MORAL TALES: INTERVIEWING PARENTS OF CONGENITALLY ILL CHILDREN

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Thesis presented for the degree of PhD in the
University of London

July 1982

Goldsmiths' College

For Jan and Nina

ABSTRACT

The thesis is a sociological study of parents' responses to congenital illness in their child. The parents of 27 children suffering either from congenital heart disease or a cleft palate/ hare lip were administered semi-structured, tape-recorded interviews in their home following each outpatient and inpatient contact and also in hospital during the child's inpatient stay. The thesis critically examines psychological, psycho-analytical and sociological explanations of parents' responses. Following arguments developed by Voysey (1975), these responses are treated as situated accounts constructed for the research interview which display the respondent as a morally adequate parent. The normative character of the accounts is demonstrated by a crude quantitative application of Sacks' analysis of descriptions (Sacks 1972). The results support the qualitative analysis of a number of topics. These include parents' responses to health professionals, to a disfigured baby and to child-rearing and their interpretations of the causes of the illness. Close attention is paid to the construction of accounts, particularly the role of the interviewer in this process. Policy implications are derived from the analysis which, unlike those based on a psychiatric model, seek to introduce organizational structures consistent with the moral order of parents and staff. The working of a clinic intervention study is described. Finally, the thesis suggests implications of the research for interview studies of familial responses to other medical conditions including mental illness and serious adult illnesses.

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Acknowledgements

My first thanks are due to the Social Science Research Council which funded the project on which this thesis is based. I would also like to thank the children and parents who so kindly consented to participate in this study, some of them under very stressful circumstances. My gratitude is due to the staff of the Brompton Hospital Paediatric Cardiology Unit, particularly Dr E. Shinebourne and the staff of Sydenham Children's Hospital, led by Mr D. Forrest, for their co-operation and assistance throughout the research.

Robert Hilliard and my predecessor, Mary Kirk, carried out many of the interviews used in the study for which I am extremely grateful. Sarah Montgomery typed and retyped chapters with extraordinary patience and good nature.

Finally, I would like to thank my supervisor, David Silverman, who made so many helpful comments and suggestions during the writing of this thesis and without whose encouragement I doubt whether it would have been completed. Needless to say, he bears no responsibility for its limitations.

Chapter 1

INTRODUCTION

1 Becoming a Researcher: a Personal Account

This study is about parents' responses to congenital illness in their child. I show how parents account for their experiences in the research interview and, in particular, the many complex ways in which they formulate a moral identity for themselves through the construction of their talk. The development of the view of parental responses as moral accounts is evidence of the changes which have taken place in my work since I first embarked on medical sociological research. I will briefly consider some of these changes before I outline the origins of the present study and describe the organisation of the thesis.

My earlier study was designed to document the practices of a general hospital psychiatric unit (Baruch and Treacher 1978). These units were to replace the mental hospitals and had become a crucial element of mental health policy following the 1959 Mental Health Act. Like many changes in therapeutic practice in the National Health Service, the new policy had not been subjected to adequate research before its introduction (Cochrane 1972, Little 1974).[1] Also, psychiatry had been on the receiving end of a great deal of criticism from within its own ranks (Laing 1967, Szasz 1962), from sociologists (Scheff 1966), Goffman 1968a), from historians (Foucault 1967) and novelists (Keysey 1962) at the time the research was contemplated.[2] While most of these influential works were published in the early and mid-1960s, their impact occurred in the late 1960s and early 1970s. The study was greatly influenced by these radical critiques of psychiatry and, like them, produced findings which were highly critical of the psychiatric profession. Unfortunately, these criticisms tended to obscure the part of the study devoted to documenting the role of patients' relatives as the patient passed through the unit. As Thorley and Stern (1979) generously state, the research 'provided rich anecdotal evidence of the process by which relatives of in-patients in a leading British psychiatric unit have their non-psychiatric constructs and explanations medicalized' (p.193).[3] Following the publication of the book, this evidence was ignored by health professionals and academics alike in favour of the claims made about the psychiatric profession. Indeed, the period following publication provided this investigator with a salutory lesson about the possibilities of sociological research in highly sensitive areas of social life, especially those involving the sensibilities of professional people. Members of the psychiatric profession were extremely hostile to the research for understandable reasons, while the ancillary mental health professions predictably supported it.[4] Academics criticised it on methodological grounds and the university mental health department responsible for the unit reacted by restricting access of non-medical researchers. Thus I was forced to conclude that radical critiques far from creating radical change may reinforce and entrench existing positions. Let us now consider three related aspects of my earlier research which are taken up quite differently in this study. They include:

(a) the view of the doctor-patient relationship;

(b) the status of the research methods;

(c) policy issues.

The view of the doctor/patient relationship

This is by no means the only study which has taken a hefty swipe at the medical profession. In line with its historical conception of the way the psychiatric profession had colonised the mental health field, relegating other mental health professions to minor roles,[5] consultant psychiatrists were portrayed as self-interested; exploitative of patients and their junior members of staff; and incompetent. The superordinate-subordinate relationship existing between psychiatrists and patients was criticised and was said to require reform.

The documentation and radical critique of medical dominance is, of course, a fashionable feature of medical sociological research and theorising[6] but it has received a great deal of criticism in recent years. Strong (1979a) has argued that such views can be traced to social scientists failing 'to understand themselves and their position within society' (p.205). This leads to distortions of the medical enterprise. Medical sociology, like the medical profession, seeks to advance its interests as a profession and, therefore, it is in its own interest to discover and publicise 'nasty things about doctors' (Strong, 1979a p.205). There is little doubt that the ground for my criticisms of the psychiatric profession was fertile in terms of two principle determinants of professional strategy identified by Strong. Psychiatry had been successfully penetrated by social scientists and as we have seen, was in a state of crisis. Thus I and my co-author claimed in the Preface of our book that we were in a position to succeed 'in contributing to the ongoing discussion of the best ways of tackling mental health problems' (Baruch and Treacher, 1978 p.x). In addition, our political sympathies attracted us to those who were perceived to be the 'underdogs' i.e. mental patients and made us hostile to those seen as the 'oppressors' i.e. doctors. From a sociological perspective, our position was influenced by the underdog tradition associated with the Chicago School. Hence, it was inevitable that a highly critical view of the psychiatric profession would emerge regardless of any empirical findings to the contrary.

The accounts in the present study also give grounds for arguing that doctors mistreat parents. For instance, they criticise doctors for being incompetent and insensitive to their needs. However, my approach is influenced by the new tradition of ethnomethodology and the old one of quantification which stretches back to the work of Durkheim. These provide for a different interpretation of respondents' criticisms of the medical profession. We shall see that such accounts tell us about the moral character of respondents and not the way they are in fact treated by health professionals.[7]

The status of the research methods

The study was carried out by following the careers of several patients and their families from the initial outpatient consultation through inpatient care and a year after the patient had been discharged. The patients and members of their families were interviewed periodically using semi-structured, tape-recorded interviews and all decision-making meetings relevant to their situation, including outpatient consultations and ward rounds,were observed. Also, tape-recorded interviews were administered to members of staff.

The research stance was similar to that proposed by Douglas (1972): namely, the investigator establishing as far as possible the validity of his data regardless of the methods used to generate that data. Thus the above methods were accorded equal status and were used to provide a unified account of the practices of a general hospital psychiatric unit. For instance, the accounts of patients and relatives about their relationships with the staff were checked by observing doctor/patient encounters, by interviewing the relevant members of staff about these encounters, and by documenting case notes. Likewise, the researcher's observations about the unit's decision-making practices were supported by data obtained from interviews with members of staff. Finally, the state of the unit was evaluated by comparing the findings acquired from these various sources against the researcher's notion of what constituted a proper mode of functioning.

The weaknesses of this approach will be examined in detail in the next chapter but two are mentioned here. First, it wrongly assumes that interview data are competitive with material derived from naturally occurring settings. In the present study, the research interview is considered as a situation in its own right with its own form of social organisation. Second, as the debate about functionalism in the 1950s and 1960s showed, assumptions about what constitutes a proper mode of functioning, whether applied to the practices of a hospital or to familial responses to illness in a member, inevitably are arbitrary. Put simply, they depend on the orientation of the investigator rather than on objective considerations. Indeed, one is forced to conclude that where medical sociological research is carried out in the context of a normative framework it is predictable that findings will be obtained which support the standards the framework invokes. This is a common feature of studies of doctor/patient encounters which are critical of medical dominance. As Silverman has argued 'It is easy, after all, to show that doctors are usually in control of consultations. But the polemical weight of this ever-repeated research "finding" is limited when we recognise the truism that doctors do possess a specialised competence to which patients want access and this competence must have an impact on the social organisation of the encounter' (Silverman,1981a p.274). In the present study, parents' responses have not been evaluated according to pre-determined standards about a healthy or pathological adjustment. Nevertheless, I do propose a number of ways in which our respondents' adaptation to their situation can be assisted without assuming that what they report reveals unhealthy behaviour. This leads us into the matter of policy considerations.

Policy issues

Strong (1979a), in his review of the thesis of medical imperialism, notes that social science research, as an instrument in the formation of health policy, has been sharply attacked for being co-opted by those who have the power to frame health policy and in terms of the political dangers in supporting the status quo. Locker (1979), in a trenchant critique of such research, provides an example of the consequences of a management bias in medical sociology. He argues that 'the study of illness behaviour has been reduced to the study of help-seeking since this is relevant to the practical problems of disparity between need and demand, inequalities in access to medical care, the provision of treatment at an early stage of serious disease and the allocation of a large part of the General Practitioner's time to the management of "trivial" disorders' (p.xxxvi). The methodology of this research is rooted in variable analysis with the aim of identifying the interacting social and psychological forces affecting the individual as he reacts to changes in his state of health. Locker has criticised this approach for being deterministic and for offering inappropriate conceptions of social reality and social action. Dingwall (1976) has also made similar criticisms of positivism.

Let us consider two types of response to such research and, in particular, their contribution to policy issues. Policy issues, as defined by Silverman (1981b) refer 'to the debate about existing social institutions and to the practical struggles of their participants to maintain, reform or interrupt their functioning' (p.369). Ironically, the radical response, of which my previous work in psychiatry is an excellent example, is as rooted in a policy orientation to research as its predecessor. As we have seen, it was mainly concerned with contributing to the best ways of tackling mental health problems. Interestingly, radicalism frequently gives rise to the very inadequacies which its supporters are fond of levelling against managerialism. For instance, they attack the latter's methodological bias, particularly the use of models constructed from complexes of variables but are themselves prone to ignoring methodological problems that arise in describing and correcting the untoward practices of agencies of social control. The radical political persuasion of the researcher replaces rigorous methodology so that the changes the investigator proposes are about restructuring class inequalities and reorganising the institution under study.[8] As we have seen, these demands are unlikely to make any impact, except a negative one, on the participants.

A second response to managerialism has been work favouring the perspectives of symbolic interactionism and ethnomethodology and their derivatives. Instead of seeking to identify the variables which affect health and illness related behaviour, these perspectives are broadly speaking concerned with elucidating the processes of definition and evaluation out of which such behaviour emerges. Here I am not interested in the legitimacy of such perspectives or their analytic value. Rather, I wish to consider whether research based on them has made any contribution to policy issues. The extent of its contribution is best reflected by doing a content analysis of some recent work in the area. Locker's thesis (Locker 1979), which has been published, covers 400 type-written sides excluding the appendix. It devotes two sides to policy considerations, having discussed a wide variety of topics relevant to such considerations including lay accounts about illness behaviour, the causes of illness, recognising illness and going to the doctor. He is simply content to follow Fay's argument that an interpretative social science, unlike positivistic ideas of manipulation and control, 'increases the possibility of communication' by 'creating the conditions for mutual understanding between members of the same or different social order' (Fay, 1975 p.80). Presumably, Locker, in quoting Fay, is implying that if doctors had possession of his research findings about the way laymen respond to illness, then their practices towards patients might improve. In response, I would argue that it is not beyond our imagination to be more positive than this and come up with sensible policy suggestions. Silverman (1981b) makes this point in his review of a collection of empirical studies edited by Atkinson and Heath (1981) - he criticises the scarcity of practical proposals. The same scarcity is evident in Voysey's work on parents' responses to serious illness in a child where the last two pages are given over to policy matters (Voysey, 1975). Likewise, Atkinson and Drew (1979) eschew the possibility of making practical recommendations on the basis of their research into the organisation of verbal interaction in judicial settings. Indeed, the position they adopt on this issue comes close to the conservative posture of functionalism towards institutions.[9]

I would contend that it is not impossible to marry a technical or rigorous approach to the analysis of data with the generation of policy relevant suggestions.[10] Indeed, my approach, which is in part quantitative and so allows the analysis to be replicated, is likely to yield more reliable suggestions than a less rigorous one. Of course, the sceptics will question how it is possible to move from treating interview data as situated accounts to proposing suggestions which are obviously concerned with activities and states of affairs external to the research interview. My response is that whether parents' accounts actually describe their conduct on the occasions they are discussing is unimportant. What matters is that parents are able sensibly to apply them in the context of discussing issues to do with the family's situation. Therefore we should treat them seriously.

Let us briefly consider what this means in practical terms. In Chapter 6, I examine parents' accounts of how they make congenital illness compatible with normal childhood. One of the findings which emerges is that the nature of their response to their child varies according to his situation. For instance, when he is in hospital for surgery or investigation, they report treating him more indulgently than when he is at home. Now this may appear unremarkable until we consider the assumptions underlying psychiatric approaches to the psychological and social aspects of congenital disease in children. Such approaches tend to assume a static conception of both the child's and his parents' personality, as well as judging it according to healthy/pathological criteria. Given this orientation and since psychiatrists are likely only to be in contact with parents and children in a hospital setting, it is predictable that parental reactions such as indulgence will be construed as indicative of an overanxious personality which is likely to give rise to an overanxious child.[11] My findings suggest that this is not the case and that psychiatric techniques aimed at changing parental attitudes are undesirable while they fail to take account of the circumstances in which parents' responses arise. To sum up, policy suggestions are relevant to the medical sociological enterprise so long as they are based on sound analysis of the data and some will be proposed during the course of this study.

II The Origins of the Present Study

The study was part of a project funded by the Social Science

Research Council between 1978 and 1981. The aim of the project was first, to examine the impact of technology upon medical encounters in two contrasting hospital settings, a paediatric cardiology unit in a postgraduate teaching hospital and a cleft lip clinic in a suburban children's hospital. Second, it was designed to investigate the impact on the family of two medical conditions characterised by different symptomatology, prognoses and forms of medical intervention. Parents of a child suffering either from congenital heart disease or cleft lip were administered a semi-structured, tape-recorded interview in their home following each outpatient and inpatient contact and also in hospital during the child's inpatient stay. The interview study was my responsibility although the other researchers contributed to the interviewing of parents (see Appendix).

Since this is as much a study about interviewing as about being interviewed, I want to say something about the two medical conditions in order to give the reader some sense of the assumptions which informed the issues discussed with parents by the interviewer. These assumptions are a mixture of medical 'facts' and informed lay conceptions about such facts and their impact on the family. Additional material of this nature will be provided during the course of the thesis, and in the appendix on the collection of data. From the medical point of view, the causes of the two conditions are uncertain and this is the story doctors tell parents. However, many of the questions asked early on in the study were based on the assumption that the cause was a burning issue for our respondents regardless of doctors' seeking to reassure them that their past conduct was not responsible for their child's situation.

The identification of the two illnesses occurs in different ways. Congenital heart disease is present at birth but is not necessarily detected at this stage of the child's life. For instance, the heart disease of several children within the sample was not identified until their first school medical checkup. On the other hand, a cleft palate and hare lip are always detected at birth so that parents are in possession about the facts of their child's medical circumstances as soon as he is born. Again, the questions asked by the researcher assumed that the timing and manner of identification of the condition made an impact on parents.

The nature of the conditions varies as do their prognoses and the way they are dealt with by the medical profession. Congenital heart disease comprises a number of different conditions of varying degrees of seriousness.[12] Some produce symptoms, like blueness and breathlessness, which are patent to any observer while others do not produce any outward changes in the child which would suggest illness. Some conditions, like a small hole in the heart (ventricular septal defect), do not require any form of medical intervention while others are only capable of palliation and still others can be fully corrected. Those children who are likely to require surgery undergo a catheter test. This is a low risk investigative procedure which enables the details of the condition to be established with great certainty. Children of the parents who participated in the study were catheterised typically several months following their initial outpatient consultation. All of them were required to attend periodic outpatient consultations where their progress was monitored by the consultant and his team. The researcher took it for granted that the sense parents made of their child's condition and treatment as well as their relationships with doctors and hospitals were important for an interview study to explore due to their problematic and hence 'interesting' nature.

A cleft palate and hare lip can occur independently of each other although in the majority of cases in this study children were born with both these conditions.[13] The central issue from the medical and parental point of view is the correction of the hare lip (see plates 1 and 2 for the appearance of a baby born with a hare lip).[14] Thus it is surgical policy to correct the damaged lip as soon as possible after the birth of the baby (i.e. at three weeks) in order to ameliorate its impact on the family (see plates 3 and 4 for examples of a corrected hare lip). The correction of the cleft palate takes place at ten months. Both conditions give rise to further medical problems such as dental complications and speech difficulties. These children, as well as attending annual outpatient consultations with their parents, undergo speech therapy and intensive dental and orthodontic care. Most of them require further cosmetic surgery during the teenage years. It is the policy to leave surgery until then and to do a little correction a a time in order to take account of the child's changing physical development.[15] The researcher expected that the issue of the child's appearance would be crucial to parents' reactions to these conditions as would be their relationships with doctors and other health professionals.

The researcher also tentatively hypothesised that both congenital heart disease and a cleft palate/hare lip might make child rearing

Plate 1

Plate 2

Plate 3

Plate 4

problematic as well as creating difficulties for relationships within the family and between parents and those they came into contact with in their everyday lives. It is obvious that all of these assumptions have much in common with the idea that such conditions have deleterious consequences for the family and the child. In the next chapter, I question this idea when I examine psychological approaches to a disabled child in the family.

If my approach to the collection of data was based on such assumptions, then those which informed the analysis of the data could hardly have been different. They were influenced by the work of Voysey (1975) who developed the idea,proposed by Cicourel (1964) and Silverman (1973), that the research interview is a social situation in its own right. She also argued that parental accounts, far from indicating a breakdown in family functioning, depict their status as normal, morally adequate parents. The child's illness may constitute a challenge to their competence in public situations, like the interview, but they can meet and defeat this challenge by making situationally appropriate uses of the normal family in formulating accounts of their experiences. Hence the paradox of studies of parental responses to a seriously ill child is that the interviewer, in his discussion with parents, concentrates on the problems of having such a child, while they seek to display their essential normality. They do not deny that there are problems but claim that these are manageable within the context of normal parenthood.[16]

Voysey elaborated her thesis by investigating the relationship between what parents said and the meanings made available to them by public agencies officially empowered to control family related activities. However, her work contains two methodological weaknesses. First, she barely examines the complex ways in which respondents display their morality through the construction of their talk and second, she does not provide a way of identifying the normative character of parents' accounts. Thus one of my objectives is to give a detailed empirical substantiation of some of Voysey's ideas.

III The Organisation of the Text

In Chapter 2, I propose a method for establishing the normative character of parents' accounts involving a crude quantitative application of Sack's analysis of descriptions (Sacks 1972). Before doing so, I examine a number of different views of the status of interview material used in studies of parents' responses to serious illness in a child. Having established in this chapter that the central relationships reported in our respondents' accounts are between parents and the child and between parents and health professionals, I then examine what these consist of in the following chapters. Chapters 3 and 4 in the first half of the thesis consider the way their relationships with health professionals develop during the course of the child's medical career. In the early stages, they are characterised by conflict and the accounts take the form of an atrocity story, whereas in the later stages, parents report happily deferring to the consultants responsible for the treatment of their child while displaying a certain involvement in the medical process. The second half of the thesis examines various aspects of parents' relationship with the sick child. In Chapter 5, I examine their reactions to a disfigured baby, particularly their interpretations of its status and their experiences of early parenthood. The analysis shows the power of cultural stereotypes of normality for parents of the disfigured despite the finding of other studies that such stereotypes in no way reflect the experiences of mothers of normal babies. Chapter 6 presents the way parents of heart diseased children make congenital illness compatible with normal childhood. They propose various strategies for helping the child to adapt to his illness but these strategies are at variance with a number of assumptions about the illness and its treatment. However, they justify the strategies by appealing to familiar everyday conceptions of the child. Chapter 7 investigates parents' versions of the causes of the two congenital illnesses being studied. I show how previous attempts to understand this issue have failed to consider the complexities of respondents' accounting practices. I also examine the theories parents invoke. The final chapter responds to some possible criticisms of the approach I have adopted in the analysis of accounts. I then propose a number of policy suggestions based on the analysis in the preceding chapters. Finally, I suggest the implications of my approach for interview studies of familial responses to other medical conditions including mental illness and serious adult illnesses. I should add that I have elected to review most of the relevant medical sociological literature in the chapters dealing with the empirical findings which emerged from the project, although Chapter 2 covers a wide spectrum of studies.

IV Concluding Remarks

Until the 1960s, the major work in sociology included functionalism and other forms of large-scale theory; positivist empiricism in the form of survey research; and the empirical richness of the Chicago School with its tradition of participant observation research. The 1960s and early 1970s saw the deployment of a number of critiques against such work. Gouldner (1971), amongst others, provided an important theoretical critique of functionalism. Positivism was attacked for its concensus view of society, its determinist notions of human action and for using natural scientific modes of explanation (Douglas 1970, Taylor, Walton and Young 1973). The work of the Chicago School was criticised for trading off members' knowledge (Wieder 1971, Pollner 1974).

These critiques led to general programmatic statements about the character and direction of sociology. My work seeks to move beyond these critiques and statements towards the development of more rigorous methodologies which can generate soundly based theories and have soundly based policy implications.

Chapter 2

THE ANALYSIS OF INTERVIEW DATA: THE STATUS OF PARENTS' ACCOUNTS

A) The Interpretation of Interview Data

1 Introduction

It is striking how independent interview studies of parents' responses to different congenital illnesses in a child reveal remarkably similar findings. The extract below is taken from Burton's research into parents' reactions to their child's cystic fibrosis (Burton 1975).

Extract 1

Parent	I went to the baby clinic every week. She would gain 1lb one week and lose it the next. They said I was fussing unnecessarily. They said there were skinny and fat babies and I was fussing too much. I went to a doctor and he gave me some stuff and he said 'You're a young mother. Are you sure you won't put it in her ear instead of her mouth?' It made me feel a fool (p.29).

A second extract comes from our study of parents' responses to their child's congenital heart disease.

Extract 2

Parent	When she was born, they told me she was perfectly all right. And I accepted it. I worried about her which most mothers do, you know. Worry about their first child.
Interviewer	Hm.

Parent	She wouldn't eat and different things. And so I kept taking her to the clinic. Nothing wrong with her my dear. You're just making yourself... worrying unnecessarily, you see.

Both are retrospective accounts of the earliest stages of their child's career. The mothers say they were concerned about their baby's eating habits and so regularly took their child to the local baby clinic. They imply that they informed the clinic doctor of their worries who dismissed them as groundless and as those of over-anxious parents.

Yet these accounts are treated quite differently when analysed by the researchers. Briefly, Burton treats her findings as an accurate report of an external event and argues that parents' early encounters with medical personnel can cause psychological damage to the parents as well as lasting damage to the relationship with doctors. On the other hand, I see parents' talk as a situated account aimed at displaying the status of morally adequate parenthood. In this instance, the display is produced by the telling of an atrocity story (see Chapter 3).

These two views of the status of interview data are by no means the only ones to be found in recent research into family adaptation to serious illness in a child. The analysis of such data raises two issues, one of which is theoretical and the other methodological. It has been easier for researchers to put forward theoretical justifications for their interpretations of respondents' responses than to demonstrate the accuracy of these interpretations. Moreover, close examination of theoretical propositions reveals many weaknesses. The objectives of this chapter are:

(a) to examine a number of different views of the status of interview material;

(b) to propose and demonstrate a method of analysis based on the work of Sacks (1972).

It must be emphasised that in pursuing the first objective we shall limit ourselves to the examination of interview studies of parents' responses to serious illness in a child. However, the discussion is relevant to interview studies of other topics.

II The Psychological View

One familiar approach to the interpretation of parental responses has been to assume that illness in a child has deleterious consequences for both the family in general and the psychological state of its members. Thus parental statements are not considered in the context of the account they provide but are taken typically as indicators of some form of cognitive or emotional maladjustment. Examples of this type of approach are available in studies of parental responses to a variety of childhood illness including leukaemia (Friedman et al. 1963), cystic fibrosis (Burton 1975, Meyerowitz and Kaplan 1967), congenital deafness (Meadow 1968), congenital heart disease (Apley et al. 1967, Bentovim 1980), and cleft palates/hare lips (Lansdown 1981).

The model of parental response assumed by these authors is summarised by Meadow (1968):

'Parents of handicapped children are faced with multitudinous problems. In addition to the instrumental concerns of providing the special medical, educational, rehabilitation or correctional treatment required for the child, there are expressive concerns related to guilt, denial or "disavowal", feelings of incompetence or self-doubt and chronic sorrow (Zuk 1959, Davis 1961, Cummings 1966). The integration of the entire family may be threatened, the previous balance of relationships destroyed (Farber 1960, Jordan 1962). In short, the identification of a handicapped child often precipitates a full-scale family crisis' (p.299).

Researchers adopting this framework then proceed to view parents' responses according to whether they are healthy or pathological. For example, Friedman et al.(1978) distinguish between those responses that are constructive and realistic and those that are the converse and so indicate some form of psychological maladjustment. Thus seeking medical information is considered 'constructive only up to a point', but beyond this point it reflects increased anxiety or conflict which cannot 'be resolved by the acquisition of more detailed information about the disease' (p.78). Burton uses a similar type of interpretation. She argues that lack of knowledge of the child's illness on the part of working class fathers and their reluctance to learn more may be attributable,first to their greater unwillingness to assume responsibility,and second to their more pronounced tendency to deny the implications of the disease. In other words, psychologically they avoid the reality of their child's situation.

In these types of explanation the parents <u>reported</u> behaviour indicates an internal psychological state which produces the behaviour in question. Taken to its extreme, parental assertions which normalize the child's condition and family life may be discounted as defense mechanisms against excessive guilt or feelings to do with rejecting the child. In other words, many things parents report in relation to their sick child are taken to demonstrate some form of abnormal familial or psychological adjustment.

When a framework is used in this way it amounts to the imposition of interpretations by fiat on the part of the researcher since the criteria according to which parents' responses are judged as healthy or pathological are at best ambiguous and at worst non-existent. The problems with this framework are similar to those found in psychiatric diagnostic procedures. These procedures are supposedly objective but research has shown that decisions about the sanity of patients are often based on the subjective assumptions of psychiatrists about the people who present themselves at psychiatric clinics. As Rosenhan (1973) has demonstrated in his classic study, there is a tendency to designate sane people as insane.[1] Thus 'psychiatric diagnosis, in this view, are in the minds of the observers and are not valid summaries of characteristics displayed by the observed' (p.251).

There is a further problem with the framework we have been examining. It treats parents' reports as accurate depictions of events and states of mind external to the interview situation. While parents are likely to orientate themselves in this way when answering the interviewer's questions, there are good reasons for supposing that people's recall of many aspects of their behaviour is unreliable. As Strong (1979b) has argued '... we fail to notice much of what we do, for we attend only to those things that concern us most' (p.227). Moreover, what respondents say 'depends very much on what questions are asked, who asks them and the general sense of the occasion' (p.226). Even if respondents' reports were reliable, there is no way the researcher can check a reported internal state since he does not have access to such data. In summary, the psychological view of parents' responses does not provide a satisfactory account of the status of interview data.

III The Psychoanalytic View

A more sophisticated psychological interpretation of parents' accounts than the one we have just examined relates their production to internal feelings present at the time of the interview.[2] According to this view, the telling of an atrocity story is cathartic in that it enables respondents to rid themselves of pent-up feelings and emotions about doctors and their child's illness. Having done so, subsequent accounts depicting their co-operative relations with the medical profession and family adjustment reflect psychological equilibrium.

While this point of view represents an advance on the healthy/pathological framework insofar as it locates its interpretations within the context of the interview, it nevertheless has a number of weaknesses. First, it fails to consider the specific social and moral properties of accounts. Second, we would not expect an atrocity story to be repeated since the telling of it on the first occasion would have had a cathartic effect. In other words, repressed mental energy would have been released and dissipated. However, we find that respondents not only repeat such stories about their initial contact with the medical profession in the first interview but also in subsequent interviews, and these stories take the same form as when they were originally presented.

The central deficiency of this approach is that it wrongly equates the research interview with the psychoanalytic consultation. As conceived by Freud (1904), this situation is designed in order to minimise the influence of features external to the psychoanalytic process. In this way, the analyst and patient can orientate themselves to unconscious processes which are difficult enough to establish without the encumbrance of such features. Of course, outside the consulting room, relationships are mediated by social factors to such an extent that psychoanalytic investigation of situations like the research interview or large-scale social organizations is a methodological impossibility.

IV Sociological Perspectives

One sociological approach to the issue of what parents' accounts constitute is that suggested by Davis (1963). Unlike the psychological approach, the processes by which parents identify their child as ill are not assumed but are given central significance. In his study of parental responses to paralytic poliomyelitis in their child, Davis argues that parents seek to sustain a definition of their child as normal by two strategies, those of 'normalization' and 'disassociation'. 'Normalization' indicates the process whereby parents seek validation from others, whereas 'disassociation' refers to the avoidance of those who are likely to invalidate their definition.

Discussion of such strategies is important since the independence of parental definitions is asserted. Moreover, it has been found by Davis that family life, far from being thoroughly disrupted, continues with its existing style and structure. In other words, parents present a favourable picture of family life and one in which its integrity is assumed. Davis explains this finding by relating a number of variables such as mores, values, attitudes, religious and other principles to parents' accounts. Thus he proposes that parents are constrained to enact their roles with 'that blend of sorrow, courage, altruism and solidarity that American mores define as appropriate in such situations' (p.115).

As Voysey (1975) has pointed out in quoting Blumer (1956), this approach suffers from the 'short-comings in contemporary variable analysis'. Blumer says 'there seems to be little limit to what may be chosen or designated as a variable... variables may be selected on the basis of a previous impression of what is important, on the basis of conventional usage, on the basis of what can be secured through a given instrument or technique, on the basis of the demands of some doctrine, or on the basis of imaginative ingenuity in devising a new term' (p.683). Blumer also argues that variables have no fixed indicator and that 'indicators are tailored and used to meet the peculiar character the local problem under study'(p.685). His final criticism of this form of analysis is that although the data and findings on which it is based are here-and-now, this context is excluded in presentation. A further criticism, which will be discussed when we have examined West's (1979) approach, concerns how such variables might actually produce parents' responses.

West (1979), in his study of parents' responses to their child being labelled epileptic, has a more articulate view of the status of interview data than Davis. On the one hand, he recognizes the situated nature of parents' accounts and sees them 'as procedures, resources or methods by which they do interpretative work in particular contexts' (p.719). He also notes that respondents erect 'fronts' in the interview situation and that the content of their accounts may be a product of what they expect from the interviewer.

On the other hand, his view of interview data goes beyond seeing it as situated. He supports the view of Douglas (1972) that the investigator's 'interest has to be in judging the validity of the data one collects regardless of the method used to generate that data' (p.94). In West's case, this was pursued in two ways. First, he sought to breach 'fronts' erected in interviews, or what he terms a 'presented reality', by developing a closer relationship with families than is usually the case in research. In this way , he hoped to get close to their own subjective reality. For instance, he claims that people often present themselves according to the moral prescriptions of the 'official'/medical perspective. Hence, 'whenever a particular topic suggested a very definite "ought-type" response', he adopted 'an attitude of scepticism checking and re-checking the respondent's answer' (p.725). The second way involved invoking the principle of triangulation (Denzin 1970). Here multiple methods of observation bearing an empirical reality are used in order that valid sociological propositions may be derived. In an ideal research world, this means using diverse data sources, multiple investigators, different theoretical perspectives and a combination of methodologies. For instance, one of the areas West investigated in the interview was parents' conceptions of their encounters with the medical profession. He discovered that 'doctors were portrayed as evasive about diagnosis, or even providing no diagnosis at all, uncommunicative about prognostic information, medication and other rules of patient management, avoiding questions about problems, stalling and so on' (p.726). According to West, this was a reverse conception from the one he expected since he had postulated that the physician was the most important significant other in constructing and shaping an 'epileptic career'. He therefore checked the validity of parents' claims by observing a number of outpatient clinics and found them to be accurate.

Although seeking to discover the truth is a worthy aim on the part of a researcher, West's proposals contain a number of weaknesses. Let us first examine his ideas about breaching fronts. The first problem is to decide what statements are to count as evidence of a front. Presumably West would suggest an 'ought-type' response but, as I shall argue shortly, accounts as a whole are constructed according to norms which are prescriptive; in other words, *all* responses are 'ought-type' responses. In response to this West would argue that he is referring to those statements which conform to the medical point of view. Yet one of the instances he presents of parents' judgement of the medical profession could hardly be called conformist (see p. 36). Thus he would have to explain why parents sometimes appear to erect a front and at other times deviate from the 'official' morality.

Of course, he might reply that non-conformist statements are produced when the researcher has become closely involved with his respondents. However, we are entitled to know in advance the criteria or rules which establish whether the investigator has formed a relationship of a different order from the one usually found in field work. Even if we accept that a close relationship is formed between the investigator and the respondent, the question arises as to how we know that a different account is any truer than a previous one. It is plausible to suggest that when a respondent is faced by an interviewer who questions the validity of his account he may feel obliged to construct an alternative version in order to conform with the interviewer's expectations.

The researcher would solve this problem by observing the situation which the respondent reports, like West did when he observed outpatient clinics in order to check the validity of parents' accounts about their encounters with doctors. The adoption of this procedure has the following consequences for the status of parents' accounts. First, as Halfpenny (1979) has suggested, parents' responses are taken to reflect their mental images of doctors (or beliefs) which cause their behaviour. Second, in observing outpatient. consultations as a basis for measuring the reliability of parents' beliefs about doctors, West seems to imply that these beliefs are caused by what happens on such occasions. In other words, parents' accounts are reduced to the level of a dependent variable, the nature of which is determined by an independent variable - the outpatient consultation. However, as Blumer (1956) has argued, it is a fallacy to assume that the influence of the latter is automatically exercised on the former since there is a process of interpretation intervening between the two. In West's case, we are not told what this consists of, so we can only assume that the intervening variable consists of unobservable psychological processes. The same criticism can be made of Davis in that he also fails to explain how American mores and values are transformed into parents' beliefs. As Voysey (1975), Blumer (1956) and others have argued, one must examine the actual ways actors invoke features of their culture rather than impose them on the data if one is to account for orderly social action. This implies a different status of interview data from the ones we have been considering. We shall now consider what this comprises.

V The Display of Moral Adequacy

Before presenting the views of Voysey (1975) and Locker (1979) on the status of parents' accounts about a seriously ill child, let us consider the status of accounts generally. Following arguments developed by Cicourel (1964), Garfinkel (1967) and Sacks (1972), Cuff (1980) states that an omnipresent feature of all accounts is their display of moral adequacy. Any account can be scrutinised in terms of whether it comes over as a 'proper' description of what is happening in the social world and how it displays the character of the teller. The issue of moral adequacy is most evident when accounts are about a *social unit* of which the teller is a member.

In the present study, the nucleus of the social unit consists of parents, who are also the interviewees, and their children.

When a teller recounts events to do with himself and other members of his social unit, he is talking about unit events in which they are inextricably implicated and in which they are morally involved. By moral involvement Cuff is referring 'to the way members can standardly and routinely deploy their social knowledge about the nature of the unit for what has happened' (p.36). As we shall see, our respondents legitimately extend the notions of social unit and moral involvement to cover those members who would not ordinarily be considered to be part of their unit. Doctors are included in the parent/child unit because they are accorded competences not available to parents and which are called upon by them for some unit troubles.

Regarding the act of assigning responsibility for a unit trouble, Cuff draws our attention to the delicate nature of this task for respondents who are members of the unit, especially when they blame those who are not present. They are likely to be heard as one-sided or partisan and so be morally condemned unless they assemble accounts in such a way that they consider their own involvement. In practice, this means developing versions of the event under discussion which consider the possibility of the respondents being responsible for the unit trouble. Cuff calls these versions 'determinate alternative possible accounts' and suggests that these must be attended to if the account is to be heard as morally adequate. As will be seen, a central aim of this study is to show how parents display the status of moral adequacy by presenting determinate alternative possible accounts when considering unit troubles or problems.

Cuff's theoretical orientation is implicit in the work of Locker (1979) and Voysey (1975). Locker treats respondents' descriptions as situated accounts. He argues that they are constructed to accomplish the interview and demonstrate competence as a respondent. His respondents have the status of wife and mother and he claims that 'what is known about these statuses provides (them) with a vocabulary for describing their experiences in ways which render them common' (p.121). Via these processes, the world becomes cognitively manageable and intersubjective. The importance of these statuses is twofold. First, they and what is associated with them may be invoked to account for action. Second, some of what respondents say in interviews may be read as demonstrations of adequate performance in given statuses such as mother.

According to Locker, this status has a number of important implications for those who occupy it since children are held to be non-persons and incompetent. First, parents may be held to constitute the moral character of their child in as much as they are held responsible for his or her behaviour. Thus the deviant status of a child, such as that conferred by congenital illness, may be taken to indicate a moral defect in parents. Second, parents are held responsible for providing an environment which satisfies the material and emotional needs of their children. Inadequate parenthood consists in failing to provide for these needs and as such raises doubts about the moral character of parents.

Locker notes that while parents are held to be responsible for their conduct as parents on the assumption that an adult will know what is involved in bringing up a child and be motivated to act accordingly, there are limits to their child-rearing competences. Parents are not expected to handle all the problems that may arise when their child becomes ill and in such circumstances are justified in seeking expert help, indeed they are obliged to do so.

Thus Locker assumes that parents' accounts of their children's illness episodes are constructed in ways which allow them to be seen to conform to socially accepted cirteria attached to the role of parent which define good performance. Moreover, he assumes that their descriptions of their own conduct or other aspects of the world around them are displays of their personhood and their community membership. These descriptions provide for the interpretation of parents' actions as the conduct of moral actors acting in ways that might reasonably be expected of anyone in the same circumstances. Finally, he assumes that through their accounts parents demonstrate their access to a culturally acceptable stock of knowledge which they are able to employ to make adequate sense of their experience of the world. In accomplishing this, parents are able to present their experiences as part of a normal order.

Locker's theoretical orientation is rooted in Voysey's pioneering work on parents' responses to serious illness in their child. Like Locker, she treats parents' statements as situated accounts which are designed to produce a display of normal parenthood.

However, she is concerned to go beyond the situational determination of meaning since parents' statements may indicate less their own constructions than the imputations of others, in particular the social control agencies on which they rely. Here she draws on Douglas' (1971) notion of a public morality which is constructed and maintained by official agencies of control and to which members are accountable in sustaining a common order in public places. The agencies on which parents of sick children depend are those officially empowered to control family-related activities. They produce and uphold an official morality related to a conception of normal parenthood to which parents are held accountable since they are responsible for their child.

Thus Voysey treats parents' statements as public accounts which are so formulated that they appear to satisfy the official morality of normal parenthood. As such, they may tell us nothing about parents' activities which in practice may deviate from this morality. However, when called upon to talk about these activities they may invoke concepts like 'normal family life' to account for them. For instance, respondents can argue that mothers who go out to work do so to improve the family's standard of living and thus present an appearance which is congruent with the prescriptions of the public morality. To sum up, Voysey's claim is that 'Parents maintain a normal respectable appearance because they make situationally appropriate use of the normal family in formulating particular accounts of their activities' (p.56).

The theoretical contributions of Voysey and Locker have greatly influenced my own treatment of parents' accounts. However, there are two methodological weaknesses to be found in their work. First, they fail to show how parents display the status of moral adequacy through the construction of their accounts. The analysis in the following chapters makes up for this omission by giving greater attention to the process of construction of parents' talk than they do. Second, they in no way demonstrate the normative character of respondents' statements or provide a way of identifying the statuses to which these statements refer. Thus their interpretation of interview data is open to the charges of being selective and designed to fit their theoretical propositions. Equally, the analysis of respondents' talk which I present is open to the same charges unless I show its normative character and identify the relevant statuses. I intend to do this by applying an apparatus developed by Sacks (1972) for recognizing and identifying possible descriptions. The application will take a quantitative form.

B) Confirming the Normative Character of Parents' Accounts

I Introduction

Sacks allocates a major role to the way members use norms to relate sequences of activities or states of affairs. His comments about norms also apply to hearing descriptions of activities. Let us examine the following statements from Extract 2 in order to show the importance of norms in the making and hearing of descriptions:

> 'She wouldn't eat and different things. And so I kept taking her to the clinic.'

As members, we know that there is a norm which can be stated as: a mother ought to take her baby to the clinic when it isn't eating. This norm allows the pair of actions 'wouldn't eat' and 'kept taking her to the clinic' to be heard as a sequentially ordered pair. Thus norms are used 'to explain both the occurrence of some activity given the occurrence of another and also its sequential position with regard to the other' (Sacks 1972 p.339). Moreover, the norm provides 'the relevant membership categories in terms of which identifications of the doer of those activities for which the norms are appropriate are formulated' (p.339). In other words, although the doers in the above statements are referred to as 'she' and 'I', through our knowledge of the norm relating 'not eating' to 'being taken to the clinic', we know that 'she' refers to the membership category child and that 'I' refers to parent. According to these membership categories, the appropriate doers of the activities in question can be identified as baby and mother. Thus Sacks' apparatus can be applied to parents' talk in order to demonstrate how they use and how we hear them using norms in constructing their accounts as well as the membership categories to which these norms refer.

II Method

From a practical point of view, it was not possible for the individual researcher to carry out the proposed analysis on all the interviews amassed in this study.[3] It was therefore decided to analyse the story initially presented by respondents of their experiences in the first interview. At the beginning of the interview, the interviewer usually invited parents to present their version of events by asking the following types of question:

> 'We've got sort of a rough idea of what, you know, what we're looking for, so if you just kind of tell your story really of what happened.'
>
> 'Could you just sort of tell me the story, more or less

what happened about Jean?'

'And er... I mean maybe you could tell me something about well, just sort of history of er... well of of er what he's had and so on.'

'So what, was he born in hospital presumably?'

'Um for instance, when did you first hear about the murmur?'

'What happened from when he was first born?'

'When did you first hear about the hare lip... what did they first tell you?'

In answering these questions, parents provided a truncated account of their experiences. When they had completed this account the interviewer asked them to elaborate various aspects of what they had said. The analysis is taken to this point. The advantage of using the initial story is that many of the central features of the interview as a whole are discussed in a relatively short space. The sample membership totalled twenty-seven families and all the initial interviews are included in the analysis. Following the apparatus developed by Sacks, the researcher read the transcipt material as any reader might do and exhaustively noted all the pairs of actions or states of affairs described. At the same time, he identified the norm which sequentially related one action or state of affairs to the other, which also provided the relevant membership categories.

III Results and Discussion

The table below shows the frequency of the type of norm defined by the membership categories which connect one action to another. (We shall exemplify the nature of the norms below.) In each case, the first mentioned category indicates the member who has an implied duty towards the member indicated by the second mentioned category.

Table 1

	Norms	
Membership categories	No.	%
Parent - Child	160	51
Parent - Professional	86	28
Professional - Child	49	16
Professional - Parent	16	5
	311	100

We saw earlier how theories about the moral responses of parents to their child's illness stress the importance of the responsibilities towards children entailed by the status of parenthood. The limited analysis of the interview data empirically supports this view. Parent-child norms are central to parents' accounts and on their own amount to more than all the other norms put together. Thus when parents provide an account of their responses they are heard to attend to their duties, rights and obligations towards their child, even though they might have been expected to emphasise the medical aspects of their child's career, e.g. professional-child relationships. This state of affairs is even more striking when we consider that there are no appeals to the obligations or duties of children. As Voysey (1975) has suggested, following the arguments of Pucetti (1971), children are treated as temporary non-persons since their moral character is assumed to be in the process of formation. Pucetti has argued that the ascription of personhood depends on an object being accorded both an intellectual and moral character. This presupposes 'access to and familiarity with a conceptual scheme' and 'the ability to assimilate a conceptual scheme in which moral words and phrases have a place' (Voysey, 1975 p.31). Hence, children are non-persons and 'their behaviour is not, then, to be interpreted in terms of the motives assumed to inform adult conduct' (Locker, 1979 p.126). This view of children is reflected in the way parents do not invoke any norms indicating that their child has duties or obligations towards others. Indeed, we can argue that the frequency of parent-child norms is a result of the view of children as non-moral actors. Table 2 shows the distribution within the accounts of the sample membership of norms classified according to the medical conditions studied.[4]

Table 2

Total sample membership congenital heart disease (chd) = 15
" " " cleft palate/lip (cp/l) = 12

	Sample	
Membership categories	No.	%
Parent - Child (chd)	14	93
" " (cp/l)	12	100
Parent - Professional (chd)	15	100
" " (cp/l)	12	100
Professional - Child (chd)	11	73
" " (cp/l)	6	50
Professional - Parent (chd)	6	40
" " (cp/l)	7	58

We should note how parent-child norms are invoked by the entire sample, regardless of the child's condition. (There is one set of parents who does not invoke these norms and we shall consider this deviant case shortly.) This finding does not support the view which informs psycholgoical approaches to parents' responses that a 'serious impediment to deriving valid generalizations about the effects of long-term and fatal childhood illnesses upon family functioning relates to the specific character of the various disease entities' (Meyerowitz and Kaplan, 1967 p.250). Supporters of such approaches might be able to claim that parents make distinctions between the effect of different childhood conditions on family life. For instance, our sample members frequently claimed that they were fortunate that their child was not born with brain damage. Yet it is probably true that parents of a brain damaged child might claim that they are equally fortunate not to have a child with thalidomide type malformations. The point is that although parents distinguish between the effects of different medical conditions on the family, their methods of interpretation are similar. In saying this, we do not rule out the possibility that different illnesses may affect the character of parents' responses. However, this is an empirical issue and not one to be decided in an a priori way (see below for further discussion).

We shall now examine the nature of some of the norms invoked by parents. Table 3 shows the frequency of the different types of norms. Again, we should note the centrality of norms concerned with parenting.

Table 3

Types of Norm & Membership Categories	Norms No.	Norms %
Affective states and similar reactions to the child's illness and treatment (Parent - Child)	101	32
Action taken and decisions made in relation to child's illness (Professional - Child)	41	13
Action taken in relation to child's illness and treatment (Parent - Child)	38	12
Deferring to professional expertise (Parent - Professional)	38	12
Affective states and similar reactions to professional's judgements, decisions and actions (Parent - Professional)	38	11
Deferring to parents' rights (Professional - Parent)	16	5
Responsibility for child's illness (Parent - Child)	11	4
Knowledge about child's development and illness (Parent - Child)	10	3
Challenging and criticising the professional (Parent - Professional)	9	3

(Table 3 contd)

Types of Norm & Membership Categories	Norms No.	Norms %
Informing parents (Professional - Child)	5	2
Taking action (Parent - Professional)	4	1
Affective states and similar reactions to child's illness (Professional - Child)	3	1

The most frequently heard norm was concerned with the way a parent emotionally reacts to her child's illness. If we also include parents' affective reactions to professionals, then these norms were over three times more frequent than the next most frequent norm. We have been examining the initial story which contains some account of parents' responses to the earliest stages of their child's career. As we shall see in the next chapter, this account is often constructed in terms of an atrocity story where something untoward has occurred to the child involving both parents and health professionals. One of the central features of these stories is the way parents appeal to their emotionality as a normal, moral response of anyone who is in their situation. Hence, the frequency of this norm in the presentation of the initial story fully supports the importance given to it in the analysis of the atrocity story. Here are some examples drawn from the initial story of appeals to emotionality and the appropriate norm required to make sense of them:

Parents' Descriptions	Norm
(1) He's been lately for about a fortnight, 'e really wasn't well, that's the worst he's been, 'e was really ill and I was worried.	A parent has a right to worry about her ill child.
(2) I thought well, he's just gonna die, you know, I was in a right old state meself.	A parent has a right to be in a state about her child dying.
(3) And he said oh she's got a heart murmur. And then we got, I came home and had a good cry about it all.	A parent has a right to cry when informed by a professional of her child's heart murmur.
(4) Anyway she told me that it would be a slight hole so I was quite upset about it really.	A parent has a right to be upset when informed by a professional of her child's hole in the heart.
(5) She was very small and that frightened me.	A parent has a right to be frightened about a small baby.
(6) It was the initial shock. When the doctor came and said your wife and son are doing very well but he's got a hare lip and cleft palate.	A parent has a right to be shocked when informed by a professional of his child's hare lip and cleft palate.

While norms concerned with parents' affective responses were most frequently heard, norms to do with professionals' emotional reactions were least heard. Again, this is in keeping with the analysis of parents' atrocity stories in which professionals are depicted as being without emotional characteristics. The most frequently heard professional norm connected their duty to act and make decisions in relation to the child's illness. Here are some examples:

Parents' Descriptions	Norm
(1) The doctor was taking her away to intensive care in Bromley 'cos if she stayed 'ere she might die.	A professional is expected to take a dying child into intensive care.
(2) Dr. D said, oh I think we'd better keep him in he's got a hole in the heart.	A professional is expected to keep a child with a hole in the heart in hospital.
(3) He was underweight and they took him to the hospital where he was put in a special care unit.	A professional is expected to put an underweight baby in an intensive care unit.
(4) They found this lump on his head and they wanted to X-ray it to make sure it wasn't anything wrong with his skull or anything.	A professional is expected to X-ray a child with a lump on his head.
(5) He had a chest infection and they wanted to keep him in.	A professional is expected to keep a child with a chest infection in hospital.
(6) You know he bashed his lip or scratched it and they didn't ring us.	A professional is expected to inform the parent of a child who has damaged his lip.

The norms we are identifying are the bricks with which we hear our respondents build their accounts of morally adequate conduct. It is therefore predictable that one of the ways in which parents and hearers judge the moral character of professionals will be according to whether they are displayed as fulfilling their duty to act and make decisions in relation to the child's illness. It is equally predictable that another way parents' moral character will be heard to be judged, apart from emotional considerations, is according to their duty to act in relation to the child's illness and treatment. This norm is the second most frequently heard parent-child norm, and it takes the following form:

Parents' Descriptions	Norm
(1) When she was... she's always been prone to coughs. And we've not been here very long and I took her up to the doctor's.	A parent is expected to take her ill child to a professional.
(2) He was very breathless and I kept saying to midwives and doctors and various bods that came round, um I said to the midwife look, I said, he's breathing so fast.	A parent is expected to inform a professional when her child is breathing fast.
(3) I'd been trying to give her her feed and she wouldn't take anything at all... It was just running down. And I kept telling them she wouldn't take anything.	A parent is expected to inform a professional when her child is not feeding properly.

Parents' Descriptions	Norm
(4) He had a bad... high temperature, so of course you know I dosed him up with a Junior Disprin, you know, the usual cufuffle.	A parent is expected to treat her child with a high temperature.
(5) He was sitting in his buggy just looking absolutely lifeless. So I thought right up to the doctor's and see what she says.	A parent is expected to take a lifeless-looking child to a professional.

The fourth most frequent norm heard connects the duty of parents to defer to professionals. The frequency of this norm, like the last one, lends support to Locker's proposition that parents are expected to defer to professional expertise in those circumstances which are beyond their child-rearing competences.

Parents' Descriptions	Norm
(1) They also said to me be prepared for them to admit him. So I went up there expecting them to take him in there and then.	A parent is expected to accept the judgement of a professional.
(2) He told us to take him home. So we brought him home from the hospital.	A parent is expected to carry out the instruction of a professional.
(3) Well um... the first thing the sister who delivered him said was, 'Don't worry, it's all right. Everything's all right'. And I didn't even realize there was anything wrong with him to start with.	A parent is expected to believe the judgement of a professional.

Parents' Descriptions	Norm
(4) When she was born they told me everything was perfectly all right. And I accepted it.	A parent is expected to accept the judgement of a professional.
(5) I didn't think there was any need to stay in hospital then. The nurses cuddled her enough, I think looked after her.	A parent is not expected to be required when her child is cared for by a professional.

We have already seen that the medical condition of the child does not affect the distribution of norms defined by membership category. This is also the case for three of the five most frequent types of norms identified in Table 3 (see Table 4 below).[5]

Table 4

		Sample	
Type of Norm & Membership Categories		No.	%
Deferring to professional expertise (Parent - Professional)	(chd)	11	73
" "	(cp/l)	10	83
Affective states and similar reactions to the child's illness and treatment (Parent - Child)	(chd)	11	73
" "	(cp/l)	10	83
Affective states and similar reactions to professional's judgements, decisions and actions (Parent - Professional)	(chd)	8	53
" "	(cp/l)	8	92

(Table 4 contd)

Type of Norm & Membership Categories		Sample No.	Sample %
Action taken in relation to child's illness and treatment	(chd)	10	67
(Parent - Child) " "	(cp/l)	7	58
Action taken and decisions made in relation to child's illness	(chd)	10	67
(Professional - Child) " "	(cp/l)	5	42

There is a significant difference between the two samples in the proportion of parents who are heard to invoke affective states and similar reactions to the professionals' judgements, decisions and actions. However, if we consider this norm together with the one which relates parents' affective reactions to their child's illness and treatment, then the difference between the two samples is greatly reduced: 92% of parents of a heart diseased child are heard to relate an affective reaction on their part either to their child's situation or to the professionals' judgements, decisions and actions while the corresponding percentage for the cleft palate/ hare lip sample is 100%. There is only one set of parents who is not heard to invoke a norm concerned with affect and this is the same family which fails to invoke any parent-child norm.

