent during the follow-up period. More than half the respondents at each of the interviews said their illness caused them physical discomfort, and more than half said it caused worry or unhappiness. Between one quarter and a half of the respondents at each interview said that their illness interfered with their sleep. Most people experienced a variety of effects of their illness during the year after the acute infarct.

These findings suggest that the effects of the illness are more varied and more frequent than has been reported in the research literature. For some of the aspects of daily life, sleeping, eating and physical discomfort, there are no comparable data available. The only item, for which there was a lower frequency in the present study than in other studies, was mental distress, at the time of the first interview in hospital. At the first and second interviews the proportions of respondents who said that their illness affected their work or their recreation were about the same as found elsewhere. At the third and subsequent interviews, between three months and one year after the infarct, more people than might have been expected reported interference with their work and recreation. Similarly, at the fourth and fifth interviews, more people than would have been expected said that their illness caused worry or unhappiness or that it interfered with sexual activity. The personal and social after-effects of myocaridal infarction are more persistent and more widespread than had often been appreciated.

In each interview, those respondents, who said that their illness had an impact on any item in the Grogono Scale, were asked to say how important it was

to them. Table 5.5 shows the number of respondents who reported each item to be very important, important or not important. Because the number of people who identified an item as important is dependent upon the number who said that the item was affected by their illness in the first place, it is necessary to set the numbers in the context of the total who said that the item was affected. On the whole, the number of people who said that each item was important was a straightforward reflection of the number who identified some interference in the first place. But there were some exceptions. The proportions of people who said that physical discomfort, sleep or sex were important to them were lower than the proportions who said other items were important. These items tended to be less significant than the amount of interference indicated. The proportions of people who said that their work or the worry were important to them were higher than the proportions who said other items were important. Interference with work and existence of worry are the most significant after-effects of myocardial infarction.

So far in this section we have used data from the Grogono Index to identify those aspects of the respondents' lives that were most affected by their illness. We have seen that work, recreation and sex were the activities most frequently affected during the year after the infarct, and that many people experienced physical discomfort and mental distress during that time. After the respondents had completed the Index in each interview, they were asked several questions that elaborated on the information provided and set it in a broader context. First, they were asked which of the items in the Index was most important to them; next they were asked to say a bit more about it. And then they were asked if there was anything else about their illness that was particularly important to them or worried them.

Table 5.6 shows the number of respondents at each interview who said that each item on the Grogono Index was the most important thing to them about their illness. The predominant feature of the table is the significance of work. At each interview, around half of the respondents said that their work or usual daily tasks was the most important thing. Work was identified as the most important aspect of the illness much more frequently than any other single item. The only other item to be identified in each interview as the most important by one-tenth or more of the respondents was worry or unhappiness. The significance of these data is that they raise the importance of these items, in comparison with others in the Grogono Index. Although considerable numbers of respondents said that their recreation, sexual activity and physical comfort were affected by their illness, very few said that these were the most important items. The major areas on which attention should be focused are work and, to a lesser extent, mental distress.

After the respondents had identified the most important item on the Grogono Index, they were asked to say a bit more about it. This was a completely open-ended question, that was intended to let the respondents express whatever views they wished about the subject they had mentioned. A great variety of views were expressed.

Table 5.7 shows the number of respondents who identified their work as the most important item and who made different comments about it. More than one-third of those who identified work as the most important item made some comment indicating that they had a positive attitude to work; they said they liked working, that everyone needed to work, that they were actually thinking about what they had to do at work, or something similar. These people showed what appears to be a desire to return to or continue at work for its own sake. A further group of respondents made other comments directly about their work. Several respondents at each interview made comments expressing uncertainty about when they would be able to return to work, comments revealing anxiety about the insecurity of their jobs, or comments about some change in their job, tasks, responsibilities or hours of work. A third group of respondents mentioned money or their standard of living. The number who mentioned money was slightly smaller than the number who expressed a positive attitude to work itself. A final group of respondents made comments that reflected the significance of their work in the context of the wider personal and social aspects of their lives. They wondered, for example, whether they would ever get back to normal; they commented on the effect of being off work on their family life; or they mentioned the worry associated with being off work. Often one person would reveal different attitudes during one answer. In the words of a foreman paint-sprayer in a garage, who was off sick at the second interview:

> "I've never been one for being away from work unnecessarily. I like being at work - I don't want to stay at home. Also it's a necessity for income. I know you pay in for social security but that's for emergencies when you need it. You must have it but you shouldn't claim it for longer than is necessary."

And similarly, from a newspaper typesetter:

> "I've got to get back to work to live. You get a certain amount from the National Health but you've got to get back. It worries me because I want to get back and do something. I don't like this inactivity. I don't like hanging about."

There was a strong positive involvement in work, both for its own sake, and because they financial and personal consequences of inactivity were unpleasant.

Table 5.8 shows the number of respondents who identified worry as the most important item and who made different comments about it. As a small number of respondents identified worry in the first place, it is necessary to be very cautious in the interpretation of this table. What seems to emerge is that there was a tendency among this group of respondents to mention the more immediately personal aspects of their illness. Some made comments about their illness itself, some about their prospects of recovering or dying, and some about their family. The emphasis on personal matters differs somewhat from the more outward orientation of many of those who identified work as the most important item.

Table 5.9 shows the number of respondents who identified items other than work and worry as the most important, and who made different comments about them. The variety of items that were said to be the most important - ranging from recreation, through depending on others, to physical discomfort - is reflected in the variety of comments made. Four main groups of comments may be distinguished. First, there were comments concerning the resumption of activity, a number of respondents expressing a desire to be active again in things besides their work. Second, there were comments (mainly in the first interview) concerned with the effect of the illness on the respondent's family or home life. Third, there were comments about the illness or recovery. And fourth, there were respondents who mentioned some kind of worry or mental distress; when added to the number of respondents who identified worry as the most important item, these replies increased further the significance of mental distress after myocardial infarction.

After being asked to complete the Grogono Index and to identify the most important item, the respondents were asked whether anything else about their illness was particulary important to them or worried them. This question appears in retrospect to have contained an element of ambiguity. Some respondents may have interpreted as referring to anything other than the items contained within the Grogono Index, and some as referring to anything other than the items they identified as the most important or mentioned in their comments. Table 5.10 shows the number of respondents who said there was something else important, and the number who identified different items. A substantial number of respondents felt that there was something else about their illness that was important to them or worried them - between a third and a half of the respondents at each interview. A considerable variety of different items were mentioned in relatively small numbers. These items ranged from the illness itself, its future course and the possibility of a recurrence, through its effects on work, other activities and family life, to worry and distress. The most frequently mentioned pair of items were recurrence and prognosis; the figures suggest that they should be considered

alongside work and worry as the most frequently significant to the survivors of myocardial infarction. We will return to the respondents' knowledge and concern about their illness in Chapter Seven.

3. CONCLUSIONS

The impact of the illness on respondents' daily lives and activities was measured by the Grogono Index of Health. The majority scored between six and 10 points on the scale at the first and second interviews; this may be interpreted as a moderate level of incapacity. By the fourth and fifth interviews the scores of the majority of respondents were between one and five points; this may be interpreted as low levels of incapacity. Few respondents suffered from severe effects of their illness in the first months after their infarct. Slight to moderate effects persisted for nearly all respondents for one whole year afterwards. The picture seems to be one of moderate incapacity at first, followed by slight, but persistent disability.

There are no data from other studies that are directly comparable with these findings about incapcity, but the interpretation may be guided by studies in which findings about particular aspects of incapacity have been reported. First, the finding of moderate levels of incapcity at the time of the first interview is intuitively reasonable in the context of the programme of active mobilisation through which the respondents were passing. But it does modify the picture that tends to emerge from studies which employ return to work as the primary indicator of capacity and recovery (Joint Working Party, 1975). Because these studies tend to use return to work as an all-or-nothing measure, they may leave the reader with the impression of higher levels of incapacity in the early weeks after the infarct than those reported here. Second, the persistence of a small amount of incapacity among many patients during the subsequent months may not be revealed by the use of return to work as the only criterion of outcome; but it is consistent with the findings of studies that have used other measures. It is widely accepted that about 20 per cent of survivors of myocardial infarction have not returned to work at one year after the infarct (Joint Working Party, 1975). Other studies have shown that a further 20 to 30 per cent or more of infarct patients have returned to work, but experience changes or problems at work at about one year (Cay et al, 1973; Kushnir et al, 1975b). This corresponds with the finding of Finlayson and McEwen (1977) that 50 per cent of their subjects at one year had experienced long-term alterations in their family responsibilities. In this context, the findings of the present study, that two-fifths of the respondents experienced moderate or severe incapacity at one year, and that most of the remainder experience a little incapacity, appear to be securely founded.

The use of the Grogono Index to measure the effects of illness on daily life in this way has both advantages and disadvantages. The main advantage is that it is a composite index, composed of different activities and aspects of daily life. It results in a very different picture of incapacity, from that which emerges from the use of a single indicator, such as cardiovascular capacity or return to work. It may prove to be of greater value than a single indicator in assessing the needs for or effects of a comprehensive rehabilitation programme. One major query that is unanswered is whether the scale, because of its breadth of coverage, would be sensitive enough to relatively small changes in patients' condition that might be of importance to providers of particular rehabilitation programmes. The experience in the present study suggests that certain modifications to the scale as published would improve it. First, there are ambiguities in some of the items as included. Some respondents, for example, indicated that they depended on other people for help in moving about but not in washing, feeding or dressing. Second, there were difficulties in that some respondents wished to indicate an effect of an intensity that lay between the alternatives available to them. With these considerations in mind, the scale as published seems to be both workable and valuable.

The modifications to the Grogono Index introduced in the present study also deserve some comment. First, the scale was completed by the respondent rather than by their doctors. This change appeared to cause a small number of unexpected interpretations, such as respondents in hospital saying that their illness interfered slightly but not completely with their work. But these drawbacks would probably be outweighed by the greater accuracy of information in other respects. The second modification of the scale was the introduction of the system of weighting the scores according to the importance the respondents attached to each item. This made little difference to the overall distribution of the scores, and therefore appeared to be of little value in that respect. But it was of considerable use in helping to clarify the relative significance of each of the items included in the index. The third modification was the introduction of subsidiary questions and opportunity for comment, that allows an assessment of whether additional aspects of daily life should be included in the Index. Three such items - money, the effect on family relationships, and the patient's perception of his illness and its future course - were identified. Systematic exploration would presumably identify others. From these considerations, we can see that the Grogono Index is a workable tool, that is capable of being improved, and that is potentially of great value for a variety of purposes in research and the running of rehabilitation services.

The use of a scale to measure the effects of the illness in this way suggests a variety of research studies that might be needed. The first question that arises is whether the overall levels of incapacity, at different times

after the infarct, that have been reported in this study, would be found in other series. Then there are possible studies that would develop the material presented here. In what way is the severity of patients' medical condition related to the level of incapacity they experience? Why are the effects of the illness so much more severe in some people than in others? Finally, the use of a broadly based index of the impact of the illness on the individual provides a potentially valuable tool for evaluating the effectiveness of rehabilitation programmes. Do exercise programmes improve the quality of life of patients as well as improving their cardiovascular function?

Two areas of interest in relation to the development of services are emerging from the data about the overall impact of the illness. The first concerns the question of who are the most appropriate persons to deliver the care or services that may be required. This in turn depends on the terms in which the problems of the patients are identified, defined and explained. We have seen that many of the respondents identified medical symptoms of different kinds. Many of these are of primary concern to the patient's doctor; he will assess their significance and provide the treatment. We have also seen that most of the respondents reported the illness or something to do with it to have appreciable and lasting effects on a variety of aspects of their daily lives. The nature and level of sick people's daily activities and personal well-being are a product not only of their medical condition, but also their personal and psychological make-up, and of their external physical and social circumstances. The resolution of these difficulties and problems may depend upon help from people with personal and social knowledge and expertise, as well as with medical skills. Rehabilitation is not simply a medical process.

The second area of concern in the development of services is connected with the time at which services are available. The illness and its effects continue long after the acute episode of myocardial infarction and the patient's discharge from hospital. There are many problems of ill-health and incapacity during the year after the infarct. It may be that more effective medical care and rehabilitation during the early weeks and months would lessen the subsequent problems. On the other hand, the condition of some of the respondents detericrated at some point during the year after the infarct. For this kind of person additional later intervention, whether medical or social, might be appropriate.

The second set of data presented in this chapter showed the numbers of respondents who reported that their illness affected different aspects of their daily lives. Data were collected through the Grogono Index and subsidiary questions. The findings showed the great significance of work in this context.

The work or usual daily tasks of all respondents were affected by their illness at the time of the second interview, and the work of three-quarters of them was still affected one year after the infarct. Nine-tenths of the respondents said that this was important to them at the second interview, and one-half said at one year that it was important. Furthermore, two-fifths or more of the respondents said that work was the most important single item in the Index. These findings suggest that myocardial infarction is associated with long-term problems at work among a higher proportion of patients than has previously been indicated (Cay et al, 1973; Kushnir et al, 1975b; Finlayson and McEwen, 1977). Here, we have emphasized the frequency with which work is affected by the illness, and the importance of this to respondents. No other studies have systematically compared the effects of myocardial infarction on work with its effects on other aspects of daily life. Nevertheless, the findings of this study (of patients of working age) are in accord with the emphasis placed on work (though not simply return to work) in the professional literature (Joint Working Party, 1975). The effects of myocardial infarction on the sufferer's work are of the highest priority.

Two aspects of daily life, besides work, were identified in this study as being frequently affected by the illness and as being important to the respondents. Of these, hobbies and recreational activities were the most frequently affected. A certain degree of mental distress was also reported by more than half of the respondents during the year after the infarct. A substantial proportion of these people said that their distress was very important to them. Much of the worry appeared to focus on the illness itself - particularly on the prognosis and the prospects of a recurrence, but some of it was less clearly defined. Recreation and worry appear, therefore, after work, to be the most important aspects of daily life that are affected by myocardial infarction. This conclusion agrees with the findings of Martin (1967) and Finlayson and McEwen (1977) that the recreation of a substantial number of patients is affected by myocardial infarction, but also suggests that it ought to receive more attention than it has previously done. The conclusion also agrees with the findings of numerous studies about the extent and importance of emotional distress during the year after the infarct (Martin, 1967; Wishnie et al, 1971; McGrath and Robinson, 1973; Finlayson and McEwen, 1977). It reinforces the view that emotional well-being is not simply something to be manipulated in order to promote physical recovery, but is also an aspect of the patient's condition that should be attended to as important in its own right.

Three other aspects of daily life - physical discomfort, sexual activity and sleep - stood out as being affected by the illness among an appreciable number of respondents and as being important to them. Physical discomfort is

obviously related to experience of ill-health and symptoms. In the present study, it was found that the sexual activity of almost half the respondents was affected seven months and one year after the infarct. This is a higher proportion than that found in three of the studies quoted earlier (Skelton and Dominian, 1973; Kushnir et al, 1975b; Stern et al, 1976), but appreciably lower than the fourth (Bloch et al, 1975). Although the prevalence of physical discomfort and emotional distress make it likely that patients' sleep would be disturbed after infarct, and although sleep disturbance has been reported among patients' wives (Skelton and Dominian, 1973), the present study appears to be the first in which the prevalence of this particular problem has been reported. Physical discomfort, sex and sleep are all areas in which doctors may be able to increase their contributions to patients' well-being.

This has been the first study that has attempted to make systematic comparisons of the effects of myocardial infarction on several different aspects of patients' lives. The potential importance of this research, in identifying problem areas and, hence, the relative priority of unmet needs, is such that the work should be developed and extended. First, there should be a more thorough search for items not included in the Grogono Index - money, the effect on the family, and the illness itself are obvious examples. Second, there should be work to develop better measurements of the severity of the impact of the illness on each item for each individual. With these improvements, this kind of systematic comparison of the effects of the illness on different aspects of personal life could become a major tool in the identification of unmet needs and the development of services.

On the basis of this material, it is possible to make suggestions about the directions in which services might develop.

(i) The fairly high proportions of respondents, who experienced symptoms and ill-health, or who reported physical discomfort, in the months after the acute infarction, suggests that there may be a case for increased medical attention during these months. Further work would be needed to establish whether this might best be provided by specialists or general practitioners, whether it should consist of clinical medical care or rehabilitation, and whether the needs are greatest among those already in contact with a doctor or those out of contact.

(ii) There are problems that are less clearly medical in nature. Those include the interference of the illness with sexual activity and with sleep. Perhaps they are problems with direct physical causes in which medical advice or drug therapy would be appropriate. Alternatively, the restoration of physical capacity and well-being, through programmes of physical exercise, may be the most effective course of action.

(iii) Emotional and personal problems might warrant the intervention of a social worker. Casework may be needed for the resolution of personal anxieties, such as the fear of dying. And it might help alleviate emotional distress, sleep-interference or reduction in sexual activity.

(iv) The illness affected many respondents' daily activities, particularly their work, recreation and jobs around the home. There are various possible ways of improving patients' performance in these areas. On the one hand it might be argued that improved medical care leading to improved health would solve these problems. Alternatively, it could be argued that a rehabilitation programme of physical exercise would improve patients' physical fitness (Rechnitzer et al, 1967; Grant and Cohen, 1973; Kellerman, 1973; Kirchheiner and Pedersen-Bjergaard, 1973; Ressl et al, 1975) and perhaps their emotional status (McPherson et al, 1967); it might be expected that it would lead to improvements in their ability to undertake working and recreational activities, but there is no evidence to show that it would lead to improvements in actual performance. As a further possibility, it could be argued that emotional and occupational problems are not primarily medical concerns. In this case, the increased involvement of such staff as psychiatrists, social workers, Department of Employment officials, employment medical staff, and occupational therapists becomes a possibility.

In examining these possibilities, issues fundamental to the provision of rehabilitation services arise. How can we clarify the boundaries of competence between doctors and other professions? When are personal or social problems serious enough to justify the involvement of another profession? How effective are these professions in solving their clients' or patients' problems? How should the medical care be coordinated with that of the other professions? The aftermath of myocardial infarction is associated with a whole range of problems - physiological, personal and socio-economic; it may be necessary to develop further not only medical rehabilitation, but also a variety of psychological, social and economic services, to solve them.

CHAPTER 6 USE OF AND NEEDS FOR HEALTH AND REHABILITATION SERVICES

In this chapter, the focus of attention moves away from the personal aspects of the respondents' recovery. In the preceding chapters we have examined the respondents' ill health, incapacity, life at home and work experience, as aspects of their recovery and well-being after myocardial infarction. These are the aspects of patients' lives that the health and rehabilitation services attempt to improve. In the next two chapters, we will examine the levels of different kinds of services used by the respondents, their comments about the usefulness of these services, and their statements about needs for additional services. In this chapter we will examine data about patients' use of hospital services, about their contacts with their general practitioners, and about their use of a variety of medical, vocational and social rehabilitation and resettlement services.

1. HOSPITAL CARE

In presenting data about the respondents' receipt of hospital care, we have two purposes. The first is simply to provide information about the use of services, as background for the subsequent material. The second is to examine more specific material, about treatments, services and communications, that is directly related to the personal and social aspects of recovery, or has implications for them. The intention is not to comment on the acute hospital treatment per se, except insofar as actions then prepare the patient for his recovery and subsequent life. Much of what is done for and said to the patient in the coronary care unit, in the medical wards and in outpatients, affects his outlook and behaviour subsequently.

