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TRIALS AND FIBRILLATIONS:
The Social Context of the Coronary Experience.

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ABSTRACT

This thesis has two aims. It is intended that it will provide a detailed description of the experience of a heart attack from the perspective of those who have this illness. It is also intended that it will elaborate a model for undertaking inductive research and theory generation. This model takes as its point of departure the work of Glaser and Strauss(1967). It builds upon their works by attempting to develop a model that will allow for the generation of higher-order sociological concepts from the data gathered in the field. The method developed here has been labelled the "theoretical interpretation" of the research findings. It involves the application of other sociological concepts to the descriptive account of the data. In so doing, it is intended that the low-level descriptive concepts derived from the field-work will be integrated into the more general body of sociological theory. The sociological concepts which are applied to the research findings are the ideological perspective, and the notion of the alienation of self and body.

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LIST OF ABBREVIATIONS.

Am.J.of.Publ.Health	American Journal of Public Health
Br.Heart.J.	British Heart Journal
Br.Med.J.	British Medical Journal
J. of Chronic Dis.	Journal of Chronic Diseases
New Engl.J.of Med.	New England Journal of Medicine
N.Z.Med.J.	New Zealand Medical Journal

INTRODUCTION.

The original intention of this thesis was to provide an account of the heart attack experience. As such, it combined a desire to conduct a piece of health-related research with the desire to develop a facility with qualitative techniques. Initially, it was intended that the techniques outlined by Glaser and Strauss in their book, The Discovery of Grounded Theory, would provide the working model for the techniques of analysis. However, as the field-work progressed, and as knowledge both of their methodology, and the complexity of the subject matter increased, it became apparent that a straight application of their procedures was not possible. In this way, the direction of the thesis changed to allow for a less rigid framework than was originally intended. There were areas where the thesis and the principles of "Grounded Theory" did concur. These related primarily to the field-work stage of research and to some of the underlying motivations for their book. These motivations relate to a commitment to the inductive mode of inquiry, a desire for method and theory generation to proceed together and an emphasis upon qualitative techniques of investigation.

Because the thesis does not rigorously apply the principles of "Grounded Theory" to the research situation, it is necessary

that some time be spent locating its orientation, defining its scope and emphases and elaborating upon the points of similarity and divergence from the dictates of "Grounded Theory". Chapter 1 is devoted to a discussion of these issues. This chapter also provides an outline of the model being used here for the development of theory. Chapters 2 and 3 conform quite closely to a general symbolic interactionist structure. They are concerned with a discussion of the research findings. These two chapters provide the basis for Chapter 4. This chapter has as its focus the theoretical interpretation of findings. This is the final step in the process of the generation of theory from field data. The method for this generation is the interpretation of findings in the light of other sociological theory. Thus, it brings the concepts developed in other sociology of health work to bear upon the low-level descriptive concepts presented in Chapters 2 and 3.

The principle concept which has been used to structure Chapter 4 is the ideological perspective. This is part of a wider, more general notion; the frame of reference. The ideological perspective is used to explain the differing conceptions which individuals and health professionals have of heart disease and the differing experiences that result from these understandings.

Symbolic interactionist studies traditionally provide brief pen-portraits of those individuals who participated in the field research. It has been decided not to do this here. The research

sample consisted of ten individuals drawn from each of three coronary care units, and nine individuals drawn from a non-hospital based coronary rehabilitation programme. Staff who ran both the units and the rehabilitation programme were heavily involved in the initial stages of this research. They selected the participants and also arranged the times for the first interview. The sample size and the involvement of unit and programme staff have compounded the inevitable problems of confidentiality. It is felt that it is necessary to sacrifice traditional symbolic interactionist practice to protect the identity of the participants in this study. However, because the sample is frequently broken down into sub-groups, some of the diversity and colour of the participants will, hopefully, be gleaned from the text itself.

Linguistic conventions became problematic at different times during the writing-up of this thesis. Some considerable difficulty has been experienced with the use of such labels as "patient", "respondent", "doctor", "health system", "ex-patient", and "heart attack victim".

Initially, it was felt that the label "patient" was unsatisfactory. It was felt that this label conceived of the individual in solely medical terms. However, as the research progressed, it became apparent that in many instances this label captured the essence of this role with particular clarity. For this reason, it has been retained in the text. Similar

difficulty was experienced with the use of "respondent". It was felt that the emphasis should always be upon the individual's status as a person, rather than upon their more temporary and less significant status as a participant in a study. However, it has not always been possible to avoid this term; there are instances where it is necessary to differentiate these individuals from all others.

Although doctors do constitute the most powerful of all health practitioners, and their definitions of any situation will be dominant, it is considered that recognition should be given to the fact that they are not the only health practitioners in this setting. Thus, the label "health professional" has been used in preference to "doctor". This label is all the more valuable because it gives recognition to the designation of all these individuals as members of a specific professional group.

When referring to the system of care that currently operates in this society, the term "medical system" has been used. The purpose behind this designation is to underscore the current emphases in the system for the provision of health care. This emphasis is upon medical/technical matters, rather than upon that more diffuse and social issue; health.

The last two labels that have provided particular difficulty for this thesis are "ex-patient" and "heart attack victim". The first has been excluded from the thesis. The reason for this is

that it is considered to be inappropriate to designate people by reference to this status when they are no longer considered to be, and do not consider themselves to be, patients. That is, if they are ex-patients, they have a different primary status by which they can be defined. It is considered to be preferable that they be designated by that status rather than as patients. The label "heart attack victim" has given particular difficulty throughout this thesis and it remains unresolved. In fact, many of the respondents in this study also mentioned dissatisfaction with this label. The field of heart disease is full of imagery. The label "heart attack victim" only serves to reinforce this, usually quite erroneous, imagery. It seems to describe an event that is instantaneous and largely confined in time and in effect. For the majority of those who have this illness, it is neither of these two things. However, it has not always been possible to avoid the use of this term. The use of the label has been circumspect; effort has been directed to finding alternative ways of referring to people who have this illness.

Because the chapters in this thesis are quite long it has been necessary to organise the material systematically, and in a quite highly structured fashion. Some time has been spent trying out different methods for presenting different sections and sub-sections within each chapter. The structure that has finally been chosen is outlined below. It is hoped that this will make the task of plowing through the material a little less tedious for the reader.

The intention throughout this thesis had been to portray the experience of a heart attack in a form that is true to the information which participants in this study have supplied. An essential part of the method being used here has been to pass the results of the study back to the participants before it becomes a "public" document. It has been heartening to hear back from approximately fifty percent of the participants and to know that, not only are most of them fit and well, but also that they have found the interpretation of their experiences to be both accurate and interesting. It is hoped that those "outsiders" who read this will also find it to be stimulating.

Heading Pattern For This Thesis.

Each major heading within a chapter is centred and each significant word is begun with upper-case lettering.

Sub-sections within these are located at the left-hand side of the page. The first letter of each significant word is in the upper-case.

Parts of these sub-sections are numbered consecutively, and the titles are all lower-case.

Within these, sub-parts are denoted by underlined headings. Titles are all in the lower-case. They occur on a new line, but there is no break with the fore-going text.

CHAPTER ONE:

Epistemology.

The Structure of this Chapter.

This chapter has been divided into four major sections. The purpose of these is to detail the process by which the methodological approach used in this thesis was developed.

Section One.

This section is concerned with a discussion of the validity debate. This debate is crucial to sociology and takes place at three distinct levels. The significance of this debate lies in the fact that the manner in which it is resolved determines the type of research that will be conducted. Three parts of this section are devoted to a discussion of the three levels at which this debate takes place. At the end of each part there is a brief discussion of the position taken by this thesis. The final part of section one is composed of a discussion of the position taken by each of the four sociological paradigms with respect to the validity debate. This has been done to demonstrate the four distinct ways in which the debate is resolved within sociology.

Section Two.

Section two develops the last part of the previous section by elaborating upon the interactionist approach. This has been done because the interactionist approach has provided the basis for this thesis. Thus, it is necessary that it be examined in more detail. This section is divided up into five parts. The first two parts look at the two traditional focii of interactionist so-

ciology of health. The third part locates this thesis in relation to these two focii. The fourth part provides a very general discussion of some problems associated with the use of the interactionist approach. This discussion is completed with a discussion of the manner in which a resolution of these problems has been attempted in this thesis. The final part of this section provides some concluding comments.

Section Three.

Having looked at the interactionist approach in some detail and also considered some of the problems associated with this position, it is necessary to consider the precise nature of the contribution which it has made to this thesis. This forms the basis of section three.

Section Four.

This section builds on the previous three sections. It constitutes a discussion of the specific "problem" which this thesis investigates and then moves on to consider the epistemology and specific method used to investigate this problem. It does this in the context of a discussion of the three principles which informed the previous discussion. This section is completed with an outline of the methodological approach which this thesis has adopted.

The Validity Debate.

Introduction.

Attempts to produce the highest degree of validity in sociological research have given rise to a wide ranging debate about the nature of social reality and about how to approach and measure it. Validity may said to exist when a measure accurately reflects the concept that it is intended to measure (Babbie; 1979:585). Validity does not refer to whether or not a piece of research can be falsified. Rather, it refers to the internal consistency of the research design itself. Thus, validity is both a methodological and an epistemological issue. In practical terms this means that the methods used have a direct bearing on the results obtained. Because validity is concerned with issues such as the nature of reality, it is important that the social context be taken into consideration when a study is being designed.

The validity debate exists at three different levels; at the philosophical level it can be embraced within the positivist-idealist debate. This debate centres upon differing conceptions of the nature of reality. At the level of the general approach to sociological investigation it is referred to as

the inductive-deductive debate. Here, the focus is upon the manner in which theory should be developed. Finally, the qualitative-quantitative debate focuses upon the specific method used for collecting data. The next section will deal briefly with the validity debate. The section concludes with a discussion of the principal orientation each sociological perspective has to this issue. It also briefly outlines approach taken by this thesis at each level of the debate.

The material in the next section is presented in debate form. However, although it is accurate to speak, for example, of the positivist-idealist debate, it is not so accurate to label an individual as wholly positivist or idealist. Thus, where individuals and specific pieces of work have been included, these are for discussion purposes only. In reality, an individual or piece of work may be said to be more or less positivist or idealist rather than totally committed to one view rather than another.

Idealism and Positivism: The Nature of Reality.

Historically, this debate arose out of differing conceptions about the nature of the relationship between sociology and the natural sciences. The positivist argument arose out of the Enlightenment philosophy of rationality and objectivity (Hamilton;1974:1-14). Sociology's generally accepted founding father, Auguste Comte, asserted that sociology was "the science

of society". In so doing, he advocated a positivist conception of sociology which argued that social reality was fundamentally no different to the reality of the natural sciences. That is; the same sorts of reasoning, methods and explanatory activity which characterise the natural sciences ought to be applied to sociology. Thus, the ultimate goal of sociology would be to promulgate universal law-like propositions relating to social life. Clearly, for positivists, social reality was considered to be directly accessible and measurable. A problem with this approach is that it makes difficult, if not impossible, the study of social meaning systems. This is because it tends to deny the significance of the subjective realm in favour of an analysis of objectively measurable similarities and broad social patterns.

Idealism, on the other hand, asserts that there exists a fundamental difference between the physical and the social world. The implication of this position is that while physical events may be directly accessible and measurable, social events are not. Social reality does not "exist"; rather it is "experienced" by individuals and groups. What this means is that it is not possible to directly measure social existence. It is necessary to interpret and understand, not the events themselves, but the way in which they are experienced by the participants. Verstehen, or subjective interpretation, characterises this approach. Thus, idealism argues for the primacy of the subjective in the social world.

Perhaps the classic elaboration of the idealist position was that by Dilthey(1). His works were basically a reaction to what he termed the "crass, naturalist metaphysics" of Comte (Truzzi;1974:8). Dilthey argued for a basic difference between the natural and the social sciences. In doing so he expressly rejected the claim (made, for example, by J.S. Mill) that social science's best hopes for success lay in their emulating the methods of the natural sciences. Basically what Dilthey was postulating was the primacy of the subjective in social science. It was his belief that "humanistic and artistic insight"(ibid) was the key to the development of knowledge within the social scientific disciplines.

The positivist-idealist debate occurs within the sociology of knowledge. The idealist position argues that because all knowledge is a social product, the researcher must inevitably play a part in the creation of that product. Positivism, on the other hand, denies, or has difficulty in accomodating such a position. Furthermore, idealism argues that the researcher interprets rather than merely collects that data. Blumer (1969:36), for instance, argues that data is reflexive; it can "talk back"(ibid:22) to the researcher. Idealists argue that without this process of interpretation sociological data is useless; it must have meaning to the creator as well as to those social groups it is supposed to represent.

Thus, differing conceptions of the nature of social reality and the form in which it is accessible (that is, directly or via subjective interpretation) set the broad parameters of sociological investigation. Assumptions at this level inform the approach to theory construction, this is discussed below.

the nature of reality and the position of this thesis:

Social investigations can tend towards either a positivist or an idealist approach. The choice as to which approach will be employed depends largely upon the nature of the problem under scrutiny. The idealist approach lends itself to the study of how individuals (and the groups which they comprise) experience and construct particular events. Positivist work is generally confined to the discovery of broad patterns or to the analysis of historical events. Of course, there are instances where it can be argued that one of these approaches has been applied to a situation which was better suited to the other approach. Such is the case in the Burrige (1981) study. This study will be briefly discussed here for two reasons. Firstly, it highlights the effect which the use of an inadequate methodology has on the validity of research results. Secondly, this study was conducted in the same area as the research of this thesis. Thus, it can be used to demonstrate the reasons for the selection of methods for this thesis.

The Burrige (1981) study concerned itself with the effectiveness of coronary after-care. In so doing it employed a variety of quantitative techniques which were directed at establishing whether or not coronary rehabilitation was valuable. The validity problems to which this study is subject arise out of the attempt to measure attitudes via the construction of a variety of secondary indicators. From a sociological point of view it is erroneous to assume that attitudes can be measured in this highly structured way. Attitudes form part of the realm of subjective meaning, and as such, they must be measured in a way that enables their subjective nature to come to light.

The Burrige study used a positivist approach to what are, in essence, idealist phenomena. An idealist approach would have emphasised the gaining of an understanding of how subjects experienced the programme, whether different "types" of subject experienced it differently, what they saw as its objectives and finally, what the values and problems were that were associated with participation. Thus, to gain an adequate level of validity, the research would have attempted to see the programme as the participants saw it. The mismatch between the subject of the research (that is, attitudes) and the approach used (that is, positivist) casts doubt on the validity of the results obtained. For these reasons this thesis has employed an idealist framework in the investigation into the experience of the heart attack.

Although necessarily brief, this discussion has attempted to demonstrate that it is essential that a synchrony be established between the nature of a piece of research and the broad philosophical position which underlies the methods applied to its investigation.

Induction and Deduction: Approach to Theory Construction.

As with positivism and idealism, the debate over induction and deduction is, in part, derived from the controversy as to whether sociology is, or should be, a science (in the natural scientific sense of the word). The key figure in this area of the debate is Karl Popper (1968). The deductive model basically describes the scientific method in that it emphasises what has been loosely referred to as "hypothesis testing". This approach is employed in research that is guided by prior theory. Knowledge generation of this type begins with a set of assumptions (theory) about the subject area. From this general theory a set of propositions are derived (hypotheses) which then form the basis of the actual research exercise. Data gathering takes the form of a search to validate or falsify these propositions and to specify the conditions under which they obtain. The primary intention of such work is to derive general law-like propositions about social existence.

The intention of those who work within the deductive tradition is to be able to make predictive or testable statements about social organisation and social development(Wallace and Wolfe;1980:5). Deductive theory generation fits in quite closely with the positivist framework in that it emphasises the value of the scientific method, a model developed and used widely in the natural sciences. A logical extension of this position would locate sociology within the general scientific framework. It is for this reason that most deductive work is also positivist.

A final and most important aspect of the deductive position is the idea that reality is divided up into qualitatively distinct levels. Only one of these levels, that of the empirically observable, is directly amenable to investigation. It is this conception of reality which commits deduction to the position that it is not possible to extrapolate from reality (as observed) to theory (Bhashkar;1975:12-20).

A primary problem with the deductive approach is that by starting with a set of assumptions about the nature of social reality and then progressing to test these, it is by no means certain that the most significant facets have been investigated (Blumer;1969:26). It is also open to debate as to whether this approach actually establishes the social facts which it claims to or whether it merely produces a set of well tested assumptions and biases. The criticism is that because so little is known about social reality and so much of it is abstract and

not directly accessible, theory testing is an inappropriate activity (Glaser and Strauss;1967:1-18).

A further problem with the deductive approach is its tendency to develop into the positing of general laws of human behaviour. Of course, the implication of this is that there is one objective reality about which these testable generalisations can be made. Thus, it is often accused of adopting a social engineering approach to social investigation.

A final general problem with the deductive approach is that it tends to ignore the subjective/symbolic realm. This is partly a product of the positivist-deductive desire to establish social facts of the same type as physical facts. Although there is contemporary debate on this issue, the underlying philosophical principle which embodies this criticism can be traced back to Dilthey (Truzzi;1974:8-17).

The inductive position solves many of these problems, but it does so at the expense of the certainty of verified "social facts". Dispensing with "social facts" is, however, not a problem for the inductive sociologist. Inductive data gathering functions to provide the basis for the development of a theory (Glaser and Strauss;1967). Rather than conducting research on the basis of pre-determined theoretical propositions, work within this tradition is initiated with only a very general idea of a problem or issue. It is the purpose of research to provide

information from which theoretical principles and concepts can be induced. Thus, the nature of social reality is problematic and unresolved; there are no pre-set definitions of what will be found (Blumer;1969:1-60). Inductive sociology does not involve the amassing of social facts. Rather, it consists of the unravelling of social meaning and situational definitions of reality (as opposed to reality itself).

Although inductive work does not emphasise social facts, problems of data selection and measurement technique remain. It is still necessary for the researcher to "choose" between different classes of experience; some will be more relevant than others. It should not be assumed that problems of selection bias are avoided by the adoption of an inductive method. The inductive approach to theory generation appears to be more in harmony with the needs of a social science. This is largely because its rejection of rigid and a priori theory provides considerable scope for the symbolic/ideational sphere (the distinguishing feature of social life) to come to light.

Although perhaps more applicable to social science than positivism, idealism is not without its problems. A major deficiency of this approach is its inability to generate macro-theory with any degree of success. There have been attempts to rectify this, for example; Glaser and Strauss (1967), but these have not been successful. Their failure is largely due to the fact that the attempts have focused upon

abstracting back from data until the concepts look sufficiently abstract to be labelled macro-theory. This activity is open to several major criticisms, the most significant of which is the assertion that macro-theory is not simply micro-theory with all the adjectives taken out, as Glaser and Strauss (1967:80) claim it to be. Rather, there is a qualitative difference between lower and higher order concepts which comprise micro and macro theory respectively.

approaches to theory construction and the position of this
thesis:

Having outlined the major features of induction and deduction and also considered some of the problems which besets each approach, it remains to locate the position of this thesis at this level. The debate over approaches to theory construction is the most difficult level at which to make a clear choice. This is because it is not a choice between mutually exclusive alternatives. Induction contains elements of deduction and the deductive approach can be seen to benefit from the introduction of certain inductive principles. In fact, it is likely that no piece of research is purely inductive nor purely deductive. It is probably more accurate to see research as based upon a mixture of these two. It is only at the stage of report writing that research appears to come down on one side or the other. Ultimately, then, it is a question of emphasis; a given piece of research will emphasise one or other approach. This emphasis

depends upon two things; the conception of reality (epistemology) the individual researcher has and the nature of the research material (positivist or idealist).

As was identified in the previous section, this thesis takes an idealist approach to the nature of reality. Its subject matter constitutes an investigation of heart disease. In accordance with the idealist position, it must look at the "experience" of this illness rather than at its "objective" nature. Given this focus, it is necessary that data gathering be done in a fashion that allows this experiential side to come to light. The Burrige study shows the problems that are associated with applying a deductive framework to this type of investigation. As was noted in the discussion of it (above), the problems associated with this approach were both methodological and substantive. Thus, an inductive approach is considered to be more suited to the needs of the data gathering phase of this thesis.

If induction is emphasised in the data gathering, deduction has relevance in two places. The first step in any investigation is the definition of a problem. This is inevitably a deductive step because the identification of a problem can only be done if one has a prior conception of the problem area. Thus, the first step of this research is deductive. The second area where it is necessary to employ a deductive step is in the generation of theory. As has already been discussed, alone, induction cannot

be used to generate adequate theory. Its theoretical powers are limited to the extrapolation of low level concepts. In order to generate meaningful higher order concepts of general sociological relevance, it is necessary that concepts from other theories be applied to the low level concepts derived from the data. This bridges the gap between data and observable reality, on the one hand, and theoretical conceptualisation, on the other.

Qualitative and Quantitative Techniques: The Method for Data Gathering.

The final level at which the debate occurs is that of practical research technique. In many ways the position taken at the first two levels will determine this selection. Implicit in each method is a set of assumptions about the nature of social reality, of sociology and the appropriate avenue for obtaining access to reality or some representation thereof.

Quantitative techniques are used primarily by sociologists working in the positivist-deductive tradition. These techniques are particularly suited to the primary deductive activity; hypothesis testing. Most of the statistical techniques of sociology belong within the quantitative tradition. Its primary intent is to establish the broad parameters of a problem or issue, and then to specify the conditions under which they would vary. It thus shares the positivist orientation to social real-

ity and belief in the primacy of social facts. As was the case with the positivist and deductive positions, a major criticism levelled at quantitative techniques is that their very structure has the effect of obscuring rather than illuminating social existence (Dilthey (1961), Blumer (1969) and Glaser and Strauss (1967)).

By focusing on the readily quantifiable aspects of social organisation, the experiential and subjective aspects are missed. This, the opponents claim, is or should be the very essence of any sociology. More generally, the criticism is that quantification emphasises the object rather than the meaning inherent in the object itself. This is deemed to be not only a superfluous, but an inappropriate activity for sociologists to engage in. Furthermore, quantitative techniques can be regarded as a process of "creation" in so far as they are themselves concepts; they do not spring from the data unaided. This is a fundamental problem because it contradicts the deductive approach (which often informs the use of quantitative techniques) that there is no unmediated access to reality. Taking such a position with respect to reality makes it difficult to support hypothesis testing as the primary activity for theory generation.

Qualitative techniques are more frequently used in sociological research which is guided by the idealist-inductive tradition. Specific techniques employed include participant observation and in-depth interviewing. The stimulus to use such

techniques springs from a desire to come to a subjective understanding of the issue (verstehen). It is claimed that the techniques used in quantitative sociology do not permit this type of focus. Quantitative techniques concentrate upon establishing broad trends that can be generalised across populations, rather than aiming at deriving an understanding of why such patterns exist.

the method for data gathering and the position of this thesis:

Qualitative techniques are employed in this thesis. They have been used because it is considered that they provide the only reliable and valid means for extracting information on the subjective experience of heart disease.

The Relationship of the Four Major Paradigms to the Validity Debate

The four paradigms(2) which guide sociological research can each be identified as taking a distinctive position at each level of this debate (discussed above). This section will conduct a review of the position which each paradigm adopts. This review is necessarily brief and selective. It is not intended that it will provide an exhaustive overview of each approach; that is beyond the scope of this thesis. The function of this section is

to demonstrate how the debate is resolved by each of the major sociological paradigms.

1. functionalism

The earliest sociological paradigm, functionalism, adopts a broadly positivist-deductive position that employs quantitative techniques. The primary focus of functionalism is the social system. The emphasis within functionalism is upon the generation of theoretical concepts which, when reduced to propositions, are capable of being tested. This clearly marks functionalism as a deductive activity.

Parsons' work on a voluntaristic theory of action (1937) provides a clear example of functionalist work. It began with an attempt to develop a system of concepts that were both general and abstract. This system was a synthesis of what Parsons saw as the more useful assumptions embodied in the philosophies of utilitarianism, positivism and idealism (Doyle-Paul Johnson;1981:391-395). Having developed the general theory, Parsons went on to test it. However, because theories are not directly testable it was necessary to develop a series of propositions or hypotheses which would specify certain aspects of the general theory. The relationship which these propositions have to aspects of empirical reality is then observed. This is usually done via the experimental method or the structured observation of the social world.

As part of his more general sociological analyses, Parsons addressed issues of health and health care. Perhaps his most basic, but at the same time significant contribution to this field was the claim that illness was a social phenomenon. Using what is now a standard functionalist framework, Parsons based his analysis around the concepts of role, structure and function. From this he developed two models; the illness-as-incapacity model (the structural model) and the illness-as-motivated-deviance model (the role model)(The Social System; 1937:436-439). Running through his work on sociology of health is the concept for which he is perhaps most widely known in this field; the sick role. Having formulated the general model(s) the functionalist mode of investigation then goes on to test and refine it.

Subsequent sociologists such as Mechanic(1962) further tested and elaborated these concepts. Some of Mechanic's material is derived from comparative international analyses of health systems, mental illness and social stress. His analysis rests upon the construction of scales which can then be correlated with other group and individual attributes. In line with the general functionalist approach, Mechanic views illness as a form of motivated deviance. His research was conducted in a variety of institutional settings (totalitarian states, armed forces) where life styles are considered to be rigorous. From this analysis he concludes that the sick role provides a route for legitimated deviant behaviour.

Functionalism has been criticised for failing to do many things, for example, its failure to account for system change and therefore its inherent conservative or status-quo bias. It has also been criticised for opting for a method which does not adequately deal with social meaning and the role of ideology. Nevertheless, it has produced some useful concepts; structure, role and function being cases in point. It also provided the basis for much of the early sociological inquiry. Thus, its effect on current trends in sociological investigation is not insignificant.

2. marxism.

Much of early marxist sociology can be located in the positivist-deductive tradition. Early marxism was unicausal in that it attempted to establish general principles which would enable prediction and explanation. Such an emphasis tended to favour a positivist orientation. More contemporary refinements and developments of the marxist position have seen a shift to the idealist-deductive type of inquiry. This is largely because the idealist dictum; that social reality is not directly observable and measurable, began to assume considerably more significance. An additional reason for the shift from a positivist to an idealist position was a reaction to the close links which positivism has with natural science. The knowledge produced by scientific inquiry has come to be seen as merely another part of bourgeois ideology. Thus, marxist sociology has attempted to move beyond

the positivist position in its analysis.

Whether positivist or idealist, marxist sociology remains deductive in all but a few fringe instances (for example; Wallach-Bologh; 1981). At the periphery there have been attempts to combine a marxist and a phenomenological approach. The intention behind these moves is to provide a theoretical perspective that is both critical and grounded. However, such work is infrequent. There is, of course, another approach within marxist sociology. This may be termed dialectical in that it is not purely deductive nor inductive. Rather, it combines the two in a continual process of data gathering and theoretical refinement in the light of data gathered. Capital (1976) is the example par excellence of this type of work.

For the most part, marxist sociology remains deductive. Whereas, for instance, interactionist sociology embodies a set of methodological principles and only a rudimentary theory, marxism is characterised by a fairly well defined set of theoretical propositions which delineate the parameters of empirical reality. This means that research will be conducted within a pre-set framework that is; a prior theory. Because the bulk of the work in the marxist tradition is structural (that is; its focus is at the social system, or macro level) it, like functionalism, tends to emphasise quantitative techniques. There are exceptions to this however, such as Stafford's work; Learning not to Labour (1981) which looks at the socialisation of the unemploy-

ed(3). Finally, a large percentage of marxist work is conducted solely at the theoretical level, involving little or no data gathering and analysis. This largely obviates the need to employ the type of techniques suggested by an inductive position.

Within the sociology of health the major marxist works are positivist-deductive. Waitzkin's(1979) analysis of the growth and development of coronary care technology is an example of this type of work. It begins with the premise that in order to understand the proliferation of this hardware it is also necessary to understand the capitalist profit structure. The developments in coronary care had sprung from motives other than a desire to improve the quality of care. This conclusion is reached after an examination of several major pieces of epidemiologic research(4) which demonstrated that coronary care units confer no advantages in terms of morbidity and mortality, over simple rest at home.

In order to come to terms with the wider system within which the development of coronary care technology has occurred, Waitzkin analyses the inter-linkages between the various structures which have been involved in coronary care unit development.

This analysis covers the role which the state played in legitimating almost every step of the development of this technology(1979:1266), the connection between corporate giants such as Hewlett-Packard and Warner-Lambert and academic medical

centres and their research(ibid), and private philanthropies such as the American Heart Association(ibid:1264), and the research which they sponsor. The deskilling of the labour force was also a necessary part of the development of coronary care technology. The final part of his paper deals with an analysis of the changes in the structure and composition of the health care labor force since the introduction of coronary care technology some twenty years ago(ibid:1266-67).

Navarro(1976) also takes as his point of departure the premise that developments in the medical system can only be understood in relation to the wider political and economic system of which they are part. He addresses what he terms the "under-development of health"(ibid:3) in several different contexts (Latin America, Chile - post, pre and during the administration of Allende, and rural and working class America). He chose these disparate settings to demonstrate that the under-development of health is everywhere determined by the same economic and political forces. A consideration of the mal-distribution of health resources cannot be considered apart from this wider context. This part of Navarro's analysis is conducted through an empirical investigation of such things as the distribution and nature of health care resources, morbidity and mortality profiles of the populations concerned, and the structure of the health care labour force.

In addition to conducting an empirical analysis of the under-development of health in these various settings, Navarro also critiques the traditional analyses of health and the health care system. Analyses such as that by Illich are seen to be in error. They are based upon the assumption that concepts such as class and capitalism have been transcended by those of industrialism (1976:101-34). Such analyses are seen to reduce political problems to managerial ones in that they claim that problems in the distribution of health care can be solved by eliminating industrialism. According to Navarro such proposals attack the symptoms not the causes of the mal-distribution of health care.

Navarro's analysis takes place at two levels. As such it demonstrates quite clearly the two major approaches taken in marxist sociology of health work. He conducts an empirical investigation of a particular area. He begins this analysis with certain theoretical premises, and then uses a range of empirical evidence to substantiate and document these premises. He also conducts a theoretical analysis. In this case he critiques other theories of health. Again this involves the employment of certain fundamental premises about the structure of the health system.

3. feminism.

Feminist sociology has developed largely in response to the failure of existing perspectives to deal adequately with the question of the role of gender in social structures and relationships. Marxist theory provided part of the theoretical base for feminism. However, its precise influence varies between the different theoretical positions within feminism. Because feminist work is aimed directly at challenging existing structures and definitions, it is difficult to locate it squarely on one side of the positivist-idealist debate (the same was true, but to a lesser extent, in the marxist case).

A strong strand of idealism is evident in much feminist thought(5). Because a fundamental intention of feminist analysis is to document women's subjective experience, qualitative techniques are the most frequently used data gathering tools. In fact, feminism has made major contributions to the development of qualitative techniques. These contributions stem from feminism's rejection of what it labels the "male model" for research. This refers to the fact that, even when they are qualitative, mainstream techniques still emphasise rigid and objective data gathering as the ideal. Oakley's contribution to Doing Feminist Research(1981) documents the differences between feminist and mainstream qualitative research. In this way feminism has played a major role in reasserting the vital importance of the subjective in sociological research and theory construction.