There is also a significant difference between the two samples in terms of the norm relating the duty of a professional to act and take decisions in relation to the child's illness: 67% of parents of a heart diseased child are heard to invoke this norm while the corresponding percentage for parents of a child with a cleft palate/ hare lip is 42%. This difference is probably due to the different career trajectories taken by children suffering from these conditions. (Here we are invoking a form of variable analysis!) Whereas the career of cleft palate/hare lip children is described by parents as commencing in hospital, the career of heart diseased children usually involves a number of different health professionals before hospital care commences. Apart from this exception, the claim we made earlier that the medical condition does not greatly affect the character of the norms invoked by parents remains valid. Finally, we should note that although the distribution within the accounts of the sample of 'deferring to professional expertise' and 'affective states and similar reactions to the child'd illness and treatment' is the same, the latter norm is much more frequently mentioned.

IV A Deviant Case

We have shown that a central feature of the character of parents' accounts is norms which relate the duty of parents to the sick child. This finding supports the theoretical propositions of Voysey and Locker. We have also shown the centrality of norms which relate parents' affective states to the situation of their child and the activities of the professionals. Hence, it can be argued that an account which does not display these norms is likely to be heard as morally inadequate. There is one such account amongst the present sample and it is not without significance that the parents are health professionals and that on a number of occasions the interviewer drew their attention to their apparent lack of emotionality.[6]

Let us compare the characteristics of the initial story presented by these parents, the A's, to those of the rest of the sample. If we consider the five most frequently heard norms, then the following differences emerge:

Table 5

Type of Norm & Membership Categories	A's no.	Sample mean no.
Affective states and similar reactions to the child's illness and treatment (Parent- Child)	-	3.7
Action taken and decisions made in relation to child's illness (Professional - Child)	2	1.5
Action taken in relation to child's illness and treatment (Parent - Child)	-	1.4
Deferring to professional expertise (Parent - Professional)	-	1.4
Affective states and similar reactions to professionals' judgements, decisions and actions (Parent - Professional)	-	1.3

Table 5 compares the mean distribution of the five most frequent norms within the initial stories presented by the sample against the number invoked by the A's. We see that in the A's account there are no Parent-Child norms and in particular none which are concerned with affective states. We can best convey its deviant nature by presenting the initial story and comparing it with the norms other sample members are heard to invoke.

Extract 3

Mr & Mrs A

1 Mr A — Well the story really started with him going in for a minor op last year and *the anaesthetist just er investigations discovered a murmur* which she wasn't very happy about and *referred us to a paediatrician* after the op who agreed that it was an unusual sight and um mumurs are commonplace really.

2 Interviewer — Hm.

3 Mr A — But on the sight and nature of it, it sort of wanted further investigation and um *hence he called in Dr EAS*. I- he already had a very good suspicion at that stage, after doing an ECG and that sort of thing.

4 Interviewer — This was at um...?

5 Mr A — At Rosstown. Um, here, the paediatrician had a very good idea that it might be um a... a septal defect, and Dr EAS just confirmed that diagnosis. So, of course, it's not a definitive diagnosis until the catheter and that's what we're waiting for at the moment.

(my emphasis)

The norms heard in this extract either relate the duties of professionals of different statuses to an ill child (see Extract 3 utterances 1 & 3, statements emphasised) or their duties to medical diagnostic techniques. We should also note the use of a technical language associated with the parents' professional status which is never heard in other parents' accounts at this stage of the child's career. For instance, Mr A's observation that 'murmurs are commonplace really' refers to the medical view that most children are born with a heart murmur and that this need not necessarily indicate a pathological condition. However, most parents in the sample reported reacting emotionally to the news that their child had a murmur, thereby indicating that to them a murmur was indeed pathological. This is the main difference between the A's initial story and that of other sample members: the latter consistently appeal to emotionality in connection with the discovery of their child's illness (see p. 51 nos. 3, 4 and 6). The differences in the initial story are evident in the remainder of the A's account and provide an important basis for emphasising the consistent features of the accounts of the rest of the sample. For instance, unlike the A's, the majority of parents invoke norms which connect the duty to remain with their child when he is in hospital. Similarly, most parents invoke norms which relate their past conduct to the occurrence of the child's illness whereas the A's are never heard doing this. It must be stressed that we are not viewing the A's account as deviant in terms of pre-conceived assumptions about what constitutes adequate parenthood. Rather, the claims we are making about its status are based on a comparison of the considerable differences between its normative character and that of the rest of the sample. As Strong (1979b) has argued, such limiting cases are extremely valuable in illuminating consistent features of social life.

V Conclusion

The interview has been a favoured sociological research instrument for practical and theoretical reasons. From a practical point of view, it allows the researcher to collect a great deal of information about a large number of subjects' social activities which would not be possible using other methods. For instance, direct observation of family life would be extremely time consuming. It would entail using a limited sample and would not allow for the child's career to be followed at any length. It also raises serious ethical issues since it is doubtful whether families would find it acceptable for an outsider constantly to monitor their activities. From a theoretical point of view, the interview has the advantage over questionnaires of allowing respondents to express the meaning of their experiences in a relatively free manner. As Voysey (1975) has stated, following the arguments of Cicourel (1964), 'questionnaires in effect filter the social processes under study through a pre-defined "grid" of categories assumed to represent the range of possible alternative responses appropriate to the area of research' (p. 66). Furthermore, the claim that standardized questionnaires eliminate 'observer biases' is not true when one considers the many assumptions and interpretations made by researchers which are usually ignored in the presentation of results. Brown and Harris (1978) present a similar point of view to Voysey's when they say 'although used in almost all large-scale sociological enquiries, there must be the gravest doubt about the ability of (such) questionnaires to collect accurate and unbiased accounts of anything complex or of emotional depth' (p.10).

These are some of the arguments in favour of using the tape-recorded,semi-structured or unstructured interview. However, we have seen that this method raises a number of theoretical and methodological issues. The central questions are:

(a) What status is interview data accorded?

(b) Can the interpretations made of this data be demonstrated in such a way that they are not open to the criticisms of being selective and simply suited to the chosen theoretical orientation?

Most of the studies we examined earlier are deficient according to the status they give interview material. Their main weaknesses are in the assumption that respondents' reports of events and states of mind can be taken to indicate accurate depictions of these events external to the interview situation and the non-existence of a method which demonstrates this assumption.

Those researchers who treat interviews as giving access to a reality with its own form of social organization which is not competitive with the events which respondents report, have also found it difficult to translate this perspective adequately when analysing data. Their central claim is that parents display the status of moral adequacy by making situationally appropriate use of normal parenthood in formulating accounts of their experiences. We have strengthened this claim by applying to parents' responses an apparatus developed by Sacks for the making and recognition of possible descriptions. The relevance of this apparatus for our data is in the way it allocates an important role to norms in the identification of membership categories and the relationship between descriptions of sequences of events. The quantitative application of this apparatus complements the analysis of the construction of parents' accounts in the following chapters. Parents' display of moral adequacy is not simply the outcome of invoking norms relevant to parenthood. As we shall see, the success of such displays equally depends on us hearing the way these norms are built up into particular accounts.

There are those, like Douglas (1972), who would criticise our approach on the grounds that it is merely concerned with a 'presented reality' generated by the research method and makes no attempt to judge the validity of accounts regardless of this method. However, we would argue, following the claim made by Sacks, that our analysis shows 'the fine power of a culture. It does not, so to speak, merely fill brains in roughly the same way, it fills them so that they are alike in fine detail' (p.332).

Chapter 3

MORAL TALES: PARENTS' STORIES OF ENCOUNTERS WITH THE HEALTH PROFESSIONS

"And when we <u>do</u> tell you, you get, cause I told her she was upset, when we tell you you - I said, well what do you expect you know? You do get upset. You know. And um... she said well what do you want to know then? So, rather than her tell me, I had to sort of ask. I said to her well I don't know what to say really. I don't know nothing about medicine. I just want to know what's actually happened. She said what do you wanna know, come on. What do you wanna know?"

Mr Wo describing his encounter with a nurse

1 Introduction

Webb and Stimson (1976) have drawn our attention to a particular style of talk - the story - and have suggested that atrocity stories are central to people's talk about their encounters with the medical profession. In these stories, which were presented to an audience of fellow patients, the teller/patients portrayed themselves as taking a very active role in encounters with a doctor. The doctor's actions were criticised. He was depicted as passive and was not afforded the respect which is normally associated with this status. Webb and Stimson claim that this presentation was in marked contrast to the encounters they observed. Here patients were passive and deferred to their general practitioners. They argue that 'the emphasis on the active part played by the patient in the story owes more to the story being a vehicle for making the patient appear rational and sensible and for redressing the imbalance between patient and doctor than it does to the event itself' (p.111).

As Dingwall (1977) has noted, atrocity stories are more common than Webb and Stimson allow. He has suggested that 'we should expect to find such accounts wherever culturally illegitimate attempts are being made to control aspects of the life of some high status group' (p.376). These stories figured prominently in the interviews conducted with parents.

The central feature in all the stories I have chosen to analyse is that something has gone wrong. This mishap involves our respondents, one of their children and members of the health professions. With striking uniformity, the stories address the unstated question "How could you, as parents, have allowed that to happen to your child?" In other words, our respondents attend to the issue of their appearance as moral persons, competent members and adequate performers. Hence, in formulating their accounts, they attain the status of moral adequacy.

At this stage, we should note a number of other characteristics of parents' atrocity stories. To begin with, they are most commonly presented in first interviews and retrospectively describe encounters with health professionals which have taken place early on in the child's medical career. These encounters are characterised by conflict and disagreement. In various ways, members of the health professions are depicted as casting doubt on the competence and rationality of parents. Yet, as we shall see, through their stories parents demonstrate that these aspersions have no basis. Thus the significance of our respondents' atrocity stories lies in the way they establish the rationality of their actions and also their own reasonable and moral character. This is accomplished by appeals to standards of the everyday world which parents assume are shared by the interviewer.

II The Sample and the Context of the Account

Table 6 presents some of the salient characteristics of the interviews from which the stories are drawn.

Table 6

Interviewees	No. of interviews	Child's age	Child's condition
Mrs R	1st	5 years	Congenital Heart Disease (CHD)
Mr & Mrs C		10 months	CHD
Mrs St		3 months	CHD
Mr & Mrs I		5 years	Cleft Palate
Mr & Mrs Wo		6 months	CHD
Mr & Mrs Al		14 months	Cleft Palate & Hare Lip
Mrs F		5 years	CHD
Mrs Hen		6 years	CHD

The number of families involved in the study totalled 27 and so the above eight represent 30% of the sample. This selection is random insofar as it was based on interviews transcribed at the time of writing. These were transcribed before my interest in atrocity stories. All the first interviews have been transcribed and examined since then and they also present this form of account which, as we have seen, is confirmed by the quantitative analysis presented in Chapter 2. There is a predominance of respondents whose child suffered from congenital heart disease since we were able to monitor the child's medical career from the time contact was made with the specialist heart hospital, which was not always possible for children suffering from a cleft palate/hare lip. Here we elected to adopt a cross-sectional approach and selected a sample of children from each of the following age groups:

0 - 3 yrs.; 4 - 10 yrs.; 11 yrs.+[1]

As was indicated in Chapter2, the format for first interviews initially involved asking parents to tell us the story of the child's career. Later, in any order, the interviewer asked them to elaborate issues such as their understanding of the child's condition and its future prospects; their reaction to the specialist hospital and to other health professionals with whom they had been involved; their versions of the cause of the illness; their capacity to cope at home; what arrangements they had made for their child's hospital admission, and the reaction of other siblings.

The interviews divided into two parts. The first part was characterised by a question-answer format with parents reporting in a rather formal manner their experiences. The second part was more informal and conversational in style. It would commence when it was apparent that the interviewer had exhausted his questions, then one of the parents would usually offer the researcher refreshments. Subsequently, many of the issues reported on earlier were recapitulated and elaborated by the parents without any request by the researcher.[2]

The task of the rest of this chapter is to show how parents' moral displays are accomplished through the atrocity story. This will be achieved by analysing the construction of their talk, with close attention being paid to the 'realities' in which they locate themselves and members of the health professions. Subsequently, some of the structural features of the atrocity story are discussed, including a comparison with elements of Propp's treatment of fairy tales (see Culler 1975).

III Parents' Displays of Moral Adequacy

Here I reproduce in full two stories which show most of the salient features of all the other accounts I have identified as atrocity stories. By analysing these two stories, I shall establish a framework within which the other stories can be located.

Mrs R

Extract 4 Story 1 Interview 83

1 Mrs R What it meant to us was something that happened to people in their fifties. You know. I didn't associate um... I mean I never thought about a child having, a child that had got something wrong there you know? Umm. When she was born, they told me she was perfectly all right. And I accepted it. I worried about her which most mothers do. You know. Worry about their first child.

2 Interviewer Mm.

3 Mrs R She wouldn't eat and different things and so I kept taking her to the clinic. Nothing wrong my dear. You're just making yourself...

worrying unnecessarily you see. And, you know, and then came January and we were told that umm she'd got something wrong and I mean we, she was five years old then. And of course it was such a blow to the system and I said she's not got heart trouble. You know, she'd dance about. I mean she gets tired but she dashes about and all, you know.

Mr & Mrs C

Extract 5 Story 2 Interview 19

1 Mrs C ... see we'd gone on for eight months, we didn't know there was anything wrong with 'im, because 'e was doing everything 'e was supposed to do you know...

2 Interviewer When, sorry when you went to the GP, you didn't sort of know up till then.

3 Mrs C No, no, I never dreamed that 'e'd got a bad... The only thing we noticed didn't we, that 'e breathes quite 'e breathes through his stomach. If you notice, like this, instead of, you know. And I've mentioned that to the health visitors and they said a lot of breastfed babies do it.

4 Interviewer Yes.

5 Mrs C Well, I just took their word for it, you know, you just don't think.

Initially, we can identify a number of features which influence the talk of interviewer and parent. The issue under consideration in both stories is the identification of congenital heart disease in the parents' child. Both parties take it for granted that the other knows that this condition exists from birth and yet, in Mrs R's story, it was not identified until her daughter was five years old and in Mrs C's case, when her son was eight months old. The tellers are attending to the discrepancy between when the condition first existed and when it was subsequently identified. Hence, they are both answering the following moral question which their stories answer: 'How could you have allowed the identification of your child's heart condition to be left until she was five years old (in the case of Mrs R) and until he was eight months (in the case of Mrs C)?'

In answering this question, both respondents are attending to the issue of their appearance as moral persons.

Before examining how they accomplish their status of moral adequacy, we may note two other features related to the production of these stories. First, the issue which they topicalise (the identification of heart disease) is usually discussed by parents in the first interview which takes place following the child's initial outpatient consultation with the specialist hospital. This is when an initial verdict on whether he or she is suffering from heart disease will have been given. The other stories I have chosen to analyse are taken from first interviews. Thus atrocity stories are typical of what Davis (1963) has called the inventory stage and appear with less frequency in subsequent interviews when the child's medical 'career' has become established.[3] I will take up this point in greater detail at the end of this section. Second, both stories are initially presented early on in the interview and are repeated at a later stage in a more elaborate manner than the truncated form they take here. This is also a common feature of our respondents' story-telling practices and I shall discuss it at greater length in Part III when I consider the characteristics of atrocity stories. At present, it is sufficient to note that the atrocity story and the form it takes may be occasioned by such matters as the timing of the interview in relation to the child's medical 'career' and the 'state of play' in the interview itself.

Let us now analyse Mrs R's and Mrs C's stories for their displays of moral adequacy. Both accounts set into play two 'realities', chiefly concerned with child-rearing responsibilities and aspects of child behaviour and development. The parents locate themselves in one of these realities and locate the health professions in the other reality. We will call the former the 'parental' reality and the latter, the 'medical' reality. We may note that those who speak in the I/we voice occupy the 'parental' reality and are the story-tellers as opposed to 'they' who belong to the 'medical' reality but who are absent from the encounter in which these stories are being presented. Thus, according to Cuff (1980), the tellers' accounts could be heard as one-sided unless they produce versions which consider their own responsibility in the unit event under consideration. Clearly, they do this by constructing a 'reality' in which they are located. Furthermore, both 'realities' are governed by rules and standards which define the nature of activity within them and what is to count as an adequate performance by those who occupy them.

We may also note the intersubjective nature of the 'parental' reality partly through the appeal to features of an everyday world which are the common experience of ordinary people. For instance, Mrs R talks about her child dancing and dashing about which is a commonly-held conception of children (see utterance 3). The appeal to intersubjectivity is also established by the use of devices such as 'you know' (see Mrs C utterances 1 and 3; Mrs R utterances 1 and 3); 'of course' (Mrs R utterance 3); 'you just don't think' (Mrs C utterance 3). These devices appeal to an intersubjective world and add substance to how 'I/we' i.e. story-teller(s)-parent(s) view 'reality' as opposed to the way 'they' i.e. health professionals view it. As we shall see in other stories, these devices sometimes make the 'medical' reality seem alien and beyond understanding. The use of such devices applies to interviewers as well as story-tellers. For instance, in Mrs R's story the interviewer's utterance 'Mm' (see utterance 2) acts as a confirmation of her appeal to the shared nature of her reality.

If we now return to the characteristics of the two realities, we see that the standards of the 'parental' reality are related to the type of activity that might be expected of a mother bringing up her child and in the case of Mrs R, a first child. Broadly speaking, this is concerned with appearances or routine aspects of child development which indicate an underlying order. Thus, in utterance 1, Mrs C is saying that her child was performing according to expected standards. In other words, his performance constitutes the standard against which she measures its adequacy, and she is also indicating that his adequate performance constitutes wellness which is a way of reading the former. Deviations, such as breathing through the stomach, are taken to indicate illness although what this might consist of is not an issue which can be resolved within the 'parental' reality. We also see that the same method of interpretation is employed by Mrs R when she says that her 'daughter wouldn't eat and different things' and after making this observation she appeals to a world where it is reasonable for a mother to worry about one's first child.

It is clear that heart disease is not a feature of the 'parental' reality as far as child-rearing and child development are concerned. The use of 'dreaming' by Mrs C in connection with the disease is significant (see utterance 3). When we dream we experience phenomena not ordinarily available to us and according to Mrs C, if heart disease in a child is to be located anywhere for someone occupying her 'reality', it will be in this 'world' of dreams. Thus, in saying 'I never dreamed that 'e'd got a bad...', Mrs C is appealing to the notion that heart disease associated with her child is beyond the totality of her experience as a member of the 'parental' reality. Likewise, in saying, 'what it meant to us was something that happened to people in their fifties', Mrs R is appealing to the way 'members' ordinarily think of heart disease as something which strikes middle-aged or elderly people. Indeed, what she is saying makes a certain epidemiological sense. In appealing to the standards of their 'reality', Mrs R and Mrs C are also defining the limits to parental competence. These standards prescribe what a mother should look for in her child, what she can legitimately worry about, and what she should do when they are breached.

According to Mrs C and Mrs R, a mother should then defer to those who occupy the 'medical' reality. Like parents, health professionals occupy a world which provides for the reading of underlying realities beneath appearances. The type of knowledge possessed by these experts is given added authority by parents who almost invariably refer to them, even to a single health professional, as 'They'. We may note that their judgement is binding and final on parents. Mrs R says 'I accepted it when they told me she was perfectly alright' and we can assume she also accepted it when she was told at the clinic, 'nothing wrong my dear. You're just making yourself... worrying unnecessarily, you see'. The mother stresses the patronising way in which this judgement is conveyed and in so doing reinforces the rationality of her reality, i.e. worrying is a legitimate response of a mother towards a first child.

Similarly, Mrs C claims, 'well I just took their word for it, you know, you just don't think' when 'they said a lot of breast-fed babies do it' (see utterances 3 and 5). 'You just don't think' appeals to an attitude towards the judgement of experts which is commonly held and which strengthens the response of 'I'. ~~i.e.~~ It seems reasonable to trust such judgements and to avoid contemplating whether they could be wrong once they have been passed.

Earlier, I suggested that these two stories constituted an attempt by the teller-parent to account for the discrepancy between the existence of heart disease at birth and its discovery at a later date. This discrepancy, I argued, raised doubts about the moral status of Mrs R and Mrs C. However, we have seen that they produce accounts which display their status as moral persons by appealing to an intersubjective reality according to whose standards they performed adequately. On the other hand, the same is not proposed for the health professionals who failed to employ their specialist knowledge in a competent manner.

The accomplishment of moral adequacy - a framework

Having analysed these stories in detail, we can now produce a framework showing how story teller-parents accomplish their status of moral adequacy which will also apply to all those other accounts I have identified as atrocity stories:

1. Story tellers-parents locate themselves in worlds occupied by lay people which are shared in common. They achieve this by appealing to features of an everyday world and by using intersubjective devices.
2. They locate the health professionals in a world quite distinct from that occupied by lay people.
3. They appeal to features of their world and show that according to these features they acted reasonably, consistently and competently given the situations described in their stories. In so doing they can be said to be producing 'determinate alternative possible accounts'.
4. Members of the medical world are often shown to have acted incompetently according to the standards of their world.
5. Story tellers-parents sometimes acknowledge the reasonableness

of the medical world according to its standards and rules, but often display it as unreasonable in the context of their everyday world and that shared by lay people in common.

6. Finally, by attending to the relevance of medical standards and rules, they enhance their status as competent members.

Like the stories of Mrs C and Mrs R, the others I have chosen to analyse display certain features which parents use to construct the two realities and display their status of moral adequacy. These include (a) emotionality; (b) child-rearing practices; (c) priorities in outpatient clinics; (d) the meaning of diagnostic labels. Although these phenomena appear to be unrelated, they are used in remarkably uniform ways in the stories. Their most striking characteristic is the way parents consistently differ from members of the health professions in their attitude towards them.

Emotionality

In constructing the world they occupy, parents characterise themselves as creatures of emotion. Ironically, these appeals to emotion are invoked in an orderly, consistent manner. For instance, Mrs St claims the following in her story concerning her failure to collect her son's prescription from the hospital pharmacy:

Mrs St

Extract 6 Story 3 Interview 66

Mrs St Well, that was the initial day we heard he'd got a hole in the heart and <u>obviously</u> my mind was just racing around, I was in a daze. (my emphasis)

The appeal here is to the type of response any parent might have on first learning that their child has a serious illness. Moreover, the use of 'obviously' refers to the shared nature of this type of response and strengthens Mrs St's individual reaction. By invoking emotion in this way, Mrs St locates herself in a particular order and mitigates her error.

Thus, appeals to emotion are not used indiscriminately for if they were we would begin to doubt the moral character of our respondents. In the stories under discussion, they most commonly appear on the occasions when children are presented as being identified with a serious illness or when something unexpected and serious happens to them. As we saw earlier, Mrs R presented her response to finding out that her child was congenitally ill in the following manner:

Mrs R

Extract 7 Story 1 Interview 83

Mrs R And <u>of course</u> it was such a blow to the system.

(my emphasis)

Again we may note the use of 'of course' to emphasise that this response, expressed in the form of a common saying, is congruent with an order of reality which is shared.

The same applies to the use of 'you' in Mrs I's account of how she reacted to the way the consultant announced unexpectedly and without forewarning at outpatients that her daughter 'might 'ave to 'ave another operation'.

Mrs I

Extract 8 Story 4 Interview 34

Mrs I I mean you could knock us over with a feather.

Whereas our respondents clearly locate themselves as creatures of emotion in their stories, they present medical personnel living in a world devoid of feelings. Sometimes this characterisation takes the form of doctors failing to take account of parents' reactions.

Mrs St

Extract 9 Story 5 Interview 66

Mrs S But mind you I think obviously it was apparent to Dr D to go to the hospital but when you've got confused and upset parents it would have been better to tell us.

This utterance comes at the end of Mrs St's story and so a lot of work has taken place to establish that she cannot be held responsible for not collecting the prescription from the pharmacy. Here we see that she appeals to three features. First, that what constitutes common knowledge for doctors may not be readily accessible to parents. Second, that parents are subject to emotional reactions which affect one's ability to make proper judgements. Third, that doctors ought to take account of such considerations, as should anyone else in the same relationship to people who are confused and upset. By appealing to her non-rationality in this way, Mrs St reveals her rationality and as such is claiming that she also occupies a rational-accountable world.

However, there are occasions when the medical stance taken towards emotion is presented to us as going beyond unintentioned insensitivity. Here, Mr & Mrs Wo are discussing his encounter with a nurse having learned that his son has acquired a chest infection:

Mr & Mrs Wo

Extract 10 Story 5 Interview 111

1	Mr Wo	... She you know, she was sort of having a go at me. Having a go at me.
2	Interviewer	Yeah.
3	Mr Wo	As if=
4	Mrs Wo	For being worried, wasn't she, yeah?
5	Mr Wo	For being worr- She says I can't understand parents, they always want to know everything. She said, she said that's exactly what // she said to me.
6	Interviewer	She said that?
7	Mrs Wo	Yeah.
8	Mr Wo	She said, I just can't understand parents, they always want to know everything.
9	Mrs Wo	She was funny you know?
10	Mr Wo	And when we do tell you, you, you get, 'cause I told her she was upset, when we do tell you you- I said well what do you expect, you know? You do, get upset.

This lengthy extract documents a complete disjunction between medical and parental formulations of emotions. Clearly, 'being worried' which is presented as an instance of parents wanting to know everything is not part of the medical world and, moreover, is seen as defective by its members. However, as the talk gathers momentum we witness a reversal of the medical position. The parents work as a team and with the help of the interviewer produce a version of emotions which makes those who have them appear reasonable and moral and those who attack them seem unreasonable, immoral and even 'funny'. Furthermore, our respondents support their formulations by appealing to their shared nature. All this is achieved by the use of devices to which we have already referred; by repeating key utterances such as 'having a go at me', 'she said', 'when we do tell you' and 'I can't understand parents, they always want to know everything'; by elaborating the last utterance with the adverb 'just' which makes it quite clear that what was said was no accident.

The morality of the parents' response arises out of Mr Wo's appeal to circumstances in which it is natural to get upset if your child is ill - 'well what do you expect' - and in which anyone (but a medical person) would get upset if they were in Mrs Wo's position - 'you do get upset'.[4]

We have seen that emotion plays an important role in most of our stories in displaying the moral character of parents' appearances. First, it is used to locate them in an everyday world shared by ordinary people. Second, they appeal to emotion in a discriminate fashion. Third, they use it to account for a variety of actions. Finally, the medical world is presented as devoid of emotion.

Child-rearing practices

In the stories presented by Mrs R and Mrs C, child-rearing was an issue because of the delayed identification of congenital heart disease. However, in some stories this issue appears in its own right especially when they concern the adequate fulfillment of child-rearing duties in situations which require competences parents do not possess. Here, they may be forced to rely on those who possess expert knowledge but at the same time they cannot be seen to abrogate responsibility for what happens since the child in question is theirs. The following two stories are concerned with this problem. The central issue which each story exposes is the failure of the mother to carry out competently an aspect of child-rearing. As we shall see, apparent incompetence can be used to produce an account which establishes the parents' status of moral adequacy.

One story describes Mrs Al's experience of giving medicine to her son while he was an inpatient, after a corrective operation on his cleft palate.

Mr & Mrs Al

Extract 11 Story 6 Interview 200

Mrs A To give him medicine was a fight for me. I literally had to hold him down and force it down his throat.

The other story documents issues to do with Mrs Al failing to anticipate changes in her son's physical development. We learn that when he started to roll on his back 'he got so much saliva because he was teething, and because his pipes were open at the back he used to gasp for air'. Like Mrs R's and Mrs C's stories, these themes raise doubts about the moral character of Mrs Al and yet she reveals herself to be a moral person.

Again, this is accomplished by constituting two realities, in one of which members perform adequately whereas in the other they perform inadequately. Let us see what form the 'parental' and 'medical' reality takes here. First, there is an appeal to the type of knowledge and practices to which members can be expected to have access. In the 'medical' reality, 'they have different ways of laying a child, either on their stomach or on their side' and on the only occasion 'they' gave medicine to Mrs Al's son 'they knew how to hold him, to make him relax and they just poured it down'. Thus, those who are identified in the 'they' voice have special skills and a specialised knowledge.

On the other hand, members constituted in the 'I' voice may not have access to such expertise. In presenting the state of her knowledge, when her son was three months old, Mrs Al says 'I didn't know' with reference to changes in the bodily movement of babies.[5] However, they do have access to other resources that make a type of knowledge available which is not of the formal variety to be found in the world of experts. I take it that utterances such as 'Goodness knows how he would have coped if I hadn't been in the room... I used to have to pick him up and shake him' and 'I literally had to hold him down and force it (the medicine) down his throat' appeal to maternal intuition and common sense. In other words, a mother can only rely on her instincts. She makes it her place to be in her son's room when he is choking and to give him medicine while he is in hospital in spite of not having access to the knowledge and skills available to experts.

Other criteria which inform the activities in the respective 'realities' concern the relationship between their members. There is an obligation for those referred to as 'they' to provide members of the 'parental' reality with expert knowledge and for the latter to seek such knowledge. Thus Mrs Al asserts that 'no one told me at Hospital X or Hospital Y' to anticipate changes in her son's development and with respect to giving medicine 'they didn't show me. I was just looking. They didn't say this is how you've got to do it. They just brought it in the next day and said it's up to you'. Given these failures to inform, we are left to conclude that those who inhabit the 'medical' world performed inadequately, while Mrs Al's performance was consistent from the point of view of the rules and resources which are available to her.

We may note two further features of these stories which add to their moral force. First, the activities of medical personnel are acknowledged to be part of an institutional order in which 'they've got to keep to a routine' so that 'they didn't have the time'. Thus the appeal is not to negligence but to a feature of the medical world which guides staff's conduct in a way which precludes the proper instruction of parents.

Second, it may be legitimate to claim ignorance regarding aspects of child development when situating related events in the past. However, it is proper to expect such matters to become part of parental relevances as 'experience' is gained in rearing a child. We would expect to hear such knowledge revealed in the telling of the story if it is to be a morally adequate account. Indeed, in talking about what she didn't know and what was not made evident to her by medical personnel regarding changes in the way babies lie, Mrs Al says, 'well of course by the time he was three months he used to roll on his back'. 'Well of course' appeals to a type of knowledge we all have access to when we have acquired a certain level of experience in bringing up children.

These versions are 'determinate alternative possible accounts'. They reduce the risk of Mrs Al's account being heard as one-sided and they attend to the shared nature of knowledge about hospitals and children. The same features arise in other stories. For instance, Mrs St does not attribute negligence to Dr D for failing to inform her. Rather, his failure is seen as arising out of his involvement in a reality where collecting-prescriptions-from-hospital-pharmacies is so routine that he fails to understand that this is not the case for 'non-members'. In the same story, she describes confusion arising over the correct dose of medicine for her son. The problem is finally solved by her midwife. Mrs St says, 'I mean the initial dose was three doses of 0.05 in the first 24 hours followed by 0.03 once a day. We thought it was 3 lots of 0.05 every day plus 0.03, which is a very high dose'. Again, it may be in order to appeal to lack of knowledge at the time the event took place, but it appears to be a requirement of a story being heard as morally adequate that the relevant knowledge should be displayed in the context of the interview.

Priorities in outpatient clinics and the meaning of diagnostic labels

What has emerged in my account of parents' atrocity stories is the appearance of two 'worlds' or 'realities', one of which is occupied by the health professions and the other by parents. The rules and standards which guide the conduct of the former are often alien and inaccessible to parents, whereas their own rules are shared in common, since they are constructing a 'reality' to which ordinary people are able to relate. On the other hand, from these stories we learn that health professionals are unable to relate to the 'parental' reality, yet parents are dependent on them in order to fulfill child-rearing responsibilities. We have already seen that this is a recipe for disharmony. The cleavages between the respective 'realities' in these stories, as well as those we shall now consider, are central to their moral force.

During her first interview Mrs F told us a story about her problems with a paediatric unit to which her daughter was referred for suspected congenital heart disease. She said she learned at an outpatient consultation that they managed to lose her daughter's X-ray and later 'they lost the heart graph'. She waited to hear from the hospital but 'heard not another thing for about a month'. Mrs F's moral character could hardly be in doubt, but since it is her child's X-ray and heart graph that have been lost, she is required to establish adequate parenthood. First, she appeals to features of an everyday world which locate her as an ordinary person. For instance, she says 'My husband had been waiting in the car for three hours with all the children' while she was waiting in the outpatient clinic for the staff to find the X-ray. This utterance is followed by 'You can imagine what it's like' which appeals to a common stock of experience related to adults and children being stuck in cars. Second, she accounts for the improper behaviour of the hospital by appealing to 'red tape and bureaucracy and everything else and there's so much'. In her story, all the practices of the hospital are constituted in these terms. Third, while the activities of the medical world are governed by 'red tape and bureaucracy', the actions of parents are guided by an intuitive sense of doing the best for their child which may mean taking the type of individual action which forces the hospital to act properly. Thus she reports telephoning the hospital and thereby making the staff respond. Her story ends with a trunctated utterance: 'So the whole thing you know'. The unfinished form of this utterance appeals to our ability to complete its sense and so establish its claims to reasonableness. Finally, we may note that the justice of Mrs F's case against the hospital is confirmed by the hospital staff when they are presented as apologising to her for their behaviour. Mrs F says 'She (the doctor) was saying, I'm terribly sorry and all this, you know'. Likewise, Mr and Mrs Wo end their story of the nurse's contemptuous behaviour towards Mr Wo with a colleague offering an apology:

Mrs Wo	I thought I'd better come and tell you in person because you've been messed about so.
Mr Wo	And she said I apologise and I went.

Other features of 'medical' reality which are appealed to and are presented by story-tellers as disjunctive with the everyday world concern the setting in which medical encounters take place and the conversational practices of doctors. These features are presented by Mr and Mrs I in order to account for the difficulty they found in asking the doctor questions about their child at outpatient consultations. Mr I explained the problem in the following way:

Mr and Mrs I

Extract 12 Story 4 Interview 34

Mr I You go straight in the room then... well you just expect to see the surgeon and a nurse or two there. But when you get in there, there's normally about a dozen people in there and you don't know whether you're right asking questions or what. Cos, you know, he's trying to explain as well, isn't he really, you know, to the other students. You just sit there and you're just trying to catch what's happening yourself. You know, rather than asking, you try and listen to what he's explaining to them, you know.

A number of comments may be made about this extract. First, Mr I's utterances take the 'you' form which, as we have noted on a number of occasions, is an appeal to the proposed intersubjective nature of his orientation to outpatient consultations. Second, the composition of the setting is considered alien to those who share his world. Other parents have said much the same. There is an appeal here to what it is like to go on stage and be confronted by an unexpectedly large audience and be struck by stage-fright. Third, the conversational practices of the surgeon are partly seen as legitimate, after all we know that students have to learn, but they undermine the conversational practices of ordinary members. Do you ask questions when the person you wish to speak to, particularly a surgeon, is addressing others? In the case of Mr I, clearly you do not. The only avenue left to a responsible parent who wants to know the state of his child's condition, is to become a student. You fall in with this world, although this is clearly inadequate given the purposes of your visit.

In the same story, Mrs I takes up her husband's general comments by recounting her experience of a particular consultation. Previously, I referred to her response to the surgeon announcing that her daughter might have to have another operation (see Extract 8, Story 4). This reaction is again set against a background in which the surgeon's talk is directed towards 'everyone else and not us'. Mrs I is reduced to falling in with the order of the clinic but this does not mean she accepts it:

Mr and Mrs I

Extract 13 Story 4 Interview 34

Mrs I I was sitting there thinking why is he telling them and not me?

Parents display themselves as occupying a 'world' in which evaluations and prescriptions about their sick child should be directed towards them in the first instance. On the other hand, doctors and surgeons are located in a 'world' in which they orient themselves to different standards which include technical/medical considerations and teaching students.

As we have seen, parents may fall in with this world out of necessity and it appears from what Mrs I says they might even be willing to do so if it wasn't for doctors 'mumbling on with all the medical stuff'. So the language of the medical world is commonly treated as incomprehensible to ordinary people:

Mr and Mrs I

Extract 14 Story 4 Interview 34

Mrs I I mean the terms he was using, we don't really understand anyway unless he's saying the simple talk you do understand.

In the everyday world, the claim is that we use an untechnical language which we can all understand. Common sayings like 'you could knock us over with a feather' are routinely used not only in interviews but also as we go about our lives and communicate with others.

The same appeal to the disjunction between the languages of everyday and medical 'realities' arises in Mr and Mrs Wo's story of his altercation with a nurse. In their story, they tell us that they were telephoned by the hospital and told that their son 'has got a chest infection and they think he's got pneumonia'. They are concerned and worried and Mr Wo says he sought clarification of his son's state. Their concern is grounded in how they, as lay people, relate to medicine and how they define chest infections and pneumonia. First,Mr Wo says 'I don't know nothing about medicine'. Second, Mrs Wo claims 'I thought pneumonia was terrible' and he adds 'you know you get people in hospital with pneumonia'. Thus, ordinarily pneumonia is of a different order to a chest infection and far more serious. Clearly, getting upset and wanting 'to know what's actually happened' is congruent with the Wo's definition.

Let us now see how the 'medical' world is presented as defining these conditions.

Mr and Mrs Wo

Extract 15 Story 5 Interview 111

Mr Wo She said, well every chest infection's called pneumonia.

Thus, in this world, the names of the two conditions are synonymous and are routinely interchangeable. However, for those who do not have access to a medical vocabulary, failure to make a clear distinction between these labels is nothing short of scandalous.

Mr and Mrs Wo

Extract 16 Story 5 Interview 111

Mr Wo I've never heard of, you know, (doctors) you know, chest infection, you don't turn round and say Oh, you've got pneumonia. I mean I've never heard of someone having a chest infection as pneumonia.

Probably none of us ordinary folk have either. The morality of Mr and Mrs Wo's position is patent to all but those who occupy a 'medical' world.

Summary

Before examining some characteristics of atrocity stories which augment the display of moral adequacy, we may note a number of issues connected with the analysis I have conducted thus far. The atrocity story is only one form of account our respondents present about the health professions. As I mentioned earlier, it typically arises in the first interview and usually refers to those encounters which have taken place early on in the child's medical career. As we have seen, parents acknowledge their inexperience at dealing with the medical aspects of their child's welfare but at the same time maintain that health professionals expect them to be accomplished in this sphere. Through the atrocity story, parents account for their inability to fulfill these expectations and display the status of adequate parenthood.

While the issue of moral adequacy remains a feature of their accounts of later encounters, its character is different from the form it takes here. Parents display a willingness to move from their 'reality' to the 'medical reality' by appealing to the doctor's formulations regarding the medical state of their child, in constituting their own versions. In so doing, they give the appearance of fulfilling their parental responsibilities at this stage of the child's 'career'. Of course, the assimilation of medical formulations, which are usually technical, is problematic for parents and in making this evident, we sometimes witness them accounting for their lack of knowledge.

Other aspects of their accounts about the co-operative nature of their later encounters include a familiarity with and a trust of the specialist hospitals as well as the appearance of being accomplished at dealing with medical personnel. In summary, parents present themselves to the interviewer as members who are now in control of the situation. However, this area is a topic in itself and will be discussed at greater length in the next chapter.

IV Further Characteristics of Atrocity Stories

The plot

Structuralists (see Culler's (1975) discussion of Propp) have long argued that different stories can be grouped together according to whether or not they share the same plot. When we examine the functions of the actions pursued by the characters in our atrocity stories we see that they constitute a basis for classifying and grouping the plots to be found in the latter. Below, we will establish the functions according to which atrocity stories can be grouped. Second, we will consider whether there are any similarities between the plots they employ and theories identified by Propp in his study of a corpus of fairy-tales. We will demonstrate that the central themes of atrocity stories go well beyond accounts about clients and professionals.

We can divide functions into those which apply to health professionals and those which apply to parents. The actions of the former can be classified in terms of three sets of related functions which constitute an aspect of the plot. The first one is the failure to inform properly. The actions of health professionals contained in the following utterances are members of this class.

Mr and Mrs Al

Extract 17 Story 6 Interview 120

Mrs Al They didn't say look this is how you've got to do it. They just brought it in the next day and said it's up to you.

Mr and Mrs Al

Extract 18 Story 7 Interview 120

Mrs Al Well of course, by the time he was three months, he used to roll on his back. I didn't know, no one told me at Hospital X or Hospital Y.

Mrs St

Extract 19 Story 3 Interview 66

Mrs St ... It was apparent to Dr D to go to the hospital pharmacy but when you've got confused and upset parents it would have been better to tell us.

Mr and Mrs I

Extract 20 Story 4 Interview 34

Mrs I ... I was sitting there thinking why is he telling them and not me... I mean he's talking to everyone else except us.

(my emphasis)

We may note that a variety of actions could be substituted for the ones emphasised in these extracts without altering their role in the stories. These include 'advise', 'impart', 'convey', 'enlighten', 'instruct', 'educate', etc. 'Inform' subsumes all these actions.

The second function related to health professionals, detectable in some of these stories, is the failure to act competently. In the stories of Mrs R and Mrs C, the actions of the professionals concern their failure to diagnose congenital heart disease when it initially existed, while in Mrs Hen's story they are portrayed as delivering her baby incompetently.

In one story, that of Mrs F, both functions are attributed to the health professionals. They lose her daughter's X-rays and heart graph and they fail to inform her regarding the state of this situation for a period of one month.

Finally, one other function can be isolated which arises in Mr and Mrs Wo's story. This can be called the failure to act courteously and here refers to the contemptuous behaviour of the nursing staff towards Mr Wo. As we have seen, this function is combined with the failure to inform properly.

If we now turn to the actions of parents, we see that they can be classified according to one function which shall be called the struggle to overcome. The role of parents' actions is to portray them as soldiering on with a particular task despite being without the appropriate resources. For instance, Mrs Al speaks of giving her son medicine despite his considerable resistance and her lack of skills and in another story, of saving him from choking despite being unaware of changes in his bodily movements. Mrs St obtains her son's prescription made out for the hospital pharmacy in spite of not being able to collect it from the latter, while Mrs F does not allow the inefficiencies of the paediatric unit to get the better of her. In summary, the actions in these stories as well as others have the role of displaying parents as struggling to carry out tasks while at the same time overcoming disadvantages.

I suggested earlier that it might be valuable to consider our corpus in relation to fairy tales in order to see whether there are any similarities between the roles and functions. The issue which underlies this comparison is whether the latter in atrocity stories constitute a paradigm which could be found in fairy tales and possibly other texts regardless of particular actions and characters. I wish to argue that this is the case, although my claim is based on inconclusive evidence and is thus suggestive. The fairy tales Propp analyses contain motifs, like 'a dragon kidnaps the king's daughter', which when decomposed into their constituent elements are strikingly similar to some of those available in our stories. For instance, health professionals like dragons are on occasions portrayed as wicked while parents like kings (who are possessors) are depicted as brave and struggling on behalf of someone beloved and innocent. We could plausibly extend the motif 'a dragon kidnaps the king's daughter' to the next stage of the plot in a fairy tale where 'the king battles with the dragon for his daughter' and make evident the theme outlined above. The king is a possessor and brave; the dragon is wicked; the daughter is beloved and innocent; and battling is a form of struggle. Similarly, Mrs Al's portrayal of shaking her son in order to prevent him from suffocating might take the form of 'the king saving his drowning daughter' in a fairy tale. Shaking and saving are both versions of rescuing; the king and parent are interchangeable since they are both possessors; the choking son and drowning duaghter are also interchangeable and could be replaced by anyone beloved and innocent on the verge of a preventable death.

In applying Propp's structuralist approach to atrocity stories, my aim has been to show that this form of analysis makes available features which might otherwise go unrecognized. Of course, there are differences between fairy tales and atrocity stories. For instance, I suspect that characters in the former are consistently imbued with absolute moral qualities unlike those in the latter. Nevertheless, as I have indicated, parents seem to be employing a paradigm which we can detect in very different texts.[6]

The role of the audience and the construction of proper descriptions

The paradigm of these stories is of the kind which elicits the support of the audience on behalf of those who are struggling. In the situations in which our stories are produced, interviewees are often able to mobilise the open support of interviewers for their case by displaying, in a credible fashion, staff behaviour as outrageous. This was evident in our interview with Mr and Mrs Wo who presented a series of atrocity stories in describing their encounters with the medical profession.

Mr and Mrs Wo

Extract 21 Story 5 Interview 111

Mr Wo I said well what's the matter with him then? For all I know he's got a chest infection and you're treating it as pneumonia. She said well every chest infection's called pneumonia, said you know so...

Interviewer Sounds as if she was putting you down.

Mr Wo Yes.

Webb and Stimson (1976) have also noted this characteristic and suggest that 'the stories... involve the audience by virtue of the teller's ability to portray and the listener's ability to realise that this sort of thing happened to me and might happen to you' (p.110). They go on to say that the characters are portrayed as 'real' people and the incidents actually happened. One of the ways respondents achieve this is by constituting proper descriptions. In describing the abnormality of a particular event or state of affairs, they do not overstate their case. For example, in Mrs F's story she refers to the consequences of the hospital losing her child's X-ray and heart graph which included the following:

Mrs F

Extract 22 Story 8 Interview 18

> ... the doctor said, would you go and get Susan F's X-ray and they (the nurses) were gone half an hour, and I was sitting in with Dr B, I mean nothing to say to each other, you know.
>
> This was... five o'clock, the time I got out of there. My husband had been waiting outside in the car for three hours with all the children. You can imagine what it's like three hours in the car...
>
> And then I heard not another thing for about a month... well a month and I said to my husband, I think I'll ring and just ask them what's going on you know, because I expected to wait but not a month, not even a letter or anything.

Here, we have three statements about waiting and what makes the events which they describe appear real is the appropriate use of what is abnormal in a given context. Sitting with a doctor in silence for half an hour can be heard as credible whereas if she had said she sat with the doctor for three hours in silence, this statement would be open to challenge. The same can be said of the other two instances of waiting. The contexts in which they arise define what length of time it is appropriate to invoke in claiming that what the participants were subjected to was abnormal.

The use of reported dialogue

Another method which is evident in these stories and adds to the appearance of verisimilitude is the use of reported dialogue. A number of respondents use this method in the extracts I have presented. Reported dialogue makes events come alive and provides a sense of immediacy unlike indirect speech. Compare the following:

Mrs F

Extract 23 Story 8 Interview 18

Mrs F And I phoned and they said, well we're terribly sorry but we've lost the heart graph. So I said well you know, what you gonna do about it? She said, well at the moment there's nothing we can do about it. I said, well can I come over with her? I said, tomorrow, cos I knew it was Thursday and you have to have the heart readings done, so that I can see Dr B, 'cos I wanna get things sorted out. She said, yes of course you can.

My translation:

And I phoned and they said they were terribly sorry but they'd lost the heart graph. So I asked them well, you know, what they were gonna do about it, etc.

Often substantial portions of parents' stories are presented in the form of reported direct speech with a question and answer sequence. We can observe them operating what Sacks (1972) calls a 'chaining rule' of Q-A-Q-A which can, in principle, be extended indefinitely. Their ability to operate this rule successfully helps to display them as competent story tellers. Moreover, the employment of the rule in the story by the parent/questioner seems to give her a great deal of control in her relationship with the hospital in a situation which has previously been presented as being out of her control.[7]

The dramatic quality of atrocity stories

Webb and Stimson have observed in relation to the structure of atrocity stories that they have a dramatic quality. The story teller sets the scene, introduces the characters, explains the issues and then as the plot is unfolded, he reveals the major areas of conflict between the participants. This claim requires some elaboration by careful scrutiny of the text. To begin with, we note that our stories often begin and end with statements which in a telescopic fashion summarise the nature of the story and the teller's position in relation to the events to be presented. Second, what is revealed in between beginnings and endings amounts to the unpacking of these statements. What has just been claimed ought to be viewed as a framework for making sense of the structure of our stories. On some occasions, the meanings contained in initial and final statements will neatly complement each other with the plot representing an elaboration of both. Mrs Hen's story started in the following way:

Mrs Hen

Extract 24 Story 9 Interview 31

Mrs Hen	No way can I prove anything. But I'm sure if they'd left me alone and let me go my full term, even if she couldn't be born normally to have a caesarian, I'm sure she would have been O.K.

Her story ended with the following observation:

Mrs Hen Well, quite honestly I believe her being under such strain for that whole forty-eight hours I mean obviously, you know, I'm in labour, I was under strain anyway. She was just over 6lb 4oz. She wasn't a big baby and I'm sure the strain of that must have done some damage. Um I... don't know. I've just got a niggle.

The bulk of her story is given over to a detailed and dramatic account of her confinement which I shall refer to shortly. At present, we may note that it unfolds her claims that the birth process was a strain for her and her baby; that the latter would have been OK had they left (her) alone; that although the practices of the hospital staff cannot be blamed conclusively, they were, nevertheless, dubious.

Some stories only have a beginning containing the nature of the story and the teller's position which becomes unpacked as the story unfolds (see Mrs R Extract 4 Story 1) while some tellers leave these general statements till the end of their accounts (see Mrs St Extract 9 Story 3).

Atrocity stories are dramatic in another sense, quite apart from the way they are constructed. The events that tellers portray are tense and emotionally stirring as would be expected when their central theme concerns the desperate struggle of the individual in the face of adversity. I have already referred to Mrs Al's story about her son choking. Through the vividness of what she describes i.e. her son gasping for air, the cot actually shaking and his arms coming up for air, we are made to understand that what is at stake is nothing less than the survival of a baby on the verge of death. Moreover, the dramatic quality is heightened by an appeal to the baby's helplessness.

A sense of drama is conveyed by reports of other types of event where the teller appeals to the relationship between what is normal for a given activity and the abnormality of her experience of that activity. I have already presented the statements which began and ended Mrs Hen's story of her confinement. The core of her account developed these statements:

Mrs Hen

Extract 25 Story 9 Interview 31

Mrs Hen They started at 6 o'clock in the morning. I went right round till late at night and nothing hap... I mean I was in labour but nothing was happening much. They kept bringing new born babies in... you know and all I wanted to do was to go to sleep and in the end they knocked me out. I slept through the night and I woke up having contractions and no pain, so they gave me more pills and I carried on all the way through until a quarter to eight that night, Sunday night. So it was a whole weekend and she was born with a struggle at a quarter to eight that Sunday night. She was whipped straight away and I didn't see her.

The dramatic quality of this account arises partly out of an appeal to the difference between what counts as normal and abnormal labour and partly as a product of the teller's construction. Here, I am referring to the use of devices such as 'right round till late', 'kept bringing new born babies', 'all the way through' and 'a whole weekend'. Moreover, the repetitive use of 'and' to connect sequences contrasted with the short, sharp statement that her daughter 'was whipped away' conveys the impression of an experience that was protracted in the extreme. It is taken for granted by the teller that her audience will understand that this experience was beyond human endurance especially when the birth itself is described as a struggle following an arduous labour. Clearly, this dramatic account affirms her moral stance when she attributes blame to the maternity hospital for her daughter's condition.

Teamwork

This is a further characteristic of atrocity stories, which is by no means unique to them. Goffman (1971),in his discussion of teamwork, has observed that 'we commonly find that the definition of the situation projected by a particular participant is an integral part of a projection that is fostered and sustained by the intimate co-operation of more than one participant' (p.83). Let us consider the two stories where both parents are present and note a number of instances where they work together to produce and sustain definitions.

If we examine Mr and Mrs Wo's story, (see Extract 10 Story 5), we see that Mr Wo is the main speaker. This is in keeping with the content of the story since it is he and not his wife who is present at the hospital having an altercation with the nurse. Yet, she intervenes on three occasions (see utterances 4, 7 and 9) in such a way that we almost have the impression that, in fact, she did accompany her husband. Each intervention is significant in its own way. In utterance 4, her statement reminds Mr Wo why the nurse was 'having a go at him' which he confirms in utterance 5. This is a feature of many interviews, where one member of the parental team will bring to the notice of the other and the interviewer information which may have been left out of the account.[8] Such interventions sustain the momentum of what is being said. In the following extract, from Mr and Mrs I's story, we can also observe the same practice. Mr I has described what it is like to attend a typical outpatient consultation and then arrives at the end of his account:

Mr and Mrs I

Extract 26 Story 4 Interview 34

Mr I	You... rather than asking, you try and listen to what he's explaining to them you know.
Mrs I	Yes, that shows the point really that I'm trying to make. The last time we went...

Here, Mrs I has taken up her husband's appeal to intersubjectivity and subsequently proceeds to describe her experience of one particular outpatient consultation. What we also see here and in Mr and Mrs Wo's story, is the way each speaker adds substance to what the other is saying and thereby increases the authority of the main claim of the account (see Mr and Mrs Wo Extract 10 Story 5, utterances 8 and 9).

We may also observe that parents' co-operative practices as story tellers reflect the way they speak of each other as members of a team in their stories. This may take several forms. For instance, we frequently find the appeal to 'us' and 'we' as a unit. Or where, as in Mr and Mrs Wo's story, an absent parent is under attack from a health professional, the parent present in the situation produces an account which preserves his partner's good name. In the next chapter, I shall consider further the way parents use the notion of teamwork when only one partner is present at an interview.

To sum up, by paying close attention to the structural features of the atrocity story we have elaborated a number of characteristics which strengthen parents' displays of the status of moral adequacy.

V Policy Implications

It might be objected that the approach which has been adopted in this chapter makes it impossible to establish policy initiatives since parents' stories derive their significance from being treated as situated accounts. I would argue that, nonetheless, this approach can offer a more reliable basis for policy responses than other approaches discussed earlier. Whether such approaches invoke social structures to account for the atrocity story, as Webb and Stimson do, or treat them as representations of external events, they impose an unexplained psychological variable on the account.[9] Second, lacking a longitudinal basis, these approaches have viewed atrocity stories as universal means by which enduring or pervasive inequalities in the doctor/patient relationship are redressed.

However, we have seen from the evidence marshalled in this chapter that the frequency of the atrocity story is determined according to the stage of the child's medical career. We have established this finding (unlike Webb & Stimson) by adopting a longitudinal perspective. It is this as well as the treatment of stories as situated accounts which provides a reliable basis for policy responses.

The thrust of parents' stories is first, that parenting is a moral issue and, second, that they are, understandably, inexperienced in the medical aspects of the child's welfare and at dealing with hospitals and health professionals at the early stages of its career. Finally, they claim that the latter do not take this into account. As one mother put it, there is a need for members of the health professions 'to be concerned about the parents as well as the child's condition'.