Data about the respondents' stays in hospital were presented in Chapter Two. Fifty of the 52 respondents were admitted to the Coronary Care Unit of the Kent and Canterbury Hospital. The mean length of stay in the Unit was six days. The respondents' total length of stay in the hospital ranged between eight and 53 days; the modal length of stay was 12 days. This was a typical length of stay in hospital for patients with acute myocardial infarction in 1974/5, but was not as short as that reported in some studies of early mobilisation (Boyle et al., 1972; Tucker et al., 1973; Hayes et al., 1974). On discharge from hospital all but one of the respondents returned directly to their own homes. The other person went to a convalescent home.

In the first interview, the respondents were asked about special arrangements for the way they would manage when they left hospital. Seven people said that special arrangements had been made. Six identified their spouse or other family member as making the arrangements, and one his employer. Four of these people identified ways in which the family had been organising practical help

for them, by changing their own work patterns, or by enlisting the aid of neighbours or friends. Two said that beds and toilets had been installed downstairs for when they returned home. All the respondents were also asked whether they were expecting to see anyone about the way they would manage when they left hospital. Eleven people said that they were. Five of these identified members of the hospital staff; four of them said that they were expecting to be told what they could and could not do when they went home. Three said that they were expecting to see people about problems to do with their work, and one each identified their general practitioner, their landlord and the British Legion. All the respondents were then asked whether there was anything else that needed to be done to improve the way they would manage when they left hospital. Eleven people said that there was. Five of these said that they needed a change in job or lighter work. Two said that they needed someone to help with family problems. Two said that they needed advice about the activities they could undertake at home, and two identified other problems.

During the year after the infarct 11 respondents (one fifth of the total) were readmitted to the Kent and Canterbury Hospital because of their heart. Four of these people were admitted during the first month after their initial discharge, and four more during the subsequent two months. During the year, two other respondents were admitted to hospital for other conditions.

Data were presented in Chapter Two about the respondents' outpatient consultations. All respondents had at least one outpatient consultation after their discharge from hospital; the large majority had two or three consultations. The consultations were spread widely in time after the initial infarct, but were held most frequently in the third and fourth months. No data were collected about the contents of the consultations.

2. GENERAL PRACTITIONERS

Data were collected in each of the follow-up interviews about respondents' contacts with their general practitioners. The general practitioner may well be an important person during recovery and rehabilitation after myocardial infarction. Mayou et al. (1976b) found that 90 per cent of their series of infarct patients saw a general practitioner after discharge from hospital. They concluded that "General practitioners may have great opportunities for organising a graded programme of rehabilitation and may often communicate ideas more easily to their patients than hospital staff." The general practitioner is well placed to keep an eye on changes in the patient's physical condition on a week-to-week basis. He may be the most appropriate person to provide emotional support to the patient and his family. And he may be the best person

to discuss the illness with the patient and advise him about its effects on his normal daily activities, such as work and recreation. It has sometimes been felt, by cardiologists and others, that some general practitioners have not been sufficiently aware of the growth of active exercise in coronary rehabilitation, and that they have therefore delayed the patient's recovery unnecessarily (Joint Working Party, 1975). Despite the potential importance of these ideas, there has been little research that has examined systematically the contributions of general practitioners to recovery and rehabilitation after myocardial infarction.

The respondents were asked in each of the follow-up interviews about their contacts with their general practitioners. Table 2.17 shows that 45 respondents (nine-tenths of the total) saw their general practitioner about their heart between their discharge from hospital and the second interview. These people were also asked when they first saw him. Fourteen said they first saw him on the day of their discharge or one day later; 15 first saw him two or three days afterwards; seven first saw him four or five days afterwards; four saw him six or seven days afterwards; and five first saw him eight or more days afterwards. Table 2.17 also shows that the majority of respondents at the third and subsequent interviews had seen their G.P. about their heart. More people had seen their G.P. than had had outpatient consultations.

At each of the follow-up interviews respondents were asked how frequently they had been seeing their general practitioner. Some of the respondents replied in terms of the frequency within a specified time period. Others simply gave the total number of times they had seen him. Table 6.1 shows the number of respondents who reported different frequencies of contact with their general practitioner. Without relating the reported frequency to the actual times after the infarct of discharge and of each interview for each respondent, it is only possible to provide only a very broad and tentative picture of the amount of contact with general practitioners. Three respondents said at the second interview that they had seen their G.P. once per week since their discharge, and three had seen him three or more times. The large majority of respondents saw their G.P. once or twice only, or relatively infrequently at this time. Between the second interview and third interview a total of 10 respondents said that they had seen their G.P. more than once a month or three or more times in total. Again, the large majority gave replies indicating that they had seen him less frequently: once a month; or once or twice in total. After the third interview, the frequency of contact was reduced still further, with very few respondents seeing their G.P. more than once per month. The general practitioner is more readily accessible to the patient than are hospital medical staff, and is seen more frequently by the patient than they are.

Nevertheless, for the large majority of respondents contacts with the G.P. occurred at intervals of weeks or months, rather than days.

In each of the follow-up interviews respondents who had seen their general practitioners were asked what the G.P. had been doing for them. Table 6.2 shows the number of respondents who identified different activities; it refers not only to those respondents who consulted their G.P. about their heart only, but also to those few respondents who consulted about their heart and another illness. The activities most frequently identified were physical examination and the prescription of drugs. Slightly smaller numbers of respondents said that their G.P. had discussed their illness or recovery with them, or had taken some action in relation to sickness absence certification. In the second and third interviews nearly all of these were the provision of sick notes, but at the third interview, most said that their G.P. had certified them as fit to return to work. A small number of respondents said that their G.P. had given them advice about some aspect of their daily activities. Physical examination, prescription of drugs, sickness absence certification and discussion of the illness are the tasks undertaken by general practitioners with the greatest number of patients after myocardial infarction.

Table 6.3 shows in some detail the subjects that the respondents said their general practitioners had discussed with them. The most frequently identified subject was the nature of the illness or the progress being made by the respondent in his recovery. The discussions varied from quite detailed explanations by the G.P. about the infarct to brief comments after an examination about the patient's progress. Many of the comments seemed to be assurances by the G.P. that satisfactory progress was being made. The second most frequently identified subject was that the G.P. had asked the respondent about his progress.

Table 6.4 shows the subjects about which the respondents said they had received advice from their general practitioners. The main impression that emerges from the table is of the variety of different subjects mentioned by one or two respondents each; they included exercise, rest, diet, travel and work. Four respondents at the second interview said that they had been advised by their G.P. to rest or take it easy. This was more than had been encouraged to take more exercise, but still was a very small number in total. General practitioners did not usually provide systematic advice about the resumption of activities that would contribute to a graded programme of rehabilitation.

3. REMEDIAL THERAPY

The major development over the last 30 years in medical rehabilitation after myocardial infarction has been the increasing acceptance of physical

exercise. This has taken the form both of specific exercise programmes and of general encouragement to patients to reactivate themselves. The research studies quoted in Chapter One have shown that properly run programmes of exercise are safe for infarct patients, and that they are associated with improvements in a variety of aspects of the patient's physical condition: cardiovascular function, complications, fitness and physical work capacity. There is very little evidence resulting from controlled studies to show that exercise programmes have any effect on patients' psychological status, work or other daily activities. Nevertheless it is widely believed that they are beneficial in these areas. At the time of the fieldwork of the present study, no programme of physical exercise, designed specifically for cardiac patients, was provided in the Kent and Canterbury Hospital, although one has been introduced since. Nor was occupational therapy available in the hospital. Medical rehabilitation was undertaken by doctors and nursing staff, in the normal clinical context, and occasionally by the use of physiotherapy.

In each interview, the respondents were asked whether they had had any contact at all with a physiotherapist. Those who reported any contact were then asked subsidiary questions about the amount and nature of the physiotherapy. Table 6.5 shows the number of respondents who had received different physiotherapy treatments. Ten respondents at the first interview and four at the second said that they had had breathing exercises. Only one or two respondents at each interview said that they had received other forms of physiotherapy; not all of these were directly related to the heart or cardiovascular system. In each interview the respondents, who had not received any physiotherapy, were asked whether they had needed any. One respondent at each of the first three interviews said that they had needed some physiotherapy to help their remobilisation or recovery after the heart attack. Apart, therefore, from breathing exercises, few respondents had received any physiotherapy and few expressed any need for it.

In each interview, the respondents were asked whether they had had any contact with an occupational therapist. None had done so. They were also asked whether they had needed any occupational therapy. Two respondents at each of the first two interviews, one at the third and three at the fourth said that they had needed occupational therapy, because of boredom or lack of anything to do. One respondent at the fifth interview said he needed advice about what activities he could do, because his G.P. would not give him any decisions. As with physiotherapy, very few people expressed unmet needs for occupational therapy.

4. SOCIAL WORK

The growth of interest in patients' emotional and social problems after myocardial infarction has been accompanied by increasing attention paid to social work for these patients. McGrath and Robinson (1973) and Clarke (1974) reported studies in which specialist social workers worked in coronary care units. They noted the different tasks undertaken by the social workers: reducing anxiety, dealing with marital and family problems, assistance with employment, discussing the nature of the illness and the pattern of recovery, and ensuring that the treatment was understood. Both these studies, and an earlier article by Jefferson (1966), concluded by emphasizing the importance and necessity of social workers in the care and rehabilitation of myocardial infarction patients.

In the present study, the respondents were asked in each interview whether they had had any contact with a social worker. Those who reported any contact were asked subsidiary questions about the amount of contact and what was being done. Fourteen respondents reported contact with a social worker. Table 6.6 shows the number of respondents who reported contact with different kinds of social workers. The social workers were employed in a variety of contexts in hospital, in social services area teams, and as works' welfare officers. Nearly all the respondents, who said that they had been in contact with the social worker, reported one contact only. They identified a considerable variety of tasks undertaken by the social workers. One or two respondents said that the social worker had simply asked them if they had any problems or had asked them questions. Four mentioned money: in two cases the social worker provided a form for claiming benefits; in the other two the respondents reported only an intention to help with money. Eight respondents mentioned things to do with their work: in two cases, the social worker offered to help with work problems; in five cases the social worker said he would help in a particular way, by arranging training, seeing the employer or finding a new job. Two respondents said that the social worker had offered them home helps; they found this reassuring, but had not wanted the home helps. Two others mentioned other aspects of their home life; one had wanted a telephone and another had wanted help in dealing with his children; these were not provided. Two respondents mentioned discussions about becoming registered as disabled persons. One said the social worker had made arrangements for him to go to a convalescent home. From these findings two points stand out. First, the respondents reported that their contacts with social workers were primarily concerned with practical arrangements, particularly to do with work and money. This contrasts quite strongly with the emphasis placed in other studies on dealing with emotional problems

and helping the patient to come to terms with the illness. Second, the respondents reported the contacts primarily in terms of their own requests for help, the social workers' offers of help, or the social workers' statements of intention to help. Very few identified specific ways in which the social workers had actually helped them.

After being asked what the social worker was doing for them, the respondents were asked if it had been useful, and why. Two respondents at the first interview, and one at each of the second and third interviews, said that they did not know, or that the question was not applicable, because the social worker had not done anything yet. Three respondents at the first interview, two at each of the second and third, and one at the fourth interview said that the contact with the social worker was very useful. One of these identified a specific practical arrangement that was useful; all the others said the offer of help was appreciated, or that they had obtained reassurance or emotional support from the contact. One or two of the respondents at each of the follow-up interviews said that the contact was partly useful or not useful. All but one of these people identified specific items, with which they had wanted help, or with which the social worker had said she could help them, and with which no help had in fact been provided. These items included the payment of expenses connected with the illness, help with children, and finding work. Offers of help or reassurance couched in general terms are felt to be useful, but failure to provide specific items of help causes dissatisfaction among clients.

The respondents were asked in each interview about their needs for social work. Those who had been in contact with a social worker were asked whether they needed the social worker to help them with anything else, in addition to what she had been doing. Those who had not been in contact were asked whether they were waiting to see a social worker; two respondents at the second interview said that they were waiting to see one. Those not waiting were then asked whether they had needed to see a social worker and, if so, why. Table 6.8 shows that between one and five respondents at each interview said that they needed social work or more social work. Seven people altogether said they needed some help. They identified a wide variety of different problems: how to cope financially on a reduced income; information about social security benefits; how to find a new job; how to have a downstairs lavatory and bathroom installed; difficulty with children; "someone to cheer me up". These respondents were on the whole realistic about the advice that a social worker might provide. The level of expressed need for social work among the present series was as high as the level of successful social work intervention.

5. VOCATIONAL REHABILITATION AND RESETTLEMENT

The health services in Britain contribute in many ways to the vocational rehabilitation of patients after myocardial infarction. The attitudes and outlook of doctors and others help determine the patient's own view about returning to work. The existence of programmes of physical exercise, and the whole pace of recovery, may affect the extent of residual disability and the timing of return to work, and hence the need for specific measures of vocational rehabilitation. The Joint Working Party (1975) suggested that doctors should encourage positive attitudes towards work, identify problems early on in the illness, institute rehabilitation and cooperate with other services, and review continued sickness absence. We saw earlier in this chapter that sickness absence certification was one of the tasks undertaken most frequently by general practitioners for the present series of infarct patients. There has been little empirical research in Britain into vocational rehabilitation after myocardial infarction. Studies (Groden and Cheyne, 1972; Wilkinson and Mattingly, 1973) have described the different kinds of patients treated in different institutions, and have shown the proportions returning successfully to work. There appears to have been no general descriptions of the nature and range of vocational rehabilitation services used by myocardial infarction patients.

In each of the follow-up interviews in the present study, the respondents were asked about vocational rehabilitation. Those who were employed or unemployed were asked whether they had been in contact with anyone about training or other special help in getting back to work. Table 6.9 shows that four respondents at the second interview said that they had received help. Ten respondents at the third interview and 12 at the fourth said that they had received help since the previous interview, as did five at the fifth. Table 6.10 shows the sources of the help received. Employers were the earliest and the most frequent source identified. They helped their employees in two ways. In the earlier stages of the illness they enquired about their health and made them feel that they had not been forgotten. Later they discussed and agreed such aspects of returning to work as the nature of the job, the hours to be worked, and the timing of the return. All but one of these respondents said that they found the help that they received from their employer completely useful. Some said that they found the employer's concern for their welfare reassuring; others said that the practical arrangements made their return to work easier than it would otherwise have been.

Five respondents said that they had seen a disablement resettlement officer. Two of the respondents said that the D.R.O. had discussed the possibilities of work, rehabilitation, retraining and registering as disabled. Another said that the D.R.O. had sent him back to the labour exchange. Three

had seen a D.R.O. in connection with attending an Industrial Rehabilitation Unit. In one case, the D.R.O. had suggested an I.R.U., but the respondent had refused, on the grounds that he had been before and not settled. In another case, the D.R.O. arranged attendance at an I.R.U., but the respondent said he collapsed after four days and spent the next three months in bed. In the third, the respondent was attending an I.R.U. while in contact with the D.R.O. None of these respondents said that the help they had received from the D.R.O. was completely useful. Those who said it was partly useful explained this by saying that he had not yet finished helping them, so that they did not really know yet if it was going to be useful. Two of the four who said this help was not useful explained by saying that his suggestions for rehabilitation or retraining were not appropriate for themselves. The other two said that, although they had followed his suggestions, this had not resulted in a successful return to work for them. This very small number of cases appears to conform to the pattern discussed earlier in relation to the research literature. People without severe employment problems are coped with routinely by the health services and employers and are satisfied with the services they receive. Those with more severe problems may receive help from specialised rehabilitation agencies, but these agencies frequently do not produce satisfactory outcomes.

In the follow-up interviews, the respondents were asked about their needs for vocational rehabilitation. Those people, who said that they had received some help in getting back to work, were asked if they had needed any extra help of this kind. Those, who had not received any, were asked whether they were waiting to see anyone of this kind. Four respondents at the second interview and one at the fourth said that they were waiting. Those, who were not waiting to see anyone, were then asked whether they had needed any help at all in getting back to work. Table 6.11 shows that between four and six respondents at each interview said that they had needed some help, or some extra help, in getting back to work. Thirteen people altogether said they needed help. They expressed a variety of different needs. Some had wanted help from their employers to find a new job suited to their capacity. Some said they needed to be assessed, in order to find out what they could do. Some said that they needed help from the employment services, for retraining or to find a lighter job. Some said they needed jobs with less travelling. And some said that they simply needed a new job, or help from someone in getting back to work. The respondents' needs arose from their illnesses, from jobs that had become unsuitable, and from unemployment. Focusing simply on the individuals involved, rather than their economic environment, the problems would not seem to present insurmountable difficulties. When we consider the level of unmet needs for help in returning to work and the cautious assessments of the usefulness of the vocational

rehabilitation services, it is apparent that further consideration should be given to the relationship between the contributions of the health and the employment services to the rehabilitation of coronary patients.

6. CONCLUSIONS

In this chapter, we have seen that the main item of care received by the respondents was their treatment as hospital in-patients. This episode, which usually lasted between one and two weeks, was oriented more towards the acute treatment of the infarct, than towards rehabilitation or aftercare. The respondents were mobilised fairly quickly after their infarct. They were given a sheet, advising them about the activities they should be undertaking at different points in time, by the hospital staff, but did not undergo a formal programme of physical rehabilitation. After their discharge from hospital, very nearly all the respondents had one or more out-patient appointments and saw their general practitioners one or more times. Few respondents had any contact with physiotherapists, social workers or the vocational rehabilitation services. The emphasis was clearly on medical care rather than rehabilitation. In this respect, the services were probably typical of the situation in England in 1974 and 1975, though there has probably been a growth of physical rehabilitation programmes since then.

In general, the respondents expressed a low level of unmet needs for personal or domestic help from rehabilitation or aftercare services. Despite the emotional distress and the effect of the illness on the respondents' home life and recreation, the large majority of people appeared to accept their situation. Very few identified improvements that might be achieved, or considered that they needed anything more in the way of rehabilitation or aftercare services to improve their life at home.

A quarter of the respondents said that they needed help or extra help in returning to work. We have seen that the present series of patients was, on average, slower to return to work than others in Britain. In addition, one-fifth of the series experienced unemployment after their infarct that was associated with their illness. When considered together, those factors suggest an appreciable level of work-related difficulties and problems, that might be solved more satisfactorily.

There is a need to review the ways in which doctors are involved in activities which are not purely medical. This is a problem fundamental to medical rehabilitation. It concerns general practitioners and hospital specialists. At its most restricted, medicine is concerned with the elucidation and treatment of disease processes in the anatomy and physiology of the body.

The issues concern the location of the boundaries of the intellectual model that doctors bring to their work, and of the boundaries of the actions that doctors take in diagnosing and treating patients. These questions arise in many contexts: sickness absence certification; advising patients about the nature of work for which they may be fit; advice about recreation, sex, housework and other activities; psychological treatment and emotional reassurance; family difficulties, and housing or financial problems. There has recently been some discussion and official policy on this question, in so far as it is concerned with the relationship between doctors and the remedial professions (Brunel Institute of Organisation and Social Studies, 1977; D.H.S.S., 1977b). The question is not simply one of professional autonomy or interprofessional relationships. Rather, it is a question of the nature and definition of medical tasks in rehabilitation in the National Health Service.