At the level of the inductive/deductive debate it is also difficult to locate feminism. Because the feminist perspective has an in-built theoretical focus, it cannot, with any real accuracy, be labelled inductive. At the same time, however, it does not really adopt the "scientific method" when conducting research. This is primarily because of its rejection of the "male model" of research and its insistence upon the validation of women's subjective experience. Thus, it is difficult to locate it within the deductive tradition. The primary function of feminist research is to develop theoretical concepts that are grounded in the subjective experience of women (induction) not to test hypotheses derived from a prior theory (deduction). It would appear, therefore, that although feminism is not inductive in the purest sense of the word, it does adopt certain methodological tenets which are inductive. Perhaps the source of its divergence from pure induction is that it makes explicit its initial step. That is; the first stage in any inductive work is a deductive step; the derivation of a problem area inevitably involves a stage of deductive reasoning.

Feminist sociology of health work can be classified into three categories; that dealing with professionalism and hierarchy, the doctor-patient relation, and sexuality and reproduction. Gamarnikow's(1979) work on The Sexual Division of Labour within medicine analyses the manner in which patriarchy is part and parcel of the overall structure of nursing. For example, she discusses the "genderisation"(ibid:109) of nursing.

Here, the relations between doctor, nurse and patient and the relative powers of each may be seen as essentially a patriarchal relationship. Gamarnikow's analysis employs an historical method which traces the development of nursing from its earliest beginnings up until the present day.

In analysing the doctor-patient relation and the related issue of medical paternalism, Barrett and Roberts(1978) employ field research techniques in which they interview general practitioners and two groups of middle-aged women; high and low consulters. Their analysis is directed at explicating the covert social control functions of general practitioners. This is done via an exploration of the way in which general practitioners respond to women consulters. It also involves coming to an understanding of the way in which the women see themselves and their general practitioners. It was found that general practitioners tended to confirm rather than question women's traditional roles. They also found that the women would accept such value laden prescriptions as "scientific", and hence value free. Furthermore, the women more often than not colluded in the general practitioner's definition of themselves as less important than their husbands and children (ibid:47).

The area of sexuality and social control has been addressed by numerous feminist authors. Gordon's(1979) analysis of The Struggle for Reproductive Freedom defines the issue of reproduction and reproductive freedom as political questions.

Like Gamarnikow(1979), Gordon conducts an historical analysis of the appropriation by the medical profession of reproduction and women's sexuality. She locates the medicalisation of these aspects of women's lives as a nineteenth century phenomenon, and the commodification of reproduction as a twentieth century development(ibid:119). The main line of her analysis is that birth control has developed as a lucrative source of income for the male-dominated medical profession, research institutions and pharmaceutical industry. The movement of the medical profession into the area of reproduction was spurred on by the eugenic and population control movements from the 1920's to the 1960's so that now the medical profession has legitimate and virtually complete control over this aspect of women's lives.

In much the same way that marxist sociology does, feminist sociology of health analysis is conducted at the historical, the theoretical and the practical research levels. There are broad similarities between the types of historical and theoretical analyses conducted by marxist and feminist sociologists. It is at the level of practical research that they differ. Feminist research emphasises subjective and qualitative research techniques, such as field work and indepth interviews while marxist research is primarily of an empiricist and hence a quantitative nature.

4. symbolic interactionism.

Under this general label is subsumed the range of idealist-inductive approaches that routinely employ qualitative techniques. This group includes symbolic interactionism, ethnomethodology(6) and phenomenology. Symbolic interactionism is the earliest form of work done in this tradition. Ethnomethodology and modern phenomenology(7) developed later and both represent attempts to re-direct or shift the emphasis of interactionist research. Schutz's work has made substantial contributions to the development of both ethnomethodology and phenomenology. Ethnomethodology's focus is upon everyday existence. It emphasises that the mundane is as significant as the extraordinary, if the intention is to understand how meaning is created, sustained and shared within and between groups. In this way, it is close to the symbolic interactionist method and may be seen as an extension and refinement of it. Phenomenology extends symbolic interactionism in another direction. It can be interpreted as an attempt to provide a philosophical or theoretical base for symbolic interactionism and ethnomethodology. These two traditions primarily constitute methodological statements. Phenomenology emphasises the essence of reality and it explores the nature of this essence through an examination of consciousness. In so doing, its primary intention is to describe rather than analyse human consciousness.

From this brief description of the interactionist position its location as an inductive-idealist approach becomes apparent. For instance, an integral part of phenomenology is a rejection of traditional models of science and an emphasis on subjectivity as an essential part of any scientific endeavour. Both ethnomethodology and symbolic interactionism describe a method that places primacy on the subjective understanding of the reality of different groups.

Interactionism is based on the analytic induction tradition as pioneered by such sociologists as Florian Znaniecki. Writing in the 1930's, Znaniecki attempted to delineate the nature and subject matter of sociology. Although also concerned with developing a model of sociology as a scientific enterprise, a position that resembles positivism, Znaniecki is more noted for his emphasis upon the subjective nature of human life:

"The other way of obtaining an inductive knowledge of human activity would be to use consistently the humanistic co-efficient in dealing with it and take it as it appears to the agent himself(sic) and to those who co-operate with him (sic) or counteract him (sic)" (1934:45).

His emphasis, thus, is upon the subjective realm, and the insistence that subjective considerations form the basis of any sociological endeavour. His approach is, therefore, inductive and idealist.

The major problem with the interactionist perspective is its conspicuous lack of a theoretical or analytical focus. As discussed above, phenomenology, while intending to provide a philosophical/theoretical basis for sociology, aims only to describe not analyse its chosen subject matter. Similarly, symbolic interactionism and ethnomethodology, while they contain elaborate methodological statements, stop short of any attempts at the analytical understanding of human experience. Such a lack of theoretical sensitivity is evident, not only in the statements of intent, but also in much work carried out in this tradition. Rarely is any attempt made to integrate findings back into general sociological theory.

The Interactionist Method.

Before moving on to consider the specific problem which this thesis has set itself, it is necessary to further explore the interactionist method. In doing this the nature of interactionist studies will be addressed, and this will enable the current piece of research to be located within the general interactionist structure. In addition to this, some discussion of the limitations of the method has been included. This is done in the context of a discussion of the modifications to the interactionist position that were made during the research process. This provides the basis for the final section which discusses the re-

search problem and its epistemological foundations.

As was discussed above, the emphasis of the interactionist method is upon the symbolic realm. That is; its concern is to derive a subjective understanding of how meanings are created and sustained within and between social groups. Such an emphasis has implications for the way in which research will be carried out and the resultant concepts constructed. Although it is almost an oversimplification to discuss "the" interactionist method, there is one feature which unites interactionist work; its emphasis upon the "grounding" of research. The fundamental tenet of this type of sociology is that concept construction must take place within the context of the social world, rather than in the academic setting.

This discussion takes as its point of departure interactionist sociology of health. This is primarily because the health field has constituted a major area for this type of research. Health issues are also the subject matter of this thesis. Interactionist sociology is, therefore, doubly pertinent. This review is divided up into two sections that correspond with the two principal foci of interactionist research; the providers and the consumers.

The Consumer.

As well as pioneering a new interactionist approach(1967), Glaser and Strauss have made significant contributions to the sociology of health. In line with interactionist principles, their work attempts to come to terms with the experiential side of illness. Their works form the basis for this part of the review.

As the title implies, consumer oriented research focuses upon the recipients of health care. In fact, such work makes an important contribution to the sociology of health in that it helps to redress the balance of research which is largely in favour of the health provider type. This imbalance is both political and historical in origin. It is political in that a large proportion of the money available for doing research comes from health and allied institutions. These institutions are more concerned with funding research into issues of concern to health-providers than they are with issues of concern to health care consumers(Wallach-Bologh;1981:189-190). It is historical in that the sociology of health had its origins during that period of sociology which was guided by the functionalist paradigm. This meant that research of a systems analysis kind and also with a professional focus was favoured, such an emphasis is based upon functionalist assumptions.

Consumer oriented studies are generally of a longitudinal kind. Commonly, longitudinal studies are small (in terms of the

overall number of respondents), intensive and run for quite long periods of time. Longitudinal studies are often of the case history type;

"In and of itself, the case history is an enterprise of great merit in sociology. One need not always do an abstract study. Through a story, which is explained and interpreted with theory, the sociologist can show a type, an average, an extreme or an exemplar case. The case history then provides a very dense, readable imagery for sociological theory....From the history, people can gain much understanding of general phenomena through its theoretical interpretation and explanation".(Glaser and Strauss;1970:185)

Thus, Anguish;(ibid), follows a woman dying of cancer through her last four months of life. Chronic Illness (Strauss;1975), on the other hand, is slightly less specific in that it pursues a group of individuals suffering from a number of chronic diseases over a longer period of time:

"So the emphasis is very much upon the social and psychological aspects of living with chronic illness" (ibid;1975:viii)

These two studies have several aims in common. They share a concern to portray and understand illness as a process. They also emphasise that illness is something that is experienced not only by the individual and the health care providers, but also by the family and other close associates of the sick person. Thus, for instance, in Chronic Illness (1975) issues such as what life is like back home for the chronic disease sufferers and their families are addressed. Because Anguish (1970) takes place exclusively within the hospital less emphasis is placed upon the home context. However, the influence and effect of factors

outside the hospital (family, financial troubles etc) are still traced in this case history.

It is this emphasis upon illness and health as processes, and upon the wider social context that marks interactionist research out as distinctive. The development of interactionist studies have, thus, resulted in a major shift or redirection of the sociology of health's focus.

The Providers.

As with the other paradigms, interactionist research also focuses upon health care providers. The seminal work in this area is Becker's Boys in White(1961). This study documents the process by which a student is transformed into a doctor. Shapiro's Getting Doctored(1980) also focuses upon the socialisation of medical students. He reviews the transition of his own year from undergraduate to medical student status. In doing this he looks at the nature of the selection process and the effect which the nature of this process has upon the development of the medical student's self-image. Phenomena such as pre-medical societies are considered here. These are viewed in the context of necessary rituals through which the student is transformed and develops a physician self-image. The selection of certain "types" of individual through all the stages on the way to becoming qualified is considered to be an important factor

in the creation of doctors.

Sudnow (1967) provides a slightly different focus. His work looks at the way in which members of different wards or sections of the hospital experience and relate their experiences with death:

"On high death wards, staff members frequently ask upon arriving at work; "How many today?" Deaths are counted, not with any special interest, but along with such matters as the number of new admissions". (ibid:36)

Sudnow finds that death is far from a uniform category. The way deaths are counted (that is, numerically, or by using such terms as "hundreds") depends upon the specific context in which death occurs. Thus, not all young deaths are seen as tragic, nor are all adult deaths seen as inevitable. Two examples of the latter case were; deaths from barium enema exams and maternal death in childbirth (ibid:40). An additional variation in the way in which deaths are seen relates to the experience of the individual, thus;

" New student nurses and, apparently young medical students make a habit of counting such events as deaths and locate their own growing experience and sophistication by reference to 'how many times' such and such has been encountered, witnessed, done, etc".(ibid:37)

In addition to looking at the way deaths were recalled, Sudnow observed the behaviour of different health personnel when confronted with actual deaths. The description of the morgue attendant is a superb example of the way in which actors

negotiate a shared reality. It investigated the way the attendant manages his interaction with others. It also looked at the way in which others reacted to him; completing the other half of the negotiation. For example, it looked at the effect of his arrival at a particular location in the hospital (1967:56).

The Relationship of these "Types" to this Thesis.

The current piece of research is consumer-oriented in that it follows a group of individuals who have had a heart attack for a period of three months. It is, therefore, also a longitudinal study. Effort is directed towards documenting the experience of heart disease for the individual, the family and significant others. Comparatively little attention is paid to the attitudes and experiences of the staff who are involved in the care of coronary patients. The intention is to come to some understanding of how individuals and their families and friends experience hospitalisation and the recovery phase. The experiences and attitudes of staff are not considered to be central to the validation of these things. Staff were interviewed at different phases throughout the fieldwork, but this was only done to supplement the material that was being gathered on respondents and to provide information on things such as ward routine and hospital policy.

A General Critique of the Interactionist Approach.

Having looked at the general features of the interactionist method, it is necessary to review some of the problems associated with this approach. These problems can be grouped under two general headings; the specific method and theory building. This section also discusses the way in which this thesis has attempted to resolve these problems.

1. the specific method:

The problems associated with method have been outlined by Oakley(1981) as the three traditional interviewing criteria. These criteria are; the emphasis upon interviewing as a one way process (ibid:30), its insistence that subjects serve a "narrow objectified function as data" (ibid), and finally, confining the meaning of the interview to its statistical comparability (ibid:30-31). Of course, these criticisms do not apply equally for all interviewing situations. Basically, they stem from Oakley's claim that the bulk of interviewing assumes a predominantly male model(ibid:31-40) so that even the most qualitative piece of research will emphasise the more quantifiable aspects of the interview. This is done in an effort to demonstrate objectivity in data gathering and analysis.

The problem with this approach to interviewing is that it tends to destroy the essence of the interaction. This usually

means that its quality and most of its symbolic meaning are lost. Thus, the effort to satisfy the urge to be scientific and objective sacrifices a fundamental aim of the interactionist method.

The alternative to this emphasis on the objective and more readily quantifiable is to design a methodology which is sensitive to the subjective aspects of human social life. This involves reversing the three traditional interviewing criteria (Oakley;1981). The difference between these techniques and those used in interactionist work will not be readily apparent. The source of their divergence is in the depth and quality of the interaction between researcher and subject. The nature of this difference can only be perceived when one actually engages in this type of research. Here, the emphasis is upon the researcher deriving an understanding of the way in which individuals have experienced whatever is the focus of the study. Thus, the emphasis is upon the way in which individuals structure and create the meaning of their social worlds. This is also the aim of symbolic interactionist work. However, it is contended here that, although this may be the aim, the methods often obscure this end. It is felt that the method being emphasised here increases the likelihood that the researcher will actually achieve these objectives. This approach emphasises subjective understanding and thus goes to considerable trouble to facilitate the expression of this understanding. In this way, it follows closely the method outlined by Oakley(ibid).

2. theory building:

The problems of interactionist theory building have already been alluded to. They relate primarily to the debate about whether or not theory can be developed by systematically abstracting backwards from the data. This is the position adopted by Glaser and Strauss(1967). The criticism of this approach is that there is a qualitative gap between data and theory. Thus, contrary to Glaser and Strauss' claim, the generation of theory does not merely involve the omission of "substantive words, phrases or adjectives" (ibid:80) from the account.

The position taken by this thesis is that abstracting backwards from the data, while being desirable, does not yeild sociological theory. It is contended that such an activity only yields abstract descriptions (that is; descriptions with all the adjectives taken out-Glaser and Strauss;1967:80) and that this does not constitute sociological theory. The approach used in this thesis is the theoretical interpretation of data. This involves applying other sociological theories to the data once it has been analysed and categories have been derived (see: Approach used in this Thesis).

Concluding Comments.

The intention of this section has been to provide an overview of the type of research being conducted within interactionist sociology of health. This has been done because this approach has provided the basis for this thesis. As is the case with any approach, interactionist sociology has problems associated with its use. These were outlined in the final section. The following section provides a discussion of the contribution which symbolic interactionism has made to this thesis.

The Contribution of Symbolic Interactionism to this Thesis.

The epistemological foundation of this thesis is loosely based around the tradition of analytic induction as pioneered by such sociologists as Florian Znaniecki (1937). Blumer (1969) provided the major contemporary articulation of the the symbolic interactionist approach. The Discovery of Grounded Theory (1967) also draws heavily on the work conducted in the inductive tradition. Glaser and Strauss (ibid) are perhaps more useful as most of their work has been done within the context of the medical system. Thus, they have direct relevance to the subject matter of this thesis. Their major work (ibid), provided some of the initial stimulus for this study. This book attempts to outline a method for the generation of sociological knowledge.

Its primary emphasis is on how to generate theory by using a variety of qualitative techniques. The issues which they address relate to basic epistemological concerns which must be resolved before any research can be undertaken.

The relevance of the grounded theory approach to this thesis is its emphasis upon three closely related factors. Firstly, grounded theory emphasises the inductive collection of data. Secondly, the desirability of theory and method as simultaneous and complementary activities is stressed. Finally, their preferred method for data gathering (that is; fieldwork) accords with the approach used here. These three factors are discussed in greater detail in the section on epistemology and method. The work of Glaser and Strauss (1967) has made a significant contribution to this thesis. However, there are several fundamental problems experienced with their work which prevent its wholesale application to the current piece of research. For instance; the nature of facts as social artefacts is not explored by Glaser and Strauss. They imply that facts have an independent existence and that they are directly observable and accessible to the researcher (1967:23). That they do, in fact, possess these qualities is far from certain. Similarly, the relationship between the researcher and the research situation is an area which receives comparatively little attention. The implicit assumption is that the researcher is capable of the unbiased extraction of data, that she or he will not be contaminated by previous theoretical exposure, and will not exercise any

selectivity in the data gathering process.

At one level these problems may be seen as mere overoptimism in the ability of sociologists to perform research in a purist fashion. However, if they are placed back within their tradition, (that is; symbolic interactionism) these claims may be seen as fundamentally contradicting basic interactionist tenets. Central to the interactionist position (Blumer 1969:2) is the assertion that it is the symbolic meaning which objects have, not the objects themselves, which are significant. In fact, throughout his work Blumer is careful to discuss "empirical reality" rather than reality itself. Facts, then, do not have an independent existence for the interactionist. This distinction is not mirrored by Glaser and Strauss; their discussion of research focuses upon the extraction of "facts" and "entities" not their representations or interpretations.

In a similar vein, the "unbiased" and "objective" (Glaser and Strauss;1967:34) collection of data is not an activity which an interactionist would attempt. Yet, Glaser and Strauss repeatedly claim that the grounded theory method enables such data collection. Towards the end of their book (ibid:253) they discuss the impact of previous theoretical exposure on researchers as inevitable, but apparently do not see it as problematic for their approach. Nor do they see it as likely to influence the direction and selection of data during fieldwork.

Thus, it seems that Glaser and Strauss feel that they have developed a technique which permits the objective and uncontaminated collection of data from the real world. Theory emerges from this slice of reality virtually unaided, the researcher assuming the relatively passive role of facilitator. Furthermore, it is their contention that the material which is obtained from the field in that objective fashion, is completely sensitive to the symbolic/ideational realm of respondents' lives. In these respects, then, Glaser and Strauss deny some of the fundamental principles upon which their tradition is based. Such a claim is at best, tenuous.

The "Problem" and its Epistemological Foundation.

The "Problem".

The specific task which this thesis has set itself is the exploration of coronary heart disease. Broadly speaking, the intention is to derive an understanding of this particular disease from the point of view of those who suffer from it. That is; the research approaches the problem from the point of view of the "consumer" (see above). Of course, given the two main approaches of interactionist health research it would be quite legitimate to focus upon the "providers". The decision to survey the "consumers" is, therefore, partly personal. However, it does seem that as the emphasis within symbolic interactionism is upon

meaning systems, a strong case can be made for attempting to provide some insights into the experience of this disease. A final reason for emphasising "consumers" is the belief that the balance of sociological research, to date, rests heavily in favour of the "provider"-oriented type (that is; upon health practitioners). As has been noted, this is partly a consequence of the historical development of the sociology of health.

The decision to focus upon the consumer is also partly political. It is considered that provider-based research constitutes the investigation of powerful groups and that a focus upon health consumers constitutes research into the existence and experiences of powerless groups. Provider research traditionally focuses upon systems and thus, has a "medical" focus, this only serves to reinforce the technological fascination that surrounds the whole medical system. To the extent that it does this, it draws attention away from the "social" aspect of health and illness. What this means is that when the research balance is in favour of the provider type, the conception of the health field is limited to a consideration of medical issues. The tendency then is to see all health issues in medical/technical terms. When this happens the social and experiential side of health is reduced to a side issue or, even worse, seen as trivial and addressable within the frame of reference provided by the medical/technical approach. It is considerations such as these that led to the decision to focus on health care consumers.

Epistemology and Method.

The information that is gained in the field will be organised into a set of specific theoretical concepts. Within the grounded theory framework, these may be seen as the fundamentals of a "substantive theory". These concepts will then be interpreted in the light of sociological theory. This stage diverges from that advocated by Glaser and Strauss (1967:79-98). It is their contention that theory can be generated by systematically abstracting backwards from the data. However, as has already been discussed, this is not considered to be an appropriate method for generating theory.

Because there existed no general body of theoretical knowledge of direct relevance to this subject area, the fieldwork was begun in the "uncontaminated" manner recommended by Glaser and Strauss. This "unbiased" initiation of data collection clearly demonstrated that lack of theoretical exposure does not ensure value and assumption free research. It is more accurate to discuss what values and assumptions are being used than whether or not they can be eliminated entirely.

There was no other sociological work on heart disease in New Zealand, thus the only source of general "orienting" material was the substantial body of epidemiological literature on the subject. Unfortunately, these works paid only passing attention to the more significant social dimensions of their sub-

jects. What this meant was that parts of the first interview were quite inappropriate for certain subjects. The result of this was that at times the interview had to be reconstructed as it progressed. This did not create any major difficulties however, as the interview was semi-structured in format. Thus, it allowed for considerable flexibility.

An example of this problem was that a considerable part of the first interview related to the paid employment habits and experiences of respondents (most of the epidemiological research was based upon occupational groupings and also was primarily concerned with males(8)). This was based upon the belief that the "coronary-type" (see Chapter 2 footnote 2) actually constituted a majority case. Such an assumption and resultant questions meant that the retired and many of the women were excluded from that part of the interview. This group actually constituted about 45 percent of the final sample.

This experience has reaffirmed the belief that the "unbiased" or "objective" collection of data is an impossibility. Indeed, it is considered that it should not even be discussed as an ideal toward which sociologists should strive. This holds especially true for those attempting to work within the interactionist tradition.

There are three principles which are embodied in the work of Glaser and Strauss and which have guided this research from its

inception. These three principles are; that data should be gathered inductively, that theory and method should proceed together and that qualitative methods constitute the most appropriate tools for the gathering of sociological data. Before proceeding to a consideration of the research findings, it is necessary that the manner in which these three principles have influenced the research be addressed.

The significance of these principles lies in their relationship to the validity debate, and this can best be explored via a comparison of the Burrige (1981) and the current study.

1. inductive data gathering:

By inductive data gathering is meant the initiation of fieldwork with as few pre-conceived ideas about what is relevant and significant to the investigation as possible. It is never possible to enter the field with no set ideas about what will be found. However, an awareness of the importance of a relative absence of pre-conceptions when combined with qualitative methods (discussed next) helps to ensure that the research is as unstructured as possible. This lack of rigid structure is important because it allows the participants in the study to structure the interview in their own way and to provide the details that are most relevant to them. This helps to ensure that the data gathered will reflect the reality of the

participants with quite a high degree of accuracy.

The Burridge (1981) study began with the intention of establishing whether or not coronary rehabilitation was valuable. To do this it devised a set of indicators that the researchers considered would reflect this value. No rationale was given as to why these indicators were thought to be the best indicators of programme value. The net result of this approach was to give the researchers a highly structured set of expectations as to what was significant about the rehabilitation experience. The fieldwork then consisted of the systematic and selective re-searching of these indicators.

In contrast, the research for this thesis consisted of an exploration of the coronary experience. It also had an interest in coronary rehabilitation. Data collection consisted of long semi-structured interviews with respondents, observation in several coronary care units and participation in some of the coronary rehabilitation classes. The interview was structured by a chronological ordering of the events which surrounded the heart attack. This was used to provide an initial topic for discussion. The interview was approached in such a way that it could range over a wide variety of topics and issues that respondents deemed to be relevant and significant to their experiences.

The primary difference between these two approaches is that the latter allows the respondent room to structure the interview

her/himself. This means that each interview will reflect the reality of each individual respondent. It is only by attempting to come to a subjective understanding of these realities that any conclusions can be drawn about the value of coronary rehabilitation (which the Burridge study attempted) or about the coronary experience in general.

2. qualitative techniques:

The preference for qualitative techniques emerges largely from the emphasis upon inductive data gathering. By and large, qualitative techniques are semi or unstructured; they thus lend themselves more readily to inductive work than do the more structured quantitative techniques. As was mentioned in the previous section, lack of an a-priori structure is important because it ensures that respondents are given the scope to define material that is relevant and significant for them.

The Burridge study utilised a variety of quantitative techniques. These centred around a structured, mailed questionnaire. The questions were designed to form indicators from which the value of coronary rehabilitation could be inferred. No room was left for subjects to express themselves; their reasons for choosing between the mutually exclusive alternatives were not even canvassed. This highly structured approach provided little in the way of an understanding of the experiences of its subjects. Such an understanding is essential if any conclusions

are to be drawn about the contribution which coronary rehabilitation makes to recovery.

In contrast, by emphasising the subjective experiences of respondents, this thesis was able not only to draw valid conclusions about whether or not rehabilitation was valuable, it was also able to document the precise manner in which it was valuable and to illuminate the way in which this varied according to the age and sex of the participant (unfortunately it was not possible to document the way in which this varied according to the ethnic background of the participant).

The foregoing clearly demonstrates the difference in depth of material and consequently, of understanding which is afforded by the two approaches. Techniques which emphasise the subjective realm are clearly indicated if the intention is to draw some conclusions about the value of a programme.

3. theory and method should proceed together:

The principle that theory and method should proceed together is more difficult to demonstrate. Furthermore, it is not possible to do this by comparing the Burridge and the current study; the Burridge study is not a sociological investigation. It was relevant to the last two principles because its subject matter was sociological. However, this final principle does not relate to subject matter, rather, it relates to the process of

research. As such it is of relevance only to works that are conducted within the sociological tradition.

A major problem with much sociological research (especially interactionist) is that it is theoretically barren. That is, it does not locate its results within sociological theory more generally. The result of this is that there is a large mass of sociological data/research whose relationship to sociological theory remains unexplicated.

It is the contention of this thesis that unless the attempt is made to integrate results back into sociological theory, research is not sociological. That is, it makes no contribution to sociological knowledge unless it is so integrated. There are many ways of doing this. The approach being adopted here is to interpret the analysis of the data in the light of other sociological theories. This may be construed as an attempt to find out where this research "fits" into the general body of sociology. This may be interpreted as a divergence from the dictates of induction, but it is deemed to be an essential step if this thesis is to have a place within the sociological tradition.

Approach used in this Thesis.

The method being adopted in this thesis constitutes a combination of inductive/deductive reasoning. This process involves the following:

* a deductive step to define the problem.

* the inductive gathering of data. That is; using the field-work approach and beginning the data gathering with as few pre-set definitions of what will be found as possible. In this way research is begun with a "problem" area. This is then investigated in order to discover what are the relevant details, concepts and categories for those who participate as subjects in the study. This enables a "subjective" understanding of the research "problem" to be derived. This leads to;

* the inductive development of a descriptive account of the material. This involves the derivation of categories (approximating Glaser and Strauss'(1967) substantive theory).

* the theoretical interpretation of this description. This involves the application of other theories to the research findings. This then provides a theoretical understanding of the research.

Concluding Comments.

This chapter began with a consideration of the validity debate. This provided the basis for a discussion of the approaches

taken by the four major sociological paradigms to the creation of knowledge. It also provided the basis for the rest of the chapter which involved a discussion of the specific approach taken by this thesis. As was noted in the discussion, the significance of this debate is that the manner of its resolution largely determines the type of research that will be conducted. The discussion of the debate devoted some time to an outline of the way that it has been resolved in this thesis.

Sections two and three provided a discussion of the interactionist approach. This approach provided the basis for this thesis. Thus, it was necessary that some space be devoted to a discussion of the contribution which it has made. A very general critique of the interactionist approach was also included in this section.

The final section involved a discussion of the specific "problem" which this thesis has investigated. Included in this section was an outline of the epistemology and specific method which has informed the research and the analysis.

Having located the research within the appropriate sociological tradition and outlined the nature of the "problem" and the method of investigation, it remains to consider the results of the fieldwork. Chapters 2 and 3 are devoted to a discussion of these results.

Footnotes.

1. For the writings of Dilthey in English see; Rickman(1961) and Hodges(1954 and 1952).
2. A paradigmatic framework, in the Kuhnian(1974) sense, is being applied to the structure of sociology.
3. Stafford's analysis is based upon the earlier work by Willis;Learning to Labour. This general approach is in turn based upon the assertions of Wright(1978) that marxist concepts were testable and that they, thus, did not exist solely at the theoretical level as is often claimed.
4. See, for example, Hill et al(1977), Colling et al(1976), Mather et al(1976), Dellipiani et al(1977)
5. One notable exception to this is Kuhn and Wolpe's Feminism and Materialism(1978).
6. Garfinkel is perhaps the best known sociologist working in this tradition.
7. Earlier work in phenomenology was conducted by Husserl, Merleau-Ponty and Schutz, and predates symbolic interactionism. For examples of modern phenomenological work see Filmer and Philipson.
8. See for example; Weinblatt(1966), Longstreet(1962), Karasek(1981), Morris(1956), and Paffenbarger(1970). There is one exception to the emphasis of heart disease research's focus upon males and occupational groupings. That is a recently funded piece of research being conducted out of the Otago Medical School into heart disease and women. However, as with the above papers, this piece of research has an exclusively medical focus. At the time of writing the publication details of this research were not available, thus, it does not appear in the Bibliography.

CHAPTER TWO:

Results From Interview One.

The Structure of this Chapter.

This chapter is concerned with a descriptive account of the first interview. It has been divided up into seven substantive sections. These sections relate to the seven general areas used to structure the first interview.

Introduction.

A general outline of the research undertaken.

Research Design.

A discussion of the methods used in the course of the fieldwork. These two sections provide general introductory information.

History to the Heart Attack.

This section looks at the time up until the onset of the attack. Specifically, it concentrates upon whether the individual experienced any warning signs, and if so, what was done about them.

The Heart Attack.

This section reviews the events surrounding the heart attack. It pays particular attention to the differences in help-seeking behaviour of the different groups within the sample.

Information.

The focus of section three is the informational/educative aspects

of the hospitalisation period. The functions and effects of the educational programmes run by the coronary care units is also discussed here.

Behaviour.

Section four looks at the changes in respondent activities resultant from the heart attack. It also discusses advice given about altering behaviour once the respondent returns home.

The Return Home.

The return home highlights differences in return home experiences for the different sub-groups of the sample. This section also discusses the experiences of respondents' families once the individual returns home.

Families.

A section on the involvement of families has been included. Because not all families were able to attend the interviews, this section is brief and focuses upon hospital provision for family involvement, rather than the specific experiences of families.

Rehabilitation.

A major focus of this research was the role and value of cardiac rehabilitation. There is currently wide debate about the role, nature and effectiveness of coronary rehabilitation. This section discusses the attitudes and experiences of respondents to rehabilitation in an effort to provide a detailed basis upon

which discussions about the need for cardiac rehabilitation can be premised.

Introduction

The research component of this thesis presents the results from the pilot study of a larger research project which inquires into the social context of the coronary experience. The intention of the research is to come to an understanding of the way in which a heart attack is experienced. An additional intention is to provide some detailed material on the nature and value of coronary rehabilitation for those who have heart attacks. The following two chapters discuss the results from the pilot study. These chapters outline the significant findings of the interviews. This provides a base for the Chapter 4 which constitutes a theoretical interpretation of the research findings. In that chapter the major themes which emerged from the interviews will be discussed as they relate to general sociological theory.

Chapters two and three have been divided, somewhat arbitrarily, into discrete chronological sections. This division is for discussion purposes only. In reality there is, of course, considerable overlap between each section.

Research Design.

Thirty-nine respondents were selected for this research; ten were selected from each of three coronary care units in the North Island, and nine were selected from a non-hospital based coronary rehabilitation programme, again, in the North Island. Two interviews were conducted with each individual over a period of three months. In three cases the second interview did not eventuate. This was due to the death of one respondent, and difficulties in arranging a mutually convenient time with the other two respondents. Three out of the four groups of respondents lived in centres other than that of the researcher, and this produced some logistical problems which could not be resolved in two instances.