There is an interesting parallel between our research and the responses of mothers to their treatment from maternity hospitals. First time mothers can often be heard to complain that they feel control of the birth process has been wrested from them, that they are treated impersonally by doctors and as fodder for high technology procedures. Thus two polarized points of view have developed - many lay people are fervently against the technological approach to birth while sections of the medical profession advocate it. Yet accounts about the birth of the second child are different since tellers present themselves as in control of the situation,as able to deal effectively with doctors and sometimes welcoming limited applications of medical technology. While there is little doubt that the medical profession has been over zealous in its use of technological procedures during the birth process (Chard & Richards 1977), I would suggest that had mothers' accounts been examined from the perspective adopted in this chapter, then the interpretation of them would have been more balanced and the debate in obstetrics would have been less divisive. There is ample evidence which shows that where patients are properly informed about unfamiliar medical interventions and where their anxieties are taken into account, they cope with both better than when they are uninformed and left anxious (Egbert et al. 1964).

This is the substance of the policy initiative that should be implemented for those parents who are coping with the early stages of their child's medical career. In fact, on our recommendation, the specialist hospitals have implemented extra consultations designed to attend specifically to parents' concerns at these early stages. Currently, we are studying their effectiveness and the initial evidence suggests that parents find them valuable.[10]

VI Conclusion

We have seen that an analysis of atrocity stories has important policy implications for encounters between parents and paediatricians. For this reason, it would be valuable to establish the prevalence of these stories in other areas of medical activity and so extend the analysis proposed in this chapter. There is little doubt that in areas which arouse considerable controversy (such as abortion), we would find that different points of view are given moral force by clients and professionals presenting atrocity stories. A proper analysis of the latter is likely to yield a more balanced interpretation of the arguments under consideration than one which takes them at face value or appeals to external structures as a way of interpreting them.[11]

Chapter 4

PARENTS, DOCTORS AND THE SICK CHILD: DIVIDING RESPONSIBILITY

I Introduction

In the Introduction and Chapter 2, we emphasized that a central feature of the methods used in empirical research is that they give access to a reality with its own form of social organization. In recent years, nowhere has the problem of methodology been taken more seriously than in the study of the doctor-patient relationship. Researchers have emphasized that a major requirement is that material should be drawn from 'naturally-occurring medical settings and does not rely directly upon data generated by research initiated questionnaires or interviews' (Silverman, 1980a p.15). In the last chapter, we examined some of the problems of using interviews in this area. However, the doctor-patient relationship is a constant theme of parents' accounts offered in the research interview, particularly in this study of parents' responses to congenital illness in their child and therefore we are faced with the question of what role to accord such data.

In adopting more reliable methods than those used in previous studies, recent research has provided new and refreshing insights into the issue of medical dominance. The previous studies saw doctors as manipulative and in a position to exercise a high degree of control over the patient. For instance, Freidson (1970a, 1970b) argues that in many situations doctors do not need to convince their patients but instead rely on their control of access to desired services and on the unvoiced appeal to the patients' 'faith' in their expertise. Other studies have documented how doctors use information-control as a means of manipulating the patient for their own purposes (see Davis 1963, Bloor 1976). Two of the main characteristics of these and similar studies is that they purport to view doctor-patient encounters from the side of the patient and are critical of the doctor's conduct. As Sharrock (1979) has observed in his examination of this literature, 'the powerful stand accused of ineptitude, insensitivity and hypocrisy, at worst, of working to produce exactly the misery, distress, oppression and degradation that they claim to be alleviating' (p.127).

An altogether more dispassionate view of medical dominance is found in recent work (see Silverman 1980a, Strong 1979b, Hilliard 1979). Among other things, these observers suggest that medical dominance may reflect realities of technical expertise and that more realistic standards should be established to assess medical encounters. Silverman, in a study of the doctor-parent relationship in specialist paediatric clinics, has produced evidence to show that parents may actually welcome doctors taking decisions about their child's treatment, especially when such decisions involve taking risks with the child's life. He suggests that one of the ways they do their duty is 'by bringing their child for treatment to the people best placed to decide (doctors at a reputable hospital)' (p.6). Silverman's claim has, as we shall see, some similarities with the way parents themselves use the notion of reputation. In the research interview, their appeals to features of what they consider are the consultants' and specialist units' reputation are indeed designed to reinforce their status as morally adequate parents, i.e. they have done their duty by their child. Moreover, these appeals are part of accounts in which medical dominance is assumed to be a normal aspect and on many occasions a desirable feature of doctor-patient relations.

Whether parents ensure, as Silverman implies, that the child is seen by reputable doctors, or whether the notion of reputation has any relevance to a doctor's competence are open questions. Parents invite hearers to believe that this is the case but as Abel-Smith (1976) argues 'There are few fields of consumer expenditure where the consumer is as ill-equipped to exercise his theoretical sovereignty as in the health services' (p.48). In practice, referral to a consultant and a specialist unit is a matter of routine on the part of the general practitioner or general hospital and patients have very little say in this process. Even when they do, and choose a doctor according to his reputation, 'this is no certain indication of his technical proficiency' (p.48).

In short, the relationship between what parents say they do and what they do in practice is questionable. Silverman's observations about the way parents fulfil their responsibilities in relation to doctors are more appropriately considered from the point of view of parents' accounts. As we shall see, in the research interview appeals to reputation take on a specific meaning in complex accounts about parents' involvement in their child's medical career. These accounts are partly a response to parents' perceptions of medical dominance as a feature of their relationships with the specialist doctors. Here medical dominance refers to how parents routinely pass on responsbility for their child's welfare to doctors. Hence their accounts are constructed so that the reality of this dominance appears compatible with the moral obligations towards the sick child entailed by the status of parenthood. Shortly, we shall examine other factors which contribute to their construction.

The view of medical dominance and methodological approach supported here has much in common with that put forward by Sharrock (1979) and differs substantially from that found in research on patients' attitudes towards doctors, in particular in studies of patient compliance. Sharrock argues that those researchers (see Bloor 1976, West 1976) who claim that the doctor-patient relationship consists of a struggle between the two whereby the doctor seeks to establish his control over the patient at each and every turn produce data which, in fact, do not support this claim. Rather, their research on doctor-patient encounters shows that the patient's conduct displays <u>an acceptance</u> of the medical profession's position. He suggests that the patient is unlikely to recognize himself in the sociological description of his own activities 'because the research is premised in a misunderstanding of what the native thinks he is doing or intends to do, and because poor descriptions of his activities are then processed through sociological ideas which are not well designed for understanding the activities which they depict' (p.144).

Similar methodological problems are also apparent in surveys of how patients view doctors. Mechanic's work is representative of this tradition (see Mechanic 1968). In this kind of research, all the emphasis is placed on establishing those expectations of the patient which determine his choice of doctor, which also play an important part in whether he conforms to his prescribed treatment, whether he returns and even the therapeutic effect the doctor may gain through the influence of his authority.

Mechanic's work and other studies of patient compliance present the same deficiencies as the older research on medical encounters in the way they conceive of medical dominance. Both impose models of the doctor-patient relationship by fiat without considering the practices of the participants. As Stimson (1974) shows, in an examination of research on how the patient uses the treatment that has been prescribed for him by the doctor (see Lipman et al. 1965, Joyce 1962), medical dominance is presented from the medical profession's point of view:

> 'The ideal that is presented is that the patient should obey or comply with what the doctor says. It is an ideal of the patient as a passive and obedient recipient of medical instruction. Alternatively, the words used may indicate a divergence from this ideal of the submissive patient' (Stimson and Webb 1975, pp.10-11).

As I have argued, such studies make no attempt to understand the practices of doctor and patient in relation to their encounter. Rather, they simply view the patient's conduct in the context of a predetermined model of patient compliance.

Hence I would argue that there is some value in using interview data in studying the doctor-patient/parent relationship although not in competition 'with what happens in the naturally occurring settings which participants report' (Silverman 1980a, p.15). Specifically, we can learn how parents construct moral identities for themselves in this area and what features they appeal to in doing so. We have already seen the construction of part of this identity in parents' atrocity stories.

In these stories, health professionals, particularly doctors, were displayed as having shortcomings according to everyday and professional standards. This view was in marked contrast to the way they assessed the consultants responsible for the treatment of their child at the specialist hospitals. Without exception, parents held them in the highest regard. At times, they were accorded super-human qualities:

Mr & Mrs Her

Extract 27 Interview 53

Mr Her	I think we both put him on a pedestal this bloke, you know.
Interviewer	Yeah.
Mr Her	Mr F is yeah.
Mrs Her	Yes I think.
Mr Her	He's some sort of God, ain't he really.

How do we account for the difference between the way doctors were depicied in atrocity stories and the favourable assessment of the consultants?

One explanation may lie in what we call interviewer effect. The atrocity story was a retrospective account of events which, by and large, had occurred before contact had been made with the specialist units and the research team. Thus parents were no longer relying on the doctors they criticised and furthermore these doctors were unknown to the interviewer. On the other hand, their children were currently seeing and relying on the specialist doctors. It was also understood that the research team intended to make its findings available to them. Thus it is questionable whether parents would voice criticisms in these circumstances. However, this argument must be seen in the context of the agreement reached between the research team and the respondents whereby parents were informed that their names would not be revealed in research reports. Indeed, in the interviews, some parents made sure that their responses would be treated confidentially before answering questions aimed at eliciting their perceptions of the specialists:

Mr & Mrs A

Extract 28 Interview 124

Interviewer	Yes. What did you make of Dr EAS?
Mrs A	Well, you know er (chuckles).
Mr A	It's all right. He's not going to play that back to him (everyone laughs).
Interviewer	... obviously the only way we can work is to keep ( ) separate.

Although these remarks were made in a light-hearted manner, the parents revealed their concern regarding the confidentiality of their views. In doing so, they obtained a reassurance from the interviewer who appealed to the ethical and professional nature of the research.

In summary, the claim that parents' favourable assessments were simply influenced by their perception of the interviewer's relationship to the doctors fails to take account of the parents' understanding that their identity would remain anonymous. It also ignores other underlying assumptions (some of which we have already examined). Questions concerning the quality of the medical care clearly raised issues to do with our respondents' status as parents.

They were regarded as responsible for the child's welfare and their adequacy as parents would therefore be reflected in the presentation of their ability to obtain competent medical care. Thus had they perceived the specialists in unfavourable terms their own moral adequacy would have been in doubt. The point is that the position they occupied in relation to the specialists differed significantly from their relationship to doctors depicted in the atrocity story. Here parents legitimately criticised doctors and health professionals without damaging their own moral status since it was understood that at the time the child's medical circumstances were beyond their experience. However, by the time they had come into contact with the specialist units the child's medical career was established and they were expected to show how he was being cared for by able and efficient doctors.

Parents' judgements were an integral part of accounts in which they formulated their own involvement in this process. Here they appealed to a number of features concerned with the medical process through which they demonstrated how they exercised their responsibilities and rights on behalf of the sick child. Thus the objectives of this chapter are:

(a) to show how parents displayed their involvement in the medical process;

(b) to establish what features in the consultants and the specialist units they found praiseworthy;

(c) to examine the implications of their accounts for the doctor-patient(parent) relationship.

II The Sample and the Context of the Account

The interview data used in this chapter are drawn from the total sample membership and are representative of all the interviews in which parents discussed their involvement in the medical process (see Appendix for details of the sample). Following contact with the specialist units, the stage of the child's career appeared not to influence the nature of their accounts. This topic appeared in all interviews regardless of whether it was introduced by a relevant question from the interviewer.

Its relationship to other topics in the interview was similar to parents' accounts of how they managed the sick child (see Chapter 6). In these accounts, they had few problems in displaying their moral authority and competence. As parents, they claimed that they knew what was best for their child since they were responsible for its upbringing and they showed how the child depended on their care. Likewise, the discussion of their child's medical care provided another opportunity for demonstrations of parental authority. This was in marked contrast to the atrocity story and accounts of the cause of the condition which raised the question of whether they had acted in ways which were harmful. As we shall see, this difference was reflected not only in the content of the account but also in its construction.

III Parents and the Medical Process

Parents claimed that they were responsible for and involved in establishing that medical care and action was in the interests of their child. They expressed this in a variety of ways. These included general statements which indicated the seriousness with which they took their responsibilities, discussions about the risks attached to treatment, deliberations about whether or not to pursue private care, and finally claims regarding the importance of their understanding of the child's condition.

As we shall see, central to these topics were the notions of parents being responsible as a team and the overriding status of the parent-child relationship.

General statements

Here, parents' statements displayed them as having a say, in many cases the final say, in the direction of their child's medical career. Let us consider one such account:

Mrs Hen

Extract 29 Interview 31

Mrs Hen	But from my point of view now, now she's had the operation and everything, I know... well and my husband knows, that we've allowed perfectly capable doctors, I've got every faith in the doctors here, umm we've allowed them to give her a completely different life to what she would have had.

We may note three features of this account which were common to many of the accounts we shall be considering. First, the notion of 'allowed' which suggested that our respondents actively decided what happened to their child. Other parents made a similar claim:

Mr M

Extract 30 Interview 127

Mr M However to be honest with you, before taking what is to me probably one of the most important steps in my life which was to commit my daughter into the hands of anybody...

Here the significance attributed to the parental role was enhanced by his appeals to 'the most important step in my life', 'committing my daughter' and 'into the hands of anybody'. The implication was that the status of whoever took responsibility for the daughter would have to be commensurate with the seriousness Mr M attached to such a decision. Similar sentiments concerning the nature of the parental role in the medical process were expressed by his wife in a separate interview.

Mrs M

Extract 31 Interview 128

Mrs M I mean, you know we're responsible for her being here, it's our job - you know.

The truncated utterance 'it's our job' and the intersubjective device 'you know' (see utterance emphasized) appealed to a shared understanding regarding the nature of parental responsibilities towards one's child.

Some parents acknowledged uncertainties. In doing so, they emphasized the active role they pursued in decisions regarding their child's medical prosepects (see Extract 32, utterances emphasized).

Mrs Wl

Extract 32 Interview 14

Mrs Wl But at the beginning you wonder whether you've found the right person. And I did wonder whether I had at the beginning, whether I should have gone elsewhere. (my emphasis)

To sum up, in describing their role in relation to the child's medical career, parents presented themselves as the people who decided who should treat the ill child and argued that this was proper since the child in question was theirs.

A second significant feature of Mrs Hen's account was the way in which parental responsibilities were expressed in the 'we' voice. Parents interviewed individually frequently stressed that their decisions were joint ones. Indeed, in Mrs Hen's account we see the importance attached to this in the way she made the following readjustment:

'I know... well and my husband knows that we've allowed...'

The use of the 'we' voice was sometimes invoked in parents' atrocity stories but less frequently than in the accounts being examined here since our respondents' morality was partly derived from the presentation of a solitary parent in conflict with several health professionals. In the context of the present discussion, several parents elaborated on the notion of joint management of their child's medical prospects. For instance, Mrs Hen made the following observations having stressed how she and her husband had allowed 'perfectly capable doctors' to treat their child:

Mrs Hen

Extract 33 Interview 31

Mrs Hen	But I... I don't know it's really sort of brought us much closer together. I mean we were a family unit anyway, but now this has happened it's obviously brought us that much more together and you feel you're in it together.

Here she appealed to characteristics such as 'being brought closer together' which are commonly perceived in a favourable light during times of adversity. Moreover, the morality of these qualities was strengthened since they were invoked in the context of the family. Appeals to the family and the husband and wife as a team ensured that parents' accounts of their role in the medical process were respected and not questioned by the interviewer. After all, what more could a parent do than 'feel you're in it together'.

Where the interviewer raised doubts about parents working as a team, such doubts were quashed immediately. Before the following discussion, the mother had slipped from using the 'we' voice concerning her and her husband's involvement in the decisions concerning their child's treatment to the 'I' voice and finally to saying 'they (the doctors) do tell me and I talk to my husband about it or if he's up here he has a chance to talk to the doctors'. To the interviewer, this utterance appeared to be at variance with earlier claims regarding husband and wife as a team:

Mrs Dis

Extract 34 Interview 145

Interviewer	He talks to the doctors as well?

Mrs Dis Oh yes, very much so. He obviously can't spend the time up here that I do. But when we come up to outpatients he always asks anything he wants to ask himself. He doesn't expect me to ask the questions and relay the answers to him. He always comes up to outpatients with me. I never come up alone because I feel and he feels as well that he's just as totally involved in this as I am, even though the day to day things are mostly my responsibility. His feelings for Tom and about the whole thing are just as strong as mine so he wants to know first hand himself about it all. He's coming up this afternoon in fact, we shall see Dr EAS this afternoon to find out what they are going to do after the catheter yesterday. (my emphasis)

The mother recognized that the interviewer had spotted contradictions in her previous utterances and consequently sought to re-establish the notion of their joint participation in the medical process. She accomplished this in the following way. First, she demonstrated that in fact her utterances were less contradictory than they appeared by appealing to the shared understanding that there are practical restraints on any husband's involvement due to work (see utterance emphasized). Second, she made the distinction between 'day to day things' which were less important than other events, and outpatients, where questions concerning the child's medical prospects needed to be asked and where her husband's attendance was appropriate. Third, we should note the use of absolutes such as 'always' and 'totally' to display the nature of the father's commitment which was given as much weight as the mother's: 'His feelings... are just as strong as mine'. Finally, the evidence that they worked as a team was provided when she observed that Mr Dis was 'coming up this afternoon' to speak to Dr EAS. It was also reinforced at the end of the interview when she proposed that he would be more than willing to speak to the researcher following the meeting with Dr EAS.

Other parents elaborated the notion of teamwork by producing an account of how they coped with everyday situations linked to their child's condition:

Mrs Wr

Extract 35 Interview 127

1 Mrs Wr Um, um, you know, we share, like when he started this cough, you know, I had visions of it turning out as it did before and also he's had a nasty cut on his finger.

2 Interviewer Yes

3 Mrs Wr And um, we sort of um, decide together what we ought to do, you know. I've said Oh just have a look at his finger and see what you think before you go to work, you know? Do you think we ought to get something done? Because um they told us that if umm... the bacteria mustn't get into that hole...

4 Interviewer Right.

5 Mrs Wr And if he has any dental treatment or anything like that later on, he must go on a course of antibiotics. Well, when his finger started to get nasty, you know, we began to worry a bit.

Mrs Wr revealed the shared nature of her and her husband's decision-making practices in relation to a problem which we can assume in normal circumstances would only require the involvement of one parent: namely a cut finger. The morality of the parents' deliberations was enhanced by the fact they considered this a problem in the first place. The interviewer knew and Mrs Wr implied that precautionary measures against bacteria getting into the hole were only advised by the doctors in relation to dental treatment. Indeed, the interviewer's utterance 'Right' (see utterance 5) referred to this understanding.

To sum up, parents' discussions of their involvement in the child's medical career were put in the 'we' voice in order to indicate that this responsibility was a shared one. The importance they attached to this claim was apparent in the way they elaborated it regardless of whether the interviewer sought such elaboration.

A third feature of Mrs Hen's account (see Extract 29) was the appeal to having 'every faith in the doctors'. I would suggest this was something which parents perceived as being in their power to bestow on the specialists since it was invoked in the context of accounts about how they were actively involved in determining their child's medical career.

Thus most of our respondents were suggesting that the decision to allow the child to be treated was conditional on them having faith. This notion was also conveyed by the terms 'confidence' and 'trust':

'One trusts them completely. One has to for the child's sake, I think. And then the trust builds up. You're prepared to trust them more then.' (Mrs Wl)

'And um I suppose having the confidence that we have got in Dr . EAS.'(Mrs Wr)

'But I've got every confidence in him (Dr EAS), I feel that he's a great bloke.' (Mrs St)

'And after speaking to Mr F I had every confidence in him, so I didn't interfere any more. I just... you know, I felt quite confident.' (Mr C)

'I mean Mr F 'ad said oh she'd 'ave to 'ave another operation, I mean I would let 'er because I've got all my trust in 'im anyway.' (Mrs I)

The last two quotations reveal a tension that was apparent in all the accounts we are examining: namely, the parents' wish to be seen as people who sanctioned their child's medical care yet who could not determine what form it should take: appeals to 'confidence', 'trust' and 'faith' were one method of resolving the dilemma. The same tension existed in their discussions of the risks attached to treatment.

Risks

There were two ways in which parents discussed this issue. One involved reference to a statistic or to risk as a concept; the second a consideration of the dangers of surgical treatment as they perceived them. Again, the display of parental participation in decisions concerning their child's fate was apparent in all these accounts.

Mr & Mrs C

Extract 36 Interview 301

Mrs C — I knew he had to have an operation but from the last time we were there I expected he'd be OK until he was about ten but when Dr EAS said he must have an operation within the next two months I thought Oh God but then obviously he gave us the 80%-85% plus chance - let's face it I don't think you can get any better than that.

Mr C — I mean there's always a risk whatever operation you do

Mrs C — Any major surgery.

The problem for parents who invoked such percentages as a way of making surgery appear an acceptable proposition was that part of the percentage which referred to an unsuccessful outcome. We should note that our respondents either never stated this figure or never did so without first having referred to the positive side of the equ~~o~~ation. Second, in all but one of the accounts it remained *implicit* that the unsuccessful outcome referred to the child dying. Of course, this meaning was clear to both parent and interviewer and the former was morally obliged to account for it in some way. In the above account, Mr & Mrs C worked as a team. He appealed to the notion that all operations are risky. However, from Mrs C's subsequent remark, it was apparent that this appeal was somewhat dubious in the context of the percentage applied to her child. Thus she qualified his statement by appealing to '*major*' surgery.

The method of interpretation used in Mr & Mrs C's account has some similarities with respondents' appeals to reference groups. A ubiquitous feature of their accounts was the appeal to children whom they considered worse off than their own child (regardless of how ill he was) as a way of showing that their child was better off than might be assumed. Likewise, whatever percentage parents quoted, there was always a figure available indicating a greater risk. Nevertheless, parents were always obliged to square the percentage referring to an unsuccessful outcome with their obligations towards the ill child.

Mr & Mrs Fol

Extract 37 Interview 121

Interviewer	Do you get the impression that they see it as fairly risky?
Mrs Fol	Oh he said it's one of the easy operations. And he said it was 95% successful. And I sort of, you know, I thought about the 5%. He said well there's an element of risk with all operations, not just this one. Any operations have got a risk. I put the 5% down to human error more than=
Interviewer	Hm.
Mrs Fol	Um, technique or anything, I should think. Really that's how I see it.

In this account, the parent invoked the figure referring to an unsuccessful outcome but did not explicitly take it up in terms of her child dying. Nevertheless, she attended to this possibility by saying that the 5% frightened her and put the matter into perspective by locating it in the realm of human error rather than technique. I suspect she was implying that human error, although worrying, is a feature of surgery generally or indeed of any technical procedure. In other words, if we made decisions solely on the basis of human error, everyday life would come to a standstill since so many activities involve us being dependent on people who exercise technical skill.

In the last two accounts, the consideration of an unsuccessful outcome had a ritualistic quality. After all, parents' moral character would have been open to question had they decided against surgery given the percentages they invoked. However, some respondents presented situations where, according to them, their decision mattered a great deal:

Mrs Hen

Extract 38 Interview 31

Mrs Hen	I mean when we were first told, you know, the arteries to the lungs were too restricted and if they did operate they could operate, but it would be a terrifically high risk, I wouldn't let her have the operation.
Interviewer	You wouldn't let her have that=
Mrs Hen	No. No I wouldn't have done. Because he told us if we... if they let it umm she would probably live another 20 to 25 years, but if they did the operation it's very unlikely that she would come out of the operating room and no way was I gonna sign 'er life away at six years old, not when she could have had 20.

In invoking this situation, Mrs Hen presented a dramatic account of a parent's responsibilities when her child is faced with surgery involving a great deal of risk. Its dramatic quality was partly derived from the contrast between her daughter living another 20-25 years and not coming 'out of the operating room' and partly from the defiant utterance 'not gonna sign 'er life away'. We should also note how Mrs Hen portrayed the doctors (they) as respecting the parent's moral right to make decisions on behalf of her child. In the account, the doctors were depicted as presenting the surgical options rather than telling the parent what they would do. This construction allowed Mrs Hen to display her decision-making responsibilities.

Throughout this discussion, it has been argued that a consideration of the risks of surgery was not only a means whereby parents displayed how they exercised control over their child's medical career but that such considerations were morally required of them. This claim is borne out when we examine the following account. The parents had treated the prospects of their son's forthcoming surgery in a matter of fact way when the interviewer posed the following question:

Mr & Mrs A

Extract 39 Interview 124

1	Interviewer	Yes you sound very sort of sanguine about it. I mean not that it's a kind of dramatic operation as far as the hospital is concerned but people get terrified with the idea of anything being wrong with the heart.
2	Mr A	Well don't misunderstand us. I don't think either of us are very happy about it but, you know, and probably at the time we've-

it was a bit of a blow um but on the other hand, you know, we've had a little time to get used to the idea.

3 Interviewer Hm.

4 Mr A And er... we've just got to accept it. That's all.

5 Interviewer Yes quite.

6 Mr A There's no real good getting- doing a lot of wringing of hands over it. Um and certainly we don't want to pass on anxieties to the other children. Um the older girl does understand what's involved and she was upset enough and that was us trying to play it down so (chuckles) you know.

7 Interviewer Yeah.

8 Mr A Rather than not get over concerned about it. It's got to be done. We're aware of the risks and you know. It's no good sort of er...

9 Interviewer How, how did you come to know what an ASD is?

(my emphasis)

We have seen before how a deviant case can highlight regular features of accounts. Here, the interviewer alerted the parents to their sanguine approach to the child's operation and questioned their normality and membership of the everyday world (see utterance emphasized in utterance 1). At first sight, it would appear that they had no choice but to fall in with the interviewer's notion of how 'most people' react to heart disease. However, these parents did have the option of not doing so since they were both involved in the health field.[1] Thus they could legitimately have invoked the type of meaning regarding heart disease the interviewer attributed to the hospital. They did not do so and instead asserted that they were concerned (see utterance 2) and 'aware of the risks' (see utterance 8). If they appeared sanguine, then it was understandable given the time they had 'to get used to the idea' and their wish not to cause their children undue anxieties. (We have seen on a number of occasions how appeals to emotionality are used to legitimate conduct which in other circusmtances would be open to question.) In other words, their claim was that they were like 'most people' as far as risks were concerned. This extract is a testimony to the powerful influence that the interview exercises on the moral nature of accounts. In this situation, our respondents are obliged to give a higher priority to their role as parents than any other status.

Parents also took up the issue of risks by discussing the dangers of surgical treatment as they perceived them. Thus one couple displayed their concern by referring to the possibility that the hospitals' equipment might be faulty and appealed to a recent programme on television which had revealed this as a problem in the National Health Service. Some couples spoke of the dangers of anaesthesia while others (parents of children suffering from heart disease) showed their concern by wondering whether their child should be operated on when he appeared so well. Here they attended to the discrepancy between parental feelings towards their child and the authority of the medical diagnosis:

Mr & Mrs Lil

Extract 40 Interview 72

Mr Lil ... we can only make emotional judgements on um on our feelings about our daughter and not um be er unbiased and the judgement of the doctor who can see it, you know.

Interviewer I mean what would your emotional judgement be regarding an operation if it was...?

Mr Lil Well to be honest I'd probably say no. If it was really just going from emotions I'd say no, and possibly because I think I have a sort of deep-seated fear that, you know, once you start mucking about with the body, as it were, you know, you're not doing any good. But um, you know, that's what I say, it's, you know, that's why I'd be inclined to leave it to the doctor to decide, because then I know he can make an objective judgement.

Here the father conveyed a reasoned approach first by appealing to commonly held notions concerning the dangers of medical intervention - the claim was that no responsible parents wished to subject their child to unnecessary surgery. Second, he made the distinction between judgements made on the basis of emotion and those which are objective. Although he argued that emotionality was rational in such circumstances, it should not take priority over objective considerations given the issue to be decided. Thus a responsible parent defers to those who are in a position to be unbiased. Similar sentiments were evident in Mr & Mrs A's account.

Mr & Mrs A

Extract 41 Interview 124

1 Interviewer And you wouldn't have any reservations about doing an operation?

2 Mr A Um... well we'll have to rely on er be guided by it, you know, the people that know a lot better. *Obviously*, instinctively, *you know*, *you think* Help don't touch him. He looks fine at the moment. That's the sort of natural instinct.

3 Interviewer Yeah.

4 Mr A But then, you know, one has to rely on the advice of an expert and if we are assured that er this defect will impair him progressively as he reaches adulthood, then um commonsense suggests that this must be done now while he's still fit.

5 Interviewer Hm.

There was an inexorable logic to such accounts with parents displaying their essential humanity which they claimed anyone would share (see utterances emphasized, utterance 2) but ultimately deferring to the 'advice of the expert'. The appeal to 'commonsense' suggested that to have done otherwise would have been reckless. We have already taken up the relationship between these accounts which ultimately revealed a preference for medical dominance, and sociological research which has attacked such dominance. There is a considerable variance between these two versions of the medical role.

However, it would be unwise to treat this preference for dominance and the other ways in which they deferred to medical authority in isolation from the rest of what parents said about risks. Deference, like appeals to confidence in doctors, was the outcome of deliberations which displayed our respondents as participants in decisions concerning their child's medical career. Indeed, Mrs Hen's account (see Extract 38) suggests that in similar circumstances all of the respondents would have made a similar display of parental authority.

Private care

Appeals to private care were a third way in which some (27% of the sample) parents displayed how they were in a position to exercise control over their child's medical prospects. As we shall see, many of them admitted that private care was a morally contentious issue. In doing so, they were acknowledging the wider political debate about such care. Although their children were not treated privately, the preference shown for private medicine in certain circumstances indicated that the welfare of their child was more important to them than political considerations. There were several features of private medicine which parents considered worthwhile. They perceived it either as a way of obtaining superior medical attention for their child or as a means of circumventing a lengthy waiting list. Thus, private care was presented by respondents as a means of doing the best for their child. There were a number of ways in which this sentiment was conveyed:

Mr & Mrs Al

Extract 42 Interview 200

Mr Al I just wanted <u>our</u> son to have the proper treatment really.

Mrs Al I suppose every parent feels like this, you see.

(my emphasis)

According to these parents, private care and proper treatment were inextricably linked. Furthermore, we can sense in these two utterances that such care required justification and this was achieved by appealing to the nature of parenthood. Shortly, we shall examine in greater detail what lay behind the necessity for such justification. Another way in which parents expressed 'doing the best for their child' by going privately was through appeals which revealed the extent of their commitment:

Mr Ht

Extract 43 Interview 146

Mr Ht <u>We</u> were prepared to do whatever was necessary to get <u>our</u> daughter to the best surgeon in this country, if not the world. <u>We</u> even talked about mortgaging <u>our</u> house in order to do what was necessary in order to do that.

(my emphasis)

We should note that this account presented these plans as being agreed by both parents (see utterances emphasized, Extract 43). Second, as in the previous extract, there was the appeal to the nature of the parent-child bond which justified, or indeed obliged, a parent to make the type of sacrifice entailed in mortgaging a house. Indeed, the essence of the account was to do with the sacrifices that Mr & Mrs Ht, as parents, were willing to make. The extent of the sacrifice was revealed not only in terms of finance but also geography. Other accounts displayed the notion of sacrifice according to a geographical dimension.

Mr M

Extract 44 Interview 127

Mr M ... Can we find alternatives in other countries? Yes, we have considered this but Dr EAS is a top guy um here. If you - I think he is - if someone were to tell us if there was an alternative in the U.S.... And we would like to find it, obviously.

A third feature of accounts of private care was the way in which parents, especially working class ones, attended to the possible accusation that their aspirations to private care were immoral. One way in which they did this was to acknowledge that, in fact, they were immoral in being so selfish.

Mr & Mrs C

Extract 45 Interview 19

Mrs C But as I say, how we feel is, he's our child and at the moment he's the most important thing to us and we don't care about anything else. It's an awful thing to say, but it's how... well I feel like that. You know, if it was anything, you know, if there was a waiting list for a week and err somebody said well so and so 'ad hers done I'd feel that I'd have to have 'im done. You know,

> I wouldn't, I know it's an awful thing to say,
> but he's mine and I'm only worried about him.

This account contains many of the understandings we have already described, such as appeals to sacrifice and the parent-child relationship which ironically with the self-criticism for being selfish displayed the respondent as a moral parent. In the following account, the parents attended to the way they characterised the benefit of private care in a similar manner:

Mr & Mrs Al

Extract 46 Interview 200

1 Interviewer What does it mean to you to go privately?

2 Mr Al That you'd get prompt attention.

3 Mrs Al It's a horrible thing to say but money talks and we'd get people telling us what would happen after, they wouldn't just brush you by.

Here Mrs Al, like Mrs C, neutralised her being seen in a poor light by invoking self-criticism before characterising the advantage of private care.

The final feature of parents' accounts was the telling of a story about a friend or relative who had used private care. These stories were so constructed that they complemented and so strengthened the reasons parents had presented for going privately. Thus Mr & Mrs C who wanted to circumvent what they perceived to be a lengthy waiting list told a story about a friend who had a tonsillectomy privately and was diagnosed, treated and discharged within ten days thus saving considerable time. Likewise, Mr & Mrs Al told a story about Mrs Al's sister who had a private GP consultation and was given the type of preferential treatment which they claimed they were seeking for their child. The moral of these stories was that parents' appeals to private care were sensible in the light of the experience of others.

In conclusion, we should note that the children of all of these parents continued to be treated under the National Health Service which suggests that the discussion of private care, in the context of the interview, was more a matter of parents displaying their capacity to exercise control over the direction of the child's medical career and was also an expression of the extent of their concern for their child. When we consider their accounts as a whole, we will see that they resolved decisions regarding treatment and risks, by invoking favourable judgements of the consultants and the specialist units.

Understanding the child's condition

Most parents attached a great deal of importance to understanding their child's condition. In the following discussion, I will not be concerned with their competence but rather the way their accounts displayed their involvement in the medical process. Later, I shall examine the relationship between studies which have examined parents' knowledge of medical conditions and the analysis presented here.

We should note how parents acknowledged that there was a limit to what they could understand from a medical point of view and indeed, a limit to how much they should know:

Mrs Hen

Extract 47 Interview 31

Mrs Hen ... I think you can learn too much, but then not know enough, if you know what I mean.

Interviewer What do you mean by that?

Mrs Hen Well if you can... being here I'm obviously meeting other mothers who have got different... I mean in such a small area there can be so much wrong and obviously different children have got different complaints. And talking to the mothers, I mean a lot of them are much like me. They know what's wrong with their child and that satisfies them, that's been explained and they know how it can be dealt with. But we spoke to one mother and she knew practically everything. You know, she said, certain procedures for certain operations. And she told us herself that the doctor said to her, really you know too much to be concerned with but then you don't know the rest that goes with it to even the balance out, if you know what I mean. Like it's a bit difficult to explain.

In fact, Mrs Hen continued elaborating what she meant but we need not concern ourselves with that part of her account since the views relevant to this discussion were understandable from the above extract. First, she was arguing that it was morally reprehensible for a parent to acquire knowledge beyond that needed to understand the condition of one's child since to do this inevitably meant that the parent would only have a partial understanding of her child's illness. Second, this claim was strengthened by the appeal to the views of medical authority. Third, Mrs Hen appeared moral by locating herself in a world of parents who were satisfied at knowing no more than was relevant to their child. Hence, the essence of the account was that it was proper for a parent to understand her child's condition but that there was a limit to the understanding appropriate to parental status. Other parents condemned those who knew too much:

Mr & Mrs Rey

Extract 48 Interview 25

Mrs Rey I mean other mothers are more... the worse, they're dreadful, you know, I mean really put the fear of God up you. They probably don't know what they're talking about half the time so really you mustn't err err take too much notice of what they say.

Thus a parent who knew too much not only did wrong by her child but was a nuisance to those parents who were simply content to know only what was wrong with their offspring. Just as parents who knew too much were criticised, so were those who did not want to know at all. In other words, our respondents stated that a parent was morally required to have some understanding of her child's condition in order to be properly involved in his medical career. Some conveyed this requirement in the following way:

Mrs Dis

Extract 49 Interview 145

Interviewer	So you don't feel then an isolated being in this process?
Mrs Dis	I don't feel somebody's doing things with Paul that are removed from my understanding or from even my grasp. A lot of them will not tell you things unless you ask. I know a lot of mothers can get by like this, a lot of them prefer to. I don't. I like to know what is going on.

The significance of this account was fourfold. First, it expressed the notion that by understanding a parent participated in their child's treatment process; second, the acquisition of such understanding was an active process since doctors were sometimes reluctant to oblige the parent; third, parents who accepted their lot were passive and so, by implication, not fulfilling parental obligations since they were not involved in what was done to their child. Finally, the mother's comparison between her position and that of other parents partly derived its morality from the reasonable way in which it was presented. The same reasonableness and similar sentiments were apparent in the following account:

Mrs Ht

Extract 50 Interview 144

Mrs Ht	Some people choose not to know and they feel not knowing helps them but we don't, we need to know.

As in the previous account, the display of reasonableness arose in the way the respondent deferred to the <u>right</u> of other parents not to know. Inherent in all these and the following accounts was the claim that it was best for a parent to be in possession of 'the truth', however unpalatable it might be.

Mr & Mrs Lil

Extract 51 Interview 72

Mr Lil — I must admit, it's nice to, well I say 'nice' to know, it's rather hard to put it. I mean obviously you want to hear the doctor say, oh yes, she's gonna be perfect and everything, going to be wonderful but um it was er, how can I put it, sort of nice or refreshing, I don't know the way to express it, but it was nice to hear that, you know, the doctor sort of put it in straight terms, so at least you could take it um when he said now, her life expectancy couldn't be much more than mid-twenties, I mean it's not something you really particularly want to hear, but at least you know the facts.

Mrs M

Extract 52 Interview 128

Mrs M — I'd much rather be kept you know, completely in the picture. I don't want to be sort of... you know, try - well not fobbed off but er sometimes doctors sort of don't really tell you what they're thinking=

Interviewer — No

Mrs M — They just give you vague clues but er... I I'd rather have complete honesty.

Mrs Dis

Extract 53 Interview 145

Mrs Dis We have always asked that we will be told everything there is to know about him and the truth as well. We feel we would far rather have everything there is to know in the beginning rather than have somebody say well a little later on, as time progresses, we don't want to find out that something else has come up that has been known originally or even suspected originally. We would far rather get the whole lot at once.

We have seen how parents appealed to a variety of features in expressing the desire to understand their child's illness, in particular the wish to be involved or in control. However, in the final analysis they claimed that this was their right. They formulated this right in the following way:

Mrs Hen

Extract 54 Interview 31

Mrs Hen I couldn't have let anything happen to her if I didn't know what the devil was going on. I suppose it's just my nature. But if they just said well, something's gone wrong and it needs to be done umm we're going to... we're going to cut the artery or whatever, I wouldn't have accepted that.

Interviewer Why not?

Mrs Hen Because I just wouldn't. I'd want to know why

they're going to cut the artery, what for,
what would it do?

Mr & Mrs I

Extract 55 Interview 15

Mrs I I mean he's a brilliant man and I wouldn't never go against him. But I go against it when they don't say why they're going to do it and give me a reason for doing it. If I'm going to sign for her to have an operation then I wanna know why they're doing it and what's happening.

We should note how these accounts reflected features of the atrocity story. They portrayed the possibility of the parent being in conflict with the medical profession and this was evident not only in the content but in the way parents were characterised in the solitary 'I' voice and doctors in the 'they' voice. However, unlike the atrocity story, they were not defensive: parents' rights to understand were grounded in the appeals to the overriding status of the parent-child relationship. The claim was that since this relationship required the parent to consent to surgery, then such consent could only be sensibly granted with adequate knowledge of the child's condition and treatment.

However, we noted earlier how parents acknowledged that there was a limit to what they could know. They accepted that specialist medicine required a degree of technical expertise beyond their capacity. Indeed, to have claimed otherwise would certainly have appeared improper. In the interview, they bridged the gulf between the right and responsibility to understand and their limitations in achieving such understanding by appealing to the way they held the consultants and specialist units in the highest regard. We shall now examine the features parents invoked in praising them.

IV Judging Doctors and the Specialist Units

Broadly speaking, parents' judgements fell into two categories. In one category, respondents appealed to features of the relationship developed between the consultants and the staff of the unit and them and the ill child. In the other category, parents appealed to manifestations of the specialists' and units' reputation. At this stage, we should emphasize that parents rarely judged the above according to their technical abilities. Rather, it was taken for granted that these abilities could be inferred from the doctor's reputation and the way he related. For instance, when a parent reported how other parents had told him that a particular consultant was 'a marvellous man', the interviewer was expected to share with the respondent the understanding that this 'character reference' included an evaluation of his competence as a physician.

To some, it may appear hardly surprising that respondents should appeal to their relationship with the doctors or to his reputation since they were interviewed by sociologists. On the other hand, the meanings parents used may tell us something about the structural position of consumers of health care in relation to the providers. We shall explore this issue at greater length in the next section.

We should also note how these meanings are ones which any consumer of a professional service might invoke in an account of the provider's competence. In this sense, they do not apply solely to the medical profession but refer to any profession such as a lawyer, barrister or architect.

Reputation

There were two types of appeal used by parents to convey the notion of reputation. The first type involved reporting the views of other people. The second type consisted of appeals to characteristics concerned with the specialist status of the doctors and the units. To some extent, these methods of interpretation overlapped - for instance, parents often reported what another person had said about some characteristic to do with the specialist status. Before examining such reports, which were by far the most common way of displaying reputation, we shall consider some of the characteristics which parents invoked.

We have already noted how some respondents displayed their absolute commitment to obtaining the best treatment for their child by claiming that they were prepared to go anywhere in the world. In a similar way, several parents characterised the reputation of a doctor and his unit by appealing to geography. For instance, Mr & Mrs Fol who referred to the risks of surgical intervention by contemplating the chances of an unsuccessful outcome in terms of human error (see Extract 37) made the following judgement:

Mr & Mrs Fol

Extract 56 Interview 121

Interviewer Does that sort of thing that they - you're sort of worried about like blunders rather than the operation itself? Don't know.

Mrs Fol Human error yeah yeah, I mean I know that when - children there - I mean the

Mr Fol Suppose we are, yeah.

Mrs Fol Children are from all over the world and you think well she's in the best possible place.

As we have seen, to pose the idea that the life of one's child could be exposed to human error placed parents in an uncomfortable situation in the interview. Mr & Mrs Fol resolved this problem by noting that the unit's catchment area covered the entire world and by claiming that, on this basis, anyone would arrive at the same judgement regarding its status. Later, in the same interview, her father extended the relationship between the unit and the world in the following way:

Mr & Mrs Fol

Extract 57 Interview 121

Mrs Fol's father It wasn't till today that I really knew that it was noted all over the world thi- this hospital.

(my emphasis)

The way Mrs Fol's father constructed this utterance made it appear as if he had been struck by something profound (see emphasized utterance). The notion of geography was also applied to the activities of the specialist himself. Mrs Wr's remarks concluded a discussion about the merits of the consultant. In this discussion, she had questioned the accuracy of the diagnosis since, according to her, it had changed on several occasions. Nevertheless, she was prepared to believe the consultant:

1 Yes we, we felt that that was, that obviously we realized that um... Dr EAS was a very invaluable man on the subject you know.

She went on to clarify the idea of invaluable in terms of his status but with some difficulty:

2 Mrs Wr But um I might be wrong but I think Dr EAS specializes in cardiac. Does he?

3 Interviewer Yeah.

4 Mrs Wr Yes. Um is it paediatric? Just paediatric?

5 Interviewer Just pae- That's right. He's a paediatric cardiologist.

6 Mrs Wr Oh yes yes.

7 Interviewer So he specializes in children.

8 Mrs Wr Children, yes.

At this stage, her authority to question the validity of the diagnosis as well as her belief in the consultant appeared precarious. The interviewer voiced these doubts:

9 Interviewer And you, you were aware of that are you saying?

10 Mrs Wr Well, we assumed, yes. And um... um in fact when we were there waiting to go in to see Dr EAS, we um in the waiting room we were talking to um an Indian lady and um who said that her

> husband is a doctor. And um that she knows, she knows Dr EAS, she said he was a, she said he was a marvellous man, you know. She said he goes all over the world lecturing etc. And which made us realize even more, how knowledgeable he was. And after him telling us what he thought was wrong, we thought Well, he knows that is the, you know, that is the verdict, in fact, you know.

Again, we witness how a temporary breakdown in the interview reveals the hidden agenda of discussions about the parents' involvement in the medical process. Thus Mrs Wr, like all our respondents, made a display of her right and responsibility as a parent to participate in this process. As we saw earlier, the extent of this participation was by necessity limited and so parents sensibly deferred to the doctor. Here, Mrs Wr nearly made a mockery of her role by apparently not knowing the consultant's status. However, she redeemed her character by appealing to his world-wide reputation. We should also note how she was lulled into a false sense of security by the sympathetic utterances of the interviewer (see utterances 2-8) before he exposed inconsistencies in her account (see utterance 9).

The other characteristic parents called upon in establishing the reputation of the units was their equipment. Those who had displayed concern over the dangers to their child from faulty equipment in the NHS made the distinction between specialist units and general hospitals and argued that the latter were more likely to have defective equipment than the former. In other words, they equated the idea of specialisation with having the highest standards. This claim was a recurring theme of parents' accounts.

The most common way of verifying reputation consisted of appeals to the opinions of other people. These appeals shared several characteristics. First, like all judgements of doctors or units, they were invoked in discussions about parents' participation in the medical process. Second, it was considered that the favourable verdict of another person amounted to an authorative judgement. In this way, parents properly conceded that they were not in a position to know directly the merits of the specialists but that at the same time showed how they were fulfilling their responsibilities by using all sources of information available to them. The judgement of these sources was taken to be authorative by virtue of their having direct experience of the work of the units and their staff. The majority of these sources were medical - according to parents, they were people either who had worked at the units or who could be viewed as reliable as a result of their status, for instance GPs. Thus the appeal to the views of such people supported parents' claims that they were obtaining the best medical care for their child. Moreover, they strengthened this claim by appealing to more than one source in invoking the 'they' voice (see below).

Third, the appeals took the form of what parents had heard or had been told. They did not claim that they had actively canvassed opinions but rather they had happened on them:

> 'They told me at Charing Cross. Lots of people <u>have said</u> it'
> (Mrs St)

'They *all* *said* the same thing about Dr EAS at the hospital' (Mr C)

'We've *heard* a great deal about the hospital' (Mr Wr)

'Like I mean, got a doctor down here, *she* *says* like we're lucky inasmuch as we're within easy reach of the hospital' (Mrs Fol) (my emphasis)

In formulating their account in this way, parents were invoking the idea that an unsolicited opinion of the excellent reputation of a person or an institution carries more weight than one which has been sought after since there is always the possibility that the latter may be given in order to provide reassurance. There was a morality implicit in this form of account. By displaying themselves as recipients rather than active seekers of these opinions, they were avoiding any possible accusation of being over-anxious and lacking in faith. This was explicit in the following account:

Mr & Mrs A

Extract 58 Interview 124

1	Interviewer	Have you actually asked about it, asked people?
2	Mr A	Well, medical people that I know, you know, obviously, and they've asked How's Richard? What's happened? you know, What's happening?
3	Interviewer	Hm.
4	Mr A	I've said oh well he's seen this fellow at the hospital and they've said very good, very good, you know, obvious- just comment like this to people.
5	Interviewer	Hm.

6	Mr A	Um, that knew., um that er - <u>I haven't gone around sort of making a specific thing about it, enquiring about it</u>.
7	Interviewer	No.

(my emphasis)

It appears that the interviewer's utterances (see utterances 3 & 5) were taken by Mr A in such a way that he was compelled to answer his question directly. It can be argued that the form this took had more to do with the parent seeking to convey the impression that he did not abuse his privileged position as a health professional, rather than attending to over-anxiety or lack of faith. However, the fact that all accounts were constructed so that our respondents, regardless of whether they had medical connections, appeared recipients of opinions makes it more likely that the A's were attending to their status as parents rather than professionals.

Finally, according to the opinions reported by parents, we should note how the reputation of the doctors and units was uniformly of the highest order. We shall now consider the other way in which they made their judgements: namely, by appeals to the doctor-parent/ patient relationship.

Doctor-parent/patient relationship

Parents' reports of how the specialists related to them were constructed according to the ways in which they perceived highly qualitifed professional people of this status. The overriding feature expected of such people was that they would have little time for ordinary human relationships, or indeed ordinary people, because of the nature of their work. Thus one type of account contrasted the specialist's status with the favourable way in which he treated parents and their offspring. He was accorded ordinary human qualities and was presented as relating to them on their terms rather than in an impersonal way. It was striking how parents marvelled at the consultant's display of everyday courtesies such as greeting the child or calling him by his Christian name.

The second type of account used this concept of status quite differently. Here parents spoke of their relationship with the specialist as difficult or problematic and even critically. However, without exception, they appealed to features of his status not only as a way of legitimating interactional difficulties but also as a means of displaying how they perceived him in a favourable light.

Let us first examine those accounts which contrasted the professional's status with the positive relationship between doctor and parents or children. Several parents established this by reporting how the specialist had conveyed technical information:

Mr & Mrs Fol

Extract 59 Interview 122

Mrs Fol That Dr EAS couldn't have been nicer. He really did try and explain it all. As... all the questions we asked, he tried to answer.

Mr Fol Yeah, he said have you got any more questions like and well, you know, didn't have any.

Mrs Fol In simple terms for us.

Mr Fol You know, we sort of asked him everything we wanted to ask.

Evidence for the doctor's niceness was reported as being his courtesy in asking them whether they had any more questions and the way he used everyday language to explain technical matters. Parents frequently judged the specialists in the same way.

Mrs Ht

Extract 60 Interview 144

Mrs Ht We don't understand medical terminology but he always had time for us. He used to draw thousands of diagrams and he used to explain everything to us in language we understood...

Mr & Mrs Du

Extract 61 Interview 133

Mrs Du Don't ask too many questions and... That was the attitude I got with him. Whereas Mr F (her child's present surgeon) he's more willing to sort of talk things over with you. And he answers your questions.

(my emphasis)

From a certain point of view, the appeal to someone answering questions or explaining something in simple terms as a way of establishing that person's good qualities appears rather strange. In normal circumstances, we take such courtesies for granted. However, parents were talking about doctors and two characteristics of their status as professionals informed the choice of these features. First, doctors were well known to parents for their aloof manner (see Chapter 3 and Extract 61 utterance emphasized).

Second, they dealt with technical issues beyond the understanding of the ordinary lay person. Some parents, particularly fathers, conveyed this by sympathetically comparing the doctor's situation with their own.

Mr & Mrs Lil

Extract 62 Interview 72

Mr Lil	You know, I mean the thing is it's very easy to talk in jargon. I mean I certainly wouldn't compare myself in any way with a heart specialist, I'm a telephone engineer. If people say, you know, somebody says, oh you work in telephones don't you? I say yes. And they say what's the matter with it? It's very easy to say, oh well the loop disconnect passes so and so, so and so, see? And you forget that they're not... they're left there saying, what the hell's that sort of thing, you know.
Interviewer	Have any of the doctors along the line done that to you?
Mr Lil	Um no. I think they're basically all very good.

Mr Ht

Extract 63 Interview 146

Mr Ht	I think that perhaps it's difficult, I'm an engineer and I can understand I have difficulties in explaining to someone who is not an engineer, engineering technique, and I can appreciate that for a doctor it is equally difficult for him to explain to the layman some of these problems.

These fathers compared their status to that of doctors (although Mr Lil denied this) but at the same time, by this comparison, recognized that they, like any consumer of a professional service, were dependent on the doctor explaining his findings in non-technical terms.

Parents also emphasized the consultant's general treatment of them and their child. They contrasted his human approach with their expectation of a cold-blooded professional:

Mr & Mrs Lil

Extract 64 Interview 72

Mr Lil	But we went in there, Dr EAS sort of looked at her and he was much more human than I expected. You know, I don't know, I suppose you get these preconceived ideas of what it's going to be like and you see a specialist, and I thought he'd sort of be rather more reserved... I don't know how to put it really. I suppose it's a sort of <u>Lancelot Spratt</u> sort of idea.

(my emphasis)

Here, the father appealed to a well known cinema character in order to convey his notion of a specialist. For most parents, this characterisation, which was not of any doctor but an upper class one, constituted the standard against which they displayed how differently their child's specialist behaved. As in their atrocity stories, parents were depicting two realities, an everyday one and a medical one. However, unlike in the stories, these realities were not portrayed as being in conflict with each other. Rather, parents appealed to conduct which demonstrated how members of the medical reality could identify with the parents' everyday world. The treatment of children was stressed.

Mrs Hen

Extract 65 Interview 31

Mrs Hen I mean the doctors and nurses are super here. And I mean I can remember as clear as day what it's like at the other... when I had her - Two completely different attitudes. I mean you were just a number, but here you're a person. The children are individuals. They're all called by their first names which makes it so much better for them.

There are three features of this account common to many others. First, there was the appeal to a story the mother had told earlier in the interview about the untoward way health professionals had treated her and her child at the outset of its medical career. This was used as a basis of comparison. Second, the behaviour of the staff currently responsible for her child was characterised as personal. Respondents frequently invoked and elaborated this notion:

Mr & Mrs Her

Extract 66 Interview 53

Mr Her When he got to the stage of about eight or ten, he asked me, well I supposed 'e liked girlfriends and it would affect 'im with his friends, and did it affect his social life, did he wake up at night worrying about it? You know, he really went into the closer aspects.

Mr & Mrs Lil

Extract 67 Interview 72

Mr Lil	And when she came in he said, hello there, to her, you know. And I thought well he's talking to the person, you know, and not talking about her heart as it were.
Interviewer	Yes
Mr Lil	Which I thought was vitally important really. Because at least you appreciate that he appreciates that it's a person and not just something that's gotta be, you know, it's the whole, it's the whole person.

The third feature of Mrs Hen's account we should note was the appeal to the child being called by its first name. Similar appeals were made by other parents:

Mr & Mrs Her

Extract 68 Interview 53

Mr Her	He's got a bloody good memory for names. You know, he remembers my name, remembers Ron's name.