There is also a need to develop further the organisation of rehabilitation services. In the present study we could observe two routine systems, relevant to the after-care and rehabilitation of patients. The first system was centred around medical care. It involved discharge from hospital, communication and contact with the general practitioner, and visits to out-patients. This system was concerned largely with monitoring the patient's medical condition and providing the appropriate treatment. The second system was centred around absence from work. It involved sickness absence certification, payment of social security benefits, and certification of fitness to return to work. These two systems operated routinely for the majority of respondents; the major decisions were about the nature of treatment and timing of action. In other aspects of recovery, however, there was less evidence of routine procedures and systems to identify and tackle particular problems. Patients were given notes advising them about daily activities by the hospital, and many also discussed their illness and activities with their general practitioner; but information from these two sources was not coordinated. Respondents who experienced particularly severe vocational problems did not have these assessed early in their illness, and many problems persisted for months. There was little regular assessment of emotional or family problems by social workers. Little consideration was given to the possibility of therapy to overcome inactivity at home after discharge from hospital. These are all problems which are difficult to pin down and quantify. The disorganisation, lack of coordination and lack of leadership of rehabilitation services at the local level were problems about which the Tunbridge Committee felt strongly (D.H.S.S., 1972a, Chapters 3 and 6). Since the non-acceptance of the Tunbridge Committee's recommendations, no new, substantial national policies about the local organisation of rehabilitation services as a whole have been published. The problems remain, and the local organisation of rehabilitation services still needs to be developed.

From this material we may indicate two areas in which further research may be desirable.

First, there are questions about the nature of needs for services. This is a topic on which there is a substantial social administration literature. The points that are of particular importance here are "On what criteria do people judge unmet needs to exist?" and "In what ways, and why, do different groups of people make differing judgements about the existence and nature of unmet needs?" These questions underlie problems such as "Why is it that cardiologists see a need to develop programmes of physical exercise as part of the rehabilitation of coronary patients, but that very few patients feel a need for the improved recovery that such programmes might produce?" and "Why is it that the patient can identify substantial restrictions of activity and well-being following an illness, but does not translate these into "problems" that could be solved or into "needs" for services?" A fuller understanding of these issues is essential if the planning and development of health and rehabilitation services is to proceed rationally rather than on the basis of clinical intuition or political strength.

Second, there are questions about variations in and the development of professional practice in rehabilitation. Much of Chapter One of this report has demonstrated that different emphases within coronary rehabilitation have held the stage in different places and at different times: comprehensive rehabilitation centres, physical exercise, early mobilization and vocational rehabilitation. It is easy to see that other programmes could come to be equally strongly advocated and developed: work placement schemes, psychological treatment, social work counselling, recreational therapy, education for self-care. From the literature reviewed it is very difficult to tell how far these different activities are actually carried out in different places at different times. Nor do we know why these variations and developments occur. In a market economy or a privately organised health service these questions may only be of academic interest. But in a publicly provided health service, they have implications for professional education, for the relationship of the N.H.S. with other services, for the allocation of resources to meet professional commitments, and for the very nature of health service objectives and the efficient use of resources in achieving them. For these reasons, research into the development and diffusion of professional practices in the health services is of great practical importance.

CHAPTER 7 ADVICE AND INFORMATION AFTER MYOCARDIAL INFARCTION

In this chapter we examine in some detail one aspect of the services and care received by the respondents: education and advice about activities of daily living. The respondents were asked a series of questions about the advice they had received after their infarct about exercise, rest, sex and smoking. Exercise, rest and sexual activity are considered mainly as of concern in recovery and rehabilitation. Advice about smoking is significant in terms of the prevention of further coronary episodes.

During the last twenty-five years there has been a substantial amount of professional interest in the advice given to patients after myocardial infarction, but much less empirical research. Many physicians (e.g. Hellerstein and Goldston, 1954; Naughton et al, 1969; Semple, 1970; Wenger, 1976) have identified the advice given to patients about exercise or other activities as an important part of a broader rehabilitation programme. In discussions of physical exercise programmes, advice is sometimes seen as an implicit adjunct to the physical training, and in vocational rehabilitation it is a necessary component. Some authors have argued that better advice should be given to patients and their families about various daily activities, such as exercise, diet, smoking and sex (de la Chappelle, 1964; Sibley, 1965; Parsons, 1974; Cohen et al, 1976).

The main line of research into education and advice has been to describe the contents of the programmes from the staff point of view, and to examine its effectiveness in terms of the patient's recovery. Advice given in a variety of contexts is effective in improving patients' work performance, and in reducing disability and smoking (Shaw and McNiven, 1974; Woodwark and Gauthier, 1972; Burt et al, 1974). Advice on its own is not as effective as a comprehensive rehabilitation programme in promoting patients' fitness for work (Singh et al, 1970). In the research, there has been very little systematic study of the exact nature of the advice given to patients by differing people, both professional and lay, and how the patients react to that advice. These data are important, because they would allow us to develop programmes of advice with knowledge of what the patients identify as significant, and of what they feel that they need to know.

In the present study, the respondents were asked in each of the follow-up interviews a series of questions about the advice they had received about exercise, rest, smoking and sex. They were asked whether any health service staff had given them any advice about each item. If they had received any advice, they were asked who had given it, what advice had been given, whether

they had followed it, and why. Each respondent was asked whether any friends, relatives or other people had given them any advice about each item and, if so, who and what advice. All were then asked whether they would like any (more) advice about each item. At the end of the sequence of questions, all the respondents were asked whether there was anything else to do with their illness about which they would have liked any more advice.

It was medical policy in the Kent and Canterbury Hospital at the time of the study to give each infarct patient a stencilled advice sheet, at about the time of their discharge. This was a brief guide intended to help patients plan their activities during the weeks after their discharge. It covered such items as daily routine at home, exercise, recreation and work. It suggested that the level of activity should be gradually increased during the first few weeks, and implied that normal activity should be resumed at about three months after discharge. A copy of the advice sheet is reproduced in Appendix A.

1. EXERCISE

Cardiologists in Britain believe that coronary patients should be encouraged to take active exercise in order to promote a full recovery. Semple (1970) argued that doctors should emphasize the safety of exercise to patients, in order to reduce their anxiety and invalidism. The Joint Working Party (1975) stressed the importance of physical conditioning after myocardial infarction and the need for advice and education to overcome over-protective attitudes and delayed recovery. In these circumstances, it is important to know whether patients are, in fact, encouraged to take exercise and how they react to such encouragement.

The respondents were asked in each interview whether they had been given any advice by health service staff about taking exercise, and, if so, who had given them it. Table 7.1 shows that nearly all the respondents said they had been given some advice about exercise. The most frequent sources of advice were the advice sheet, general practitioners and hospital doctors. Tables 7.2(a) to (d) show the nature of the advice received from each health service source. The most frequent advice was to take some exercise, to take more exercise, or to increase the amount of exercise taken. This was true of all the main sources of advice at each of the interviews. A few respondents at each interview said that they had been advised to take no exercise or a little exercise, to take less exercise, or to take it easy. Several respondents at each interview said that they had been given other advice. This included items such as to take gentle exercise and not to overdo it, or to use their common sense, or to take short walks but otherwise take it easy. The overall

impression that emerges from these data is that the majority of respondents at the second and third interviews felt that they had been encouraged to increase the amount of physical exercise they were taking, but that this was to be a gradual process.

In each interview, the respondents were asked whether they had followed the advice that they had been given about taking exercise. The overwhelming majority in each instance said that they had followed it completely. Very few said that they had only partly followed it, or had not followed it at all. These included one respondent at the second interview, two at the third and one at the fifth who said that they had not followed advice to take more exercise.

It is sometimes believed that an over-cautious approach to the patient's illness, by his family or other lay people, is a major cause of delayed recovery and failure to resume full activities (Joint Working Party, 1975). In the context of the present study, it was thought that the advice the respondents received from lay people about exercise and rest might influence their reaction to advice from health service staff. The respondents were asked what advice friends, relatives or other people had given them about taking exercise. Table 7.3 shows that far fewer respondents received advice about exercise from lay people than from health service staff. About one-quarter of the respondents at each of the second and third interviews had received advice from one or more lay sources. They identified quite a variety of different advice. Approximately equal numbers were encouraged to take more exercise, discouraged from taking exercise, or advised to undertake or not to undertake particular activities. According to the respondents' testimony, the advice they received from lay sources did not have the effect that they did not follow the advice they received from health service staff.

In each interview, those respondents who had not received any advice about exercise were asked if they would have liked any; those who had received some were asked if they would have liked any more. Exactly half the respondents said at some time during the follow-up period that they would have liked more advice about exercise. Table 7.4 shows that most of them said that they wanted more detailed or specific guidance. They wanted precise information about the activities that they should or should not undertake, or advice that was not stereotyped but was applicable to their particular circumstances or state of recovery.

2. REST

Thirty or more years ago prolonged rest was the standard treatment for

myocardial infarction. It was felt, in developing this study, that the advice that the respondents received, from professional and, especially, lay sources, encouraging them to rest, might counteract any advice encouraging them to take more exercise. The respondents were therefore asked a series of questions about the advice about resting that they had been given.

Table 7.5 shows that nearly all the respondents at the second interview said that they had received some advice from health service staff about taking rest. The majority of these said they had obtained it from the advice sheet, but appreciable numbers had also been advised by a hospital doctor or their general practitioner. A minority of respondents said at the later interviews that they had received any advice about resting. On these occasions the general practitioner was the most frequent source of advice. Tables 7.6 (a) to (d) show the nature of the advice received. The piece of advice reported most frequently was to take a rest, either in bed or in a chair, for a defined period during the day. Advice to take a defined period of rest is compatible with advice to take exercise at other times of the day or to increase the amount of exercise taken. Relatively few respondents in the second interview, and hardly any subsequently, said that they had been advised to rest generally during the day or to take it easy. This advice, given only to a minority of respondents, might be inconsistent with advice to increase the amount of exercise or activity.

In each interview, the respondents were asked whether they had followed the advice that they had been given about taking rest. Very nearly all the respondents said that they had followed it completely. On only three occasions did a respondent say that he had partly followed the advice; on only two occasions did someone say he had not followed it. Nearly all the respondents said that they had followed the advice they had been given.

Lay people's advice about rest may be a significant influence on patients' behaviour. In each interview, the respondents were asked what advice friends, relatives or other people had given them about taking rest. Table 7.7 shows that fewer respondents received advice about rest from lay people than from health service staff. The advice sometimes tended to be in conflict with that given by health service staff. About half the respondents who had been given lay advice about rest said that they had been advised to rest generally, to take it easy, or not to overdo it. These people constituted about one-fifth of the total respondents at the second interview, but fewer subsequently. They received the advice in almost equal numbers from their spouses, other relatives and friends. Most of the other advice about resting was concerned with taking a rest during the day; this appeared to reinforce what had been said by the health service staff. The need to provide education for patients' relatives

and other people, about rest and exercise after myocardial infarction appears to be relevant only for a minority of patients. In the large majority of cases lay people's advice was consistent with the professionals' advice, and the respondents said that they had followed the professionals' advice.

In each interview, those respondents who had not received any advice about rest were asked if they would have liked any; those who had received some were asked if they would have liked any more. Fifteen respondents said that they would have liked more advice. The small number, compared with those saying they wanted more advice about exercise, presumably reflects the relatively straightforward advice to take a daily rest, and the fact that resting does not give rise to immediate cardiac symptoms in the same way as exercise may. Table 7.8 shows that the majority said that they wanted more detailed or specific information: how long should their daily rest be? If they were supposed to rest, how much were they allowed to do? As with exercise, it appears that it is not the patient's illness and recovery themselves that generate questions about the proper regime to be followed. Instead, the provision of a certain amount of advice and guidance appears to stimulate a desire for more specific instruction.

3. SEXUAL ACTIVITY

We saw in Chapter Five that about half the respondents in the present series said that their illness interfered to some extent with their sexual activity during the year after their infarct. Various other studies have found that one-quarter or more of infarct cases experience reduced levels of sexual activity about one year after the infarct (see page 21). A number of authors (Naughton, 1973; Kent, 1975; Green, 1975) have emphasized the need for better communication between doctors and patients about sex, but there do not appear to have been any previous studies of the nature of the communication that does occur, or of patients' reactions to it.

In the present study, the respondents were asked in each of the follow-up interviews whether anybody had given them any advice about their illness and sexual activity. Those, who said that they had, were then asked who had advised them, what advice they had been given and whether it was useful advice. Table 7.9 shows that just over two-thirds of the respondents at the second interview said that they had been given advice about sex. All of these people said they had obtained advice from the advice sheet. A few respondents at the second and third interviews said that they had obtained advice from other health service sources, mainly from a hospital doctor or from their general practitioner. When asked what advice they had been given, some of those who

identified the advice sheet as the source replied that they should resume sex when they were back to normal; others simply said that they had been given the advice contained in the advice sheet. The respondents who identified other sources identified a considerable variety of kinds of advice. Two or three people said that they had been advised to resume sexual activity when they were back to normal, to do what they felt like doing, not to undertake anything that caused symptoms or distress, or to limit their sexual activity. With the exception of one brief sentence in the advice sheet, only a few respondents were given any advice about sexual activity, and what they were given varied considerably in nature.

In each interview, the respondents were asked whether the advice they had received was useful. Very nearly all the respondents who had been given advice personally by the health service staff said that it was completely useful. Only one person said that their G.P.'s advice was not useful, and one each said that a hospital doctor's and a G.P.'s advice was partly useful. Many more respondents said that the advice contained in the advice sheet was less than useful. Nineteen respondents at the second interview said it was completely useful, 11 said it was partly useful and seven said it was not useful. Some of those who found it useful expressed acceptance or satisfaction.

> "I think it's sensible enough to know."
>
> "It's not really troubled me. If it's all part of the recovery process, then I'll accept it."

Those who found the advice only partly useful made a variety of comments. Four said that it was just common sense, or that they could use their own knowledge or judgement about what to do or not to do.

> "I suppose so. I should think on this one you know yourself what to do."

Two said that the advice was only partly useful because of their age:

> "I'm 55, so I don't know. I don't chase sex like I would if I was 30."

Others commented that they wouldn't have known what to do without the advice, that the advice was vague, or they just followed the advice. Five of the respondents who said that the advice sheet was not useful commented that it was vague, impersonal or inappropriate to them.

> "It's a bit ambiguous - what is normal physical activity? I assume it's going back to work."

Some of them reacted quite strongly to it:

> "It's so nebulous that you can put whatever construction on it that you choose. Useless advice. Negative advice!"

Others commented that the advice was not useful, because they would not bother with sex anyway, whether because of their age or their illness. It is clear that advice about sexual activity after myocardial infarction is appreciated by many patients. But, if the advice is so brief that it is impersonal and vague, then it may not be appreciated by a significant minority.

In each interview, the respondents were asked about the advice they had received, from lay people, about sexual activity. In the second interview, two people said that they had had advice from their spouse, one from a brother, and one from a friend. In the third interview, only one person said he had received lay advice, from a friend. Very little advice is provided from lay sources about sex to coronary patients.

In each of the interviews, the respondents were asked whether they would have liked any advice, or any more advice about their illness and sexual activity. Twenty-one respondents said that they wanted more advice about sex. Table 7.10 shows the nature of the advice that was desired. Five people at the second interview said that they wanted some elaboration on the advice sheet: how did it apply to them? When was "back to normal"?

> "More specific advice. That advice goes to everybody. You don't know if it applies to you. They say go back to normal when you have returned to your normal physical activities, but we don't know when that is. We don't know what applies to us or others who've had a different type of heart attack."

Most of the queries at all of the interviews seemed to be concerned with the fundamental question of whether or not to have sexual intercourse. The queries were phrased in a number of ways; they related to the time at which sexual activity should be resumed, whether or not to have sexual intercourse, and what to do or not to do. One man who had not been given an advice sheet said at the second interview:

> "The last two times I've had intercourse, I've had a pain in my chest. So I think I should have been told something about it. They've told me nothing."

Another, who had found the advice sheet ambiguous said he wanted to know:

> "What the limitations on sexual activity are. How long before you start again."

In this way, a fairly substantial minority of the respondents wanted more guidance about sexual activity. As with exercise, they wanted to know more precisely what they should have been doing at different stages of their recovery.

4. SMOKING

In recent years much attention has been paid to the dangers of smoking and to methods of persuading people to stop smoking. Smoking in general, and heavy cigarette smoking in particular, is strongly associated with high mortality from coronary heart disease (Joint Working Party, 1976). Recently attention has been paid to the usefulness of stopping smoking as a measure of secondary prevention after myocardial infarction. The aim is to reduce the incidence of further infarcts and prolong the lives of people with established coronary heart disease. Two studies (Mulcahy et al, 1975; Wilhelmsson et al, 1975) have shown that people who continue smoking after myocardial infarction experience higher mortality rates than those who stop. There is therefore a substantial case for the provision of anti-smoking advice, as advocated by the Joint Working Party (1975). This is reinforced by the work of Burt et al (1974), who found that 63 per cent of their post-infarct males who had been given intensive anti-smoking advice, and only 27 per cent of those who had been given conventional advice, no longer smoked one year or more later. With this evidence, it is reasonable to believe that advice against smoking is a valuable method of secondary prevention after myocardial infarction.

In the present study detailed questions were asked about the respondents' smoking habits and the advice they had received about smoking. In each of the follow-up interviews the respondents were asked whether they were smoking at that time, and, if so, how much they smoked a day. Table 7.11 shows the number of people who smoked and the form in which they smoked. Thirty-six respondents smoked before their infarct. Twenty-six stopped smoking at some time between their infarct and the time of their second interview. Two more gave up smoking between three months and one year after their infarct. The large majority of those who gave up smoking did so in the immediate aftermath of their infarct rather than in the subsequent months. An appreciable number of respondents resumed smoking, after they had given it up. Eight, of the 26 who had stopped smoking at the time of the second interview, resumed later. The problem is therefore not only one of stopping smoking, but also one of preventing people from starting again. These changes meant that, at the time of the fifth interview, 13 of the 36 original smokers still smoked. Twenty-three (two-thirds of the smokers) were not smoking at one year. This is very close to the proportion of those patients in Burt's series, who received intensive anti-smoking advice and then stopped.

There were changes in the form in which the tobacco was smoked, and in the amount. Table 7.11 shows that there was an initial fall in the overall number of people who smoked manufactured cigarettes, and that the numbers fell

slightly in the later interviews. There were also falls in the number of respondents smoking self-rolled cigarettes and cigars, followed subsequently by a small increase. The number of people who smoked a pipe fell between the time of the infarct and the second interview, and rose again subsequently to its previous level. There were similar variations in the amount of tobacco smoked. Before their infarct, most smokers of manufactured cigarettes smoked 20 or more per day. At the time of the second interview, most of the cigarette-smokers had reduced to between one and nine a day, but the amount subsequently rose again to around 20. Similarly, there were reductions, followed by small increases, in the amounts of tobacco consumed by smokers in other forms.