The interviews were semi-structured. They were designed to enable respondents to express their views and relate their own experiences. The range of interview length was from fifteen minutes to three and a half hours. This range is somewhat misleading however, as only one interview was completed in fifteen minutes. This was of necessity, as the respondent had to catch a bus to an outlying rural area which was poorly serviced by public transport. At the other end of the time scale, only one interview lasted three and a half hours. The other seventy-three interviews ranged between three quarters of an hour and an hour and a half. The first interview was conducted with

the respondent alone, except in two cases where the spouse accompanied the respondent. This was due to some temporary memory loss as a result of the heart attack, in the case of one respondent, and slight deafness, in the case of the other respondent. Spouses were encouraged to attend the second interview.

The purpose of this research is to document some of the experiences of individuals who have had a heart attack. These experiences are then to be related back to general sociological theory to provide an understanding of the patterns that have emerged. Attention also focuses upon the role and function of coronary rehabilitation in the lives of those that have had heart attacks, and in the lives of their families. It was intended that the experiences of the families would receive considerable attention by this research, however, the logistical problems of organising interview times that suited respondent, family and interviewer often proved impossible. Family members have been included whenever possible, but this has not always been consistent enough to yield meaningful findings. The general demographic characteristics of the sample appear in appendix 1.

history.

Eighteen of the thirty-nine respondents had previously diagnosed cardiac-related conditions. These were either angina, hypertension, previous coronaries, or some combination of all three. Seven of these eighteen had had coronaries, two had had by-pass surgery and one had had surgery for an aortic aneurysm. The remainder of this group had angina or hypertension.

Twenty-eight respondents had experienced some noticeable symptoms in the weeks prior to the attack. Twenty-three had experienced pains in the chest, arms or neck and five were noticeably irritable or tired.

Nine respondents went to the doctor about their symptoms. Three of these were told to alter their behaviour (stop smoking, delay an overseas trip, and modify eating and drinking habits). Two respondents were recommended for tests (one, an eeg, was not done, the other was having regular blood tests right up to the time of the attack. These tests had revealed nothing considered to be significant). Three respondents were diagnosed as having other conditions; a sprained neck, a cold, the third was given painkillers. One respondent was being treated continuously, having had tests at Greenlane over the last six months. Only two out of the thirty-nine respondents were told that they were likely candidates for a heart attack.

The reasons why respondents did not seek medical advice when symptoms became noticeable centre on two factors which can be summarised by the following quotations (1);

"I didn't say anything to the doctor because I didn't want him to think that I was a hypochondriac or anything...and I had a horror that when he couldn't find anything that he would think that I was one of those grizzling old women".

and; "I never said anything to the doctor, and apparently it was alright because he never picked it up".

The first quotation summarises the decision-making process of most of the women and the younger men in the sample. The latter quotation was found to be the basis for inaction in more cases of middle-aged and older men(2). These respondents felt that if there was anything seriously wrong with them, their doctor would pick it up without them having to say anything.

The fear of being thought a hypochondriac recurred throughout the study in a variety of contexts. This constitutes a major theme in this study. It was found, for instance, among some respondents who did not read the information which they were given while in hospital. They felt that reading about what had happened to them would give the impression that they were "dwelling on it". It also appeared when reticence about discussing the attack and subsequent experiences with others who had had heart attacks was mentioned, again, for fear of being seen to "dwell on it".

Another area where it was observed was in discussions about getting adequate rest and not engaging in too much physical activity too soon. Here it emerged as a desire not to be seen as "taking advantage of it" or "using it to get out of doing things". This attitude was not so much a response to pressure from others who were associated with respondents, as it was an individual reaction to the heart attack. Thus, it was very much an "internal" response on the part of the respondent to the way s/he felt others might see him/her. Often it manifested itself as a desire to "prove that it hadn't got the better of me" or "there is still a bit of fight in the old codger yet". In other instances it became apparent that this was very closely linked to the feelings about the type of image which respondents wished to project of themselves. For instance; it was observed as a concern that they were not seen as one of those "grizzling old women", irrespective of the fact that others did not see them in this way. This did not appear to be prompted by pressure from significant others (family, friends, employers), especially in the early months after the attack. In fact, quite the reverse situation was observed; many respondents commented on the over-protectiveness of the people around them.

The Heart Attack.

The tables in appendix 1 summarise the events surrounding the heart attacks of the thirty-nine individuals studied. It can be seen that the configuration of situations where heart attacks began fits fairly closely with the general patterns found in the population at large. That is; the majority experienced their heart attacks while resting.

Seeking Help.

Help-seeking behaviour, in the group studied, produced some interesting sociological patterns. It was found that, far from being a random phenomenon, the choice of first "helper" differed quite consistently depending upon the age and sex of the respondent concerned. The remainder of this section addresses the issue of choice of first "helper".

1. health professional was the first contact (21):

Seven of these individuals were either medically trained themselves (1 respondent) or there was a medically trained person close by when the heart attack began (6 respondents). Two respondents contacted a medical practitioner in the belief that it was something other than a heart attack. One of these thought

that it was stomach ulcer trouble recurring. The other respondent was being treated for what was mistakenly believed to be nerve damage. It was two days after first medical contact (at accident and emergency) that this respondent was admitted to the coronary care unit. Nine respondents recognised the symptoms as being a heart attack, four of these had previously had one or more heart attacks. One of these respondents subsequently went into heart failure because the pains were incorrectly diagnosed on two separate occasions by emergency doctors. Three respondents were at work and their colleagues either sought medical attention on their behalf, or instructed them to seek it.

2. lag before medical attention sought (15):

Three of these respondents sought medical attention because of the onset of evening. Eight sought attention because of the duration of the pain (as opposed to the intensity). Three respondents were put off seeking attention immediately because:

It was out of surgery hours and they
did not want to disturb the doctor 2

A sign at accident and emergency
insisted that patients see their own
doctor first and it was out of surgery
hours. 1

One respondent was in town when the heart attack began. This individual forced herself home, which was some distance away,

while she was having the attack. Once home, she contacted her general practitioner.

3. other first contacts (3):

One respondent sought the advice of a neighbour who used to work for a chemist. One was discovered on the side of the road by a traffic officer. Another respondent, a female, sought the advice of her female neighbour, and a final respondent contacted her daughter who rang the emergency services when her mother became unconscious.

4. discussion:

Women tended to ignore symptoms and to wait longer before seeking help. Their first contacts were more often family members, friends (women) or women with some medical association (for example, one worked for a chemist). When they did have medical contact, they displayed concern that what was wrong with them was not serious enough to warrant medical attention. They were afraid of being seen as hypochondriacs, and thus avoided making medical contact for as long as possible. They tended to seek out a woman friend or family member to obtain some support and legitimation that their symptoms were serious before making contact with medical personnel. It appeared that their past experiences with medical practitioners led them to believe that they would not be taken seriously if they sought advice.

The men who did not mention their symptoms to the doctor generally believed that if they were serious the doctor would pick them up. Their reasons for inaction were, therefore, quite different to the women's and, again, it is likely that their confidence in their practitioner's ability to discover illness springs from their past experience with their doctor.

The middle-aged group of men (50-59 years) demonstrated the greatest willingness to seek out professional advice. In some cases they were at work and, thus, were in a situation where they either had to carry on, or have some medical justification for not doing so. Thus, medical justification of the illness was sought. It is also of note that this group more frequently recognised their symptoms as being indicative of a heart attack. This group most closely approximated the "coronary type" (3). Thus, they more readily associated themselves with the illness. This imagery which surrounds heart disease has become a recurring theme throughout this study (discussed in detail in Chapter 4).

Women and younger men tended to look elsewhere for the cause of the symptoms. When the attack actually occurred they either didn't stop to think about what it was that was happening, or they attributed it to a pre-existing and non-heart related health problem. In other words, a heart attack was not seen as a relevant or likely illness for them to succumb to.

All respondents trivialised and tried to ignore warning signs (for example; minor chest pains, numbness in arms, angina) when they occurred. Even when the heart attack had been diagnosed some refused to accept they had, in fact, had a heart attack. As one individual said;

"I don't think that it was one of those coronary things that you go out feet first"

Once again, the popular image of a coronary was uppermost in individuals' minds. When their experiences didn't "fit" that image, they tend to alter the reality to make it consistent with the image. Thus, they would deny that it was a heart attack, or trivialise it by saying that "it wasn't a real heart attack".

Information.

Information Received.

This section deals with the information given to respondents while they were in hospital (38 respondents), or by a cardiologist, in the case of one respondent who was not hospitalised. It is significant that by far the majority of respondents commented on the need for, and value of information that was sensible to the layperson. Only three respondents received no information at all while in hospital. Thus, discussion focuses upon the varying amount and quality of information received by individuals and the reaction of respondents to this information.

In-Hospital Information.

a) Received Printed Information	36
Did Not Receive Printed Information	3
b) Received Verbal Information	
general talk	26
specific discussion about heart disease and respondent her\himself	12
no verbal information	1

In addition to printed material, some coronary care units had organised audio-visual displays for patients. Respondents generally agreed that this was a superior method of presentation. It was found that this method required less concentration than did the printed material. Furthermore, respondents felt that information was easier to remember if they had heard it (as opposed to read it), and that it could be more easily recalled by glancing over the Heart Foundation pamphlets at a later stage. In addition to this, some respondents simply did not enjoy reading, nor did they find it a particularly easy method for gleanng information. Audio-visual presentation more closely approximates the primary learning medium in our society and was preferred by many respondents.

Variation in Amount of Information Received.

There did not appear to be any uniformity in the range of information (both verbal and printed) received by respondents, even for those who were treated in the same unit. The amount of material received did not even appear to be related to the informational needs of respondents. For instance; one respondent who was required to adopt a strict diet and to cease smoking received no information on either of these things.

There were two factors which determined whether or not a respondent received the full quota of material. Those who fitted the, already mentioned, "image of a heart patient" did better than those who did not fit the image so closely. The second criterion for receiving the maximum amount of information was whether the individual was classed as a "good" patient, that is, those who, for a variety of reasons (4), fitted well into the hospital structure and assumed the role of patient with little difficulty. Often the inability to assume this role was determined by lack of hospital experience; respondents did not know what was expected of them. Difficulty in behaving like a "good patient" was also related to discomfort in the hospital setting:

"um, I talked too much, knowing damn well, and that is my defence, that they are writing down in their notes; 'hyperactive, talks too much' or whatever terms they care to put on it; 'obviously of a nervous disposition'. Whereas what they don't realise is that it is brought on by them. And that you are not comfortable in that sort of situation".

Those who fitted the popular conception of a heart attack victim (that is, male middle-aged executive-type) generally fared best in terms of getting reliable and detailed information that they could understand. This was for three reasons.

1. They accepted the diagnosis more readily, and thus adopted the appropriate behaviours with greater ease, quickly conforming to the good patient role.

2. They demonstrated greater skill in dealing with the medical and nursing staff. This appeared to be primarily because the social background of these respondents and the staff were roughly similar. Respondents and staff thus felt more "at ease" with each other and their communication was, as a result, less formal and structured. Because the life experiences of these two groups were roughly similar, advice and discussion was more relevant than it was for respondents who did not share the same background. These respondents had also had more experience in dealing with professional people and thus knew 'how to ask' questions. Furthermore, they were not intimidated by the hospital setting to the same extent as were the other respondents.

3. The hospital staff responded differently to different "types" of patient. This was reinforced by number 1, above. The quotation from a staff nurse which appears below (page 82) provides some evidence of this. In fact, further

inquiry into who those patients were that she no longer tried to educate, revealed that they were predominantly those from social backgrounds to that from which she came. This is not to suggest that staff should, nor even that it is possible to, treat all patients in a broadly similar manner. However, what should be noted is that the manner in which patients are treated does have an effect on the way in which that individual and her/his family experience the hospitalisation. Thus, the precise manner in which patients are treated should be a matter of concern, as should the criteria upon which different types (that is; good or bad) patients are identified.

Patient skill in dealing with medical personnel appeared to be a more reliable determinant of the amount of information received than was patient need for information. Here, the middle-aged men, especially those of a professional background, fared the best. Most of the other respondents were reticent about asking questions, statements like; "Well they don't like you to ask too much, do they" were common among these individuals. This reticence was reinforced in some instances by staff attitude. One staff nurse interviewed said;

"You can talk to some patients until you are blue in the face, and they still wont hear you. It isn't worth even trying with patients like that".

Staff intransigence was not always the reason for failure to obtain information. The encouragement by staff to ask questions

was common in all units studied. However, almost as common was the statement that

"I didn't know what to ask"

"My mind just went blank"

"well, questions don't spring to mind in situations like that"

"it wasn't until I got home that questions started occurring to me".

"it was at the end of the consultation and I think that he had already switched off. I don't think that he was really interested in what I was feeling".

It appeared that discussion, rather than a question and answer type of structure would be the best method for imparting information. In this context, it is of note that the meetings held by one unit for patients after they had left the hospital, was the forum where they felt most comfortable asking questions:

"You find that everyone has the same sort of problems, that you are not on your own, what you are worrying about is something that everyone who has had heart trouble is possibly having the same problems with the same things. And it helps to know that it is not just you"

"You find out that you are not peculiar"

Information Value After Discharge.

For the majority of patients the lasting impression of the coronary care unit was of general openness and information availability, even if individual respondents lacked the ability to extract this. In this context, the inability to extract information was seen as an individual problem rather than a structural one that might relate to the way in which hospitals

and coronary care units are organised. Because it was seen as an individual problem, respondents saw themselves as being responsible for not obtaining sufficient and satisfactory information. Responses such as; "I probably should have asked more", "I reckon the information was there, it was just me" or "I am just a bit slow to catch on", all locate the reasons why the information was not received or understood somewhere in the individual, rather than in faulty hospital procedures which tend to assume equal levels of confidence and articulateness in all patients.

Recall of information was, however, limited in all cases. If the in-hospital educational efforts are to be of lasting value they need to be reinforced at regular intervals after discharge. This is where the long-term rehabilitation groups have much to offer. These schemes provide a forum where material can be passed on, and where individuals can seek out advice in an informal and less intimidating setting than that provided by G.P. or specialist consultations. They have the added advantage that they occur on a weekly basis, and this means that contact is regular and personal relationships can be established among members and staff. The need for practical information and support was greatest once the individual returned home. It was here that advice about the six weeks recuperation, to walk away from stressful situations, losing weight, ceasing smoking and so on, meet head on with the demands of day to day living. Thus, it was here that the compromises between what is ideal (as described

to respondents while in hospital) and what is practicable were made. Home was the setting where all the major adjustments took place. For instance, old behaviour patterns had to be broken and new ones established. Information was considered to be of vital importance in achieving this;

"It is half your medicine is to find out what is wrong with you... if they explain how your heart attack could have been caused by some of the things that you were doing, then that makes it easier to change when you get home. You have to know why you need to change".

The rehabilitation programmes become a bridgehead linking the hospital with the "real life" situations of patients after they have returned home. Thus, staff involved in the programmes have the opportunity of coming to understand the practical and day to day problems of the person who has had a heart attack. In this way the programmes have a unique advantage in that they give the health professionals some exposure to "real life" events, and this enables them to temper their advice with practical understanding. In addition to this, weekly contact with health professionals and other participants is of considerable value to the individuals themselves. These aspects of rehabilitation are considered in more detail in section seven which deals specifically with rehabilitation.

Type and Content of information.

The specific content of advice is also important; this is especially so for advice relating to the return home. For instance; a standard piece of advice given to women on leaving the hospital was, "to turn a blind eye to the state of the house". This advice proved to be useless as one woman explains;

"Well that is all very well and good. And when you are in hospital you think; O.K. I can do that. Going home meant that I had to stop myself from doing a lot of things that I hadn't had to bother about while I was in hospital. You are at home and you see things that want doing, naturally you have to stop yourself, or do them. Telling a person they oughtn't to do them, and sending them home and having them in the house where they need doing are quite different things".

The advice to simply turn a blind eye trivialises a vital area of the return home experience for many women. It is also indicative of the general lack of understanding, on the part of hospital personnel, of precisely what is involved in returning home for those who have heart attacks. What this meant, in practical terms, was that women rarely achieve the six weeks recuperation required for the healing of the heart. This sex-based difference in the quality of convalescence was highlighted by a statement made by one of the men in the sample. It related to how different it would have been if it had been his wife who had had the heart attack.

"It would be harder for women, I would say, to look after themselves like you are told to because they have still got to carry on with the housework and the family. But old dad can bludge along because he knows mum is going to do all the work."

Information presentation also influenced receptivity patterns. For instance; the constant reference to "him" and "he", and line drawings of men in suits and ties (for example, as found in Heart Foundation literature - see appendix 2) only served to reinforce the popular, but erroneous, image of a heart attack victim. These examples may sound trivial, but they are not. Material presented to individuals while in hospital is seen as "expert" information. It should come as no surprise, therefore, when this information reinforces all the popular imagery, that nonconforming individuals have difficulty in seeing themselves as heart attack victims, and in adopting the appropriate behaviours and attitudes.

Multi-media presentation of information was the most successful method of patient education. This involved audio-visual presentation which was then re-inforced by printed matter given to respondents to take home.

"I am not a great reader, so if they hadn't given me that audio-visual thing and then said here's a couple of pamphlets, I wouldn't have read them."

"They gave me some pamphlets and then they spoke to me about it, which was much better".

One respondent appears to have had the ideal experience:

"I was quite surprised at how forthcoming they were with information. Starting right down in casualty, they told me what to expect while I was in the unit, how long I would be in there, what they would be doing"

However;

"If there was contact with the dietitian department it didn't work particularly well in my case".

Individuals respond differently to different methods of information presentation. To be effective a range of presentation formats would need to be employed in each individual unit. The audio-visual system proved to be widely preferred by respondents. This was not surprising as it constitutes the primary learning mode in society at large. Informal discussion between a range of health personnel and a number of patients and their families, conducted at intervals after discharge, was also favoured by a majority of respondents.

A final dimension of this issue relates to the specific nature of information given. This refers to the focus of the material presented. Frequently respondents could recall being "told something about that", but the actual information was forgotten. This often related to the drugs which they were taking. It appeared that information was presented in such a way that the individual knew what the drug was for - "that one's for my blood", but did not know what the drugs actually did, or what the likely other effects of the drug might be. In this way, the knowledge given was very selective and focused at a general level; a general description was often what passed as an explanation. The net effect of this practice was to withhold all but the most superficial of information, while still giving the appearance of information availability and accessibility. It is likely that this was one reason why respondent recall of information was so limited - it was of such limited relevance and use to them.

Verbal Information

Returning to the data presented on page 78; twenty-six respondents were spoken to in passing about their illness. Twelve were spoken to in detail; this involved having their illness and related issues explained in language which they understood, or they attended a meeting where provision was made both for questions and for general discussion. Respondents expressed a definite preference for having some contact with health personnel after discharge. They also expressed some interest in meeting others who have had heart attacks to discuss various methods of coping.

"I think that an exchange of ideas and information and what actually happened with them. It must help. And you can form your own opinions from that, and form the best way that you want to do things from what they have said, to fit with your own style"

The value of this type of contact centred mainly around the fact that it enabled individuals to obtain support and general information, because;

"If you are like me, you don't like to bother the doctor unless there is something really wrong. So if it is something you can't quite put your finger on, you won't go"

Such informal informational networks were favoured by the women in the sample. They felt more at ease in such situations and this reinforcement and support system closely resembled the

networks which they used in their everyday lives. The interest in informal contact with others was often hampered by an intense desire not to appear to be a hypochondriac, or to be dwelling on the event. Often this desire led individuals to avoid mentioning things that could be of significance, or to perform tasks beyond their physical capacity, in an effort to prove that they are not 'taking advantage of it'.

The fear of being seen to be a hypochondriac has been a pervasive theme throughout this study. It is difficult to understand why it has exerted such a powerful influence upon this group of individuals. This fear seemed to be more characteristic of the men than it was of the women. It thus seems likely that it is, at least in part, a reaction to the threat of becoming dependant or physically weak. The women in the sample did not discuss physical restriction in quite the same manner. For them it was more a case of 'having to keep going anyway' rather than performing excessive physical tasks in an effort to prove that it has 'not got the better' of them. For the women, the fear of being seen to be a hypochondriac was quite specifically related to their encounters with health professionals. They would avoid such contact for as long as possible to be sure that 'it really was something serious'.

Unco-ordinated Nature of Information Systems.

Within individual hospitals there appeared to be no overall structure for co-ordinating the diverse sources of information of relevance to a heart patient. For example, very few respondents realised that they could request to see a dietitian and that there were diets and recipes that had been developed specifically for people in their situation. The services of social workers to assist in the preparation of various application forms for benefits available also missed many patients. One hospital in the sample is developing what promises to be a valuable occupational therapy service. In cases where the nature of the work situation appears to be having an adverse effect upon the individuals health, the therapist makes contact with both the patient and the employer to attempt to improve or alter the damaging aspect of the job. This service also functions to make people in the workplace aware of the likely effects of the heart attack when the individual returns to work. It is to be hoped that this service will not be made available on a referral only basis, where the hospital staff decide who requires it and who does not. A referral system removes the final decision as to who receives a service and who does not, from the consumer and places it in the hands of a professional. Therefore, access to services is dependant upon professional recognition of need or desert. It is by no means certain that all patients are equally able to demonstrate need (in the appropriate manner) in the consultation situation.

Information and Families.

"I was glad the family was there and I didn't have to explain it to them myself".

"Well, your family is involved, I mean, inevitably. They must be".

This summarises the attitude of many respondents when questioned about contact between families and hospital staff. It did not appear to be the specific policy of any of the units to involve families. Mention was made of the value of family involvement by both staff and respondents, but this apparently universal value was not reflected in the actual practice of any of the units studied. The reasons for this omission are unclear. It seems that although statements of belief indicate that family involvement is valued, the focus of care is still at the individual level. This means that considerations of the group or social context are likely to be relegated to the periphery of the health professional's attention.

Family members, especially spouses, were often encouraged to attend the rehabilitation classes, but they were never included in the proceedings. Thus, they saw little point in continuing to attend beyond the first session. This was unfortunate because there is much that could be passed on to families at these meetings. One wife expressed the desire to learn

cardio-pulmonary resuscitation, but could find no-one to teach her, unless she was prepared to do a full Red Cross first-aid course. Familial support and understanding are often essential if behavioural changes are to be accomplished and sustained. However, little systematic attention was given to the families by the health professionals. The following quotation summarises the feelings of many of the respondents to this issue:

"Well, I don't think that they were given any information"

WOULD IT HAVE BEEN HELPFUL IF THEY HAD BEEN

"Well, they are the ones that have got to deal with it when you go home".

The lack of specific provision for family involvement when combined with the intimidation that many felt when dealing with medical personnel created a situation where families (especially spouses) felt cut off from the whole hospitalisation process:

"I have always been frightened to push forward. They don't always appreciate your wanting to know too much".

Lack of involvement and adequate information has consequences that reach beyond the hospitalisation period. As such, these are consequences of which health professionals are, by and large, unaware. Things such as the household division of labour during convalescence and the, often very slow, return to health, involve the whole family, yet their role and needs are rarely, if ever, taken into consideration.

Finally, just as there are "good" patients it appeared that there were "good" kin. Once again, assignment to the category "good kin" appeared to be dependent upon the wider social background of the family concerned. Kin of the professional or middle class patient were (like the patient her/himself) more comfortable in the hospital environment and demonstrated greater skill in dealing with and eliciting information from hospital staff than did families from other social backgrounds.

Keeping Information

Thirty-two of the thirty-nine respondents kept the information after they were discharged from hospital. Of the remaining seven, three did not receive any information of a printed nature, and four either did not take the information home, or they threw it out shortly after leaving the hospital. The four who did not keep the information did not see themselves as of the "heart attack type". Again, those who most closely fitted the image tended to get the most out of the material:

"I still don't associate myself completely with having a heart attack. I know I did, but I just don't see myself as one of those people".

The way in which the image is reinforced by the information given by the hospitals has already been noted. It would seem therefore, that the image is fairly pervasive, existing not only in the public mind, but also in the minds of those involved in

the care of heart attack victims. It is ironic, but when reality challenges the imagery, it is the reality that is rationalised or conceptually altered so that it does not conflict with the image, rather than the reverse. For instance, the respondent quoted above, continued to disbelieve that he had had a heart attack (despite the fact that he accepted the diagnosis) because he didn't see himself as the "heart attack type", and furthermore, his experience of the heart attack did not fit with the popular image:

"We didn't even have sirens or flashing lights"

It would seem that although there is an abundance of information on heart disease, it is doing little to dispel popular myth and misconception. The result of this is that those who do not fit the image experience some considerable difficulty in accepting the fact that they have, in fact, had a heart attack. This is frequently exacerbated by the fact that family and friends also have difficulty in reconciling the image with the reality.

Those who find that they do not fit the image of a heart attack victim are likely to experience greater difficulty in conforming to the required behaviours. This is largely because once they leave the hospital the belief that it "really was" a heart attack becomes progressively more difficult to sustain. Rehabilitation classes have an important role to play here in that they continually reinforce the "reality" of the heart attack. They have the added advantage in that they give

individuals contact with others, and this exposes them to the range of individuals who have heart attacks. In this way they are instrumental in demonstrating the erroneous nature of the image of the heart attack-type.

Behaviour.

"Common Sense".

"Common sense" was found to be an almost universal piece of advice given to individuals. It was also used by respondents as an explanation for a wide range of decisions made upon returning home. Although it appeared that all involved felt this to be a sufficiently explicit piece of advice, inquiry into what "common sense" actually was revealed it to be an extremely diverse concept; we may all have common sense, but its properties differ markedly among us. For instance, one respondent, while discussing the reasons why smoking had not been given up said;

"But I am not being silly about it. I am being reasonable. I don't inhale much smoke, so how can it hurt?"

On the issue of diet, a respondent who was retired and who indulged in minimal amounts of physical activity explained;

"I was never a big eater, we have a fried breakfast every morning, that's been consistent over the years. Fairly typical I suppose, that's just common sense".

The appeal to use common sense, on the part of medical personnel, is reflective of the unspoken philosophy upon which medical encounters are based. This philosophy assumes that values and experiences (5) are shared by both patients and health professionals. The assumption is made that common sense is everywhere the same; that it has uniform properties. However, in the current study such uniformity was not found. For instance, the standard six week span before returning to previous activities did not take into account the special needs of women;

"My family thought that if I was well enough to go back to work I was well enough to do all the housework as well. So that the day that I went back to work I had to take over all the household jobs as well".

Similarly, when discussing the return to work common sense is a frequently used piece of advice;

"My doctor told me to be sensible about it. He said that I could go in and potter around in the office. What I didn't tell him was that the office was an hour's drive away".

There are three factors that bear mention in relation to the exhortation to use common sense. The first is that many respondents demonstrated a desire to 'prove themselves' after returning home. This was not expressed in bizzare forms of behaviour, rather, it was found in the desire to resume established tasks and activities promptly after returning home. Here, commonsense may diverge sharply from what is sensible, given the fact that the individual has had a heart attack. Respondents often mentioned the fact that because their "minds hadn't had a

heart attack" it was difficult to be as physically restrained as was necessary. In the initial weeks (the first three or four) after returning home, most respondents managed to restrain themselves from behaviour that might impede recovery. Weeks five to six often required inordinate amounts of restraint to conform to convalescing behaviour. By five weeks, "common sense" had often become a flexible guideline that could be used to justify a wide range of behaviours.

The second issue relating to this prescription, is that once common sense has been approved in one set of circumstances (for example, with respect to diet) it tends to get extended to other areas of individuals' lives, especially those areas where individuals are beginning to feel restricted.

Resumption of Physical Activity and the "Non-Typical" Patient.

The conflict between the image of a heart attack and the reality of many respondent's experiences re-emerged in this section. Respondents who did not see themselves as the "norm" demonstrated some scepticism when given advice about returning to strenuous physical activities that they had previously enjoyed. In particular, they expressed scepticism about their physician's ability to assess whether such activities would place them at risk. They also suggested that their physician seemed to be "against" that particular activity. This scepticism generally

took the form of uncertainty as to whether medical staff actually understood what was involved in the activity. Respondents felt that because the more usual sporting activities associated with a heart attack victim were bowls and golf, anything involving more physical exertion tended to be rejected out of hand. Unfortunately, considerations of confidentiality prevent case examples being cited here.

The significance of these problems lies in what they reveal about the nature of the interaction between medical staff and the non-typical patient. It would appear that more sensitivity to the difficulty which such individuals have in reconciling the image of a heart attack with the fact that they have actually had one, is needed. There are many ways in which this could be done. The, previously mentioned, imagery contained in printed material could be altered so that it acknowledges a wider range of heart attack victim-types. As has been noted, this is the first source of authoritative material on heart attacks for many individuals. It is thus of critical importance in shaping the understanding which individuals develop of heart attacks.

Changing Dietary Patterns.

Diet emerged as an area full of conflicting and insufficient information;

"They told me to only have two eggs a week when I got out of hospital, but I got eggs for breakfast every morning while I was in hospital"

Respondents were told to "lay off fats", "cut down on dairy products" or simply to "lose weight", but they were rarely given sufficient information to be able to consistently keep to recommended changes. A somewhat lengthy quotation from one woman who was attempting to restructure her diet captures all these problems:

"They gave me a pamphlet that tells you to go onto a low fat diet, but it doesn't tell you what sort of food to cook, how to cook it, what sorts of combinations of food you can make to satisfy yourself if you are not having the sorts of food you had before. Quick meals for those who don't always have the time to cook. They don't tell you what to replace fast foods with. It is very easy to fall back into old ways when you don't have the time, or when you just don't have enough information to know what to do".

The Return Home.

On leaving hospital the individual exchanges patient status for the, equally temporary, status of convalescent. Returning home also involves movement from an institutional setting, where role obligations and routines are structured and well defined, to a situation where old roles and behaviours must be either resumed or abandoned. During this period the heart attack and accompanying experiences must be assimilated into the image which the individual has of her/himself. Thus, as well as being a time

of transition, the return home can be disturbing or unsettling for the individual. Feelings of insecurity at this point were quite common, for returning home means leaving the security of the ward and its monitoring systems. Often new behaviours and routines must be learned, for instance, medicine taking routines must be set and adhered to, diets often change, sometimes dramatically, and major behavioural modifications, such as ceasing smoking, must be undertaken. Up until this point these have all been organised by the hospital staff, but the return home sees the individual assuming responsibility for them.

The Experience of Women.

In addition to these common features of the return home, there were differences in individual experiences. As in past sections, these differences clustered along age/sex lines. The women interviewed (whether married, single or widowed) experienced greater difficulty in returning home to their old roles than did the men. Housework comprised a major aspect of the lives of all the women studied. This required higher levels of physical exertion on a more regular basis than did the work of the men in the sample. This meant that they were required to alter or cease more of their usual home activities for the six weeks convalescent period. The advice commonly given to women relating to household activities has already been touched upon; "Turn a blind eye" does not constitute realistic advice. In

addition to this, it demonstrates an almost total lack of understanding of the reality of life outside of the hospital.

Housework constitutes a large and important part of the lives of the majority of women. To be told to ignore it, trivialises a central aspect of the experiences of most of the women who have this illness. The depth of this insensitivity was graphically demonstrated in the case of one woman who was discharged home four days early (because of lack of bedspace) to a home with two teenage children:

"Well I wasn't pushing to come home because I felt that it was foolish to come home too early. I wont say that I wasn't glad to, I was, but I didn't even ask. The doctor came around and said; you can go home...That was exactly a week after I went in. I realised that going home meant that I had to stop myself doing things that I hadn't had to bother about in hospital...they said that for at least the first few weeks I shouldn't do the cooking and washing and all the bits and pieces that go into doing housework. But telling a person that they oughtn't do them and sending them home and having them in the house where they need doing are quite different things".