This utterance exhibits a characteristic feature of parents' accounts of the specialists. In their atrocity stories, they argued that it was proper for health professionals to place themselves in the position of parents. In these accounts, they revealed how they placed themselves in the position of doctors (see Extracts 62 & 63). Hence, implicit in Mr Her's observation was the understanding that the consultant saw many parents and children and so could not be expected to remember all their names. The identification of the consultant's relationship to the child covered a variety of features which, according to our respondents, qualified the doctor as competent to look after children and in particular their child:

> 'He seemed... 'e loves the children, 'e's really good with children isn't 'e?'
>
> 'I mean he's got plenty of patience with kids like, you know?'

We should also note how doctors in line with their personal approach, were referred to either by name or by the 'he' voice as opposed to the impersonal 'they' voice so characteristic of the atrocity story.

However, relationships with the specialists were reported sometimes as difficult. Parents voiced complaints about the way they or their child had been treated but then proceeded to argue that such behaviour on the part of the consultant was to be expected and moreover was acceptable given his status. Before the following utterances, the mother claimed that she thought the doctor was 'cold'. The interviewer took this up in such a way that she was forced to confront her criticism.

Mr & Mrs Ca

Extract 69 Interview 140

1 Interviewer What I mean when you say he's cold, I mean does that mean, you know, it's as if he's treating him as, you know, just a lip and a palate rather than a...

2 Mrs Ca Just a patient. Yeah. Just a patient. Well, that is as it should be I suppose. I mean he's got so many. He can't think of them all, can he?

3 Interviewer Hm.

4 Mrs Ca As long as - I mean to me, as long as he does what he does well and Johnny is... made to look normal and good as possible, that is all that matters.

5 Interviewer Hm.

6 Mrs Ca Whether he's cold to me or to the child or anybody doesn't matter, really.

7 Interviewer Hm.

8 Mrs Ca As long as he does...

9 Interviewer Hm.

10 Mrs Ca What he does, and that's it.

From this account, it would appear that parents were required at all costs to preserve the good name of their child's doctor and so their own identity as responsible people. If they presented their relationship with the doctor as impersonal, then the significance of this was reduced by appealing to features of his professional status which testified to his competence. These features included technical abilities and the specialists' obligations to many patients. These obligations were often invoked and used in the same way. A characteristic way of expressing them was the notion of being 'busy'.

> 'I feel that I'm not wasting Dr EAS' valuable time, um because I know he's a busy man and that was it really.'
>
> 'But... I didn't sort of see him to sort of speak to or talk to. I sometimes I mean he was very busy when he did come that day anyway.'

'But you know, I just feel that Mr F probably hasn't got time to um... He's such a busy person.'

'And we can both go to him any time, if we've got particular questions to ask. And of course Dr EAS said we could always ring. I know he's a very busy... chap. But you know...'

Again a comparison with parents' atrocity stories would be valuable. In these stories, the failure of health professionals to give parents their time was held to be inexcusable. Here, this failure was perceived as legitimate and even approved of since to be busy was considered as a sign of the doctor's importance. To put it another way, parents bent over backwards to interpret the specialist's conduct from his point of view. Finally, the other way in which they conveyed the same notion was by presenting a story of how parents reacted to waiting to see the consultant:

Mr St

Extract 70 Interview 97

1 Mr St And we got an appointment within a few days. Um but everybody in the waiting room - people with the same problems as us - you were in the waiting room at the hospital and this was remarkable. Some people had been there for 6 or 7 hours and no one had a word of complaint for the length of delay. Everybody there had children and they all understood that Professor EAS was giving ten minutes if it was necessary for that child and 2 hours if it was necessary to that child.

2 Interviewer Yes

3 Mr St I mean you just had to look, wait, but you knew you were in excellent hands and no one complained all that time sitting there in that horrible little room with no windows or anything, kids running around everywhere. No one murmured. It was amazing. Even guys that don't look as though they've got much intelligence with their kids, they're like quite willing to wait and I thought that doesn't happen very often you know.

4 Interviewer Well are you saying that's a kind of mark of respect or...?

5 Mr St Yes, yes. I thought the whole system was a mark of respect for the hospital. Definitely. And Profess- Dr EAS and his team. Very impressed. 'Cause I only went there the once, you see. To sit in the waiting room.

I have documented this lengthy extract in full since it so clearly displays the way parents were able to gloss situations which in the everyday world they would consider outrageous. Indeed, this was the essence of Mr St's account. By contrasting the patience of parents, even the most unintelligent ones, with the lengthy time they had to wait and the appalling conditions in which they waited, he portrayed the excellence of the specialist. This excellence was also reflected in the way he initially elevated the consultant's status from doctor to professor (see utterances 1 & 5).

Summary

Parents' judgements of the consultants and the specialist units were linked to the way they perceived their role in the medical process. This was established in discussions of their choice of doctor, the risks of surgery, private care and the importance of understanding their child's condition. In each of these topics, parents stressed the active nature of their involvement and argued that this was proper given the overriding importance they attached to the parent-child relationship. Nevertheless, they acknowledged that ultimately they relied on the specialists and made this dependence appear compatible with their parental responsibilities by invoking favourable judgements of them. They appealed to reputation and the way the consultant's related in establishing these judgements.

V Discussion

1. It is striking how little attention has been paid to the doctor-patient (parent) relationship in terms of the moral nature of respondents' accounts. The analysis in recent studies has moved unconsciously from treating interview talk as situated to perceiving it as a report on external events (Webb & Stimson 1976, West 1979 and Locker 1979) or has suggested that parents' statements reflect the medical definition of their situation (Voysey 1975). However, we have seen that this topic is central to parents' accounts because they claimed that the fate of a third party (their child) was at issue and the responsibility for its welfare was passed on to members outside the family unit.

Parents did not formulate their duty in terms of a Parsonian obligation to ensure that their child was cared for by competent specialists. Their judgements of the specialists were linked to features which were characterised by their negotiable aspects. Choosing a doctor, risks, private care and understanding the illness were areas which, in the interview, allowed parents to display their concern and sense of involvement. Of course, in the final analysis, they acknowledged that responsibility for their child was passed on to the medical profession. Paradoxically, this was the grounds for establishing their involvement and favourable judgements.

Earlier, I raised the issue of whether the features parents selected in constructing their judgements were an artefact of the research interview or were derived from their position, as consumers, in relation to the medical profession. Since the study was presented to respondents partly as an investigation into relationships between staff and parents, it is hardly surprising that they appealed to such relationships in formulating their judgements. On the other hand, it would appear that there were few understandings to which they could appeal other than reputation and relationships. As Abel-Smith (1976) argues, if the medical profession makes little effort to measure the competence of its members once trained, then it is hardly likely that consumers will be in a position to establish this.

Central to this discussion and the chapter as a whole is the notion of medical dominance. Through their accounts parents presented a moral structure with two types of reality, an everyday and a technical one of which medical dominance was a feature. Both doctors and parents were depicted as having access to the two realities but as we have seen, the freedom of parents to use a technical language and occupy the technical reality was limited whereas doctors had more freedom to move between the two. Indeed, it came as a surprise to our respondents that doctors did in fact deal with them and their child in everyday terms. However, there were constraints on doctors' freedom which were apparent in the way parents emphasized certain rights to do with their child such as the choice of doctor, the right to understand the child's condition, and the right to make decisions about surgery. Medical dominance was acceptable because these rights appeared to be respected.

The view of medical dominance presented here differed a great deal from that found in the atrocity story. In the latter, it was displayed as a source of conflict because parents did not have access to the technical reality nor was their everyday world respected. The construction of the accounts reflected these differences.

2. As we saw earlier, I made no attempt to determine how far parents understood their child's illness. Rather, I examined the way their accounts displayed their participation in the medical process. In doing so, I am not suggesting that it is unimportant for parents to acquire an understanding or for studies to be undertaken, especially where complex conditions are involved.

However, there is a tendency, which was sometimes observed at the units where this research was carried out, for doctors to concentrate on the communication of such information to the exclusion of less technical and more personal issues which may concern parents. Those parents who were reluctant to learn about their child's condition or who repeatedly sought the same information were seen in a poor light by doctors.

Similarly,studies which are partly devoted to examining parents' comprehension of their child's illness frequently explain their inability to understand in moral terms although the explanation is presented as if it is objective. For example, we saw earlier how Burton (1975), in a study of parents' responses to cystic fibrosis in their child, suggests that lack of knowledge on the part of working class fathers and their reluctance to learn more may be attributable first, to their greater unwillingness to assume responsibility and second, to their more pronounced tendency to deny the implications of the disease. A similar type of explanation is produced by Friedman et al. (1978) about those parents of a child suffering from leukaemia who persistently seek information: their conduct is accounted for in terms of over-anxiety.

These studies have much in common with the research on patient compliance we examined earlier since their explanations are based on the doctor's point of view. It is interesting how it rarely strikes these authors that parents may have been badly informed. However, leaving this matter aside their main deficiency lies in the way they fail to appreciate the moral framework in which understanding takes place. In these studies, the standard against which parents' knowledge is measured is that of the medical profession. I suspect that most parents in the present sample would have fallen short of this standard, even though they displayed their morality by claiming how important it was for them to understand their child's condition. They were invoking their own level of understanding and although the acquisition of medical knowledge was taken seriously, the correspondence between their version and that of the doctors did not matter a great deal so long as they appeared to be fulfilling their responsibilities towards the sick child.

3. It is noteworthy how the issue of death was discussed in the context of risks, a concept clearly drawn from the medical world. Some observers, including Illich (1976) and Comaroff (1979), view the 'medicalization' of everyday life with dismay. Comaroff argues that 'the semantic categories of modern allopathic medicine fail to provide modern man with an adequate set of symbolic terms in which to comprehend his existence'(pp.1-2). Presumably, they would view parents' discussion of risk from this standpoint. On the other hand, as Morgan (1975) has argued in relation to mental illness, this view fails to appreciate that those areas of social experience which are most mediated by moral and emotional conflicts may require the rationality provided by medical concepts in order to sustain a sense of order. To put it another way, it is questionable whether parents could have sustained the appearance of being sensible and rational had they discussed the possibility of their child dying without formulating this in terms of risks. Furthermore,

it would be wrong to assume that the experience of such a possibility was somehow neutralised by this formulation since both respondent and interviewer shared the understanding that the notion of risk referred to death.

4. As we noted earlier, Freidson (1970a, 1970b) argues that doctors do not need to persuade their patients but instead rely on their tacit appeal to the patient's faith in their knowledge and competence. Thus he gives the impression that the patient is passive in this process. However, according to our respondents' accounts, this is in~~n~~accurate. They did not present 'faith', 'confidence' or 'trust' as an inevitable outcome of their relationship with the doctor. They recognized how 'faith' referred both to their inferior knowledge and their child's care being under the control of doctors. Again, paradoxically, this made it all the more urgent that, as parents, they should show how the *granting* of 'faith' was conditional on their being assured of the specialist's competence.

5. My comments gathered on private medicine are suggestive since sociology has limited data on this topic. Parents' appeals did not simply arise out of a calculation of private medicine's merits over those of public medicine. Certainly, it was assumed to have advantages. However, references to private medicine had the same status as other features of their accounts which displayed their morality as parents. They were not necessarily statements about intentions but rather were used to convey what their child meant to them.[2] I suspect that one of the ways in which private medicine attracts patients is by appealing to people's attachment to the

family.[3] Thus investing in private medicine is equated with caring for the family. Recent work by Strong (1979b) shows how the behaviour of private doctors is suited to this sentiment. A great deal of trouble was taken to make patients feel that they obtained the best possible medicine by fostering 'the impression that the technical quality of care was something special' (p.224).

VI Conclusion

In the introduction to this chapter, I raised the issue of whether there was any point in using interview data in the study of the doctor-patient relationship. In one way, the views of those who are against the use of such data in this area have been fully supported. We have shown that the construction of accounts is occasioned by the moral nature of the interview and bears little relation to external events. However, since such accounts are as pervasive a feature of everyday life as the naturally-occurring situations to which they refer, there is every justification to continue studying them. The danger arises when they are used to examine features of the situations discussed, as has so often occurred in past sociological research.

Finally, the analysis presented here has fully supported the need, initially identified in the discussion of the atrocity story, for a longitudinal approach to the study of the doctor-patient relationship. This need is also fully confirmed by findings from naturally-occurring material. The findings from both these sources present a very different picture of dominance from that found in traditional studies of the doctor-patient relationship.

Chapter 5

THE PRESENTATION AND DISPLAY OF BABIES: PARENTS' RESPONSES TO DISFIGUREMENT

1 Introduction

It is sometimes assumed that birth is a time of intense joy and achievement and that motherhood is intrinsically satisfying. Oakley (1981) presents data which undermine these common cultural conceptions of joy and satisfaction. She shows how it is normal for mothers to be unprepared for the pain and shock of birth; to be disinterested in their baby when holding it for the first time; to feel physically uncomfortable after the birth; to suffer 'baby blues'; to feel lonely in hospital; to be anxious about child-rearing; and to find it generally traumatic adjusting to a maternal role. Eventually, mothers do adjust to their new situation and find that bringing up a baby has its compensations, although these are not of a 'romantic story-book variety'. In summary, Oakley's study seems to identify, in a convincing way, the normal experiences of pregnancy and early motherhood.

These standards of normality differ from those used by parents in accounts of their experiences of a hare lip baby. Often, their versions of normality were identical with the conceptions Oakley's study disputed. This discrepancy cannot be explained by differences in the levels of maternal experience amongst the sample members. We might expect the accounts of inexperienced mothers to contain appeals to an idealised conception of motherhood but, as Oakley's study shows, this is not necessarily the case since her respondents were having a baby for the first time. Furthermore, 60% of the sample of parents who had a baby with a hare lip had already given birth to an undamaged child. In other words, they were conversant with the problems of adjusting to 'normal' parenthood.

One explanation of the discrepancy between Oakley's findings and those of the present study concerns the complex interaction between the respondents' perceptions of their experiences and their views of the objectives of the researcher. Oakley's objectives were to expose and clarify 'some of the problems involved in becoming a mother in modern society' (p.1). Thus it is likely that her sample members used the study and, in particular, the extended interview format to reveal experiences which were problematic. It is apparent that for the majority of the mothers, the interviewer was one of the few people with whom they could share their experiences and from whom they could acquire information about pregnancy, child-birth and child-rearing.[1]

Hence the problematic experiences of these mothers (who gave birth to <u>normal</u> babies) were emphasized, while non-problematic ones were taken for granted.[2] For instance, Oakley's respondents rarely mentioned their baby's appearance, whereas the parents of disfigured babies claimed that the appearance of babies is an important part of the experience of all parents, including those of undamaged babies. In accounts of these parents, the central issue was the presentation and display of the baby. They perceived these activities to be common to all parents of newly born children.

The discrepancies we have been discussing raise important doubts about the reliability and status of findings obtained from extended interviews. However, this is only true if we treat such data as a reflection of a reality external to the interview. From the above discussion, it is clear that analysis of interview data must take into account the situated nature of this method. Oakley only does this to a certain extent. Ultimately, she treats her respondents' accounts as authentic descriptions of the various stages of pregnancy, birth and baby-care. Clearly, this leads to inaccurate interpretations.[3]

However, another explanation of these discrepancies concerns the differences between the experiences of parents of normal babies and those of disfigured babies. The former were not required to take account of cultural stereotypes of normality since their status as normal parents was assured. In this sense, Oakley's respondents could afford to reveal their problems or indeed, as we have seen, challenge such stereotypes. On the other hand, parents of the disfigured were faced with an entirely different situation. Their normality as parents was in doubt and they were therefore constrained to invoke cultural stereotypes as a way of re-establishing their position amongst 'normal' parents. We shall explore this issue at greater length later.

It may seem questionable to dwell on what is meant by normal parenthood when seeking to report parents' responses to a disfigured baby. However, as Goffman (1968b) has argued, the moral career of the stigmatized involves learning and incorporating the standards of the normal society so that they acquire a general idea of what it is like to possess a particular stigma. From this point of view, such individuals will be sensitized to standards which the normal take for granted. Furthermore, it is only in the context of these standards that their actions become intelligible.

Of course, strictly speaking, parents of disfigured babies are not themselves stigmatized. However, they are treated as such as a result of their unique relationship to the disfigured baby. This gives them a status defined by Goffman as the 'wise': people 'who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual' (p.41).

Goffman's work illuminates the way the stigmatized and others who share this status manage face-to-face interaction in the company of normal people. Many of his insights have much in common with parents' reports of their encoutners in the company of their disfigured baby. However, there are some important differences. Goffman's observations apply to the stigmatized as a class, rather than the specific experiences of parents of the facially disfigured arising from the visibility of the baby's stigma. For instance, he cites information control as one of the main strategies available to the stigmatized and suggests that this strategy can only exist where the identity of the stigmatized person is unknown. However, parents of disfigured babies said they found managing information about their baby's disfigurement in public places more problematic than those, such as parents of congenitally heart diseased children, where the stigma is invisible. The availability of faces but not hearts seems to be crucial here.

Second, as we have seen, Goffman is interested primarily in interaction rather than the accounts that stigmatized people present about their experiences. Earlier, we saw the problems which arose from treating accounts as versions of external reality. Hence the accounts that will be examined here will not be taken as revealing how parents actually coped with their baby's disfigurement. Rather, their construction will be examined in order to establish the understandings that parents employed regarding the experience of disfigurement and the impression that was created in the research interview through the use of these understandings. This will be achieved by considering:

(a) parents' interpretations of the disfigured baby's status;

(b) their experiences of early parenthood.

This approach means that Goffman's notion of the 'wise' can be extended to cover the role of such people in a situation like a research interview. In this context, the 'wise' are treated as informants who possess intimate knowledge of the unusual and unique experience of having a disfigured baby. It will be seen that their views are displayed with a certain authority and are treated respectfully by the interviewer. Certainly, this differs from parents' perceptions of how 'normal' people treated them in the company of the baby. The majority felt patronized and some felt humiliated.

Thus in the research interview, parents' status is similar to that conferred on any stigmatized person who in an interview reveals to the uninformed the concealed underlife of an institution. Like our respondents, he is treated with the dignity usually accorded to those who have had experiences which fascinate 'normal' people because they are totally foreign to everyday life.

II The Sample and the Context of the Account

Table 7 presents details of the interview sample on which the analysis of data is based.

Table 7

Parents	Child's condition	Age of child
Mr & Mrs D	cleft palate and hare lip	4 yrs.
Mr & Mrs Wa	" " " " "	12 yrs.
Mr & Mrs Her	" " " " "	16 yrs.
Mr & Mrs Ca	" " " " "	5 yrs.
Mrs Wl	" " " " "	14 yrs.
Mrs Bi	" " " " "	15 yrs.
Mr & Mrs Al	" " " " "	14 months
Mrs Fd	hare lip	3 yrs.
Mr & Mrs Fi	" "	1 yr.
Mrs Sm	" "	1 yr.

The accounts analysed in this chapter are drawn from interviews administered to all the parents of children suffering from a hare lip. A salient feature of these accounts was their retrospective nature. It was impossible to carry out any interviews right from birth because of the practical difficulties of making contact with sample members. Normally, contact was made at the cleft palate/hare lip outpatient clinic of the children's hospital. By this time, the initial corrective surgery had been carried out on all the babies.

Medical intervention during the early stages of the baby's career moves rapidly. A few days after its birth, the paediatric surgeon sees parents either at the hospital of birth or informally at the local children's hospital. He then advises them that surgery on the lip will take place within three weeks.

A further reason why the accounts are retrospective was to do with the small number of new patients coming under the consultant's care in any one year (between 5 and 10). Moreover, a proportion of these were only born with a cleft palate. The overall objective of the research was as far as possible to document the entire career of cleft palate/hare lip children and, as we noted in Chapter 3, this could only be accomplished by selecting a cross-section of children from each of the following age-groups:

0 - 3 years;
4 - 10 years;
11+ years.

Thus accounts of parents' experiences of a hare lip baby have been drawn from interviews carried out with parents whose children's ages varied. Some parents of teenage children produced less data than parents of younger children on their experiences of their baby in the community or in the maternity hospital because of an earlier medical policy, at that time. Unlike the current policy, parents were separated from their baby. Such babies remained in hospital for several months until corrective surgery had been carried out on the lip. Apart from this variation, the accounts of parents' early experiences appear not to differ according to the age of the child at the time of the interview.

The accounts we shall be examining are about parents experiences before and immediately after corrective surgery had been performed. They arose in the first interview between the researcher and the respondent. Their experiences of the disfigured baby rarely arose as a topic at subsequent interviews.

On initial examination, parents' accounts raise important doubts about their own adequacy as parents. For instance, they reported reactions such as being horrified and disgusted by the baby's appearance and, in some cases, not wanting outsiders to see the baby. From their perception of the standards of normal parenthood, they assumed that these reactions would be unacceptable. Hence, their accounts addressed the following moral question: 'How could you, as a parent, have behaved this way towards your baby?' We will see that, by appealing to standrads which are usually taken for granted by parents of undamaged babies, they established the legitimacy of their conduct and thus their status as adequate parents. Moreover, their accounts suggested that any parent would have reacted similarly in their situation and this claim strengthened their display of the status of moral adequacy. As we shall see, the standards to which they referred concerned the importance of appearances in the presentation and display of babies.

Parents' accounts were significant in another way. On many occasions, they appealed to their feeling of isolation in contrast to the shared experience of parents of normal babies. In doing so, they further encouraged the listener to empathise with their past situation and to treat their talk sympathetically.

In the next section, we shall examine parents' interpretations of the baby's status. There was an important association between these interpretations and parents' views of social situations involving their baby and themselves.

III Parents' Interpretations of the Disfigured Baby's Status

In presenting their interpretations at the beginning of their accounts, parents established the centrality of appearances in formulating the status of the baby. Clearly, this was important since what they went on to report mainly concerned their experiences of presenting and displaying the baby to other people. However, we shall see that their initial interpretations were modified. The appearance of the baby mattered a great deal but not to the total exclusion of other features. With striking uniformity, parents admitted that they had perceived their baby as 'horrible' or a 'mess' (see Plates 1 and 2):

Mr & Mrs Wa

Extract 71 Interview 20

Mrs Wa	So I said, you know, it was horrible what I see. I said 'cos having a baby with a hare lip I thought'd be, you know just pulled up
Interviewer	Mm.

Mrs Wa But umm, it isn't, it's entirely different. I mean the lip and the gum was completely a big gaping hole, you know, and the nose was stretched across. I mean most people think, you know, a hare lip is just er a scar and the lip pulled up you see.

Mrs Wl

Extract 72 Interview 23

Mrs Wl I rejected her, because I just didn't want a child like this.

Mr & Mrs Her

Extract 73 Interview 53

Mr Her Yeah this one was a cavity

Mrs Her Yeah there was a lump sticking out

Mr Her Yeah, he was a real mess, you know, it really was a terrible shock. Well he was so bad that he was so very bad. I mean his face wasn't a face in the true respect.

Mrs Bi

Extract 74 Interview 101

Interviewer Do you ever think back about, I dunno, it's a long time now but, you know in a sense;

Mrs Bi You don't forget it.

Interviewer You don't forget it.

Mrs Bi No you don't. Well I don't. Um I know from the day she was born, from when they first showed me her. I can still see, you know. I don't think you forget it.

It's a shock and you know, you know my husband saw her first and when they came and explained to him (formally) um <u>it's a shock for anybody</u>// you know... I mean ugly is the word. They are born really ugly.

Mr & Mrs Fi

Extract 75 Interview 137

Mrs Fi — And when I saw him, when he was born. I'd... my first reaction was that's not my baby. Now that's silly I know, but <u>it's just the reaction, the way you feel</u>.

Mrs Fd

Extract 76 Interview 95

Mrs Fd — <u>Can't imagine</u> somebody whose baby's really disformed. It's a shocking sight.

(my emphasis)

These dramatic interpretations established the significance of appearances in defining the baby's status. Second, through the use of intersubjective devices (see utterances emphasized) it was implied that anyone would have reacted similarly since a parent expects to give birth to a baby with an undamaged appearance. Yet most parents, regardless of how negatively they perceived their baby's appearance, went on to modify their views.

They appealed to a variety of commonly-held conceptions about babies and appearances in re-formulating their baby's status. For instance, some parents appealed to their baby's lovable nature:

Mrs Fd

Extract 77 Interview 95

Mrs Fd	There were all these babies around that were all lovely and... but Johnny was just as lovely. I loved him so anyway.

Mr & Mrs Fi

Extract 78 Interview 137

Mrs Fi	And I thought, you know, it's my baby and I think he's lovely and that's all that counts.

These responses conveyed a certain defiance. It was as if the parents were saying that they were not going to allow their perceptions of the baby's appearance to interfere with the unique experience of having a baby. Defiance was a recurring feature of parents' accounts.

Other parents referred to the baby's health apart from the hare lip:

Mrs Bi

Extract 79 Interview 101

Mrs Bi	I didn't mind, so long as the, you know, her health was good.

Mr & Mrs Ca

Extract 80 Interview 140

Interviewer	So it didn't really bother you?
Mr Ca	No, not when I saw he was strong and tough. I remember saying to my wife that there wasn't much

> wrong with him... I took his clothes off and he was all... (chuckles) all there. And I said, there's nothing to worry about.
>
> (my emphasis)

Of course, strength, toughness and sexuality (see utterance emphasized) are generally held to be desirable features of being male. The gender of the baby was proposed as significant in other ways. Mr & Mrs Fi, who had a son, claimed the following:

Mr & Mrs Fi

Extract 81 Interview 137

1 Mrs Fi — We were just thankful that it was a boy and not a girl.

2 Interviewer — Yeah.

3 Mr Fi — Yeah, cos one thing I couldn't stomach is a girl with a hare lip.

4 Mrs Fi — No it would be awful.

5 Mr Fi — It would be terrible. I haven't actually seen one, so I dunno.

6 Mrs Fi — No but they say it's more common in boys than in girls.

7 Interviewer — Yeah, I think that is so. Most of the people I've seen have boys.

(my emphasis)

Here the parents and interviewer (see utterance 2) both appeal to the idea that appearances are far more important to females than males. It was for this reason that they were 'just thankful that it was a boy and not a girl'. Precisely why appearances are more important to females than males was discussed by Mr & Mrs Ca who also gave birth to a boy. Initially, however, they expressed the same sentiments as the Fi's:

Mr & Mrs Ca

Extract 82 Interview 140

1 Mrs Ca And-
2 Mr Ca If it had been a girl I would
3 Interviewer Yeah.
4 Mrs Ca Oh it would have been
5 Mr Ca It would have upset me
6 Interviewer Yeah.
7 Mr Ca But seeing that it's a boy, you know, I think boys
8 Interviewer Yeah.
9 Mr Ca (will be) boys. I don't think it matters much really.

The discourse in this extract emphasizes how conduct in social life proceeds smoothly only on the basis of meanings which are taken for granted. Without making it clear, the respondents and interviewer knew that their utterances concerned appearance and its importance to girls as opposed to boys. We, as readers, know this too since we share the same cultural background. The claim was that appearances constitute a master status for girls whereas boys can get by on other characteristics like strength and toughness (see Extract 80). In saying 'boys will be boys, I don't think it matters much really', Mr Ca was appealing to the generally held view that boys do not need to take too much care of their appearance as it will not affect their chances in life. Later on in their discussion, Mr & Mrs Ca revealed that a niece had recently been born with a hare lip and they then spelt out the importance of appearances to girls.

Mr & Mrs Ca

Extract 83 Interview 41

Mrs Ca	I must admit when my brother had- 'is wife had a little girl, I was more upset for her than I was for him (the Ca's son).
Interviewer	Yeah.
Mrs Ca	I don't know why. It's because a girl it- it's well <u>her face is her fortune</u> I suppose if you- when they get older I mean.
Interviewer	Yeah.
Mrs Ca	Boys somehow or other, muddle through they've got...
Interviewer	Hm.
Mrs Ca	You know what I mean.
Interviewer	Yeah.
Mrs Ca	It's harder for a girl to go through life I should think, with something like that so...
Interviewer	Right.

(my emphasis)

In using the saying 'her face is her fortune', Mrs Ca was referring to the commonly held idea that a girl's chances of being socially successful and, in particular, of achieving the status of wife and mother, depend on how she looks. From this perspective, 'it's harder for a girl to go through life' if she is facially disfigured. Again, we should also note the interviewer confirming and sharing this point of view. The observations of the Fi's and the Ca's appear to be a comment on the way femininity and masculinity are evaluated in our culture. However, before we accept this judgement of the relationship between gender and appearances we should examine the accounts of parents who gave birth to disfigured baby girls. In the sample, there were only two families with girls suffering from a hare lip. In neither case did the parents comment on the relationship between gender and appearances. Indeed, Mrs Wl claimed that giving birth to a daughter was a source of joy:

Mrs Wl

Extract 84 Interview 25

1 Mrs Wl Well, we'd already got three boys. I mean having a daughter was a great thing anyway, apart from anything wrong with her and it was all right, she was going to be all right and live a normal life.

2 Interviewer Yes, yes, I can understand that. So the most significant thing for you was having a daughter.

3 Mrs Wl Yes

4 Interviewer Whatever she was like and whatever she looked like?

5 Mrs Wl Yes once I accepted her, you realize that.

6 Interviewer Yes I do understand that.

7 Mrs Wl Yes I think that was probably the shock. I'm not very fond of babies when they're first born anyway (chuckles) I'm more concerned with myself.

8 Interviewer So what do you mean by that?

9 Mrs Wl Well, I think Oh gosh, take it away, I've done all the work now I'll have it later on.

In comparing this account with those of the Fi's and Ca's, we see how cultural attitudes do not determine parents' interpretations. Rather, they are like a pool of stereotypes which are picked out to suit particular interpretations. The interviewer's interpretations and questions were based on the notion that facial disfigurement, especially when it involves a baby girl, overrides all other considerations in formulating its status. Mrs Wl rejected this assumption by appealing to the unique experience of having a girl after three boys. We might expect a parent who had given birth to a normal baby of a different gender from her previous children to say much the same as Mrs Wl. Moreover, it was reasonable for her to attribute reactions such as shock and difficulty in accepting the baby to the experience of childbirth rather than the baby's damaged appearance: mothers often tell harrowing stories of giving birth.[4]

From a psychiatric perspective, it might be argued that Mrs Wl's account and that of Mrs Bi who also did not attach any importance to her disfigured baby being female was evidence of denial.[5] However, this claim is an instance of a cultural attitude masquerading as an 'objective' observation. In other words, the notion of appearances being more important to females than males is claimed to be universally applicable but in fact we have seen that there are a number of ways in which disfigurement can be sensibly interpreted.

Psychologists have argued that the method of interpretation we have identified occurs because people like their beliefs and behaviour to be consistent (see Hilgard et al. 1971). If they find them inconsistent they manoeuvre in one way or another to reduce the discrepancy by altering their beliefs, by changing their behaviour or both. Brown (1965) calls this a consistency theory and the most relevant theory for our data is cognitive dissonance (Festinger 1957). The kind of disagreement or disharmony with which Festinger has been chiefly concerned is that which occurs after a decision has been made - after an individual is committed to a course of action. Under such circumstances, there is often a lack of harmony between what he does and what he believes and there is pressure to change either his behaviour or his beliefs.

Clearly, our respondents were unable to change their disfigured baby for one with a normal appearance but they were in a position to change their beliefs about the nature of its appearance and other characteristics. As we have seen, most parents modified their initial interpretation of the importance of the baby's disfigurement in defining its status by appealing to the way other features were consistent with those of a normal baby. Festinger's theory is one way of explaining parents' methods of interpretation in the research interview. However, it does not explain why they should make their position consistent specifically with cultural stereotypes of normality. This requires a sociological explanation which shall be presented later.

Parents appealed to other factors in modifying their definitions of the disfigured baby. For instance, Mrs Wl spoke of the pleasure of having a baby in the context of having three grown-up children:

Mrs Wl

Extract 85 Interview 73

Mrs Wl	Anybody who has a baby after their children have grown up I think it's excellent. We found it great.
Interviewer	Yes.
Mrs Wl	Mm. But it hasn't affected us at all. Only that it's brought more into the home.
Interviewer	Yes.
Mrs Wl	As a baby. I'm not talking about her being as she is. I mean that hasn't made any difference.

Some appealed to reference groups, such as mentally handicapped babies, in evaluating the baby's status. They claimed that their child's condition was remediable:

Mr & Mrs Ca

Extract 86 Interview 140

Mrs Ca	But you know it's not... um well something will be done. He won't go through life like a vegetable or something like that. So it's just a shock at the beginning when you see him but not too bad after you've accepted that and you know that it's going to be.
Interviewer	Yeah.

Mrs Ca ... fine afterwards.

A number of parents appealed to the unique nature of their relationship to the child:

Mrs Bi

Extract 87 Interview 101

Mrs Bi I, it didn't bother me um she was mine, I wanted the child and that was it.

Mr & Mrs Ca

Extract 88 Interview 140

Mrs Ca But um, no I can't honestly say that... how can I put it? He's yours.

Interviewer Yeah.

Mrs Ca .. no matter what was wrong with him. You know, wouldn't have made any difference.

So just as this unique relationship was the source of parents' initial reactions to the baby's appearance, it was also the basis for claiming that the bond between parent and baby transcended such responses.

We have seen that most parents modified their initial perception of the disfigured baby so that they arrived at a less negative interpretation of his status. However, two couples, the Als and the Was, reported finding no redeeming features in their child:

Mr & Mrs Al

Extract 89 Interview 200

Interviewer As you see it becoming better do you feel easier about taking him out?

Mrs Al Oh yes. That's gone he's perfect now. Whereas before because it was... I didn't really have any love for him as a baby.

(my emphasis)

The unfinished utterance 'because it was...' implies that the Al's baby was unlovable due to its disfigurement. The Wa's acknowledged similar sentiments:

Mr & Mrs Wa

Extract 90 Interview 20

Mrs Wa The only thing that, you know, really upset us, you know looking at it. I mean you couldn't umm... I still couldn't find myself to sort of love him as I had, you know my other son when he was a baby. I couldn't sort of cuddle him up. And my husband just couldn't bear to look at him, you know, if he had to hold him he just used to put him up on his shoulder.

Mr Wa Well, I couldn't stand feedin' him or anything like that cos I... I don't think quite so much that, I thought I might be clumsy and do more damage that's the only thing I was afraid.

Mr Wa legitimated his conduct towards the baby by appealing to the motive of not wishing to damage it. Some parents, like Mrs Al (see emphasized utterance Extract 89) and Mr Wa found it improper to admit that their conduct towards the baby was grounded in its defective appearance. They were trapped by two conflicting standards regarding appearances: on the one hand, the value generally attached to them (e.g. being good looking etc.) and on the other hand,the notion that appearances by virtue of their superficiality should not entirely determine one's feelings about a person, especially when its one's own child.

These parents considered their baby's disfigurement to be a master status which excluded it from properly belonging to the world of babyhood, regardless of whether it was normal in all other respects. The following remarks, which describe Mrs Wa's reactions following initial corrective surgery on her baby, confirm this observation (see Plates 3 and 4).

Mr & Mrs Wa

Extract 91 Interview 20

Mrs Wa Yeah and umm I mean just 'aving the lip sewn and the nose formed, oh and it was wonderful you know, oh really lovely and the nurses said you know, what do you think of your baby? They'd bathed him and brushed his hair to all spiky points and they I think, it was then I felt, you know, well I've got a baby.

For Mrs Wa, the concept of a baby embodied the notion of a normal facial appearance. Hence, her child was only entitled to be called a baby when it was held to display the appropriate features.

To sum up, parents typically structured their accounts of the disfigured baby's status in the following way:

1. They established the importance of its appearance by reporting how shocked or horrified they were by its disfigured face.
2. Subsequently, they appealed to the nature of appearances and other characteristics commonly associated with babies in modifying their initial interpretation. As we saw, appeals to these features depended on their situation.
3. Two couples admitted that they found nothing which could redeem their initial perception of the baby. Its membership of society depended entirely on the state of its facial appearance.

IV The Display and Presentation of Babies

A striking feature of parents' accounts was their description of encounters in early parenthood which included those

- on the maternity ward;
- outside the home.

These encounters were described from the perspective of displaying and presenting the baby. As I argued earlier, these activities were held to be central to the experience of early parenthood. In their reports of such encounters, parents achieved the status of moral adequacy by:

(a) displaying their isolation from parents of undamaged babies;

(b) being courageous;

(c) casting doubt on the sincerity of responses of others to their baby;

(d) reporting strategies they used, such as hiding the baby's disfigurement, in order to create the impression of normal parenthood.

Before investigating parents' accounts of their encounters, let us examine briefly some of the normal activities and features related to babies as a class to which they referred. Our respondents claimed that having a baby involves parents in eagerly preparing for the event. Mrs Her made the following observations:

Mr & Mrs Her

Extract 92 Interview 53

Mrs Her Um I think when you have your first baby, like I 'ad Ann, and she's twelve years older than Ron and then I went to work and wasn't interested in 'aving babies. And then we decided to go in for 'aving Ron um we had everything then, there was no problem, no money worries, you know, I 'ad all the clothes I wanted, a beautiful pram, everything all the girls at work brought me presents and things didn't they?

In some ways, the circumstances of Mrs Her's second child are similar to those of many women nowadays. Women give up work during their first pregnancy and the average age in Britain for having a first child is twenty five years (see Oakley 1981). We can therefore assume that today many women are in a financial position which allows them to prepare for a baby in the way described by Mrs Her. According to her, the preparation is a shared event - 'all the girls at work brought me presents and things', and it involves obtaining items which, among other things, are used for the purposes of displaying and presenting the baby - '... all the clothes I wanted, a beautiful pram...'. It is reasonable to suggest that such activities are the experience of many expectant mothers and we can certainly assume that this was the case for 70% in the sample, who either like Mrs Her were having their baby a considerable period of time after a previous child or were working at the time of their first pregnancy. Some parents described their disappointments from the perspective of the joy and celebration of having a baby:

Mr & Mrs Al

Extract 93 Interview 200

Mrs Al — I feel we've missed out on his life quite a lot.

Mr Al — I think so.

Interviewer — You've missed out.

Mrs Al — Yeah we've missed out on having a little baby.

Interviewer — What enjoying him as a baby?

Mrs Al — Yes. We've had to worry. When he was first born the joy was taken out of it. Usually the husband goes out with all his friends and celebrates. You didn't feel like it.

Mr Al — No I didn't.

According to the Als, the birth of a baby is a pleasurable event which is shared with others. Many of our respondents appealed implicitly to this conception when describing their own experiences.

Another activity discussed by parents was looking at babies:

Mr & Mrs Ca

Extract 94 Interview 140

Mr Ca It's very difficult as my husband says. How do you not look?

Interviewer Hm.

Mrs Ca I mean you look at a normal baby so why shouldn't you look at a=

Interviewer Yeah.

Mrs Ca ... but there's something about the look

Interviewer Hm.

Mrs Ca ... you give. You know?

Thus 'looking' is an activity relevant to a baby whether or not it is damaged. Here a baby, by virtue of its newness, is treated as if it belonged to a class of objects. After all, looking is exactly what we do when seeing a new object for the first time. Furthermore, people feel they have a right to look at and admire a new object because the owner seeks and expects such attention. We should also note how a baby, regardless of the human qualities attributed to it by adults (see Davis & Strong 1976), appears like an object especially in public situations where it is often asleep.

Let us now consider the features of a baby which are normally looked at:

Mr & Mrs Her

Extract 95 Interview 30

Mrs Her It's different if you 'ave a baby and p'raps it's got something wrong with its leg, <u>you can cover that</u>

up like when you first take it out.

Mr Her Hm.

Mrs Her A baby with something wrong with its face, well you're looking at his face, the first thing you look at.

(my emphasis)

Although this discussion is about a defective baby, standards that apply to a normal baby are being invoked. A normal baby is usually well clothed so it is likely that an onlooker will only be able to see its feet, hands and face. Furthermore, when a baby is taken out in a pram, its feet and hands will be covered only leaving the face available for observation. Hence, Mrs Her argues that looking at a baby primarily involves looking at its face. We should also note that unlike other parts of its body, the possibility of concealing a baby's face should it be blemished is limited since it is normal for the face to remain available for observation. (Shortly, we shall see how parents of disfigured babies reported managing this problem.)

Again, there are parallels between babies and new objects. For instance, when we look at a new car we are initially struck by its body and paintwork and not by the state of the engine or the interior since they are not directly observable. Moreover, the possibilities of concealing defects in its body are limited and if we do observe such defects we are likely to judge the car as a whole and the owner on this basis. Hence, a baby and its parents are also likely to be evaluated by others according to the state of the baby's face as this is the only feature which can be seen. These understandings regarding the activities and features related to babies as a class informed parents' accounts of their encounters.

Encounters on the maternity ward

According to our respondents, most mothers on maternity wards identify with each other and experience feelings of comradeship. However, our respondents claimed that they did not share these experiences. Their accounts echoed the following sentiments about maternity wards presented by Mrs Ca whose disfigured baby was, in fact, born at home.

Mr & Mrs Ca

Extract 96 Interview 140

Mrs Ca But if they're, if they are a bit abnormal it must be shocking.

Ward life was held to be shocking in the context of mothers' perceptions of its normal activities and features. They identified the ritual of looking at each other's baby as a central activity:

Mr & Mrs Fd

Extract 97 Interview 95

Mrs Fd It was only the next day, a girl came over and spoke to me. 'Cos they come over and see the new babies, you know, somebody else that was in the ward.

Mr & Mrs Wa

Extract 98 Interview 20

Mrs Wa There was six beds in a ward so there was five other mothers in there as well and, you know, being a bit curious I kept thinking, oh they're looking, you know, they're looking

Mr & Mrs Fi

Extract 99 Interview 131

Mrs Fi I didn't want people to look at him.

(my emphasis

Hence given their own interpretations of the baby's disfigurement and this feature of ward life, the strategies some mothers reported adopting were sensible:

Mr & Mrs Fi

Extract 100 Interview 137

Mrs Fi And I wanted to put his cot where he wasn't facing anyone.

Mr & Mrs Wa

Extract 101 Interview 20

Mrs Wa Anyway, I used to get him out of his cot and I used to hold him this way 'cos I was at the end of the ward, so they couldn't see his face.

So the position of Mrs Wa in relation to other mothers on the ward was presented as influencing her conduct. Other mothers also reported holding the baby towards them so that the face remained hidden. The routines of the nursing staff were presented as a problem:

Mr & Mrs Wa

Extract 102 Interview 20

Mrs Wa And to make it worse the nurse always seemed to leave my son till last before she fetched 'im in.

Here, we are left to infer that she and her son became the centre of attention as a result of the nurses' behaviour. Accounts, like this one, sought to convey how much mothers and their babies were at the mercy of the most trivial aspects of ward life. What makes them even more striking is the way the respondents' predicament was described as occurring unitentionally: nurses and mothers were not out to humiliate them yet they could not avoid doing so.

In presenting these stories, mothers did not simply depict themselves as victims of unfortunate circumstances. They claimed they took actions which asserted their own normality:

Mrs Fd

Extract 103 Interview 95

1 Mrs Fd And they, when I was in the hospital, when Dick was born, I felt it more then because, you know all the girls with their perfect babies

2 Interviewer Right.

3 Mrs Fd And there's me with my poor little lump and I made my husband bring all the pictures in of Sam, my other little boy.

4 Interviewer Yeah.

5 Mrs Fd And I wanted to show them... Sam, so they knew you know I suppose that I could have one, a perfect= (chuckles)

6 Interviewer A perfect one

7 Mrs Fd Yes, it's silly, isn't it how you think.

(my emphasis)

In describing this action, Mrs Fd did three things: she conveyed her ability to establish her own normality in the hospital; by so doing she also conveyed her normality to the interviewer; and finally she reinforced this notion by saying that the need to do so was 'silly', the implication being that there was of course no need to prove her own normality anyway.

Another area where mothers illustrated their determination not to be excluded from normal activities was taking photographs of the new born.

Mr & Mrs Fi

Extract 104 Interview 137

Mrs Fi — And when the photographer came the following day, after he was born, she said oh does anybody want a photograph of their and I found myself debating about it. Shall I or shan't I have a photograph taken? And I thought well why not. And as it happened she took him away and I was going to ask her to turn his face on one side but I didn't get the chance. But as it happened she did.

This account can be read in terms of the parent seeking to display her 'real' attitude towards the baby's disfigurement. After all, photographs exist to record and preserve appearances. Hence it would have been reasonable had Mrs Fi said she decided against having her baby photographed. However, she claimed she did otherwise and in saying 'And I thought well why not' she revealed her courageousness and implied that she was not going to allow her son's disfigurement to prevent her from participating in some of the normal activities related to babies. And if she wanted the baby's face turned, this was also reasonable. We all have defects and blemishes which we prefer to be hidden in photographs!

Respondents also referred to the way mothers on maternity wards commented on each other's baby:

Mr & Mrs Fi

Extract 105 Interview 137

Interviewer How were the other mothers?

Mrs Fi Didn't say a word. They just like you do with everybody's baby, isn't he lovely? But they didn't actually say anything.

According to Mrs Fi, comments made to a parent about a new born baby take a certain identifiable form involving praise and admiration. I suspect 'isn't X lovely' or words to that effect are said to all owners of new objects as well as parents of new born babies. However, when this saying is delivered to the owner of a defective object the recipient has the problem of evaluating its sincerity. Mrs Fi judged such comments in the following way:

Mr & Mrs Fi

Extract 106 Interview 137

Mrs Fi Yeah, you think to yourself, well you're only saying that... I think they were sort of not saying anything because they didn't want to upset me or I think they were thinking to themselves Aren't we lucky? <u>We've got perfect babies.</u>

(my emphasis)

The claim was that praising and admiring a defective object was a way of being polite to the owner and so avoiding an uncomfortable situation and hurting their feelings. According to Mrs Fi, the fortunate are in reality only concerned about their own situation.

Mothers' stories of their experiences on the maternity ward largely depicted them as outsiders unable to share in the usual experiences of motherhood. The sense of isolation was strengthened by the way they contrasted their baby and the babies of other mothers. As we have seen, our respondents' babies were invariably described as defective whereas undamaged babies were referred to as 'perfect' (see Extracts 103 and 106) or in similar terms:

Mr & Mrs Wa

Extract 107 Interview 20

Mrs Wa And they wheeled another mother out just 'ad her baby and of course, she got in with a beautiful boy, black hair beautiful face, so naturally I 'ad the baby in this arm and pulled the shawl over.

Mr & Mrs Her

Extract 108 Interview 53

Mrs Her ... And I always remember she was only about... my friend 'ad a beautiful baby, he was really beautiful a great big baby, you know.

Mr Her Big fat baby 'e was a beautiful baby, a big fat one.

Finally, the feeling of separateness was further strengthened by the way our respondents' situation was always presented in the

'I' voice whereas that of other mothers took the 'they' or 'we' voices. In other words, those taking the 'they' or 'we' voices shared a common identity which contrasted with the identity of 'I' i.e. mothers of disfigured babies.

Encounters outside the home

Eventually mother and baby have to leave hospital and return to the outside world. We have seen how parents considered looking at the baby's face to be a central activity. They described this activity occurring in a number of everyday situations familiar to the majority of mothers of newly-born babies. These included:

The neighbourhood:

> 'I mean I've lived around here for what... about 40 years and er I know everybody you know' (Mrs Her).

The welfare clinic:

> 'I remember the first time I took him down the welfare... I felt I had to take him down the welfare' (Mrs Her).
>
> 'I remember when I had to take him to the clinic for the first time' (Mrs Al).

Shops and shopping:

> 'You go into a shop and the women behind the counter' (Mrs D).
>
> 'But I found when I went down into Highford shopping, you know from Smith Street I used to walk with the pram and get all my shopping in Highford' (Mrs Wa).
>
> 'I took him down the road to show him off to all the people in the shops' (Mrs Fd).

Play groups:

> 'Used to take him up the play group, all the mums and,

you know' (Mrs Fd).

Work:

'When my wife was pregnant there was a big build up to it. You've got this big thing about how you're gonna be off work for a couple of weeks and taking him around to show everyone' (Mr Fi).

A striking feature of all these situations was their public nature. They were presented as the familiar everyday social world of mothers and, to a lesser extent, fathers. Like the mothers on the maternity wards, people in these situations were depicted as wanting to look at the baby:

'People look' (Mrs D).

'People used to look at him' (Mrs Fd).

'When I used to bump into my friends, they'd say, oh you know, what did you 'ave, I 'aven't seen the baby' (Mrs Wa).

'So I thought, well, if they look in the pram, you know, a little tiny baby, they'd just 'ave a quick little look' (Mrs Wa).

'Deep down you think if only he could have done it earlier. You know it's 'cos people look in don't they' (Mrs Ca).

'Yes well everyone used to go up and have a, you know, really look' (Mrs Ca).

Also, like the mothers on the ward, these people were described as commenting on the baby in the sympathetic way the fortunate typically respond to the misfortune of others:

'You get, it's funny, you get people bringing up articles to you and showing you pictures Oh look at this Oh don't worry about that' (Mrs Fi).

'People go Oh poor little thing and all that sort of thing' (Mrs Ca).

'They all sort of say Oh well, you know, we're sorry and all that sort of thing' (Mrs Her).

'They'd say Oh what's the matter with 'is mouth and Oh ain't it a shame Oh ain't he...' (Mrs Wa).

We can imagine that when such comments were made parents received them without protest. However, in the interview they confided the following:

'And to be honest, after two days of it I just didn't wanna know anymore. I got so fed up with people telling me it was nothing to worry about' (Mrs Fi).

'You cannot help it but you don't need it. You don't need pity. You don't need anything like that. And as my husband says, if they just leave you alone, nor sort of make a spectacle out of you. I do know the last thing you feel you want is people peering at it and going Ooh and isn't it...' (Mrs Ca).

'That's the worst thing of all. I'd rather people completely ignored me than give me sympathy' (Mrs Her).

'And I couldn't stand it' (Mrs Wa).

Here parents were pointing to the contradictory nature of the comments they reported receiving. Such comments were ways of commiserating with parents and sympathising with their misfortune. However, according to our respondents they merely succeeded in confirming how far their situation differed from that of other people. Thus they were appealing to the way the unfortunate do not wish to be reminded of their misfortune especially in those circumstances where they seek to share a common identity with others. We should also note how the interviewer was treated as a confidant i.e. he could be trusted with parents' criticisms and also be expected to understand that they were not borne out of malice.

It was against this background that our respondents produced a variety of responses which were taken to be reasonable given both their interpretation of the baby's disfigurement and the conduct of others in public situations. The significance of these responses lay in the way they reinforced the notion that they were normal people. Some parents, like Mrs Bi produced accounts which showed their defiance:

Mrs Bi

Extract 109 Interview 101

1 Interviewer What about the social side of it? I have spoken to parents with babies and children what about, you know, the question of taking them out when they're young and you know doing the things one normally does like shopping // Does that=

2 Mrs Bi It didn't bother me.

3 Interviewer That didn't bother you?

4 Mrs Bi It didn't bother me. No. That didn't. That I can say truthfully and my husband's the

		same, that didn't worry me an inch. I mean she, when we had her home, um she didn't have her lip here. She had a gap from there to there. And I just took her out. I didn't think of that. But people who saw her you looked at their face and that was it you know. They wanted to (shudder) away sort of thing, you know, turn away.
5	Interviewer	How did that make you... feel?
6	Mrs Bi	Um choked you know.

Here, the interviewer's questions were based on the assumption that taking the baby out was problematic if not impossible. This was apparent in the difficulty he had in actually formulating them (utterance 1). However, according to Mrs Bi, this assumption was totally misplaced. She reinforced her display of defiance by the vivid way she described her baby's disfigurement; and by presenting the negative reactions of others and her feelings about them. Several parents displayed defiance in a similar manner. Like Mrs Bi, Mrs Wl did not accept the interviewer's assumption:

Mrs Wl

Extract 110 Interview 73

Interviewer	I mean I have read one interview.
Mrs Wl	Yes.
Interviewer	With some parents and they said they went about covering the pram.
Mrs Wl	Oh no.
Interviewer	And you know, virtually hiding the child away.

Mrs Wl No, no we didn't do anything like that. I didn't, I didn't at all. I just treated her as a normal child.

Other parents were equally emphatic in their denunciation of actions, such as 'covering the pram':

Mr & Mrs Ca

Extract 111 Interview 140

Mrs Ca I mean my sister-in-law apparently her second child had it. She wouldn't take him out.

Interviewer Yeah.

Mrs Ca She was - didn't want anybody to see it. Well I mean it wouldn't have stopped me taking him out.

Mrs Ca uses her sister-in-law's 'weakness' to display her own morality. In other circumstances, her comments would appear self-righteous. However, she was not open to this accusation because she was also a parent of a disfigured baby and unafraid to take him out.

Inspite of the way some parents of hare lip babies considered avoidance of others and protection of the baby's face reprehensible, such responses were legitimate since parents had described the conduct of others towards them and their baby as intolerable.

Thus Mrs Al reported holding the baby close to her so as to hide its face and Mrs Wa admitted showing only the undamaged part of her baby's face when it was lying in the pram:

Mr & Mrs Wa

Extract 112 Interview 20

Mrs Wa	So I found what I was doing I was always putting him turning him so he was on his good side... and then if I met, you know, a friend, I hadn't seen for a while Oh isn't he a lovely baby. They didn't see it, they didn't ask so I didn't say anything.

Mrs Her spoke of having hoped to avoid people altogether:

Mr & Mrs Her

Extract 113 Interview 53

Mrs Her	I didn't wanna meet people I 'ad to take 'im down the welfare and that walk the first day was terrible in case I met anybody you know and oh I was sweating buckets by the time I got there. I sort of took 'im out of the pram quickly and put 'im on the scales.

Most mothers would treat a visit to the welfare clinic as a routine activity. However, for the mother of a disfigured baby it was presented as a living nightmare - 'Oh I was sweating buckets by the time I got there'.

Finally, we should emphasize that the nature of parents' responses presented in their accounts complemented their interpretations of the baby's status. Those like Mrs Bi, Wl and Ca who appealed to features other than their baby's appearance were less likely to say they hid the baby or avoided others in public situations than parents like the Wa's, Al's and Her's who gave its disfigurement a master status.