From these data, it can be seen that advice about smoking should be aimed not only at persuading people to stop, but also at helping them not to start again. In the present study, the respondents were asked about the advice about smoking they had received. In each follow-up interview, those respondents, who had been identified as smoking before their illness or at the time of the previous interview, were asked whether any health service staff had given them any advice about smoking. Those who said they had been given any advice were then asked who had given it, and what advice was given. Table 7.12 shows that, at the second interview, 31 of the 36 respondents who had smoked previously said that they had been given advice about smoking. The most frequently identified sources of advice were hospital doctors, followed by general practitioners and the advice sheet. Thirteen respondents said they had been given advice from one source only, nine from two, and nine from three or more. All respondents said they had been advised to stop smoking. At the third and the fifth interviews, well over half the respondents who had smoked at the time of the previous interview, said that they had been advised about smoking. At the fourth interview, one-third of the smokers said they had been given any advice. On very nearly all occasions, hospital doctors or general practitioners had advised the respondents to stop smoking. Very little other advice was identified by the respondents. Nearly all the respondents who smoked received clear medical advice to stop smoking.

The respondents were also asked in each interview whether any friends, relatives or other people had given them any advice about smoking. Table 7.13 shows that, at the second interview, one-third of the respondents who had previously smoked, had been given advice by some lay person. Between one-third and two-thirds of the respondents who had previously smoked said in each of the subsequent interviews that they had been given some advice by a lay person. The respondents' wives, and their brothers and sisters, were the main sources of advice. Again, almost all the advice was to stop smoking.

It is likely therefore, that the advice given by health service staff and by lay people was mutually reinforcing for the majority of respondents who received it.

The data, about respondents' smoking habits and the advice they were given, have been examined to see whether any relationship between the two could be found. There is no evidence that variations in the pattern of advice, from health service or lay sources, were associated with variations in stopping or resuming smoking. This suggests that specially established intensive programmes of advice are not necessary in order to persuade the majority of people to stop smoking after myocardial infarction. It also suggests that it is insufficient simply to increase the amount or frequency of advice, in order to persuade those who continue smoking to stop.

In each interview, all the respondents who had smoked at the previous interview were asked whether they would have liked any advice, or any more advice, about smoking. Ten people altogether said they wanted more advice about smoking. As suggested in Table 7.13, most were people who accepted the need to stop smoking, and wanted to know how to stop. The simple advice to stop smoking was not, in itself, enough; they wanted more help to manage it. A few respondents wanted advice about other matters. Two said they wanted to know whether changing from cigarettes to a pipe would be satisfactory.

5. NEEDS FOR OTHER INFORMATION AND ADVICE

It is well established that people in Britain are generally satisfied by the care they receive from the health services, but that they experience a considerable amount of dissatisfaction about information and communication relating to their illnesses. Cartwright (1964) found that 42 per cent of her sample of hospital patients reported dissatisfaction with the information they had received in hospital. Half of these were unable to find out all they wanted to know about their condition, their treatment or their progress, but many gave only general indications of dissatisfaction. Carstairs (1970) also found that most patients were satisfied with their hospital care. She

found that the physical environment attracted most comments indicating dissatisfaction, and that nine per cent of in-patients and four per cent of out-patients were dissatisfied with information and communication. Comments were made both about the lack of information and the lack of opportunity to obtain it. From these findings we would expect that a considerable proportion of coronary patients might be dissatisfied with the information they had received about their illness, or would wish to know more about it.

In each interview, after being asked about their contact with the health and rehabilitation services, the respondents were asked whether there was anything at all to do with their illness or treatment that they would like to have been told more about. In each of the follow-up interviews, after being asked about the advice they had received, the respondents were asked whether there was anything else to do with their illness, that they would have liked more advice about. The replies to these two questions have been consolidated into Table 7.14. More than three-quarters of the respondents said they wanted more advice or information about their illness or its effects. It may not be possible to satisfy this desire, when medical knowledge, about the causes of coronary heart disease for example, is limited. But the wish for more information was the most frequently expressed unmet need identified in the present study.

Two-thirds of the respondents wanted to know more about their illness or recovery. Some wanted to know about the causes of the heart attack.

> "I would like to know what had caused it. I thought that it might have been the gardening."

Others wanted to know about the nature of their illness:

> "I want to know what it's all about, what's actually happened."

> "If someone could explain exactly what the trouble is. All I know is that I've got heart trouble and low blood pressure. No one has actually told me what's wrong."

Most people knew what was the matter with them, but some wanted to know about the severity of their illness:

> "Just about how severe it was, how much damage was done."

> "You are never told the amount of damage that has been done or whether it will have any lasting effect."

Later on during recovery, attention shifted from the severity of the initial infarct to current symptoms and problems:

> "Why it should have an effect on me one day and not another. One day I can go upstairs and nothing happens, and another day under the same circumstances I get a tightness in my chest."

> "What pains to expect and put up with, or what pains should cause me concern (so that I should) do something about them."

There was a clear and substantial desire among the majority of respondents to know more about their illness, its causes and its medical consequences.

A second group of respondents, especially at the second and third interviews, wanted advice not so much about the nature or severity of their illness as about their future prospects. They wanted to know more about the possibility of a recurrence of the heart attack. Most of these people were concerned to know whether they would get better or get worse; how long it it would take to get better or whether their illness would last for the rest of their life.

> "I felt very weak after my discharge. How long is it before I'm normally strong again? How much care am I going to need?"

> "Do you get any better as time goes on? Does your heart get better or does it deteriorate?"

> "About the heart part. If it heals up or if it's going to keep me down all the time."

These people seemed to assume they would carry on living; they wanted to know more about how their illness would affect them in future.

Two-fifths of the respondents wanted more information about their treatment. Some people did not know much about their treatment at all; others wanted to know why they were given a particular treatment.

> "In hospital, why one bottle was dextrose and the next bottle insulin? Why they were alternated."

> "Also I'm on six different drugs and it would be nice to know what each one is for."

Some people wanted to know how long their treatment would last; this related to their prospects of recovery.

> "I'd like to know if it's a cure or a part cure. They said these tablets were for the damage to the heart wall. I don't know if it's cured or if I have to keep taking the tablets for the rest of my life."

And some wanted advice about how to get treatment if they needed it.

> "What to do if I had a recurrence? What's the quickest way of getting help?"

Some of these people wanted information about past or present treatment, some wanted to know about their future treatment, and some wanted advice about what to do in the future.

A quarter of the respondents said they wanted more advice or information about their work. Some people wanted to know if they would be able to return to their own jobs. A farm tractor-driver said:

> "Can I go back to my job? It is sometimes a heavy job, but I like it. Is it advisable? That's what I would like to know."

At the later interviews, people wanted advice about the kind of work they would be able to do, or should be doing. A foreman gas-mains layer said at the fourth interview.

> "There are times at work when I have to get stuck in and do the work as there are only two in my gang. I don't know if this is all right."

And some people wanted more advice about the timing of their return to work. A post office telegraph operator said, three months after his initial heart attack:

> "Also my doctor says he thinks I might go back to work in five weeks. He must be mad. He doesn't even know where I work."

Most of these respondents wanted specific advice about their work; they wanted advice that related their illness to the circumstances of the particular job that they might be doing.

Two-fifths of the respondents said that they wanted more information about the effects of the illness on their daily activities other than work, or advice about what they should be doing. About half these people identified specific activities.

> "I want to know if I can have a bath. I'll ask my doctor when he comes next."

> "Is it going to last for ever? For instance, I've taken up sailing and I don't know if I can still do that."

The others did not identify specific activities, but said they wanted advice, for example about:

> "Everything. They haven't told me anything. Just everything that I should and should not do."

Or:

> "A list of what I can do to use as a "yardstick" as to what I will be able to do. The specialist said I'd only had a slight heart attack, and yet I'm not able to do this or that. So if anyone had a bad attack, they must be frightened to move."

Many of these comments revealed considerable uncertainty on the part of the respondents, as to what they should be doing, and a corresponding dependence on the doctors' advice.

A few respondents said that they wanted advice about their diet. It was medical policy in the Kent and Canterbury Hospital at the time of the study not to give dietary advice until the results of blood chemistry tests were available. Some respondents simply said they wanted some advice about what they should eat.

> "Diet. I don't know if I should be on a diet or not. They haven't said what I can or can't eat."

> "Just the diet. Knowing what type of food it's advisable not to eat."

Some people had been given some advice, but wanted more specific or detailed guidance.

> "The doctors say I'm too fat, but they don't say how. I don't eat much, I don't eat bread, cakes, potatoes anything like that. I don't eat much at all. They just say eat less. I can't eat much less. They should give you a diet sheet."

> "Just diet. I thought it might be useful to know what to eat. The only thing I've been told is to lay off animal fats. But I don't know. It'd be useful to have a diet sheet. So that I'd really know what to eat. They are pretty vague about it."

Others had been given advice or put on a diet, and then found that this caused them difficulties.

> "Diet. Much more advice. I'm on two diets. One - low cholesterol. Two - 750 calories a day diet. What I can have on one diet I can't have on the other. I don't really know enough about the diets to know what I can eat. I'm just eating what I think is right, cottage cheese, lettuce, tomatoes. Very limited."

> "The diet sheet. I'm on 500 calories but I don't want a diet sheet but a list of calorific values of each food. But I have just been given a diet sheet which is useless, as I don't intend to each fish and that's the first thing on the list. They also tell you what to have for tea. I don't have tea. Just dinner at night. All I wanted was a list of the calorific values of each food."

As with other items, the provision of some advice to respondents had the result that some of them wanted further advice that was more specific or more closely suited to their personal, specific needs.

A final group of respondents identified other ways in which they wanted more advice. A few people identified specific topics on which they wanted more advice.

> "Is there anything I can do or take, - or see someone about - this irritability I'm getting? I'm driving people mad. I just want to get away from people. I worry too much, I know."

> "It would be a help if there was some way you could find out what sort of money you will get when you retire. You just don't know where to go to find out."

Others made more general comments about the advice they had received or wanted.

> "I don't even know what I've had. I don't know what advice I need or where to get it."

> "If they gave you a card telling you where you went for advice on all different things."

As with many of the specific areas in which advice was desired, different individuals had different needs.

6. CONCLUSIONS

Many doctors have argued that the education and advice given to coronary patients is an important part of their rehabilitation programme. Many have also argued that there is a need for better advice to be given to patients and their families. There have been a few studies that have shown that the special provision of advice and guidance can be effective in promoting patients' recovery or changing their behaviour. But there have not been any previous attempts, reported in the research literature, to describe the nature and amount of advice given to coronary patients, and to use this as a baseline for identifying unmet needs. The present study is the first to provide systematic data of this kind.

Nearly all the respondents in the present study received advice about exercise from health service staff. Most said that they had been advised to increase the amount of exercise they took during the weeks after their discharge from hospital. In general, they appeared to feel that they should be taking moderate, rather than vigorous, exercise. Nearly all the respondents said that they had followed the advice they had been given by health service staff, even though, on some occasions, advice from lay sources had conflicted with it. Half the respondents said that they wanted more advice about exercise; most of these people wanted more detailed or specific advice about what they should or should not do.

Nearly all the respondents also received advice from health service staff about taking rest. Most said that they had been advised to take a rest during the day, but a few said that they had been told to rest more generally. Nearly all said that they had followed the advice they had been given. A number of respondents also said that they had received advice from lay sources about resting. Much of this lay advice was to rest generally or take it easy. Just over a quarter of the respondents said that they wanted more advice about resting.

We have little direct evidence on the relationship between the advice about rest and that about exercise. A few respondents said that they had been advised to take it easy or not to do too much exercise, but that this had not dissuaded them from following medical advice to increase their activity. In general, one may only speculate whether the general tone of advice to people to take a rest during the day or to rest in other ways reduced the amount of activity that was undertaken. This kind of effect might occur as the direct product of conflicting advice, or as a by-product for example of the patient still considering himself an invalid if he has to rest during the day. In general, the result seems to have been that the respondents felt that they should pursue a moderate, or gradual, resumption of activity, but not a vigorous one.

Most of the respondents said that they had been given advice about sexual activity. The main source was the advice sheet, distributed by the hospital staff. This advised the patients that sexual intercourse might be resumed normally when they had returned to their normal physical activity. Two-fifths of the respondents said that they would have liked more advice about resuming sexual activity. On this topic, there appears to be an appreciable need for more personal advice, suited to the particular circumstances of individuals.

Thirty-six of the respondents smoked before their infarct. Nearly all of them were given advice, from a variety of health service and lay sources, to stop smoking. Two-thirds of them did so. These constitute the same proportion as those who stopped after being given intensive anti-smoking advice in the research study reported by Burt et al (1974). There was no evidence in the present study that different intensities or amounts of advice had different effects on smoking behaviour. There is no case for the immediate widespread introduction of intensive anti-smoking programmes after myocardial infarction. Instead the advice should be maintained at its present levels. Research is needed on three topics. Whether intensive advice raises the proportion of people who stop smoking still further? Why some people stop smoking and others do not? And why some people, who have stopped, resume smoking but others do not?

Nearly all the respondents identified other subjects about which they wanted more or information. They wanted to know more about a considerable variety of subjects: the nature and severity of their illness, their prospects of future recovery, their treatment, what they should be doing in the way of work and other daily activities, and their diet. Even within these broad areas, most of the respondents brought their own individual query or approach to the subject. This suggests that standardised packages of advice or information would not be wholly successful in meeting patients' needs. Instead, it would be necessary for a member of the staff to talk to each patient individually, to find out his particular problems or queries, and to answer them taking into account both the patient's medical condition and the circumstances of his daily life. A number of benefits might flow from improved education and advice: expectations of higher standards of service; reduced anxiety and uncertainty about the illness; greater rapport between doctors and patients; more and better decision-making by the sick person about their own activities and resettlement; reduced dependency on services; and hence less need for formal rehabilitation services and the consequent expenditure. But these are untested hypotheses; at present we are simply faced with the strong desire of coronary patients to know more about the illness and its possible effects.

We may now draw together some ideas about the more general development of programmes of education and advice after myocardial infarction. In Britain, there is probably not much in the way of formal programmes of advice after myocardial infarction. Some doctors emphasize this side of their work more than others. A few developments have been reported in the research literature. Advice must be quite widely given in the ward, clinic and surgery. Some doctors provide written advice, and others presumably tell patients what they should be doing, in the course of physical exercise rehabilitation programmes. Beside all this, there is a tradition in British medicine of concern with the overall well-being of patients. This twin base, of a variety of educational and advisory activities, and of concern with patients as individuals, is of great importance to the future development of advice.

Professional involvement in this area should develop in two ways. First much of the advice should be suited to individual needs and presented individually. It should take account of the individual characteristics of the patient's illness and of his daily life at work and at home. And it should be presented in such a way that the patient can see and feel that it is based on his individual needs. Second, there may be areas in which the doctor wants the patient to pursue a definite or preplanned course of action. These could include the resumption of physical activity or stopping smoking. In these

circumstances patients seem to want advice that is quite detailed and specific, even though this increases the chances that some particular detail will be inappropriate or irritating for any given individual. It is also necessary that, once the adviser has given the advice, he should keep in quite close contact with the patient. He would then know what the patient is actually doing, and would be able to reinforce or adjust his advice appropriately.

There are no obvious indications as to which is the most appropriate profession or part of a profession to give this kind of advice to coronary patients. General practitioners sometimes claim greatest knowledge of the patient's personal life, but they may be little involved in the management of the acute episode or the subsequent physical rehabilitation. The consultant physician is well-placed to direct the programme from the cardiological point of view, but frequently might not have the time to become personally involved in assessing and advising about the personal life of each patient. Junior hospital doctors might be able to provide this kind of personal advice, but it seems likely that the demands of professional exams, and the pressures on them to focus on the organic aspects of disease, would absorb the attention of most. Nurses in Britain are usually restricted to giving care and treatment; they may assist in rehabilitation but rarely take primary responsibility for a part of a rehabilitation programme. Health visitors have a major educational role in primary care, but have not been greatly involved in rehabilitation. The provision of education and advice is not central to the work of the remedial professions, although they might well have contributions to make in discussing the functional implications of the disease. From the point of view of medical rehabilitation, many of the problems about which the patients require advice are too closely related to their continuing illness or treatment, or too small, to justify the involvement of a specialist in medical rehabilitation. It has been argued that hospital social workers are the best people to give this kind of advice. But from the evidence presented here, it seems that much of the desired information is about the illness itself or the effects of the illness on daily activities. This suggests that the best person would have a professional education and background concerned primarily with disease and health. There is no single, outstanding candidate for the job of providing advice and education to coronary patients.

If it is agreed that there are unmet needs for advice and education, and if it is decided that these activities should be developed further, then there are a series of consequent issues to be faced. Is it desirable for a single professional group to take the lead in this development, or is it sufficient for different people to give their advice at different times, as at present?

If different contributions are acceptable, is it desirable to coordinate them at local level, as the Tunbridge Committee (D.H.S.S., 1972a) argued, and to exchange ideas at a policy level about the way they relate? If these questions about coordination and inter-professional relationships should be discussed, should the initiative be left to the professions themselves or should the Department of Health encourage a particular profession to identify its contribution in this area? In considering these issues, it is open to the Department to determine whether to take a more or less active role in encouraging the development of services to meet the needs, among coronary patients, for advice and information, that have been described in this chapter.

At the same time it is clear that the problems give rise to a wide range of research questions, that are relevant to the development of services and therefore of concern to the Department. From the present study, we begin to have some understanding of the advice that people are given, the way they react to it, and of what more they want. It would be useful to know, from further research or from informed comment, whether the present findings are unique to one hospital only or typical of the country more widely. In addition there are a number of further issues.

(i) We have studied what advice patients are given. But what knowledge do patients have about their illness and about what they should be doing in the first place? Where do they get this knowledge from? Why do some people know more than others? This understanding, of patients' knowledge about their illness and what they should do, should be the basis of any rational attempt to provide them with more knowledge or advice.

(ii) The knowledge that patients have and the advice they are given are important largely because of the ways in which they affect behaviour. But we know virtually nothing of the way in which patients translate this kind of advice into action. We know little for example of the amount of exercise, rest or activity that people take while recovering from a heart attack, and little about what stimulates them to stop or restart smoking, to resume sexual activity or to change their diet.

(iii) The present study, in common with others, has reported high levels of unmet needs for information and advice. Why does this occur? Do patients fail to express their needs during consultations? Or do health service staff fail to respond when the needs are expressed? Or is it that, by providing some advice, staff somehow stimulate the desire for more? Or is it that the social researcher, by requiring his respondents to articulate ideas about the illness and information,

raises questions in the respondent's mind for the first time and thus stimulates the desire for more information?

(iv) While the answers to the previous questions are being sought, it will even so be possible to proceed with the experimental development and evaluation of services. Properly organised randomized control trials of giving advice to coronary patients are needed. There are many aspects of the advice (i.e. the treatment) that could be examined: the subject matter (exercise, smoking or diet); who gives the advice (specialist, G.P., or therapist); how the advice is given (verbally or in writing; individually or in a standard programme; didactically or informally); to whom the advice is given (patient, family or others). It would be necessary to assess the outcome of such interventions in terms of the patient's knowledge about his illness and what he should do, the unmet needs he expresses, and his actual behaviour.

There are substantial programmes of research waiting to be done.