Families generally continued to perform household tasks for about two weeks after the women returned home. In only one case (the husband had retired) did it continue for the full six weeks convalescent period, and for women in paid employment support of any kind dropped off sharply after they returned to work.

"I think that it will all stop when I go back to work: If you are fit enough to work you are fit enough to do the house".

"What happened was that they seemed to feel that if I was home all day I had plenty of time to do the house, and if I returned to work then I was well enough to do the house as well".

The difficulty experienced by the women in performing household tasks and in getting consistent help and support from their families is further complicated by the fact that they felt that they were failing in their role as homemaker if they did not do all these things. This was especially so for the women who were not also in paid employment; in these instances housework comprised their only source of status. They hesitated to ask for help because; "it is my job" and "I don't want to put an extra load on them". The result was that their health suffered. Wives in employment usually took time off work to look after their husbands once they returned home; this never happened for the women. Their experience of a heart attack reinforced their past experiences of illness more generally in that their individual health needs were subordinated to the support and nurturance needs of the family. As one woman said; "mum always keeps going". Here, the practical effects of a culture which defines women as care-givers in the family, but not as care-receivers, can be clearly seen.

Families and the Return Home.

The return home also highlighted the need for family involvement in the entire process. Families need to know and understand what has happened and what to expect in the future. In the minds of most people, the function of a hospital is to cure the sick. Once an individual returns home it is usually assumed that s/he is no longer sick. Said one respondent;

"I was surprised to find that when I went home I was still sick, that the hospital only kept me there until I was out of danger. Actually, getting better only started when I got home."

Rarely were family members, or respondents themselves in many cases, made aware of the very real and difficult issues that they would have to resolve after they returned home. Once again, the advice given by hospital staff was superficial and tended to deny, or disguise the true extent to which the heart attack would influence the lives of all involved.

Returning to Work.

The second major variation in return home experience was along employment-based lines. This section focuses upon the work-related experiences of those respondents who were employed prior to the heart attack. The professional men (there were no professional women) had little difficulty in getting the required time off work to convalesce. Once again, the group who fitted

the image had the fewest problems. Financially, the self-employed were the hardest hit by the heart attack. These individuals were ineligible for accident compensation and thus had to rely on the sickness benefit. Unfortunately, the application procedure for this benefit meant that there were long delays between submission of application and receipt of benefit. Consequently, some financial hardship was experienced in these cases. In addition to this, the staff of the Social Welfare Departments concerned made the application procedure humiliating and degrading. This led respondents to reconsider whether it was "really worth applying", again causing delays before the benefit was received.

"at the moment I haven't had any money out of the Social Welfare Department. They haven't sent me a cracker yet, apparently they have approved it...To start with I felt degraded by going there. The type of people that work there are not my kind of people anyway. So I wasn't very impressed with them. So I filled out all the forms, they had someone come out and talk to me. They weren't very helpful. I said that if I didn't get the benefit fairly quickly I would apply for the emergency benefit, and he said; Oh yes, if you haven't got any food in the house you can come up here and apply for it. Sarcastic thing. I thought that they were there to help us, but that wasn't the impression that I got. I felt that they were really degrading. I was completely reliant on them, and I only get \$65.00 a week, for all that hassel. They have kept me waiting a month. I really got worried and I said to them, you people are going to give me another heart attack at this rate."

Wage earners and non-professional respondents usually used up their accumulated sick leave. Often this was their accumulated entitlement for their entire working lives. Although

this meant that their pay continued throughout hospitalisation and convalescence, it did raise some concern as to how the individual would cope if s/he required time off for sickness during the next twelve months.

Returning Home For Those Who Live Alone.

Finally, the return home experiences of those who lived alone were significantly different from those of all other groups identified in this study. Although lengthy, the following quotation highlights the major problem areas for this group;

"It is something that I will always remember....I did have someone to stay with me, a neice of a friend, she was 15 and a half. I had a great homecoming, there were people from the flats, and we had afternoon tea...I felt alright...Then they went and this little girl and I were left on our own, and that was alright... I wasn't worried because there was someone in the house....Then the little girl came into the room and sat on the bed and cried because she was homesick. But I think it was having to see me as I was, when I had always been so bright. She went home, and I thought; what am I going to do. I can't stay on my own, I can hardly walk around. That really frightened me. My friend stayed the Friday night. And I thought what am I going to do, I can't stay on my own and I can't get anybody in.... I hated being on my own, I kept going to the door and looking out. I got frightened and my heart started to beat so fast that I could hardly walk. I crawled to the door and had a little bell in my room. I got that, and my heart was going so loud, it was banging in my ears. I got my dressing gown on and I crawled to the front door and I rang and rang. And nobody heard, and then I saw the lady from one of the flats, she is deaf, and I prayed and prayed that she would hear me, she turned around and I beckoned her to come".

Although not all as intense as this case, all those those who lived alone experienced feelings of isolation and insecurity upon returning home. The hospitals in this study all insisted that those living alone either stayed with someone or had someone to stay with them for the first few weeks or so. This insistence helped somewhat, but the time when the individual again had to face being alone always arrived. It is in cases like these that the rehabilitation programmes had much to offer. They provided contact which helped to bridge the transition from hospital to home.

Families.

The value of family involvement was frequently mentioned by those involved in the care of cardiac patients. It was certainly considered to be important by those respondents interviewed for this study. Unfortunately, in most instances, family involvement in hospitalisation and post-discharge events appeared to be incidental or largely fortuitous. Nowhere was it a consistent part of hospital practice to involve the patient's family, although it was often mentioned as desirable. Even when spouses were encouraged to attend rehabilitation classes no provision was made for them to take an active part in the proceedings. In fact, they usually ended up sitting in a corner of the room by themselves, just watching. Thus, it was unusual for them to

attend more than one class. Rarely were spouses seen as an integral part of the illness and recovery process, with legitimate fears of their own and often in need of reassurance and practical advice.

Failure to constructively involve families further contributed to the individualisation of the heart attack. More often than not the, potentially large, contribution which family members could make in helping respondents to recover was lost. On a very practical level one wife noted;

"But I do think a bit of information as to what to do in a cardiac arrest is essential. Patients shouldn't be allowed to leave the hospital until the well member has been given basic instruction as to how to do CPR. They tell you in the 'phone book what to do in an earthquake, but no-one tells you what to do if you have a heart attack".

Teaching things such as this to family members could easily be done within the framework of any of the rehabilitation programmes. Furthermore, it would profitably use the time that is otherwise spent passively watching the participants. The classes could also be used to reinforce information given to patients and their families while the individual was in hospital. An additional function which they might serve would be to give families support and contact with others in their position.

It is difficult to understand why more effort was not made to involve families for, as one respondent said;

"well, it is they who have to cope with it when you get home".

This approach is, however, consistent with other aspects of hospital practice. That is; it tends to deny the processual nature of disease. That illness has consequences and effects beyond the confines of the hospital is largely ignored.

The evidence of this study suggests that it is important that there be some continuity between hospitalisation and the return home. Rehabilitation goes some of the way to providing this, but the programmes are still removed from the normal social context of the individual. Consistent family involvement in both hospitalisation and post-release care would provide the link between the illness and the ordinary existence of those who have heart attacks. The family has an important role to play in assisting the return to "normal" life and also in supporting the modification of behaviour. Often respondents lamented the fact that their families continued with old dietary and smoking behaviours while they were trying to give them up. Here again the individualisation of illness can be seen. By ignoring the context of behaviour and individualising the illness, hospital staff gave implicit support to the belief that ceasing smoking, or altering diet is part of the individual's treatment alone. It is, therefore, not relevant to the family as a whole. This is not to suggest that hospital personnel intended their actions to be interpreted in this way, but in practical terms, this was their effect.

Rehabilitation.

Introduction.

The final area considered in the first interview was rehabilitation. In three of the four groups studied group rehabilitation was an important component of the post-release phase.

Each of the three rehabilitation groups were distinctive. The first was short-term, running for six weeks following discharge. It was run through the hospital's physiotherapy department, whose staff contacted patients while still in hospital and initiated some low level mobility exercises. These were to be done during the patient's stay in hospital. Once patients returned home they could attend weekly classes where they would do minimal amounts of exercise with other patients. This scheme also allowed time for group discussion of any problems or queries that had arisen during the previous week.

Respondents perceived the primary function of this programme as giving them some continuing contact after they had left the hospital. Its secondary function was to remind them of the value of exercise, which they should be making part of their daily routine. The link between the physiotherapy department and the

coronary care unit was more consistent in this group than it was in the other hospital-based group. In both groups it was stated policy that all patients should have the opportunity of joining the classes. However, this group contacted and recruited a far higher percentage of patients than did the other group.

The second hospital-based group was also run through the physiotherapy department; coronary nurses were also rostered to attend the weekly meetings. The nurse gave advice on issues that the physiotherapists were not qualified to discuss and also monitored patients when necessary. The primary function of this group was to monitor the exercises of the patients, which was done on a one to one basis (that is, a physiotherapist working with each patient individually). This group also ran a post-release evening meeting at which a variety of health professionals were available. Individuals and their families were encouraged to attend this meeting. After a six week exercise period respondents could move on to a jogging class. This involved small amounts of jogging (ten to fifteen minutes in duration) within the hospital grounds. Regular stress tests were also conducted on patients, and spouses were encouraged to attend this session. The aim of these stress tests was to demonstrate to patients and their spouses the former's physical capacity. This was usually in excess of what either had expected.

This group was the less successful of the two hospital-based groups in making coronary care patients aware of its existence.

Almost half of the respondents did not know about either, or both, the exercise classes or the evening meeting.

The final group was non-hospital based. Thus, it relied more heavily upon word of mouth to recruit members. There was a lapse of approximately two months after release before individuals were permitted to join this group. Individuals were first screened by a cardiologist who decided whether or not they would be able to cope with the exercises and at what level (pulse rate) they should begin. The focus of this programme was on walking/running both as a method of conditioning the heart and body, and as a method of rebuilding confidence. Individuals could attend up to a maximum of five times a week. The majority attended two to three times weekly. Exercises were done inside a gymnasium, this enabled a group atmosphere to develop and also made monitoring easier. This programme also had developed a social club which had extensive and wide ranging activities. This enabled spouses and families to take part in the rehabilitation process.

The fourth group of respondents was drawn from a hospital which had no structured group rehabilitation programme. This hospital ran what is described as rehabilitation on an individual basis between the patient and her/his doctor. The coronary care unit ran in-hospital meetings which spouses could attend to discuss various aspects of heart disease and exercise.

Discussion.

This section addresses the issue of group versus individual rehabilitation. Respondents in the first three groups were asked, why they attended the classes? What did they see as the principal advantage of participation? What, if anything, could be added to them? Would they prefer an individual type of programme? Respondents in the fourth group were also invited to discuss the advantages and disadvantages of individual rehabilitation and whether or not they would attend group rehabilitation classes if they had the opportunity.

1. group participation:

"Well, I think it is because it is there, you do it. If I had to get up each morning and go for a run, I mightn't do it, or I might be running late, and I wouldn't do it. But with this, I just put it in my diary, the days I am coming here, and that is it, I work my other appointments around it. The most important thing is that it is there".

The above quotation encapsulates the most commonly expressed advantage of the group programmes. They are there; they exist specifically for those who have had heart attacks, and they run at a set time each week. As the above respondent notes, the individual can plan around them, this ensures that the individual gets a set minimum amount of exercise each week. Most respondents felt that if left to themselves, they would tend to lapse once their initial enthusiasm had worn off. This feeling was reinforced by statements from respondents in the fourth

group;

"But now I am back to work I am not so bored and I haven't had any exercise for a couple of weeks".

Thus, the concept of structure emerges. It is an important concept for two reasons; it introduces an element of compulsion which respondents felt to be important in helping them to establish and maintain behavioural changes. The second important facet of structure is that it is controlled. The classes were all run by health professionals who monitored and controlled the level of exercise of each individual and who were also available to answer any questions and worries that participants might have had.

The element of compulsion is composed of two distinct parts; self-legitimation and other-legitimation. Self-legitimation refers to the fact that, because this activity is obviously sanctioned by professionals, individuals can justify to themselves taking time off from daily obligations to spend on self-related activities. Other-legitimation refers to the need respondents expressed to have a 'stamp of approval' on their daily exercise. In other words, it had to be seen as "necessary" and "functional", otherwise others (for example; employers and family) would see their taking of exercise as attempts to use the illness to "get away with doing less" or to "malingering". The existence of a group to which they could be referred by their doctors meant that this was, indeed, part of their treatment. Therefore it was necessary and would be tolerated.

These concepts are extremely important, and, in themselves, constitute sufficient justification for the continued existence of such programmes. More importantly, however, is the commentary which they provide on how society as a whole views individual health-directed behaviour which does not involve an element of medical direction. Taking time out from activities considered to be significant or important, to maintain one's own level of health, is not, it would appear, a highly regarded activity. Health care that does not involve a degree of professional intervention and control is not accepted as a valid activity:

"I do not feel that I could take time off work, or from doing the housework to go for a run around the block. But if there was some place that I could go where people who have had heart attacks were doing those exercises, then I don't think my employer or my family would mind me taking time off to go to it, especially if my doctor approved of it".

2. health as an active state:

As mentioned above, health is not generally seen as something in which the individual has a high degree of involvement. It is usually seen as something which is restored by a professional trained in such matters.

"I didn't realise that exercises helped your heart, and your body too".

The existence of these programmes demonstrated to the participants (and their families as well) that health was more than the absence of illness. By participating in the classes, respondents learned that health was something that individuals can influence by their actions:

"A lot of it was purely habit because we didn't realise that diet was anything more than just eating".

Thus, participation in the programmes established the link between various types of behaviour and a range of health outcomes. The appropriation of individual control over health, through the denial or control of information, became clearly apparent through these interviews. Participation in the programmes had the effect of giving individuals permission to look after their own health. It did this by providing them with a source of information and then giving them the confidence to use that information on their own behalf. Health was thus transformed into an active state.

3. confidence levels:.

"Perhaps it is because we are doing something. That is important".

Once health becomes something that the individual can 'do something about', a transformation takes place. Virtually without exception respondents expressed the belief that to "be able to do something yourself" was of great importance in the overall recovery. The degree of active involvement in the recovery proved to be a major determinant of its quality and extent. This participation gave individuals a confidence that was not shown by respondents who did not attend the rehabilitation classes. Again, the imagery which surrounds the whole area of heart disease was found to be of considerable significance.

Respondents generally believed that a heart attack meant that they would be reduced to the status of a virtual invalid. The encouragement to exercise, to be active, and seeing others doing these things, changed their focus from invalidism to a return to health:

"Last Friday there was a fella there, and he was so happy, I've never seen someone so happy. He said; it has taken me two and a half years, they brought me in here on a stretcher, I have just done six miles. He was so thrilled".

The "cardiac cripple" is well known to those working in the cardiac field. This phenomenon generally occurs when individuals feel no hope, are frightened and feel unable to control what happens to them. Rehabilitation groups, where individuals can see others "coming back", have an important role to play in helping individuals to avoid being trapped by this role.

4. social, physical and educational aspects:

This section discusses the major components of the programmes. The value of the classes as a place where exercises could be learnt, practiced and controlled was undisputed:

"because it is controlled. When I jog by myself I find it a little lonely in case something goes wrong. I basically come here for the controlled exercise".

In addition to this, the classes served a support and reinforcement function;

"You can talk to someone about things before they start to really worry you.... and you can come along here and your mind is put at rest."

This was important because most of those interviewed expressed some reticence about contacting their doctor, except in emergency situations. They used the staff at the classes to obtain answers to small day to day concerns, and to check whether their concerns were important enough to bother their doctor with. Without this intermediate and immediate source of advice, respondents would either put up with the worry until it went away or until it became intolerable.

The social value of the rehabilitation classes centred on the way in which they reinforced and supported individuals;

"To hear someone else that might have the same sort of thing, well it is valuable because you know that it is not only you, you're not a freak, it is not only you that is doing these sorts of things".

This was a frequently expressed sentiment. Those who did not find such contact and reinforcement valuable tended to feel that to show an interest in, or need for such things, would make others think that they were being hypochondriacs. Although this aspect of the classes did not have universal appeal for participants, it did serve an important function for a sizeable group.

The educative potential of rehabilitation was not developed to any degree by any of the programmes. Access to information was, however, a high priority for most of those who participated in the study. It constituted a commonly suggested addition to the programmes. Having discovered that there were things that they could do to aid their recovery and improve their level of general well being, respondents wanted to know more. Information and education was emphasised while in hospital, but seldom reinforced after individuals returned home. Advice and information was freely available at the rehabilitation classes although this was largely on a random basis. In short, there was no regular and explicit supply of information.

A final value of group rehabilitation was that it appeared to help individuals to maintain behavioural changes. Losing weight and ceasing smoking were the two principal changes required of respondents. As yet no universally successful method of giving up smoking has been developed. This is largely due to the fact that current techniques do not address the reasons why people smoke and the function which smoking serves in their lives. Thus, there is a core of individuals for whom no technique is successful.

For those, in this study, who were unable to give up, smoking constituted virtually the only pleasurable activity left after the heart attack. For instance, loss of employment and confinement to an unsatisfying home life created feelings of

depression that were, in some instances, extreme. Medical responses to this depression varied, but generally centred upon some form of psychiatric intervention. Requiring respondents to cease smoking, and their subsequent failure to do so only added to this depression. In no case was the source of the depression addressed by medical professionals. Nor did they provide any aid in modifying the unsatisfactory social context of the individual. Attention only focused upon the individual and her/his inability to alter and come to terms with a changed set of circumstances. In situations like this, requiring an individual to give up smoking, without attempting to alter the social context, or replace the smoking with another, equally satisfying activity, is not only insensitive, it also is potentially dangerous.

The value of group participation in aiding individuals to give up certain behaviours is well known, and is used by groups such as weight watchers. Weekly "weighing in" and weight recording gives the individual something to aim at. It also provides a source of support when things such as weight plateaus are reached. This sort of goal setting and support in set backs is also of value for those trying to give up smoking. It is unfortunate, but none of the programmes studied, developed the full potential of group participation, as a technique of behavioural modification.

5. professional contact:

Although in certain instances doctors encouraged respondents to make contact with them, should they have any worries, most were unwilling to do so. The reasons for this reluctance varied. Where respondents believed that it was not a clear medical problem they felt the doctor was an inappropriate source of advice (for example, where respondents needed reassurance, or were suffering from minor amounts of depression and physical discomfort). In cases such as these, respondents who were participating in a group programme received the required reassurance, those being treated individually endured their problems alone.

Other common reasons for not seeking general practitioner advice were, feelings that the worry might be too trivial and also a desire not to waste the doctor's time:

"they don't have enough time, they take your blood pressure, check that you are reasonably O.K. ask questions like; have your feet been swelling, have your hands been swelling, um, any other problems? Which leaves you the opening but not the time. If you have something that is niggling you, you think, Oh, it is too trivial. I won't bother. Unless the doctor can sense that there is something wrong you will go to the doctor and come away unsatisfied. The doctor has so many patients, they don't have the time. If you have got a room full of people in the waiting room, you don't feel like holding the doctor up for ten minutes while you have something explained to you. Not if you are a person who has sat in waiting rooms yourself, and face it, who hasn't".

Although doctors may, themselves, be keen to support their patients once they return home, respondents do not perceive the doctor's role in this way. The doctor's role is primarily seen in narrow, specifically medical terms; to check up on their hearts. Support and advice is sought elsewhere or not at all.

"If there was a place separate, only you would need to have somebody who knew what they were talking about, because they could give out wrong information. I think that would be better than having the doctor trying to find out from a person. Whereas if you went to one of those places it would come out in conversation. People are much freer talking in that sort of situation than they would be in a doctor's room".

The above quotation was taken from an interview with a respondent who was from the individual rehabilitation group. This quotation spontaneously describes a central feature of the group rehabilitation schemes.

Respondents in the professional occupations, and those who fitted the "cardiac image" fared the best in terms of attention received from general practitioners. In the case of the professionals, respondents often knew their general practitioner socially and had no hesitation in contacting them for advice on a range of issues. Those who saw themselves as fitting the image were more willing to contact their practitioner for advice. Those who did not fit the image often felt that they were not taken seriously by their doctor; they felt that their problems were either trivialised or reduced to psychological problems and inadequacies:

"I went to him one time when I was feeling really terrible and he just shrugged me off and said, Oh, you are tired, come back and see me again before you go back to work".

"I went to see him, and he never even got up from behind his desk, I don't see how he can claim to know whether something is serious or not, when he doesn't even bother to come round to the other side of his desk to check me out"

"I went to see him (specialist) one time up at the hospital. He said to me, Oh you are just one of those over-anxious types. He didn't even go back to his office and get my notes out, I don't even think that he remembered me. How can he know that there is nothing wrong if he doesn't even bother to find out who I am".

Experiences like these resulted in loss of confidence in medical practitioners as a source of advice and support:

"I think that you lose a little bit of confidence in your doctor after episodes like that".

6. individual rehabilitation:

Group social activities do not appeal to everyone. This was apparent from interviewing respondents who participated in both types of rehabilitation. However, the advantages of group rehabilitation extend beyond the social contact which such schemes provide. Lower levels of compliance to behavioural changes were found in the individual rehabilitation group. This non-compliance stemmed from two sources. Firstly, the need to continue with the changes lost urgency the further away from the heart attack the individual got. A large drop off in numbers continuing with the behavioural changes was observed shortly after the six weeks convalescence period.

The second source of non-compliance relates to the concept of structure, as discussed in section one, above. This was especially so for the exercise component of the behavioural changes. Exercise is seen as recreation, walking, the most commonly prescribed activity, even more so. As such, it was not defined as something that individuals could legitimately do for an extended period of time. During the six weeks convalescent period it was accepted, but tolerance of it declined sharply after this point. Those who had a legitimate place where they could exercise (for example, the group rehabilitation classes) continued with the exercise beyond the six weeks. This was so even when the classes only lasted six to eight weeks. Those who did not participate in group schemes rarely continued with regular exercise for more than two or three weeks following discharge.

The value of rehabilitation classes as a forum where individuals could check out any problems experienced after leaving the hospital has already been discussed. Respondents in the individual group often demonstrated uncertainty as "to whom they belonged" after they left the hospital:

"I rang through to ...(the cardiologist). The receptionist said you go to your G.P. So I rang him and he said go back to(cardiologist). So I went back to him, and he said; perhaps you should go through....(the physiotherapist who had seen the respondent while in hospital). I said; what the hell would they know about heart attacks. He said ring them up. They told me to ring the G.P."

This was never a problem for those who participated in a group scheme, even after (in the case of the hospital-based classes) they were no longer attending. Respondents from these groups were in no doubt about who they would contact if anything was bothering them. As noted above, respondents from the individual group often spontaneously described a system like that operating in the other areas;

"Mostly it has been left to me, um, I think that if there were something else, um, some place you could go to ask advice."

"I think an exchange of information and ideas and what has actually happened with them, it must help, and you can form your own ideas from that".

It is interesting to note that virtually the only reason offered for not wanting to participate in a rehabilitation programme, was a dislike of meeting a group of people who would continuously talk about their heart attacks. In reality, this rarely, if ever happened at the classes;

"Because we don't speak to each other about our heart attacks, we hardly ever mention it to each other".

"But talking to these people, total strangers, eh, and talking to them, but only rarely about the heart attack".

Conclusion.

The experience of a heart attack is usually explained in two ways. It can be seen as a uniform experience. This involves the argument that if it is virtually the same physical or medical

event, it must be roughly the same sort of experience. Alternatively, it can be seen as a widely random experience being as diverse and unique as human beings themselves. This chapter has provided a third way of understanding this experience. It has suggested that the reality of the heart attack experience lies somewhere between that suggested by the other two approaches.

The experience of a heart attack will be influenced, in part, by the unique characteristics of the individual concerned. However, what this chapter has shown is that this experience also has a structural dimension. This means that the experience of a heart attack will differ depending on the social groups to which an individual belongs.

The analysis of the first interview also demonstrated that the experience of a heart attack will be influenced by the nature of the interaction between the individual and significant others. The most significant interaction in this context is that between the individual and health professionals. Two things were found to influence this interaction. The "imagery of a heart attack" was instrumental in determining the nature of the interaction, and thus the experience of the individual. This imagery defined one group of individuals as the norm, and by implication it defined those who did not conform as deviators.

Interaction was also influenced by the social group origins of the individual. Thus, interaction was quite different between males and health professionals than it was between females and health professionals. It was also different between young males and health professionals than it was between older males and health professionals. Within these groups the nature of the interaction was more nearly uniform than it was between them.

The "imagery of a heart attack" also directly influences the way a heart attack is experienced. While most individuals were found to subscribe to the imagery prior to the heart attack, not all those who have heart attacks actually conform to it. Thus, for some individuals the experience of the heart attack is punctuated by a degree of personal conflict.

A major contention throughout this research has been that a heart attack is a social process, not an event located at one point in time. Chapter 3 is devoted to an examination of the material gathered in the second interview. This interview took place some three months after the first. It was thus intended that it would provide information on the influence (if any) of the heart attack some distance from the initial event. This is a time when the individual is supposed to be some considerable distance to complete recovery and the regularity of contact with health professionals would suggest that the individual is "cured".

Footnotes

1. Note on use of quotation marks in text:
The use of " " indicates a verbatim reproduction of part of an interview.
The use of ' ' indicates a summarising statement which is representative of the views of two or more subjects.

2. It was found that the sample was composed of three distinct groups. These recur throughout the following three chapters. The three groups are; women, younger men (under 49-50 years) and older men (over 50-51 years).

3. The imagery which surrounds the whole area of heart disease has become a major theme in this research. This will be dealt with in considerable detail in Chapter 4, this chapter discusses the major themes which emerged from the research.

As this theme appears in numerous places throughout this and the following chapter, some preliminary discussion of it is warranted. It has been found that there exists a very precise and widely held definition of what heart attacks are like and who has them. Those who have heart attacks are generally believed to be male, middle-aged (approximately 45-60 years), of professional/executive employment status, physically unfit and tending towards obesity. This constitutes the "coronary-type" or the "popular image of a heart attack victim". In addition to there being a "coronary-type", there is also a widely held conception of the standard heart attack. This is a sudden massive pain in the middle of the chest which is of short but intensive duration and which renders the encumbent unconscious. This image is, in fact, partly traceable to the words commonly used to describe this illness, that is; "heart attack". The imagery which surrounds heart disease is powerful and highly resistant to modification.

4. Those who were most readily classed as "good patients" were the respondents who most easily accepted the fact that they had had a heart attack (that is; those who fitted the image) and who had little difficulty in assimilating this experience into their own conception of themselves. These individuals adopted the appropriate behaviours more easily and thus, were seen as good patients. Those who had difficulty accepting the diagnosis and fitting it into their self-image were less

likely to "behave properly" (that is; follow the hospital routine and display an interest in learning about their illness). They were therefore, more likely to be classed as "difficult patients" and were treated accordingly. This usually entailed staff spending as little time as possible communicating with them and their families, and perhaps not responding as sympathetically as they otherwise would, to any problems which arose.

5. This common background again relates to the image of a heart attack victim. See footnote two.

CHAPTER THREE:

Results from Interview Two.

The Structure Of This Chapter.

Introduction.

This section provides a short introduction to the second interview.

Rehabilitation.

This section is composed of four major parts. Each part deals with a long-term consequence of rehabilitation. The final part of this section provides some summarising comments on the role of rehabilitation.

Medical Contact.

This section provides a discussion of the nature, effects and limitations of medical contact as an alternative to structured group rehabilitation.

Keeping to Changes.

There are three major parts in this section. The first two consider the major determinants of the failure to adopt and sustain behavioural changes. The final section considers the wider effects of the attempt to effect changes in lifestyle.

Personal and Social Effects of the Heart Attack.

The final substantive section in this chapter involves a discussion of the long-term personal and social consequences of

the heart attack.

Conclusion.

The chapter finishes with some brief concluding comments about the heart attack's long term effects.

Introduction.

The second interview occurred three months after the first meeting and focused upon the period that intervened between the two interviews. It inquired into the attitudes and feelings of respondents to their experiences since the heart attack. Much of the information gained in this interview reinforced trends and patterns that were evident at the first meeting. In addition to this, important information was extracted that is rarely obtained in studies of illness. This information relates to the life of the individual and family some time after the illness event. From three months post-discharge onwards little consistent contact is sustained between individuals and health professionals. The assumption that tends to be drawn from this is that the illness no longer plays a significant role in the life of the individual. In some cases this holds true. However, for the majority of individuals the effect and influence of the heart attack is ongoing over a considerable period. To be sure, medical checks and the refilling of prescriptions often continues after three months. However, this contact is of little use in

providing support and information for the individual. Thus, the second interview provides valuable and rare insights into the lives of those who have had heart attacks, and of those closely associated with them.

Rehabilitation.

Introduction.

A major focus of this study has been the role and value of cardiac rehabilitation. The results from this part of the inquiry will be considered first. The two hospital based programmes were of six to eight weeks duration. Thus, by the second interview respondents were no longer attending. The individual hospital-based programme, of course, had no specific provision for formal post-discharge follow-up (other than G.P and specialist consultation. On average post-discharge medical checks took place at three monthly intervals for all respondents. The non hospital-based programme had no set cut-off point, and six out of the original nine were still regularly attending the classes. Of the remaining three, one had died, and the other two were no longer attending because other commitments had a prior claim on their time. Thus, for over three quarters of the total sample, regular (weekly) contact with health professionals had ceased.

Discussion with respondents about problems experienced (uncertainties, fear, lack of confidence), and the need for information, both relating to general health and heart-related matters, revealed that there was a definite relationship between participation in some type of formal rehabilitation and the ability to cope with a range of problems and issues. The nature of this relationship was such that the higher the degree of involvement of the individual, the greater was her/his ability to resume a satisfying lifestyle, to cope with a variety of problems, and to be able to obtain access to a range of information, to name some of the more important facets of the post-release experience. Of course, this did not obtain in all cases. There were respondents in the individual rehabilitation group who experienced no problems. However, it should also be noted that in no case was participation in the group rehabilitation classes a negative experience. All respondents, without exception, commented on the advantages derived from participation in an organised programme. Obviously, the specific value of participation differed for each individual. Broadly speaking, however, the advantages were grouped around the six major areas discussed in the section on rehabilitation in Chapter 2.

The general function of rehabilitation has already been discussed. This section will, therefore, deal with the specific function of rehabilitation in the long term. As stated in the introduction to this chapter, research rarely inquires into the

long term effects of a particular service or treatment. Furthermore, on those occasions where research has focused upon a time some distance from the initial event, the techniques used have paid no attention to the wider social and experiential context of the participants. Thus, there is little information on the way in which an illness is fitted into the social context of the individual, the family and significant others, and on the long term effects which this illness has on these people. However, this should not be taken to mean that it does not have such effects. Even at the time of the second interview, the impact of the heart attack and the hospitalisation period were still clearly evident.

Discussion.

1. milestones:

Recovery is a process. In the case of a heart attack this may cover months or even years. Contemplation of such a time span can, in itself, prove to be distressing. Establishing and reaching milestones proved to be an invaluable part of recovery for many of those interviewed. The precise nature of these milestones varied in each individual case, but, in general terms, they centred around increasing physical endurance and levels of confidence. These two factors were, of course, inter-related; as physical limits expanded, self confidence increased, and as

self-confidence increased more physical activities were attempted. This was especially the case where the individual had some regular contact with a rehabilitation programme. Regular contact and monitoring of exercise, as it is being performed, reassured individuals that they were not over or under-extending themselves. By working through a group programme that was gradually increased, individuals could see that they were improving. The regular increase, though slow in many cases, of both the level of exercise in the classes, and the range of activities attempted at home, played an invaluable role in the personal recovery of the individual. Indeed, increasing physical capacity often became a crucial measure of recovery.