V Policy Implications

So much of what parents said concerned the conduct of other people towards their predicament that the possibility of radically altering their experiences for the better is doubtful. (The discussion below will elaborate further on why this is the case.) Certainly, the value of current interventions such as early corrective surgery and showing parents photographs of babies with repaired lips is borne out by the accounts we have examined. Mothers might also benefit from being asked whether they would like to stay in a side room at maternity hospitals. They feel most vulnerable after the birth of the baby and this type of accommodation would be a suitable setting for them to work out with their spouse some of the problems involved in having a disfigured baby. The chances of this happening on a public ward are limited. Second, parents could be helped by being told that responses such as disgust at the baby's appearance are normal and not incompatible with more positive feelings. In the present study, some parents were able to make this adjustment while those who treated the baby's disfigurement as a master status found it impossible until long after the initial corrective surgery.

VI Conclusion

The present study has shown the power of cultural stereotypes of normality for parents of the disfigured despite Oakley's finding that such stereotypes in no way reflect the experiences of mothers of normal babies. Thus the irony is that parents of the disfigured, whose situation is vastly different from that of 'normal' parents, appeal to stereotypes of normality whereas the latter rarely invoke them and sometimes even challenge them as fictitious or idealised.

According to Voysey (1975), this is hardly surprising. She shows that the statements made by parents of a disabled child are organized or informed by an official morality of child-rearing and family life which is implemented routinely by agents specifically concerned with managing the phenomena of having a disabled child. These agents include the medical profession, social workers, voluntary associations, newspapers and magazines. In a variety of ways, they express what Voysey calls an ideology which defines the situation of parents so that it appears consistent with the normal order of child-rearing.

Clearly, parents of disfigured babies are likely to make far more use of these agents than typical parents and so be more exposed to the ideology than the latter. In the present study, parents reported using the media as well as doctors, nurses and health visitors for advice on child-rearing. Unlike the mothers in Oakley's study, they reported making little use of their own parents who were not qualified to help since they had raised only normal babies.[6] Furthermore, the pressure on parents to define their situation as normal according to cultural stereotypes also arises as a result of their contact with lay people. As we have seen, parents organized their accounts according to their perceptions of the normal experiences of early parenthood in maternity wards and outside the home. It was against this background that most mothers produced responses which defined their situation as consistent with the normal order of parenthood. Thus they claimed they took the baby out in spite of its disfigurement; they objected to the attention and sympathy of outsiders since this damaged their identity as ordinary parents; they reported that photographs were taken of the baby just after it was born; they appealed to features of normal babies in interpreting the status of their baby e.g. health, gender, etc. As Voysey argues: 'Parents of a disabled child manage to appeal to normal motives despite the differences between their situation and that of normal parents because the definitions of their situation, or the meanings of having a disabled child that are available, and the ways in which these are made available to them, constrain them to redefine such differences and present themselves and their situation as understandable within normal terms. They appear respectable because that is how others require them to appear.' (p.212)

The issue we have been discussing here is a familiar one for sociology and politics: namely, the status of phenomena like cultural conceptions of parenthood, which according to the investigator do not reflect the situation of the individuals and groups they seek to depict. Unlike Oakley, we have argued that such conceptions <u>are</u> part of the experience of parenthood. Her account is faulty because it confuses the notions of validity and reality.

In other words, cultural ideals regarding parenthood and child-rearing may bear a questionable relationship to the experience of any parents, but they are nevertheless part of their reality in so far as they inform the way these experiences are interpreted and presented, especially by parents of the disabled. Thus these conceptions are unlikely to disappear simply because their validity has been disputed.

Dawe (1973), Thompson (1978) and Hobsbawm (1981) have made similar points in their respective areas of interest. Dawe, in proposing a reflexive sociology, argues that sociological analysis 'must be grounded not only in the analyst's own experience' but 'must possess a genuine sensitivity to other meanings, other situations, other biographies' (p.29). Although this is stating the obvious, it is often missing from those areas of study where it is essential for real understanding and communication. For instance, it is inadequate to interpret schizophrenia as a political expression without regard for the utter anguish and despair of the schizophrenic. Furthermore, Dawe argues that if sociological analysis is to have more than purely idiosyncratic significance, others must have shared it and found it meaningful. In other words, it must be representative.

In the remainder of his paper, Dawe elaborates the notion of the representative experience. He criticises those varieties of sociology which, whilst they take the notion of subjective meaning as their starting point, destroy its importance to sociological analysis 'either by conceiving of it as imposed from without;

treating its discovery as being unproblematic and straightforward; or viewing it as being constituted by a set of games and recipes' (p.30). In summary, Dawe claims that an adequate sociology can only be created if it is based on a profound understanding of the diverse meanings and purposes with which it has to deal.

Similar claims are apparent in Thompson's opposition to Althusserian Marxism. Althusserians argue that 'Marxism as a theoretical and political practice gains nothing from its association with historical writing and historical research. The study of history is not only scientifically but also politically valueless' (Hindess and Hirst 1975, p.310, 312). However, Thompson shows that the study of "experience" (or social being's inpingement on social consciousness) is a necessary part of the practice of historical materialism and that Althusserians, in failing to have a way of handling "experience", falsify the "dialogue" with empirical evidence inherent in knowledge production and Marx's own practice. They thereby fall continuously into modes of thought designated in the Marxist tradition as "idealist".

According to Thompson, experiences such as unemployment, inflation, etc. are part of the real world and exert pressure upon existent social consciousness. Moreover, the relationship between social being and consciousness is a dialogue so that consciousness (such as cultural perceptions of parenthood) 'thrusts back into being in its turn: as being is thought so thought is also lived - people may within limits live the social or sexual expectations which are imposed upon them by dominant conceptual categories' (p.201).

Finally, Hobsbawm produces a similar argument in his analysis of the current struggle within the Labour Party. The left claim that only genuine left-wing policies will appeal to the electorate and will thus be a basis for Labour gaining power at the next general election. Hobsbawm suggests that this proposition is dubious since it is based on an inaccurate analysis of the situation and aspirations of Labour's potential supporters: such considerations have to be taken into account if the quest for power is to be successful. Thus Hobsbawm suggests that 'the future of Labour and the advance of socialism depends on mobilising people who can remember the date of the Beatles break-up and not the date of the Saltley pickets; of people who have never read Tribune and who do not care a damm about the deputy leadership of the Labour Party. These are regrettably, not revolutionaries, even though they want a new and better Britain, and if they can be shown that socialism can achieve this, a socialist Britain' (p.7).

In a similar sense, if we wish to see the situation of parents of disfigured and normal babies improved, this can only be achieved 'on the basis of a deep and hard-won understanding of the meanings and purposes which inform their lives... You have to begin from where people are, not from where you like them to be' (Dawe 1973, p.30). This means that we must take account of the powerful influence of cultural stereotypes of parenthood and not ignore them in the hope that they will simply go away.

Chapter 6

MAKING CONGENITAL ILLNESS COMPATIBLE WITH CHILDHOOD: PARENTAL SOLUTIONS

I Introduction

As Hilliard (1981a) has argued, the emphasis of much of sociological research into outpatient encounters in paediatric settings ironically remains focussed on adults rather than children. Yet he has shown that, by attending to the status of the child, parents and doctors establish roles for themselves and each other which provide the grounds and focus for their encounter.

The same neglect of the child is apparent in studies of familial responses to congenital illness in children (see Voysey 1975, Davis 1963). There is a tendency to concentrate on parents' responses and their definitions of the illness, as opposed to the child's response to it. Thus little attention is paid to aspects of family life which involve the activities of the congenitally ill child. Indeed, in these studies the child tends to be displayed as a medicalised object. There are two reasons for this. First, the micro-sociologist's interest in respondents' accounting practices and the related research strategies tend to rule out children as respondents. A study of familial responses, using intensive interview methods with children, is unlikely to yield adequate data. Second, in theorising about children, medical sociologists have correctly defined them as non-moral persons and treated all aspects of their existence as being dependent on their parents (see Voysey 1975, Locker 1979).[1] However, this has wrongly reduced interest in them as social actors in their own right. Put simply, childhood by and large does not fit into the medical sociologist's framework except in simplistic or reductionist terms.

This is a serious shortcoming especially when one considers the tremendous influence of the concept of childhood on members of industrialised society. Historians of childhood might disagree about when a special condition known as childhood was 'invented' (de Mause 1974), but most would accept that the nature of child care has undergone considerable changes this century. As Ariès (1973) argues, 'New sciences such as psycho-analysis, paediatrics and psychology devote themselves to the problems of childhood and their findings are transmitted by way of a mass of popular literature. Our world is obsessed by the physical, moral and sexual problems of childhood' (p.395).

Thus, as one might expect, a preoccupation with child care and childhood was apparent in a series of interviews held with parents of children aged three or more who were suffering from congenital heart disease. In particular, the child's responses to its predicament was a regular topic of discussion between parents and the interviewer. One issue which figured prominently was the child's perceived capacity to cope with its illness and the hospitalisation process. Parents felt obliged to address this issue for a number of reasons. First, the child was perceived as normal in all respects other than its heart, so the life it led was similar to that of its peers. Second, the child was seen to be conscious of and responsive to different environments. Finally, periodic visits to hospital involved a disruption of its everyday routines. Thus parents could not ignore their child's adaptation to its illness and treatment.

In discussing how they managed this situation, parents were faced with a problem. The strategies they reported adopting were frequently at variance with a number of assumptions about the illness and the hospitalisation process, presumably shared by themselves and the interviewer. For instance, they admitted minimising the gravity of the condition to their child or using potentially dubious methods in order to persuade it to co-operate with hospital procedures. Having presented these strategies, they felt obliged to account for them. Not to have done so would have raised doubts about their status as morally adequate parents.

Whereas with various other topics that arose in the interviews parents were able to appeal to the authority of medical formulations,[2] with this one they could not do so since the child's response to its medical circumstances rarely figured as an issue between doctors and parents. Doctors usually dismissed the matter with a 'catch-all' statement such as 'Treat him normally', leaving parents to find other ways of explaining their strategies. They fell back on familiar everyday conceptions of the child as:
1. an innocent; 2. a rational actor; 3. a dependent.
The parental strategies corresponding to these conceptions were:
1. the protection format; 2. the reasoning format; 3. the caring format.

All of these categories could be applied without contradiction to the same child in different contexts. Before exploring them, we shall describe some of the characteristics of the sample and also comment on the significance of what parents said on these matters in relation to their accounting practices.

II The Sample and the Context of the Account

Table 8 indicates some of the characteristics of the interview sample used in the analysis.

Table 8

Name of parent	Age of child at time of interview	Stage of child's medical career at time of interview
Mrs F	5 years	Pre-catheter
Mr & Mrs A	6 years	" "
		Post-catheter
Mrs R	5 years	Catheter
Mr & Mrs R	"	Post-catheter
Mr & Mrs Fol	3 years	Pre-catheter
	"	Post-catheter
	"	Operation
Mrs Hen	6 years	Operation
Mr & Mrs C	11 months	Post-catheter

Total number of interviews = 10

There are a number of observations to be made about this sample. Apart from one child (Mr & Mrs C's), the rest are of an age where they will be taken to have acquired some of those characteristics commonly associated with becoming a person. They have a reasonable use of language; parents consider them to have a memory and to be conscious of the environment to which they react in understandable ways. Thus it is predictable that the topics of this chapter arise in interviews with parents whose children are over three years old. We should also note that certain kinds of congenital heart disease are frequently not diagnosed until children reach school age. This gives the matter of how the child should be helped to adapt to the illness additional urgency, since it will have been considered and treated by its parents as normal until the time of diagnosis. These are some of the considerations which have informed the choice of interviews for analysis. Since we have included all those sample members whose child is three years or older, the selection of transcripts is representative.[3]

It is important to note that apart from the category of dependence/care, the other categories are rarely topicalised in interviews with parents of children aged one year or under. (We shall examine one such instance later.) Indeed, the reasons they give for hoping that their child will be treated before the age of two or three years are based on their conception of it as a 'non-person'. They argue that at this age, it will be unaware of the condition and treatment and consequently will not have any memory of the experience. However, this wish is often denied since the treatment of routine conditions is based on the assumption that the older the child becomes, the more robust and fit he will be for cardiac surgery.

It would be valuable to review briefly other areas of parents' talk for their role in displaying the status of moral adequacy in order to see how they differ from the topic under consideration. For parents, the identification of congenital heart disease in a child raises questions of parental responsibility. For instance, with striking uniformity they consider whether they caused the child's illness. Mothers discuss whether they smoked during pregnancy, took drugs, drank alcohol excessively; or they may blame their spouse if the disease has occurred in his family. Usually, they establish that they were not at fault by demonstrating that they actually did nothing to imperil the foetus or, if they did do any of the above, they appeal to medical formulations which indicate that these factors do not cause congenital heart disease (see Chapter 7).

When we examine their talk, we also see that parents discuss their understanding of the child's illness as a moral problem. The technically sophisticated nature of heart disease is often opaque to parents at the beginning of the child's medical career. Yet, since they are responsible for the child, they feel they ought to be able to provide an account of its condition to relatives, friends and, of course, interviewers. Parents justify their lack of understanding by appealing to the fact that their initial concern was only with the child's survival. Thus they claim that when they attended the first specialist outpatient consultation, they were so overcome by the clinician's verdict that it would survive that they did not take in his explanation of the nature of the disease.

As we have seen, another source of moral conflict concerns parents' initial encounters with health professionals. In the interviews, these often take the form of atrocity stories which describe conflict between the latter and parents over something untoward that has happened to the child. The stories answer the unstated moral question 'How could you, as parents, have allowed that to happen to your child?' Generally, the stories display parents as having done their best in the circumstances whereas health professionals performed inadequately.

These topics, like the atrocity story, depict parents in situations in which they have failed and in which it makes sense to ask whether they have fulfilled their obligations as parents. The defensive nature of their accounts is in contrast with their talk about the way they treat their child within the family. This provides them with the opportunity to draw authoritatively on their status as parents and so present their knowledge of children and the most appropriate ways of dealing with them in relation to their illness and hospitalisation. Here they are on familiar territory and they convey a sense of expertise which differs markedly from their talk about child-rearing in those accounts which present their relationship with health professionals during the early stages of the child's career. Sometimes they use their familiarity with the child at home to demonstrate that their knowledge of children is superior to the knowledge displayed by health professionals. For instance, the following extract comes from an interview with a mother and father following their child's inpatient stay for cardiac catheterisation.

Mr & Mrs Fol

Extract 114 Interview 121

Mrs Fol Before she'd been to the catheter. And I'd already rung a social worker and the social worker hadn't really helped me much. She hadn't explained=

Interviewer Hm.

Mrs Fol What she'd be like sort of thing. And I didn't know what to expect. Um... and I ask- I asked the Health Visitor here... and she'd not really known what to expect afterwards and um (1.00) I said how can I best prepare her for it like and she said Oh just act naturally. But we've got some books for her to read.

Interviewer Hm.

Mrs Fol She quite enjoyed reading the books, didn't she?

Mr Fol Yes (mumbles)

Mrs Fol And it did explain things like that hospitals smelt differently and it was all in a big room and you know.

Mr Fol There ( ) and things like that.

Mrs Fol And about stretchers and things like that. So it did help the books // definitely helped... um... a little bit.

Mr Fol It did.

Mrs Fol So she knew some of the things sort of that were gonna be different.

Admittedly, this level of preparation is rather unusual for our respondents but we should note that these parents are in no way connected with the health professions. Thus the sophistication of their strategy is all the more remarkable when we consider how much it is in line with the thinking of a section of the medical profession (Bentovim, 1980).

From the point of view of their account, we see that in making a comparison between what they did and what was advised by health professionals, the parents are producing a version which displays their competence and the latter as incompetent. Mr & Mrs Fol make use of a commonly held assumption that social workers and health visitors, as experts, ought to be in the possession of techniques designed to help children adapt to hospitals. Thus when the mother reports that 'the social worker hadn't really helped me much' and the health visitor said 'Oh just act naturally', she lowers their standing in our eyes. This utterance is in sharp contrast to the mother's claims which begin with 'But we've got some books for her to read'. The health visitor's proposal, by its superficiality, unsuccessfully hides her lack of knowledge whereas the mother's strategy is specific, based on a conception of how a child reacts to hospitals and how its anxieties can be allayed. We are left with the impression that she is more competent than the health professionals.

Thus accounts of the child's adaptation to its illness and hospitalisation are occasions when our respondents authoritatively display the status of adequate parenthood and as such they fulfill an important role in the interview. Now, we must turn to a fuller consideration of parents' strategies and the conceptions of the child which complement them.

III The Strategy of Protection: The Child as an Innocent

The question of whether to reveal to the child the full nature of his illness was considered by parents to be delicate and sensitive. Clearly, something had to be said since all the children in the sample were admitted to hospital for investigation or surgery and this change in their routine had to be explained. One strategy parents reported adopting was to say very little. The child was either not told of its condition or presented with a perfunctory description:

Mrs F

Extract 115 Interview 18

Interviewer	What does Anne... What have you told her about it?
Mrs F	Well I told her that she's got umm... _just_ that she's got bangs in her heart, a bumping in her heart and that the doctors _just_ wanted to find out what it is.

(my emphasis)

Mrs R

Extract 116 Interview 83

Mrs R	She doesn't know that there's anything wrong with her heart. She's _just_ here to have some tests, to have some pictures and that's it, you know.

(my emphasis)

These parents invoke strategies which can be read as being commensurate with the normal range of childhood experience. However, in so doing they have distorted the usual meaning of heart disease. As I have stated elsewhere, they see it as a serious condition that could threaten their child's survival. This contradiction made it necessary for them to justify to the interviewer what they had reported telling their child. Here, they appealed to a variety of features which referred to the child's vulnerability and the right to retain its identity. Mrs F said the following:

Mrs F

Extract 117 Interview 18

Mrs F And she's just settled at that, you know. I don't want to say anything too much to upset her 'cos otherwise if we have problems with her going into hospital it's going to make the whole thing worse for me, you know.

This type of appeal is irresistible insofar as it would be morally reprehensible to upset a child unnecessarily and make a difficult situation for the parent even worse. Yet we should note that this claim is in direct opposition to the views expressed by psychiatrists who suggest that children adapt better to a heart condition if they are made aware of its existence. For instance, Bentovim (1980) argues that 'It is necessary for children to have the opportunity of ventilating their own feelings so that the distortions, fantasies and bizarre misconceptions of what is going on inside can be corrected and reality accepted' (pp.181-182).

We can see that the enactment of this prescription is no simple matter for parents. Parental reticence in informing the child is based on their notion that the outcome of this act will be to make their child emotionally distressed. As members of the everyday world, they share a morality which does not approve of unduly or unnecessarily distressing children. Hence they limit what they tell their child.

A similar appeal to the child's emotionality is made by Mrs R.

Mrs R

Extract 118 Interview 83

Mrs R She's pro- err probably a little bit like me. If you tell her something too soon, she either gets excited, you know, or if it's something like umm you've got to go to the doctor's next week... um as it gets nearer, mmm What am I going to the doctor's for? What's it gonna be? And she starts asking questions <u>and you know</u>.

(my emphasis)

Here the mother interprets he child's emotional response in terms of similarities between herself and her daughter. Thus the response is framed in terms of excitation, and agitated and anxious questioning with the interviewer being left to make sense of this situation since it is assumed that he shares the mother's understanding (see utterance emphasized). The claim is that the daughter, having been identified with her mother, will not be able to accept the medical facts of her situation.

Implicit in these accounts and explicit in the one we shall examine shortly is another aspect of the child as an innocent: namely, the right to retain its identity as a child in common with its peers so that it can continue to participate in peer group activities. Underlying this conception and the one we have just examined is the notion that the child should not be disadvantaged. Mrs R claimed the following:

Mrs R

Extract 119 Interview 83

Mrs R	You know, my neighbours, I didn't bother to tell them until the day before she was coming in, because um, they've got three children. They go to the same school as her and I didn't want it I didn't want her children saying, Oh, you've got something wrong with your heart. You mustn't do this, you mustn't do that.

The fine sentiments expressed here partly derive their force from the contrast with an earlier part of Mrs R's account in which she admitted her anxiety over her child being pushed and jostled in the school playground. Thus she displays her morality by putting to one side this anxiety in the interests of her daughter's right to retain her identity as well as her right to participate in the same activities as her peers. Neighbours and their children are held to be the kind of people who do not share the same sensibilities as a parent towards a child suffering from congenital heart disease. Thus it makes sense not to inform them of the impending hospitalisation until the last moment.

Similar sentiments are expressed by Mr R in an interview which took place after his daughter's stay in hospital. Again the emphasis is on the right of the child to enjoy its youth.

Mr & Mrs R

Extract 120 Interview 82

Mr R	But you know, I think she's still quite young for the moment and school days are very important days as well as being happy times. Er, you know, I just look at it this way... If she's running around the playground with a fair amount of kids and she stops because she gets out of breath, you know, her friends will wait for her. If they know she's got a heart condition, you, one will say, Oh I know why you can't run. There's something wrong with you. Now, you know, to her eyes that's the most important thing at the present. To her. Well I think it is, <u>because it would be the most important thing to me if I was her age</u>.
Interviewer	Yeah.
Mr R	So you know, she's not of an age whereby she's really ready to know that perhaps there's something that's seriously wrong.

(my emphasis)

We should note here, as is evident in the previous extract, the contrast between the innocence of our respondents' child and the potential wickedness of her school friends. This claim adds substance to the parents' strategy. A further similarity between this extract and an earlier one (Extract 118) is Mr R's appeal to his own experience as a basis for understanding his daughter's. The claim is that this understanding is authoritative insofar as the respondent, as an adult, knows the outlook of a child. This device which consists of the respondent putting himself in the position of the other also encourages hearers to do likewise and so share the same world. The interviewer's 'Yeah' (see utterance 2) refers to this process. Frequently, parents and researchers collude in other ways in making apparent their understanding of children. For instance, knowing glances might be exchanged when a parent reports that her child has been 'naughty', particularly 'good' or 'funny'.

The conception of the child we have been exploring complements the strategy of protection. This strategy may take the form of a 'step-by-step' approach as the child's medical career progresses:

Mrs F

Extract 121 Interview 18

Mrs F	Er and I just told her for a couple of days (referring to the length of the hospital admission). I haven't said anything about an operation or two weeks in hospital because I'll get this hurdle over with first and we'll go from there, you know.

It is worth noting that this strategy has its equivalent in the outpatient encounters between doctors and parents of children who require routine management.[4] The research team has observed how the former also limit the information they pass onto parents, implying that parents, like children, can only cope with a certain amount at a time. The other way parents convey the strategy of protection is in sayings like 'trying to play low key all the time', and underplaying the nature of the condition or the reasons for hospitalisation.

Mrs R

Extract 122 Interview 83

Mrs R	I just say to her Oh <u>just</u> for this <u>just</u> for that. You know
Interviewer	Yeah
Mrs R	I try not to...

(my emphasis)

The matter of factness here and in Mrs F's account (see Extract 115) is emphasized by the use of the device 'just'.

In summary, when parents were asked whether they had told their child of its heart condition and why it had to go to hospital, they responded by invoking the strategy of protection. They accounted for this strategy by appeals to a conception of the child as an innocent. In doing so, they were attending to commonly held views about the nature of children including their emotional vulnerability and the right to retain their identity. We might expect parents to offer similar types of account if they were being asked about other events not normally considered suitable for discussion with young children, for example, sexual issues, divorce, death, and so on. Like heart disease, we consider that these matters belong to the adult world and not to that of the child.

IV The Reasoning Format: The Child as Rational Actor

Accounts of the reasoning format and the child as a rational actor arose as a result of some incident which occurred during the child's visit to hospital. This usually involved its failure to co-operate with hospital procedures. Parents claimed that there were reasons for its lack of co-operation and that it would be possible to appeal to the child's rationality so that such behaviour could be avoided. Before exploring the child's properties as a rational actor, we should note that parents consider children, as a class, limited in their ability to understand explanations concerning illness and hospitalisation. For instance, the As said the following:

Mr & Mrs A

Extract 123 Interview 58

Mrs A We'd explained to him beforehand you know, as far as one can, what was expected.

(my emphasis)

Thus discussions about the child's exploits as a rational actor usually contained explicit or implicit appeals to its limitations. As we shall see, these appeals were reflected in the explanations parents gave to their offspring. Nevertheless, our respondents attributed to the child some ability to reason and this was particularly useful when, for instance, discussing its lack of co-operation as a patient. When parents presented these accounts, they attended to the possibility that the child's lack of co-operation would be taken as a reflection of their incompetence as parents. For instance, the following remarks were made by a mother after she had reported that both she and her daughter were taken completely by surprise by the large number of doctors present at an outpatient consultation. The daughter's response was to be 'stopped dead in her tracks' and the mother then commented:

Mr & Mrs Fol

Extract 124 Interview 122

Mrs Fol	And (1.00) you know, little things like and like the more you can prepare them for it, the better they are.
Interviewer	Hm.
Mrs Fol	Admittedly, you can only sort of do it like the weekend beforehand 'cos otherwise they expect it to happen that day.
Interivewer	Hm.
Mrs Fol	But if you can explain things to her, she she repeats it all, she chews it over and then she remembers it all and she goes over it all in her mind and she sorts it all out doesn't she?
Mr Fol	Yeah, she comes back to you like a couple of days after with something.
Interivewer	Hm.
Mrs Fol	That you've told her and she's remembered, so she's prepared for it.

(my emphasis)

To begin with, we should note that Mrs Fol, like Mrs A, acknowledges that children are not fully qualified rational actors (see utterance emphasized). However, she goes on to attribute a number of qualities to her three year old daughter, all concerned with her ability to reason, including the capacity to remember, to repeat what has been explained, to 'chew it over', and to 'sort it out' and 'go over it all'. Her claim is that this rationality is at a primitive stage of development. The moral of the account is first, that children behave in rational and accountable ways and second, that since they have the ability to reason, unfamiliar situations should be made apparent to parents so that they can prepare their children for them.

The attributes we have been describing here are on occasions extended by parents to children of a much younger age who outwardly do not display behaviour commonly regarded as indicative of the reasoning process. Again, parents invoke this attribute when presenting an account which describes how the child failed to co-operate in the implementation of a medical procedure. The following extract is taken from an interview with Mr & Mrs C held after their eleven month old son's inpatient stay for cardiac catheterisation. During the interview, they refer to an incident which occurred towards the end of his stay in hospital. On several occasions, the staff tried to carry out a heart echo-cardiogram without success. This diagnostic procedure requires that the patient remain in a still position for thirty minutes. However, Mr & Mrs C's son would not co-operate even after sedation. They present this incident in the form of an atrocity story arguing that the staff failed to consider the meaning their son attached to this particular procedure.

Mr & Mrs C

Extract 125 Interview 160

Mrs C Yeah, it was awful. I'm not saying this because of Steven, but Steven is not stupid, he knows what's going on. You say to him, brush your hair, he gets the brush. He's quite with it in that sense. He washes his hands, he does things like that. I don't know whether it's because of his heart he's got all these extra abilities. Everything you tell him to do he seems to know. I don't know whether it's because of Roy. Of course, he must have thought off we go down here, I hate it down here.

First of all, Mrs C refutes the unstated objection that she, like many parents, exaggerates the abilities of her child. We are made to understand that her claims are derived from a more detached point of view. Thus eleven month old Steven is able to interpret the world around him. His attributes include intelligence, an awareness of the environment and the ability to understand and anticipate events. Moreover, they are seen as endowments which go beyond what is normal and are accounted for by his unique condition and by having an older brother. It was the use of these extraordinary abilities which led Steven to reject the echo-cardiogram. Of course, the question that arises is, if her son is so gifted, why was it not possible to explain to him the necessity of co-operating with the medical staff. She then argues what we might have guessed all along.

Mr & Mrs C

Extract 126 Interview 160

Mrs C See it's very difficult to explain to a child of a year you've got to have it done. I could perhaps reason with Roy (who is 5 yrs). You could say You've got to sit still, the man's not going to hurt. You can reason with him. But with a year old child you can't, I mean Steven perhaps understands there's all these white coats walking around but he doesn't really know.

Thus Mrs C confirms the distinction made earlier in this chapter between parents' versions of children who are over three years old, and those who are still to be treated as babies. The latter may have some rational qualities but, unlike the former, they cannot be reasoned with. The model of the mind attributed to babies of Steven's age is a behaviouristic one - he sees white coats and they stimulate fear and resistance due to their association with former unpleasant events.

As Mrs C points out, the rational qualities displayed by older children are of a different order from those of babies. Let us examine another account to see what they consist of. Here it would be valuable to describe briefly the context in which it arises. Parents whose child required hospital admission were asked by the interviewer whether they intended to stay with him. We shall explore their responses in greater detail when we discuss the child as a dependent, but here, we should note that this issue involved them in a moral dilemma. They felt obliged to display the wish to give their sick child continuity of care and attention, but this conflicted with their obligations to other siblings. In the following extract, we see that this dilemma is made all the more acute by the way the interviewer frames his question:

Mr & Mrs A

Extract 127 Interview 38

Interviewer	Do you expect you'll manage to be there all the time at the hospital? One of you.
Mrs A	Well, we should do, yeah.
Mr A	We'll try. We'll try. (2.00)
Mrs A	And that way he'll accept it, I mean at nights we go home you know?
Interviewer	Yeah.
Mrs A	Um and he said himself Oh it's only the babies have the mummies stay at night time and- 'cos they do that at the other hospital um and he accepted that I had to go home in the evening or near day's end. He was quite happy about that. He didn't cry at all and he knew I'd come as fast as I could in the morning, so he didn't, you know, it didn't worry him, I don't think very much and he assumes it will be the same again when he has to go.
Mr A	Total stay there was only what // four days in all.
Mrs A	Four or five days.
Mr A	So um.

The interviewer's question is provocative (see utterance 1). Having established the absolute standard of 'all the time', he then gives it the appearance of being reasonable by suggesting that only one parent need remain with the child. The parents are unable to do so for we have learnt elsewhere in the interview that they have two other children and live some distance away from the hospital. However, this claim may be regarded by hearers as insufficient. After all, regardless ot the practical considerations, the hospitalised child may not be able to cope without the presence of his parents. So they strengthen their case, by appealing to the rational qualities he displayed during a previous hospital admission. He 'understands', he 'knew' and he 'assumes' are statements which portray him as a being that can reason. Evidence of this capacity is revealed when the mother quotes him as saying 'Oh it's only the babies which have the mummies stay at night time'. This utterance plausibly reflects a child's way of reasoning which, according to the mother, enables him to deal realistically with the fact that she has to return home 'at nights'. He tolerates this with equanimity insofar as 'he was quite happy', 'he didn't cry at all' and 'it didn't worry him... very much'. In summary, these respondents appeal to their child's capacity to reason and his reasonableness in order to account for their deviation from the absolute standard invoked by the interviewer. Since it is the child's needs which are at issue in this account, their explanation of his reaction is sufficient to maintain their status as morally adequate parents.

According to our respondents' accounts, reasoning with a child takes a different form from reasoning with adults. Adults are expected to have acquired rudimentary medical knowledge and so, understand without further explanation why treatment in hospital is required if a diagnosis of heart disease is made, as do our respondents. However, parents argue that children, on the other hand, have to be reasoned with according to their age-related frame of reference in which pleasure and enjoyment play an important part (see Extract 120). Parents report that they use the child's attachment to its world of pleasure to persuade it to co-operate with the hospitalisation process.

Mr & Mrs A

Extract 128 Interview 58

Mrs A Yes and I just said um because they found that your heart wasn't quite working properly and it needs something done to it to have it mended you see, so he said Oh I see. So he said But I don't feel ill. So I said, no you don't, you know. So I said when you're a big boy, you wouldn't be able to play football and all these other racing about things that he likes doing and that angle. He just couldn't bear the idea he'd be sitting down sort ot, you know, finding it difficult to breathe and so on and not being able to rush around. And so he just said Oh all right, you know. He just er... <u>in fact I think he told somebody he has to go into hospital in London because so when he's big he can still</u>

play football (laughs)

Interviewer Oh that's all right.

(my emphasis)

The situation described here is one commonly encountered by parents: namely, how does one, as a parent, persuade a child to participate in some task or activity which it is reluctant to carry out? In practice, we know that there are a variety of strategies open to them, including authoritarian solutions, crude forms of bribery and reasoned persuasion. With remarkable uniformity our respondents, like the As, invoked the latter. By doing so, they displayed first, their knowledge of everyday 'modes' of handling children; second, their competence as parents since the chosen strategy was inevitably described as being successful; and third, the essential normality of their child in that they selected aspects of its universe which are common to all children, whether ill or healthy. Moreover, these accounts provided a source of light relief (see utterances emphasized in Extract 128). We should remember that the issues raised in interviews were generally serious, morally contentious and emotionally sensitive so that a parent's presentation of a child's charming but naive interpretation of why he needed to go to hospital diffused the tension. As Davis and Strong (1976) have suggested, children are not only held to live in a world of pleasure, but they are also a source of pleasure for adults.

Parents invoked a variety of pleasure producing activities in persuading their child to co-operate with the medical process.

These were always connected with what children valued. Thus Mrs Fol claimed that when her daughter said 'she didn't want any more injections', she responded by suggesting that if she didn't have them then 'she wouldn't be able to go to school like the other children'. Another parent spoke of promising to buy her daughter a new nightdress as a method of persuading her to accept hospital admission. Furthermore, it was taken for granted by our respondents that the interviewer understood that although these strategies were potentially dubious, they were nevertheless reasonable and appropriate since they were being directed at children. Thus they were not seen as bribery. In this context, Mrs Fol made the following remarks.

Mr & Mrs Fol

Extract 129 Interview 111

Mrs Fol	So I say if you don't have any more you won't be able to go to school, like the other children.
Interviewer	Yeah.
Mrs Fol	Which I mean she would but-
Interviewer	Yeah.
Mrs Fol	That's the easiest way of explaining to her.
Interviewer	Hm.
Mrs Fol	'Cos she can comprehend that.

(my emphasis)

The claim is that children have a prescribed set of relevances which it is legitimate to exploit in order to gain their understanding and co-operation.

In summary, the conception of the child as a rational actor and the reasoning format were most commonly appealed to in discussions about its co-operation with hospital procedures. From parents' accounts, it appears that all children (and an eleven month old baby) react in rational and understandable ways to these procedures and can be persuaded to accept them so long as appeals are made to their relevances. This is exactly what parents claimed they did and thus displayed their own moral worth.

V The Caring Format: The Child as a Dependent

As I mentioned earlier, parents were asked in interviews held before hospital admissions whether they would be staying with their child, and in interviews held during or after the admission, whether they thought this had been important. We noted that these questions appealed to an unstated moral obligation that parents should be willing to do this. It was apparent that this obligation could conflict with their duties towards the rest of the family. However, most respondents argued that the needs of the sick child came before those of other family members and often stated that alternative arrangements had been made for their care.

Parents who wished to remain with their child in hospital were faced with another problem - they were informed at outpatient consultations that the hospital had available only a limited amount of overnight accommodation and that priority was given to those who lived furthest away from the unit. I assume that this policy informed some of their responses to the interviewer's questions. For instance, one mother prefaced her remarks in the following manner:

Mrs R

Extract 130 Interview 83

Interviewer	Right. And that in fact, brings me to the last thing really I want to talk about which is, you know, you're here, and err, do you think it's important that you're here? And if so for what reason?
Mrs R	Well, umm, I thought at first it might be a purely selfish reason for my wanting to stay here because of her being here, you know?[5]

By confessing her capacity to be selfish, Mrs R neutralises the possibility that expressing the desire to remain with her daughter could be read in this way. Other parents attended to this possibility and so displayed their reasonableness, by simply acknowledging that the hospital had limited accommodation. Thus parents did not feel that they had a right to remain with their child; it was something that had to be justified. This was done by presenting an account which described a dramatic incident that occurred during the child's stay in hospital. The aim of this story was to present convincing evidence to the interviewer that the child needed and depended on its mother and that the latter, as a parent, had a unique caring role to play. The central feature of this incident involved the child being separated from its mother for a short period of time:

Mrs Hen

Extract 131 Interview 31

Mrs Hen	But then ten minutes later she'll turn round and

want to know where I am and she'll want me there.

Mr & Mrs Fol

Extract 132 Interview 111

Mrs Fol 'Cos I mean I only had to sort of go round to the loo and she missed me for two mintues and she was yelling

(my emphasis)

Mrs R

Extract 133 Interview 83

Mrs R It got to about nine-thirty and I said to her, Julia I'm going to go and have a shower

Interviewer Yeah

Mrs R Umm, You will come back mum, you won't go and leave me here. And I said yes. I'll be here. I'm coming back. And I was a bit longer than I anticipated.

Thus by invoking separation, parents constructed a critical test of how much they were needed. The child's response would be the determining factor. It is apparent from Mrs Fol's account that this response took the form of emotional distress (see Extract 132, utterance emphasized). This was also displayed in other stories.

Mrs R

Extract 134 Interview 83

Mrs R When I came back you know, she was in a huddle, crying her eyes out, you know. And as soon as she saw me, you know, two arms go round my neck, you know.

The child's response was taken by our respondents as prima facie evidence that it needed its mother. One could say that its very survival depended on her presence. It is striking that in the stories no mention was made of the existence of the nursing staff who were invariably available on the ward in sufficient numbers. Thus the force of these stories lay in the way they established the significance of the maternal role in the hospital setting:

Mrs R

Extract 135 Interview 83

Mrs R	Um but it did... in actual fact I did have to lay on the bed with her to get her to calm down, to settle her down. So I think she needed me here because... er I think she would have been upset this morning you know, I don't know if it would have upset the works.
Interviewer	So you...
Mrs R	And her having this test done today, I don't know. But I think, umm from her point of view it was important that I was here, now having seen the way she was.

The claim is that only a mother can provide her child with effective care and that remaining with her overnight is important in ensuring that the hospital is able to carry out its tasks. Other respondents conveyed the importance of their presence by describing the child's fear that it would be subjected to medical procedures when its mother was temporarily absent.

Mr & Mrs Fol

Extract 136 Interview 111

Mrs Fol	(fear of) what they're gonna do to her when I leave her. I'm sure.
Interviewer	Is that sort of irrational fear or...?
Mrs Fol	Not in a child's eyes
Interviewer	No.
Mrs Fol	Definitely not. Because when I did leave her they stuck needles in her.
Interviewer	Yes.
Mrs Fol	Did horrible things, you know. It was pain. Horrible to her.
Mr Fol	Yeah, but you see...
Mrs Fol	'Cause also if she's, usually if she bumps herself and it's pain you're there and you rub it better or something.

In this way, mothers displayed their unique position in relation to their child and so justified their presence. Again, in Mrs Hen's account it was suggested that her daughter, quite understandably, experienced hospital procedures, like injections, as painful and that she considered 'Mum was a nasty person' for allowing the staff to carry them out. In spite of this, Mrs Hen argued that her child depended on her mother and would make this evident when she was absent (see Extract 131). Thus she could claim the following:

Mrs Hen

Extract 137 Interview 21

Mrs Hen	So I know really me being here is helping her

although she still quite can't understand
why I've let them hurt her.

Finally, we should note that parents' stories of these dramatic incidents, like their atrocity stories, were given additional force by the use of direct speech. The child's distress and desperation were conveyed in the following manner:

Mr & Mrs Fol

Extract 138 Interview 111

Mrs Fol And I went down to the kitchen to get her bottle and she was out, Where's Mummy, you know like this.

Mrs R

Extract 139 Interview 83

Mrs R She said to me I thought you weren't coming back.

On the other hand, mothers' reports of their own direct speech conveyed an image of them as reassuring and comforting people:

Mrs R

Extract 140 Interview 83

Mrs R And I said, No, I'm here. I told you I would stay if I could. I'm here. Don't worry. I can't sleep with you tonight but I will stay with you until you go off to sleep.

In this section, we have seen that parents characteristically establish the importance of their presence in hospital by presenting a dramatic account of their child's reaction to being separated from its mother for a relatively short period of time. The question which arises, is why their accounts should take this form. After all, they could have used a variety of 'adequate' responses, including the fact that their child had never previously been parted from its parents; or that they were the only ones properly equipped to provide for its particular needs. However, these responses were rarely presented. I have assumed that the device of the dramatic incident was employed as a result of the fact that both parents and the interviewer knew that overnight accommodation at the paediatric cardiology unit was limited. I also suspect that the hospitalisation of a young child is not the only circumstance in which parents might appeal to dramatic incidents to legitimate their presence. For instance, parents whose child is in the early stages of attending playschool sometimes find it difficult to leave their offspring. In accounting for this, they invoke an incident or a series of dramatic incidents where the child becomes emotionally distressed when they try to leave him. Like our respondents' accounts, these stories make it appear that for parents to have acted otherwise would have amounted to negligence.

VI Policy Implications

On a policy level, the issues examined in this chapter concern the sorts of measures which would help young children adapt to their illness and hospitalisation. There are two issues which should be discussed before making any recommendations. One is the over-medicalisation of family life and is evident in psychologically oriented accounts of familial response to congenital disease (see McMichael 1971, Meyerowitz & Kaplan 1967). There is a danger of treating the child's condition and treatment as a master status so that its behaviour and family life are read as abnormal even where there is evidence to the contrary. Since parents do not interpret the child's situation in this way, neither should we. On the other hand, there is also a danger in simply taking what the child has to undergo as normal. As Voysey (1975) has argued, parents' statements can be read as public accounts which are so formulated that they appear to satisfy the official morality of normal parenthood (passim). Thus they may tell us nothing about the aspects of the child or family life which, in practice, may deviate from this morality. There is evidence that some of the practices of the paediatric cardiology unit were in keeping with this official morality.[6]

Any recommendations that are made must take account of these two problems. Moreover, they should in no way undermine parents' conceptions of their role. We have seen from the accounts examined in this chapter that when talking about their treatment of children they are on familiar territory and convey a sense of expertise. Thus one proposal could take the form of making available to parents simple techniques, such as the use of puppets and work books, which would aid them in preparing their child for cardiac catheterisation and surgery.[7] This proposal differs somewhat from the policies of hospitals which employ these techniques since they are carried out by members of staff rather than parents (see Friedberg & Caldart 1975). Obviously, the proposal I have suggested is contingent on parents being adequately informed of what is involved in the hospitalisation process, before the child's admission.[8]

A second recommendation concerns the uncertain availability of overnight accommodation for parents. Such accommodation should be available to all those who request it. As we have seen, the undertainty only leads to additional moral pressure being brought to bear on parents.

Finally, our analysis of parents' strategies and conceptions has certain implications for the techniques currently adopted by those whose job it is to help parents and children overcome psychological and social difficulties. We have seen that parents' responses vary according to the situation under discussion. For instance, the hospitalisation of children elicits a caring response on the part of mothers which is accounted for in terms of the dependence of children. On the other hand, where parents decide not to explain the illness to their offspring, they appeal to the child's right to enjoy an unrestricted life like its peers. Thus the way parents react varies as does the conception of their child.

This observation is in marked contrast to the assumptions underlying psychiatric approaches to the psychological and social aspects of congenital heart disease in children. For instance, Bentovim (1980) argues that 'The anxious mother will have an anxious child; the immature, over-reactive mother will restrict her child's contacts with other children, will not leave her children with babysitters, will be overconcerned about his catching infections' (p.181). Of course, such 'types' may exist but their existence, by and large, is a feature of a simplistic framework which takes responses out of context and interprets them in terms of a static conception of personality. Thus our findings suggest that psychiatric techniques aimed at changing parental attitudes are undesirable and have limited application, unless they take account of the circumstances in which parents' responses arise.

VII Conclusion

The preceding criticisms of the psychiatric approach are reflected in Dreitzel's objections to 'the enormous research effort made by anthropology, psychology, psychoanalysis and sociology to clarify the process of socialization' (Dreitzel 1973, p.5). He argues that the futility of this research lies in the way the child is treated as a tabula rasa which mysteriously responds to the input of stimuli by adults, while the latter are simply taken to be stable factors of the child's social environment. He therefore advocates a shift to an approach which focusses on the social construction of the parent-child relationship 'understood as an interaction process which involves the child as an active partner no less than the adult' (p.25).

Dreitzel's proposal is similar to the position adopted in this chapter, although we have not directly observed parents and children interacting in their everyday world. Nevertheless, the research interview as well as the unique nature of the child's predicament provided our respondents with an opportunity to reflect on the nature of parenthood and childhood. According to them, children are not passive or uncomprehending. Rather, parents argue that children do interpret the world around them. Hence, they are obliged to take account of their child's understanding of his situation in formulating their strategies. Indeed, we saw that parents were critical of the members of the medical profession who ignored the interpretative abilities of children. As medical sociologists, we should not make the same error.

Chapter 7

RESPONSIBILITY AND BLAME: PARENTS' INTERPRETATIONS OF THE CAUSES OF TWO CONGENITAL ILLNESSES

I Introduction

Locker (1979) identifies three types of explanation which lay people may present about illness. The first type is similar to a professional explanation and is conveyed in medical terms. For instance, Down's Syndrome can be explained as a defect of growth due to a fault in the formation of the ovum. The second type is a response to the question 'Why has this happened?'. For example, the common cold can be explained as being caused by a virus but may also be accounted for in terms of people crowding together in places where they infect each other. The third type of explanation is a response to the question 'Why has this happened to us?'. This is a moral question which requires the questioner to consider how far he is personally responsible for the illness. As Locker argues, the type of explanation adopted depends on the assumptions that are made about the condition being considered.[1]

Sociologists studying familial responses to serious illness in children disagree about the types of explanation offered by parents. Davis (1963), in his study of familial response to polio in a child, and Burton (1975), in a study of parents' responses to children suffering from cystic fibrosis, claim that parents asked the question 'Why has this happened to us?' or 'What have I done to deserve this?'. Mothers and fathers perceived the illness to be a catastrophe which challenged their self-image as responsible parents and made them wonder what they had done to deserve such a punishment. On the other hand, Voysey (1975), in her study of parental responses to a variety of serious childhood illnesses, reports that although some parents raised the moral question 'Why did it have to happen to us?', most never did so. She argues that they employed other meanings 'derived from medical knowledge as it is made available to parents in interaction with doctors' (p.108). These meanings reflect the way medical explanations do not make parents responsible for the child's condition.

How do we account for the differences between Voysey's findings and those of Davis and Burton? Clearly, they cannot be explained by differences in the conditions studied. Both from a lay and a professional point of view, polio and cystic fibrosis and the illnesses in Voysey's sample[2] are of the same order. They are serious childhood conditions which are either unremediable or partially remediable.

Rather, the difference between the respective findings is to do with the way data are analysed. Unfortunately, Voysey and Davis give the reader limited access to the interview data on which their interpretations are based. However, I would suggest that in both cases transcript material has been selectively interpreted. For instance, Voysey assumes that parents' statements about their responses to the sick child are consistent with the meanings made available to them by the social control agencies with which they interact. Thus one is left with the impression that she emphasizes those accounts which are consistent with this assumption: doctors do not make parents responsible for congenital conditions so preference is given to statements which reflect this attitude. Davis' work shows a similar bias. He explains parents' feelings of responsibility for the child's polio in terms of the 'American value assumption that misfortune rarely touches those who take the proper precautionary measure' (p.36). Having established this explanation, it is likely that parental responses which confirm it have been selected.

These criticisms are strengthened by the findings of the present study. An examination of the data reveals that parents sometimes used all three types of explanation in accounting for their child's condition, although mostly they offered explanations which were similar to Locker's professional type and which considered the issue of responsibility. Thus the construction of parents' explanations was altogether more complex than suggested by Voysey, Davis and Burton.

The objectives of this chapter are:

(a) to examine the construction of parents' accounts about the cause of the child's condition with particular reference to their role in the research interview;

(b) to consider the theories of causation which informed parents' explanations, again with reference to their role in the interview;

(c) to propose policy initiatives based on the analysis of parents' accounts.

II The Sample and the Context of the Account

Table 9 presents details of the interviews on which the analysis of data is based.

Table 9

Parents	Child's condition	Stage of child's career at which interview carried out	Number of interview
Mr & Mrs Wo	Congenital heart disease	Post 3rd Outpatient (OP)	1st
Mr & Mrs Fol		Post 1st OP	
Mrs Hen		Inpatient (IP)	
Mr & Mrs R		Post IP	
Mrs R		IP	
Mrs M		IP	
Mr M		IP	
Mrs St		Post 1st OP	
Mr Wr		Post 1st OP	
Mrs Wr		Post IP	
Mr & Mrs C		Post 1st OP	
Mrs C		IP	2nd
Mr & Mrs Fi	Hare lip	Post IP	1st
Mrs Sm		Post IP	
Mrs Fd		Post IP	
Mr & Mrs Al		Post IP	
Mrs Wl	Cleft palate and hare lip	Post IP	
Mr & Mrs Her		Post IP	
Mr & Mrs Wa		Post IP	

These families constitute 55% of the total sample membership.

The interviews selected for analysis are representative of all those in which the cause of the child's condition was discussed. In other words, any interview not included could have replaced the ones selected without affecting the results of the analysis. All except one of the interviews was the first meeting between the researcher and the family. The cause of the child's condition arose as a topic at subsequent interviews only as a result of an interviewer's question. There was no difference between the parents' responses on these occasions and those produced at the earlier interview. In some of the interviews chosen for analysis, parents themselves initiated the discussion of the causes of their child's condition without any prompting from the interviewer. In the remainder, the interviewer invited parents to discuss the issue.

As we shall see, accounts of causality have much in common with the majority of topics discussed in the first interview. They concern parents' failure to fulfill certain obligations. In particular, their causal accounts depict them as having failed to produce a normal child. Hence, parents' explanations address the following moral question which they assume is implicit in the interviewer's questions about causality:

'Were you, as a parent, responsible for your child's condition?'

In the following section, I will show that our respondents' responses to this question display them as rational, sensible and well adjusted people while at the same time taking account of culturally held theories about the cause of congenital illness.

The most common and significant theories consider the illness as a moral punishment for some wrongdoing committed by the individual, which by implication casts doubt on the adequacy of parents.

In section IV, we will closely examine the types of explanation parents present. It will be apparent that they are of great importance to the identity of our respondents in the interview. Usually, parents present a united front to the interviewer and can be seen to work together as a team. However, they depart from this format when presenting causal explanations. Indeed, they take on individual identities with distinctive characteristics. In terms of this breach in the husband/wife relationship, the discussion of causal explanations is therefore unique.

III The Construction of Causal Accounts

Two accounts are presented below in full:

Mrs Sm

Extract 141 Interview 132

Mrs Sm And it wasn't until they actually brought him to me for feeding that same night... and I suddenly you know, as soon as they tell you that, you suddenly start looking and prodding and poking a bit closer. And I thought Oh gosh, now, you know, what have I done? The usual my fault. You know, I've given birth to a funny sort of child. And um... it wasn't until I moved rooms then in the hospital because I smoke and therefore I didn't want to inconvenience the girl in the bed opposite and they moved me and then when they were sort of looking at John and I, my... automatic question was is it like that because I've smoked when I was pregnant. And they said No. They, you know, were pretty confident that that wasn't the reason. And they said that if it was smoking that caused that, they would know and therefore it would be another reason to add to the ills, health hazards for smoking when you're pregnant and they said that wasn't the cause of it. It was just simply that... They tried to explain but I mean with all the medical terms I'm not all that good. And they just briefly said that it was... when he was growing it was just that the bit down the nose had not joined up with the two bits that form the top lip and they hadn't quite grown together in the full term of the pregnancy. So I mean there was nothing that could be done now. It was just something that would have to be put right in later times. And I don't know how many surgeons and consultants came.

Mr & Mrs C

Extract 142 Interview 19

Mrs C Whereas the second one, you don't worry about it

	and of course then when you're told there's something wrong you go back, you think back to yourself, Oh God did I take anything? I don't smoke, I don't drink, I don't take tablets. I mean it's just something that happened.
Interviewer	Have you asked the doctors what could have caused it?
Mrs C	No, they... err yeah, he just said that it's when they're forming and the heart hasn't formed. It's like it could have been born without a hand or something like that. He said it's nothing you did while you was carrying which I mean, let's face it, I don't smoke and I don't drink or nothing like that.

These two accounts show most of the salient features of the majority of parents' causal accounts. We shall use them as a starting point for our discussion and expand by reference to other data. Before doing so, we should make some general observations. At first sight, it appears that the two extracts reflect the findings of Burton (1975) and Davis (1963). The parents say they felt they were to blame or at least could have been blamed for their baby's condition. However, a closer examination reveals that they also employ the type of explanation that a professional might give. Indeed, in presenting this explanation our respondents actually refer to what doctors said about the cause of the illness. Hence, an initial consideration of these accounts supports the criticisms made earlier of the above authors and Voysey (1975). We must conclude that parents' explanations require more thorough analysis than they have hitherto been given.

Like Mrs Sm and Mrs C, 60% of our respondents talked about the cause of their child's illness without prompting from the interviewer. The accounts of parents who discussed the topic in response to a question from the interviewer did not differ significantly. This suggests that parents were morally required to provide some account of the cause both from their point of view and from that of the interviewer. Hence it was an integral part of the story of giving birth to a congenitally damaged child.

Mrs Sm's account is part of her response to an invitation at the beginning of the interview to tell the story of her experience of giving birth to a congenitally ill child. Thus her explanation of the illness is firmly placed in the past: it is part of history. Most respondents treated the topic in the same way as Mrs Sm and Mrs C:

Mrs Hen

Extract 143 Interview 31

Mrs Hen	I mean at first... When I was told she really wasn't... 'er breathing was bad, the first thing I said was, I mean obviously, is it my fault?

Mrs Wl

Extract 144 Interview 73

Mrs Wl	How did it happen is the first thing you say isn't it? Why did this happen to me and how did this happen?

Mr & Mrs Wa

Extract 145 Interview 20

Mrs Wa Well you just don't believe anything at the time, you think you know nothing's gonna make 'im look any better and then you start thinking oh, you know, why should it happen to me?

In this way, our respondents conveyed a sense of detachment from their reaction. The claim was that the views they held at the time of the interview were different from those they reported as being part of their responses on first learning of the child's condition. These responses included rejection of the child, anger, a sense of meaninglessness as well as their perceptions of the cause. This sense of detachment was strengthened by the way they currently judged these responses. With hindsight, these reactions were perceived as irrational and so not to be taken seriously:

Mrs Wl

Extract 146 Interview 73

Mrs Wl Yes but this is only at the beginning, you don't get that now. It's only when it first hits you that you say that.

Mrs Hen

Extract 147 Interview 31

Mrs Hen But I mean I was worried. I was out of my mind I suppose for about 24 hours... I felt down-right rotten.