CHAPTER 8 CONCLUSIONS AND RECOMMENDATIONS

In this chapter we will draw together some of the main material and themes from the preceding pages. In so doing, we will organize our conclusions into three main areas. First, we will review the findings of the present study in the context of other people's research and ideas about recovery and rehabilitation after myocardial infarction. Second we will examine the implications of our findings for the development of rehabilitation and after-care services for coronary patients. Third, we will examine what further research, relevant to the development of rehabilitation and after-care services for coronary patients, may be needed.

1. THE RESEARCH FINDINGS AND CONCLUSIONS

Myocardial infarction is an acute episode of a physical illness, that results in physical incapacity and many personal and social problems for the sufferers. Just as the patient may recover from the illness in a physical sense, so may he recover from the personal and social damage it has caused. There are many different aspects of recovery. This fact leads to two sets of questions. The first set is directly about recovery. Which aspects of recovery are most important? Do patients recover more satisfactorily in some ways than in others? If so, in what ways do they make the most successful, and the least successful, recovery? The second set of questions is about the relationship of health services to recovery. In what ways do different aspects of medical treatment and rehabilitation relate to different aspects of recovery? How appropriate are different kinds of rehabilitation to the different kinds of problems that occur during the months after myocardial infarction? These two sets of questions form the themes of this section of the chapter.

Recovery after myocardial infarction is a multi-faceted process. The present study has been one of the first to collect systematic data over a wide range of the personal and social aspects of recovery. We have shown that myocardial infarction affects many aspects of the sufferer's daily life for many months after the acute infarct. These aspects can be examined in terms of the number of people affected, the length of time involved, and the severity of the impact.

The research studies quoted in Chapter One of this report showed that myocardial infarction affects many different aspects of the sufferers' daily lives and personal well-being. They showed that the work, home life and emotional status of most, if not all, sufferers were affected in the period immediately after the infarct. They also showed that perhaps half of the

sufferers continued to experience the effects of the illness not only on these aspects of their lives, but also on their recreation and sexual activity, during much of the year after the infarct. Most of these studies have concentrated on single aspects of the illness; they have not attempted to assess the overall impact of the illness on the sufferers. The present study, by collecting systematic data in the Grogono Index about the effect of the illness on different aspects of the respondents' daily lives, has made an assessment of changing overall impact of the illness. The Index made use of a scale that ranged between nought points, indicating no incapacity, to 20 points, indicating complete incapacity. The mean score of the respondents fell gradually from eight points at the first interview (indicating moderate incapacity) to five points at the fifth (little incapacity). The effects of the infarct are moderately, but not overwhelmingly, severe for the majority of people 10 days after the acute episode. Some effects persist for most people for most of the following year. These findings provide an indicator of the broad effects of myocardial infarction upon the survivors. They are a baseline against which the needs for, and the effectiveness of, a comprehensive coronary rehabilitation programme should be assessed.

Previous research studies have provided data about different aspects of recovery at different points in time, but have not provided sufficiently comparable data to allow us to assess which aspects of patients' daily lives are affected most frequently and most significantly. We can see, for example, that all patients work and emotional status are probably affected in the immediate aftermath of the infarct, but it is impossible to tell which is most frequently affected one year later, or how important these effects are then. In the present study we can begin to assess the relative significance of the effects of the illness on the respondents' daily lives. We have seen that the effects on respondents' work are at the most significant. All the respondents at the first two interviews, and three-quarters at the fourth and fifth, said that their illness affected their work - more than said any other individual item was affected. The effects were greater than in other areas, both in keeping people off work and in the limitations imposed after they had returned to work. And more people said that their work and the effect of the illness on it were very important to them, than said that other items were important. Although work emerged as the most important single aspect of recovery, a number of others were not far behind. They included recreation and the performance of other activities around the house, which are quite closely related to each other. These were followed by the respondents' emotional state and a desire for more information or advice about the illness or its effects. These, in turn, were followed by the effects of the illness on the respondents' physical well-being, sexual activity and sleep. This

attempt to assess the relative frequency and importance of the different consequences of myocardial infarction confirms some of the broad trends that were emerging in the professional literature and from previous research. It also adds new items to the list and, for the first time, provides an explicit ordering of them. In these ways, it may be useful in suggesting where the attention and priorities of those concerned with rehabilitation and after-care might be focused.

These widespread and persistent effects have implications for the way we consider rehabilitation services. The first, and most important, point concerns the objective of the rehabilitation services for patients. The objectives, whether explicitly formulated in policy-statements or implicit in the minds of practitioners, should take account of the whole range of the effects of the illness. The objectives might be expressed in such terms as:

> "to restore patients to as full a state of health and well-being as possible, and to return them to as full a range of activities as possible."

Because there are many aspects of recovery, the objectives should be stated in comprehensive terms.

Although no data were collected in the present study, about the ways in which health service staff thought about the recovery of patients or expressed the objectives of their actions, we do have some data about the kinds of treatments and services provided. There is a lack of comparable data, about the services that are generally used by coronary patients, either in the research literature or in routine health service statistics. Our findings showed that health service staff, besides their primary concern with the patients' illness and physical progress, were most involved in advising patients about exercise and the resumption of physical activity. These concerns are similar to the emphasis in the Joint Working Party report on coronary rehabilitation. Other aspects of recovery were discussed, but apparently either infrequently, such as diet or emotion, or impersonally, such as sex. Despite the contact of some of the respondents with social workers, employers or the employment services, there appeared to be relatively little penetration of the health or rehabilitation services into the actual daily activities, difficulties or problems of the respondents at work or home.

If the objectives of rehabilitation services are expressed in comprehensive terms, the next issue to be considered is what kind of services are needed to achieve those objectives. Does the existence of comprehensive objectives mean that we should consider the establishment of a full range of

services, with one particular service for each aspect of the patient's recovery that we wish to affect? Or is it possible that the development of one kind of service (e.g. graded exercises as a programme of physical rehabilitation) would improve so many aspects of the patients' recovery that a multiplicity of services are unnecessary. The answers to these questions depend in turn on the answers to others. If we want to plan our interventions rationally, we need to know the causes of the problems we are facing. Is, for example, delayed return to work caused by physical incapacity, psychological fears, patients' dislike of their work, a low demand for labour, or some combination of these and other factors? Many professionals and politicians have beliefs about these matters, but there is not a great deal of evidence about causes of variations in different aspects of patients' progress and recovery. Additionally, we need to know more about the effectiveness of different kinds of treatments and services in promoting recovery in different ways. As we saw in Chapter One, much of the evidence is inconclusive. It is likely that different kinds of rehabilitation programmes promote different aspects of patients' recovery. For example, an exercise programme may improve fitness and have a lesser effect on morale and working performance; or an educational programme may improve patients' outlook and level of knowledge, and thus increase their level of activity and fitness. If this is correct, it is most unlikely that any single kind of rehabilitation programme will come close to promoting complete recovery, in all its physical, personal, social and economic aspects. It would be necessary, therefore, to have a comprehensive rehabilitation service, consisting of different kinds of treatments to deal with different kinds of problems.

From the multiplicity of the aspects of recovery and from the notion of comprehensive rehabilitation, we may turn to a number of the individual aspects and the related services.

The subjective aspects of the physical illness were important to many of the respondents in the present study. We found that between one-third and one-half of the respondents at each interview reported that they had experienced since the previous interview some symptom or event, directly related to their heart. These were usually pains in the chest or arm, breathlessness or tiredness. The respondents identified the subjective aspects of their illness as important in other ways. From the second interview onwards, around half the respondents at any one time felt that they were not making very good progress. Of those people, who identified worry or unhappiness as the most important item in the Grogono index, more related this to their illness, recovery or possible death than to any other item. When asked at each interview whether there was anything else besides the items

contained in the Grogono index that was important to them, more people identified their prospects of recovery or the possibility of a recurrence than anything else. When asked whether there were other items, about which they wanted more information or advice, more people identified their illness or present state of recovery than any other item, and an appreciable number said that they wanted to know more about their future prospects of recovery.

There appears to be relatively little research that has been undertaken on patients' subjective experience of their illness and recovery after myocardial infarction. What patients experience personally and what they understand about their illness may be important in the context of their recovery and rehabilitation. These factors will influence the way patients seek medical care, and hence their continued dependence on, or their growing independence of, the health services. They will influence what patients think it is safe or desirable to do; and hence they will affect the whole range of daily activities, at work, at home, with the family and in recreation. And they will influence the patients' morale and emotional status, both directly, and indirectly through their effect on the patients' daily lives.

If this emphasis, on the patients' own experience and knowledge of their illness is correct, then there are implications for the development of health and rehabilitation services. At present there are two relevant trends in cardiac rehabilitation. The first is the emphasis on the psychological nature of patients' problems, as defined in terms of anxiety or depression. This leads to the argument that psychiatric intervention is needed to alleviate these symptoms. If, instead, we accept Garrity's (1973) evidence about the close relationship of patients' perception of their health to their morale, and focus on what the patients are worried or anxious about, then we are concerned with the interpretation of medical symptoms or events. The second trend is the emphasis on advice about practical activities, such as exercise, work or sex. The efforts of the doctor or adviser are directed towards telling the patient in some detail as to what he should or should not do at particular stages of his recovery. And, as we have seen, many of the patients want more personal advice or more detailed advice. Now, it may be that the need for these two divergent trends, towards psychiatric intervention on the one hand and practical advice on the other, could be reduced substantially by attempting first to educate the patient more fully about his illness and its effects. An educational activity of this kind would provide the patient with factual knowledge about his illness, its causes and its likely effects. And, most importantly, it would teach the patient how to understand the symptoms he experiences, and then to relate them to the progress of his illness on the one

hand and his daily activities on the other. If this was successful, it would be a programme that educated patients in self-management and helped them to achieve the independence that is one of the goals of rehabilitation. As Wenger (1975b) has argued: "..... educational programmes must be designed to enable (coronary patients) to fulfil an optimal role as participants in the health care team."

The second main aspect of the recovery process is the patients' performance of daily activities. The most substantially affected activity was work. Half the respondents were off work for four months or longer. Even after they had returned to work many continued to feel the effects of their illness, in terms of limitations of the tasks they could do or the hours they worked. These things have been studied before; the present study gives a new significance to them, because it demonstrates the importance attached to their work by the majority of respondents and the extent of their positive involvement in their work. Other activities were affected among a substantial number of respondents. Recreation was affected dramatically during the first three months or so and fairly substantially for the whole of the year after the infarct. This was to be expected, from other research studies; we have detailed the reduction in physically demanding activities around the house, such as gardening and home maintenance and improvements, and in all kinds of activities away from home. Similarly, we have seen many aspects of daily life at home, such as getting upstairs and lifting things, were affected, as was sexual activity.

All of these activities are, first of all, important in themselves. They were things that the respondents felt were important, and things that they liked doing. Many of the respondents said that they liked working or that they liked to be active. Others said that they felt obligations to work or be independent. And others, though off sick, were actively involved in thinking about their work. Similarly, many of the problems anticipated by respondents revolved around their possible inability to do their job or particular tasks. But these activities are not only important for themselves. Work is obviously a determinant of many other aspects of daily life, relationships with family, workmates and other people; income, hence consumption, household expenditure and its concerns and status. Similarly, recreation, sexual activity and the performance of daily tasks at home all are the channels through which social relationships with other people are constructed and altered. Alterations in these physical activities would have substantial social effects. Additionally, each kind of activity would have effects on the individual himself. The performance of enjoyable and worthwhile activities presumably raises people's morale, their feelings of well-being and

their self-esteem, thus helping overcome some of the psychological problems we have discussed. Furthermore, insofar as these activities are physically demanding, the performance of them may increase patients' fitness, thereby reducing the frequency of symptoms and, perhaps morbidity. In many respects, therefore, it is appropriate to consider the performance of everyday activities as an important and central aspect of recovery after myocardial infarction.

In the present study, we can identify a number of ways in which the doctors and other health service staff presumably influenced the patients' resumption of daily activities. First, a substantial amount of information will have been conveyed, both in hospital and afterwards, about the patient's illness and progress. This will have had both direct and indirect implications for how the patient is getting on and what he could expect to do. Second, the programme of mobilisation in hospital, and the oversight provided by the general practitioner afterwards, will have affected the rate of progress. Third, a fairly substantial amount of direct advice was provided, both through the advice sheet and by personal contact with hospital doctors and general practitioners. This advice covered the amount of exercise to be taken, the daily routine to be followed, and the kind of activities to be undertaken. The staff were telling the patients directly, but in general terms, what and what not to do. Fourthly, there will presumably have been a certain amount of more specific discussion about the patients' return to work, if only in the context of signing sick notes. For the majority of the respondents these four activities seem likely to have constituted the main part of their treatment influencing their resumption of daily activities.

If the emphasis on the patients' resumption of everyday activities is correct, then there are implications for the development of health and rehabilitation services. In Chapter One we discussed definitions of rehabilitation in terms of the restoration of patients to activity. If the focus discussed here is appropriate, then the objectives of rehabilitation should be expressed, not primarily in terms of the restoration of physical fitness, functional capacity or the ability to undertake certain levels of activity. Rather, the objectives should be expressed in terms of enabling the patient to resume, satisfactorily, certain specified activities, such as work, household tasks, recreation, sex. This, however, raises questions about the methods of rehabilitation that are most appropriate, and hence about the knowledge and skills of those providing the rehabilitation. The dilemma emerges in the following terms: if a doctor, or remedial therapist, wants to return a patient to a particular kind of activity, such as mending his car or going swimming, does that mean that the doctor has to guide the patient as to the specific level of exertion and the tasks that he should be undertaking at each point in time? If so, the doctor presumably has to know quite a lot about each of the everyday activities that

may be significant in the patient's recovery, and the way in which the patient performs them in different circumstances. If not, then the doctor has to find some more general way of guiding the patients, that is based on his medical knowledge, rather than on inevitably incomplete information about all kinds of everyday jobs and activities. In these circumstances, we can identify three main strategies for the involvement of health service staff in rehabilitation.

(i) Medical rehabilitation could focus on the restoration of physical capacity. This is the primary target of exercise programmes in coronary rehabilitation and much of physiotherapy. The working assumption behind this kind of therapy is that the restoration of functional capacity is usually a sufficient condition for the resumption of daily activities such as work and recreation. This may be correct, but, as we saw in Chapter One, there is no evidence available to support it. Indeed, it is reasonable to argue that as performance of the activities of daily living is influenced by a variety of psychological, social and economic factors a rehabilitation programme with a broader base than the restoration of physical fitness will be necessary.

(ii) The rehabilitation could focus on the resumption of particular daily activities. The model here would be the training of old people, in activities of daily living, that is undertaken in occupational therapy departments, or the restoration of the capacity to do particular kinds of jobs that is undertaken in industrial rehabilitation units. It is at this point that cardiac rehabilitation units, staffed by doctors, remedial therapists and other professions, come into consideration. A rehabilitation programme, in which the doctor or therapist related his knowledge of the patient's medical condition to detailed information about the patient's work, home life and recreation, and used both to plan the patient's progress seems in principle feasible. It might however, be expensive, in terms of staff time and attention, in relation to the benefits.

(iii) Medical rehabilitation would be based not only on the restoration of physical fitness, but also on the education of the patient. At present, patients relate information about their illness and its effects to ideas about what they should be doing, but only one suspects with uncertainty and without much guidance from doctors or therapists as to what that relationship should be. The educational programme could aim to help the patient understand the nature of his particular illness and the principles that should govern the relationship between his illness and the numerous aspects of his daily life. The patient would be the person to apply his understanding in his daily life.

It is at this point that the two aspects of recovery, which we have been discussing, come into a close relationship with each other. On the one hand we have been considering the subjective aspects of the physical illness: what the patient experiences in the way of symptoms and what he knows about its causes, severity and effects. On the other hand we have been considering the effects of the illness on the patient's daily activities, and have argued that they are a major aspect of his recovery. In this report we have been examining recovery after myocardial infarction largely in terms of the sufferer's perception of his condition and his activities in his daily life. If this is a viable model, we presume that the sufferer bases his actions in his daily life on his perception of his illness, and that his actions and activities in turn affect both his perception of his state of health and his "objective" condition. We are, therefore, advancing a model, that is not simply medical such as doctors are sometimes said to hold; nor is it simply psychological or sociological; nor does the emphasis fall exclusively on work and vocational rehabilitation. Our emphasis on people's perceptions of their illness, requires contributions from medicine, psychology and sociology, and our emphasis on the physical performance of everyday activities is potentially the subject matter of many sciences and professions. The focus of the rehabilitation services should be on patients' understanding of their illnesses and the ways in which they translate this into action, in their everyday activities and lives.

However we define a model of recovery after myocardial infarction, and however we develop the implications for rehabilitation, there will inevitably be limitations to the effectiveness of rehabilitation services based on a single model of recovery or on a single objective. We have emphasized the problems of understanding and the limitations in the performance of daily activities, experienced by the respondents in the present study. These were the most significant aspects of recovery to emerge from our data. Nevertheless, it should not be forgotten that many respondents experienced other problems, medical, psychological, social and economic. In whatever form health service rehabilitation is cast, health service staff must remain aware of other problems that their patients experience, and must be prepared to communicate and collaborate with other rehabilitation and resettlement agencies. Whatever model of recovery and rehabilitation is used in the health service, doctors and the remedial professions can only contribute to a comprehensive rehabilitation service.

2. THE DEVELOPMENT OF REHABILITATION AND AFTERCARE SERVICES FOR CORONARY PATIENTS

In the earlier chapters of this report we have made a number of specific suggestions about the development of rehabilitation and aftercare services for

coronary patients. In the previous section of this chapter, we attempted to develop some more general ideas about the significant aspects of the recovery process for coronary patients, and began to explore the implications of these ideas for the development of services. In this section we will draw this material together, and attempt to present systematically our conclusions on the main objective of the study: the exploration of coronary patients' needs for rehabilitation and aftercare services. We will present our conclusions about the ways in which these services might develop at the professional level of the National Health Service. First we will review the particular areas in which developments may be needed, and then we will discuss some more general implications.

The first area, in which there may be a need for the development of services, is work. The respondents experienced a variety of difficulties and problems. As a whole, the series returned to work later than is considered desirable. A few people failed to return to work at all. Some became unemployed. Many people expected that they would have difficulties in their work and actually experienced them; these related to the physical and mental aspects of their jobs. A few experienced alterations in their jobs, such as reductions in the number of hours worked or in the tasks undertaken. And a number experienced fairly substantial reductions in their incomes. In general, it seems likely that these kinds of experience are typical of coronary patients in the country as a whole. The problems were rarely of overwhelming severity for any one individual. Usually, they did not seem to demand the full range of intensive, specialised vocational rehabilitation measures. Rather, it seems that there was an aggregation of problems of secondary importance, which, when taken cumulatively, probably would have had an appreciable impact on the patient's well-being and economic performance. There was some scope for the development of services to deal with these problems. This might take the form either of more aggressive medical management in relation to work, or of the institution of routine therapeutic measures in medical rehabilitation or vocational resettlement.