The value of the programmed setting of goals operated at two levels. Firstly it functioned at the individual level; here gradually more and more physical activity was attempted. Secondly, it operated at the social level; by participating in a group activity the individual could see others at differing stages of recovery. This provided a degree of reinforcement; individuals could see that there would be progress:

"Yes, yes. I find myself now, instead of walking around the flats, I find myself running a bit. First I would just walk slowly. Yesterday I was smiling to myself, I thought, look at me. If it wasn't for coming in here I don't know how I would have got on."

"Yes it was handy, of course when I first went there I was doing very little. I went up there in the first week, well I was rather tottery at that time, but I was alright, I get stronger each time...sort of learnt too, by what others were doing. I think you learn a lot that way."

"One of the things that the other people spoke about was comradeship. That there were others who had had the same thing and they felt that it was good to get amongst them and talk and find out that they were at different stages of recovery. I felt that what they were saying was; I can't walk to my letterbox now, but that person can walk down to the end of the street, so I will be like that one day. And so it gave them hope. I think that that was what they meant by comradeship, because we didn't cuddle or hold hands or anything like that".

2. individuals learn how to "operate" the system:

This prolonged and informal contact with health professionals had the additional effect of demystifying, to a degree, the medical structure and the world of health care. Of course, this demystification was limited by the fact that rarely, if ever did a doctor participate in the classes. However limited the effect was, it was still important. Almost in spite of themselves (for it was never an explicit intention), the programme structure demonstrated to participants that there was information that was accessible and meaningful to laypeople. Respondents learned, for instance, that there were dietitians in the hospital who would talk to them, or that they could make an appointment to see the occupational therapist. In short, participants learned how to operate the medical system. The following quotations provide some case examples of this:

"WHERE WOULD YOU GO TO GET ANSWERS TO (a variety of topics)?"

"I would go to the dietitian and ask"(on diet)

"I would ring the nurses in the coronary care unit"(worries about the heart)

"I reckon that those girls in the physiotherapy department would tell me"(related to exercise)

Those who participated in the programmes were better able to extract information and get access to advice than were those who did not. Programme participants were more confident that their worries or questions were legitimate and that they were entitled to answers. The individual rehabilitation group demonstrated inferior recall of information received while in hospital. While all respondents could remember that there was an abundance of material, the actual information was often forgotten. Thus, those who participated in the rehabilitation classes had the advantage that the information could be reinforced at intervals after discharge:

"Well, I wasn't quite myself while I was in hospital. Perhaps I couldn't absorb as much. You are not conscious of so much. You are more conscious of what the illness is doing to you, more so than when you get out, what you are and aren't going to be able to do, you don't think about that. But as time goes by you get over that initial bit and you can think about other things. See, questions don't really occur to you while you are in hospital, and you tend to forget a lot that you were told in there".

The weekly contact provided by the classes gave respondents a forum where they could exchange information with others. This enabled the reinforcement of information given while in hospital. The classes also provided a check; those who may have missed out on material in hospital had a second chance to receive it. Thus, the number of individuals who received educative material was higher in the formal rehabilitation groups than it was in the

individual rehabilitation group.

3. reinforcement of information teaches a method of coping:

Without exception, respondents commented positively on the ready availability of printed information while in hospital. In a minority of cases verbal information was also received. It was found that there was quite a high degree of variability in the quantity and quality of information (all types) given to individual respondents. Differences in the amount of information given was found to vary according to the social characteristics of the individual concerned (for example, age and sex). These findings have been discussed in detail in Chapter 2. The suggestion here is not that all individuals should be treated in a uniform fashion. Rather, the contention is that the specific manner in which individuals are treated does have an effect, and that this effect is ongoing long after the individual leaves the confines of the hospital. That is to say; the nature of the interaction between patient and professional, far from being neutral in effect, can have a pervasive influence on the subsequent experiences of the individual. Thus, care should be taken to ensure that patients are not treated on the basis of their social characteristics and the assumed needs or problems that these are taken to imply.

Formal rehabilitation, by requiring at least one face to face personal contact hour per week between individual and

practitioner, ensured that some minimal amount of information was regularly passed on. The value of this interpersonal communication was primarily that information that had previously been discussed in general terms was made relevant to the individual's own specific situation. When specific problems arose, the individual could see how they were handled. Thus, respondents learned a method for coping that could be applied to a wide range of issues. This method was all the more valuable because, having learned it from the "experts", respondents felt that it was safe, and that it would work. Here again, the need for reinforcement once the hospital phase is over can be clearly seen:

"Yes, yes. I knew that (physiotherapist) was there, it was like a calm. I had a turn, it was quite painful and it did fill me with a little bit of fear. It didn't ease up all morning. I took two of the little pills you put under your tongue, they didn't work. But (physiotherapist) said to me that I could have taken more, but I didn't know that then. I came up here the next day to the classes. (Physiotherapist) looked at me and she knew that there was something wrong, and she made sure that I told her. She told me to go and lie down for the afternoon, and she told me to make an appointment with the doctor".

"They make sure that you don't feel like you are putting them out. Even if it is only for reassurance".

"Yes, I learnt a lot about being able to diagnose, if you like to say it, my pulse rate, and angina symptoms through over-exertion. My awareness of my own capabilities has improved".

4. exercise:

Exercise was a major component of all three rehabilitation programmes. At the second interview twenty of the thirty respondents from the rehabilitation classes were regularly setting aside time to do exercise specifically intended to improve their health. Many respondents commented that, rather than being onerous, this exercise made them feel better in themselves physically. They also noted that it provided them with a regular source of relaxation; this was a time when they shed all their daily obligations, and did something that was entirely self-directed. A transformation of considerable degree had, thus, taken place in their attitudes. The experiences of the last three months had transformed health from a passive to an active state for these individuals. The other ten respondents who had not continued with exercise felt that they were getting enough exercise in their daily activities. These individuals generally saw the exercises as being part of the initial treatment for a heart attack which finished when the classes finished. That is; they did not consider that the exercises were designed, in part, to promote a more generally healthful lifestyle.

Three respondents in the individual rehabilitation group had set aside time for exercise on a daily or weekly basis. The other seven were either not aware that exercise was something

that individuals who have had heart attacks did, or felt that their work ensured that they got satisfactory amounts of exercise.

The significance of rehabilitation programmes in establishing a personal routine of exercise can be clearly seen from the above results. Even if the physical value of exercise for those who have had heart attacks is disputed, the testimonies of the respondents in this study bear witness to the value of exercise as a method for increasing levels of personal well-being.

5. social contact:

Contact with other participants was never maintained once attendance at the classes had ceased. Thus, at the time of the second interview only those in the non-hospital based programme still had contact with others. Although not all respondents felt that they benefitted from social contact, there was a significant number who did. For these individuals, contact with others abruptly ceased at the conclusion of the programme.

The benefit derived from contact with others was twofold. By listening to others talk, respondents realised that "you are not alone what is bothering you is also bothering others". "You are not peculiar". The affirmation that the worries were legitimate and acceptable was extremely important. In a

disturbing number of cases there was a very real fear of being seen as a hypochondriac. The second value of social contact became progressively more important the further away from the heart attack the individual got. It appeared to be extremely difficult for family and friends to sustain an interest in the heart attack and subsequent recovery. The rehabilitation classes, with the social contact they afforded, provided individuals with an outlet where the achievement of each small goal could be applauded and seen as significant. The rehabilitation classes, especially the long term one, gave respondents contact with a group of people who had continuing interest in their small day to day victories.

6. some concluding comments about rehabilitation:

Although rehabilitation will be discussed in some of the following sections, a few brief concluding remarks about the concept of cardiac rehabilitation will be made here.

The first point to be noted is that organised cardiac rehabilitation is neither essential nor valuable for all those who have had heart attacks. Some individuals experience no adverse effects from the heart attack and, upon returning home, resume in large degree, their previous lifestyle. However, this occurs in very much a minority of cases. Because it does not yet seem possible to predict who will benefit from rehabilitation, the preferred course of action is to give all individuals the

opportunity to participate in a programme. It was also apparent from this research that effort should be expended upon providing a similar service for families, especially spouses. The experience of families is discussed in more detail below.

There is a tremendous diversity in the nature of rehabilitation programmes. Precisely what type of rehabilitation is offered depends largely upon the priorities and aims of those providing the service and upon the resources available. As has already been shown, the consumers prefer some post-discharge contact to none at all. Their major areas of concern focused on the need for ongoing educative material that is both accessible and understandable, a place where they can do monitored exercise (this fulfills the need for some compulsion, and for health professional control and legitimation), a forum where they can ask questions and have some contact with others who have had similar experiences.

There appeared to be no reason why such a service should be provided by a hospital. Indeed, there is much to recommend some form of self-generating group run by the individuals themselves. However, some initial input by hospital staff and other health professionals is essential if such programmes are to be successful. Only they can provide a monitoring service and medical advice, and without their legitimation it is unlikely that any such group would be able to survive in the community. In addition to this, it is important that rehabilitation be seen

as part of the health service. This type of programme represents an attempt to rectify the current imbalance within the medical system which focuses upon bodies and diseases to the almost total exclusion of the people who inhabit the bodies and experience the diseases.

Medical Contact.

Medical contact is the reverse side of the rehabilitation coin. Opponents of cardiac rehabilitation cite the frequency and quality of individual-G.P./specialist contact as conclusive evidence that rehabilitation is unnecessary. It is important, therefore, that the precise nature of medical contact be critically examined.

As stated above, it is often argued that family doctors provide sufficient contact, support and advice to meet most of the heart patient's needs. This study found no evidence to support this contention. Although G.P.'s often see themselves in the role of the "old family doctor", this image is shared by only a very small minority of patients. Thus, even if general practitioners are competent enough to give the required socio-emotional support, because patients do not see the their doctor in this way they will not seek nor will they accept such support from this quarter. It was found that respondents saw the

different health professionals with whom they had contact in quite clearly differentiated ways. In this context, the G.P was seen as occupying a specific role that carried with it a small number of well defined activities. These activities related to such things as; providing regular check-ups, prescribing and altering medication, and referring patients on to specialists for more serious problems:

"My doctor is an expensive pill dispenser. When I need more pills I go and get a script from him. I don't think he is competent enough to do anything else."

"...and you don't feel like making an appointment with your doctor to ask, um, am I doing too much. He would probably think, Oh stupid woman. There is nowhere actually to go to ask about these things."

This respondent belonged to the individual rehabilitation group, and her comments provide a striking contrast with the response of the following respondent to the same question. This respondent had participated in a group rehabilitation scheme.

"WHERE WOULD YOU GO TO FIND ANSWERS TO (a number of small issues)".

"Oh, if I thought I was overdoing it or something like that, I would ask one of the people at the club, that's what they are there for, to help with that sort of thing".

If the G.P consultation and cardiac rehabilitation schemes are compared, the inadequacies of the G.P services, as they are currently constituted, is obvious. Rehabilitation classes occur at least once weekly, and last for approximately an hour at a time. In no case did a G.P consultation occur with this frequency nor duration. The nature of the interaction in these two situations also differs markedly. G.P consultations are

primarily one-way and formal in nature. In contrast, the interaction between respondent and the health professionals involved in the programmes emphasised a two-way exchange, and an informal structure. Thus, rehabilitation differed from other health professional contacts in several important ways. The interaction was more flexible in nature, each individual contact period was longer, and these meetings occurred with far greater frequency. This enabled participants to relax, open up and feel able to discuss a whole range of issues that they would not have done in a more formal, rigid setting. The relationship between individual and professional, then, came to resemble other social relationships; it began to fit into, and become part of, the lives of all involved. It is from this solid base that personal support developed:

"You can't just ring up your G.P and make a five or ten minute appointment for sometime next week, just to get support or reinforcement. I mean, by next week you may not even need it. And when you get there, what are you going to say? But you can go along to the classes, they are more like friends there, you feel that they are really interested in you as a person, not just a sick heart".

Social contact is another area where the G.P service does not have the same scope as rehabilitation. An important source of information on coping strategies is other individuals who have had the same experience. Unless the G.P her/himself has also had a heart attack, this valuable avenue for learning is lost. It is for precisely this reason that social contact is built into many rehabilitation programmes.

A final area of difference between the G.P. consultation and rehabilitation, is the nature of the activities engaged in in each of the encounters. In Chapter 2, health as an active and passive state was discussed. The emphasis of rehabilitation is very much upon involving respondents in their own recovery, in giving them the ability to do something about their own health. Thus, rehabilitation classes focus upon teaching exercises, discussing home activities, and passing on information to better facilitate healthful behaviour. The G.P. encounter rarely possesses any of these components. It is usually conducted in a surgery where both participants will usually remain seated (unless it is a stress test), and the emphasis is very much on the clinical aspects of medical care. In fact, respondents themselves often commented on the way in which the G.P. encounter focused on the illness, while the rehabilitation classes focused upon health. This positive focus became extremely important for a number of individuals who were struggling to cope with post-attack depression and fear.

In concluding, there is no doubt that the G.P. service plays an important part in the post-release phase. However, it is equally clear that this role is not rehabilitation. Respondents displayed a considerable reluctance to seek this type of service from their general practitioners. The structure of the G.P. service is such that it precludes the major features of a rehabilitation programme from being easily accommodated within its framework. Thus, medical contact, alone, in the post-release

phase cannot provide for the wider social needs of those who have had heart attacks.

Keeping to Changes.

Introduction

For many individuals the heart attack resulted in some quite basic changes in behaviour. Chapter 2 looked at the range of behaviours which were identified as requiring modification or elimination. Individuals interviewed displayed differing degrees of success in handling these changes. While success or failure was undoubtedly, in part, attributable to individual personality factors, it was possible to trace some more general determinants that had a bearing upon individual success in changing behaviour.

The ability of the individual to keep to the required changes had a definite and significant effect upon the quality of life and general well-being of the individual. Behavioural changes required a new way of looking at life, perhaps even the setting of new goals. In other words, there was a context to the changes that were required of the individual; they did not occur in a vacuum. Failure to adhere to these alterations, thus, can result in wider feelings of more general failure. For this reason, it is important that realistic goals be set when embarking on a programme of lifestyle change, for the negative

results of failure can be quite devastating.

Major Determinants of Failure to Adopt Changes.

The need for changes first becomes apparent during the individual's stay in hospital. The manner in which changes are discussed, the emphasis placed upon them, and the support received in beginning these changes all have an influence upon subsequent long-term success or failure.

Smoking and diet are the two major changes required of individuals. The conflict between dietary advice and food provided by the hospital was discussed in Chapter 2. However, several points raised in that section bear reiteration. Respondents found it difficult to take seriously advice to reduce the fat and cholesterol content of their diets when the food served by the hospital was high in both. While understanding that it was desirable that they do so, they generally felt that

"It couldn't be that important or else they would have fed us differently".

Ability to maintain dietary modification was closely linked to the specificity of advice given and the degree to which it was reinforced once the individual left the hospital. This was all the more significant if the individual was the family member responsible for food purchase and preparation. In those instances where the individual did not regularly perform this

task it was important that the family member responsible for cooking was provided with detailed information on food preparation. As discussed in Chapter 2, it was not sufficient merely to inform respondents that they should adopt a low fat diet.

Smoking cessation proved to be an area of major difficulty for many respondents. In-hospital advice to give up smoking took one of two forms. Hospital staff either adopted a highly aggressive approach, berating individuals to stop immediately, or they displayed a very liberal attitude, reminding respondents that it was, after all, their choice, that they were free to give up or to continue. Neither approach was particularly successful in the long term. Responses to the first approach personalised the issue:

"...(the doctor)... has just got a thing about smoking. I can't believe that it is all just smoking, I think ...(doctor)... just doesn't like it"

While respondents interpreted the second approach as saying that smoking wasn't that important in the causation of heart disease:

"Well they said that it was up to me. If I wanted to I could, but if I didn't then I didn't have to. I don't want to, so I am still smoking".

The function, or role, which the activity had served in the life of the individual exerted a considerable influence upon the ease with which it could be discarded or altered. Once again, smoking provides a good illustration. Among those who smoked

there was a group who had wanted to give up for some time prior to the heart attack. For this group, the heart attack was a positive experience in that it provided them with sufficient motivation to discard the activity.

"The night I had my coronary was a night that I won't forget. I think the pain of that night put the fear of god in me. One good thing tho', it's made me give away smoking. Oh, I had wanted to do that for years. I had given it up before, but always gone back to it. But now there's no way I'm going back to it. I suppose, in a way, it was the best thing that ever happened to me".

Dietary change, if it was accompanied by early and significant weight loss also appeared to have this positive effect on the way the heart attack was viewed.

In marked contrast were those cases where smoking, or food consumption played an important role in the daily life of the individual. There were, for instance, those for whom smoking constituted virtually the only pleasurable activity left after the heart attack. These respondents were discussed briefly in Chapter 2. In these cases, giving up smoking was an extremely traumatic experience. There were others for whom smoking constituted a device for coping with stress. Here, abandoning smoking required the learning of an entirely new method for coping with stress, usually for which the individual received no support. The attempt to give up, in itself, often added to levels of stress, a thing which individuals were told to avoid. In cases such as these, the intermittent resumption of smoking was a common occurrence. The sad irony of these cases was that resumption also increased stress levels, for the failure to keep

to changes carried with it heightened feelings of guilt and failure. This Catch-22 situation often initiated a cycle of depression which was virtually impossible for the individual to break. This aspect of behavioural change is discussed in more detail in the second part of this section. Clearly, then, it is important that the social context of the individual, and the interface between this context and the activity requiring modification be taken into consideration in any attempt to help the individual make such changes.

The third determinant of the ability to adopt behavioural change relates to the ease of access which an individual has to support structures. Ready access to support frequently facilitated the transition to new behaviours; it was also of considerable importance in their maintenance. It is in this area that the value of rehabilitation again becomes obvious. Because the heart attack and subsequent experiences are usually individualised by respondents and their families, the rehabilitation classes constitute an important forum where individuals can both give and gain support for the changes being undertaken. Rarely were dietary, smoking, exercise and other changes undertaken by families:

"Of course having my family all eating the same food as they always have doesn't help. And it's quite a nuisance having to cook separate meals. I don't know how long I will keep on doing it."

Similarly,, those who lived alone often found it difficult to institute behavioural changes:

"I think it is because I live by myself. I am at home and there is no-one there to keep me in check. Being weighed in at the classes helps a lot though, coz it makes sure I don't overdo things during the week".

Support mechanisms were all the more valuable when the individual encountered problems. Stressful or difficult situations subjected individuals to inordinate amounts of pressure, and in these conditions it was not unusual for respondents to consider, or actually to resume the behaviour. Where there were others on whom the individual could call for support, it was less likely that they would return to the old activity.

The final major determinant of the ability to keep to behavioural changes was the degree of involvement required in the activity concerned. For instance, individuals who were regularly involved in the preparation of food, and therefore, who had well established behavioural routines for this activity, experienced more difficulties in altering dietary patterns than did those who did not do the cooking. In these instances, detailed information on how to make changes would provide tremendous practical support in the effort to sustain the alteration.

The Wider Effects of Behavioural Change.

As was suggested earlier in this section changes do not occur in a vacuum. It is important therefore, that the wider context of the changes be examined. For it is certain that this context has an effect on the sustainability of any given change.

1. illness as a positive experience:

When changes were relatively easy to achieve and there was little or no residual damage, the overall effect of the heart attack was positive. Being able to "do something" ones-self that had a bearing on the course of the illness/recovery created a sense of control and security. This, in turn, had a marked and positive influence upon the overall outlook of respondents. The feeling of control and involvement that emanated from active participation in the illness and recovery process had a significant and positive influence upon respondent's attitudes. This was especially evident at the second interview. Insecurity was greatest in those who had received the least information, who were not involved in any post-release programme and who had not succeeded in adopting behavioural changes. Once again, women and young men fared the worst. The middle-aged men (who fitted the image) were more competent in soliciting information and were also more frequently required to alter a number of activities. The net effect of these factors was that these men experienced a higher degree of involvement in their illness/recovery than did

the other groups. The response of health professionals to those who had difficulty keeping to changes varied depending upon the social characteristics of the individual concerned. Those who did not fit the "image" were more likely to be labelled as having psychological problems than were those who did fit. Conversely, the group that did fit the image and had difficulty in keeping to changes and were more likely to be treated sympathetically than were those who did not conform. The effect of compliance difficulties is dealt with more fully below. It appears that by involving individuals in their illness/recovery in an active way, a positive component can be introduced into an experience that can be not only negative, but also devastating in consequence.

2. illness as moral transgression:

For those required to effect one, or a number of behavioural changes, and who found this difficult or impossible to achieve, the heart attack and any subsequent complications took on the character of a punishment. During the first two to three weeks after discharge, behavioural changes were usually sustained without much difficulty. However, as individuals resumed progressively more of their old activities, differences became apparent in ability to keep to changes. Again, these differences clustered along age-sex lines. Those in the group who conformed to the image were less likely to see their heart attacks as punishment. Because the heart attack was seen as an individual problem, family support in attempting to change was often

minimal. Lapsing back into old behaviours was usually prompted by a crisis or by a more than usually stressful situation. Rarely was it simply a matter of disinterest in continuing with the changes.

"Then of-course I ended up smoking again because I was out working one night and I went into a restaurant in town and I lost my wallet out of my back pocket with about \$500.00 in it. So you can imagine how I started to panic over that. So since then I have started smoking again. I suppose I am disappointed in myself that I have started smoking again. But I have real depressing days when I don't feel like doing anything."

In some instances the heart attack and subsequent restrictions, when combined with the home context produced enough stress to make coping with lifestyle changes virtually impossible:

"You see I packed in work just before Christmas because I was feeling so tired. They now seem to think that it was the drugs that were making me tired, not the work. And it is quite a while since I have been constantly at home, I have never been a housewifey person. I would much rather be working. I don't like housework, but the family don't like it when I am working. When I am at home I smoke a lot more than when I am out, I think that it is the boredom."

The most common medical response to such difficulties was to interpret the problem in psychological terms. This involved attributing the inability to comply to some underlying individual inadequacy. The most common treatment in these instances was anti-depressant drug therapy and other medical forms of psychological intervention. In no instance was any attempt made to come to some understanding of, and then help the individual to modify those aspects of the social context that were causing the

problems. The women who had problems in adjusting were more frequently treated in these terms than were the men. Some effort was usually made to alter the nature of the paid work that the men were performing. No attempt was made to alter the damaging or stressful aspects of the home environment; a primary source of stress for many women.

In all cases, respondent's reactions to the inability to continue with changes produced very obvious feelings of guilt. It also produced a belief that they deserved to stay ill and depressed because they had not managed to achieve the required changes. It should be noted here that the changes usually required of individuals were far from trivial. Alterations were most often required in very basic aspects of individual's lives. These commonly required the unlearning of old habits that had been performed on a daily basis for most of the respondent's adult life. These then had to be substituted with new, unfamiliar activities.

The lasting impression of many respondents was that they somehow deserved their heart attack; that it was their fault. While it may be argued that individual behaviour does play a role in the development of a variety of illnesses, including heart disease, this in no way supports such a belief in direct individual culpability for the illness. There are a number of implications of such a belief and these require some examination.

Perhaps the most important implication of this attitude is that it assumes that individuals have equal and sufficient access to information about the causation and prevention of disease. If individuals do not have such knowledge it is difficult to understand how they can be equally responsible for becoming ill. As was outlined in the previous chapter, only two respondents were told that they were likely candidates for a heart attack, the remaining thirty-seven were taken by surprise by the attack. The two individuals who were told this made the prescribed changes in their behaviour at the time of the warning. When questioned as to whether they felt that their lifestyle, prior to the heart attack was unhealthful, or likely to result in a heart attack, very few respondents answered in the affirmative. To be sure, many knew that smoking was currently under attack as an unhealthful activity. However these individuals also felt that:

"Smoking is blamed for everything nowadays. I don't see how it can do all those things to you".

In other words; the reasons why smoking is unhealthy had never been adequately explained. Thus, it is difficult to justify individual complicity in illness when a large proportion of the information on health and illness is systematically withheld from the population at large.

The apportioning of blame for illness is frequently reinforced by medical personnel. It was found that hospital staff would take on the role of a moral arbiter, and indicate that they too held the individual to be, at least partially,

responsible. This became especially apparent when individuals were directed to give up activities such as smoking. Here, requiring the suspension of what were, in many cases, pleasurable activities, came to almost resemble the prescribing of penances for sins committed. This association became all the more powerful when the reaction of medical staff to failure to comply with the changes was observed. In these cases, the individual saw her/himself, and was seen by others, as being inadequate; a "weak person" who would not do as s/he was told, and as therefore deserving the illness. The reasons for the failure were ignored, as were the effects of the guilt which it produced. Returning home after a heart attack produces many pressures to adjust and cope. The pressure that guilt which the failure to change induces was often an unnecessary and additional burden.

Long-Term Personal and Social Consequences of the Heart Attack.

Although modifications to individual lifestyle are the more easily measurable, the heart attack does have other long-term consequences for both individual and family. These may be termed the social and personal effects of the heart attack. These consequences are more intangible and are, therefore, more difficult to obtain information on.

Many respondents were reluctant to discuss the effect which the heart attack had had on them personally. Furthermore, because this is such a personal area of individual's lives, it was felt that probing in the interview should be circumspect. Thus, it was not always possible to obtain information on the nature of these effects. Fortunately, however, most respondents would make reference at some point in the interview to the effect which the heart attack had had on them, and on the way that they now saw themselves. In this way, a lot of the information which has provided the basis for this section was gained in an indirect fashion.

The reluctance of individuals to go into this area in any detail is, in itself, revealing. It was felt that this might be indicative of two things. At first it was thought to reflect what might be considered to be almost a cultural premise: that as a society we do not readily talk about ourselves and our feelings. Indeed, given such a structural constraint on this type of interaction, individuals have very little experience with verbalising their feelings. There was a certain type of response which seemed to be indicative of this type of situation:

"Oh, I am just going along quietly, you know, not overdoing things".

"I think that as long as I am careful, it shouldn't have too much of an effect".

By referring back to the practical issues of what they can do to avoid another heart attack, individuals avoid having to expand on

their feelings. In this way, the discussion of the effect of the attack is limited to those pragmatic and more obvious areas of their lives.

The second possible reason for this reluctance to discuss feelings about the heart attack emerged from the interview itself. Although it was not always possible to get respondents to answer specific questions on this issue, they would frequently express feelings of vulnerability and fear at other times during the interview. Comments such as:

"It made me think a lot more about things".

"I still feel vulnerable"

"It does sort of, um, frighten me at times - you know?"

"You worry about what on earth has happened to you".

were very common throughout the second interview. It seemed that most individuals were familiar with these feelings. Perhaps their reluctance to talk about their feelings was indicative of the long-term effects of the heart attack. They were, in short, still reacting to it, and often were quite shocked at the depth of this effect.

The responses of those individuals who could discuss their feelings and personal reactions to the heart attack most frequently expressed fears of becoming an "invalid" or a "burden" on their families.

"Not in itself. It didn't frighten me as such. I am not worried if I die. The only thing I was worrying about was (wife's name). How it would be if I couldn't do anything. Would she have to look after me".

"I do not want to be a nuisance or a burden to anyone. This having to sit around and be neither use nor ornament. It could get very depressing. It hurts me dreadfully to think that I am being a nuisance to them. That is the way that it has affected me. The thought of my children dropping everything for me regardless of the consequences, that upsets me".

There is a strong resemblance between these feelings and those expressed in the first interview about not want to be seen to be a hypochondriac. These two factors combined to put individuals under enormous pressure to 'carry on' after the heart attack. These feelings were also significant in that they cut across the age-sex cleavages that have been evident in other areas; all those who were able to discuss these feelings expressed fears of becoming an invalid and being a burden on others.

The introduction to this chapter noted that two indepth interviews with each respondent enabled information to be gathered that rarely comes to light in traditional health studies. There was another general group of responses to the questions that related to feelings about the heart attack. These focused upon the limitations imposed by the illness. Most studies involving individuals who have had coronaries ask questions about the extent to which previous activities have been curtailed. However, they do not, as a rule, ask questions about how individuals feel about this. Thus, the limitations imposed by the illness are seen as relevant, but the way that individuals

feel about such limitations is not.

"He can drive now, and is starting to help with the lawns. That hurt him a lot; that I was out mowing the lawns and going to work and looking after him. Those sorts of things perhaps hurt him more than his illness in some ways".

"WAS THAT VERY HARD FOR YOU?"

"I used to do all those things, and then she had to look after me and go off to work at the same time. It did really get me down".

"It is when the spirit wants to keep going, and you just can't".

"That awful feeling of utter exhaustion. I was never like that before. I have to do everything so slowly now".

"It's having to slow down so much. I find it so difficult. When I think about doing things slowly it's O.K. But when I'm actually involved in them, it's so hard. It just isn't me".

You have to see yourself so differently. It really is hard - quite a shock to the old system. You feel the same about yourself, but, of course, you're not the same anymore. So you start to see yourself as, um, older? or something like that. Changed, but still sort of the same, I guess. It really is quite strange at times".

These responses all point to the fact that the limitations involved changing the way that individuals saw themselves. It was not the restrictions per se that had an effect. Rather, it was what these restrictions involved in terms of re-orienting the conception of the self. Thus, keeping to limitations was not just a simple matter of obeying the rules. Staying within restrictions involved a complex process of learning to see ones-self in a new way. This "new" self was often seen as a very much diminished self. For example, one of the above respondents

equated it with ageing.

Three months after the first interview the heart attack was still a significant part of the individual's self-image. In this context, it should be noted that the temporal relationship between the second interview and the heart attack varied considerably. In some cases it was anything up to 12 months after the attack. Thus, the heart attack continues to have an influence on an individual for a considerable length of time.

The heart attack also continues to play a significant role in the lives of families for a considerable period of time. At the second interview spouses still expressed frustration and anxiety over the way that they had been excluded from the hospitalisation.

"I never got anything from them. All I found out was secondhand information from (husband's name). They just never told me anything. I was quite upset about that - I needed to know and I still do. I felt like they thought that it was just him and it didn't have anything to do with me. But it was his life and I was terribly worried".

"I think that there could have been a lot more talk between the patient, the doctor and the wife or husband. Get them in and have a good going over; have a good session. Also, between the two of you, you can ask the doctor a lot more questions than you can when you're alone".

The long-term effect of being excluded from the hospitalisation was that uncertainty and insecurity became almost a routine part of the families' lives. There was a continual tension between wanting to protect and regulate the ill member's

life so that another heart attack was avoided, and not wanting to be over-bearing or over-protective. This usually resulted in strenuous attempts to "act as if nothing had happened", covert attempts to "keep an eye" on the individual to "make sure that everything is O.k.", and a lot of quiet worrying. All parties involved were well aware that the heart attack was potentially life-threatening and that it could strike again with little or no warning. This often led to the feeling that, as one spouse put it; "I am living on a time-bomb. But I'm not supposed to admit it or act like it's even there".

Although the rehabilitation programmes served many positive functions for participants, their value for family members was virtually non-existent (the exception to this was the non-hospital based group). Spouses rarely attended the classes because there was nothing constructive for them to do while they were there:

"There wasn't much point in her coming along. She would have been bored".

There is a sad irony to this situation; for the first four weeks after leaving the hospital spouses often drove participants to the classes. One wife even sat outside in the car for the entire duration of the programme.