Or if we consider Mrs Wa's account (see Extract 145) we see that it commences with the utterance 'Well, you just don't believe anything at the time'. This refers to a state of mind where considered and sound judgements cannot be made. Some parents conveyed their irrationality by describing some action which they would not have done under normal circumstances:

Mrs Fd

Extract 148 Interview 95

Interviewer	Did you at that time bother to think about the cause of it or why it happened?
Mrs Fd	Um, well it's so stupid, it really is. And I mean it really is absolutely silly. We had a medical book here and it was all about reproduction and that it showed you all these different stages that the egg comes to and when I was at work, we used to have this Irish lady and she used to tell us these silly stories. I never would have believed her and she used to say if a pregnant woman was walking down the street and a rat runs across and she touches her tummy that mark will come out on the baby itself.
Interviewer	Mm.
Mrs Fd	Tut really stupid, you know. I don't believe it. And we'd been looking at this book and I... it's really..., when I think now that I could have thought that, you know, but it was the way I was anyway. And after my son had been born my husband came back in the evening and I made him destroy

the book. I I felt it was a way... I had something to blame it on you know. It's really (chuckles) I suppose after I mean after one you start thinking rationally about it. I mean it was just one of those things.

(my emphasis)

The emphasized utterances refer again to an unsound state of mind as a result of which one acts irrationally, which is contrasted with Mrs Fd's current state of 'thinking rationally'. It is from this point of view that past actions, like the one described in the extract, are held to have been 'stupid' and 'absolutely silly'.

We should also note that occasionally the interviewer colluded with parents in presenting early reactions as irrational:

Mr & Mrs Wa

Extract 149 Interview 20

Mrs Wa	You know I did get a bit... well it's 'is fault, you know, not my fault, it's 'is fault... And I found I was getting a bit short-tempered, you know, you get that.
Interviewer	Yes well you were emotional anyway.
Mrs Wa	Yeah.[3]

I have dwelt on the way parents judged their initial responses as irrational since they are the context in which their explanations of the cause are located. We must now examine them more closely. We have already seen how parents commenced their discussions with utterances which treated the cause as a moral issue and a matter of personal responsibility. Parents asked two similar types of question: one taking the form of 'Why did this happen to me?' and the other 'What did I do wrong?'. However, the questions were not posed in a straightforward manner. For instance, Mrs Sm (Extract 141) said 'And I thought, Oh gosh, now you know, what have I done? The usual my fault'. Mrs C (Extract 142) prefaced 'Oh God, did I take anything?' with the comment 'You think back to yourself'. Mrs Hen (Extract 143) prefixed 'Is it my fault?' with 'obviously'. By using these devices, our respondents were proposing first that the birth of a congenitally damaged child produced this type of question and second that anyone confronted by the same situation would react in a similar way. Hence they were not reporting that they felt they were to blame - far from it. They were implying that to consider the issue of blame was not only understandable but was what any rational person would do under these circumstances. Thus they enhanced their image as rational and sensible people.

Some parents reported following 'Why me?' questions with utterances which asserted that they had been punished for no apparent reason:

Mr & Mrs Wa

Extract 150 Interview 27

Mrs Wa Why should it be my baby, you know? I've 'ad one baby, perfectly all right. I mean I've got umm... there's six of us in our family... there's eleven I think in my husband's family, they've all 'ad children, not a thing wrong, you know. And my brother's 'ad five children, nothing wrong. And there's me. Just my second, you know.

Mrs Wl

Extract 151 Interview 73

Interviewer	When you talk about why did this happen to me, what do you mean by...?
Mrs Wl	Well, why should it happen to me. It didn't happen to my daughter, it didn't happen to my son, and it didn't happen to other people's children, why should I be the one?

The nature of the child's condition was considered to be such that it could only be explained by a moral fault in the parent or by some wrongdoing that she had committed. Yet here Mrs Wl and Mrs Wa claim by association that such an explanation was without foundation in their case. For instance, Mrs Wl implies that she is no different from her 'daughter', 'her son' or 'other people' and yet she gave birth to a congenitally damaged child. Mrs Wa reinforces her case by saying that the ill child is only her second whereas other family members have had numerous normal children. Other parents conveyed the same sentiments by suggesting that they wanted their child whereas there were parents who brought unwanted children into the world who were perfectly normal.

Thus the thrust of parents' accounts at this stage was to demonstrate that questions such as 'Why me/What did I do wrong?' either did not apply to them or had only arisen in the heat of the moment. However, a closer study of their accounts reveals that in the interview they did in fact treat these questions very seriously. In other words, they deferred to those commonly held theories of the cause of congenital illness which suggest that unadvisable behaviour during pregnancy can damage the foetus. Parents felt compelled to answer to the implications of these theories, and thus qualify as rational and sensible people.

Mrs Sm's and Mrs C's accounts (Extracts 141 and 142) were typical of the way parents dealt with this issue. Having posed a question concerning personal responsibility for the child's condition, they then, like Mrs Sm and Mrs C, presented an inventory of the types of behaviour which they assumed could cause congenital illness. (We will consider these later.) Unlike Mrs C, the majority of parents admitted having done something which they considered potentially harmful. These utterances were followed by statements which exonerated the respondent. Their most common feature was that they appealed to the authority of medical formulations either directly or indirectly. These formulations were considered by parents to be decisive:

Mr Wr

Extract 152 Interview 126

Mr Wr	Obviously it's just a defect
Interviewer	Yeah.
Mr Wr	Which hasn't formed. It's nothing to do with the parents I don't think. Um we thought at first my wife had glandular fever when she was carrying my son. We thought perhaps it was to do with that

but we've been given to understand that it's nothing to do with that at all and in fact it's just a minor defect in his growth. Umm could happen to anybody. It's eight in a thousand I think. Eight in one thousand I think is=

(my emphasis)

Mr Wr does not state directly that his information comes from the medical profession, but this is implicit in the words 'we're given to understand'. Other parents were more direct in appealing to the authority of doctors.

Mrs Hen

Extract 153 Interview 31

Mrs Hen So I mean I did smoke when I was pregnant, not a terrific amount, but I did smoke. So automatic that shoots straight to your mind, I smoked while I was pregnant, you know. And the doctor completely assured me it was nothing I had done. Nothing you know to do with genes and all the rest of it. He said it is just...

Finally, some parents conveyed the same message in a truncated way with utterances such as:

'To me it just happened while he was developing like and it's nothing anybody can do to change the way' (Mr Wo)

'It's just one of those things' (Mrs Fol)

'And I mean I know really none of those things would have made any difference. It just happened' (Mrs Fi)

These interpretations were significant in a number of ways. As we noted earlier, parents intended the interviewer to treat them as decisive and conclusive. Here parents were using a commonly held conception of the medical profession as an expert body of people. Hence, their judgements are to be treated by non-experts as sacrosanct. In other words, such judgements are unchallengeable.[4] This assumption made it legitimate for parents to close off the topic of cause and illegitimate for the interviewer to pursue the matter any further. For instance, Mrs Sm continued describing her experiences:

Mrs Sm

Extract 154 Interview 132

Mrs Sm ... And I don't know how many surgeons and consultants came, they were popping in and out all the time. And it started off they were going to take him, they said...

Likewise, Mrs Fol, Mrs Fi and Mrs Hen carried on a chronological description of events. Other parents simply turned to another topic.

On the few occasions when the interviewer pursued the issue of causality after parents had presented the decisive medical formulation, this created problems for both him and the parent. Let us consider the following example. The mother, Mrs Wl, has examined whether the cause was hereditary but concluded that 'as far as we're concerned it is not hereditary, as far back as we know'. At this stage, it was still reasonable for the interviewer to ask the following question:

Interviewer	Right. Did you also do another thing I've come across which is to look at things that you might have done?
Mrs Wl	Yes I did. I went through all that. I went through everything I took in pregnancy and everything that happened, different things, you know. And you do wonder, but <u>you can go on wondering forever and you never know</u>.

(my emphasis)

Clearly, this utterance contained an appeal to the medical explanation which we examined earlier and it functioned as a conclusion to the discussion. When Mrs Wl said 'you can go on wondering forever', it is as if she was telling the interviewer 'we could carry on talking about this issue but it will get us nowhere'. Her claim was that there is little point in talking about subjects we can never have any knowledge of. Thus she implicitly requested the interviewer not to question her further. However, the interviewer pursued the issue:

Interviewer	Yes, um I don't know, well what kind of medical explanation was offered to you about that? Presumably you discussed that with um...

In doing so, he failed to take account of the mother's wishes which were not stated explicitly, since this would contravene interview etiquette. Parents never openly said they did not want to talk about a particular issue. It was left to the supposed good sense of the interviewer to assess what were sensitive matters to parents and how far they could be discussed. In this case, the interviewer overstepped an unstated boundary. In doing so, he not only disrupted the polite atmosphere of the interview but he challenged the mother's display of being sensible and well adjusted to her situation.

However, she complied with the interviewer's line of questioning and presented a number of other possible causes of her child's cleft palate/hare lip which all took a 'could have been' form. She concluded by repeating her sentiment that 'it doesn't matter, does it?'

By this time the interviewer understood the implications of persisting with the topic but found it impossible not to acknowledge openly that he had gone too far. The following exchange took place after Mrs Wl's question:

1 Interviewer No of course not.
2 Mrs Wl It's not going to help anything. No but I'm just saying, it doesn't really matter does it?
3 Interviewer Well, there's nothing one can do about it.
4 Mrs Wl No nothing one can do and nothing one can do to stop it happening again.
5 Interviewer Sure.
6 Mrs Wl With another child.
7 Interviewer Yes.
8 Mrs Wl It's just one of those things, that's how I look at it anyway.
9 Interviewer Yes I appreciate that, all I wanted to do was to establish that, you know, these were concerns

10 Mrs Wl Yes and how one would see exactly.

11 Interviewer Yes.

12 Mrs Wl Yes that's important.

13 Interviewer You know because I'm also interested to see whether there are any similarities *between people like yourselves who have children... and also mothers who give birth to children with heart abnormalities*

14 Mrs Wl Yes that's right. You're at the heart hospital aren't you?

15 Interviewer That's right.

16 Mrs Wl Oh that's right, yes she did tell me, your colleague did, that you were with the heart patients.

17 Interviewer That's right.

18 Mrs Wl That's right.

19 Interviewer You see, so this um is partly why I'm going back. Has anyone discussed these areas with you or...

20 Mrs Wl What medically?

21 Interviewer No did my... did my colleague talk about them?

22 Mrs Wl Yes she did talk about them.

23 Interviewer Yes, um just sort of leave that area for the moment...

(my emphasis)

Rarely do we find the interviewer having to account for his questions. Here, we observe him having to work hard to re-establish the normal format of the interview. To the statement emphasised in utterance 9, we could add 'I didn't mean to question your credibility'. Unfortunately, he made his task still more difficult in utterance 13 by using the phrase 'people like yourselves' as if implying that the respondent belonged to a different world from himself. Between utterances 14 and 18, the conversation almost broke down. Neither the interviewer nor the parent knew where to take it and the former was compelled in utterance 19 to offer another justification for having persisted with the topic. Finally, in utterance 23, he suggested moving on to another matter. It is unusual to see interviewers saying 'like to sort of leave that area' and it is an indication of how far normal interviewer/ interviewee relations have collapsed.

The analysis of cases which deviate from usual patterns can often be enlightening. This example reveals the hidden agenda of the research interview and of discussions about causality. Interviewers are subject to a code of conduct which allows them to question parents so that they can learn about their experiences but prevents them from casting doubt on what parents say. As we have seen, parents have a set way of accounting for the cause of their child's condition which, regardless of any uncertainties they may secretly harbour, ultimately displays them as blameless, rational and well adjusted. Thus an interviewer who seeks to question the adequacy of the parental account only succeeds in raising doubts about his own moral worth. The reason why discussions of causality usually took place only at the first interview was because parents produced accounts which concluded with a decisive and authoritative verdict on the cause of their child's condition. Thus they effectively prevented any further questions on the subject.[5]

To sum up, parents typically structured causal accounts in the following way:

1. They reported having asked whether they were to blame and indicated that this was the normal initial reaction of anyone who had given birth to a congenitally damaged child.
2. They presented an inventory of actions committed by them during pregnancy which they assumed could have caused the damage; some parents also wondered whether the child's condition had been inherited.
3. They explicitly or implicitly appealed to medical explanations which stated that the illness had occurred by chance and thus was not the parents' responsibility. A minority of parents who had been given to understand that the conditions had been inherited, invoked this explanation but without any sense of blame.

IV Theories of Causality and Types of Causal Agent

As Locker (1979) has argued, identifying a cause of a condition involves selecting appropriate agents from a culturally limited range and fitting them to the problem in question. In this section, I want to examine the various ideas parents put forward about the cause of their child's condition apart from the explanation they reported receiving from the doctors at the specialist hospitals. Parents mentioned five possible different types of cause which will be called toxic agent, inheritance, biographical, environmental and medical incompetence. Possible explanations were sometimes constructed from more than one causal type. However, the explanations most commonly used were based on the notions of a toxic agent and inheritance. There was an obvious link between the questions 'Why me?/What did I do wrong?', the exploration of toxic agents and inheritance as a basis for assigning responsibility and the roles of mothers and fathers when discussing these explanations.

Toxic agent

Without exception, mothers reported asking the questions 'Why me?/What did I do wrong?' (see Extracts 141-145). They never said 'Why did this happen to us?' or 'What did we do wrong?'. Surprisingly, this differs from the findings of Burton and Davis who claim that these questions took the 'we/us' form in their studies. The significance of the formulation in the present study lay in its influence on the theories they put forward as possible explanations of congenital illness. In this respect, the notion of a toxic agent based on widely available knowledge about substances expectant mothers should avoid was particularly appropriate. Let us first consider how mothers discussed a number of different agents.

Two mothers wondered whether smoking had caused their child's condition. The following extract comes from the interview with Mrs Sm. We saw earlier how she had raised this matter at the beginning of the interview when reporting her experiences of her child's hare lip. Like many parents, she elaborated on topics discussed at the report stage later in the interview.[6] For mothers who admitted taking toxic agents, there was a problem of reconciling their actions with a display in the interview of being a responsible parent:

Mrs Sm

Extract 155 Interview 132

1	Mrs Sm	... Well when I was pregnant... I used to smoke about twenty a day and when I found out... The thing is, they say that if you stop smoking when you're pregnant, you need, it doesn't matter. The effects are as if you'd never smoked at all but the thing is you don't know you're pregnant until about eight to ten weeks...
2	Interviewer	After you.
3	Mrs Sm	After you're actually pregnant.
4	Interviewer	Yeah.
5	Mrs Sm	So you still, you've smoked your way through two months of your pregnancy anyway and I used to smoke about twenty to thirty a day because I was working and I used to light one up, put it in the ashtray and next I'd look and it wasn't there anymore. But when I realized I was pregnant and I'd got the tests through positive, I did cut down and I was smoking about ten a day. Sometimes

> only eight to nine. Sometimes it would be twelve to thirteen. But I did try and my husband would only leave me ten in the morning (chuckles) so I didn't have much option. I mean there was no way I was gonna walk down the shop for a packet of cigarettes. But I must admit, it did go up a little towards the end of the pregnancy. Once I'd left work in November... I found I was smoking a little bit more than ten a day, I must admit. Not every day but most days. Um I don't know... I suppose you automatically think to yourself Oh it won't happen to me. The usual sort of attitude.

Unlike Locker's respondents who accounted for trivial conditions, mothers in this study were required not only to produce explanations which were culturally relevant to congenital illness but also to use their knowledge of causal factors in such a way that they reaffirmed their own moral character. Underlying Mrs Sm's account is the commonly held notion that toxic agents can damage the foetus during the first three months of pregnancy. She acknowledges that she smoked but seeks to produce good reasons to show that, in fact, she acted in good faith. Thus with the collusion of the interviewer, (see utterances 1 - 4) she invokes the idea that action can only be based on knowledge. She implies that had she known she was pregnant she might have taken action against smoking earlier than she did.

Of course, there are aspects of this account that we could question: for example, might one not suspect pregnancy earlier than 8 to 10 weeks and therefore start to take precautions? It might seem that the interviewer has been unrigorous in his questioning of the parent. However, this possible criticism fails to take account of the constraints inherent in a research interview. As we saw in Mrs WL's case, parents expected their accounts to be accepted without their honesty being questioned. It is worth emphasizing this aspect of the interviewer/interviewee contract because, as we will see, many of the explanations put forward by parents were, when examined rigorously, without scientific foundation.

Mrs Sm goes on to make a series of claims aimed at establishing that she did try to do her best in the circumstances (see utterance 5). Thus she reports that: she smoked 20-30 cigarettes a day because she was at work and implies that most of them went unsmoked since they were left to burn themselves out in an ashtray; she cut down the quantity when she learnt she was pregnant; her husband left her ten cigarettes when he went to work; she would never dream of going to the shop to buy another packet and so on. Eventually, she seems to arrive at a point where she acknowledges that she has offered inadequate excuses since she says her behaviour was based on 'the usual sort of attitude', 'it won't happen to me'.

Explanations based on the notion of a toxic agent put forward by other mothers were similar to Mrs Sm's. For instance, several mothers speculated about whether drugs they had taken during pregnancy had damaged their baby. The following extract is typical of such accounts:

Mr & Mrs Fi

Extract 156 Interview 137

Mrs Fi	I had some Debandox for sickness. Now I know very well that's got nothing to do with it but all the time it was running through my mind supposing I hadn't had those tablets.
Interviewer	Hm.
Mrs Fi	Would it have happened? I know now that it would have happened anyway because by the time I'd taken the tablets, that had already happened and there was nothing I could do about it. But it makes you wonder... And perhaps before I knew I was pregnant, did I do something?

Mrs Fi produces an explanation based on taking a medically approved drug, Debandox, which was widely prescribed for sickness during pregnancy. At the time of the interview, it had aroused a great deal of controversy after a lawsuit in the USA where it was proposed that it had caused multiple congenital malformations. Mrs Fi assumes that the interviewer shares this knowledge. Likewise, when she says '... by the time I'd taken the tablets, that had already happened and there was nothing I could do about it', it is taken for granted that her audience understands that she took Debandox after the first three months of pregnancy when the ingestion of drugs cannot cause congenital malformations, unless taken in large dosages.

In this type of explanation, it is the mother's voice taking the 'I' form which is most prominent. The voice of the husband/father is absent from the conversation and from the content of the account. On those occasions where fathers spoke, their utterances, as we would expect, reflected the nature of the proposed causal explanation:

Mr & Mrs C

Extract 157 Interview 19

Mr C — It's a good job there's nothing wrong with him that they could have said was well, you, took those tablets during pregnancy.

Mrs C — Oh God I...

Mr C — ... And that was the trouble if you 'adn't a took those he'd 'ave been all right.

Mrs C — I think, I think I would 'ave just gone beserk. Like this thalidomide... no if that 'ad been me... oh I don't know what I would 'ave done.

For the most part, parents presented a united front to the interviewer. They reported working as a team in coping with the social and medical consequences of their child's condition and this teamwork was reflected in their approach to the interview. For instance, when they discussed any improper treatment one partner had received from medical personnel, the other partner made a display of defending the good name of his spouse. The use of 'we' when describing these experiences reinforced the display of teamwork (see Extract 171 for example). However, the discussion of causality proved to be an occasion when mutual support was not forthcoming. None of Mr C's or Mrs C's utterances take a 'we' form in Extract 157. Mr C's presence is like that of some detached adjudicator presiding over the actions his wife might have committed. We are given to understand that had his wife taken certain tablets during pregnancy she would have been totally responsible for the damage to their son (i.e. 'he'). Mrs C, whose utterances take the 'I' form, accepts this role. Indeed, the role of 'I' is strengthened by Mr C's use of 'you' which directs attention exclusively towards his wife and also by the way those statements which attribute responsibility are presented as being uttered by 'they'. Parents frequently referred to doctors or even a doctor as 'they' and this, as we have seen, made utterances in this voice authoritative.[4] Some wives openly objected to such treatment by their husbands. Mrs Wl made the following remarks:

Mrs Wl

Extract 158 Interview 73

Mrs Wl	He claimed to trying to think that it wasn't him, his side.
Interviewer	Your husband.
Mrs Wl	Oh yes couldn't possibly have been. Now that's typically male, isn't it? Yes it's all your fault, so I thought so what it's happened now, what does it matter?

These remarks were made possibly because her husband was not present at the interview. When husbands were present they usually gave the impression that the cause of their child's condition was the spouse's business and the latter rarely questioned this interpretation. However, there were exceptions to this format. The notion of inheritance was also presented as a possible explanation for the illness. On such occasions, husbands appeared responsible if there were any reasons for supposing that the child's condition had or could have occurred in his family. We will examine these accounts shortly.

Mothers speculated about a variety of toxic agents, apart from cigarette smoking and medically approved drugs which they perceived as relevant causes of congenital illness and which were meaningful to their situation. The following quotations illustrate the wide range of choice. We are given the impression that any agent which entered the mother's body during pregnancy was considered an appropriate candidate for a causal explanation:

- 'You go over it and over it you know and sort of ( ) and I sort of you know wonder whether it was something there 'cos I was swimming, you know like ( ) did I swallow ( ) some water?'
- 'Or you wonder whether um you know um the pill and I worried about that a lot. Er I don't know if they've connected with similar things but I'm not ( ) connected with heart... And anyway they though all you hear about the pill is the things they've connected it with you know. Not all that great compared with the number of people (laughs) who are taking it.'
- 'I even wonder, I mean I played around with drugs when I was about seventeen eighteen you know, so do hundreds of people and they have six healthy babies.'

- 'But the only thing I think could have made Jo be born that way was um this doctor used to come um he used to say have you been injected against this and that and we were going on holiday to Wales and there was a smallpox outbreak in Bridgend, so I was done against smallpox and then he said to me, Have you had polio injections? I said no and then 'ad that done... after that I fell for Jo and I've always got the feeling that's got something to do with it.'
- 'But I did drink, I was still at work and there used to be a lot of Friday drinking and I used to do it. And I often thought it could have been alcohol that caused it. Funny things do go through your mind.'

Table 10 shows the distribution of toxic agents considered by mothers.

Table 10

Type of agent	Number of mothers
Smoking	3
Pill	3
Medically approved or disapproved drugs	4
Innoculations	2
Viral infections	2
Alcohol	3
Bathing water	1

The above quotations show that mothers did not discuss these agents as definitive causes. Rather their explanations were presented as speculative and inconclusive which is demonstrated by the use of 'wonder' and 'thought'. Second, the agents invoked were historically and culturally specific. For instance, we would not expect innoculations against smallpox to figure in parental accounts in the future since people no longer require protection against this condition. From a cultural perspective, we can expect a variation in the proportion of British and American parents of congenitally damaged children who invoke alcohol as a causal agent. In the USA, the Surgeon-General has recently announced that it is unadvisable for pregnant women to drink any alcohol. Here, the attitude of the medical profession towards the consumption of alcohol in pregnancy is liberal.

To sum up, explanations based on the notion of a toxic agent were put forward by mothers who had asked the questions 'Why me?/ What did I do wrong?' but who subsequently appealed to the medical formulation of a defect in the foetus' development which occurs by chance. Underlying the explanations are principles of conduct in pregnancy made widely available to women through a number of different channels.

There is little doubt that as a result of the enormous professional interest in the problems of pregnancy women appear to have access to a lot of information. However, the timing and selection of the information given may contribute to the moral anguish experienced by many pregnant women and particularly by mothers of congenitally damaged babies. We shall examine this issue later.

Hereditary explanations

The idea that the child's condition was inherited was the second most common theory of causality. In the following discussion, I shall not examine the objective relationship between parental and medical understandings of inherited illness, but rather the way in which parents discussed this theory in the context of the interview.

In all cases, it was implied or stated that the condition was 'bound to happen if you've already got it in the family', (Mrs Fi). The discussion of inheritance involved parents examining their respective family backgrounds. We noted earlier how explanations based on the notion of a toxic agent created a rift between husband and wife related to which partner was held to be potentially responsible. Again, a division between the sexes was apparent when it was suspected, proposed or known that the child's condition had occurred in one of the parents' families.

Let us first consider some accounts which definitely traced the child's condition to a family of origin. Parents invariably reported discovering this fact after their child had been born and diagnosed with congenital heart disease or a cleft palate/hare lip:

Mr & Mrs Al

Extract 159 Interview 200

Mrs Al I didn't know it was in my family until he was born and then I asked aunts and it went back that way but no one in my family's had the lip. My great uncle had the palate, my cousin had the palate. I remember. She's still only in her 40's now. But I never knew it was anything. I just thought she spoke strange. She had the palate and the son had the palate but he died.

Mrs Fd

Extract 160 Interview 95

Interviewer And then when did you learn that it was in your husband's family? When did you come to realize that?

Mrs Fd Straight after actually when you know it was spoken about and um obviously 'cos my mum was here, when I went into hospital because she had to look after my other little boy.

Interviewer Hm hm.

Mrs Fd And my mother and father-in-law came up in the evening. They were talking about it.

Clearly, the claim that a parent did not know of the occurrence in his family before the child was born was important in sustaining a display of adequate parenthood. It meant that the parent had not acted negligently, a judgement which certainly could have been made had the parent acknowledged that he had known about the illness in his family but had failed to inform his spouse either before marrying or starting a family.

As a result of this claim, the parent who did not have a background of congenital illness usually made a show of accepting his partner's situation with magnanimity:

Mr & Mrs Al

Extract 161 Interview 200

Mr Al	I just thought it was luck of the draw.

Mrs Fd

Extract 162 Interview 95

Mrs Fd	No I belie- Well I believe it's something in... in the family and it's just that you know.
Interviewer	Yeah, how did you feel about that?
Mrs Fd	What that it was in the family?
Interviewer	Yeah. Hm, hm.
Mrs Fd	Just our bad luck really, that's it you know. I wouldn't wish it on anyone else. It was just unfortunate that it happened to us. It was... you know, nobody's fault. Can't be helped. Could have been on my side.
Interviewer	Yeah, sure.
Mrs Fd	You know.

Without doubting their sincerity, these parents could afford a display of generosity. After all, as far as they and their partners were concerned, it was established that the child's condition had been inherited. Furthermore, had they openly blamed their partner, they would have appeared cruel and unfeeling since it is commonly accepted that one cannot be held responsible for the conduct of past generations. Indeed, one mother of a child suffering from congenital heart disease who admitted blaming her husband because of a history of heart disease in his family was duly apologetic in the interview. She felt it necessary to justify why she had blamed him.

Mrs R

Extract 163 Interview 83

Mrs R I was uptight because I hadn't... it hadn't been discovered before, I was uptight to think there had been times when I told Julia off and I felt really guilty because now I know she's got something wrong with her, you know, I thought to myself, oh you, you've told her off. You feel awful about it so in a fit of temper I got home and I was so very very upset over it, you know. And my husband was equally, I think choked in his own way. I said to him This is all your fault. It's a weakness on your side of the family. And he looked at me and I felt terrible after I said it, but I just couldn't help it. I had to say it.

Having admitted she blamed her husband, Mrs R appeared blameworthy herself and thus was compelled to produce an account which made her behaviour appear reasonable and understandable in the circumstances.

The partner to whom the child's illness could be traced had to find a way of managing this situation in the interview. We have seen that those who said they were unaware of the condition in their family before the birth of the child moderated the judgement that they were irresponsible. These parents also established their moral adequacy by appearing to accept their situation in a courageous manner.

Mr & Mrs R

Extract 164 Interview 82

Mr R — And no grandchildren there... there are now, of course. One of them, of course has got a heart condition.

Interviewer — Hm, hm.

Mr R — And of course, my mother had rheumatic fever. And I learnt something the other day, where people who have rheumatic fever sometimes end up having heart condition as well. So this is why I think a lot of this area from my wife's point of view probably ended up pointing towards my family, if you're looking for a cause, you know. And who knows? I mean she was obviously like this.

(my emphasis)

We can imagine that for a parent to acknowledge publicly that he and his family of origin could be responsible for damaging his child is a painful task. Mr R appears not to flinch from the discomfort engendered by his admission. The appearance of bravery is enhanced by the repeated use of 'of course' and 'obviously' which suggest that he has fully accepted the implications of his mother's rheumatic fever and a nephew's heart condition. Another father, who thought that his baby's heart condition was connected to the fact that his mother's parents were first cousins, displayed his bravery in the following manner:

Mr M

Extract 165 Interview 127

Mr M	If there is a genetic incongruity then we shall most certainly (not proceed) in having a child because it's unfair on the child.
Interviewer	Hm.
Mr M	And we've already told the doctor that if he in anyway thinks that the condition is attributable to a root cause like that then we will most certainly subject ourselves to tests.

Admittedly, the father's account takes the 'we' form in relation to not having children or being subjected to tests. However, we know that 'genetic incongruity' refers to his side of the family. Hence in admitting this and showing his willingness to be 'subjected to tests' he, like Mr R, confronts his moral responsibilities.

Another group of parents could only speculate as to whether their child's condition had been inherited since they were unable to trace the illness to their families. Yet, even in these accounts divisions were apparent between the spouses in which one partner appeared blameless while the character of the other was spoilt or made to look dubious. A parent could accomplish this by making the following type of statement:

Mr & Mrs Fol

Extract 166 Interview 122

Mrs Fol	Um and he, my husband's dad has got a bad heart and we thought maybe it was hereditary.

Interviewer Hm.

Mrs Fol But it's not. It's just one of those things.

In saying 'It's just one of those things', Mrs Fol seems to negate the idea that her child's condition was inherited. However, by connecting it with her father-in-law's 'bad heart' we are left with the impression that there is something dubious about her husband's family. Other parents created a similar impression in a more striking fashion:

Mr & Mrs Fi

Extract 167 Interview 137

1 Mr Fi You obviously go into things like... if there's an illness in the family... you know, you obviously go into that sort of thing, anybody does unless they're stupid.

2 Mrs Fi I mean there was- there is nothing in our family that I know of... then your family's a little bit small isn't it? I mean you don't know anything about your mother's family, so there could be anything.

3 Mr Fi My mother hasn't got any family.

4 Mrs Fi No, precisely, so there could be anything there.

5 Interviewer Hm.

6 Mrs Fi That we don't know about.

Here Mr Fi, by virtue of the standards he has invoked (see utterance 1), is himself made to look rather stupid. Mrs Fi claims that congenital illness does not exist in her family but implies that this may not be true of her husband's family. She establishes the legitimacy of this claim by appealing to the idea that congenital illness could exist in members of her mother-in-law's family since their whereabouts are unknown. Mrs Wl made the same claim about her husband's family:

Mrs Wl

Extract 168 Interview 73

Mrs Wl — Well I don't know really. I mean I probably looked all around the family I thought back to all my family and nothing I could think of. We don't know many of my husband's family, only the immediate family so I don't really know that. But as far as we're concerned it is not hereditary as far back as we know.

(my emphasis)

Like Mrs Fi, Mrs Wl notes that she has considered 'all' her family and did not discover any history of congenital illness. Also like Mrs Fi, she casts doubt on her husband when she claims they are unfamiliar with his extended family. Yet, she then appears to say conclusively that the condition is not inherited. She even presents this as a judgement she shares with her husband by using the 'we' voice. However, she finally reinforces previously expressed doubts about him with the utterance 'as far back as we know'.

To sum up, parents' explanations of the condition being inherited were similar to those based on the notion of a toxic agent insofar as they revealed a division between husband and wife, because one partner was held to be responsible or potentially responsible. Also, both types of explanation were sometimes invoked, one explanation perhaps attributing responsibility to one partner, and one to the other. We should emphasize that these explanations were usually part of the structure of causal accounts we examined earlier. In other words, most parents who invoked them ultimately appealed to medical formulations which suggested that the child's condition was a chance occurrence.[7]

Environmental, biographical explanations and medical incompetence

These explanations were the least common presented by parents Environmental and biographical explanations took a similar form to ones based on toxic agents and inheritance i.e. one parent, in this case the mother, traced her child's illness to some action or event in which she was involved. For instance, Mrs Wl presented the following environmental explanation:

Mrs Wl

Extract 169 Interview 73

Mrs Wl	I had an electric shock during pregnancy and this could have been it.
Interviewer	An electric shock.
Mrs Wl	From the vacuum cleaner.
Interviewer	Yes .
Mrs Wl	You see and that could well have done it actually 'cos that was in the early three months of pregnancy.
Interviewer	And that's when they reckoned this?

Mrs Wl Yes, well they explained to me that it was just two parts that didn't quite go together and it stopped for a second and it could have happened then you see. Because that's all it is, isn't it? It's centered down the bone structure of the heart. And that sort of happened, the shock could have sort of stopped the growth for that minimum of a second and it could have been that.

It is unclear form Mrs Wl's account whether this explanation was actually confirmed by the medical profession. It is more likely that she linked the medical version of how a cleft palate/ hare lip are formed to her experience of an electric shock. From a common sense point of view, this explanation sounds plausible, especially when she locates the event within the first three months of pregnancy.

Mrs Wa perceived a causal relationship between her child's condition and her biography:

Mr & Mrs Wa

Extract 170 Interview 20

Mrs Wa And I thought, well perhaps it was because I never got married until I was 24 and I was 28, I think it was 28, 27 when I had Johnny. Wait a minute, getting on for 28. I thought p'raps getting married late and 'aving babies late, you know could be something to do with that.

(my emphasis)

The device 'you know' in the utterance emphasized refers the reader to Mrs Wa's version of medical research into the relationship between the mother's age and producing a congenitally damaged child. In a strictly objective sense, this version is obviously inaccurate. However, like Mrs Wl's account, it appears reasonable in the context of the interview since the mother does not claim to be an expert and because it is conveyed tentatively: Mrs Wa prefaces her explanation with the term 'perhaps'.

The last explanation we shall examine represents something of a deviant case compared to the other types of explanation in the sample. It is based on an alleged act of medical incompetence occurring during childbirth and has the characteristics of an atrocity story. The principle features which distinguish this explanation from the other causal accounts are first, that an outsider, rather than a parent, is blamed for the child's condition and second, the parents appear united. Of course, this characteristic is a feature of atrocity stories and probably of any account in which a third party is blamed: there is nothing like the misconduct of an outsider to unite a group!

In her account, Mrs Hen initially describes how, from her point of view, the induction of her baby and the 'strain' they were both under 'must have done some damage'. She then reports how her husband perceived this situation:

Mrs Hen

Extract 171 Interview 31

Mrs Hen But err I mean he said they were rough with her. They were very rough with her. And he said a

> student nurse was delivering. I would 'ave 'ad quite obviously a qualified midwife. But he said they were extremely rough with her. And we both got a sort of agreement on it, if you know what I mean, we've got our own ideas. I mean he saw one side and I saw the other side, we we both agree there was a rough deal. My daughter and I had a rough time.

The force of this account is partly derived from the story it tells and partly from the judicious use of pronouns. The observations of 'I' and 'he' concerning the conduct of 'they' are presented as complementing each other so that our respondent is in a position to convey her conclusions in the 'we' voice. This pronoun displays the parents as a team against 'they' the medical profession. The account is also strengthened by the utterances 'a student nurse was delivering. I would 'ave 'ad quite obviously a qualified midwife'. It is taken for granted that students are more likely than qualified personnel to commit errors.

This causal account was the only one of its kind. However, it has proved useful in emphasizing the most striking feature of the other explanations: namely, an individual parent either holding himself or being held responsible for the child's illness.

V Policy Implications

In the interview, parents appeared to be adjusted to the cause of their child's condition. We must remember the explanations we have been examining are presented as belonging to earlier experiences. In the final analysis, they invite us to accept the medical formulation of the cause of congenital illness as the most valid explanation. Nevertheless, their accounts pose the issue of personal responsibility to such an extent that we can assume that for parents a good deal of tension exists between the medical and other explanations. Hence it would be valuable to consider the relationship between our respondents' causal accounts and first, the way in which information concerning conduct in pregnancy is made available to expectant parents and second, how specialist hospitals handle the concerns of those who give birth to a congenitally ill child.

The extraordinary number of different toxic agents selected by our respondents suggests that the way information is conveyed by the ante-natal services and other channels is far from adequate. This claim is borne out by the findings of two recent surveys conducted by 22 community health councils and the Sunday Times (1981). These surveys show that a number of features of ante-natal clinics, such as long waiting times, lack of continuity of care, lack of encouragement to ask questions, create problems of communication between pregnant women and medical personnel. It was reported that too often women felt they were merely pacified and not given information of any substance.

Where women are given information about how they should maintain a healthy pregnancy, this is often presented with little explanation. They are told what substances they should avoid or take in moderation but are not advised about why they should do so or what the consequences will be if they fail to follow this advice. For instance, it is relevant for an expectant mother to know what the consequences will be if occasionally she happens to drink more than the advised amount of alcohol. These inadequacies in ante-natal care lead to a moral atmosphere which contributes to the experiences reported by our respondents. Expectant women occupy a number of different worlds besides pregnancy and at some time or other are bound to act in ways which are considered unhealthy from a medical point of view. They are liable to feel, because of inadequate explanations, that should they give birth to a congenitally damaged child, such actions were responsible.

The atmosphere of responsibility and blame is also stimulated by the inappropriate timing of ante-natal care. One of our respondents referred to this and it was a major finding of the two surveys mentioned above. The first twelve weeks are held to be the most important for the development of the foetus since it is in the first trimester that bad diet, drugs and other toxic agents have the most damaging effects. Yet GPs frequently procrastinate in objectively establishing pregnancy partly because the relevant procedures are costly and partly because the incidence of miscarriage is sufficiently high[8] to warrant delaying of testing. Moreover, it is normal for there to be a month's delay between the first GP appointment and attendance at the hospital clinic. Thus many women will be made aware of what types of conduct contribute to the health of the foetus when it is too late i.e. after eight or even twelve weeks. By this time, they may feel they have already acted in unadvisable ways. Whether they actually have or not is irrelevant to our interests. What we can say is that a situation has been created which fuels mothers' sense of blame should they give birth to a congenitally damaged child.

Clearly, there is a need not only to improve the timing and nature of ante-natal care but also to treat seriously such care as preventive. For instance, more resources could be directed to channels of communication such as radio, T.V., newspapers and popular magazines than are used at present. These channels could be used regularly to communicate the type of information seen by the authorities as relevant to expectant parents. Furthermore, information concerning the maintenance of a healthy pregnancy should be made available with the necessary evidence in order to make this advice intelligible.

Of course, these changes would only go some way to helping mothers who produce congenitally damaged babies with their sense of responsibility. Generally, parents are held to be responsible for the existence and behaviour of young children. Our linguistic practices reflect this. For instance, it is a common practice to congratulate the lucky parents on <u>producing</u> a normal baby, whereas we commiserate with those who <u>produce</u> damaged babies. These parents feel and are implicitly held to be responsible for producing a defective baby unless they can demonstrate otherwise.

In this sense, the clinical treatment of this issue, while genuine, fails to take account of the social experience of parents. Possibly, doctors fail to explore parents' perceptions of cause at length because outpatients and ward rounds are inappropriate settings in which to do so. Recently, one of the units at which this research was carried out has established experimental clinics which are devoted exclusively to parents' concerns and anxieties. It is hoped that parents will feel comfortable enough to raise their feelings about the cause of their child's condition and that these will be explored by doctors from the parental as well as medical point of view.[9]

VI Conclusion

Parental accounts of causality are one of the most difficult areas of interview talk for sociological analysis. There is a temptation, which is apparent in the work of several sociologists (Voysey, Burton & Davis), to be selective in the interpretation of these accounts. This occurs first, because the authors are more interested in what parents say than how they construct their accounts and second, because they over-emphasize the influence of features which are external to the interview like norms and the role of social control agencies. As we have seen, parents' accounts are constructed in such a way that they embrace several types of explanation. As always, the significance of our respondents' talk has been to display the status of adequate parenthood regardless of whether they are held to be responsible for their offspring's misfortune.

Chapter 8

CONCLUSIONS

1 Introduction

In Chapter 2, I examined a number of approaches to interview data contained in studies of parental responses to a seriously ill child. I argued that they displayed both theoretical and methodological weaknesses and proposed an approach primarily influenced by the work of Voysey (1975). Subsequently, I elaborated her thesis, first by providing a quantitative method, based on Sacks's analysis of descriptions which established the normative character of parents' accounts, and second by closely analysing their construction for the display of the status of moral adequacy. The objectives of this chapter are:

(a) to respond to some possible criticisms of my analysis;

(b) to examine some policy implications including the working of one partly derived from this study;

(c) to propose the relevance of the analysis for studies of familial responses to other medical conditions including mental illness and some serious adult illnesses.

II Some Criticisms[1]

To begin with, let us consider an objection to the view of family life presented in the preceding chapters. This view is captured in the phrase 'happy families'. Parents are depicted as coping adequately with their situation. They appear to sustain normal relations within the home and do not expect friends and acquaintances to treat them differently because they have a seriously ill child. Certainly, they are unfortunate but they are defiant and brave in the face of adversity. It can be objected that this picture of family harmony and unity is not credible. Parents may present such accounts for the benefit of an outsider, like an interviewer, but it is reasonable to suppose that in their private life, which is not accessible to the investigator given his research stance, matters are quite different. Here many of the features which psychological accounts of family life suggest are displayed.

Voysey (1975) has argued that parents' private life may be little different from what they report in their accounts. She supports this claim with two arguments concerning the role of social control agencies and others in relation to families. First, she argues that the child's condition is a permanent charge of deviance against the family which invites the attention of social control agencies and outsiders who in 'normal' family circumstances would not have grounds for intruding into its affairs.

Let us elaborate her argument by considering an example presented by one of my respondents. A mother reported going on a shopping expedition with her congenitally heart diseased daughter and a younger daughter in order to buy them some clothes. In the store, a shop assistant was comparing the size of the two girls and innocently asked how old they were. When told by Mrs R, she remarked that the younger child was larger than the older one. Mrs R admitted to the interviewer that she had been embarrassed but that she had managed to avoid giving an explanation to the shop assistant. She added that in other circumstances it was not always possible to do so. Admittedly, shopping is in a sense a public activity but few parents are ordinarily faced with the problem described by Mrs R: namely, the child's condition encouraging outsiders unwittingly to intrude into aspects of family life which are normally private. Hence, parents are continuously required to manage their appearance according to the dictates of normal parenthood and normal family life in order to combat the charge of deviance.

A second argument developed by Voysey suggests that the meanings parents use in interviews to describe their experiences of family life are the only ones available to them since social control agencies dominate the way family affairs are interpreted within our culture. Thus she supposes parents are likely to describe their circumstances in similar terms in situations external to the research interview. On methodological grounds, this argument is rather suspect. It shares a similar weakness with the way psychological accounts of familial responses explain anything parents say as evidence of pathology. Both fail to provide an empirical warrant for their explanation.

It is unnecessary to resort to such speculation since the premises of the above objection need not be accepted since they misrepresent the view of family life presented here. As I argued in the Introduction, parents do report problems but their accounts show how these problems are presented in the same terms as those experienced by any family and that they are resolved within the framework of normal babyhood, childhood and parenthood.

This finding confirmed the view of the nursing staff at one of the research hospitals who questioned the research team's proposal to include parents of healthy children as well as those of seriously ill children on the grounds that there was no difference between the two groups in terms of their status as normal members of society.

In Chapter 5, we saw how having a disfigured baby constitutes a challenge to parents' version of a normal baby but, apart form two couples, they did not interpret the baby's disfigurement as a master status. Rather they defined the baby's status in terms of its many normal attributes. Likewise, in Chapter 6 the child's adaptation to his illness and hospitalisation was presented as a source of worry for parents but the strategies they reported using were based on appeals to everyday conceptions of the child. In the previous chapter, discussions about the causes of the illness revealed tensions between husband and wife in the interview and in what they reported. But does such tension indicate a marital crisis or is it characteristic of a typical domestic problem? The data collected in this study support the latter view. When Mrs Wl reported that her husband had claimed he was in no way responsible for their daughter's cleft palate/hare lip, she remarked to the (male) interviewer 'Now that's typically male, isn't it? It's all your fault'. Here she was appealing to an attitude commonly held by women that husbands rarely accept responsibility for family affairs and that men prefer to blame others for any untoward occurrence.

Sometimes, open warfare broke out between husband and wife during the course of an interview over their respective roles in caring for the child. Let us examine one instance of such disagreement in order to establish the precise nature of the conflict. Before this conversation, the mother and interviewer had been discussing the child's stay in hospital for cardiac catheterisation.

Mr & Mrs Fol

Extract 172 Interview 121

1 Mrs Fol We're doing all the talking. Why aren't you talking?[2]

2 Mr Fol I wasn't there.

3 Mrs Fol No you weren't, was you?

4 Interviewer Are you going to try and get up there for the operation?

5 Mr Fol Well, I hope to yeah, for the operation. But as I say, I ain't gonna sit around all day waiting waiting for... I'll see her when she goes down and when she comes out you know? There's nothi=

6 Mrs Fol But how can you not sit around?

7 Mr Fol There's nothing you can do is there?

8 Mrs Fol Well no, but suppose they needed you to make a decision about something and you weren't there, you was in the pub.

9 Mr Fol They're not gonna come to you for a decision anyway 'cause you've already signed the sheet.

10 Mrs Fol Suppose so.

11 Mr Fol They're not gonna say, Hang on a minute, we've just gotta interrupt this operation 'cause we need the father here a minute. You know, are they?

12 Interviewer So you won't be there at all? (Telephone rings, recording interrupted).

13 Interviewer What, so you won't take time off work or anything like that?

14 Mr Fol Oh I can, you know, I can leave my job=

15 Mrs Fol (Referring to tape recorder) Did you turn it back on?

16 Interviewer It's on yeah. Started again.

17 Mr Fol I always, like I was supposed to really go to Wiltshire on Monday.

18 Interviewer Yeah.

19 Mr Fol But if she's going to have the operation on Monday, it's definitely going to be sort of Tuesday then I will go.

20 Interviewer Hm.

21 Mr Fol Come back, well I can drive back Monday night or Tuesday morning.

22 Interviewer Yeah.

23 Mr Fol But er=

24 Mrs Fol I don't think you should.

25 Interviewer What you want him to be here?

26 Mrs Fol He's so involved in- yeah, I think he should be there this time and sit and... it out with me (sigh-laughs)

27 Mr Fol Just, just wander down there, do that, do a bit of work.

28 Mrs Fol 'Cause his job is quite ( ) his boss is away.

29 Mr Fol I'm on a radio pager, you know, so if anyone wants me then they've only to page me and I'll come chortling down and phone.

30 Mrs Fol He's so wrapped up with this rotten new job, he

goes out the door and don't even say goodbye like (sigh-laughs).

31 Interviewer Dear oh dear.

32 Mrs Fol Ain't you?

33 Mr Fol No.

34 Mrs Fol No, I think you should take the day off and be at the hospital, but he doesn't think so.

35 Interviewer Do you think that'll make any difference to Gail?

36 Mrs Fol Yes 'cause she loves, she likes her dad.

37 Mr Fol I seen her, as I say, I'll see her before she goes to the hospital for her operation and I'll see her when she comes back, you know.

38 Mrs Fol Yeah but sometimes you can be more detached about things because I'm more emotional than you. And when it comes to all the blood tests and all the gorey bit, you might be better at it than me. And you're not going to be there. He can sit and watch people taking blood tests whereas I have to close my eyes, I can't. And I mean he can be more detached. He's defninitely not as emotional as me.

39 Interviewer Hm.

40 Mrs Fol And you might be calmer. And you might be calmer for her because she's a sensitive kid. If you're all uptight, she knows like.

41 Interviewer Hm.

42 Mrs Fol Like when he was on his course, there only had to be a tiny little noise and I was terrified and both the kids used to come screaming like 'cause they were frightened.

43 Interviewer Yeah.

44 Mrs Fol They knew I was frightened. Just from your reaction.

45 Mr Fol Yes I mean I can just, like if, if I felt that I should be there then I can anyway, no problem.

46 Mrs Fol You can't if you're in Wiltshire.

47 Mr Fol Well I won't be in Wiltshire 'cause it's probably going to be on the Monday isn't it?

48 Mrs Fol (   ) you find out.

At this point, the interviewer changed the topic of conversation to an issue less likely to arouse dispute between the parents. I have presented this lengthy extract in full so that the reader can appreciate the way 'problems' between husband and wife were formulated during the course of an interview. Although I do not intend to perform a detailed analysis, my contention is that this row over the nature of parental responsibilities towards the sick child is of the same order as any disagreement between a married couple to do with the upbringing of children. People do not necessarily abandon their commitments when faced with illness. Hence, I am in agreement with Strong's view (Strong 1979a) that the health of a child is important to parents but not to the exclusion of other aspects of family life.[3]

We are likely to hear parents appealing to similar notions in a dispute over the reluctance of a father to attend a meeting with teachers at the child's school. As we see in the above extract, one of these notions is Mr Fol's commitment to work which occurs, according to his wife, at the expense of pressing family matters. We should note how his lack of commitment is reflected in his failure to participate in the interview itself. Indeed, this failure precipitates the discussion about whether Mr Fol intends to be present at his daughter's operation. Whereas he is characterised and displays himself as calm, detached and rational (see utterances 9, 38 and 39), Mrs Fol appeals to her irrationality and emotionality as grounds for her husband being present (see utterances 38-44). In Chapter 2, we saw how discussions like this one have led investigators using a psychological model of familial adaptation to argue first, that such fathers avoid the reality of their child's situation, second, that mothers of this type are over-anxious and finally, that their marriages are under severe strain. I would suggest that these investigators are misinterpreting their data and that such conflicts and sex roles are part of everyday family life.

Although I have not examined in detail the role of work (and hence fathers) in parents' accounts, they typically took up this issue in a similar way to the Fols. Wives saw their husband's work as limiting the latter's involvement in family related affairs but nevertheless considered this as inevitable and legitimate. We should note how Mrs Fol, although critical of her husband, expresses her criticisms in an exasperated but jocular fashion as if she is appealing to the 'boyish' nature of men (see utterances 25 and 30). Thus characteristics such as involvement with work, detachment and rationality, far from indicating pathology, were used by both parents to demonstrate that there was a 'real' man in the family who, according to Mrs Fol, was therefore required to be present at his daughter's operation.[4]

The same role applied to emotionality in the case of mothers. Many unashamedly revealed how they came close to breaking point during periods when their child displayed severe symptomatic stress. The essence of their claim was that a mother has a right to react in this way and in making this claim they displayed their own maternal and feminine status. However, there was only one occasion when a mother displayed emotionality of this order during the course of an interview which does suggest the operation of a morality about when and where such displays are proper. Clearly, in public situations, like the research interview, it is acceptable to talk about but not to express emotional feelings. This finding parallels Strong's observation of the infrequent expression of emotions in paediatric clinic encounters between doctors and parents (Strong 1979b). On the occasion referred to above where a mother broke down during an interview held at the heart unit, it was clear that the interviewer had gone beyond what was acceptable in pursuing certain sensitive topics when her child had recently undergone open heart surgery. The extent to which the interviewer's conduct and the expression of emotion was held to be improper was reinforced by the way the interview was precipitously terminated.

There are other arguments why such displays and talk about them should not be taken as evidence of mental pathology as investigators adopting a psychological model have argued. These concern the way mental illness is defined from a common sense point of view. Morgan (1975) shows how common sense definitions of mental illness are made according to whether a particular action can be explained. For instance, a divorced mother of two children living off social security payments who steals from a shop will be seen as deviant whereas a wealthy woman acting in the same way will be defined as mentally ill since there is no other way in common sense terms to account for her action. In other words, in the first case we hear a norm which connects poverty with stealing which cannot be applied in the second example.

My earlier research work in psychiatry provides rich anecdotal evidence supporting Morgan's analysis (Baruch and Treacher 1978). In interviews, psychiatric patients either were unable to explain their actions and affective states or put forward explanations which, from a common sense point of view, were clearly unsatisfactory. For instance, one patient accounted for the occasion when she entered her grown-up son's room at night and held a crucifix above his head by suggesting that she wished to drive out his homosexuality which was the work of the devil. While there may be some coherence to this explanation, members of society are likely to associate such conduct with mental illness. On the other hand, parents' descriptions of their affective reactions to features of the child's illness were reasonable in terms of the norms which explained the relationship between the two.

My argument is strengthened when we compare the only instance of mental illness admitted by a respondent in the present study to the way parents typically described their reactions. This respondent reported how she tried to jump off a bridge and drown herself; removed her living-room furniture into the garden; dyed her hair orange; and posted a hamburger and peas through her neighbour's letter-box. She said she was mad at the time and that it was necessary for her to be admitted to the local mental hospital. Clearly, this response is of a different order from the reactions we identified in earlier chapters.

In distinguishing between members' accounts of mental illness and affective responses to a seriously ill child, I am not implying that these responses are heard as more moral than the former. Accounts produced by psychiatric patients are heard as moral because the hearer shares with the patient the understanding that his actions, although sometimes anti-social and dangerous, occur as a result of being ill, i.e. he is not held responsible for them.

To sum up, the objection that the picture of family harmony presented here is not credible and family life outside the interview displays the features which psychological accounts propose has been countered on the following grounds. First, as Voysey (1975) argues, the distinction between public and private may be less clear-cut than is assumed since the child's illness invites the attention of outsiders into situations normally considered the province of the family. Second, parents report problems within the family and sometimes display disagreements during the course of the interview. Third, these problems and difficulties are presented from the point of view of what any family may experience. Hence they are not seen as pathological. Finally, some data were presented to show how members of society distinguish between distress and pathological reactions.

I now want to consider some criticisms of the type of evidence I have used to support my analysis. Although this may lend the conclusion an arid appearance, I think this is justified for the following reasons. Usually, discussions concerning the warrant for the investigator's treatment of his data are not given a great deal of importance. Either they are relegated to a methodological appendix or the issues which require a proper consideration are taken for granted. However, as any researcher who has presented the findings of an empirical enquiry knows, the substance of his account is frequently ignored in favour of a critical examination of its methodological character. This is also the case when research proposals are scrutinised by his peers. These remarks are especially true of qualitative research and are captured in Blaxter's observation that 'As interpretative sociology develops, standards have to be negotiated and procedures examined for their acceptability...' (Blaxter 1979 p.650).