Second, the respondents experienced many difficulties in the performance of a wide range of daily activities at home in the early months after the infarct. These activities include going upstairs, lifting, housework, recreation and sexual intercourse. While the rehabilitation services have concentrated mainly on problems of returning patients to work, these other activities are also important. First, they are important to the patients, and contribute significantly to their personal welfare and family life. Second, they are the activities through which the patient builds up his strength in preparation for his return to work. These activities have been

inappropriately neglected by the rehabilitation services. While not wishing that the health service should run patients' daily lives for them, we can suggest that, if more attention were paid to these daily activities, there might be substantial benefits in terms of patients' overall recovery.

Third, we have seen that many of the respondents would have liked more information or advice about their illness or its effects. A large number of topics were identified: the causes, nature and severity of the heart attack; prognosis; treatment; exercise; work; and other daily activities at home. These were direct requests for information by the respondents. It is not clear that the provision of this information would necessarily improve their recovery as measured in medical or functional terms. But, if the right information and advice was provided in the right way, then it might increase the patients' capacity for self-management, reduce their dependency on the health services, and enable them to make the most of their own state of health.

Fourth, many of the patients experienced some emotional distress. This was revealed partly through feelings that they were making poor progress in their recovery, and partly in response to direct questioning about worry and unhappiness. On the whole, the distress was focused around the illness and prospects of recovery. More study is needed in this area, but it is at least arguable that a psychiatric interpretation of those problems as "anxiety" or "depression" is inappropriate. If this is correct, a three-pronged attack might be the most effective: more effective medical treatment of the symptoms and other after-effects of the heart attack; helping the patient to understand his heart attack better; orientating the patient more towards recovery and the resumption of daily activities. In these terms, medical care and the rehabilitation services may help deal with problems of emotional distress.

In addition to these particular areas in which some development of services may be needed, there are some more general implications.

First, there is the question of the objectives of rehabilitation. We saw in Chapter One that the objectives of medical rehabilitation tend to be expressed in terms of the restoration of physical fitness or functional capacity. And yet doctors and therapists are often equally involved in patients' performance of particular activities of daily living, such as work and housework. The emphasis in this report has been on the resumption of particular activities and the restoration of patients' well-being. Because the restoration of physical fitness is no guarantee of a full recovery in this wider sense, it is essential that doctors and others involved see the overall objectives of rehabilitation in terms of patients' daily lives and circumstances. Only if they do so will their own contributions be effective and their relationships with other staff satisfactory.

Second, we may note several aspects of recovery which complicate the rehabilitation task. First, we may recall the variety of people's needs and problems. In discussing their work, lives at home, their worries and their needs for advice and information, the respondents all had individual concerns that related to their particular circumstances. Second, many of these problems emerged not in the acute stage of the illness, but later when the patients had returned home and were facing real-life situations and demands. Third, many of the difficulties either persisted for several months after the acute episode or emerged later on with variations in the patient's medical condition. All of these factors make it essential that those providing rehabilitation and aftercare do not simply provide a standard programme of services, but assess, and respond to, the needs of individual patients wherever they arise.

Finally, we may consider the implications for the work of the professional staff involved. Coronary rehabilitation programmes are probably usually provided directly by doctors at present. The main lead has come from cardiologists, with considerable attention being paid to the monitoring and assessment of physiological aspects of patients' cardiac performance. There has been a growing interest among cardiologists in rehabilitation during the last few years, and some are closely involved in the personal and social aspects of recovery. If this trend continues, it would be sensible to build on this position of strength and develop doctors' involvement in coronary rehabilitation. In this report we have discussed the extension of ideas about coronary rehabilitation from concern with functional capacity to concern with the activities of everyday life, and from programmes of physical exercise to programmes of exercise and education. In these circumstances cardiologists, and other physicians who provide the medical care after the acute infarct, may wish to develop their work in several ways.

(i) By helping patients understand their illness and its likely effects better.

(ii) By attempting to overcome more of the worry and distress felt by patients.

(iii) By early identification and discussion of possible employment problems, and early referral to the appropriate agencies.

(iv) By encouraging patients to undertake more activity at home during their recovery.

All of this would imply that doctors should see recovery not only in terms of physiological processes inside the body but also in terms of the patient's outlook and performance in his normal daily environment. It would mean that cardiologists would need to develop expertise in the psychological and social aspects of illness and recovery.

If cardiologists take more of a lead in developing broader aspects of coronary rehabilitation, this would affect their relationships with other staff and agencies. Perhaps the most sensitive area would be relationships with general practitioners. Specialists sometimes feel that G.P.s are out of touch with current trends in a specialty and that they do not complement specialists' work satisfactorily. General practitioners sometimes feel that they know more than hospital doctors about the patients' home lives and that they are best placed to provide care for the whole person. Discussion of these problems should precede developments in coronary rehabilitation. Equally important are the relationships between medical staff on the one hand and social workers and employment agencies on the other. The need is for the early identification and assessment of problems, easy and quick referral, and ready co-operation. These contacts may be provided by hospital social workers and hospital resettlement officers, but the effectiveness of these staff in rehabilitation has not been proven. In any case, hospital is only the starting point of the recovery for coronary patients; the need for collaboration extends also into patients' home and working environment. The development of comprehensive coronary rehabilitation would involve cardiologists more with other staff and agencies, both inside and outside hospital.

3. FURTHER RESEARCH

In this section we shall consider what further research may be needed. It is obvious that a multitude of particular questions arise from a research study of this kind. A simple list of research questions would overwhelm the reader and provide no help with assessing the relative priority of the different items. There are four main areas in which research, of interest to D.H.S.S., could be developed.

First, there are questions about the different aspects of recovery after myocardial infarction and the causes of particular problems. These questions are very important in the development of coronary rehabilitation services, because the answers will help us understand more about the difficulties and problems which patients face and with which the rehabilitation and aftercare services have to deal.

(i) There are questions about the symptoms and other medical events that occur in the months following a heart attack. How does the classification used in this study, and the prevalence reported here, compare with other studies? To what extent does the occurrence of symptoms and other events account for patients' incapacity, low morale and feelings of lack of progress? How would doctors assess the significance of these events? Do these symptoms constitute a need for more medical care?

(ii) Questions about patients' emotional status after myocardial infarction. What is the relationship between worry and unhappiness, defined in broad terms as in this study, and more narrowly defined psychiatric disorder? Why do some people experience emotional distress and others not? Why does the prevalence change through time?

(iii) Questions about patients' knowledge and understanding of their illness and recovery. More research is required to establish what, in fact, people do know and believe about their illness. Then questions will arise about why some know more than others and why people believe different things; and about the ways people use their knowledge and the ways in which they translate it into action and activities, such as taking exercise or returning to work.

(iv) Questions about patients' resumption of work after myocardial infarction. What is an appropriate target, in terms of the proportion of patients returned to work by say two or three months after the infarct? What are the causes of variations in work experience - the patient's medical condition, his psychological state and personal outlook, his social relationships at home and work, his economic environment?

(v) Questions about life at home after myocardial infarction. If we have reasonable data about the difficulties experienced and the resumption of activities at home, questions arise about the relationship of these with other aspects of the patient's recovery. Does the resumption of activities help or hinder improvements in the patient's medical condition and mental state? Does it help or hinder an early return to work? If these activities are significant, why do some people make better progress than others?

(vi) We have a fairly good idea of the prevalence of particular problems and difficulties, much less work has been done to examine the causes. In particular, when we are considering recovery in its broad personal and social aspects, studies are needed to examine the relationships between medical, psychological, social and economic factors that cause particular problems. Is it possible to develop coherent models of the recovery process, that identify the interrelationships between different aspects of recovery? Only when we have knowledge about the causes of problems can rehabilitation services be planned rationally.

The second main area for research concerns not so much particular difficulties or recovery in themselves, but the relationship between these difficulties and "needs" for rehabilitation. These questions constitute the logical foundation on which all proposals and plans for the development of rehabilitation services are built.

(i) There are questions about the nature of coronary patients' needs. Would, for example, a broader more systematic search for particular effects of the illness identify unsolved problems that were not identified by the Grogono Index? Is it possible to obtain a deeper understanding of the relative importance of different problems and hence of the relative priority of different needs? If people have such individual problems, and such varied combinations of needs, as seems possible from the present research, how do we best plan the provision of services to meet those needs most sensitively and most efficiently?

(ii) There are crucial questions about the definition of needs, i.e. questions about the procedures and rationales used to translate statements about particular difficulties or problems into statements about the skills and tasks needed to solve the problems. There are questions about how this is done at present by laymen and by professional staff. Why, for example, do many patients express a desire for more knowledge or advice, and others do not? Why do a few patients express a desire for more help in returning to work but others do not? Why do doctors, by contrast, see returning to work as a priority area? If returning to work is a problem, what kind of services are needed to deal with it - medical, physical rehabilitation, psychiatric, vocational resettlement - and how do we judge which is needed? Underlying these issues there are questions about the knowledge and beliefs of different people about the nature of the problems they are facing and the effectiveness of particular remedies in dealing with them. When we have more knowledge about the ways in which these judgements are made at present, it should be possible to indicate with more realism the criteria on which needs should be judged in future.

The third main area for research concerns the nature of the rehabilitation and aftercare services. The main lack is of basic descriptive and quantitative material, on which to build our understanding of how the services work at present. It is only on the basis of a clear knowledge of current practice that sensible plans and policies, whether they be for example to increase the role of the remedial professions, or to shift the emphasis from physical exercise to advice and education, can be created. And it is only when we know in detail what services and treatments are provided that we can say which it is most important to evaluate in terms of their effectiveness in promoting patients' recovery. Two main sets of questions arise from the present study.

(i) There are questions about the contributions of different kinds of staff to the recovery process. In what ways does the routine medical and nursing care provided for coronary patients contribute to their rehabilitation? In what ways are general practitioners involved in the solution of medical, personal and social problems after patients' discharge from hospital? What is the relationship between the emotional and interpretative role claimed by

social workers, and patients' and doctors' views of what social workers do?

(ii) There are particular questions about the extent to which doctors, and others, contribute to aspects of rehabilitation and recovery that arise from but are not exclusively concerned with disease, illness and health. Do doctors believe that they should know and be concerned about aspects of patients' daily lives, such as work, recreation, and family relationships? What do doctors and other people do about problems in this kind of area, both in terms of the general attitudes they convey to patients, and in terms of specific advice they give or therapies that they provide or recommend?

It is only with this kind of knowledge that professional policies and health service plans can be developed coherently.

The fourth main area for research is the effects and the effectiveness of rehabilitation services. If the services do not achieve their objectives they are not worth having. If we know more about the ways in which the services promote patients' well-being and recovery, then we can say which services should be developed further and where there are likely to be gaps remaining. There are three sets of questions.

(i) There are questions about the ways in which patients react to and take action upon what is provided in the form of rehabilitation services. Patients may undertake strenuous physical activity under the direct guidance of remedial staff, but do they transfer it to their everday lives and continue it after the rehabilitation programme has ended? Patients may receive advice about taking exercise and acknowledge that it is useful, but do they follow it in practice?

(ii) There are questions about patients' satisfaction with the services. It is known that people in Britain are generally satisfied with health services; but we have shown that people may be dissatisfied with particular aspects of their care, such as certain items of advice and information, social work, disablement resettlement officers. Why is there satisfaction in some areas but dissatisfaction in others? Is there scope for more systematic use of patients' assessments of services to help identify problem areas and develop priorities in new developments?

(iii) There is a clear need for thorough evaluations of a whole range of rehabilitation treatments and services. The coronary rehabilitation programmes that need to be evaluated include programmes of physical exercise, education and advice, psychological or social work intervention, vocational rehabilitation and comprehensive rehabilitation. In each evaluation it is important that recovery is measured in a number of different ways: the patient's medical

condition, as assessed by a doctor, and as assessed subjectively by the patient in terms of his symptoms and progress; physical fitness and functional capacity; the patient's well-being and emotional or psychological status; and the patient's performance of daily activities, such as work, recreation and household tasks, and his subjective experience of problems in these activities.

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APPENDIX A

Advice Sheet Distributed to Myocardial Infarct Patients in Kent and Canterbury Hospital

As a result of your heart attack a part of the heart muscle has been damaged temporarily. This has already healed but it is preferable not to make any undue demand on the heart for the next few weeks.

This guide is to help you plan your activity when you leave hospital.

It has been suggested that the first two weeks following your discharge from the hospital be an extension of your hospital routine, i.e. you should rest following breakfast and two hours following lunch. You may climb one flight of stairs per day, but on the whole you should take things gently and relax at home, preferably wearing your night attire.

In the third week you can move about freely in the house and if feeling well you may go for short walks.

In the fourth week the amount of exercise may be increased gradually, i.e. you may take longer walks, but at a gentle, even pace.

The fifth and sixth weeks should be geared towards preparing yourself for a return to your normal routine, so if possible, may we suggest that you take a relaxing holiday.

It should be emphasised that if you are a smoker you should stop smoking altogether. If you are overweight the doctor in charge of you will instruct you regarding weight reduction. Alcohol may be consumed in moderation. For the first three months it is not advisable to subject yourself to the stress of driving. Sexual intercourse may be resumed normally when you have returned to your normal physical activity.

All patients are encouraged to return to their previous occupations, or in the case of a housewife to normal household activity, but obviously there are some exceptions. The doctor in charge of you and your own general practitioner will be able to provide further guidance on this point.

Exercise is encouraged but should be kept within personal limitation. You should not go beyond the first signs of fatigue; exercise such as swimming, cycling, golf and walking are recommended, whereas lifting heavy static objects is discouraged. This exercise should of course be in moderation, commensurate with your physical well-being and should be regular.

TABLES

Table 1.1 (a-i) Time of Return to Work after Myocardial Infarction, British Studies

(a) Sharland (1964) London

Months after M.I.	Proportion of Series at Work %
3	55
4	73
6	82
12	86

(b) Wincott and Caird (1966) Oxford

Weeks after Admission	Proportion of Series Returned to Work %
6	3
13	58
21	78
27	83
52	88

(c) Groden (1967) Glasgow

Months after M.I.	Proportion of Series Returned to Work %
3	38
4	56
5	61
6	70
7	75
- - -	- - -
12	75

(d) Harpur et.al. (1971) Chelmsford

Weeks after Admission	Proportion of Series Returned to Work %
4	1
8	24
12	49
16	73
24	77
28	81
32	82

(e) Royston (1972) Barnet

Months after Admission	Proportion of Series Returned to Work %
1	23
2	77
3	90

(f) Cay et.al. (1973) Edinburgh

Time of Follow-up	Proportion of Series Returned to Work %
4 months	69
12 months	78

(g) Shaw and McNiven (1974) Glasgow

Months after M.I.	Proportion of Series Returned to Work %
2	46
3	54
- - -	- - -
9	79

(h) Kushmir et.al. (1975a) Hull

Months after Discharge	Proportion of Series Returned to Work %
1	1
2	29
3	52
4	65

(i) Finlayson and McEwen (1977) Dundee

Months after Admission	Proportion of Series at Work %
6	77
12	74

Table 2.1 Sex and Age

Age	No. of Respondents	
	Male	Female
Under 40	1	0
40 - 44	1	3
45 - 49	12	0
50 - 55	16	2
55 - 59	17	0
Total	47	5

Table 2.2 Household Composition

Household Composition	No. Respondents
Lives alone	1
Lives with:	
Spouse only	20
Spouse + 1 child	9
Spouse + 2 children	11
Spouse + 3 or more children	7
Spouse + others	3
Sibling	1
Total	52

Table 2.3 House Ownership and Type of House

Type	Ownership					Total
	Owner-occupied	L.A. rental	Private rental	Tied to employment	Other	
Detached house	4	1	0	0	0	5
Semi-detached house	8	7	0	0	0	15
Terraced house	6	4	0	1	0	11
Bungalow	15	0	0	1	0	16
Flat	0	0	2	1	0	3
Other	0	0	0	1	1	2
Total	33	12	2	4	1	52

Table 2.4 School-leaving Age

Age	No. Respondents
Less than 14	3
14	34
15	6
16	5
17+	4
Total	52

Table 2.5 Educational and Occupational Qualifications

Qualification	No. Respondents
Educational	
A-level or less	1
More than A-level	1
Occupational	
Craft or technical	15
Professional	3
None	32
Total	52

Table 2.6 Social Class

Social Class	Respondents No.	%
I Professional	3	6
II Intermediate	13	25
IIIN Skilled, non-manual	8	15
IIIM Skilled, manual	14	27
IV Partly skilled	12	23
V Unskilled	2	4
Total	52	100

Table 2.7 Economic Position at Time of Infarct

Economic Position	No. Respondents
Self-employed	5
Employee	42
Housewife	2
Not employed	3
Total	52

Table 2.8 Estimate of Proportion of Survivors with Different Coronary Prognostic Index Scores

(Norris et al, 1969)

Score	No. Cases	% Mortality in Each Group	Survivors No.	Survivors %
< 4	130	3	126	23
4 - 5.99	200	8	184	34
6 - 7.99	159	23	122	22
8 - 9.99	130	39	79	14
10 - 11.99	66	66	22	4
12+	72	78	16	3
Total	757		549	100

Table 2.9 Coronary Prognostic Index Scores

Score	Subjects No.	Subjects %
< 4	16	36
4 - 5.99	18	41
6 - 7.99	9	20
8 - 9.99	1	2
10 - 11.99	0	0
12+	0	0
Total	44	100

Table 2.10 Symptoms and Illness since Previous Interview

Symptom or Illness	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Heart	19	22	24	25	39
Related to heart or treatment	8	11	3	6	20
Other	10	12	17	19	34
Total with any of these	28	31	35	35	47
Total Respondents	52	48	47	48	-

Table 2.11 Number of Respondents Reporting Symptoms or Events, Directly Connected with Heart, Experienced since Previous Interview

Symptom or Event	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Heart attack	2	1	3	2	8
Cardiac arrest	1	0	0	0	1
Angina; Pain in chest, arm	8	13	9	14	25
Palpitations; Heart "flutter", racing	8	1	1	2	6
Breathless; Short of breath	1	7	7	7	17
Tired	4	5	3	6	19
Weak	2	1	1	1	5
Ill-defined	2	2	1	0	5
Total with any of these	19	22	24	25	39
Total Respondents	52	48	47	48	-

Table 2.12 Number of Respondents, Identifying Illnesses or Symptoms, Related to the Heart or Treatment, Experienced since Previous Interview

Illness or Symptom	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Giddy; Blackouts; Collapsed	2	3	1	2	6
Legs heavy, ache, swollen	1	4	1	2	8
Thrombi	1	2	0	1	4
Depressed	1	2	0	1	4
Worried; Anxious; Lack confidence	2	2	1	0	5
Tense; Irritable	2	0	0	0	2
Other	2	1	0	0	3
Total with any of these	8	11	3	6	20
Total Respondents	52	48	47	48	-

Table 2.13 Number of Respondents, Identifying Symptoms or Illnesses, Not Related to Heart or Treatment, Experienced Since Previous Interview

Symptom or Illness	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Cold; Flu; Sore throat	2	8	7	5	18
Headaches	2	0	2	0	4
Other	6	6	11	17	29
Total with any of these	10	12	17	19	34
Total Respondents	52	48	47	48	-

Table 2.14 Number of Respondents Showing Different Feelings about their Rate of Progress

Progress	No. Respondents					
	1st interview	2nd interview	3rd interview	4th interview	5th interview	At any interview
Well	38	27	22	22	22	47
Average	10	16	10	13	9	33
Poorly	4	9	16	12	17	32
Total Respondents	52	52	48	47	48	-