The worries and questions of families, thus, went largely unanswered. Even for those patients who did not participate in a group scheme there were the occasional contacts with a doctor.

This provided the individual, in theory at least, with the opportunity of asking some questions and perhaps getting some reassurance. Family members did not even have this source of support. In fact, many spouses felt that if they did contact the doctor or the coronary care unit, the response would be that they were merely over-anxious or nervous. Thus, there appeared to be little point. The net effect of this was that family members usually endured their fears in complete isolation. Often they felt that they couldn't even share their fears with the ill person for fear of upsetting or angering them. Living with someone who has had a heart attack can be an isolating and frightening experience for some considerable time.

Conclusion

The value of cardiac rehabilitation became progressively more evident as time from the heart attack elapsed. Support was reasonably forthcoming from all quarters in the early phases after the attack but it dropped off sharply after this initial period. Rehabilitation classes provided the individual with an outlet where feelings and experiences could be discussed. Because many questions and problems do not arise until after the return home, it is important that there be a consistent source of post-discharge information available to both individuals and their families. These questions are usually small day to day

worries which respondents feel do not warrant a doctor's attention. Thus, if there is not a source of information (such as that provided by the rehabilitation programmes) the questions go unanswered. Contact with others who have had heart attacks is instrumental in increasing confidence levels. It also provides a support and information base which is credible to participants; it comes from others who have had similar experiences.

The second interview demonstrated that a heart attack does have an ongoing influence upon the lives of all associated with it. The extent of this effect, of course, differs according to those individuals involved. The evidence of this study, thus, contradicts much of the accumulated evidence of other investigations of heart disease (for example, that contained in the ARCOS(1982) and Burrige(1981) reports). This evidence suggests that a heart attack has little or no continuing impact on individuals beyond the first six to eight weeks. However, this thesis has found that to be the case in only a minority of instances.

It has also been found that the experience of a heart attack differs in a reasonably predictable fashion given the general (age/sex) characteristics of the encumbent. The fact that individuals do experience the heart attack and hospitalisation differently was not acknowledged by hospital staff involved in the care of coronary patients. Neither did staff take cognizance of the differing social contexts from which their patients came.

This profoundly influenced the manner in which the heart attack and recovery was experienced.

The findings of this study provide general support for existing sociological analyses of health/illness. That is, the conventional response to illness is predominantly a medical response. As such it takes little or no account of the wider social context in which illness occurs. It is interesting to note that the most controversial aspect of coronary care, namely cardiac rehabilitation, represents an attempt to break with this exclusively medical emphasis and it is also the aspect of care about which most controversy exists.

CHAPTER FOUR:

The Theoretical Interpretation of Findings.

The Structure of this Chapter.

Chapter 4 is concerned with an analysis of the findings presented in Chapters 2 and 3. It is divided into four substantive sections:

Introduction.

This section introduces the major concepts to be used in the analysis of the data presented in Chapters 2 and 3. The major concept is the ideological perspective. This is part of a wider structure labelled the frame of reference. This section also introduces the notions of conflict and conflict management which are pivotal to the analysis of the ideological perspective. The key concept; ideological perspective, is also defined in this section.

Ideological Perspectives.

This section explores the general nature of patient and health professional ideological perspectives. This provides the basis for the next section.

Analysis.

This section has three parts. The first two sections deal with an analysis of medical and patient ideology. This analysis builds upon the general information presented in the discussion of Ideological Perspectives. The final section constitutes a case study. This looks into the experiences and ideology of

women as heart disease sufferers. One of the major findings of this research was that there was a very specific imagery which surrounded the whole heart disease area. This imagery was found to have a profound effect on the experiences and reality of all the participants in this field. Another important aspect of this imagery was that it excluded certain groups. One of these groups was women. Thus, this section provides an in-depth study of one group of "deviators" from the image.

Conclusion.

This section provides some synthetic comments which attempt to pull out the main theoretical strands that have emerged from the analysis.

Introduction.

This chapter is concerned with analysing the material contained in Chapters 2 and 3. It is intended that this will enable some theoretical conclusions to be drawn about the experience of illness generally, and the experience of a heart attack in particular. A pervasive theme which was noted in the previous two chapters was the image of a heart attack victim as a middle-aged, middle class male. This "ideal type" in no way corresponds to the reality of who has heart attacks. The findings of this study would seem to suggest that it is, in fact, an ideo-

logical framework which is used by health professionals in their treatment of heart attacks. Although individuals conform in varying degrees to this image, they all subscribe to it prior to the heart attack. That is; they believe that only middle-aged, middle-class males have heart attacks.

The fact that individuals from variety of social groups may be identified as having a heart attack, and that each individual interprets that experience differently, suggests that a heart attack is more complicated than the ideological perspective of the health professionals implies.

In this thesis the notion of a frame of reference has been abstracted from the subjective understandings which individuals use to structure their experiences, their behaviour, and so on. There is considerable evidence to suggest that the notion of a frame of reference is useful in the attempt to understand the motivation behind behaviour, the nature of the behaviour that results, as well as the way in which individuals understand and structure their experiences. Berger and Luckman(1972) talk about how people construct social order and yet construe the reality of everyday life to exist independantly of themselves. In this way individuals reify their understandings/conceptions of reality-their construction of reality takes on an existence independant of themselves. In the health setting, Graham and Oakley(1981) use the frame of reference to analyse the differing understandings and expectations which mothers and their doctors

have of pregnancy and child-birth. Stimson and Webb(1975:136-7) discuss the idea of a professional ideology which is used to refer to "the system of beliefs that doctors hold about man(sic), disease and the treatment of disease"(ibid:136). It is used to refer to the orientation which health professionals have to patients, and how patients should behave towards them, the health professional's position in relation to them as patients and the health professional's exclusive ability to define what an illness is. Balint(1971:216) has termed this the doctor's "apostolic function". He adds to the notion of professional ideology a discussion of the way in which its practical effect(the professional ideology) is to induce the patient to adopt the doctor's standards and thereby accept his orientation toward their problems. Finally, Comaroff(1977) discusses the "paradigms" which differing health professionals have of pregnancy. "Paradigm" is used in this context to refer to the differing conceptions which these groups have of pregnancy.

There are certain elements common to all these concepts. The notion of individuals as actors (in Goffman's sense of the word) and their resultant behaviour as being, at least in part, a product of the designation of that individual (for example, as patient or health professional) and the individual's relationship to significant others. These concepts also imply that any form of action involves a perceptual process; the individual must come to a subjective understanding of the situation before action is possible. These notions are by no means unique to this

thesis; indeed, they are well established concepts in their own right. What they do suggest, however, is that an individual has a "mental set" which is used to make sense of and structure situations and help define the role that that individual plays in them.

There are two further aspects of these concepts which need to be considered. The first is derived from Balint's (1971) discussion of the "apostolic function" of the doctor. This concept suggests a power relationship and the potential for conflict in doctor-patient interaction. The idea of the doctor-patient relationship as inevitably involving potential and actual conflict has been explored by Bloor and Horobin (1975) and Freidson (1975) in their analyses of the contradictory expectations embodied in doctor's definitions of "good patients". What this yields is both the notion of doctors having a set of expectations and understandings (mental set - see above) as well as the idea that conflict, and by implication, conflict management, is a routine part of doctor-patient negotiations.

The final aspect which must be considered is implicit in the work of Graham and Oakley (1981). It hinges upon the notion that these "mental sets" are located in a wider structure, which may be termed an ideological structure. This means that "mental sets" are not exclusively a product of the individuals who possess them. They are, in part, social phenomena. As such, they are influenced by wider ideological and political systems.

Any attempt, therefore, to analyse and understand the way in which individuals construct their experience must locate these "mental sets" in that wider social order. In the present study this involves trying to understand how patients construct the experience of a heart attack not only in terms of themselves as patients, but also in terms of their other social attributes.

Having looked at the way in which concepts similar to this idea of a frame of reference have been used, and the themes common to all these concepts, a definition of the way in which it will be used in this thesis can now be attempted. The definition of the frame of reference adopted by Graham and Oakley(1981:52) is composed of two parts; an ideological perspective and a reference group. This definition would seem to incorporate the key features of the above concepts. The ideological perspective may be taken to refer to the way in which individuals understand a situation. This, of course, includes the whole area of perception and subjective understanding discussed above. It must also include some reference to the social characteristics of that individual (female, male, doctor, patient). The reference group refers to a set of social relations. These are significant or powerful others who have the ability to influence the ideological perspective. The specific nature of the health professional and patient ideological perspectives will be discussed in the next section.

The fieldwork of this thesis focused primarily upon eliciting information which related to the way that individuals structured the experience of the heart attack. Thus, it only systematically gathered information on the first half of the definition; the ideological perspective. The primary focus of the following analysis will, therefore, be upon delineating the salient features of the ideological perspective, rather than upon the frame of reference as a whole. Some information was gathered upon sets of significant others (for example, a few health professionals were interviewed, and there were instances where it was possible to interview family members). However, this was not systematic enough to enable a full analysis of the role of social relations in the development, change and maintenance of the ideological perspective. There are instances in the following analysis where it is possible and appropriate to discuss the influence of significant others on the ideological perspective. Where this is the case an analysis of social relations is included. The foregoing should not be taken to suggest that social relations are not important; they clearly are. Rather, the emphasis in this analysis is a product of the emphasis in the fieldwork and the type of analysis that the resultant information has made possible.

The notion of conflict and conflict management introduced by Bloor and Horobin(1975) is an important aspect of the analysis of patient's and health professional's ideological perspectives. It embodies the idea that these perspectives do not merely exist in

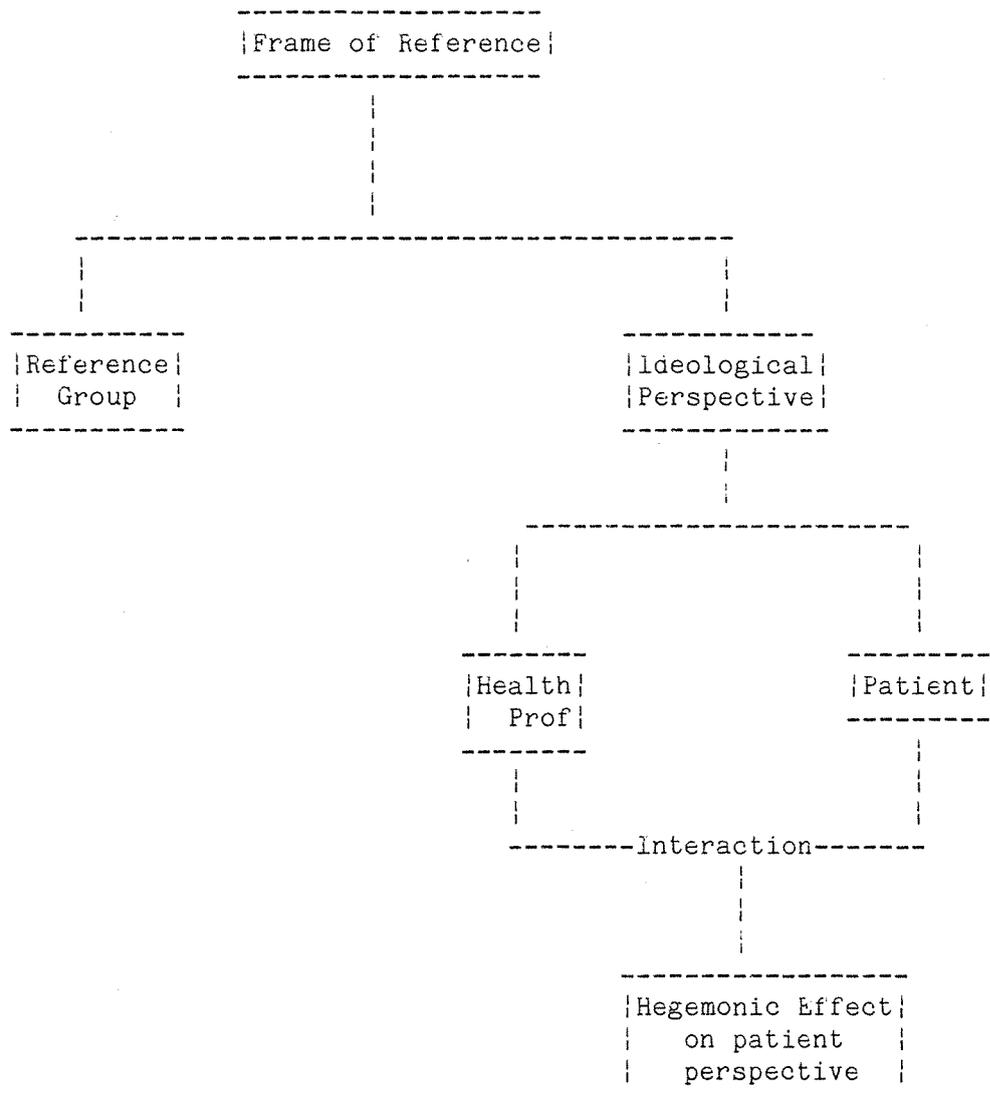
a vacuum. Rather, they interact and influence each other. In order to understand the ideological perspective of the patient (the task which this thesis has set itself) it is necessary also to understand the ideological perspective of health professionals. This is for two reasons; not only do health professionals constitute a reference group for patients, but they also possess the greater power of the two in the health professional-patient relationship. This means that while health professionals can influence the patient's ideological perspective, the patient does not have a similar ability to influence that of the health professional.

There is a similarity between this notion of conflicting ideological perspectives and such concepts as hegemony. Hegemony implies a situation in which one group successfully establishes its ideological perspective as dominant. In order to establish this dominance the powerful group must convince others to adopt its perspective even though it may be incompatible with the particular reality of the subordinate group. Hegemony also implies the active consent of the subordinate group. As such, it constitutes an extremely powerful method of social dominance and social control.

Usually hegemony is used in a marxist context (Gramsci;1971) to refer to class dominance. However, it is clearly relevant here for two reasons. Firstly, and in general terms, the field of health operates within a system of capitalist production(1).

Secondly, and as noted above, the doctor-patient relationship is a power relationship(2). In this sense, then, it is relevant to see health professionals and patients as constituting separate groups with conflicting interests. Each group has its own ideological perspective. However, the health professional perspective will dominate because this group is the more powerful. The ideological perspective of health professionals is important in another way. Because health professionals have managed to disseminate their perspective so successfully, patients with contradictory perspectives will alter or abandon their perspectives rather than challenge that of the health professional. their perspective successfully. The result is that when patients with contradictory perspectives encounter it, they will usually abandon or alter their perspective to fit more closely with that of the health professional.

Because patients are drawn from a cross-section of society it is difficult to discuss them as "a" group, which is what the concept of hegemony implies. The notion of an ideological perspective, on the other hand, enables the analysis of the differing perspectives within the "patient group". In this study young men(under 49 years), older men(over 50 years) and women were identified as three significant groups (in numerical terms)(3). This system of concepts can be summarised in the following diagram:



As noted above, a key dimension of the interaction between patients and health professionals is conflict and its management. Conflict refers to the existence of contradictory ideological perspectives. The clash between patient's and health professional's perspectives (for example, when an individual enters the hospital) results in conflict for the patient. This conflict is largely the result of the power relationship between health professionals and patients. If health professionals were not

able to exercise such, virtually complete, social control over patients, patients would not feel the need to conform to the health professional's ideological perspective. Conflict management, then, takes the form of patients altering their perception of reality so that it does not challenge the dominant group. In this way it serves to reinforce the status quo. Indeed, it can do little else because of the ideological and material advantages which health professionals as a group have over patients.

The manner in which conflict and conflict management operate can best be illustrated by looking at the major areas where this occurs during the hospitalisation period. The remainder of the introduction will deal with a brief outline of patient management of conflict during this period.

Prior to entering the hospital the patient's ideological perspective is untested. Unless the person has had some prior experience of heart disease it is likely that the only information that s/he will have received will have confirmed the image of a heart attack victim, and of the relevant behaviours which such a person should adopt. Once the heart attack has been diagnosed, the individual must fit her/himself into this imagery. This involves varying degrees of conflict depending on the extent to which the individual conforms to the image of a heart attack victim. This, then, is the first instance where the individual must handle or manage conflicting and anomalous information.

The second instance where conflict is likely to occur is external to the individual. If they do not conform to their own mental imagery, it is likely that patients will not conform to the health professional's imagery either. Thus, in addition to negotiating on one front, (that is, internally) the individual must manage conflict with external agents as well. Management of this external conflict has a profound effect upon the individual's ideological perspective. As has already been noted, health professionals constitute a powerful reference group for patients (see definition of frame of reference). It is this unequal relationship which makes conflict management so difficult. Experience of conflict means that the patient must either alter the perception of her/himself or the perception of the heart attack.

Prior to a heart attack, patients and health professionals share similar definitions of who has heart attacks. Because health professionals have power over patients, they will not alter their ideological perspective when confronted with a patient who does not conform. This means that such individuals are forced into a position where the only ground for compromise is the interpretation of the experience. Thus, such responses as; "it wasn't a real heart attack". Here, perception of the experience is altered so that it is more in line with the dominant ideological perspective. Patients who deviate from the image manage the conflict in such a way that they do not challenge the more powerful group. Those who do challenge the

health professionals ideological perspective are likely to be labelled "bad patients".

There is an additional dimension to patient conflict management. It centres around the fact that, although in the hospital it is appropriate to speak of the "health professional group", it is not so accurate to discuss patients as "a group". When an individual enters the hospital s/he does so very much as an individual. In becoming a patient, not only does the individual change roles, but s/he also moves into an entirely new social system. As with any social system, that of the hospital is punctuated by a series of power relationships (The nature of these power relationships has already been discussed). In this system the patient is conceived of as an individual but is treated by health professionals who act as a group (for example, for treatment purposes, it is irrelevant which doctor treats the patient and frequently a patient can be treated by several doctors during the same period of hospitalisation). Health professionals have a set identity as both a social and an occupational group. That is; they have a subjective awareness of themselves as a group and distinct from all other participants in this system. The patient group, on the other hand, does not possess this subjective awareness. Returning to the issue of conflict management, this lack of subjective patient awareness means that conflict will be handled on an individual basis and in relation to a powerful and unified group. When viewed in this light, the tendency to alter aspects of reality ("it wasn't a

real heart attack") rather than challenge the dominant group is perhaps more easily understood.

A final dimension of patient conflict management is directly derived from the health professional's general ideological perspective. This general perspective relates to such things as; what are appropriate behaviours for patients, and extends to such things as the "nature" of females and males generally (Barrett and Roberts;1981:44). While health professionals were found to adhere to the image of a heart attack victim, they are obviously also aware that all patients do not fit this image. Thus, in addition to supporting and perpetuating the image (for example, in research and information sheets)(4) they also act with reference to their beliefs about what is "natural" (ibid) for males and females. This means that when allowances are made for deviation from the image, they usually take the form of confirming deviators in their traditional roles. With respect to women, the primary deviators, recognition of their difference, where it occurs, confirms them in their traditional roles as housewives and mothers.

Before moving on to analyse the results of this study, a brief and general description will be given of the two major ideological perspectives, that of health professionals and of patients.

Ideological Perspectives

The Health Professional Ideological Perspective.

The health professionals' ideological perspective centres upon the ideal notion, or image of a heart attack patient. In more general terms, Bloor and Horobin(1975) and Freidson(1975) have identified a very specific and contradictory set of expectations which doctors have of patients. Barrett and Roberts(1978) have also noted that general practitioners, as a group, have a very well defined set of assumptions about male and female patients. This mental set is far from conscious in that if a doctor was asked what "type" of person has a heart attack s/he would answer that all kinds of people have them. The conception of a heart attack victim as conforming to the "image" is covert, and as such has to be abstracted from health professional's behaviour, attitudes and responses to heart patients.

The significance of this image resides in the fact that it influences not only the way that health professionals behave, but it also has considerable power to shape and influence the experiences of patients and their ideological perspective. Thus, health professionals constitute a powerful reference group for patients.

In this study there is considerable evidence to suggest that this covert ideological perspective(see above) is present. It is evident, for example, in the literature (as discussed in Chapter 2) distributed by the health professionals (and which is also written by them) which depicts middle-aged, middle class male heart disease sufferers (5). It is also evident in the advice given on resumption of previous activities. The advice on resumption of sexual activity, for example, refers exclusively to the male heterosexual patient (6).

In addition to being evident in the printed material distributed to patients, this perspective can be seen in the manner in which health professionals act toward patients of differing types. This behaviour reveals the primarily middle-aged male conception which professionals have of heart patients. For instance, discharge and advice about returning to "work" (7) and other activities showed the pervasiveness of the image. The standard of six weeks off paid employment was applied fairly consistently. However, it was not seen as significant that just returning home would place women under considerable pressure to resume household work:

"DID THEY ASK YOU WHAT KINDS OF WORK YOU DID?"

"Yes. They asked me if I had a job and I said 'No. I am a housewife'".

"DID THEY ASK YOU WHAT KINDS OF ACTIVITIES THAT THAT INVOLVED FOR YOU?"

"No."

"WHAT ADVICE DID THEY GIVE YOU UPON LEAVING THE HOSPITAL?"

"Oh, they said 'take it easy, you will just have to turn a blind eye to the mess about the house for a while'".

Furthermore, it was not seen as significant that this would place them under considerable pressure to resume their work much sooner than their male counterparts.

Quite detailed advice was often given about how to cope with going back to "work", and in some cases the occupational therapist became involved in advising on modifications to the "work" environment. The standard piece of advice given to women about how to cope with being home again rarely ventured beyond the phrase "turn a blind eye". In no case was there any attempt to intervene in the home-work environment. From the foregoing it can be seen that the medical system is geared up to meet the needs of the patient who conforms to the health professional's image of a heart attack victim. Again, it should be noted that these activities arise out of the covert ideological perspective which health professionals bring to health encounters and should in no way be construed as a conscious decision or attitude.

An additional area in which the ideological perspective can be seen is in the type of studies which health professionals design to research people who have heart attacks. One such study (Burridge;1981) has already been mentioned in Chapter 1. An additional study, conducted by a group of Auckland Medical School students within the ARCOS (b) project is also relevant

here. The Burridge study applied a narrow perspective to its research. This may be seen as an outgrowth of the health professional's ideological perspective. The study focused upon the effect which coronary rehabilitation had on three limited aspects of individual's lives. This study made no attempt to construct or even canvas the subjective realm of rehabilitation. In failing to do this it conflated the health professional and the patient ideological perspective. It also assumed that there was no difference in the manner in which these two groups understand heart disease. Furthermore, this approach also assumed that there was only one patient ideological perspective, and that that relates to the ideal notion of a heart attack victim.

The Auckland Medical student study also demonstrates the pervasiveness of the health professional ideological perspective. Its sample was composed of approximately two hundred and fifty "consecutive male patients". It thus expressly ignored 25-30 percent of the heart attack population. In so doing it made the implicit assumption that if females do have heart attacks, their experiences are not significantly different to those of males. As has been noted in this thesis, this is far from the case.

The above three instances; printed matter distributed to patients, the manner in which health professionals act toward patients and the nature of health professional studies, illustrate the nature of the health professional ideological perspective. Evidence from numerous studies(9) in the health field

shows that health professionals have quite definite (if covert) expectations of patient behaviour. Thus, the ideological perspective is not confined only to the field of heart disease. This means that it is possible to generalise that discussed here into a broad perspective which describes what a patient "is like" in any particular illness context. Studies such as Graham and Oakley (1981) and Barrett and Roberts (1978) illustrate this point. Graham and Oakley note that obstetricians and mothers have significantly differing frames of reference about the whole pregnancy and child-birth field.

"To the doctor, symptoms of importance are those that betray the patient's clinical condition...But the patient may very often report symptoms which worry her but which do not worry the doctor. She is reacting to her subjective experience of pregnancy." (1981:59)

Similarly, Barrett and Roberts note the effect which the doctor's ideological perspective has upon the way in which s/he sees the patient, as well as the influence which this has upon the patient's ideological perspective.

"Working with G.Ps over some time it became clear to us that our respondents made certain unspoken assumptions about the "nature" of men and women. Men, it was clear, had a primary natural "drive" to work to support their wife and family. Women, had a similar "drive" to nourish and cherish their husband and children". (1981:44)

With respect to the impact which this ideological perspective has upon patients:

"Women were quite remorselessly confirmed in traditional family and domestic roles and more than one instance of a woman's refusal to do housework resulted eventually in hospitalisation and ECT". (1981:46)

It can be seen that the concept of ideological perspective is useful because it provides a structure in which to analyse and understand the differing approaches (or ideologies) which patients and health professionals have. It has as its central theme, the notion that there is no necessary co-incidence between the realities of patients and professionals.

General Features of the Patient Ideological Perspective.

This section is concerned with the general features of the heart patient's ideological perspective. In the same way that the health professionals have a set of mental images that relate to who has heart attacks, so patients carry mental pictures of what a heart attack is like and of who has them. This imagery is broadly similar to that of health professionals; prior to the heart attack it describes a male, middle-aged, middle-class individual.

For those individuals who do not conform to this image, it is not possible to simply adopt the health professional's ideological perspective and ignore the difference. The conflict must be managed in some way. In this study the most common response was to alter reality. That is; to say things such as "it wasn't a real heart attack" or "I didn't have one of those full-blown coronary things". In this way, the individual takes a subjective approach to the illness experience and interprets it

in a manner consistent with the ideological perspective s/he holds, and in relation to other constraints (such as the influence of health professional ideology).

There is more to the patient's ideological perspective than this imagery and its management when it conflicts with the reality. The ideological perspective refers to the way in which the patient (or health professional) views the nature, context and management of illness (Graham and Oakley, 1981:51). As was noted in the previous section, patients and health professionals have different and often conflicting notions of "relevant" symptoms. Stimson and Webb (1975:40) also note that there is often a considerable clash between doctor's and patient's definitions of relevant symptoms. In this thesis it was found, for example, in the case of a young man who had persistent tingling sensations in his arms. He had experienced exactly the same sensations just prior to his heart attack. When he asked the nurses and the doctors (including his G.P) about it, he was told not to worry, and that he should only worry if he got pains in his chest. Of course, their "assurances" did nothing to stop his worrying. His ideological perspective included "tingling" as a relevant symptom, because this was what he had experienced last time. That is, his subjective understanding of the word "heart attack" included tingling.

Patients' ideological perspectives also include general notions about what health and illness mean. As was noted in

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Chapters 2 and 3, this centred on a passive conception of health such that it involved the absence of illness. Their notion of illness involved a continuum of varying degrees of seriousness. At a certain point in this continuum it was appropriate to seek help. The point at which help was sought varied depending on the social characteristics of the individual. There was a definite difference between the males and females in this sample such that the male applied "medical decision rule" or the "as if ill rule" (Graham and Oakley, 1981:56) while the women tended to adopt an "as if well" approach for as long as possible.

The "medical decision rule" refers to the principle upon which certain medical decisions are made. It means that it is better to label a well person ill than it is to label an ill person well. It is relevant here because it is considered that this type of principle is also used by the population at large (for example, "it is better to be safe than sorry"). However, it was observed that when faced with their own health problems, women tended to adopt the reverse principle. This involved assuming that any physical symptoms were trivial until they became unbearable. Thus, in the absence of definite evidence to the contrary, women would adopt an "as if well" approach and ignore the symptoms for as long as possible. This resulted in the females in this sample delaying longer before seeking help than did the males.

The way the medical encounter is understood is another aspect of the patient's ideological perspective. As with most of the other aspects, this is heavily influenced by the ideological perspective of the health professionals. The power which they have to define the terms of an encounter spills over and influences the ideological perspective of the patient. In this way the patient's ideological perspective may be seen as more flexible and subject to external influences than that of the professionals.

That part of the patient's perspective which relates to the nature of the medical encounter can be most easily illustrated by the problems which patients and health professionals have in communicating effectively (10). For instance, inquiry into whether they felt comfortable asking questions revealed that although the opportunity was sometimes given by doctors (for example "have you any questions?"), patients did not feel able to ask questions. The opportunity to ask usually came at the end of the consultation, but at this stage respondents often felt that the doctor had "switched off". In this sense, the manner in which the opportunity was given to ask questions actually inhibited the patient from doing this. Medical encounters are primarily one way (from the health professional to the patient) and health professionals control the relationship. Patients will only ask questions when they feel that the health professional is interested in more than the physical aspect of their illness. If they do not feel s/he has this interest, they will not see the

asking of questions as a relevant activity for them to engage in.

"Well questions, they don't spring to mind like that."

"And then he says (after the examination) 'any questions?' which gives you the opening but you don't feel that there is the time and that he is seriously interested."

"Well, they don't like you to ask questions."

Here the clash between doctor's and patient's subjective interpretations of a situation can be clearly seen. The manner in which the opening is given to ask questions actually inhibits questioning. Thus, the health professional's definition of a patient and what a patient needs remains unaltered.

The previous two sections have outlined the ideological perspectives of health professionals and patients. In large measure these ideological perspectives conflict with each other. However, there are areas where they concur. These areas of overlap are principally areas where the health professionals have, through their ideological power, been able to exercise considerable control over the potential patient population. In so doing, they have been able to assert their definition of reality as the only relevant one. The next two sections provide an indepth analysis of the concept of ideological perspective as it relates to this study.

The basic theoretical contention of this chapter is that the experience of a heart attack is problematic for the patient. It is problematic in ways other than the fact that it indicates a "sick heart". The heart attack throws up a whole series of conflicts and anomalies that must be "theorised" or conceptualised in some way in order for the individual to "cope" with the heart attack (the individual may cope well or badly). The manner in which these issues are conceptualised depends to a large extent upon the characteristics of the person and the way in which the health professionals interact with this individual.

Analysis.

This section is divided up into three parts:

1. Medical Ideology - analyses the health practitioner ideological perspective using Wallach-Bolough's conception of the alienation of self from body.
2. Patient Ideology - analyses the patient ideological perspective and in so doing pays some attention to the effect which the health professional ideological perspective has on this perspective.

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3. A Case Study - this section provides an indepth analysis of one patient group. This group has been chosen because it is diametrically opposed to the image of a heart attack victim. It thus throws into clear relief the range of conflicts associated with the whole experience of a heart attack.

Medical Ideology.(11)

This section analyses the ideology of the health professional group. As outlined in Chapter 1, the method of analysis is the "theoretical interpretation of findings". Information for this section comes from three sources; informal discussions and interviews with several health professionals, observation in the hospital situation, and information gathered during interviews with patients.

Wallach-Bologh's (1981) concept of the alienation of self from body fits well with the information gathered here on medical ideology. This concept involves the reformulation of the notion of the patient role. It sees this role as a "relation of self to body mediated by the medical profession"(ibid;190). This can be seen, for example, in the language of medicine which refers to diseases and organs but never to the social being to whom the illness happens or the organ belongs.

Alienation is based upon two things: the orientation of medicine and professional dominance. Medical orientation refers to the way in which health professionals emphasise diseases to the exclusion of the social being; a patient is merely a possessor of an illness(Wallach-Bologh;1981:190). The body is not seen as a social body. This is reflected in the approach that health professionals take to symptoms; they are seen only as indicators of specifically physical problems (ibid). One result of this approach is that the social consequences of a treatment are seen as unproblematic(ibid).

Professional dominance has been addressed by many sociologists (12). Wallach-Bologh locates the notion of professional dominance specifically within a structural context. She notes that the structural condition which enables this dominance is the medical profession's control over knowledge - it is seen as private property (1981:191). By controlling knowledge, health professionals act as curers not as resource people. Resource people would function to provide sick people with access to healing knowledge and so enable them to cure themselves (ibid). The result of this dominance is that patients are relegated to the subordinate status of objects to be cured. Professional dominance, then, provides the structural base for the alienation of patients from themselves.