Let us commence this process by considering a claim which was not central to my findings but one which could arouse a great deal of dispute and so obscure other aspects of the analysis. Throughout the presentation of the empirical data, I have argued that the use of devices like 'you know' and generally, the use of the 'you' voice is one of the ways in which respondents appeal to an intersubjective world shared by them and hearers. It can be objected that such devices bear little relationship to intersubjectivity and that their meaning has been arbitrarily imposed by the investigator. Rather, they reflect the way members of social classes have access to different linguistic codes. Thus working class parents are more likely to use these devices than middle class ones since, as Bernstein (1961) argues, they are restricted to a public language. However, a comparison of interviews administered to middle class parents with those administered to working class ones reveals no difference in the members who invoked these devices.[5] Hence, the sense must be understood in terms of the role they play in the interview. The evidence for treating them as intersubjective is based on the way parents frequently used them in ending and truncating utterances thereby appealing to the hearer's knowledge to complete the sense of the utterance. I cited a number of instances of this procedure in the preceding chapters. I would also add that parents' uses of the other voices, especially 'I' and 'they', were as purposeful as the use of 'you' in the construction of their accounts and, as I have shown, sensitivity to their uses by the investigator can have a great deal of analytic value. For instance, in Chapters 3 and 4, we saw how the conflict model of parent-doctor relations, the parties being constituted respectively as 'I' and 'they', gave way to a more co-operative model in which parents often referred to themselves as 'we' in a relationship with a single doctor, 'he'.

The most important objection to my analysis, and potentially the most damaging one, concerns the warrant for treating parents' responses as moral accounts. Although there may be a vigorous theoretical tradition which supports this perspective, the investigator is nevertheless required to provide an empirical justification. This common criticism of qualitative analysis is one which I have made of related research in previous chapters. The essence of the criticism is that the investigator selects data which support his theoretical orientation and that the findings cannot be replicated. It should be clear that throughout the analysis of parents' responses, I have been concerned to develop a rigorous methodology which is summarised below.

The central assumption is that the interview is a social situation in its own right with its own form of social organization. Thus what parents say has been considered as a response to this situation. The attention given to the role of the interviewer's questions, remarks and observations in the discussion of particular topics is consistent with this perspective. In effect, I am suggesting that the interviewer and respondent work together to produce the accounts we have analysed.[6] This observation may be stating the obvious given recent developments in sociology but it is remarkable how many studies still either pay lip-service or completely ignore the situated nature of accounts.[7]

At the same time, I am not implying that what transpires in the interview is isolated from the rest of social life. Following arguments developed by Voysey (1975), I assume that parents draw on a culturally available stock of knowledge which is prescriptive in so far as it specifies how parents ought to behave in given situations. As Dingwall (1976) has argued, 'Social orders are necessarily also moral orders. Social actors are moral agents' (p.72). Unlike Booth (1978) who sees this perspective as one which suggests that parents' remarks are determined[8], I argue that cultural attitudes are like a pool of stereotypes which are picked out to suit particular interpretations. This was especially evident in respondents' responses to a disfigured baby. As we have seen, parents of disfigured boys appealed to their good fortune in not having a girl with a damaged appearance since they held that appearances have a greater effect on a girl's life chances than those of a boy. On the other hand, parents of girls did not comment on the relationship between gender and appearances. One mother claimed that having a daughter was a source of joy after having three sons. Thus the irony is that parents present personal experiences in terms of stereotypes.

The substance of my view and findings differs to a certain extent from that of Voysey (1975) who tends to underestimate the availability to parents of meanings other than medical ones for defining the status of their child. In parents' accounts, they did not relinquish everyday conceptions of the baby and the child in favour of the medical diagnosis. Indeed, it can be argued that their moral status as parents would have been doubtful had they done so since they shared with the interviewer the understanding that conditions like congenital heart disease and cleft palates/ hare lips did not prevent their offspring from having and acquiring many of the attributes of peers.[9]

There are three types of evidence I used in analysing parents' accounts as displays of moral adequacy. First, I showed how these displays were constructed from norms. The quantitative application of Sacks' proposal regarding the importance of norms for the making and hearing of descriptions revealed that the most frequently used norms in the initial story presented by parents concerned their expectations, rights and duties in relation to children and health professionals. The next most frequently used norms concerned the rights and duties of health professionals in relation to children and parents. These findings provided the grounds for the subsequent qualitative analysis of respondents' accounts since they are based on a method which allows them to be replicated. Ideally, I would have preferred to apply this method to all the interview data collected in the study but this was not possible for the reasons I mentioned in Chapter 2. I consider the quantitative application of Sacks' idea an advance in the analysis of semi-structured and unstructured interview material since it undermines the common accusation that the analyst has been selective in his use of data.

The second type of evidence was Cuff's notion of 'determinate possible alternative account' (Cuff 1980). Cuff is mainly concerned with the application of such accounts when the member of a unit blames someone who is not present for an untoward occurrence. If the member's version is to be heard as morally adequate, then he is required to consider his own involvement in the event under discussion. I used Cuff's formulation in this way but also extended it to cover discussions which did not necessarily involve blaming an outsider. For instance, mothers used three types of alternative explanation in considering the causes of the child's illness which did not necessarily have any implications for anyone except themselves. Hence, it can be argued that for an account of an untoward event to be heard as morally adequate, the respondent is required to consider competing explanations regardless of whether an outsider is being blamed.

The third type of evidence used in the qualitative analysis of the data were instances which deviated from the regular features of an account. This statement requires elaboration. It is clear from the preceding chapters that I have considered it important that the characteristics of particular topics should be representative of the sample from which the accounts are drawn. In other words, I have not only been interested in showing their cultural availability but also the extent to which such features are used by respondents as well as how they use them. This approach differs from that put forward by Locker (1979) who claims in his study that one sample member would have done equally well as six in providing generalisable data on the way members account for illness episodes. He supports this claim by arguing that he is interested in establishing 'the constituents of a stock of knowledge at hand that is available to members of a culture to organize and make sense of their experience. This does not mean that it is used merely that it is available to use. What is described then is a common frame of reference' (p.414).

Now this argument may appear very proper from a theoretical point of view but it does not justify a sample membership of six respondents let alone one respondent. Indeed, such arguments can be used to gloss poorly designed research. While the investigator may justifiably reject the rigorous standards of quantitative research, he must adopt some standard of a quantitative kind in establishing generalisations about cultural availability. The reason for this is that in order to determine the understandings which are available it is necessary to establish their nature by investigating members' use of them. The research interview is as much about members' practices as are the situations which they describe. Hence, generalisations about cultural availability are strengthened the more the investigator shows which understandings are broadly distributed within the accounts of the sample membership. Once one accepts these arguments then the idea that a study of parents' responses to congenital illness or of the way members account for illness episodes can be built on a sample membership of one appears absurd.[10] A sample membership of this size does not allow for the possibility of identifying variance in respondents' accounts. In other words, it is unlikely to produce a certain type of evidence which supports general claims made by the investigator about the accounts of particular topics. Here I am referring to the deviant case, an example of which was established in the quantitative analysis of norms in Chapter 2. In subsequent chapters, the best examples of such cases occurred when there was a breakdown in the discussion between the interviewer and respondent about topics such as the causes of the child's illness and the doctor-parent relationship.[11]

In summary, Locker's propositions concerning the generalisability of results not being related to the size of the sample membership are faulty because they confuse theoretical with empirical issues. While it may be valid to argue from a theoretical point of view that members of a culture invoke a common frame of reference, it cannot be claimed that this frame of reference is available to members of a particular group unless the extent to which it is used by respondents is shown. It is ironic that those who are most critical of positivist research because it fails to take account of the way members of a culture interpret their world are open to the same criticism in this instance. I suspect that members would expect generalisations to be based on a sample membership of more than one.[12]

Of course, the sample in this study was not constructed with the rigour of quantitative research which bases its generalisations on a large sample from a defined population. However, the parents of twenty-seven families participated in the study and, as I indicated in Chapter 2, their accounts are remarkably similar to those produced by parents in studies of different childhood illnesses. Hence I have reason to believe that if my methods of analysis are judged to be sound then a number of my findings may be extended to parents' responses to serious illness other than congenital heart disease and cleft palates/hare lips.

Finally, it is worthwhile emphasizing the importance of a longitudinal design in supporting the analysis of parents' accounts, particularly those concerned with the doctor-parent relationship. We saw how their accounts varied according to the child's stage of treatment. The conclusion which must be drawn from this is that further study of the doctor-parent/patient relationship must take account of its longitudinal dimension. The findings from this study parallel recent work carried out by Silverman (1980a) on doctor-parent encounters which documents their variance over time according to a number of variables.

The final objection I wish to consider claims that the findings are trivial, a charge which, as Strong (1979b) points out, is often levelled against micro-analysis. Here, the charge may be that the analysis has merely shown a series of legitimations and justifications. At this stage, I do not intend to counter this objection by reiterating the theoretical and empirical arguments which have been produced during the course of the thesis. Instead, I shall oppose it from another point of view: namely, the practical conclusions which can be drawn from the study.

III Policy Implications

Let us summarise the areas of difficulty that parents describe. They include:

(a) problems at the start of the child's medical career when parents are inexperienced in the medical aspects of the child's welfare and at dealing with hospitals and health professionals. These problems were referred to in Chapters 3, 5 and 6;

(b) difficulties which parents and young children experience regarding the first hospital admission which were discussed in Chapter 6;

(c) issues arising from the causes of the child's condition which were explored in Chapter 7.

Before examining some practical responses to these areas of difficulty, it would be wise to state the limits of the contribution which this study can make. It cannot make any recommendations to do with inpatient care, although several are concerned with the family's preparation for such care. It would be improper for an interview study to be the basis of such recommendations when there are other research methods, like intensive observation, which are more appropriate for documenting ward life. Indeed, there are a number of excellent studies dealing with this topic.[13] Thus the contribution presented here is mainly concerned with the family's needs prior to inpatient care.

To begin with, let us compare my proposals with those based on another perspective. As has already been noted, psychiatry has been influential in paediatrics in helping parents and children to overcome their difficulties. The essential feature of the psychiatric perspective is to encourage parents and children to communicate their 'real' feelings about their situation using various techniques. The ideas of Friedberg and Caldart (1975), which were briefly mentioned in Chapter 6, show how such techniques may be used. A nurse educator helps the family prepare for cardiac catheterisation and surgery by using puppet work-book techniques and by holding meetings at which hospital procedures are explained to parents who also meet the members of staff. At the same time, the nurse educator keeps in close contact with a child psychiatrist. Parents and children who are unduly anxious are detected early and then treated by the psychiatrist in order to prevent more serious psychiatric conditions from occurring.

The idea of using techniques administered by an expert in order to encourage communications is similar to that of the Human Relations School of Industrial Relations. Silverman's criticism of 'human relations for looking for easy answers in the form of techniques instead of questioning an organisational structure which may be at the root of the problem' (Silverman 1970 p.76-77) is equally relevant to the use of psychiatric techniques in paediatrics. I want to make it clear that I am not deriding the use of puppets and similar methods to help children adjust to hospitalisation. Rather, it is the manner in which such techniques are administered and the underlying assumption that parents and children are always on the verge of a breakdown which are dubious for a number of reasons. First, we have seen how research informed by this assumption fails to take seriously parents' accounts of their situation which rarely reflect the experience of mental breakdown. Second, the manner in which these techniques are delivered involves rupturing the relationship between parents and their child since the expert rather than the parent administers them. Moreover, it appears that the expert is empowered to make decisions about the health of the family, possibly without their consent, so further intruding into the affairs of its members. Finally, the idea of preventing serious psychiatric reactions is the product of a model of parental responses which arbitrarily takes anything they say or do as a demonstration of abnormal familial or psychological adjustment.

The implication to be drawn from this critique and the analysis of parents' accounts is that practical responses are required which are rooted in changing or introducing organizational structures. I say structures rather than ways of interacting since I hold that it is the responsibility of the participants to work these out. Before examining in detail the practical consequences of one such proposal, let us consider what this means in relation to some of the suggestions I made in the previous chapter concerning the causes of congenital illness. I argued that prospective parents should have the opportunity to attend ante-natal care earlier than they do at present so that they can find out what kinds of activity and substance to avoid or take in moderation during the first trimester of pregnancy. I also suggested that information which explains the dangers to the foetus of such activity and substances should be made available so that prospective parents can judge for themselves how to conduct the pregnancy. At present, they are warned about the dangers with little or no explanation. The essential feature of these proposals is that a change in organisation is suggested, the uses of which are determined by the participants. Unlike psychiatric approaches, consulting styles of health professionals play no role in them.

I now want to describe the working of a proposal implemented by the paediatric cardiology unit and currently being studied by a team from the Department of Sociology at Goldsmiths' College.[14] This policy initiative was based on the interview study reported here and an analysis of outpatient consultations carried out by other members of the team (Silverman 1980a, Hilliard 1981b). As I stated earlier, parents' difficulties mainly arose at the start of the child's medical career, and included their inexperience in the medical aspects of the child's welfare; at dealing with hospitals and health professionals; and at preparing both themselves and the young child for the first hospital admission. The outpatient study supported by findings from the interview study showed that the initial outpatient encounter at the specialist unit was an unsuitable setting for parents to raise problems, mainly because so much time was taken up with the medical affairs such as establishing the probable diagnosis and treatment programme and selling this to parents, especially to those whose child was asymptomatic. The problem for parents was that there was no way they could redress this state of affairs with the specialists until the child was admitted for cardiac catheterisation, sometimes several months after the encounter.

The research team proposed establishing clinics which would take place during the period between the initial outpatient encounter and the child's admission to hospital. Each clinic would be run by a Senior House Officer (SHO) and be devoted to parents' problems and queries unlike a typical outpatient consultation. These experimental clinics have been running for just over a year with a number of families being invited to attend them (each family only attends one clinic).

My intention here is to describe how the clinics have evolved, rather than presenting objective evidence regarding their effectiveness. This is not possible since the study is still being carried out. However, I believe the description of their development provides considerable support for my view of policy initiatives. From the research team's point of view, it has been fascinating to observe how staff, parents and children have used the basic encounter in ways which we secretly hoped for but never had the courage to propose due to the practical problems they posed.

Let us start from the point at which the letter of invitation is sent to the family. This involves the consultant paediatric cardiologist's secretary establishing those patients who require cardiac catheterisation for the first time following the weekly out-patients. Parents who decide to accept the invitation reply by telephone, arranging an appointment on the morning during the week in which a clinic is held.

Unlike the site of outpatient encounters, the clinic is held in a room on the ward in which the child will stay when he is admitted. When parents arrive, those who bring young children are directed by the ward clerk to the playroom run by a member of staff while they wait for the SHO. Parents who bring a baby are directed to one of the rooms in which babies sleep and are attended to by a ward sister. In both these settings, we have observed how parents request and obtain a great deal of information to do with the practicalities of looking after their child when he is in hospital which they would probably consider too trivial to ask a doctor, even a junior doctor. Moreover, the children soon become involved in the activities of the playroom and so acquire an unfrightening impression of some of what they can expect when they are admitted. Often, they stay there while their parents see the junior doctor. Although they mainly discuss medical topics, the discussion differs from an outpatient encounter since parents have the opportunity to explore matters like the child's condition, its relationship to other illnesses and the nature of the investigative procedure at some leisure. They also confirm with the doctor whether they can stay in the hospital when their child is admitted which, as we saw in Chapter 6, was a source of anxiety for some parents. Those who require assistance from social services take the initiative in obtaining help from the SHO in arranging this with one of the hospital's social workers. Usually, they are seen by a social worker following the encounter with the doctor. Finally, the SHO shows the parents around the ward and the paediatric intensive care unit if it is known that the child will definitely require surgery.

As I pointed out earlier, at this stage of the experiment, I cannot produce any evidence which objectively demonstrates that parents and children who attend these clinics are better off than those who do not. However, the above account does provide strong grounds for my argument that policy initiatives should concentrate on the ~~give t~~he kind of ~~participant~~s organisational structures, which allows participants to innovate in terms of their own self-conscious needs. t~~he uses of which they determine.~~ In this case, the research team only proposed a new type of clinic. This gave health professionals, parents and children the opportunity to add a number of other practices which we can assume were initiated because they saw them as appropriate and beneficial. A comparison with policy initiatives based on a psychiatric perspective is striking. First, such initiatives threaten the integrity of the family by removing from parents some of their functions in relation to the sick child and passing them on to experts. The experimental clinic augments and supports the parental role. Second, psychiatrically-oriented initiatives implicitly cast doubt on the mental health of members of the family, unlike the experimental clinic. Third, as I argued in Chapter 6, these initiatives tend to assume that every aspect of family life is deleteriously affected by the child's illness whereas the staff responsible for the running of the experimental clinic limit their involvement to those aspects brought to their attention by parents. As we have seen, these mainly concern the medical aspects of the child's welfare. Finally, the clinic and the other initiatives do not require another expert, like a psychiatrist, or for members of staff to be trained in new techniques. Rather, they apply and develop their expertise in a different setting.

Earlier, I suggested that one of the possible objections to the interview study concerned the triviality of its findings. However, I would claim that this study far from being trivial, has produced securely established policy implications because it is based on a rigorous methodology. Of course, there are practical reasons concerning the ever-diminishing availability of research funds why sociologists should seek to make a contribution to the running of the organisation they study. As I have shown, this does not mean the investigator is required to disown his allegiance to his perspective. Indeed, there is good reason to believe that a perspective, like the one adopted here, which advocates organisational changes is likely to be far more meaningful to institutions like hospitals, than one which proposes new ways of interacting with people. First, health professionals have little or no inclination to become involved with sophisticated methods of interaction. Second, where such methods do succeed their success often depends on a strong personality winning the support of his colleagues. The trouble is that once he leaves the institution these methods collapse.[15] The policy proposal described here has continued to work without the involvement of the senior members of staff and even though a number of SHOs have left the paediatric cardiology unit and have been replaced by doctors unfamiliar with the experimental clinic.

IV Further Research

In Chapter 2, I argued that the theoretical and methodological approach used in the analysis of parents' responses can be applied to familial responses to other medical conditions. Let us examine its relevance to mental illness and a serious adult illness, like cancer.

In their classic study of the social origins of depression in women, Brown and Harris (1978) have suggested that 'In future work, ... we need to look in far more detail at the way women think about and experience their depression. It is important to know, for instance, how many women describe characteristic symptoms such as slowness and lethargy in apparently moral terms such as "laziness" ' (p. 273). I have already commented on the nature of the accounts produced by psychiatric patients and instead, shall extend Brown and Harris' suggestion to cover the family's reaction to mental illness in one of its members, particularly before coming into contact with the psychiatric services.

Although there are a number of studies which have examined this issue (Radke-Yarrow et al.1955, Mechanic 1967, Goffman 1968a), none have approached it from the perspective of treating accounts explicitly in moral terms. Like research on familial responses to a seriously ill child, they have taken them as factual descriptions of events or have examined the relatives' behaviour from a psychological standpoint or have sought to identify the variables, such as social class, which affect the final outcome of hospitalisation. Also like this research, these studies and my own work in this area reveal remarkably similar findings regardless of their perspective. They show that the prospective patient is reluctant to seek psychiatric help and how relatives are equally reluctant to influence him in obtaining such help. Instead, they constantly extend the boundaries of 'normal' behaviour in a number of ways in order to interpret his increasingly bizarre conduct within this framework, until this becomes impossible.

Let us briefly consider relatives' accounts as displays of moral adequacy. I would argue that accounts of the prepatient phase are a response to the moral question 'How could you, as a relative of the patient, have encouraged him to seek psychiatric treatment?' Now, this may seem somewhat absurd since encouraging someone who is ill to seek treatment is usually considered as appropriate conduct. However, the cultural meanings attached to mental illness and hospitalisation have a long history of being associated with stigmatization which is evident in respondents' accounts. For instance, the local mental hospital is often described as having a frightening reputation. Also the respondent and interviewer share the understanding that the prospective patient does not want to have anything to do with mental hospitals. Thus relatives' descriptions of how they constantly interpret and re-interpret the prospective patient's behaviour in normal terms rather than as evidence of mental illness can be read as 'determinate possible alternative accounts'. They are allowing for the possibility that if they reported that they took the first sign of such behaviour as indicating psychiatric disturbance, then their moral status would be open to question. It is also striking how the relative consistently appeals to the way he sought advice from an outsider, like a local priest or a member of the extended family who is close to the prospective patient, as a way of legitimating this decision before making an appointment with the psychiatric services. Other ways in which relatives establish their good character include relating stories which describe how they willingly put up and fall in with the demands of the prospective patient even though they appear unreasonable from a common sense version of normality. For instance, in my previous study the husband of a patient described how he painstakingly deferred to his wife's constant complaint that the kitchen floor was dirty by removing the cooker from against the wall on numerous occasions so that she could examine an area of floor which had been hidden from view. In making such descriptions, the respondent is not only providing evidence of his good character but is also demonstrating that his wife has an unsound state of mind by using devices which Smith (1978) has called 'contrast structures'. I would describe these structures as the inappropriate use of a norm. The second action (e.g. removing the cooker from the wall several times) of a pair of actions is heard not to follow on from the first action (e.g. questioning whether the floor behind the cooker is dirty) given the norm which the description of this action provides.

Over the last thirty years, there has been an abundance of sociological research into mental illness and the family concerned either with the role of family processes in causing the illness or with its role during and after hospitalisation. Nevertheless, there is still room for further longitudinal studies of the type described here since advances in methodology can provide new and refreshing insights into family's responses to mental illness. There are also practical reasons why such studies are required. These concern the changing pattern of treatment of certain childhood and adult conditions. Like the treatment of congenital heart disease and cleft palates/hare lips, the treatment of mental illness nowadays does not involve patients spending long periods of time in hospital. Rather, they typically require short term inpatient care and are then monitored in outpatients. As I mentioned in the Introduction, this change in policy was one of the reasons for conducting my earlier study.

A similar change in policy has taken place in the treatment of some other adult conditions, including cancer, and physicians wish to know how patients and their families cope in the community. At present, there is little empirical work documenting their experiences apart from research based on a psychological model. The approach evolved during the course of the present study can contribute to this area in establishing the type of moral framework patients and relatives invoke in describing their experiences. For instance, in Chapter 5 we saw how parents allocated a major role to the baby's appearance in defining his status and to the interactional difficulties they encountered in the maternity hospital and in the community. Likewise, we can expect cancer patients who are undergoing several courses of chemotherapy and their relatives to take up the issue of appearances since one of the side effects of this treatment involves the patient losing all his hair. Of course, this matters while he is in hospital but at least he shares a common identity with his fellow patients. However, this is not the case in the community and it would therefore be relevant to know how the patient and members of his family account for this experience.

As we have seen in this study, accounts of such experiences are also interesting in terms of the light they throw on features of everyday life which well people take for granted. A longitudinal interview study of the careers of cancer patients and their families is likely to take us into areas, such as employment, sexual matters ans social life which are rarely, if ever, discussed by parents of ill children. Finally, it is also likely that a study of this nature will have a number of important policy implications.

In summary, the present study provides a basis for further research into familial responses to illness using interview data. Apart from methodology, its strength lies in the way family functioning is considered within a normative framework rather than within a context of pathology.

V Concluding Remarks

As Strong (1979b) has suggested, there is a considerable difference between the type of sociology which seeks to make detailed empirical descriptions of social life and 'the sociological urge to explain the world in a swift paragraph' (p.183). If the former is to be carried out effectively, then the researcher is required to suspend the judgements inherent in the latter. This is not an argument in favour of the kind of variable analysis which fails to address forms of discourse and the contexts in which these arise. Throughout this thesis I have been critical of those approaches which do not take parents' responses seriously or the context in which they are made. Certainly, theorising, as Dingwall (1976) has said, 'is a necessary preliminary to any worthwhile practical empirical enquiry...' (p.160) since it is impossible for the researcher to orientate himself to his data, especially qualitative data, without some framework. However, he must be prepared to revise his ideas in the light of the data. This implies the need for painstaking work when analysing interview material otherwise the researcher is liable to find himself selecting evidence to suit his arguments rather than his arguments being based on the evidence. I would like to think that this thesis, despite its imperfections, provides a basis for the continuing use of the interview as a respectable sociological method of documenting people's experiences.

APPENDIX

THE COLLECTION OF DATA

I Introduction

In sociology, there is a tendency to exaggerate the merits of new ideas and research practices and to condemn those which they seek to supersede. The rise of conversational analysis means that for some the research interview and the theories which support its use should be consigned to the sociological waste tip. The same was true when investigators attacked the standardised questionnaire for doing violence to respondents' meanings in favour of unstructured and semi-structured interviews. In each case, the chosen method is constituted as the ultimate research technique. This purist approach to the collection of data has much in common with the way some sociologists refuse to consider the practical implications of their work because they fear their theoretical and methodological perspective will be violated.

To many investigators, one of the advantages of the research interview is the way it allows respondents to express themselves in a relatively free manner so that 'accurate and unbiased accounts of anything complex or of emotional depth' (Brown and Harris, 1978, p.10) can be collected. I suspect that conversational analysts would claim that one of the merits of their method with its rigorous approach to verbal interaction in naturally-occurring situations, is the way the researcher is totally excluded except as an analyst from the setting being studied and therefore cannot interfere with its processes.

Of course, both these perspectives have their limitations as well as strengths. If sociological research limited itself to the recording of naturally-occurring material, then areas of social life would remain uninvestigated since this method must restrict access to certain situations. As we have seen, the research interview cannot be used in competition with what happens in the naturally-occurring settings which respondents report. The nature of the interview is properly captured by Voysey (1975) when she refers to Circourel's notion (Circourel, 1964) that 'Any research situation is a social encounter; equally every social encounter is potentially an interviewing situation' (p.72). One of the implications of this notion is that there is no justification in elevating the status of the unstructured or semi-structured interview on technical grounds above that of other research methods or vice versa.

In truth, practical as well as theoretical reasons often determine the choice of method. As I argued in Chapter 2, the most practical way of collecting data on parents' responses to their child's illness is by interviewing them. Methods which involve an investigator intensively observing and recording their activities for any length of time are unlikely to meet with their approval. Even if such permission was granted, the size of the sample membership is likely to be small since the manpower required would be beyond the resources of most research teams.

These are some of the considerations which informed the choice of methods for the Goldsmiths' College project funded by the Social Science Research Council (SSRC). Outpatient encounters were tape-recorded and data on the experiences of families were collected by administering semi-structured, tape-recorded interviews. Since I joined a research team, I did not encounter the problems faced by postgraduate students who carry out medical sociological research on their own behalf. Such students have to overcome a number of institutional barriers before they can commence field work. These barriers typically include obtaining consent for their proposal from the academic department's ethical committee; finding a medical setting; negotiating access to this setting; finding sample members; establishing contact with them, and so on. During this process, there is always the possibility that the student's proposal will meet with disapproval from those he depends on and so will require amending in ways which interfere with his theoretical and methodological perspective.

There are other barriers. For instance, if the study involves the collection of tape-recorded interviews, then there is the problem of transcribing the data. The student is unlikely to have any secretarial assistance and will therefore be compelled to spend a great deal of time laboriously transcribing the interview material himself. Finally, there are the problems of isolation and loneliness. These can lead the student to abandon his work or become over-involved with the members of the institution he is studying which can distort his research.[1]

These remarks are based on a comparison between the experiences of my earlier research work in psychiatry and those of the present study. I was extremely fortunate to participate in a project which because of its size, funding and organisation was able to overcome these problems relatively easily. Thus my description of the way the data were collected for the study reported here must be seen in the context of the project as a whole.

II The Institutional Settings

One of the conditions for the successful practice of empirical research is that members of the research team and those who run institutions are able to find some common ground. Rarely do their interests coincide without there being some negotiation and compromise over the aims of the research.[2] In this project, the leader of the research team informally established contact with a consultant physician of the Brompton Hospital paediatric cardiology unit. The latter was concerned that parents were not acquiring a proper understanding of their child's illness partly due to the sophisticated nature of congenital heart disease and partly because members of staff might not be passing on information to them in an appropriate manner. A research project was proposed to him involving a comparison of the impact of high and low technology medicine on families and their relationships with doctors. He helped the team liase with the consultant responsible for children with cleft palates/hare lips. In retrospect, the ease with which these doctors accepted the tape-recording of outpatient encounters as well as the overall research strategy was remarkable.[3]

As far as the conduct of the project was concerned, the members of the research team were given a considerable amount of freedom to pursue their study in the manner which they had chosen. However, there was a cross-fertilization of ideas. For instance, our interest in policy matters was partly influenced by the staff's desire to make use of our findings in assisting the adaptation of families. To a certain extent, the use of quantitative methods arose as a response to the senior members of staff's view of rigorous research. In other words, quantification was a way of making our findings meaningful to them. This does not mean that the qualitative analysis of discourse was abandoned or that quantification was unuseful to us in its own right. From the preceding chapters, it is clear that I found the quantification of norms strengthened the qualitative analysis of accounts and that an interest in practical matters did not mean abandoning my research stance. As well as proposing the experimental SHO clinic, members of the team presented their data to the staff of the hospitals on a number of occasions and also contributed to medical conferences where their work was treated both seriously and generously.[4] In summary, the co-operation between a research team of sociologists and the staff of the two hospitals proved fruitful.

III Finding and Establishing Contact with Families

The number of families

The number of families which participated in the interview study was determined by methodological and practical considerations. It was considered necessary to have sufficient members to establish any variance which might exist between the experiences of individual families. Thus on the basis of a pilot study, it was decided to include twenty families from each setting. However, the total sample membership, which comprised twenty-seven families, fell short of this figure for two reasons. First, the manpower and the time available was insufficient to conduct a series of interviews with the parents of forty families. Second, as I mentioned in Chapters 3 and 5, the number of new patients coming under the care of the consultant responsible for cleft palate/hare lip children in any one year was between five and ten. One of the objectives of the research was as far as possible to document the entire career of cleft palate/hare lip children and this could only be achieved by selecting a cross-section of children from each of the following age-groups:

0 - 3 years;
4 - 10 years;
11+ years.

A number of parents of children belonging to these age groups were re-interviewed so that some longitudinal data consistent with the overall research strategy was obtained. This strategy was more easily adhered to with the heart sample since the bulk of the child's career took place during the period of study although many children, especially those suffering from serious conditions, continued to receive outpatient care after the study had been completed. Tables 11 and 12 provide details of the sample membership.

Table 11

Parents	Child's Condition	Child's Age at Start of Study	Number of Interviews
Mr & Mrs A	Congenital Heart Disease	6 years	2
Mrs Bu		8 months	3
Mr & Mrs C		10 months	6
Mr & Mrs Dis		3 years	2
Mrs F		5 years	1
Mr & Mrs Fol		3 years	3
Mrs Hen		6 years	1
Mr & Mrs Ht		3 years	2
Mr & Mrs Lil		1 year	1
Mr & Mrs M		5 months	2
Mr & Mrs R		5 years	3
Mr & Mrs Rey		11 months	3
Mr & Mrs St		1 month	4
Mr & Mrs Wo		6 months	5
Mr & Mrs Wr		8 months	3

Total number of families = 15 Total number of interviews = 41

Table 12

Parents	Child's Condition	Child's Age at Start of Study	Number of Interviews
Mr & Mrs Al	Cleft palate/hare lip	14 months	2
Mrs Bi	" " " "	15 years	1
Mr & Mrs Ca	" " " "	5 years	1
Mr & Mrs D	" " " "	4 years	1
Mr & Mrs Du	Cleft palate	9 years	2
Mr & Mrs Fd	Hare lip	3 years	2
Mr & Mrs Fi	Hare lip	1 year	1

(Table 11 cont'd)

Parents	Child's Condition	Child's Age at Start of Study	Number of Interviews
Mr & Mrs Her	Cleft palate/hare lip	16 years	1
Mr & Mrs I	Cleft palate	5 years	1
Mrs Sm	Hare lip	1 year	3
Mr & Mrs Wa	Cleft palate/hare lip	12 years	1
Mr & Mrs Wl	" " " "	14 years	4

Total number of families = 12 Total number of interviews = 20

Details of the sample membership were also provided in individual chapters so that the reader could appreciate the source of the accounts used in the qualitative analysis of particular topics.

Loss of families and non-response

Some families were lost because they lived outside the area in which it was practical for us to visit sample members at home. Only one family refused to participate in the study and one set of parents, the Ms, understandably withdrew from the project after their baby had died. Generally, parents welcomed the opportunity to discuss their experiences and maintain contact with a researcher over a period of time.

Method of contact

Finding sample members required a suitable situation in which they could be identified; contact with parents was then made. The method of identification involved the researcher observing and recording outpatient encounters. At the paediatric cardiology unit, he noted those families which were coming into contact with the unit for the first time. As this was a longitudinal study, only the parents of patients in this group who required further investigation were considered potential sample members. As indicated above, age-related criteria were used to identify potential members of the cleft palate/hare lip sample.

Following outpatient consultations, we wrote to parents asking them whether they were interested in participating in the study, informing them that their remarks would be treated confidentially and would not be made available to the staff of the hospital in identifiable form. After parents had agreed to participate in the project either by telephoning or writing to us, a researcher contacted them to arrange a convenient time to interview them in their homes. Further interviews were usually arranged over the telephone following outpatient encounters and inpatient care or in person when the child was staying in hospital. These methods were satisfactory although telephoning was a hazardous affair on a few occasions. For instance, the Wos, who did not have a telephone, at one stage were contacted via Mrs Wo's parents. By this time, the condition of the son, Sam, had improved. When I telephoned Mrs Wo's parents and asked them to arrange a meeting with Sam's parents they assumed I was a doctor from the hospital and was concerned about his condition. Of course, this misunderstanding was quickly cleared up. Generally, contacting parents became easier as the study progressed since a level of familiarity developed between them and members of the research team.

Fathers

Unlike Voysey (1975) and Locker (1979), who only interviewed mothers, I decided that it was worthwhile interviewing fathers as well as mothers. Certainly, the analysis in the previous chapters provides support for this strategy. Only five fathers failed to participate in the study (one mother was unmarried). The fathers who were interviewed attended 67% of the interviews and their participation involved the researcher visiting parents' homes in the evenings since they were working during the day-time. They were mostly interviewed with their wife.[5]

IV Interviewing

The schedule

The interviews were semi-structured and tape-recorded. The questioning of parents followed the following format. At each interview, they were invited to present an account of their experiences. Following this presentation, the interviewer questioned them further about the topics they had raised in their account. The researcher only used the interview schedule (see below) in order to elicit parents' responses to issues which they themselves had not already discussed. Thus there was no standardized form of questions.

Schedule for Interviewing with Families

Interviews will be based around a chronological account of what has happened since our last interview or before our first interview. Initially, parents will be invited to provide an account of their experiences.

The interviewer will prompt or recapitulate so that the following topics will be covered:-

(i) socio-economic circumstances of the family:

These details will usually be elicited in asking about the arrangements for a hospital visit e.g. did you have to take time off work? Who was there to look after other children? How did you travel? etc.

(ii) first diagnosis of the child's illness:

- impact on family members including siblings
- parental or medical diagnosis
- any conflict between parental and medical opinions
- medical elaborations and/or explanations offered of diagnosis
- cause of condition
- other sources of parental understandings: relatives, other parents, books, media, etc.
- postiion of G.P. and local clinic if not already involved in diagnosis
- effect on child-rearing

(iii) referral to hospital:

How did decision on referral appear to parents?

Were they given grounds?

Were they given choices or options?

Was referral for a "second opinion" or definite treatment?

What was said by the referring agency about what was to happen next?

Was the future course of treatment specified or explained?

What was said about the hospital (unit)?

(iv) Visits to hospital (outpatients):

Who went?

Was agenda of day clear?

At what stage contacts made with other parents/hospital staff etc.

Expectations of the visit - problems or issues parents intended to raise.

What happened during medical interview?

Extent of parental diagnosis.

Why do you think he asked those questions?

Explanations offered by doctors.

Whose decision as to what to do next?

Child's reaction to visit.

Anything you would like to have said/happened, but didn't?

(v) between hospital visits:

State of child and the family.

References to G.P. etc.

Sources of information on child's illness (see (ii)).

(vi) operation and other inpatient stays:

Questions on whose decision, understandings of risk, agenda etc. if not already asked.

Chronological account of stay.

Use of facilities provided by hospital for parents.

How could they be improved (what problems encountered)?

Parents domestic arrangements.

Perceived relationships amongst medical staff.

Approaches made by and to medical staff concerning child and condition.

Contacts made with other parents.

Conditions of discharge.

This schedule was designed according to the findings obtained from a pilot study (see Hilliard et al. 1977) and the literature in the area. It is apparent that the items contained in the schedule assume that the purpose of the interviews was to obtain accurate data on the events parents reported. We have also seen that the way parents were questioned was based on another assumption which concerned the researcher's perception of family life with a seriously ill child. As I indicated in the Introduction, this consisted of the idea that serious illness has deleterious consequences for the child and his parents. These assumptions about parents' responses differ from those which informed analysis of their accounts.

In acknowledging this discrepancy, I am not implying that interview schedules are of no value. First, they provide the researcher with something definite by which he can orientate himself to the work in hand. Second, they give the interview a consistent format of a limited kind. Within this format, the interviewer and respondent work together to produce the accounts we have analysed.

The interviews

Having given a great deal of attention in the preceding chapters to the interviewer/respondent relationship in terms of the construction of accounts, I shall use this opportunity to describe some of the background features of the interviews. These include the way respondents interpreted the identity the interviewer presented to them; the form of the interviews; and the effect of the tape-recorder. These features contributed to the character of the interview as a social situation in its own right.

The interviewer took trouble to ensure that parents were aware of his status as a researcher who was not a member of the staff of the hospital at which their child was being treated. Nevertheless, parents interpreted his role in a variety of ways. Some parents saw the interviewer as a roving 'ombudsman' who was monitoring the practices of hospitals, his objective being to improve the treatment of families with sick children in a social rather than medical sense. Hence his role consisted of receiving their problematic experiences and suggestions and then reporting them to the staff of the hospital. The attribution of this role was not unreasonable.

A number of parents used the interviewer in a way in which he used them, i.e. as an insider who had access to important information which was not available to them. The particular issue which generated this role was the anxiety-provoking situation of the child's date of admission for cardiac catheterisation. Although parents knew the approximate time of admission, they were not informed of a definite date until a week before the child was due to be admitted into the paediatric cardiology unit. The researcher's first visit to parents usually took place before they were in possession of this information and so it was understandable for them to ask him if he knew about the child's date of admission. This usually occurred after the interview had been underway for about thirty minutes and after they had prepared the ground in such a way that the request appeared morally justified. The researcher usually obliged parents when he was in a position to do so.

Another way in which parents treated the interviewer was as someone who was entirely sympathetic to their situation and who did not mind them discussing their experiences at great length in a manner which was sometimes self-indulgent. Hence a level of familiarity developed between members of the research team and parents which manifested itself in a variety of ways. For instance, parents became acquainted with our circumstances and would ask after our families. Frequently, a modest meal was prepared for a researcher when he visited parents at lunchtime. Indeed, as I discovered, interviewing can be a source of much fun and pleasure especially when I recall the occasion I shared several bottles of wine with a couple during an interview which lasted over four hours. However, this was the exception rather than the rule.

Three researchers shared in the task of interviewing parents. One of them, my predecessor, was female and so there is some comparative data available on whether the gender of the interviewer affected parents' responses. Close examination of the accounts shows that this was not the case even when the female investigator interviewed mothers without husbands being present. The reason why the gender of the interviewer was insignificant was because the respondents constructed their accounts according to their status as parents. I suspect that had they concentrated on their status as wife or husband then the gender of the researcher might have been important. For instance, Locker (1979) discovered 'that common sense notions about what it is appropriate for mature women to discuss with young men influenced the topics they talked about' (p.418). However, in this study there was no evidence to suggest that such considerations influenced the topics parents discussed with the researchers.

Finally, we should note that parents attended to the interviewer's role as a researcher by asking him at the end of interviews how the project was progressing and when and where the findings were going to be made available. In asking these questions at the end of the interview, it was as if they were confirming the nature of their 'contract' with the interviewer, i.e. the source of their remarks would remain confidential and would not affect their situation in an untoward way.

The interviews were characterised by a specific pattern which I referred to in earlier chapters. Home interviews took between ninety minutes and two hours to complete, while those held in hospital lasted no longer than forty-five minutes.[6] The reason for this difference was related to the situation of parents in these settings. At home, they were mainly concerned with domestic matters and so could afford to give up a great deal of time, especially when the researcher visited them in the evening. However, in hospital parents were obviously anxious about their child's welfare and mothers were engaged in looking after their offspring. They willingly gave their consent to be interviewed since it provided a welcome distraction from the routines of ward life but this meant spending time away from their child. Thus interviews held in hospitals, which were fewer in number than home interviews, were truncated affairs.

The character of home interviews was as follows. The first half of the interview was formal, taking a question/answer format. Parents reported their experiences and the interviewer asked them to elaborate their responses. This part of the interview usually ended with the researcher announcing that he had no further questions to ask and with refreshments being offered. While one parent left the room to prepare them (typically the mother), the tape-recorder was left running and informal conversation ensued between the interviewer and the remaining parent. This conversational form continued when the other parent returned with refreshments. The content of the conversation was similar to that of the first part of the interview with many of the issues reported on earlier being recapitulated and elaborated with little prompting from the interivewer. This format was a consistent feature of the interviews throughout the study although it was more pronounced in first interviews.

Frequently, sociologists speculate about the effect of a tape-recorder on the collection of data, the issue being whether it inhibits and distorts the responses of the respondent. From my perspective, this issue is unimportant since a tape-recorder is merely another feature of the interview as a social situation in its own right, in terms of which accounts must be analysed. Tape-recording became a topic of conversation at the beginning of the interview when the interviewer sought permission from parents to commence recording; when a cassette tape required changing; when the interview was interrupted, for instance by a telephone call; and finally when parents asked the interviewer at the end of the interview what he did with the recordings. Apart from these instances, the tape-recorder did not figure as an object of discussion.

To sum up, I have described some of the background features of the interviews. In terms of analysing the data, it would be unwise to treat them as independent variables which determine parents' responses. Rather, they provide the context for their responses. If the researcher wishes to use such features to account for what parents say then he must examine the way they invoke them.

V Transcribing Data

Recently, the transcription of conversational materials has become a controversial issue. Conversational analysts, who have developed a rigorous approach to transcription, tend to view less rigorous approaches as inadequate for the purposes of analysis. However, I would argue that the standard of transcription depends on the researcher's analytic interest and also on practical considerations. Thus in a study not directly concerned with universal, formal issues of sequencing, transcription of the nuances of conversation is unnecessary although it would not be unwelcome. The practical considerations concern the resources available for transciption particularly in relation to field-work and analysis. In this study, had the materials been transcribed with the exactness demanded by conversational analysis, this would have detracted from the collection of data and the analysis of accounts. Most of the interview data were transcribed by a secretary employed on the project on a part-time basis and the researcher assisted her when the quality of the recording was poor.

VI Concluding Remarks

The advantages and disadvantages of qualitative methods of data collection, like the research interview, have been comprehensively discussed in methodology texts (see Denzin 1970, Richardson et al. 1975, Sjoberg 1968). However, as MacIntyre (1979) argues 'What has been less well covered in textbooks is how one actually sets about analysing such data once collected' (p.744). The thesis has addressed this issue by seeking to develop sound methods of analysis.

NOTES

Chapter 1 INTRODUCTION

1. In spite of this, the architects of this policy had no doubt about its efficacy. In 1971, Sir Keith Joseph said:

   > "Psychiatry is to join the rest of medicine... since the treatment of psychosis, neurosis and schizophrenia have (sic) been entirely changed by the drug revolution. People go into hospital with mental disorders and they are cured, and that is why we want to bring this branch of medicine into the scope of the 230 district general hospitals that are planned for England and Wales." (Hansard)

2. In their different ways, these authors documented the way psychiatry acted as an oppressive agent of social control.
3. I consider this matter in some detail in Chapter 8.
4. For psychiatric reviews of 'Psychiatry Observed' see:

   The Lancet (3/6/78);
   Nursing Mirror (27/7/78);
   British Medical Journal (16/9/78);
   Psychological Medicine (1979 9, p.387-389).

   For non-psychiatric reviews see:

   Nursing Times (19/7/79);
   Contemporary Sociology (May 1979 Vol.8 No.3);
   Third Way (January 1979)
   New Forum (Summer 1978).

5. See Chapter 1 (Baruch and Treacher, 1978).

6. See Freidson (1970a), Waitzkin (1979), Waitzkin H. and Waterman B. (1974), West (1976). The issue of medical dominance is examined in some detail in Chapter 4.
7. We shall also see that parents' accounts of their relationships with doctors vary according to the stage of the child's medical career. Whereas the early stages of the career are charactersised by conflict, accounts of the latter stages depict parents and doctors co-operating with each other.
8. Sometimes, such demands are made in conjunction with proposals aimed at giving a profession competing with medicine an equal slice of the cake. For instance, psychologists argue that they deserve equal status with psychiatrists in the mental health field (see Baruch and Treacher, 1978, Chapter 5 and Conclusion, Smail 1978). Of course, this proposal disregards the capacity of para-medical professional groups to be as 'exploitative' of patients as doctors themselves are claimed to be.
9. Atkinson and Drew (1979) take the view that sociology has been bedevilled by its over-eagerness to involve itself in practical matters, particularly with the way new moral orders are proposed without any reference to their association with particular forms of social organisation. While this judgement is perfectly acceptable, it does not mean that the recommendations of sociologists should therefore be limited to identifying the 'constraints on what is practically possible with reference to an empirically grounded knowledge of social organisation' (Atkinson and Drew, p.219). I would argue that it is

possible to propose new forms of organisation which are fully consistent with the moral position of the participants (see Chapter 8).

10. My position has some similarities with that of Dingwall (1976) who argues that "Pain, suffering and death carry powerful emotional charges. Cognitive sociology may help us to explain them. It should not involve us in explaining them away. The apparent objectivity of social events may appear epiphenomenal to us; to others it is massively real and massively painful". (p.159)
11. See Chapter 6 for a further consideration of these views.
12. About 8 - 1000 babies are born with some form of heart abnormality.
13. About 1 - 700 babies are born with a cleft palate and/or hare lip.
14. I should stress that the seriousness (or ugliness) of the hare lip varies from child to child.
15. For an account of how cosmetic surgery is negotiated at outpatient clinics see Silverman (1981c).
16. This paradox often goes unnoticed in studies of parental responses to a seriously ill child. The investigator does not go beyond the premise on which the collection of data is based. This premise assumes that parents are faced with numerous problems (see Chapter 2). This shortcoming is also found in those studies which seek to expose the 'real' nature of some aspect of social life previously considered unproblematic. I discuss this issue fully in Chapter 5.

Chapter 2 THE ANALYSIS OF INTERVIEW DATA: THE STATUS OF PARENTS' ACCOUNTS

1. In Rosenhan's study, a number of <u>bogus</u> patients presented themselves at several psychiatric outpatient clinics. They were diagnosed as schizophrenics and admitted as inpatients. Following their discharge, some of the hospitals concerned were informed of the study and told that further bogus patients would present themselves. In fact, this did not occur. Nevertheless, many genuine patients were treated as if they were bogus.

2. This perspective was presented to the researcher when he gave a paper on parents' responses at a conference organized by the University of Surrey (1981). A good example of its application can be found in the work of Menzies (1970) who interprets her findings on the social organization of nursing in a general teaching hospital according to psychoanalytic theory. Her discussion entirely ignores the social properties of staff organization and is resonant with statements like the following:

   > "Unconsciously, the nurse associates the patients' and relatives' distress with that experienced by the people in her phantasy-world, which increases her own anxiety and difficulty in handling it" (p.7).

   Two of the problems with this type of analysis are that first, it takes such interpretations for granted and does not demonstrate them and second, competing explanations are never considered.

3. The total number of interviews was 61. Each interview consists

of approximately 40 typewritten pages at 350 words per page. Certainly, in a large-scale project devoted exclusively to interviews, the researchers would be expected to analyse all the data in terms of its normative character. This is not possible for a single PhD student!

4. The following table shows the distribution of norms indicated by membership categories amongst the total sample membership (= 27).

	Sample	
Membership Categories	No.	%
Parent - Professional	27	100
Parent - Child	26	96
Professional - Child	17	63
Professional - Parent	13	48

Here again we should note the centrality of parenting when we might have expected to hear respondents emphasize norms relating to the medical aspects of their child's career.

5. The following table shows the distribution amongst the total sample membership of 5 most frequent norms shown in Table 3.

	Sample	
Types of Norm & Membership Categories	No.	%
Deferring to professional expertise (Parent - Professional)	21	78
Affective states and similar reactions to the child's illness and treatment (Parent - Child)	21	78
Affective states and similar reactions to professionals' judgements, decisions and actions (Parent - Professional)	19	70

Types of Norm & Membership Categories	Sample	
	No.	%
Action taken in relation to child's illness and treatment (Parent - Child)	17	63
Action taken and decisions made in relation to child's illness (Professional - Child)	15	56

It is worth noting that although the distribution within the accounts of the sample of 'deferring to professional expertise' and 'affective states and similar reactions to the child's illness and treatment' are the same, the latter norm is much more frequently heard.

6. See Extract 39 in Chapter 4.

Chapter 3 MORAL TALES: PARENTS' STORIES OF ENCOUNTERS WITH THE HEALTH PROFESSIONS

1. Inevitably, parents of older children were unable to provide detailed accounts of their experiences in the period just after the child had been born, although this period was usually the point of reference for the atrocity stories presented by this group. Moreover, over the years they had become accomplished at dealing with health professionals and the worst of their child's condition had been treated. Thus there were fewer instances of the atrocity story in this sample.
2. The significance of this for the presentation of atrocity stories is as follows. During the report stage, these stories often took a truncated form and then were repeated in an elaborate manner during the informal stage. I would suggest that

parents' conception of the interviewer had much to do with this. They knew we were carrying out a sociological study but considered that we were primarily interested in their views of the hospital service. Yet offering unreserved criticisms of the latter was initially problematic since they also knew we were connected to hospitals. However, it soon became apparent that we were sympathetically disposed towards their point of view. From an analysis of the talk, it will be seen that our utterances display us as members who share and affirm our respondents' everyday 'reality'. Thus the repetition and elaboration of their stories was in order.

Another feature of the presentation of the atrocity story to the interviewer was concerned with its ability to mobilise the interest and support of the hearer. I suspect that the telling of stories which characterise an individual as heroically struggling against and overcoming the powerful is a standard way in which we attract the interest of others in many different types of social encounter. Indeed, the telling of atrocity stories by a researcher will often be heard as a satisfactory response to a casual enquiry about his research. Here the moral display centres around the claim to be a competent researcher, able to ferret out the concealed underlife of an institution.

3. As I noted in Chapter 2, the form of the atrocity story remains the same when it is produced in subsequent interviews.
4. It is interesting to note that emotional responses are largely

attributed to mothers rather than fathers. One might speculate that this arises out of the nature of the interview situation. In developing an intersubjective reality, they appeal to this version of emotions since it is held to be more acceptable to their audience than one which locates emotions in the male world. I return to this issue in Chapter 8.

5. It is taken for granted by Mrs Al that her audience knows that this is her first child.
6. For example, at the time of writing, a dramatised documentary entitled 'Life for Christine' appeared on television which depicted the struggle of a social worker against the State in obtaining the release of a young woman who had been sentenced to stay in an institution for life under the Mental Health Act (1959) for deviant behaviour which clearly didn't warrant such punishment. Like our respondents' portrayal of themselves in their stories, the social worker was in a weak position in his relationship to the authorities but continued to seek the release of Christine in spite of their unresponsiveness. One of the aims of showing this play was to publicise Christine's case so that public opinion could be mobilised in her favour.
7. This observation parallels Silverman's claim that the use of the chaining rule by a consultant at a cleft palate/hare lip Outpatient Clinic gives him substantial power to control the topics discussed and the agenda of the encounter (Silverman 1981c).
8. Of course, on some occasions conflict between parents may take

the place of teamwork when one parent questions the other's definition of the situation or completely undermines it. (See Chapter 7 Section IV and Chapter 8 Section II).

9. Webb & Stimson (1976) identify the patient's unvoiced thoughts and feelings during or following a consultation as the mechanism whereby the imbalance in his relationship with the doctor is redressed when he tells an atrocity story (p.119).
10. See Chapter 8 Section IV for further discussion of these extra consultations.
11. A version of this chapter has been published (Baruch 1981a).

Chapter 4 PARENTS, DOCTORS AND THE SICK CHILD: DIVIDING RESPONSIBILITY

1. Mr A was a chemist and his wife was a nurse.
2. Unforunately, the current trend in the UK towards private medicine may increase the moral pressure on parents to opt out of the National Health Service.
3. BUPA claims that the recent increase in family subscriptions to its insurance scheme is partly due to the appeal of a TV commercial which depicts how private medicine cares for the whole family (The Money Programme 1982).

Chapter 5 THE PRESENTATION AND DISPLAY OF BABIES: PARENTS' RESPONSES TO DISFIGUREMENT

1. Oakley was well aware of this and in the last chapter of her book discusses the personal nature of the relationship between

her and her respondents.

2. In Oakley's study, this was precisely what was involved in being 'a good informant'.
3. Having said this, her study deserves fulsome praise. I suspect that the majority of mothers of normal babies reading her book would be in substantial agreement with the findings.
4. See Oakley (1981) Chapter 5.
5. Rycroft (1972) defines denial as a defence mechanism by which some painful experience is denied.
6. Oakley found that all her respondents relied on their mothers for advice on child-rearing matters. Moreover, they soon spurned the help of health professionals in becoming their own experts.

Chapter 6 MAKING CONGENITAL ILLNESS COMPATIBLE WITH CHILDHOOD: PARENTAL SOLUTIONS

1. In the interviews, there are some striking examples of parents treating their child as a non-moral person. Thus two parents justified the outrageous behaviour of their respective children towards coloured nurses on the grounds that they had never previously encountered coloured people!
2. For instance, they appeal to medical formulations when discussing the cause of the child's condition (see Chapter 7).
3. The accounts of parents of cleft palate/hare lip children were considered unsuitable because the child's contact with the specialist hospital is limited to an annual outpatient check-up between the ages of 1½ years and 12 years.
4. Step-by-step information flow does not occur in the context

of Down's children with heart disease or life threatened babies (see Silverman 1981a).