Table 2.15 Contact with Health Services in Four Weeks Before Admission to Hospital

Service	Reason for Contact		Total
	Heart	Other Illness	
Hospital inpatient	1	0	1
Hospital outpatient	2	4	6
General practitioner	11	13	24
Other	1	2	3

Table 2.16 Length of Stay in Hospital

No. Days	No. Respondents
8 - 10	8
11 - 13	19
14 - 16	9
17 - 19	6
20 - 22	2
23 - 25	0
26 - 28	1
29 - 31	4
32+	3
Total	52

Table 2.17 Contact with General Practitioner, After Discharge from Hospital and Since Previous Interview

Contact and Reason	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Heart only	42	43	33	28	52
Heart and other illness	3	1	4	3	10
Other illness only	0	2	1	6	7
No contact	7	2	9	11	0
Total	52	48	47	48	-

Table 2.18 Outpatient Consultations, After Discharge from Hospital and Since Previous Interview

Consultation and Reason	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Consultation: Heart	11	39	27	18	50
Consultation: Other Illness	2	1	3	2	6
Total Respondents	52	48	47	48	-

Table 2.19 Contact with Rehabilitation Services Since Previous Interview

Service	No. Respondents					
	1st interview	2nd interview	3rd interview	4th interview	5th interview	At any interview
Physiotherapy	11	6	0	2	2	12
Social work	5	5	4	3	1	14
Employment services	-	1	4	6	5	12
Total Respondents	52	52	48	47	48	-

Table 3.1 Economic Position of Respondents at Each Interview

Economic Position	No. Respondents					
	Before illness	2nd interview	3rd interview	4th interview	5th interview	At any interview
Self-employed	5	4	4	2	4	5
Employee	42	39	37	34	33	45
Housewife	2	3	2	1	1	3
Retired	0	0	0	2	2	2
Not employed	3	6	5	8	8	13
Total	52	52	48	47	48	-

Table 3.2 Work Position of Respondents at Each Interview

Work Position	No. Respondents					
	Before illness	2nd interview	3rd interview	4th interview	5th interview	At any interview
Self-employed or employee						
At work	40	0	12	27	35	46
Holiday	6	0	2	3	1	11
Sick leave	1	43	26	6	1	43
Other leave	0	0	1	0	0	1
Housewife	2	3	2	1	1	3
Retired	0	0	0	2	2	2
Not employed	3	6	5	8	8	13
Total	52	52	48	47	48	-

Table 3.3 Number of Respondents, Who Said They had Problems Because of Unemployment

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Any problems	6	4	8	8	13
No problems	0	1	0	0	0
Total not employed	6	5	8	8	13
Total Respondents	52	48	47	48	-

Table 3.4 Number of Respondents Identifying Different Problems Associated with Unemployment

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Lack of money	6	4	7	8	13
Mental distress	3	3	5	6	9
Future work	1	0	1	1	3
Other	0	0	1	1	2

Table 3.5 Number of Eligible Respondents Who Had Returned to Work after Myocardial Infarction

Months after Infarct	Respondents No.	%
3	14	31
6	31	69
9	35	78
12	37	82
Not returned by 12 months	8	18
Total Eligible Respondents	45	100

Table 3.6 Number of Respondents on Sick Leave Indicating Readiness to Return to Work

Readiness	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Ready	13	10	3	0
Not ready	29	16	3	1
Total on sick leave	42	26	6	1

Table 3.7 Number of Respondents, on Sick Leave but Ready to Return to Work, Giving Different Reasons for Not Having Returned

Reason	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Doctor says not	12	9	0	0
Other	1	1	3	0
Total ready to return	13	10	3	0

Table 3.8 Number of Respondents, Giving Different Assessments of the Appropriateness of the Timing of their Return to Work

Appropriateness of Timing of Return to Work	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Earlier than should have done	0	3	3	1	7
About right time	0	11	13	6	30
Later than need have done	0	0	1	2	3
Total returned for first time	0	14	17	9	40
Total Respondents	52	43	47	40	-

Table 3.9 Number of Respondents at Each Follow-up Interview Working Different Proportions of their Pre-Infarct Working Week

Proportion of Pre-Infarct Hours	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Not at work	52	36	20	13	52
- 69%	0	3	2	5	8
70% - 89%	0	0	3	2	4
90% - 109%	0	5	16	24	28
110% - 129%	0	0	1	1	2
130% +	0	1	0	0	1
Don't know/ Not available	0	3	5	3	8
Total Respondents	52	48	47	48	-

Table 3.10 Number of Respondents at Work who Identified Alterations in their Jobs since Previous Interview

Alteration	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Alteration - still altered	0	8	9	8
Alteration - back to normal	0	0	5	2
No alteration	0	4	13	25
Total at work	0	12	27	35
Total Respondents	52	48	47	48

Table 3.11 Number of Respondents, on Sick or Other Leave, Who Said They had Problems with their Job

Problems with Job	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Problems					
In past	0	0	0	0	0
Now	5	6	2	1	10
Expected in future	16	6	3	0	19
Total with problems	21	12	5	1	23
No problems	22	15	1	0	20
Total on leave	43	27	6	1	43
Total Respondents	52	48	47	48	-

Table 3.12 Number of Respondents, on Sick or Other Leave, Identifying Different Problems with their Jobs

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Lifting	7	5	1	0	10
Heavy work	3	3	2	0	7
Not able to do job, may lose job	7	5	4	1	12
Need lighter job	2	3	0	0	3
Travel	3	1	0	0	4
Worry, stress, irritability	3	0	0	0	3
Depends on doctors	1	0	0	0	1
Employer's medical exam.	3	0	1	1	3
Other	1	1	0	0	2

Table 3.13 Number of Respondents, at Work or on Holiday, Who Said They had Problems with their Job

Problems with Job	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Problems					
In past	0	1	0	1	1
Now	0	1	6	8	12
Expected in future	0	0	0	0	0
Total with problems	0	2	6	9	13
No problems	0	12	24	27	33
Total at work or on holiday	0	14	30	36	46
Total Respondents	52	48	47	48	-

Table 3.14 Number of Respondents, at Work or on Holiday, Identifying Different Problems with their Job

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Lifting	0	0	2	0	2
Heavy work	0	0	2	2	4
Not able to do job, may lose job	0	0	0	1	1
Need lighter job	0	1	0	1	1
Travel	0	0	1	0	1
Worry, stress, irritability	0	0	1	5	5
Depends on doctors	0	0	0	0	0
Employer's medical exam.	0	0	0	0	0
Other	0	1	1	0	2

Table 3.15 Total Number of Respondents Identifying Problems with their Jobs or Employment

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
In past	0	1	0	1	1
Now	11	11	16	17	31
Expected in future	16	6	3	0	19
Total with problems	27	18	19	18	37
No problems	25	30	28	30	15
Total Respondents	52	48	47	48	-

Table 3.16 Number of Respondents Identifying Any Problems with their Jobs or Employment at Different Combinations of Interviews

Problems Reported at	Interview				No. respondents
	2nd	3rd	4th	5th	
No interviews Sub-total					12
One interview only	*				4
		*			0
			*		1
				*	5
Sub-total					10
Two interviews only	*	*			2
	*		*		3
	*			*	0
		*	*		0
		*		*	2
			*	*	1
Sub-total					8
Three interviews only	*	*	*		5
	*	*		*	1
	*		*	*	2
		*	*	*	0
Sub-total					8
All four interviews Sub-total	*	*	*	*	7
Total	24	17	19	18	45

Note: An asterisk in this table and in similar subsequent tables indicates an interview in which a positive reply was given. For example, the table shows that four respondents identified a problem with their job at the second interview only, and that seven did so at all four follow-up interviews.

Table 3.17 Number of Respondents with Different Levels of Personal Income (after deduction of tax and national insurance)

Income Pounds per week	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
Not answered, don't know	3	5	4	6	5
Housewife	2	3	2	1	1
More than £0, but less than £20	5	9	8	8	6
£20, " " " £40	24	25	20	19	18
£40, " " " £60	11	7	10	11	12
£60 or more	7	3	4	2	6
Total Respondents	52	52	48	47	48

Table 3.18 Number of Respondents Whose Post-Infarct Income was Different Proportion of its Pre-Infarct Level

Post-infarct Income as % of Pre-infarct Income	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
- 49	6	6	3	3	11
50 - 69	6	5	3	3	14
70 - 89	7	4	5	5	11
90 - 109	24	21	18	11	33
110 - 129	1	2	6	16	17
130 - 149	0	2	3	1	5
150+	0	2	2	3	4
Total for whom data available	44	42	40	42	-
Total Respondents	52	48	47	48	-

Table 3.19 Number of Respondents Who Said They had Problems because of the Effect of their Illness on their Income

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
In past	0	0	3	0	3
Now	10	12	12	13	24
Expected in future	10	4	2	4	17
Total with problems	20	16	17	17	32
No problems	32	32	30	31	20
Total Respondents	52	48	47	48	-

Table 3.20 Number of Respondents Identifying Future Problems with Income

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Reduced sick pay	2	0	2	0	3
Using, used up savings	2	3	0	2	7
Not enough to live on, difficult to manage in general	0	0	0	0	0
Reduced expenditure, consumption	1	0	0	0	1
Difficulty with specific items, bills	0	1	0	1	2
More expense	1	0	0	0	1
Worry, stress	0	1	0	1	2
Other, not clearly specified	6	1	0	2	8

Table 3.21 Number of Respondents Identifying Current Problems with Income

Problem	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Reduced sick pay	0	0	0	0	0
Using, used up savings	1	2	4	1	8
Not enough to live on, difficult to manage in general	2	1	2	3	7
Reduced expenditure, consumption	5	6	5	9	16
Difficulty with specific items, bills	7	5	4	7	15
More expense	3	3	2	2	8
Worry, stress	2	0	0	0	2
Other, not clearly specified	1	1	1	0	2

Table 3.22 Number of Respondents Identifying Current Problems with their Income at Different Combinations of Interviews

Problems with Income Reported at	Interview				No. Respondents
	2nd	3rd	4th	5th	
No interviews, Sub-total					23
One interview only	*				1
		*			0
			*		2
				*	5
One interview Sub-total					8
Two interviews only	*	*			2
	*		*		0
	*			*	1
		*	*		1
		*		*	0
			*	*	2
Two interviews Sub-total					6
Three interviews only	*	*	*		3
	*	*		*	1
	*		*	*	1
		*	*	*	2
Three interviews Sub-total					7
Four interviews	*	*	*	*	1
Total	10	10	12	13	45

Table 4.1 Number of Respondents, at First Interview, who said They Expected to Undertake Specific Activities When They First Left Hospital

Activity	No.Respondents Saying	
	A little	Some or a Lot
Jobs around house	7	4
Exercise	12	4
Physical recreation	1	4
Other recreation	1	7

Table 4.2 Number of Respondents Reporting Difficulties around the House

Difficulty	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Respondent not at home	2	0	0	0	2
Any difficulty	28	26	25	27	44
No difficulty - not doing anything	13	3	2	1	15
No difficulty	9	19	20	20	28
Total Respondents	52	48	47	48	-

Table 4.3 Number of Respondents Reporting Difficulties around the House, or that they were not Doing Anything around the House, at Different Combinations of Interviews

Reported at	Interview				No. Respondents
	2nd	3rd	4th	5th	
No interviews, Sub-total					4
One interview only	*				6
		*			0
			*		1
				*	1
One interview Sub-total					8
Two interviews only	*	*			2
	*		*		0
	*			*	2
		*	*		1
		*		*	0
			*	*	1
Two interviews, Sub-total					6
Three interviews only	*	*	*		4
	*	*		*	5
	*		*	*	3
		*	*	*	1
Three interviews, Sub-total					13
Four interviews	*	*	*	*	14
Total	36	27	25	27	45

Table 4.4 Number of Respondents Identifying Difficulty in Different Activities Around the House

Kind of Difficulty	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Everything	13	5	6	7	23
Most things	3	2	1	1	6
Stairs	3	1	2	2	7
Lifting	3	10	8	4	18
Other functional activities	3	3	5	10	16
Housework	4	4	1	2	8
House repairs, etc.	12	12	8	6	24
Other outside activities	5	11	7	13	23
Other	1	2	2	2	7
Total Respondents	52	48	47	48	-

Table 4.5 Number of Respondents Reporting Difficulty and Problems with Stairs

Difficulty with Stairs	No. Respondents				
	2nd interview	3rd interview	4th interview	5th interview	At any interview
Difficulty but not problems	12	9	10	8	17
Problems arising from difficulty	3	2	2	5	9
Total with difficulty	15	11	12	13	26
Total Respondents	52	48	47	48	-

Table 4.6 Number of Respondents Reporting Different Ways of Coping with Stairs

Method of Coping	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Go slowly	11	5	12	11
Reduce use				
Don't use	4	6	5	11
Moved bed downstairs	2	1	2	0
Bought bed for downstairs	1	1	0	0
Other	1	1	1	0
Other	2	0	0	0
Total Respondents	52	48	47	48

Table 4.7 Number of Respondents who Identified Different Numbers of Spare-time Activities

Number of Spare-time Activities	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
0	0	3	1	0	3
1	6	15	6	10	7
2	9	16	6	10	5
3	17	12	15	13	19
4	9	6	10	7	9
5	5	0	4	4	3
6 or more	6	0	5	3	2
Total Respondents	52	52	48	47	48

Table 4.8 Number of Respondents who Identified Different Numbers of Spare-time Activities Undertaken in Different Places

Location and Number of Activities	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
In the home					
0	21	13	18	15	17
1	19	12	15	14	12
2	8	18	12	10	11
3	4	7	11	7	8
4	0	2	2	1	0
Around the home					
0	13	30	18	13	15
1	27	20	17	29	26
2	12	2	10	5	6
3	0	0	3	0	1
4	0	0	0	0	0
Away from home					
0	9	46	23	22	23
1	21	6	19	15	14
2	15	0	6	8	9
3	5	0	0	2	2
4	2	0	0	0	0
Total Respondents	52	52	48	47	48

Table 4.9 Number of Respondents Undertaking Different Spare-time Activities

Activity	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
None	0	3	1	0	3
In the home					
Housework	1	3	8	3	3
Do-it-yourself (e.g. decorating)	19	1	8	13	13
Crafts (e.g. sewing, knitting)	3	5	5	1	3
Arts (e.g. music, painting)	5	4	2	4	3
Games (e.g. jigsaws, cards)	1	5	6	3	4
Other pastimes (e.g. crosswords, pets)	4	4	4	4	4
Reading	6	32	21	14	13
Listen to music, T.V., radio	3	14	16	11	12
Eat, drink	2	0	0	0	0
Letters, telephone	1	6	6	2	1
Visitors, family	0	2	0	1	1
Others in the home	2	1	4	1	1
Around the home					
Do-it-yourself (e.g. cars, outside repairs)	11	2	7	6	4
Gardening	27	5	16	12	24
Walks	13	16	22	21	12
Other around the home	0	1	1	0	1
Away from home					
Voluntary work	6	0	2	3	2
Arts (e.g. dance, sing)	4	0	0	2	3
Sports: participate	18	1	6	8	8
Sports: watch	4	1	3	1	3
Games	9	0	1	3	4
Other hobbies (e.g. collect, nature study)	4	0	1	0	2
Drive, trips	14	1	9	10	8
Clubs, pubs, drink	12	2	1	3	4
Other away from home	3	1	8	7	4
Total Respondents	52	52	48	47	46

Table 4.10 Number of Respondents Commenting upon the Nature or Level of their Spare-time Activities

Level or Nature of Activity	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
Making progress, getting back to normal	0	1	0	4	1
Relax	0	4	3	3	2
Sitting	0	7	4	3	2
Restricted activity, taking it easy, not doing much	0	5	4	6	5
Doing nothing	2	15	9	9	9
Total Respondents	52	52	48	47	47

Table 4.11 Number of Respondents Making Comments that Showed their Attitude towards or View of their Spare-time Activities

Attitude	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
Enthusiastic	1	0	0	0	2
Bored, dislike activities	0	5	3	1	1
What should I do	0	1	1	0	0
Unable to concentrate, can't be bothered	0	3	1	0	0
Can't do much, illness restricts activities, nothing too energetic	0	1	4	3	5
Not allowed to do specific items	0	1	1	0	1
Total Respondents	52	52	48	47	48

Table 4.12 Number of Respondents who Identified Different Domestic Alterations or Rearrangements due to their Illness

Alteration	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Others staying off work	8	17	1	2	1
Interfered with others' work	7	0	0	0	0
Others going out to work	1	0	0	0	2
More work for others	3	1	0	0	0
Others come in to help	0	9	2	0	3
Others come to stay	2	6	1	0	2
Moved bed downstairs	0	9	1	1	0
Installed W.C. or bathroom on different floor	0	0	0	1	2
Other physical alteration	0	2	1	1	0
Other	1	0	1	1	0
Total Respondents	52	52	48	47	48

Table 4.13 Number of Respondents who Identified Unmet Needs for Domestic Alterations or Rearrangements due to their Illness

Alteration Needed	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
W.C. or bathroom on different floor	2	1	0	0
Lift, no stairs or bungalow	0	0	2	3
Help with specific activities	1	0	0	1
Other	2	1	0	0
Total Respondents	52	48	47	48

Table 5.1 Respondents' Scores on Grogono Index

Score and Level of Incapacity	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
0 None	0	0	2	3	4
1-5 Little	9	12	20	27	25
6-10 Moderate	33	32	24	15	14
11-15 Severe	10	8	2	1	4
16-20 Very severe	0	0	0	0	1
Total Respondents	52	52	48	47	48
Mean Score	8	8	6	5	5

Table 5.2 Respondents' Work Position and Scores on Grogono Index

Work Position	2nd interview		3rd interview		4th interview		5th interview	
	No.respondents	Av. score	No.respondents	Av. score	No.respondents	Av. score	No.respondents	Av. score
Self-employed or employee								
At work	0	-	12	4	27	3	35	4
Holiday	0	-	2	6	3	4	0	-
Sick leave	43	7	26	7	6	7	1	13
Other leave	0	-	1	5	0	-	0	-
Housewife	3	8	2	5	1	5	1	5
Retired	0	-	0	-	2	9	2	7
Not employed	6	7	5	7	8	6	8	10

Table 5.3 Respondents' Scores on Grogono Index Weighted for Importance

Score and Level of Incapacity	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
0 None	0	0	2	3	4
1 - 10 Little	12	15	16	23	24
11 - 20 Moderate	32	29	26	20	15
21 - 30 Severe	8	8	4	1	4
31 - 40 Very severe	0	0	0	0	1
Total Respondents	52	52	48	47	48
Mean Score	14	14	11	9	10

Table 5.4 Number of Respondents Identifying Different Levels of Effect of their Illness on Aspects of Personal Life Included in Grogono Index

Item	Level of Effect	No. Respondents 1st interview	2nd interview	3rd interview	4th interview	5th interview
Work or Usual Daily Tasks	Complete interference	47	47	24	12	11
	Slight interference	5	5	20	22	24
	No interference	0	0	4	13	13
Hobbies or Recreation	Complete interference	37	32	19	9	10
	Slight interference	9	16	19	27	25
	No interference	6	4	10	11	13
Sleep	Complete interference	6	3	1	0	2
	Slight interference	16	22	22	13	20
	No interference	30	27	25	34	25
Eat and Enjoy Food	Complete interference	5	3	3	0	1
	Slight interference	15	13	9	10	11
	No interference	32	36	36	37	36
Pass Water or Move Bowels	Complete interference	0	2	2	0	0
	Slight interference	20	5	3	3	4
	No interference	32	45	43	44	44
Communicate with People	Complete interference	0	0	0	0	1
	Slight interference	8	9	4	8	5
	No interference	44	43	44	39	42
Depend on Others for Washing, Feeding, Moving or Dressing	Complete dependence	6	1	0	0	1
	Slight dependence	22	11	3	0	1
	No dependence	24	40	45	47	46
Sex	Complete interference	33	28	12	6	6
	Slight interference	4	10	15	14	16
	No interference	15	14	21	27	26
Discomfort Pain or Suffering	Severe	2	0	3	3	6
	Slight	20	26	26	23	21
	None	30	26	19	21	21
Worry or Unhappiness	Severe	10	8	5	5	5
	Slight	17	24	24	25	22
	None	25	20	19	17	21
Total Respondents		52	52	48	47	48

Table 5.5 Number of Respondents, Identifying their Illness as Having a Complete or Slight Effect on Each Item in The Grogono Index, Who Said it was of Different Levels of Importance

Item	Level of Importance	No. Respondents				
		1st interview	2nd interview	3rd interview	4th interview	5th interview
Work or Usual Daily Tasks	Very important	27	36	26	15	15
	Important	15	12	14	13	11
	Not important	10	4	4	6	9
Total identifying some effect		52	52	44	34	35
Hobbies or Recreation	Very important	19	20	12	8	10
	Important	13	14	17	17	15
	Not important	14	14	9	11	10
Total identifying some effect		46	48	38	36	35
Sleep	Very important	6	8	5	6	10
	Important	9	10	9	6	7
	Not important	7	7	9	1	5
Total identifying some effect		22	25	23	13	22
Eat and Enjoy Food	Very important	4	6	4	1	5
	Important	7	5	4	2	3
	Not important	9	5	4	7	4
Total identifying some effect		20	16	12	10	12
Pass Water or Move Bowels	Very important	5	2	0	0	0
	Important	8	2	3	1	1
	Not important	7	3	2	2	3
Total identifying some effect		20	7	5	3	4
Communicate with People	Very important	0	2	1	1	3
	Important	3	5	1	4	2
	Not important	5	2	2	3	1
Total identifying some effect		8	9	4	8	6

Table 5.5 .... contd.