The concept of alienation is pivotal to an understanding of medical ideology. Firstly, it highlights the control over

knowledge exercised by the medical profession and its concomitant; the subordination of patients. Secondly, it emphasises the medical approach which has as its central theme the treatment of bodies divorced of selves. Medical ideology can best be understood by an analysis of the focus of care-givers. In this research, three aspects of this focus were found to be especially illuminating.

The gulf between statements of belief, or value, and actual practice constitute one avenue for the exploration of medical ideology. Interviews and discussions with health professionals indicated that family involvement in the hospitalisation process was seen as a centrally important aspect of cardiac care. Indeed, it was often referred to as evidence of the new approach to hospital care that elevated the patient-as-a-person to a central position. However, investigation into the actual practice of coronary care units revealed that family involvement was not consistently a part of care given. Family involvement seemed to be either a matter of chance or a product of an extremely assertive spouse who demanded to be involved. Where families were kept informed this was most often done by nurses; doctors rarely made any effort either to address the patient as a person or to take into consideration the patient's social context(13). Thus, it would seem that the demands of day to day care giving, or the organisation of hospitals results in family involvement being accorded low priority.

While statements of belief indicate an awareness of the importance of the social context (in this case, family involvement) the actual focus of care exhibits quite the reverse. The existence of this gulf between belief and practice provides some support for Wallach-Bologh's (1981) conceptualisation of medical ideology. That is, despite statements to the contrary, the emphasis is still upon illness, diseases and individual bodies. This mitigates against any form of care which takes into consideration the social beings who experience these illnesses.

A second area where evidence of health practitioners' ideology is found is in the area of what can be called the "hospital focus", although this extends beyond the hospital setting to such areas as post-discharge medical check-ups. This concept relates to the conception which health professionals have of what it means to be sick. Graham and Oakley (1978:54) note that health professionals emphasise such things as patient careers and medical facts. Patients, on the other hand, are more concerned with things such as the impact which the illness is going to have on their lives. Their focus is on the return home while the health professional focus is upon the illness episode as an isolated and discrete entity. This is one, rather obvious, area in which the two ideological perspectives (health professional and patient) conflict. It is interesting, in this respect, because it is one of the few areas where the individual-as-a-patient cannot actually alter her/his ideological perspective to fit that of the health professional. Because this

clash is never completely resolved, it constitutes one of the major areas of the illness experience. At the end of the illness the individual still sees her/himself as a social being and the health professional still sees the individual as a diseased or sick body.

The health professionals' focus on the hospital to the almost total exclusion of what happens when an individual returns home is a particularly good example of this facet of medical ideology. For instance, their insistence that those who lived alone spend the first six weeks in the company of at least one other person ensured that such individuals had a reasonably good chance of getting the requisite convalescence. Thus, it went a considerable distance to making sure that their hearts healed properly. What it did not do, however, was take any account of what would happen in the seventh week when the individual had to adjust to living alone again. The insistence on company for the first six weeks ensured that in terms of medical factors, convalescence was achieved. However, this ultimately contributed nothing to the social adjustment to the heart attack.

The transition from "sick" to "well" is a gradual process. Both Stimson and Webb(1975:87) and Bloor and Horobin(1975:279) point to the processual and "social" nature of illness:

"people live their illnesses socially, they cannot be viewed as isolated individuals responding automatically to the instructions of doctors"(Stimson and Webb;1975:87).

At seven weeks post-discharge the individual is in the same position as s/he is on the day of leaving the hospital. Reconstituting the normative world, that is, the social adjustment to the heart attack, is seen as unproblematic by health professionals, yet for patients it constitutes the major hurdle to be cleared after leaving the hospital.

The inability of health professionals to confront these social issues stems from an ideology that will only address sicknesses. It is further complicated by the fragmentation characteristic of "western medicine"(Wallach-Bologh;1981:189). This fragmentation relates not only to the proliferation of specialties and sub-specialties, but also refers to the fractionated image which health professionals have of the functions of the various components of the medical system. One effect of this is that those working in hospitals conceive of their brief as relating only to the hospitalisation period and perhaps to that period immediately following (but here only in medical terms). This focus enables them to ignore the fact that the return home experiences of those who live alone will be quite distinctly different to what they conceive of as the norm (that is, married, male patients).

The emphasis on patient careers and medical facts highlights the way in which medical aspects of illness pre-empt any serious consideration of the subjective and social realms of individual's lives. Post-discharge check-ups mark the individual's passage

through the illness. This progression is punctuated by the measuring and recording of relevant symptoms and physical indicators which are medically defined. (swollen feet and hands and blood pressure, for example). It does not involve any significant degree of interpersonal communication between doctor and patient, nor does it address the social aspects of the recovery phase with any regularity.

Even though the emphasis is upon physical indicators, not all physical symptoms are considered to have equal significance. Emphasis is upon those symptoms which the doctor can measure. Indicators of the type that the patient her/himself experiences (for example, tingling - see earlier discussion in section two) are generally accorded lesser significance. Alternatively, they may be seen as indicators of some underlying psychological or emotional disturbance. Stimson and Webb(1975:10) have also pointed to the tendency of doctors to assume that psychosomatic motives usually prompt patients to consult them. Again, the subjective aspects of the illness process are relegated to the periphery of the doctor's attention, or they are seen as indicative of some individual inadequacy (for example, evidence of a "worrier"). They are not seen as symptoms worthy of attention and explanation. Graham and Oakley (1978:59) note this clash between the subjective and objective aspects of medical care in their discussion of "who is the expert?" Here they note the difference in emphasis between the doctor and the patient on what are relevant symptoms. While patients react to the subject-

ive experience of illness and are thus attuned to a wide range of physical sensations, doctors focus upon a narrow range of pre-determined symptoms which are thought to betray the patient's physical condition.

The individualisation of illness (Wallach-Bologh;1981) is a frequently noted theme in analyses of medical ideology. Barrett and Roberts (1981:46) note that this emphasis is primarily a product of medical education which concentrates "largely upon personal pathology"(ibid). Wallach-Bologh (1978:188) documents some of the effects of this emphasis when she notes:

"The failure on the part of the medical profession to treat differences in morbidity rates due to social class, occupation and environment as an object of medical concern".

The individualisation of illness has an obvious and close relationship to the previous two aspects of medical ideology. Because illness was seen primarily in individual terms, (even when, as Wallach-Bologh notes, it has an obvious social class component) family involvement could be relegated to the periphery of care. It was something that could be attended to after the more important medical tasks had been performed. Routinisation of tasks is a central feature of hospital organisation. Those tasks that are defined as important are allocated to specific health practitioners. That family involvement was seen as peripheral and non-essential can be inferred from the fact that no specific member of the coronary care unit staff was given responsibility for the task of organising family contact.

The focus of the units on the hospitalisation period and the focus of the general practitioners and out-patient specialists upon medically relevant symptoms again underscores the manner in which illness is individualised by health professionals. Advice on giving up or modifying various behaviours (for examples, see Chapter 5: Keeping to Changes) shows a similar disregard for the social context of patient's lives. Finally, the consistent refusal to intervene in the "private sphere", even when it was having an obvious and damaging effect on the health of the patient, and instead, the emphasis on altering the individual to fit the home environment demonstrates the extent of the individual focus of health professionals.

Wallach-Bologh's concept of the alienation of self and body provides a method for understanding the strands of medical ideology that were found in this study. The medical orientation, which focuses upon diseases and sick bodies, but never the social self (Wallach-Bologh;1981), was found to fit well with both respondent's experiences and the statements and practices of health professionals. Professional dominance also provides an avenue for exploring the consistent refusal of medical practitioners to accord the subjective experience of physical symptoms any significance. The notions of patient careers and medical facts further facilitate the understanding of this facet of medical encounters. In order to understand the power of medical ideology it is necessary to examine the ideological perspectives of patients. This is done in the next section.

Patient Ideological Perspectives.

The patient ideological perspective has been divided up into four sections. This division is somewhat artificial as, in reality, the first three sections are quite closely linked. The division has been made for discussion purposes only.

1. the role of the individual in the illness process:

This aspect of the patient ideological perspective relates to the understanding which the individual has of the range of behaviours "appropriate" to the patient role. Its parallel, patient perception of the role of the doctor, is discussed in more detail in the third part of this section.

Upon entering the hospital, individuals become aware of the fact that they are seriously ill. (This is not as simplistic as it sounds). That is; until they are diagnosed and/or admitted, the majority of individuals still believe that there is nothing seriously wrong with them. Once diagnosed, they begin to see themselves as "ill". There is, thus, an interpretive process involved in the adoption of the sick role(14).

It was found that the awareness of being ill was not a status transition in the pure sense of the word because health

was not a state of which individuals were actually aware. Rather, it was something that they were aware that they had lost once they became ill. Thus, it appeared that health was little more than the absence of illness. Illness was the active state. The following statements provide some support for this contention:

"I didn't realise that exercises helped your heart and your body too"

"A lot of it was pure habit because we didn't realise that diet was anything more than just eating".

An additional dimension to this passive conception of health was the approach which individuals took to its restoration following an illness. It was found that having become ill, individuals saw the restorative process as something external to themselves - health was something that was restored by others. In this way, control over health effectively lies outside of the individual. It is vested in others who have the knowledge to effect a cure.

Here, the strong co-incidence between medical and patient ideology can be seen. Again, Wallach-Bologh's (1981:199) notion of the control of knowledge as private property, and the activity of health professionals as curers not resource people helps explain this understanding of health and illness. Because knowledge has been appropriated by the medical profession, the relationship between health and illness has become mystified (15). This renders the individual unable to make the

transition from illness to health unaided, and in so doing alienates the social self from the body. In this way knowledge about the restorative process becomes a commodity. But, unlike other commodities it (knowledge) cannot be purchased directly, rather, the ability to effect a cure is purchased. The knowledge remains the private property of the health professional group. It is in this sense that Wallach-Bologh refers to doctors as curers and not resource people.

Continued health was frequently seen as a matter of good luck and its loss a matter of bad luck. Similarly, avoidance of another heart attack was put down to "fate". That this attitude to health was not a peculiarity of this group alone is borne out by Barrett and Roberts (1978:49) who note:

"Without exception they saw good health in terms of good luck. We felt that this was symptomatic of a situation where patients feel that they have no control over or knowledge of their own bodies".

Lack of control constitutes a pervasive theme in the patient ideological perspective and may be accurately interpreted as one consequence of patient alienation. Individuals, thus, interpret their role in the restorative process as passive.

2. perception of illness:

Respondents demonstrated a specific and quite complex understanding of illness. Two concepts were found to structure this understanding; "official cure" and "permissible activities". These concepts do not appear to have any parallel in other sociology of health work so they remain speculative.

It was found that individuals and significant others with whom they regularly interacted perceived the illness to be over at a definite point. This was the point at which the individual was "officially cured". Basically, "official cure" relates to the point at which the individual is expected to resume all previous roles and responsibilities. It is, therefore, the other side of the sick role in that when "officially sick" normal role performance may be legitimately suspended. The "official cure" appeared to have two stages: hospitalisation and the convalescent period. However, the "cure" did not always take the full six weeks convalescence. For instance, married women frequently resumed all their previous roles well before this point. Coronary rehabilitation appeared to be the one factor which extended the length of the "official cure". This highlights the centrality of health professional contact in the definition of legitimate illness. The only factor that consistently influenced perception of the "official cure" was the degree and length of health professional involvement with the individual. Reduction

in health professional contact was taken to imply a return to health.

Until the individual was "officially cured" it was possible to legitimately suspend normal role performance. This legitimation was of two types - self and other (see discussion in Chapter 2). The cure had been effected when health professionals no longer had regular contact with the individual.

Illness can be seen in terms of health professional sanction (usually a doctor). To be legitimately ill it is necessary that a doctor be involved on a regular basis. Because health knowledge is not accessible to the layperson, individuals are not considered (and do not consider themselves) to be competent enough to assess whether or not they are ill. Examples of this imposed incompetency abound and the requirement of a doctor's certificate to legitimately take time off work constitutes one such instance. Professional dominance (the monopoly over knowledge and the ability to decide who is well and who is ill) enables the medical profession to act as a covert and extremely powerful agent of social control(16). Possessing such knowledge and being able to make such decisions puts the medical profession in the unique position of having the ability to both create and regulate the demand for its own services.

The second concept which structured the individual's perception of illness was "permissible activities". These activities

were discussed in Chapter 2 in the context of the advantages of group rehabilitation. Not only were individuals permitted to forego normal role obligations while they were "officially sick", they were able to indulge in a range of health-directed activities as well. These were the "permissible activities".

The alienation of individuals from themselves (discussed in the section on medical ideology) results in individuals having a very low involvement in their health. This is the passive state. A consequence of this is that activities which serve no function other than the enhancement of health and general well-being are only "permissible" when the individual is "officially sick". In this context one of the advantages of the group rehabilitation schemes was that they required doctor sanction. This meant that rehabilitation was seen in the context of the "official cure". Thus, it was "alright" to go for walks, and so on, as long as the doctor said that it was a necessary part of the "cure". Alienation and professional dominance thus combine and result in health-directed behaviour requiring the definition and sanction of an external agency. It is not legitimate for individuals to do this under their own initiative.

Because individuals (given the structure and philosophy of medical care) do not have any significant degree of control over their varying states of health (they do not have access to knowledge and they exist in a system which defines them as powerless), the range of "permissible activities" is limited.

Generally, it is confined to the carrying out of prescribed activities when outside the direct control of health professionals. Thus, such activities as pill-taking and dietary modification are prescribed, and thus, "permissible activities". Because rehabilitation programmes extended the range and duration of professional contact, the range and duration of "permissible activities" was similarly extended. It was noted in Chapter 3 that individuals did not keep going with exercises beyond phase two of the "official cure" (see above). That is, health directed behaviour could not be justified (self and other legitimation) beyond this point

The group schemes introduced an element of structure, compulsion (you are referred there by your doctor, it is thus a necessary part of the "official cure") and control (professionals monitor you and in so doing make decisions on your behalf - the locus of control is with the proper authority). As will be noted in part four, this latter aspect changes over time. Through prolonged contact with a programme respondents also learnt to make their own decisions and in this process their conception of health was transformed, somewhat, to an active state. Thus, unless health directed behaviour is sanctioned by the proper authority, indulging in it over a prolonged period of time is not seen to be an appropriate activity.

5. patient perception of the role of the doctor:

In addition to having a fairly clear image of their own role, the patient ideological perspective also has a well-defined understanding of the role of the doctor. This understanding influences the way in which patients behave toward their doctors and the type of treatment which they expect and seek from them. As has already been noted, their understanding of all aspects of being ill is heavily influenced by the ideological perspective of health professionals. This part of the investigation revealed an interesting clash between the perception which doctors (especially G.Ps) had of themselves and the perception which respondents had of them (see below: clash between patients' and doctors' perception of the g.p.s role). The first part of this section deals with an analysis of medical explanations. This is relevant to a consideration of patient perception of the role of the doctor because it reveals the range of information to which patients feel that they are "entitled" about themselves, and the understanding which they have of the doctor-patient relationship.

getting explanations:

"Well they don't like you to ask".

"They explained it but I can't understand all that technical stuff".

"It isn't really important that I know. It is they who need to know"

The above quotations are three examples of the attitudes which are held about medical explanations and medical encounters.

What they all point to is the communication gap which exists between medical personnel and patients. Graham and Oakley (1978:63) note the communication gap as an important factor which structures the ideological perspective of patients.

That it was extremely rare for patients to be satisfied with the detail and extent of medical explanations is a finding which is by no means unique to this study. While the motivation behind asking questions was usually a desire to know and understand what was happening to one's body, medical professionals usually interpreted questioning as evidence of anxiety. Thus, their response was to "reassure" patients rather than to explain. Responses such as:

"That's normal"

"That's nothing to worry about"

or even worse:

"Oh, you're just one of those people who worries a lot".

were what passed for explanations.

In addition to anxiety-allaying in their responses to questioning, medical professionals frequently treated their patients as ignorant and incapable of understanding what was happening to them. Stimson and Webb (1975:123-4) and Comaroff (1979:125) also note the tendency of medical professionals to dismiss patient questioning as evidence of anxiety. That this is, in fact not the case has been pointed out by such sociologists as Bart (1981)

in her study of an illegal abortion collective. Treating patients as ignorant has consequences which reach beyond the fact that it is both insulting and degrading to be so treated. The assumption that patients have such a limited capacity to understand what is happening to them serves to underline the extent of physician power and control.

Bart(1981) notes the dehumanising effect of medical practice (with all its attendant assumptions about patients) as it is currently constituted:

"for so many health professionals regard health care not as a process, but rather as a product. Inevitably, human beings are dehumanised, divided into many parts, and placed on an assembly line where doctors have access to the most profitable parts. This reduction of human beings to particular medical parts and the consequent control exercised by doctors over those parts (and thereby over human beings) is something that feminists have found most undesirable - on many counts - and have sought to change." (ibid:110)

Rakusen (1981:82) also notes that the theme in giving explanations is actually the denial of information and the dehumanisation of the patient:

"Doctors seem to feel that they do not need to explain anything. Certainly a community health worker reports, they often find 'explaining' difficult, sometimes believing that "these women" don't understand anything anyway.... "The women are treated not as human beings but as objects. Nurses and doctors point at them and talk about them as if they had no feelings. Their preferences are never sought"".

The assumption that individuals "don't really want to know" is apparently not confined to the cardiological field(17).

Denial of knowledge plays a significant role in patient alienation. Furthermore, as Stimson and Webb(1975:121) note, it is possible for health professionals to appear to be giving information when actually they are not. For example, information on drugs is usually limited to telling the patient what the drug is designed to cure. The broader action of the drug, for example, possible side effects or the chemical composition of it is usually withheld.

Alienation is also partly a product of medical specialisation. This yields a type of medical practice which focuses upon organs, limbs and parts of bodies with little or no reference to the whole to which these parts belong. In fact more than one respondent commented upon the fact that although, apparently, the heart was being well taken care of, perhaps the foot might fall off without anyone noticing. That respondents clearly felt so alienated from their bodies in an area that receives so much public attention and funding, would alone seem to justify a rethinking of the current emphases within the medical system.

It requires skill, determination and the possession of certain "tickets" (the right race, sex, age and socio-economic status), rather than a simple desire "to know what's happening to me" to get an explanation from a health professional. In this study professional and middle-aged men were far more successful at getting explanations than any other group. Often these men

had ongoing relationships with their doctors (played golf together etc). So, it would appear that not only is it necessary to fit the image (and so to be a good patient) but it is also necessary to interact with the doctor outside of the surgery. Clearly, for the bulk of the population this is simply not possible.

clash between patient's and doctor's perception of the g.p.s

role:

As was noted in the introduction to this section this is one area where patients do not always adopt the perspective of the doctor. The reason for this refusal appeared to stem from the fact that there were simply too many instances where patients experienced the direct opposite of the dominant ideology. Furthermore, the very fragmentation and specialisation of the medical field served to reinforce, not the health professional's, but the patient's conception of the role of the G.P. The significance of this concept can be adjudged from the fact that, virtually without exception, the health professionals (especially doctors) premised discussions of rehabilitation with the researcher, with the statement that "actually the G.P is superbly equipped to provide those same services as rehabilitation does", or some variant on that theme. On the other hand, respondents who participated in group rehabilitation schemes did not see the general practitioner's role as being at all commensurate with that of the programmes.

This discussion focuses upon G.P.s. In the hospital setting, health professionals are able to very effectively maintain their hegemony over the patient. Thus, in this setting patients will almost always concur with health professionals definitions. Once out of the hospital, individuals have a little more flexibility; they will not always agree with the doctor's definitions. Of-course, they will not challenge the doctor any more than they will challenge a hospital health professional. The total hegemony of the hospital works in such a way that, without exception, respondents commented favourably on the quantity of information that was available to them. However, when questioned more fully as to what they actually learned about their hearts and their bodies again, almost without exception, they found that they had internalised nothing. In line with Stimson and Webb's(1975) above discussion of drug information, it was found here that very few respondents knew what the drugs actually did to them. Rather, they knew that: "that one's for my blood, that one's for my heart and that one's for the pains". What this means is that the image of information availability could be maintained without the health professionals necessarily having to invest anything of themselves in the encounter.

The information given was not internalised because it was passive knowledge: it was knowledge about what the health professionals were doing to the patient, not about what patients could do for themselves. Thus, it is another aspect of the denial of knowledge and alienation of individuals from their own

bodies. There were of course some notable exceptions to this, but they were, indeed, exceptions(18). Merely providing individuals with large tracts of information does not constitute educating them. This is all the more so when the entire structure of the medical system is directed at denying individuals any significant degree of involvement in the functioning and repair of their bodies.

While health professionals saw the G.P as being ideally placed to look after the individual-as-a-person (and leaving aside the issue of whether this is actually so), respondents did not see their role in this way. The attitude of respondents to this topic have their roots in their conception of the medical system which they basically see as fragmented. This appeared to be a product of the high level of specialisation in the medical system in general, and the cardiological field in particular. In fact, some respondents expressed manifest confusion as to whom they "belonged" upon leaving the hospital (19).

While the G.P may see her/himself as "the old family doctor", no-one else shares this image, and in fact the G.P probably tends to refer patients on with much greater frequency now than in the past. Barrett and Roberts (1978:46) note, for instance, the tendency for G.Ps to refer their female patients on to psychiatrists when they are "floored"(ibid) by the symptoms which the woman presents. The specialisation of hospital services "taught" individuals a pattern which defined certain

authorities as being appropriate for certain issues - each health functionary had a narrowly defined sphere of interest and responsibility. Statements by respondents (such as, "my foot could have fallen off") suggested that they felt that no-one was interested in the whole person as they moved through the medical system. The G.P perhaps sees her/his role in this way (that is, as overseeing the whole person) but it is not always seen in this way by the patient:

"I see my G.P as an expensive pill-dispenser"

"He is interested in my pulse and my blood pressure, but not in how I am in myself".

Thus, the G.P was seen as being relevant for only certain restricted aspects of the individual's health. These related primarily to medical issues. Some psychological treatment was given (there was also referral on to specialist psychiatric services, primarily for women(20, 26)), but again, this related to specific medical interventions - anti-depressant drug therapy and so on. It did not relate to attempts to come to an understanding of the social context of the individual and the way in which this might have been impinging on the well-being of that individual.

Treating the illness as if it had no social context is one way that health professionals individualise the illness experience. Treatment is directed to the illness as it manifests itself in physical symptoms. No effort is made to link it back

into the context in which it developed, nor to locate the "cure" in that context (21). In all cases the individual is treated in a context that bears no relationship to her/his normal living context (that is; they are treated in the hospital or surgery). Thus, where the illness is perhaps promoted by aspects of the living environment, or where recovery and prevention of similar episodes is hindered by this context, efforts are still directed at the individual (altering the chemical balance of the body, or perhaps counselling the individual to change - "fit" in better with her/his social context). Never do they take into consideration or attempt to alter the context itself.

It is not difficult to see why individuals consistently refused to adopt the medical professional's ideological perspective on this issue. For those individuals who participated in a rehabilitation programme comment was frequently made on the fact that it provided a service that no other aspect of the medical system appeared to be concerned with. Those who did not participate in a rehabilitation programme often made comments that described something like the programmes, or "wished that something like that was available here" when the programmes were described to them.

4. transforming the patient ideological perspective:

The manner in which the patient ideological perspective is modified through the experience of an illness has already been discussed. In that context, contact with health professionals and their ideological perspective was noted as one significant influencing variable. In addition to the co-optive effect which the health professional ideology has, the patient ideological perspective was found to be modified through contact with a rehabilitation programme. The nature of this influence was such that it could be considered to be a type of consciousness-raising experience for those who participated. Not only did participation have the effect of altering the perception which individuals had of things such as the patient role, the illness, "relevant symptoms" and so on, but it also appeared to have a limiting effect upon the extent of health professional (especially doctor) hegemony. This section is concerned with an analysis of the ways in which the patient ideological perspective altered in response to contact with a rehabilitation programme.

permission to act:

The first area in which a change of perception was observed was in the range of activities in which individuals indulged on a regular basis. In the discussion of patient perception of illness, the need for professional sanction of illness and health-directed behaviour was noted. Contact with a rehabilitation programme reduced the need for both self and other legitima-

tion of activities formerly considered to be off-limits because their primary function was health-promoting (see earlier discussion of "the official cure" and "permissible activities").

The way in which the rehabilitation programmes appeared to give individuals permission to act in the interests of their own health was noted in Chapter 3. The nature of this changed orientation was not total however, for sanction of some sort was still necessary. The programmes were run by health professionals (none of whom were doctors) who monitored the activities of individuals on a regular basis. The change in perception and behaviour extended the conception of the restorative process to include a range of things that the individuals themselves could do. In this way it altered their understanding of health and illness. Health and the return to it became the focus, rather than the illness and the necessity for professional guidance as the only means for restoring it.

There was an additional dimension to this concept. It related to the educative effect of the programmes. As was noted in Chapter 2, none of the schemes explored the educative potential of rehabilitation to its full. However, knowledge was inevitably passed on as a simple function of the regular interaction between the health professional and the individual. This extended contact altered the way in which individuals thought about health. They became aware of the fact that there was knowledge that was both accessible and sensible to them.

Having this information enabled them to make some decisions for themselves. Although their access to knowledge was very limited, and at the end of the field research these respondents still had quite a heavy reliance upon their medical practitioners, this access did have a liberating effect upon them. Learning about exercise, diet and a range of other things, and feeling competent enough, and permitted to think about their health, partially reunited the individual's selves and bodies (see earlier discussion of patient alienation).

Of course this had no effect on their relationship with their medical practitioners. Doctors consistently refused to become involved in the programmes (except in those cases where they had had heart attacks, and thus attended as participants). In this way they continued to protect their knowledge and their position as dominant in the doctor-patient relationship.

demystification:

Despite doctors refusal to participate in the rehabilitation programmes, the prolonged contact with other health professionals, and the learning that this afforded, combined to have a demystifying effect on the way in which individuals perceived the entire medical system (22). By learning methods of coping and of obtaining information once outside the hospital, the boundaries of "permissible" knowledge and self-directed behaviour were extended. As noted above, this demystified, to a limited degree, the medical structure of this system. In this way individuals began to learn how to reclaim the knowledge about their

bodies that has been appropriated from them. They were, thus, transformed into active participants in the health process.

These alterations in individual perception were not apparent in the group which did not have access to a rehabilitation programme. In fact, this group demonstrated quite the reverse. Their prolonged contact, as patients, with health professionals actually extended and deepened their reliance upon the structure of medicine, and thus, the control which it had over them. There was a very definite and obvious difference in the morale of those who had access to a programme and those who did not. In some ways these problems were a simple product of isolation. The difficulties in adjustment were seen in individual terms simply because these individuals did not have any contact with others who had had heart attacks. In short, they did not know that what was happening to them was happening to other people as well.

The changes observed in the rehabilitation groups were limited. However, they do have fairly radical implications. They did alter, to a degree, the relationship which individuals had to the medical system and the health professionals who control that system. In this way they can be seen as a very small step towards decommodifying health care. By being able to take steps to learn (knowledge) individuals ultimately alter the nature of the relationship that they have to health professionals and the medical structure (see discussion of professional dominance).

group activities serve a consciousness-raising function:

This is the final aspect of the transformation of health into an active state. It was discussed in Chapter 3 in terms of social contact. When taken in conjunction with the previous two concepts, this concept can be extended to describe the general development of a subjective awareness by respondents of themselves as a group.

Prolonged contact with others who have had heart attacks enabled a "group feeling" to develop. This subjective awareness was not evident in the individual rehabilitation group. In addition to having political significance (that is, in terms of the power of patients as individuals versus the potential power of patients as a group) group awareness served certain very practical and useful functions. This "transformation" played quite a significant role in improving the quality of individual lives (see quotes below). It did not, however, alter the distribution of power in the doctor-patient relationship. It seemed that the hegemonic control of the doctor was firmly entrenched. The nature of the positive effects on the quality of life can be summarised in the following quotations:

"You realise that you are not a freak".

"You are not alone, what is happening to you is also happening to others".

"You are not peculiar".

Social contact as a learning experience is another aspect of the consciousness developing nature of rehabilitation. Learning was not only obtained from social contact with health professionals. There was also a significant amount of interchange between participants themselves. The significance of this was that it reasserted the validity of subjective experience as a learning device. Here, individuals helped each other with a wide range of practical advice about coping. Moreover, this was information that medical practitioners could not have provided (unless they themselves had had a heart attack). That is, it was not information that is part of a medical orientation and thus considered to be significant or relevant to having a heart attack. This interchange also helped to strengthen the bonds between individual members of the group.

Thus, the rehabilitation programmes helped to reduce the reliance of individuals upon medical services and to demystify their perception of those services. Although this research has not gathered sufficient information on health professional attitudes to make any conclusive statements, it is interesting to speculate upon the reasons why there is medical practitioner resistance to rehabilitation. It could perhaps be that they perceive it as having precisely these functions and in this way, as challenging their dominance in the health field.

A Case Study.

The final substantive section in this chapter is concerned with a case study of the women who participated in this research. This is included for two reasons. Firstly, and as noted at the beginning of part three of this chapter, women constitute one group excluded from the image of a heart attack victim. As such, their experiences clearly demonstrate the range of conflicts and contradictions associated with having a heart attack and, more generally, with being patients in the medical system. Secondly, it is considered that the experiences of the women in this sample are not peculiar to those who have heart attacks. Rather, their experiences can be more generally related to their position in society as women. This section analyses the experiences of the women and attempts to explain these experiences in the light of feminist theoretical concepts. As with previous sections, this analysis employs the concept of the ideological perspective (of women and health professionals) to explain their experiences.

There was a consistent theme underlying the ideological perspective of the women. It was such that it followed closely the pattern noted by Barrett and Roberts (1978) in their study of the consulting patterns of middle-aged women. They noted that the closest that many women came to acknowledging the power relation-

ship between themselves and their doctors was the fear that they expressed when faced with having to go to the doctor (ibid:48). This, they note, was not fear at what might be wrong. Rather, it was fear at what the doctor might think if there was nothing seriously wrong with them. In this study, women's recognition of this power relationship expressed itself in a similar way. The women frequently explained their reluctance to seek medical advice in terms of not wanting to be thought a hypochondriac, being afraid that the doctor would think them stupid, and not wanting to "put the doctor out because he is so busy". Indeed, these fears were far from irrational. Each woman could cite instances in the past where she had been treated in precisely this way. Such responses by medical practitioners are one way in which they assert their dominance over patients; they have the power to decide what is a "genuine" symptom and what is not.

The women's ideological perspective was such that it defined any health problems that they might experience as inherently trivial. In fact, many of them engaged in predictive role playing where they imagined themselves in the doctor's surgery being told that there was nothing seriously wrong. This role play was so powerful that it usually prevented them from seeking help. Conversely, the role playing in which the men engaged confirmed that their problems were serious and that the doctor would be sympathetic to them. They did not expect that the doctor would trivialise their problems.

The ideological perspective of women is based upon an image of themselves that defines them as less important than, and their needs as subordinate to those of their husbands and families. That this, at least in part, stems from the material conditions of women generally seems certain and has been noted by many authors. For instance, Dahl and Snare (1978) note that women's existence is primarily in the private sphere and that as a result they tend to be invisible. In a society where value is measured in terms of participation in the public sphere, the role of women, and consequently their "worth", is consistently downgraded. Thus, it is little wonder that their ideological perspective defines them as trivial and insignificant and their problems in the same way.

An additional consequence of being largely confined to the private sphere is that when something like a heart attack happens the chances are that the individual will be alone and some distance from help. Men, on the other hand, were more likely to receive prompt medical attention simply because there was a greater chance that they would have their heart attacks in a public place. Furthermore, if they were at home, they also tended to receive attention more quickly than the women. This was because their wives frequently sought help on their behalf. It seemed that the women were considerably more assertive in getting help for their spouses than they were for themselves. This probably relates to the fact that, as the care-givers in the family, they are more often involved in providing such services

for others than they are in receiving them.

When husbands returned home, wives went to considerable effort to ensure that they received the requisite six weeks convalescence. They often took time off work themselves to look after their husbands. In some instances help to do such things as mow the lawns was hired, alternatively, the wife took over these tasks(23). This contrasts with the experience of the women where in no case was help brought in from outside the family unit to take over some household duties. Furthermore, it was extremely rare for family help to extend beyond the first few weeks, in only one case did it last the full six weeks (the husband had retired), and in no case did a husband take time off work to look after his wife.

It is in instances such as the above that the strength and implications of the definition of women as care-givers and not care-receivers can be seen. This is a significant aspect of women's ideological perspective on health and illness. It relates not only to the differing quality and quantity of help and support that male and female heart attack victims get, but it also relates to, and bears out, women's experiences of health and illness more generally. As more than one woman commented:

"Mum always keeps going"

The expectations, from apparently all the groups involved, was that the women were competent enough to look after themselves but that the men needed additional attention and care. The women

themselves concurred on this point, but they also noted how terribly difficult it was to "keep going". This situation provides some support for Barrett and Roberts' (1978:47) contention that women (especially middle-aged women) tend to collude with the definition of themselves as somehow less important and deserving of care than their husbands and children.

This provides a particularly powerful example of the way in which hegemony works. For to be effective, it is necessary that individuals actively consent to the definitions of themselves which are embodied in the dominant ideology. Indeed, the women who had had heart attacks often questioned their "right" to be ill. They felt that they had no "right" to expect any help because everyone had such important things to do and they didn't really have time to help with the house:

"and after all, it is my job".

The issue of the right to be ill had another, quite specific context for the females who had had heart attacks. This related to the imagery of a heart attack which was discussed in Chapters 2 and 3. As was noted in those contexts, there is a specific and quite detailed imagery which surrounds the whole field of heart disease. It was noted that, albeit unintentionally, the information given in hospital excluded women. This lack of recognition of women as heart attack sufferers compounded the extent to which the women felt "imposters" and contributed to their (and often their families as well) trivialising it. This tendency was also

noted in the cases of young men:

"it wasn't a real heart attack".

The extent to which women's health problems are trivialised has been well documented (for example, Graham and Oakley:1981 and Barrett and Roberts:1978). The women who had heart attacks constantly questioned their right to be ill. It was found that this formed an especially powerful part of their ideological perspective.

An additional dimension to these differing notions of female and male illness was noted in section two of this chapter (The Health Professional Frame of Reference). Again, it relates back to the "private"(Zaretsky;1976, Dahl and Snare;1978) nature of women's lives. While the hospital staff were keen to intervene and advise modifications to the "work" environment where it was considered that this might be having a negative effect on the individual's health, they never intervened in the home-work environment of the women. The most common advice for women in paid employment was for them to give up this job so that they could concentrate on their jobs at home(24). The standard piece of advice about coping with housework is also instructive in this context. "Turn a blind eye" trivialises the problems which will be experienced once the women return home. It also attributes any difficulties that they may experience in doing this to personal inadequacy (for example; "I'm just over-fussy"). Perhaps more importantly, it carries with it the implicit recognition that the work is not going to be done by the family.

There would be nothing to "turn a blind eye" to if women received adequate support from their families.

The fourth aspect of this ideological perspective appeared to arise out of previous experiences that the women had had in the medical system. As such it points to the strength of the influence which health professionals have as a reference group. This related to the consistent and almost unconscious desire to seek legitimation from a personal relationship (and almost always from another female) before seeking medical help. This can be seen as an outgrowth of the previous aspects in that the ideological perspective of the females was such that it led them to expect that their problems would be classified as unimportant, or that they were worrying about nothing, or that they would be labelled as hypochondriacs. That such attitudes and expectations arise from previous medical encounters was suggested by the fact that all of the women interviewed could recall numerous instances where their problems had been trivialised, their questions left unanswered or answered in excessively technical language or they had been prescribed placebos for genuinely physical problems.

The seeking of support prior to seeking medical help followed what might be termed neighbourhood support networks in that they involved either family members or a friend who lived in close proximity. It is likely that this behaviour was a pattern learned when the women had young families and were to a large degree confined to their homes. In situations such as these,

support from one's neighbour and other family centred social groups provided a major source of support. In times of crisis, therefore, it is not surprising to find the women seeking out these old helping networks before having to face a member of the medical profession.

Another common reaction was to attribute the first symptoms women experienced to that vast and diffuse category of ills generally described as "women's problems". This enabled the symptoms to be seen as not real symptoms, and thus they could legitimately be ignored. The effect of this labelling was to downgrade the seriousness of the problem. This finding is all the more relevant to an analysis of the differing illness experiences of females and males when it is realised that it was never suggested that the men's initial symptoms were "merely men's problems". Again, the fundamentally differing way in which females and males are seen in society generally, and by the medical profession in particular, (Barrett and Roberts;1978:45) can be seen to have a profound effect on the course and experience of an illness. Another dimension to this differing conception of what it is to be female and what it is to be male is the tendency of the medical profession to see women as inherently more susceptible to psycho-somatic illness(25), and to treat most of the problems they present with reference to this belief(26).

The final aspect of the women's ideological perspective was alienation from medical encounters. Because their perspective

embodied a notion of their health problems as inherently trivial, the women had little confidence in reading their body signs. Thus, they tended to ignore symptoms for much longer than the men. Conversely, the men believed every sign and symptom to be significant. The women were alienated from their bodies in two senses. They felt incompetent to assess whether something was serious or not, and they relied heavily on medical definitions of significant symptoms. The result was that their subjective experience of illness became dominated by those medical criteria.

It can be seen that the experiences and ideology of the women interviewed for this study may be partially related back to the fact that they are women, rather than purely heart attack victims. There were experiences and parts of the ideological perspective that were common to patients as a group. However, there was a significant area of the women's ideological perspective that was particular to this group as women. This area of the ideological perspective can be easily linked back into a general understanding of the position of women in society in general and in the medical system in particular.

Conclusion.

This chapter has developed a framework that organises the material presented in Chapters 2 and 3 into a systematic whole.

This framework embodies the concept of the frame of reference which is composed of an ideological perspective and a reference group. It has been abstracted from a number of other sociology of health works that have attempted to understand the subjective experience of individuals as patients. The application of this framework enabled the data to be understood in terms other than as a collection of individual experiences which is what it first seemed to be. In this sense, then, the ideological perspective constitutes an explanatory device which can be used to interpret the way in which individuals construct their social worlds.

The "theoretical interpretation" of data (the purpose of this chapter), then, took the form of specifying some of the constituent parts of patient and health professional ideological perspectives. The ideological perspective refers to a set of definitions and understandings which individuals have of any given situation. These definitions help them to "make sense" of the situation and to define the role that they, and others, should play in it. In this research the "imagery of a heart attack" was found to be a pervasive and powerful part of the ideological perspective of both patients and health professionals. The fact that it constituted part of the health professional's ideological perspective is especially significant. This is because health professionals have considerable power to influence the understandings which patients will have of any given situation. The importance of power in the patient-doctor relationship is discussed in more detail below.

In addition to the "imagery", patients had a set of definitions that related to health, illness and the roles of, and behaviours appropriate to the various participants in any health/illness situation. Although all patients had a set of definitions about health, illness and relevant behaviours, it was found that the specific nature of these definitions varied according to the social location of the individual. This gave the ideological perspective a structural dimension. It recognised that the details of the perspective have their source, at least in part, in the wider and more general social structures within which people live; not all heart patients experience the heart attack in the same way. It was in this context that the experiences of women, as a specific sub-group of the heart attack population, were discussed.

The health professional ideological perspective was found to have a dimension that was specific to them as a group. This dimension related to a set of definitions about the "nature" of patients. Health professionals made certain assumptions about patients and treated them quite differently given their interpretation of these individuals. Thus, for instance, they would respond quite differently to males than they would to females. These responses, in turn, could be traced back to their differing understandings of the "nature" of males and females.

The ideological perspective is a dynamic concept; an individual's understanding of the world will change given new and

possibly conflicting information. The interaction between patients and health professionals has important consequences for patients. Such interaction is not as significant for health professionals. Patient-practitioner interaction is primarily one-way; from the doctor to the patient. In this situation the practitioner has the ability to control the encounter and can, to a large degree, define its outcome. In this sense the patient-practitioner relationship may be construed as primarily a power relationship and must be understood in these terms. It is necessary to focus upon health professionals and patient-practitioner interaction in the study of the subjective experience of patients because of this power relationship. That is, because health professionals can influence patients in ways that patients cannot influence health professionals, the subjective interpretations of patients are going to be quite heavily influenced by professionals. In this way, understanding patient perspectives necessitates an understanding of the professional perspectives and the interaction between these two groups.

Patient-practitioner interaction was found to have two very important consequences for patients and for the nature of their ideological perspectives. Conflict, or the potential of conflict is a routine part of this interaction. This conflict has two sources. Health professionals' definitions of ideal patients contain within them contradictory expectations. These expectations require patients to be sufficiently familiar with symptomatology to know when to seek medical practitioner advice and

when not to. But they also require the individual, having made such diagnoses, to surrender fully to the ministrations of the doctor. These definitions are clearly mediated to the patient. For instance, patients are aware that they must not "waste the doctor's time with trivial complaints" to such an extent that Comaroff (1977:123) suggests that the definition of the doctor as a busy man(sic) almost rates as a cultural premise. These conflicting expectations must be managed by patients in such a way that open conflict is avoided. This means that patients must at least "appear" to conform to these expectations. The net result, of course, is the reaffirmation the doctor's beliefs.

Conflict is introduced into the patient-practitioner relationship from a second source. Health professionals' wider definitions of patients (for example, definitions of who has heart attacks) may conflict with the characteristics of certain patients. Women and younger men were found to constitute two such groups in this study. It is reasonable to assume that in any illness context health professionals will have certain quite definite assumptions about "what their patients will be like" and that there will be instances where some patients do not conform to these assumptions. In any such situation it is axiomatic that the patient will give the appearance of conforming, or manage the conflict experienced in some other covert manner. If it is almost a cultural premise that the doctor is busy, it is also a cultural premise that patients do not challenge doctor's definitions.

The second important consequence of patient-practitioner interaction, as it is presently constituted, is patient alienation. The conflict experienced by patients is one contributing factor to this alienation. More generally, patient alienation is a product of the ideological perspective and its concomitant, the hegemonic power of health professionals. Patient-practitioner relations are not simple situations where the two parties interact and define the situation in a mutually agreeable fashion. They are highly structured situations with quite rigid definitions of the functions of all those involved. The source of these definitions originates in the health professional group and is, thus, controlled by that group.

The outcome of the doctor-patient exchange is the re-affirmation of medical hegemony. This involves the suppression of those aspects of patient ideology that conflict with the medical definitions of reality. Furthermore, the active participation of patients in this process is required. This results in the denial of the significance of any other ways of understanding illness. The success of medical hegemony is further ensured by the structure of the medical system; it could not be accomplished by health professionals alone. Rehabilitation groups did provide a forum where some areas of medical hegemony could be challenged. However, such challenges did not affect such fundamental areas as the nature of the doctor-patient relationship. They were confined to small changes in the lives of the individuals who participated in them. In terms of the

quality of life at that level, they were successful. However, in terms of effecting changes in the structural dimension of the medical system, they had no effect.

Patient alienation is an inevitable product of the medical system; its structure virtually defines it. By having exclusive control over knowledge, which is treated as private property, health professionals ensure that the lay population does not have the ability to cure itself. More importantly, it ensures that in the effort to secure a cure they will surrender control over their bodies to the health professional group. Alienation is also ensured by the nature of the definitions of health and illness that are adhered to by this group. As has already been shown, these definitions are devoid of a social dimension. Illnesses are treated without any attention to the social beings that possess the illness. Patients, however, see their illnesses as social experiences. This conflicting understanding of the "nature" of illness results in alienation for the patient. Indeed, it cannot be otherwise, for the nature of the power relationship between patients and health professionals ensures that patients will not openly challenge the health professionals' definition of the situation.

Footnotes.

1. To an extent, at the point of sale health care is state subsidised; the individual does not always have to directly bear the cost of a service. However, the point here is that the forces which determine the nature and the price of health services are rooted in the capitalist system of production. As such, they are commodified.
2. For example, Freidson's book Professional Dominance(1970), Barrett and Roberts(1978), Graham and Oakley(1981) and Wallach-Bologh(1981) all note that the doctor-patient relationship is primarily a power relationship.
3. Of-course, there are other groups that this study could not identify, largely due to the small sample size. One such group would be Polynesians. This group comprises a significant group of the heart attack population, but only comprised two individuals in this study.
4. See discussion of the Health Professional Ideological Perspective.
5. See, for example, the Heart Foundation pamphlet, Angina in Appendix 2.
6. See Appendix 2.
7. "work" is used to refer to paid employment. This is to distinguish between paid employment and unpaid domestic work. If work is used to refer to paid employment, then domestic labour tends to become something other than work.
8. The ARCOS study is the Auckland Regional Coronary and Stroke Study. This is a large and ongoing study of these two diseases in the Auckland area. The smaller project which is discussed here is an unpublished research project by a group of Auckland medical school students (1981).
9. For example: Barrett and Roberts (1978) Graham and Oakley (1981) Wallach-Bologh (1981) Rakusen (1978).

10. Graham and Oakley (1981:63) also note the problems which patients and doctors have in communicating effectively. This is also discussed in this chapter under the heading getting explanations.
11. The ideology is labelled "medical" rather than health because the emphasis of this section is on the origin and location of this ideology in the philosophy of medical practice. As such it cannot be considered a "health" ideology because the focus of health practitioners is primarily upon strictly medical issues.
12. Eliot Freidson; Professional Dominance has provided the most comprehensive analysis to date on this concept.
13. There are, of course, exceptions to this. However, it is felt that these exceptions are of the type that proves the rule rather than indicating a new development. On this point Barrett and Roberts concur: "In our research we have studied the average GP rather than sought out the rarer, progressive, experimental doctor. Conversations with GP's who espouse left-wing, self-help or feminist views merely serve to confirm the numerical insignificance and powerlessness of such persons in the profession as a whole"(1981:43).
14. The concept of the sick role was first put forward by Parsons in The Social System(1951:428-479).
15. Navarro also talks about the mystification that characterises the medical system in Medicine Under Capitalism 1976:184.
16. Barrett and Roberts (1978:42) discuss Zola's (1975) ideas that the medical profession not only acts as an institution of social control, but that it also has successfully expanded its empire in recent years to such diverse areas as the environment, and technical and religious matters.
17. See discussion of health practitioner attitudes to patients of differing backgrounds in Chapter Two page 81
18. See footnote 13.

19. See, for example, quotation from respondent in Chapter Two, page 123 expressing this confusion.
20. Barrett and Roberts (1978:45) note the tendency of doctors to see female patients as being more psychosomatic than male patients.
21. Wallach-Bologh (1981:192) notes the way in which the medical profession steadfastly refuses to accept that at least some illnesses have a proven (from epidemiological studies) social and class base to them.
22. Again, this was not a revolutionary awakening. Rather it was a small shift in the way in which individuals approached and talked about their health and the medical system.
23. In instances where the wife took over things such as lawnmowing it was often suggested (by doctors, nurses and husbands alike) that she would probably be grateful for the extra exercise. However it was never suggested that husbands should do more jobs around the house, much less that they might appreciate the extra exercise that would be gained from such activities.
24. See also Barrett and Roberts;(1978:44) on recommendations of medical practitioners that women give up unpaid work to enable them to cope with the housework rather than suggesting that the division of labour within the household be redistributed.
25. Barrett and Roberts;1978:45 also note the tendency of medical practitioners to see women as more routinely suffering from psycho-somatic illness than men.
26. An example of this was a woman who, having had three heart attacks within 18 months had been told to give up her "work" so that she could cope better with the housework. This woman explained that she really hated housework and being in the house all day. She missed the freedom and social contact that her "work" had given her. She had also been told to give up smoking and she explained that now that she wasn't working she was so bored and lonely that smoking was one of the pleasurable activities she had in her day and it was, thus, extremely difficult for her to give up. She was told that she just had to. She explained how she had said to her cardiologist that "your husband can be cruel to you in ways other than beating you up". The cardiologist felt that this

woman "had problems" and referred her to the hospital psychiatric services. At the time of the second interview this woman was undergoing an intense course of anti-depressant drug therapy. At no time in the course of this woman's contact with health professionals was it suggested that her depression was a quite natural response to the extremely difficult and unsatisfactory circumstances in which she found herself. Similarly, it was never suggested that her home circumstances could be altered so that she would not be kept so busy by housework that she couldn't hold down a paid job as well. Throughout her contact with the hospital the focus of attention was upon her and the way that she didn't "fit" into her home situation.

CONCLUSION.

The conclusion to the previous chapter provided a detailed summary of the major theoretical findings of the research. The aim of this section, therefore, is to provide some general concluding comments upon the overall approach adopted by this thesis.

The attempt to come to an understanding of the heart attack experience as a subjective event has demonstrated that it is necessary to move beyond the traditional symbolic interactionist approach. The adoption of a strict interactionist framework would have meant that the attempt to analyse the research findings (Chapter 4) would have been an unnecessary activity. Traditionally, interactionist works have focused upon providing an account of a particular event or experience, rather than upon deriving theoretical concepts from such accounts.

During the fieldwork and the preliminary writing of Chapters 2 and 3, it became apparent that to focus exclusively upon a descriptive account would yield only a partial understanding of this experience. In short, the necessity of attempting to integrate this account back into other sociological knowledge became an inescapable conclusion.

The search for a method which would permit a more complete, theoretical understanding, focused attention upon the works of Glaser and Strauss, and especially upon The Discovery of Grounded Theory(1967). The motivation to develop an interactionist method that was capable of generating theory was sound. In particular, the early part of the Grounded Theory method was found to be helpful in the effort to move beyond a descriptive account of the research findings. However, in the last stages of this research it was found that this method did not, in fact, generate strong theory. Thus, the last stage of the theory generation process was modified. This involved developing a technique labelled the "theoretical interpretation" of the descriptive account of the research findings. This step allowed these findings to be integrated back into sociological theory more generally.

The refinement to the Grounded Theory method meant that, in addition to providing an understanding of the heart attack experience, it has been possible to make a contribution to the theory which informs the sociology of health. The "theoretical interpretation" of findings has also enabled an understanding to be developed of what initially appeared to be anomalous information. For example, developing an understanding of the experiences of women heart attack sufferers was considerably facilitated by the application, to the research account, of feminist theoretical concepts. This meant that women's experiences could be seen partially as a product of their position in society as women. In so doing it greatly facilitated

the understanding of the differences in the experiences of females and males who have heart attacks. Of course, it also added another dimension to the understanding of the general position of women and the role of gender in social relations.

It is hoped that the method adopted here has provided an additional avenue for the development of theory that is grounded in the subjective experiences of individuals. For it is felt to be of considerable importance that research which attempts to come to an understanding of the subjective realms of individuals lives also attempt to link that realm back into the social structure of which those individuals are a part. To do this it is necessary that the understanding of the subjective, be tempered with an understanding of the social structures which impinge upon those individuals and it is the method which has been adopted here. The application of other sociological concepts to the research results is one method for effecting this.

APPENDIX I:

Demographic Information and Information
to Chapter 2, Sections two and four.

I General Demographic Information.

Table 1.

Age/Sex Distribution of Subjects.

<u>Age</u>	<u>Sex</u>	
	<u>Female</u>	<u>Male</u>
35-39	0	2
40-44	2	4
45-49	0	0
50-54	1	5
55-59	1	7
60-64	0	5
65-69	3	4
70-74	1	3
75+	1	0
	-----	-----
	9	30

Occupational Classification.

The occupations of respondents prior to the heart attack are listed below. Respondent classification of occupation has been used in preference to a predetermined occupational ranking (such as that used in the census). It was found that such categorisation reduced the occupational variety of this sample to such an extent that the groupings became virtually meaningless.

Table 2.

Occupational Classification.

Administrator	Inspector of Dangerous Goods
Manager	Accountant
Housewife	Technical Manager
Housewife	Doctor
Retired School Teacher	Business On Own Account
Newspaper Delivery Contractor	Technician
Foreman	Director
Farmer	Pensioner
Retired Agricultural Instructor	Librarian
Science Technician	Retired Panel Beater
Retired Foreman	Taxi Driver
Retired Farmer	Retired Clerical
Retired Lawyer	Manager
Taxi Driver	Pensioner
Car Salesman	Retired Farmer
Retired Storeman	Retired Tradesman/ Businessman
Clerical	Housewife
Retired Draughtsman	Clerical
Foreman	Housewife
Retired Welder	

Table 3.

<u>Ethnic Status</u>	
New Zealand Maori	2
New Zealand European	29
United Kingdom	5
Australian	2
Fijian European	1

	39

Table 4

<u>Marital Status.</u>	
Never Married	3
Married	32
Widowed	3
Divorced	1

	39

II Information Relating to Chapter Two, Sections II and IV.

This information relates to the first interview only.

Table 5

The Heart Attack.

a) Onset of Heart Attack

While doing more than usual amounts of physical exercise (or shortly after)	10
At work (includes some of the above)	8
In bed or resting/relaxing	18
Time unknown)	2
Travelling or shortly) includes some after) of above	7

b) Pains Were Attributed To:

* Pre-existing non-heart related condition.		4
amputated finger) diagnosed by	
sprained neck) doctor	
ulcer pains) diagnosed by	
kidney stones) individual	
* Pre-existing heart related condition		4
replaced aortic valve	1	
angina	3	
* Gussed or recognised it as a heart attack		11
gussed	5	
recognised	6	
* Indigestion		9
* Other		11
Pulled chest muscles	1	
Didn't think about it		
at the time	9	
Pleurisy	1	

		39
c) <u>Attempted other remedies first.</u>		
various remedies for indigestion		9
aspro		1
anginine		3
ulcer medication		1

d) Reasons for seeking help.

duration or intensity of pain	12
recognised it as a heart attack	13
onset of evening/darkness	3
no choice/others decided	9
thought it was something else	2

	39

Behaviour

a) Smoking.

Never Smoked	10
Ever Smoked*	29

	39

Smoking Before Heart Attack	22	of whom
No Longer Smoking	12	
Still Smoking	10	

* Seven respondents had given up smoking some time prior to the heart attack.

b) Dietary Changes Required as a Result of Heart Attack

None	14
Moderate	11
Major	14

	39

Of Those Who Had To Make Dietary Changes:

Not Kept to Changes	5
Kept to Changes	20

c) Recreational Activity Prior to Heart Attack.*

No Physical Component to Recreation.	19
Bowls (indoor and Outdoor)	3
Golf	5
Walking (casual)	4
Walking (specific for health)	1
Fishing	1
Swimming	2
Tennis	2
Yachting	1
Basketball	1
Diving	1
Squash	1
Gardening	12

* Some respondents had more than one recreational activity.

APPENDIX II:

A Sample of Information Given to
Individuals While in Hospital.

QUESTIONS AND ANSWERS

for the patient who has
been told he has ANGINA

WHAT IS ANGINA?

Angina or *angina pectoris* is a pain or discomfort which occurs with various heart disorders. The fundamental cause is an insufficient flow of blood through the coronary arteries which carry fuel to the heart muscle itself. The pain of angina is usually felt in the centre of the chest but may spread or even be confined to the arms, the neck and jaw, or through to the back. Angina is usually a constricting pain or tightness, which may restrict breathing, but it may be merely an unpleasant feeling of weight on the chest. Brief, sharp or stabbing pains near the left breast are usually not angina, nor due to heart disease.

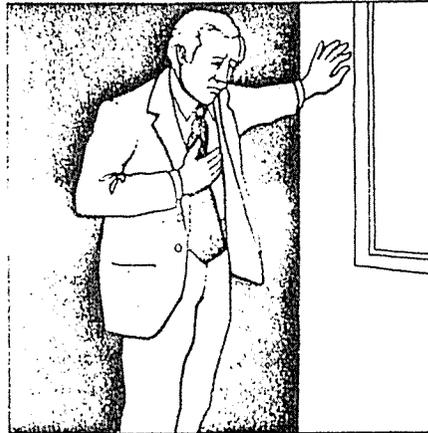
WHAT DISEASES MAY CAUSE ANGINA?

If your doctor has told you that you have angina, it is very likely that you have *coronary artery disease*. The term angina is often used as if it is a disease itself but this is merely a matter of convenience. In coronary disease, fatty and other material has been laid down over many years in the inner lining of these arteries causing narrowing or even obstruction. Sometimes angina can be caused by other heart complaints including valvular disease and even congenital heart disease in children.

WHAT DOES ANGINA MEAN FOR ME AND MY FAMILY?

If your doctor has told you that you have coronary artery disease you must face up to this and even be thankful that you have had this warning and can now take action to help yourself. Probably you have had the disorder for years because it starts early in life but produces symptoms only when one or more of the arteries has reached a certain degree of narrowing.

Angina is common and is becoming more so. It used to be thought that coronary disease was always a very serious disorder with a poor outlook. We now know that many patients who suffer from angina can live long and useful lives, and frequently the pain does not get worse and may even disappear.



IF I HAVE CORONARY DISEASE WHEN AM I MOST LIKELY TO GET ANGINA?

Physical exertion is what usually brings on angina and this is called *angina of effort*. During exercise the heart has to pump more quickly and forcefully to deliver more blood to the muscles. This requires more energy and if the coronary arteries cannot deliver additional blood with oxygen, anginal pain may result. The amount of exertion required to bring on pain varies with different patients and in the same patient from time to time. Walking on the level may cause no trouble but going uphill or upstairs, hurrying or walking into the cold or against the wind, may bring on an attack. Meals may provoke angina and heavy exertion straight after eating should be avoided. Some patients get angina when leaving a warm room to go into a cold room or bed, or when entering a cold bathroom in the morning. Anger, nervous tension, and bad temper may all lead to anginal attacks and should be controlled. Sexual excitement may also cause angina.

Not all patients who have coronary disease suffer from angina of effort. It is common to recover from a major heart attack and have no pain or any other symptoms.

IF THESE THINGS BRING ON ANGINA SHOULD I AVOID DOING THEM?

It is wise to avoid provoking angina wherever possible and individual patients learn what they can and cannot do. The fact that you have angina does not mean that you have to stop all physical exertion; indeed, the heart's performance may improve as a result of graded exercise programmes. If you can walk 2 or 3 miles a day, providing you are not getting frequent pain, your heart will probably be the better for the exercise. More vigorous exercise may be recommended, but this should be done under medical supervision and after assessment of your ability to do this.

Some patients develop angina soon after starting to walk, but after this has passed off they may carry on indefinitely without further trouble. Your doctor will probably give you certain tablets officially called *glyceryl trinitrate*, and marketed under various brand names such as *anginine* or *trinitrin*. If you crunch or chew these they will usually relieve angina within a minute or two. It is sound practice to take one of these *before* any exertion or nervous stress, which you know from past experience will usually bring on a pain. This may prevent the pain and allow you to do more. Anginine tablets should be replaced by fresh supplies every year or two. Anginine relieves or prevents anginal pain; it should not be used for other symptoms such as dizziness or breathlessness.

WHAT SHOULD I DO WHEN I HAVE AN ATTACK OF ANGINA?

If you are walking or exerting yourself, stand still or sit down and relax; usually the pain will pass off in a few minutes. Most patients find that one or even half an anginine tablet dissolved under the tongue or chewed will give prompt relief. It is not essential to take a tablet if the pain passes off quickly with rest and it should be seldom necessary to take more than two tablets for one attack of angina. If the pain lasts more than fifteen or twenty minutes or is more severe than usual, or if it is brought on more readily than before, you should contact your doctor. It is quite common to feel a slight headache or throbbing in the head after taking anginine but this should not last long. If anginal pain should wake you from sleep, take a tablet and sit upright and sleep with extra pillows. Don't forget that not all chest pain is due to heart disease and there may be other explanations.

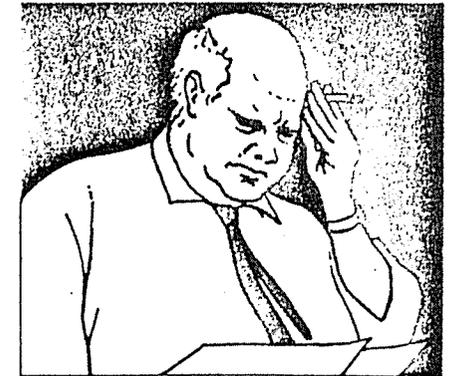
DOES EACH ATTACK OF ANGINA DAMAGE THE HEART?

Certainly not. Angina causes temporary cardiac distress, but usually no permanent muscle damage results. Patients may have angina for 10 or 20 years without developing heart muscle damage.

WHAT IS THE DIFFERENCE BETWEEN A HEART ATTACK AND ANGINA?

The same disorder causes both conditions — namely, coronary artery disease. When a coronary heart attack or thrombosis occurs there may be an actual blockage of one of the narrowed arteries and this leads to an area of muscle damage within the heart. This is referred to by doctors as an *infarction* and by patients as a heart attack. This may cause severe pain similar to angina of effort, but it persists longer and usually occurs without exertion or other obvious cause.

Patients who have had angina are more likely to have a heart attack than normal people but it is not inevitable. If you should have an unexplained severe prolonged attack of pain associated with faintness, vomiting or other symptoms, you should seek urgent medical help. If you cannot obtain this, you should go to a hospital.

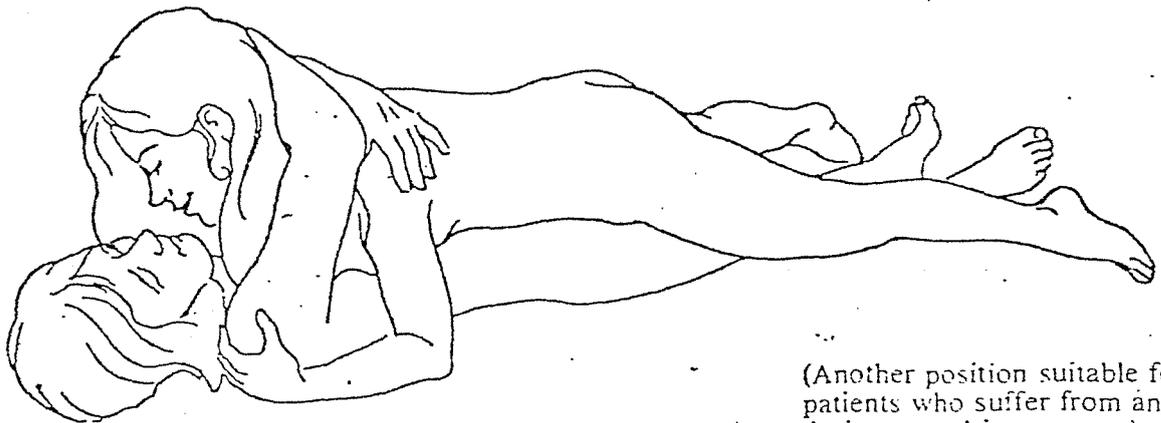




(Suitable for male patients with cardiac failure)



(Suitable for male patients who suffer from angina during sexual intercourse)



(Another position suitable for male patients who suffer from angina during sexual intercourse)

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