Item	Level of Effect	No. Respondents 1st interview	2nd interview	3rd interview	4th interview	5th interview
Depend on Others for Washing, Feeding, Moving or Dressing	Very important	8	3	0	0	2
	Important	11	5	2	0	0
	Not important	9	4	1	0	0
Total identifying some effect		28	12	3	0	2
Sex	Very important	12	12	9	7	10
	Important	8	15	7	8	5
	Not important	17	11	11	5	7
Total identifying some effect		37	38	27	20	22
Discomfort Pain or Suffering	Very important	4	6	13	6	12
	Important	7	11	10	13	8
	Not important	11	9	6	7	7
Total identifying some effect		22	26	29	26	27
Worry or Unhappiness	Very important	11	16	14	10	13
	Important	9	15	14	15	9
	Not important	7	1	1	5	5
Total identifying some effect		27	32	29	30	27
Total Respondents		52	52	48	47	48

Table 5.6 Number of Respondents Who Said that each Item on the Grogono Index was the Most Important to Them

Item	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Work or usual daily tasks	24	32	23	21	20
Hobbies or recreation	2	3	2	7	3
Sleep	1	0	0	1	1
Eat and enjoy food.	1	0	1	0	2
Pass water or move bowels	0	0	0	0	0
Communicate with people	0	0	0	1	1
Depend on others for washing feeding, moving or dressing	4	0	0	0	1
Sex	1	2	2	1	3
Discomfort, pain or suffering	0	1	5	1	2
Worry or unhappiness	6	6	8	7	10
Other	2	4	1	3	2
Combinations	7	4	6	5	3
None important	2	0	0	0	0
Don't know	2	0	0	0	0
Total	52	52	48	47	48

Table 5.7 Number of Respondents Who Identified Work as the most Important Item, and Who Made Different Comments

Comment	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Positive attitude to work	16	20	15	11	7
When will I get back to work?	0	2	1	2	0
Insecure job	6	1	0	1	2
Change in jobs, tasks, hours, etc.	4	7	4	6	4
I need or like to be active	2	9	2	1	3
When will I resume activities? What will I be able to do?	0	2	0	0	0
It affects my whole life. Will I get back to normal?	1	5	3	2	3
Money	14	14	6	6	9
Accommodation	2	1	0	0	0
Family, home life	4	4	3	2	3
Illness or recovery	1	0	2	3	3
Death	0	0	0	0	0
Worry, distress	3	5	6	5	6
Other	1	7	3	1	1
Total respondents identifying work	24	32	23	21	20

Table 5.8 Number of Respondents Who Identified Worry as the most Important Item, and Who Made Different Comments

Comment	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Positive attitude to work	0	0	1	1	0
When will I get back to work?	0	0	1	0	0
Insecure job	1	0	0	1	0
Change in job, tasks, hours, etc.	1	0	0	2	0
I need or like to be active	1	0	0	0	1
When will I resume activities? What will I be able to do?	1	1	0	0	0
It affects my whole life. Will I get back to normal?	1	0	0	0	0
Money	2	2	2	0	0
Accommodation	0	1	0	1	0
Family, home life	1	1	2	2	3
Illness or recovery	1	3	3	4	4
Death	1	3	1	1	2
Worry, distress	2	3	1	3	1
Other	0	0	0	0	3
Total respondents identifying worry	6	6	8	7	10

Table 5.9 Number of Respondents Who Identified Items other than Work or Worry as the most Important, and Who made Different Comments

Comment	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Positive attitude to work	3	2	1	2	4
When will I get back to work?	0	0	1	0	1
Insecure job	0	1	1	0	0
Change in job, tasks, hours, etc.	0	1	1	0	2
I need or like to be active	8	6	1	4	5
When will I resume activities? What will I be able to do?	2	3	0	1	2
It affects my whole life. Will I get back to normal?	2	0	2	2	1
Money	2	0	2	1	0
Accommodation	0	0	2	0	0
Family, home life	8	4	2	2	1
Illness or recovery	2	4	7	7	2
Death	1	1	0	0	0
Worry, distress	4	6	7	9	4
Other	3	3	3	6	5
Total respondents identifying items other than work or worry	22	14	17	19	18

Table 5.10 Number of Respondents, Who Identified Additional Aspects of their Illness as being Particularly Important to them or as Worrying them

Aspects of Illness	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Illness	3	0	0	3	4
Treatment	0	1	0	0	1
Death	2	1	0	0	0
Recurrence	6	6	5	8	5
Prognosis	9	8	6	2	2
Effect on life generally	4	4	5	1	3
Work	2	7	2	2	4
Other activities	5	4	3	2	2
Family	4	1	4	3	1
Money	2	1	0	1	0
Worry, distress	4	3	3	2	5
Other	3	4	5	2	2
Total identifying something important	29	25	19	19	17
Number not identifying anything important	23	27	29	28	31
Total Respondents	52	52	48	47	48

Table 6.1 Number of Respondents, Reporting Different Frequencies of Contact with their General Practitioner about Their Heart

Frequency of Contact Since Last Interview	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
More than once per week	0	0	0	1
Once per week	3	3	0	3
Less than once per week, but more than once per month	4	5	4	1
Once per month or less frequently	2	17	18	20
Three or more times	3	2	1	0
Twice only	15	5	6	4
Once only	18	12	8	2
Total with contact about heart	45	44	37	31
Without contact about heart	7	4	10	17
Total Respondents	52	48	47	48

Table 6.2 Number of Respondents Reporting Different Actions Taken by their General Practitioner

Action	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Examination	30	29	21	19
Discussed illness, recovery	19	12	14	8
Prescription	28	25	22	21
Advice	8	6	7	3
Referral to, communication with other part of N.H.S.	0	3	1	2
Sickness absence certification	18	20	17	7
Other	1	0	1	0
Total with contact about heart	45	44	37	31
Without contact about heart	7	4	10	17
Total Respondents	52	48	47	48

Table 6.3 Number of Respondents, Identifying Different Items in Discussions with General Practitioner about Illness or Recovery

Item	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
G.P. asked about progress	7	5	4	2
G.P. commented on illness, recovery or progress	10	5	7	1
G.P. provided encouragement or reassurance	1	2	0	2
G.P. told respondent about treatment	2	0	2	1
Other questions or discussion about treatment	1	0	1	1
G.P. said to come back at specific time, or if needed	2	2	0	0
Other	0	0	0	1
Total discussing illness or recovery	19	12	14	8

Table 6.4 Number of Respondents, Identifying Different Subjects about Which They were Advised by Their General Practitioner

Subject	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Increase activity, take more exercise	1	2	1	1
Rest, take it easy	4	1	2	0
Not to do specific activities	0	0	1	1
Diet, reduce intake, keep weight down	1	1	2	0
Travel, driving	0	2	0	0
Retire, stay off work	0	1	0	1
Other, general, not specified	3	0	1	0
Total reporting advice from G.P.	8	6	7	3

Table 6.5 Number of Respondents, Reporting Contact with Physiotherapist

Physiotherapy	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Breathing exercises	10	4	0	0	0
Other related to cardiovascular system	1	1	0	0	1
Other	0	1	0	2	1
None	41	46	48	45	46
Total Respondents	52	52	48	47	48

Table 6.6 Number of Respondents, Reporting Contact with Different Kinds of Social Workers

Kind of Social Worker	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Hospital	4	3	1	0	1
Social Services Department	0	2	2	0	0
Rehabilitation Centre	0	0	0	1	0
Work	1	0	1	2	0
Total with contact	5	5	4	3	1
No contact with social worker	47	47	44	44	47
Total Respondents	52	52	48	47	48

Table 6.7 Number of Respondents, Reporting Different Degrees of Usefulness of their Contact with Social Workers

Usefulness of Contact with Social Worker	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Not applicable, don't know yet	2	1	1	0	0
Completely	3	2	2	1	0
Partly	0	1	0	0	0
Not useful	0	1	1	2	1
Total with contact	5	5	4	3	1

Table 6.8 Number of Respondents Who Said They Needed Social Work or More Social Work

Needs	No. Respondents				
	1st interview	2nd interview	3rd interview	4th interview	5th interview
Social work or more social work needed	2	5	1	2	3
Social work not needed	50	47	47	45	45
Total Respondents	52	52	48	47	48

Table 6.9 Number of Respondents Receiving Special Help in Returning to Work

Help	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Help received	4	10	12	5
No help received	45	36	32	40
Total employed or unemployed	49	46	44	45
Housewife or retired	3	2	3	3
Total Respondents	52	48	47	48

Table 6.10 Number of Respondents Identifying Different Sources of Help in Returning to Work

Source of Help	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Employer	4	4	4	0
Works medical officer	0	2	2	2
Works welfare officer	0	1	1	0
Department of Employment local office	0	1	2	0
Disablement Resettlement Officer	0	1	2	4
Industrial Rehabilitation Unit	0	0	1	1
Training Centre	0	1	0	0
Other	0	0	1	0
Total receiving help	4	10	12	5

Table 6.11 Number of Respondents Needing Help in Returning to Work

Help Needed	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Some help needed	3	5	1	3
Extra help needed	1	1	4	3
Waiting to see someone	4	0	1	0
No help needed	41	39	38	39
Total employed or unemployed	49	46	44	45
Housewife or retired	3	2	3	3
Total Respondents	52	48	47	48

Table 7.1 Sources of Advice from Health Service Staff about Exercise

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Hospital doctor	13	13	2	3
General practitioner	17	25	8	6
Nurse	6	0	0	0
Advice sheet	31	1	0	0
Other	2	0	1	1
Total receiving advice	48	28	11	9
Not received advice	4	20	36	39
Total Respondents	52	48	47	48

Table 7.2(a) Nature of Advice about Exercise Received from Health Service Staff, Reported at Second Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take no/less exercise	2	2	1	1	0
Take some/more exercise	6	7	1	28	1
Other	5	7	3	2	1
Combinations of advice	0	1	1	0	0
Total receiving advice	13	17	6	31	2
Not received advice	39	35	46	21	50

Table 7.2(b) Nature of Advice about Exercise Received from Health Service Staff, Reported at Third Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take no/less exercise	4	1	0	0	0
Take some/more exercise	5	14	0	1	0
Other	4	9	0	0	0
Combinations of advice	0	1	0	0	0
Total receiving advice	13	25	0	1	0
Not received advice	35	23	48	47	48

Table 7.2(c) Nature of Advice about Exercise Received from Health Service Staff, Reported at Fourth Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take no/less exercise	0	1	0	0	0
Take some/more exercise	1	5	0	0	0
Other	1	1	0	0	1
Combinations of advice	0	1	0	0	0
Total receiving advice	2	8	0	0	1
Not received advice	45	39	47	47	46

Table 7.2(d) Nature of Advice about Exercise Received from Health Service Staff, Reported at Fifth Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take no/less exercise	0	1	0	0	0
Take some/more exercise	2	3	0	0	0
Other	1	2	0	0	1
Combinations of advice	0	0	0	0	0
Total receiving advice	3	6	0	0	1
Not received advice	48	42	48	48	47

Table 7.3 Sources of Advice from Lay People about Exercise

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Spouse	7	4	3	1
Other relative	8	6	1	0
Friend, neighbour	6	5	0	1
Other	1	3	0	0
Total receiving advice	12	11	3	2
Not received advice	40	37	44	45
Total Respondents	52	48	47	48

Table 7.4 Desire for Advice or More Advice about Exercise

Desire for Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Yes - more detailed or specific	16	9	10	5
Yes - other	2	3	3	2
No	34	36	34	41
Total Respondents	52	48	47	48

Table 7.5 Sources of Advice from Health Service Staff about Rest

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Hospital doctor	18	7	5	2
General practitioner	18	10	9	6
Nurse	8	2	1	0
Advice sheet	33	1	1	1
Other	2	0	1	0
Total receiving advice	48	14	11	8
Not received advice	4	34	36	40
Total Respondents	52	48	47	48

Table 7.6(a) Nature of Advice about Rest Received from Health Service Staff, Reported at Second Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take a rest during the day	10	4	5	29	1
Rise later, retire earlier	0	1	1	1	0
Rest generally, take it easy	1	4	0	0	0
Other	1	2	0	0	0
Combinations of advice	6	7	2	3	1
Total receiving advice	18	18	8	33	2
Not received advice	34	34	44	19	50

Table 7.6(b) Nature of Advice about Rest Received from Health Service Staff, Reported at Third Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take a rest during the day	4	2	0	0	0
Rise later, retire earlier	0	0	0	1	0
Rest generally, take it easy	2	2	0	0	0
Other	0	5	2	0	0
Combinations of advice	1	1	0	0	0
Total receiving advice	7	10	2	1	0
Not received advice	41	38	46	47	48

Table 7.6(c) Nature of Advice about Rest Received from Health Service Staff, Reported at Fourth Interview

Nature of Advice	No. Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take a rest during the day	0	1	0	1	0
Rise later, retire earlier	1	0	0	0	0
Rest generally, take it easy	2	4	0	0	0
Other	2	3	1	0	1
Combination of advice	0	1	0	0	0
Total receiving advice	5	9	1	1	1
Not received advice	42	38	46	46	46

Table 7.6(d) Nature of Advice about Rest Received from Health Service Staff, Reported at Fifth Interview

Nature of Advice	No. of Respondents Receiving Advice From				
	Hospital doctor	General practitioner	Nurse	Advice sheet	Other
Take a rest during the day	1	3	0	1	0
Rise later, retire earlier	0	0	0	0	0
Rest generally, take it easy	0	2	0	0	0
Other	1	1	0	0	0
Combination of advice	0	0	0	0	0
Total receiving advice	2	6	0	1	0
Not received advice	46	42	48	47	48

Table 7.7 Sources of Advice from Lay People about Rest

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Spouse	16	4	5	2
Other relative	12	4	2	2
Friend, neighbour	11	6	2	2
Other	0	1	0	3
Total receiving advice	19	9	5	3
Not receiving advice	33	39	42	45
Total Respondents	52	48	47	48

Table 7.8 Desire for Advice or More Advice about Rest

Desire for Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Yes - more detailed or specific	7	4	2	4
Yes - other	1	0	3	0
No	44	44	42	44
Total Respondents	52	48	47	48

Table 7.9 Sources of Advice from Health Service Staff about Sexual Activity

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Hospital doctor	5	4	0	1
General practitioner	4	3	0	1
Nurse	2	0	0	0
Advice sheet	37	1	1	0
Other	1	0	0	0
Total receiving advice	37	8	1	2
Not received advice	15	40	46	46
Total Respondents	52	48	47	48

Table 7.10 Desire for Advice or More Advice about Sexual Activity

Nature of Advice Desired	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
When is "back to normal"?	5	1	0	0
When to start sex?	4	3	0	0
Whether to have sex or not?	6	2	2	0
What to do/not to do?	0	2	3	2
Is sex good for you?	0	2	2	1
Other	3	1	1	1
Total desiring advice	16	9	6	4
No advice required	36	39	41	44
Total Respondents	52	48	47	48

Table 7.11 Smoking Habits

Smoked	No. Respondents				
	Before illness	2nd interview	3rd interview	4th interview	5th interview
Manufactured cigarettes	17	8	6	5	4
Self-rolled cigarettes	10	1	3	4	3
Pipe	4	1	2	3	5
Cigars	4	0	3	2	1
Not specified	1	0	0	1	0
Total smoking	36	10	14	15	13
Not smoking	16	42	34	32	35
Total Respondents	52	52	48	47	48

Table 7.12 Advice about Smoking from Health Service Staff

Source of Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Hospital doctor	23	5	4	6
General practitioner	12	3	2	6
Nurse	8	0	0	0
Advice sheet	12	0	0	0
Other	3	1	0	0
Total receiving advice	31	7	5	9

Table 7.13 Desire for Advice or More Advice about Smoking

Desire for Advice	No. Respondents			
	2nd interview	3rd interview	4th interview	5th interview
Yes - how to stop	3	6	3	3
Yes - other	4	0	1	2
No	29	4	10	10
Total smoking at previous interview	36	10	14	15

Table 7.14 Respondents' Desires for More Information or Advice about their Illness

Aspect of Illness	No. Respondents					
	1st interview	2nd interview	3rd interview	4th interview	5th interview	At any interview
Illness, recovery	15	20	17	5	11	37
Prognosis	4	10	10	7	3	22
Treatment	2	6	10	4	3	19
Work	1	6	6	2	4	12
Other daily activites	2	13	5	5	6	21
Diet	0	5	4	1	3	11
Other	0	7	4	2	1	10
Total wanting more	18	34	28	18	20	44
Not wanting more	34	18	20	29	28	8
Total Respondents	52	52	48	47	48	-

Fig. 1 Timing of Return to Work after Myocardial Infarction

(Nine British studies shown in Table 1.1)