5. This extract shows why it is wrong to interpret interview data in a decontextualised way since Mrs R is responding to an issue implicit in the interviewer's question and not the question itself.
6. Where parents deviated from this morality in outpatient encounters, they would be censured by doctors in their absence. For instance, we observed one mother being presented with her baby by a doctor some time after it had been examined on the examination bed. Later the doctor cast doubt on her adequacy for not having picked up the baby herself. This was her first experience of outpatients and at a later interview she claimed that she had been given no indication that the examination had ended.
7. These would be similar to those presented by Mrs Fol in Extract 114.
8. The paediatric cardiology unit has already implemented clinics which take place after the child's first outpatient consultation and which are designed to attend specifically to issues raised by parents concerning their child's illness and forthcoming hospitalisation. For further discussion see Chapter 8.

Chapter 7 RESPONSIBILITY AND BLAME: PARENTS' INTERPRETATIONS OF THE CAUSES OF TWO CONGENITAL ILLNESSES

1. It is worth pointing out that these types of explanation are relevant in accounting for many events besides illness e.g.

car crashes, a house being burnt down, etc. Moreover, they are not necessarily confined to disasters.

2. The illnesses in Voysey's sample included: epilepsy; retardation; hole in the heart; spina bifida; Down's Syndrome; absence of gullet; meningitis; and hydrocephalus.
3. We should note the different ways parents use emotionality in their accounts. When they present their atrocity stories, emotion is seen by parents as a rational response, and is used to legitimate not fulfilling certain obligations. This contrasts with the use of emotion in their causal accounts. Also see Chapter 8 for further discussion of emotionality.
4. It is fascinating to observe parents' different situated uses of the medical profession in their accounts who are typically referred to as 'they'. In their atrocity stories 'they' refers to a group who fail to live up to everyday and, indeed, professional standards of conduct. In discussions about causality, apart from Mrs Hen's account, 'they' signifies figures of authority whose pronouncements are treated as decisive.
5. Sometimes, they elaborated their account on their own initiative at a subsequent stage of the interview but the content remained the same.
6. See Chapter 3 Note 2 for a discussion of the structure of first interviews and the Appendix.
7. This applied to Mrs Wl, Mr & Mrs Fow, Mr & Mrs Fi, Mr M and even Mr & Mrs R. It is consistent with the advice they received from the specialist hospitals.

8. 1 - 6 of all pregnancies end in spontaneous abortions. The percentage of first time pregnancies so terminated is greater.
9. Unfortunately, this has not happened. Parents and doctors have tended to concentrate on current issues involving the child's hospitalisation (see Chapter 8).

Chapter 8 CONCLUSIONS

1. A number of these objections were made when I presented material from the thesis to social scientists. Thus I am not erecting 'strawmen'.
2. The conflict is nicely reflected in this utterance by the unusual use of the 'we' voice. As we have seen, 'we' usually refers to the parental couple as a team. However, in this case it refers to the mother and interviewer and 'you' is the father who is treated as an outsider. Indeed 'we', referring to the parental couple, is never used during the discussion.
3. Strong (1979a) argues 'that doctors who perhaps over-rate the importance of medicine to their patients should not surprise us. We all like to dramatise our importance in this world and a little measure of self-delusion is surely necessary to engage in any professional work. It clearly is in medical sociology, indeed in one sense the victims of medical imperialism are not so much the patients as those who practise or study it, for they are all professional valetudinarians, only too prone to belief in the centrality of medical matters. Since medicine is important to them all

the time, they tend to assume that this must be so of others' (p.208).

4. I expect supporters of the women's movement would be appalled at my remarks about the roles of husbands and wives. However, in my defence I would argue that I am seeking to describe what is the case rather than what ought to be the case.
5. I suspect that this criticism is a reflection of the way middle class people (including myself) feel our use of language to be superior to those from a working class background. In saying that there were no differences between middle and working class parents in their use of these devices, I am not claiming that their social background was irrelevant for certain types of response. For instance, it was apparent that although middle class parents of heart diseased children used the technical language associated with the condition, they were not sufficiently competent to understand the complex nature of the working of the heart from a medical point of view. On the other hand, working class parents used this language less frequently and instead adopted a plumbing model of the heart, the principles of which approximated more closely to its functions than the methods used by middle class parents. This fits in with the way the latter often made a display in the interview of being thoroughly involved and conversant with the medical technicalities of their child's situation while working class parents openly admitted they did not have such pretensions.
6. A parallel development has taken place in social psychology

regarding the status attributed to interview generated data. For instance, Farr (1977) uses Heider's notion of attribution (Heider 1958) in arguing that Herzlich's claims regarding respondents' representations collectives of health and illness are to be understood in terms of the psychology involved in giving accounts about favourable and unfavourable states of affairs which involve the respondent. Herzlich (1973), following methods developed by Harre and Secord (1972), collected a number of naive unnegotiated accounts about the individual's perception of health and illness and found that health was held to come first and foremost from the individual whereas the source of illness lay in the way of life which was experienced as external to the respondent. On the basis of Heider's theory, Farr argues that there is 'a tendency for unfavourable outcomes (in the present context, illness) to be attributed by informants to the environment and for favourable outcomes (i.e. health) to be attributed to the self. Heider suggested this was true in regard to success and failure. Herzlich's work can be interpreted as providing convincing evidence that this tendency is also present in person's conceptions of health and illness' (p.494). Although this is a rather simplistic view, nevertheless it seeks to take account of the processes involved in giving accounts.

7. This is particularly true of research which I referred to as managerialist in the Introduction. A large-scale study of the development of under threes in atypical settings currently

being carried out by members of a major research institution is a pertinent example. Broadly speaking, this project seeks to establish the nature of child-rearing practices and their effect on child development in a number of different family settings including one-parent families and families where both parents go out to work by collecting interview data and by observing parent-child interaction. It is proposed to treat the findings as indicative of the respondents' actual behaviour in situations other than the research setting. However, it can be argued that their responses are likely to take account of the way their competence as parents is being examined. This is especially true of single parents whose activities come under greater scrutiny from agencies of social control than those of parents of typical families. My remarks also apply to the observation of parent-child interaction. In another connection, I have carried out over thirty of these observations both in the home and in paediatric settings. It is striking how much mothers of infants are pressurised by the presence of an observer both to produce displays of being competent at child-rearing and reports of morally adequate parenthood. This pressure is augmented by the largely unpredictable nature of infants and children who cannot be relied on to support these dipslays.

8. Booth (1978) wrongly interprets Voysey (1975) as saying that parents' definitions of their child's illness are foisted 'on children by the arbitrary decision of professional diagnosticians' (Booth 1978, p.221). Although her argument sometimes gives the appearance of a cultural determinism, she specifically

rejects this way of understanding parents' responses. Her view is that parents have few ways available of defining their child's status, apart from using the medical diagnosis.

9. This view of the child was made available to parents in outpatient encounters with the specialists who encouraged them to treat their offspring normally despite his illness. However, as I argued in Chapter 6, parents were left the difficult task of deciding what this meant in practice.

10. To be fair to Locker, he does not conceive the unit of analysis as being the people he interviewed but rather what he calls a symptom episode or management sequence. Nevertheless, my criticisms remain. First, his analysis is frequently based on the person rather than the symptom episode. Second, he fails to provide an idea of the total data set by counting the symptom episodes referred to by respondents. Thus we have no idea whether particular items are representative.

11. I realise that requirements concerning the number of sample members is not an issue in the classic formulation of the deviant case by Garfinkel (1967) and Circourel (1964). However, this formulation which invites the researcher 'to make trouble' (Garfinkel p.37) cannot be directly applied to the research interview for the obvious reason that the good will of the respondents would be lost. In the interview, trouble happens rather than being made to happen. For this reason, it is necessary to take seriously the number of sample members.

12. The problem can be put in another way. On the one hand, the investigator who uses the research interview is using a

method derived from conventional methodology. On the other hand, he disowns the theoretical ideas associated with this methodology and replaces them with the perspective I have used which challenges the claim that the interview can be used to obtain findings on matters external to it. The question then arises as to why use the interview at all. I responded to this question in Chapter 2 by arguing that from a practical point of view, it allows the researcher to collect a great deal of information about large numbers of subjects' activities which would not be otherwise possible. Ultimately, one has to adopt a position of compromise between the dictates of conventional methodology and those of qualitative sociology if one is to produce findings which are meaningful.

13. See 'The Other Side of Paediatrics' (Jolly, 1981).
14. The project is entitled 'Resiting Medical Encounters: An Action Research Study' (Silverman 1980b) and has been funded by the Social Science Research Council (SSRC).
15. This is common knowledge to those who have studied or worked in psychiatric settings. Innovations, like the therapeutic community and its derivatives, have come and gone according to the person running the institution.

APPENDIX THE COLLECTION OF DATA

1. Recently, there has been an outcry from politicians over the low number of postgraduate social science students who complete their PhDs and the length of time they take in submitting their theses. Given my description of the difficulties post-

graduates face, I would suggest that the numbers who do complete their studies amount to a minor miracle. It is gratifying to note that the SSRC is encouraging those who wish to do a higher degree by research to take up a linked studentship whereby the student joins an existing research team. This scheme obviates many of the problems to which I have refererd.

2. Putting this another way, the acceptance of a research proposal by members of an institution, like hospital consultants, may depend on its ability to satisfy their 'political' needs. In paediatrics, there is much to be gained by a hospital showing it cares for the psycho-social needs of parents and children.
3. Given the track record of 'doctor bashing' in medical sociology, it would not have been surprising had the consultants refused permission for outpatient encounters to be recorded.
4. For instance, I presented a paper on parents' responses to their child's heart disease to a group of cardiac surgeons (Baruch 1981b).
5. As I implied in Chapter 8, there is still a great deal of scope for research which examines the role of fathers in family life in terms of the perspective used in this study.
6. The mean length of time of interviews provides a basis for establishing deviant cases. As I said, home interviews took between thirty minutes and two hours. The only family to which this did not apply were the As. Their interviews lasted no more than forty-five minutes.

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The last fifteen years have seen a strong challenge to the narrow medical model of mental illness.

The seven original essays in this book show that the 'anti-psychiatry' movement which began in the sixties is just one example of a widespread unease about the methods and aims of psychiatry. They also look critically at the immense mental health industry in the United States; new research into the origins of the psychiatric profession in Britain; the upheavals in Italian mental hospitals; the politicization of mental health workers in Norway; and the revolution in French psychoanalysis.

Critical psychiatry, conclude the contributors, may appear confused and disunited in its various manifestations, but a fundamental shift in theory underlies all these developments – and it is a movement which has yet to reach full strength.

David Ingleby lectures in Social Psychology at the University of Cambridge and is a Fellow of Darwin College.

The cover shows 'The Hospital at Arles' by Van Gogh, in the Reinhardt Collection, Winterthur, Switzerland

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Canada $6.95

CRITICAL PSYCHIATRY EDITOR: DAVID INGLEBY

PUBLISHED BY PENGUIN BOOKS

PSYCHOLOGY & PSYCHIATRY ISBN 0 14 08.0308 4

ISBN 0 14 08.0308 4

CRITICAL PSYCHIATRY

THE POLITICS OF MENTAL HEALTH

EDITOR: DAVID INGLEBY

4 Towards a Critical History of the Psychiatric Profession

Andy Treacher and Geoff Baruch

Our concern in this chapter is to explore one major issue – the dominant role that the psychiatric profession plays within the mental health industry in Britain. Kovel in his chapter characterizes the American situation as bewildering and complex, but we would contend that although the British scene is becoming more complex, and there are the beginnings of a consumerist trend (exemplified by the growth of the encounter group movement and by many different types of self-help group), there remains a striking uniformity in the way that the majority of patients are processed by the system.

To many of our readers this contention may appear to be sheer dogmatism – surely important innovations are being made in many fields; family therapy is emerging as a new approach, most professionals within the area are better trained and more sophisticated, etc., etc. We would not dismiss such arguments out of hand, but we would insist that such changes are merely 'first-order' ones.[1] To argue that changes are occurring is a bit like arguing that because we are now playing musical chairs to a new tune, some profound change has occurred; clearly, for 'change' to occur in any profound sense, we would have to play an entirely new game.

But to extend our analogy still further, we would argue that not only are the game and even the tune still the same, the bandmasters are the same, too. In the British situation the bandmasters are, of course, psychiatrists. They retain, as a result of an historical victory which they won in the nineteenth century, a position of professional dominance which has not been effectively challenged by any other professional group. Eysenck's challenge to the profession, beginning with his attack on its psychoanalytic wing[2] and culminating in his challenge to the whole profession,[3] may have ruffled a few feathers but it is clear that the profession is not prepared to concede any of its powers. Nigel Goldie's fascinating study of the relationship between psychiatrists, social workers and clinical psychologists should be read by anybody who has illusions about this. As Goldie clearly shows, there is an essential hypocrisy involved in the working relationships between these three disciplines. In the final analysis the psychiatrist can claim that he is ultimately responsible for any crucial decisions that are to be made in relation to a patient whose care may have been initially delegated to other professionals.[4]

Goldie has also explored the role of 'eclecticism' in maintaining the professional dominance of psychiatry. He argues that it is precisely because the profession adheres to an eclectic approach that it cannot be challenged at a theoretical or ideological level. Typically any challenge that is made is absorbed rather than resisted, because the best tactical defence to any challenge is not a counter-challenge but a move which effectively defuses the attack.[5]

Anthony Clare's recent much-quoted book *Psychiatry in Dissent* is a good example of this type of approach. After enthusiastically demolishing other possible models of mental disorder Clare spells out his own position in the following terms:

> I have made no mention of the so-called 'medical model' . . . The medical model is an evolving one in which scientific methods of observation, description, and differentiation are employed, in which an illness is conceptualized as a 'process that moves from the recognition and palliation of symptoms to the characterisation of a specific disease in which the etiology and pathogenesis are known and the treatment is rational and specific'. Such a process may take years, centuries even, and while many medical conditions have moved to the final stages of such understanding, others are still at various points along the way.[6]

This definition is, of course, very traditional and is largely indistinguishable from those of Lord, Mapother, Henderson, Lewis and many other influential psychiatrists who have explored the subject during the past fifty years. However, Clare is obviously a little more sophisticated than this – he writes, after all, in an era when even medical students receive some instruction in 'behavioural science'. He therefore appears rather dissatisfied with his first stab at a definition since he adds a rider which modifies it considerably:

> The medical model does not envisage disease as something which 'happens' to a person independently of any action he may take . . . Medical diseases do not exist independently of the people who are sick. The medical model, in short, takes into account not merely the symptoms, syndrome, or disease but the person who suffers, his personal and social situation, his biological,

psychological, and social status. The medical model, as applied to psychiatry, embodies the basic principle that every illness is the product of two factors – of environment working on the organism.[7]

Reading between the lines of Clare's argument, one can see that his model is designed to overarch all other approaches. As he says himself, 'it can be seen that the variety of ideological positions within psychiatry, the biological, the dynamic, the social, the behavioural, represent different emphases'. But Clare insists that if psychiatry is to progress, psychiatrists must continue to be eclectic. Psychiatrists must avoid giving their allegiance to any one model and avoid being dogmatic.

Clare's approach is, of course, very appealing to those who wallow in the various forms of empiricist anti-intellectualism which dominate thinking in the arena of mental health. This is why Clare is such a popular figure. His eminent reasonableness and apparent lack of dogma appeals to the British mind with its ingrained enthusiasm for compromise, for making do and mending. However, it should be pointed out that, as with all people who pretend to eschew dogmatism, Clare is himself clearly dogmatic in insisting that eclecticism is the only way forward.

In practice Clare's espoused theoretical position amounts to little more than a smokescreen for exerting the hegemony of the psychiatric profession, since it is clear from his book that he feels only a suitably trained psychiatrist is capable of taking the prime responsibility for the treatment of the mentally disordered. He is too subtle to spell this out directly, but when he comes to discuss the anatomy of the ideal psychiatrist he is really discussing the type of professional who can be expected to take such responsibility for the treatment of the mentally disordered.

Clare's ideal psychiatrist is a unique blend of virtue and knowledge, since he combines '"the scientific attitudes of the sceptic with a powerful impressive personality and a profound existential faith". He is someone with a solid foundation in medicine, the biological and behavioural sciences, who is able to cope with the intellectual isolation implicit in such a critical eclecticism.' In practice Clare's view is little different from the position adopted by the newly founded Royal College of Psychiatrists. In 1973, the College submitted a memorandum to the D.H.S.S. expressing its views on the possible future role of psychological services within the N.H.S. The memorandum baldly states: 'It is recognized that there is a school of thought which denies the concept of mental illness and considers that the symptoms hitherto classified as mental illness, mental disorder, tensions, psychoses, personality disorders, etc., should be regarded as psychological behavioural maladjustments and should be treated outside the medical orbit. These views are not acceptable to the College'.[8]

Such a bald statement as this is clearly designed to protect the professional interests of psychiatrists; but is Clare's sophisticated view any less a defence of the psychiatrist's hegemony? We would argue that Clare's position remains basically reductionist – illnesses may have psychological and sociological dimensions which must be 'taken into account' (to use Clare's nebulous term), but their biological core is primary and requires the skills that only the medically trained can provide.

As we have already insisted, Clare has provided us with no new insights largely because he has never broken with a tradition that has a long heritage within British psychiatry. David Will has recently pointed out[9] that this tradition has – despite its apparent espousal of psychological approaches to mental disorder – proved antipathetic to the development of psychotherapy, which is merely construed as one approach among many others.

In Clare's model we are offered a view of the psychiatrist as master detective – a veritable Sherlock Holmes who takes into account all the myriad aspects of the patient, by drawing on every known science which has relevance to human behaviour. After due accountancy a treatment is usually devised which, if we are to take Clare's criticisms of our own position seriously,[10] will most probably be a phenothiazine (which, of course, only a psychiatrist can prescribe).

No doubt Clare will protest that this is a caricature of his model, but we would insist that it is logical for a therapist with such an eclectic and positivistic stance as Clare to end up prescribing drugs as the main form of treatment. In doing so he of course operates within a centuries-old tradition – medical men have always, as Ackernecht[11] has clearly demonstrated, pursued panaceas, 'magic bullets', or indeed bromides, with relentless devotion. In doing so, they have deluded us into thinking that there are simple technological solutions to problems which are endemic to the society in which we live. In this chapter we will try to estimate the psychiatric profession's role in contributing to this process of delusion-making, but before starting this discussion in earnest it is necessary to return briefly to the point made by Will.

Will, in attacking the Meyerian tradition in which Clare operates, is a protagonist on behalf of psychoanalysis – he sees it as a liberating form of therapy which needs to be more widely adopted by the profession. But we would argue that such a position is as problematic as Clare's since it refuses to analyse the role of psychoanalysis itself. Kovel, Scull and many others have viewed psychoanalysis far more critically – they note that where psychoanalysis has become institutionalized (particularly within medicine), it has become a reactionary force. The underlying reductionism and determinism of Freud's model meant that it had immediate appeal to certain sections of the psychiatric profession who absorbed it without difficulty. But, needless to say, the more traditional and reactionary sections of the profession who sought to base psychiatry on the natural sciences (and particularly genetics) have always attempted to prevent Freudianism from obtaining a base within the profession. For them Freud's concentration on the necessity for self-analysis was anathema. Psychoanalysis' comparatively shallow roots within the British psychiatric profession is a tribute to the overall conservatism of the profession, but it is important to stress that from its inception psychoanalysis was dominated by sections of the medical profession.

David Smail, a leading clinical psychologist, has recently commented on the dual form of professional dominance that has been exerted by the medical profession in this respect. Reviewing the situation at the time when the N.H.S. was formed, he comments:

> Clinical psychologists were dwarfed by a medical guild whose powers, self-determination and freedom of action must be almost unique – the state of psychological knowledge ... did not permit psychologists to adopt anything but a secondary role. The physical methods of treatments appropriate to so-called mental illness obviously necessitated possession of a medical degree, and non-physical methods stemming, in this country, largely from the psycho-analytic school could only be practised by people (most usually doctors) who had undergone a lengthy and expensive initiation ceremony. In other words, the licence to practise treatment was based on a system where authority was accorded to would-be healers on the basis of membership of the appropriate (medical) club rather than on the basis of a scientifically demonstrable ability to assist psychological change. Above all, psychologists in the National Health Service were, and still are, prevented from direct involvement with patients by statutory constraints.[12]

The almost exclusive alignment of psychoanalysis with the medical profession in Britain contributed to its demise as a source of radical ideas. A single institution, the Tavistock Clinic, has played a quite disproportionate role in shaping the development of the psychoanalytic tradition, so that the British scene has lacked the variegated features of the American. This has resulted in an orthodoxy and conservatism which has survived the exciting but largely ephemeral work of Laing, Cooper and a number of other psychiatrists who broke away from the fold in the 1960s.

In order to understand the deep conservatism of British psychiatry as a whole, it is necessary to probe deeply into the history of the profession. Needless to say, commentators like Clare and Wing do not seriously examine historical issues in their accounts of the contemporary state of psychiatry; if they did so, they would uncover many uncomfortable issues which would undermine the assumptions from which they operate. Fortunately, Andrew Scull and David Ewins in their independent researches have recently provided us with a series of insights into the history of the psychiatric profession. At this point, our account therefore turns away from the contemporary scene to investigate the origins of psychiatry's position of dominance.

Scull in his work[13] has set himself one major task – to explain how a segment of the medical profession came to 'capture control over insanity'. The very words that Scull uses to describe his task indicate how sharply he breaks with the traditional presentation of the history of psychiatry in the nineteenth century. Usually the history is presented in a totally bland way: once upon a time some enlightened doctors set about the reform of an archaic and exploitative system of madhouses, workhouses, etc., in which the mad were cruelly treated. In doing so, they created our modern hospital system, which symbolizes the scientific and humane approach to the treatment of the mentally disordered. Interestingly, such accounts are often written by psychiatrists themselves, so there is always the uneasy suspicion that history is being distorted in order to justify the current dominance of the profession. The British psychiatrist, J. K. Wing, in his book *Reasoning about Madness*[14] provides us with the most recent example of this genre. His account of the impact of moral treatment on the asylums in Britain is particularly derisory as it totally ignores both the controversial nature of such methods and the special care that the medical profession took to establish (quite spuriously, as Scull demonstrates) that only members of the medical profession were capable of supervising them.

Fortunately Scull, through his extensive use of primary source material, provides us with a far more convincing account of developments within psychiatry in this crucial period. However, unlike Wing, he views the takeover bid by the psychiatric profession in a much broader context – as the following quotation reveals:

> In the first place one should notice that the shift in locus of responsibility for lunatics from the family and the local community to a group of trained professionals ... is a process by no means confined to the case of mental illness. The symbiotic relationship between psychiatry and insanity ... is merely a particularly important example ... of a much more general trend in the social control practices of modern societies. Elites in such societies over about the past century and a half have increasingly sought to rationalize and legitimize their control of all sorts of deviant and troublesome elements by consigning them to the ministrations of experts. No longer content to rely on vague cultural definitions of, and informal responses to, deviation, rational-bureaucratic western societies have increasingly delegated this task to groups of people who claim, or are assumed to have, special competence in these areas.[15]

In fact the use of the term 'delegation' in this quotation is questionable, as Scull clearly demonstrates that the emerging psychiatric profession actively sought to gain control of the mad business precisely at a time when it became clear that there were lucrative pickings to be had. Prior to 1750, the mentally disordered were generally not recognized as a separate category – they were heaped together with the poor and indigent and considered to be a family or communal responsibility. However, as the century progressed, new and more institutionalized methods of dealing with such groups were established in order to contain such problematical and potentially disruptive elements. Private madhouses were also founded as it became clear that the better classes were willing to pay handsomely in order to avoid the embarrassment of daily contact with mad relatives. Such madhouses were often run by laymen, but increasingly apothecaries, surgeons and physicians were attracted to the trade, particularly as they could claim that they had unique medical methods of achieving cures. As most methods of treatment were cure-alls which were quite indiscriminate in their application, it was a simple matter to include 'mental' illnesses alongside other forms of illness as legitimate targets for such treatment. Patients were therefore purged or bled or administered vomits or drugs with increasing enthusiasm.

However, as Scull is careful to point out, lay enthusiasm for such treatments proved more fickle. A number of reformers became increasingly concerned at the often cruel and inhumane régimes to which the insane were exposed. It was in this context that William Tuke developed an alternative approach at the York Retreat. Tuke's work (not mentioned by Wing in his account) was in part a reaction to the abuses that had been uncovered at the York Asylum but it is clear that his work achieved national importance, particularly through the publication in 1813 of his book, *A Description of the Retreat.*

Tuke was generally distrustful of doctors but allowed them to visit the Retreat. He concluded that they had little to offer his patients, although he did acknowledge that the warm baths they recommended did seem to help melancholics. Tuke's alternative approach viewed the insane as essentially child-like – they required humane treatment within a framework of re-education for life. Whenever possible, they were to be treated as rational and responsible. The Retreat was able to claim a high success rate with its patients, and these successes helped to fuel the rising tide of criticism of the existing asylums and madhouses. A series of Select Committees began investigations, and their reports revealed a catalogue of scandals and abuses (often involving ineffective or damaging medical treatments) and alarmingly high mortality rates.

As Scull clearly documents, these Select Committees were extremely critical both of medical forms of treatment and medical practitioners; physicians such as Best and Monro who were responsible for administering asylums were given a very rough ride when cross-examined by the Committees. More crucially, the Committees were hostile to the medical profession's claims to have special jurisdiction over the mentally ill. One lay witness to the Select Committee's deliberation had the following to say about whether medical men should be allowed to assume the roles of 'inspectors' or 'controllers' in relation to the mentally ill:

> I think they are the most unfit of any class of persons. In the first place, *from every enquiry I have made, I am satisfied that medicine has little or no effect on the disease, and the only reason for their selection is the confidence which is placed in their being able to apply a remedy to the malady.* They are all persons interested more or less. It is extremly difficult in examining either the public Institutions or private houses not to have a strong impression upon your mind, that medical men derive a profit in some shape or form from those different establishments ... The rendering therefore, [of] any interested class of persons the Inspectors and Controllers, I hold to be mischievous in the greatest possible degree.[16]

Another even more hostile witness who had monitored the practices of one of the most famous medical 'specialists' in the field (Dr Best at the York Asylum) pointed out that the mortality rate at the asylum fell from twenty a year to only four following Dr Best's departure.

In practice, the majority of the members of the Committees accepted such views, since they recommended that asylums should be supervised by laymen and not doctors. The Bills of 1816–17 based on the deliberations of the Select Committees were passed by the House of Commons but were blocked by the House of Lords, largely because the Lords were opposed to reform in any shape or form. The medical profession therefore won a fragile victory over their opponents who viewed moral treatment as a more humane and effective approach.

However, as Scull points out, there were other reasons why the medical view gained ascendancy. Moral treatment, because of its non-technicality, did not encourage the emergence of an organized professional group which would seek to prevent other groups from adopting it. In addition, exponents of moral treatment proved largely incapable of confronting the medical profession both at a theoretical level and at a descriptive (linguistic) level. The language of madness remained that of medicine. These factors combined to make moral treatment vulnerable to a takeover bid from the medical profession – and this, as Scull carefully documents, is precisely what happened.

After the failure of a further Bill in 1819, there was a veritable spate of books on mental illness written by members of the medical profession. Scull insists that these did little more than to create an extensive body of largely spurious knowledge which served a useful purpose in mystifying and confusing lay opinion. In the same period medical degrees began to include the study of mental illness, so that medical men could substantiate their claims to have esoteric knowledge not possessed by lay competitors. More crucially, medical practitioners began to advance theories about mental illness which contained a significant ideological component of great value in confronting lay critics. Using Descartes' fundamental postulate that there was a split between mind and body, they insisted that the mind (an immortal, immaterial essence equivalent to the soul) was forced to operate in this world through the medium of the brain. However, the mind itself was, because of its very nature, incapable of being deranged or rendered imperfect. Only the brain can be damaged, so that a derangement in, for example, understanding, could no longer be considered as primarily a psychological phenomenon but as a direct manifestation of a disease process involving the centre in the nervous system upon which the exercise of understanding depended. This sophisticated, but clearly reductionist, model naturally carried with it the corollary that only the medical profession, with its expertise in treating bodily disease, could be legitimately involved in treating the mentally disordered. A further corollary must also be noted – it was argued that moral treatment, since it stressed the therapeutic value of a 'physical' form of treatment (the administration of hot baths), could only be legitimately supervised by doctors.

Many of these arguments have a remarkably contemporary ring about them, at least as far as our ears are concerned, but it is clear from Scull's work that they were the ideological smokescreen which the medical profession used to establish its dominance. The profession's first clear-cut victory came with the passing of the 1828 Act, which contained the stipulation that all asylums should have medical supervision. Initially this supervision was for physical complaints only, but once the door was open to the physicians they were able to undermine lay supervision and gain effective control of the running of the asylum. With the passing of the 1845 Lunatics Act, the medical profession's claims to have the sole right to treat the mentally disordered received statutory endorsement – doctors now controlled the only legitimate institutions for the treatment of the insane, and also began to profoundly influence the way that mental disorder was to be construed by lay opinion.

It is precisely in this period that the psychiatrists can be talked about collectively as belonging to a profession. In 1851 the Association of Medical Officers of Asylums and Hospitals for the Insane was founded and by 1853 it was publishing its own 'Asylum Journal'. Needless to say, the Journal propagated the view that insanity was purely a disease of the brain and that the physician was now the responsible guardian of the lunatic and must ever remain so. However, two major difficulties confronted the profession in this period. First, it was difficult in practice to demonstrate that organic pathology did in fact exist, and second, the profession's claims to produce effective cures were shown to be spurious. Interestingly, Scull cites Bucknill and Tuke's textbook published in 1858 as crucial evidence on this point. This textbook was recognized as the standard one, and yet it contained the following damaging admission: 'in the chronic stages of insanity active remedies are rarely admissible, except to obviate some intercurrent condition, which produces too much disturbance and danger to be permitted to run a natural course and wear itself out. In recent insanity with symptoms of physical disturbance of little violence and urgency, active medicinal treatment may often times be dispensed with.'

Admissions such as these, coupled with the fact that there were no universally agreed methods of treatment anyway, left asylum doctors in a highly vulnerable position. However, as Scull persuasively argues, they were able to maintain their position of dominance precisely because of their earlier victory over lay opposition. Scull makes his point with such telling clarity that we quote it in full:

> By the Acts of 1828 and 1845, the medical profession had acquired a virtually exclusive right to direct the treatment of the insane. Thereafter, its concern became one of maintaining, rather than obtaining, a monopolistic position, a situation where those in possession generally operate from a tactically superior position. In this instance, the medical profession's control of asylums, the only legitimate institutions for the treatment of insanity, effectively shut out all potential competitors; for the latter would have had to oppose unsubstantiated claims to demonstrated performance. Furthermore, the asylum doctors' institutional base gave them a powerful leverage for getting the community to utilize their services (thereby indirectly supporting their professional authority), quite apart from whether those doing so were convinced of their competence. For while employment of the asylum by the relatives of 'crazy' people or by local Poor Law authorities did not necessarily reflect acceptance of the superintendent's claims or his esoteric definition of what was 'really' wrong with the troublesome people they sent him: yet still their ready use of his services unavoidably added to the aura of legitimacy surrounding his activities. So long as his services were in such demand, it was difficult to avoid concluding that he was performing a useful and valuable task for the community.
>
> If the attractions of a convenient institution in which to dump the undesirable sufficed to ensure at least the passive acquiescence of the asylum doctors' true clients, the families and parish officials, in their continued existence, it should be quite clear that their nominal clients, the asylums' inmates, had little choice but to cooperate in sustaining their definition of the situation. Freidson has argued that, for the profession of medicine as a whole, a significant monopoly could not occur until a secure and practical technology of work was developed. In essence this was because doctors could not force clients to come to them, they had to *attract* them. Fortunately for psychiatrists, they formed an exception to this generalization, because of the peculiar structural characteristics of their practice. Once they had secured control over asylums, they no longer had to attract clients – the institution did that for them. And once patients were obtained, they

formed literally a captive audience held in a context which gave immense power to their captors. Consequently, psychiatry was able, like the scholarly professions, to survive solely by gaining the interest and patronage of a special, powerful sponsor without having to gain general lay confidence.[17]

While agreeing with much of Scull's argument contained in this quotation, we would wish to modify Freidson's notion that a monopolistic position can be straightforwardly related to the development of 'a secure and practical technology of work'.[18] We have little space to explore this point here, but it is difficult to see how Freidson's position can be substantiated historically. The passing of the 1858 Medical Registration Act, which gave an effective monopoly to the medical profession in Britain, appears to pre-date any major discoveries which could provide medicine with a valid technology. We would therefore see the issue far more in ideological and class terms – it is perhaps churlish to criticize Scull on this ground, given the value of his work; but we do feel that he pays insufficient attention to the social and political context in which the psychiatric profession emerged.

In doing so, he follows closely in the footsteps of Freidson, whose contributions to understanding the nature of the medical profession have a strongly internalist bias, as Waitzkin and Waterman[19] have pointed out. We would therefore seek to add another dimension to Scull's argument: as Skultans[20] has pointed out in her commentary on ideas about insanity in the nineteenth century, the latter half of the century was a period of significant economic change – of a movement away from *laissez-faire* policies towards increasing state intervention as class divisions hardened. It is precisely in this period that 'psychiatric Darwinism' (to use Skultans' term) emerges with great force. Darwin's ideas, particularly as developed by Spencer and Galton, gave new force to the idea of incurability, since this could be attributed to hereditary causation.[21] Custodial care could therefore be justified as the only means of care possible. Asylums, therefore, became increasingly prison-like in their operation, but the medical profession was able to maintain its control of them largely because it could correctly insist that the inmates required extensive medical care on account of their poor physical condition.

But this is not to say that the asylum superintendents had absolute power. Legally speaking, they were merely salaried employees of the individual asylum committees, and at times these committees did use their powers to dismiss superintendents. According to Scull, the committees retained a profound scepticism about the value of medical superintendents, who were often seen as merely 'ornamental'. Asylum superintendents were also vulnerable in another respect: the actual contractual terms upon which they worked meant that they lived in almost total isolation (just like their patients). They were forced to live in asylum accommodation and to give up private practice. Their isolation is also reflected in the weak links between the asylum superintendents and the main section of the medical profession. Until very recently, psychiatry has been treated as a peripheral speciality of marginal importance to medicine, but it is important to stress that its segregation took a legal form until the passing of the 1959 Mental Health Act. The Act was significant in that it allowed mental patients to be treated within any type of hospital facility rather than in mental hospitals alone. As we have argued elsewhere,[22] the impetus to establish psychiatric units in general hospitals can be seen as the final attempt of the psychiatric profession to desegregate itself. Ironically, it appears that to be an asylum superintendent in the nineteenth century was to tar oneself with the brush that also tarred one's patients.

But it is essential to establish how the asylum superintendents were able to retain their monopoly in the face of the difficulties that confronted them. As the asylums became increasingly larger the superintendents retreated from personal contact with their charges, busying themselves with administrative duties. In practice, therefore, they became insulated from the reality of the asylums they controlled. They now actively sought administrative roles, since their role as architects of medical cures was clearly void. In the earliest asylums the medical profession had accumulated such administrative powers largely for reasons of economy – asylum committees were loath to pay an administrator and a physician when the latter could do both jobs. As the asylum grew in size it would have been a logical step to appoint a lay administrator to relieve the physician of administrative burdens but, as Scull demonstrates, such moves were (for obvious reasons) vehemently opposed by the physicians, who were able to convince the committees that asylums were in fact hospitals to be run exclusively by medical men.

So the solution to the problem of increasing size was solved by the appointment of assistant physicians (not lay administrators), ostensibly appointed to take care of the physical ailments of the patients. However, it is clear from Scull's careful documentation that they duly reflected the passion for pathological investigation which dominated medicine at that time. In 1870, 42 per cent of the patients who died in asylums were given an autopsy; by 1890, the figure had reached 76.6 per cent. The issue goes deeper than this – obviously the assistants, like the asylum superintendents, were keen to minimize the amount of contact that they had to have with their disturbed and disturbing patients. It was evidently both scientifically and socially more respectable to work with corpses than patients: the day-to-day tasks of handling the patients were, in fact, left to asylum attendants, recruited, according to contemporary accounts, from the very same strata that provided the asylums with the majority of their clientele.

In the final analysis, Scull attributes the victory of the asylum superintendents in retaining control of the asylums to two factors – the cult of science and public indifference:

> I suggest that such a persistent, almost wilful blindness [to the failure of medical treatments] derives from something more than the sacred and hence unquestioned quality with which modern societies have endowed science and certified expertise. It is true, of course, that such unexamined deference is habitually exhibited in its most acute form in the realm of medicine. Indeed, the doctor–patient relationship is so structured as to demand routinely that the client abdicate his own reasoning capacity. In its place is fostered a naïve child-like faith that the physician is operating in the patient's best interests; and that, while he does so, he is guided by an esoteric training and knowledge giving him insights which are beyond the powers of ordinary mortals to grasp or understand. But, when all is said and done, modern medicine, much of the time at least, has results, if not God, on its side. English psychiatry at the end of the nineteenth century (and most of the 'experts' currently engaged in the control of deviance) clearly did (do) not.
>
> And yet, if asylums, and the activities of those running them, did not transform their inmates into upright citizens, they did at least get rid of troublesome people for the rest of us. By not inquiring too deeply into what went on behind asylum walls, and by not being too sceptical of the officially constructed reality, people were (are) rewarded with a comforting reassurance about the essentially benign character of their society and the way it dealt (deals) with its deviants and misfits. Granting a few individuals the status and perquisites ordinarily thought to be reserved for those with genuine expertise and esoteric knowledge was a small price to pay for the satisfaction of knowing that crazy people were getting the best treatment science could provide, and for the comfortable feelings which could be aroused by contemplating the contrast between the present 'humane' and 'civilized' approach to the 'mentally ill' with the barbarism of the past.[23]

We have quoted this passage at length because it raises many themes which we wish to explore as we extend our argument to include twentieth-century developments in psychiatry; but at this point it is necessary for us to draw heavily on some recent work by David Ewins which is complementary to Scull's, although it explores the period between 1890 and 1960.[24]

Ewins shares Scull's view that the medical profession's role in relation to the mentally disordered was paradoxical – by the end of the century it had consolidated its claim to be solely responsible for treating insanity, but it could only carry out this function within the constraints of a complex administrative and legal framework. The latter had been greatly modified by the 1890 Lunacy Act, which established a series of complex safeguards against wrongful detention on the grounds of insanity. Ewins is particularly interested in the legal changes which occurred firstly with the passing of the Mental Treatment Act of 1930, and then the far more 'radical' Mental Health Act of 1959.

The explanation for these changes is to be found partly in the changing social and political conditions of this period, and partly in developments within medicine itself. Ewins argues that the success of medicine in devising new and effective methods of treating syphilitic patients in the period leading up to the First World War created a climate of opinion that once again facilitated the acceptance of the medical view of insanity as 'illness'. This in turn strengthened the medical profession's claim to ultimate control over the detention and treatment of the mentally ill without the restrictions of detailed legal regulations and safeguards.

But the success of the new methods would not of itself have been decisive in determining the ascendancy of the medical profession. Indeed, one has to question whether the new methods devised in this period *were* generally successful. Ewins himself does not argue this point in sufficient detail, but we feel it is more convincing to postulate that the important point about the new methods of treatment was not that they were demonstrably successful but that they were construed as being successful.

For that the final quarter of the nineteenth century was a crucial turning point in the history of medicine, and the changes that occurred in this period profoundly influenced psychiatry. As George Rosen has demonstrated, theories about the nature and causation of physical illness underwent considerable changes as a result of the epoch-making discoveries of bacteriologists like Koch and Pasteur. Their success in understanding and eventually treating infectious diseases resulted in the establishment of a paradigm within medicine which stressed the importance of pathological processes within the individual, while largely ignoring the social and economic factors that inevitably influenced disease processes. We need to digest this rather obvious point in greater detail because it has crucial implications for the history of psychiatry.

Rosen's approach is particularly important since he has explored the impact of social and political changes on the development of both medicine and the profession of medicine, not just in this period but also throughout the nineteenth century. Significantly, he has paid close attention to the impact of the French Revolution on the development of the medical profession on the Continent. In his own words he sees the Revolution as implanting 'ideas of public interest and social utility which provided the seed in which germinated views of the relation among health, medicine and society. The men of 1789 and 1793 could not foresee the consequences of their thoughts and acts. The triumph of the machine and the concentration of capital were still in the future, but it was in terms of the situation created by these developments that the men of 1848 endeavoured to apply the ideas of their predecessors. *Social* medicine, the idea of 1848, must be seen as the fruit of this historical process.'[25]

Rosen argues that the rapid industrialization and urbanization that occurred in France between 1830 and 1870 imposed a series of economic and social stresses that influenced very profoundly the evolution of French thought and action. During this period an energetic group of physicians and hygienists had been carrying out surveys and statistical studies of living conditions among workers in urban communities. Practical experience acquired during the Revolutionary and Napoleonic wars had made many French physicians alert to health problems. At the same time, political and social theorists, such as Fourier, Saint-Simon, Comte, Proudhon and many others, influenced French medicine, so that certain sections of it were fermented with a spirit of social change. Many doctors were in direct contact with the social realities of industrialization and the profound effects it had on the lives of the working class.

In 1838 Rochoux coined the term 'social hygiene' to describe a category of social policy that would be concerned with establishing a legal and administrative framework for providing minimum health standards. Ten years later, at the height of the 1848 Revolution, Guérin appealed to the French medical profession to contribute to the good of society. Guérin divided his social medicine into four parts: social physiology, social pathology, social hygiene and social therapy. These were to deal, respectively, with the relation between the physical and mental condition of a population and its laws or other institutions; the study of social problems in relation to health and disease; measures for health promotion and disease prevention; and the provision of medical and other conditions that societies may experience.

Guérin's idea of social medicine obviously awarded the medical profession a key role in running society. Throughout Europe, the profession was struggling to establish itself as a unified entity (with uniform training and uniform payment for the services it rendered), which would be able to provide more and better care for the majority of the population. Not surprisingly, the first proposals for a national medical service also began to emerge in this period. But what became of this movement within medicine? In France, the period of political reaction following the failure of the 1848 Revolution put paid to such proposals. Some German physicians, such as Neumann, Virchow and Leubuscher, were profoundly influenced by the theories of social medicine in France. In 1847, Neumann had issued a manifesto arguing that 'medical science is intrinsically and essentially a social science, and as long as this is not recognized in practice we shall have to be satisfied with an empty shell and a sham'. Virchow formulated the idea somewhat differently, stating that 'medicine is a social science and politics nothing but medicine on a grand scale'. But, as Rosen points out, the proponents of such ideas were not dreaming of some utopian situation: they utilized their approach to formulate definite principles from which a programme of action could be derived. The exact details of such programmes are not our concern here, but it is obvious that such physicians saw the task of medicine in a much broader light than their biologically- and pathologically-orientated colleagues.

The attempt of these men to turn medicine in a sociological and preventive direction was abortive, since the failure of the revolution in Germany created a political climate hostile to social medicine. At the same time, developments in other scientific disciplines (especially biology and physics) began to influence the development of medicine. As Rosen comments:

The natural sciences developed rapidly and achieved enormous prestige in medicine, and the emergence of medical bacteriology seemed to answer the problem of disease causation. Under these conditions it was not difficult to overlook the significance of the relationship between the patient and his environment.[26]

Or, as a leading German bacteriologist, Emil Behring, declared in 1894, the study of infectious diseases could now be pursued unswervingly without being side-tracked by social considerations and reflections on social policy.

Rosen's discussion of the developments within medicine concentrates mainly on France and Germany, but he does point out that there were some developments towards an idea of social medicine in Britain, although these were a pale imitation of the developments on the Continent. Continental and British medicine became more unified in their development precisely because of the successes of medical bacteriology. However – and this is the crux of the point we are trying to make – as medicine became more scientific, more concerned with measurement and classification and the theory of pathological processes, it became less humanistic and tended to treat the patient as an object. In *Medical Nemesis*[27] Illich has graphically argued this point: '. . . as the doctor's interest shifted from the sick to sickness, the hospital became a museum of sickness. The wards were full of indigent people who offered their bodies as spectacles to any physician willing to treat them.'

In the same period, a basic shift occurred in the taking of medical case histories.[28] In the Hippocratic tradition, a clinical history was a history of a human being who suffered and who had symptoms. In the second half of the nineteenth century, however, as pathology developed as a science, doctors became more and more preoccupied with establishing the history of a particular disease process (*historia morbi*). The individual, his social relations and his problems of living then faded into insignificance as attention was focused upon the symptoms and their bodily manifestations. Illich has argued that this process became all the more powerful and irresistible as the medical profession was able to develop effective cures for a wide range of diseases. As a result of this very real power, the profession increasingly gained control over defining what is illness and what is health.

This process also occurred in relation to mental illness. The discoveries associated with the successful treatment of general paresis of the insane (culminating in Wagner Jauregg's malarial treatment, for which he was awarded a Nobel Prize) was construed as undeniable evidence that all mental disorders were illnesses. Thus, psychiatry was able to capitalize both on its limited success with GPI and on the general advances being made in medicine. With hindsight, we now can establish just how limited these successes were: McKeown, Cochrane, Powles and many other writers have demonstrated that major changes in living standards and life-style have contributed far more to changes in health than innovations in therapy, and even Wing concedes that 'the more dramatic advances in diagnosis and in the treatment of those diseases that affect individuals (as opposed to large groups) have probably contributed significantly only since the second quarter of the present century'.[29]

Clearly it was not due to the limited successes of psychiatry that the medical profession was able to dominate the deliberations of the Royal Commission on Lunacy (1924–7). To explain this domination, we must accept Scull's points concerning the monopoly position gained by the profession and also argue that the other main reason for its domination was an ideological one.

The latter point has been argued in some detail by Ewins. He insists that the categorization of forms of deviant behaviours as mental illness is an especially advantageous form of social control. Any threat or potential threat to the existing political and social conditions of society can be eliminated or greatly lessened by forcing the deviant to enter the sick role. His actions can then be invalidated, since they are seen either as meaningless or as mere symptoms whose meaning is to be deciphered by the psychiatrist. The deviant is no longer held responsible for his own behaviour – his illness is simply something that happens to him, over which he has no control. He is thus entirely in the control of the doctor, who alone has the power to cure him.

Ewins argues that the power of medical explanations of deviant behaviour lies precisely in their ability to divest such behaviour of any political significance. If deviant behaviours are construed as pathological symptoms resulting from a disease process, there is no longer any question of conceptualizing them in other ways. (For example, there would be no question of examining the content of the symptoms to see whether they reflect the effects of having to cope with the alienating effects of living in a capitalist form of society.)

But Ewins is also concerned to explore other features of medicalization. In this connection he draws on the work of Parsons,[30] who points out that criminals, since they are labelled and extruded from the company of upright citizens, must be prevented by coercion from joining up with their fellow criminals. There is no such problem, however, when the form of deviance is illness rather than criminality. A sick person's status is conditionally legitimated when he willingly makes himself dependent upon other people who are not sick – friends, family members, doctors, etc. – rather than on fellow sufferers. This creates real barriers to group formation among the sick, and little possibility of positive legitimation. The sick role thus not only isolates and insulates the sick person, but also exposes him to very powerful forces compelling him to become reintegrated into society as a fully participating member.

In Parsons' system, these processes are seen as natural and non-problematic: entry into the sick role is merely one of several routes that individuals may take in response to personal crises. But, as Waitzkin and Waterman[31] have pointed out, the sick role can be viewed as a particularly effective mechanism of social control, since it permits limited deviance to occur, but at the same time protects the stability of the social system. It is for this reason that Ewins insists that the medicalization of mental disorder has to be understood against the background of an emerging political consensus which maintained that problems of health, and particularly mental illness, were not a matter for party politics. He correctly stresses that the Labour Party played a crucial role in contributing and shaping this consensus, but he fails to develop a sufficiently detailed discussion of the relationship between developments in capitalism and the development of the Labour Party as a vehicle for reformist politics.

At this point, therefore, we shall diverge once more from Ewin's account, turning instead to an analysis put forward by Bernard Semmel[32] in his book *Imperialism and Social Reform*. Semmel is concerned primarily with exploring the relationship between the development of imperialism and changes in welfare policies between 1890 and the First World War. In his analysis of the economic bases of social reform, he does not specifically discuss services for the mentally disordered, but his general analysis clearly provides a deeper understanding of the reasons for the changes that occurred here in embryonic form in the 1920s and 1930s and more strikingly after the Second World War. However, in order to introduce this analysis, it is necessary to make some general comments about Semmel's approach.

Semmel views the provision of social and welfare reforms within a specific historical context – one in which the ruling class in Britain was faced with containing an increasingly sophisticated and politically conscious working class. Many politicians saw Bismarck's Germany as the most suitable model to be emulated, since the 'state socialism' he had introduced in the 1880s had been consciously designed to stem social and political discontent in the working class and to undermine the growing strength of the German socialist movement. An alternative solution to the problem was suggested by Cecil Rhodes, who argued that in order to avoid class conflicts at home it was necessary to develop a policy of imperialist domination. As he graphically put it, 'The Empire . . . is a bread and butter question. If you want to avoid civil war you must become imperialists.'[33]

British politics in the period prior to the First World War were dominated by such discussions. The majority of both Liberal and Tory politicians accepted that imperialism was essential in order to provide the economic basis for social reform in Britain; moreover, the influential Fabian Society had also developed a policy of advocating imperialist policies. They therefore decided to support what Semmel calls the liberal-imperialist wing of the Liberal Party led by Earl Rosebery, whose view of the relationship between imperialism and social reform is summarized by the following quotations cited by Semmel:

> An Empire ... requires as its first condition an imperial race – a race vigorous and industrious and intrepid ... where you promote health and arrest disease, where you convert an unhealthy citizen into a healthy one, where you exercise your authority to promote sanitary conditions ... you in doing your duty are also working for the Empire.

Issues such as educational, housing and temperance reform were linked by Rosebery to the idea of efficiency:

> a condition of national fitness equal to the demands of our Empire – administrative, parliamentary, commercial, educational, physical, moral, naval and military fitness – so that we should make the best of our admirable raw material.

Since the Fabians believed that they could achieve their goals of social reform by converting the leaders of the existing parties (a policy of 'permeation'), they were naturally attracted to Rosebery's view. In keeping with these political moves, the Fabian Society therefore preferred to drop references to socialism, since this term inevitably carried with it overtones of class-oriented politics. The term 'collectivist' was used instead to describe their policies, which were primarily concerned with the promotion of the national interest. The latter could be most efficiently achieved by ensuring that the imperial economy (organized on a collectivist basis) was directed by an élite of experts. The efficiency of the economy would be the basis for improving the conditions of the most depressed classes of the community.

The Fabians' corporatist ideas clearly influenced many groups within the Labour Party, but Semmel demonstrates convincingly that there was also a crucial ideological link between the Fabians and the various political movements in which Sir Oswald Mosley played a part. His rapid political evolution was entirely consistent. From being a Tory he became first an 'Independent', then a member of the Labour Party (eventually with a Cabinet post), and finally the leader of the British Union of Fascists. His corporatist doctrines were often indistinguishable from policies put forward by the Fabians, whose basic authoritarianism is particularly clearly illustrated in relation to their social welfare policies.

These policies have particular relevance to our arguments concerning the provision of new forms of services for the mentally disordered. For example, the Minority Report of the 1909 Royal Commission on the Poor Laws (written by Sidney and Beatrice Webb) contained some remarkably authoritarian recommendations. It suggested that vigorous campaigns to improve the health of the poor should be undertaken, irrespective of the consent of the people involved. These suggestions foreshadowed the powers given to doctors under the Mental Health Act in 1959, but other sections of the recommendations are also significant since they argue in favour of positive welfare legislation and attack notions of *laissez-faire*.

The Fabians and the policy-makers of the Labour Party played an important part in this process, but they were not, of course, solely responsible for formulating welfare policies. The reforms introduced by the Liberal Government from 1908 onwards (concerned with working conditions, housing, health insurance and old age pensioners) were formulated by the left-wingers in the party, who were not necessarily influenced by the Fabians, although ironically their policies were indistinguishable from those of the Fabians. Most sections of the Conservative Party bitterly opposed such policies, but the growing power of the Labour Party, reflecting basic developments in the working class, forced the Conservatives to accept and even endorse many of the policies introduced originally by the Liberal Party and later by the Labour Party as it inherited the mantle of the Liberals. This consensus between the Conservative and Labour parties emerged most clearly during and after the Second World War. The Beveridge programme for post-war reconstruction, which included proposals for a national health service, had been drawn up during a period of coalition, but the heavy defeat that the Conservatives received at the hands of the Labour Party in 1945 made it clear to them that they had to accept the basic tenets of the so-called 'welfare state'.

The changes embodied in the 1930 Mental Treatment Act, and more crucially in the 1959 Mental Health Act, must therefore be seen as an example of the growing consensus over health and welfare issues. Both major parties were concerned with preserving the existing political and economic system, and were thus united in seeking to eliminate or control any social phenomenon that challenged the *status quo*. Both parties were also wedded to policies designed to ameliorate social conditions, and both placed great stress on productivity and economic growth. Since 'unproductiveness' was now viewed in much the same spirit as pauperism, new forms of medical treatment (notably drug therapy) which enabled the mentally ill to be returned to productive work were looked upon with great interest.

But, as Ewins points out, these new forms of treatment had wider implications: while development of community care was linked closely to its success in preventing prolonged hospitalization, it also involved more effective methods of social control. Psychiatric medicine could now not only return patients to productiveness, but could also re-socialize them in step with the norms and values of society.

These developments were particularly appropriate from the reformist point of view of the Labour Party. Psychiatrists could now be viewed as performing a similar function to that of social workers. Part of this function would necessarily involve re-socializing deviant members of society so that they would accept the 'objective reality' dictated by the more powerful groups in society. This essentially authoritarian aspect of reformist thinking also stresses the importance of 'experts' in deciding how people should regulate their lives. It is therefore not surprising that the Minority Report on the Poor Law also emphasized the importance of doctors in regulating the lives of the poor. Clearly, psychiatrists can execute such a function in very powerful ways, and in this context Ewins draws particular attention to the use of mental welfare agencies as last resorts for younger, 'difficult' members of society who have been through the hands of the educational and possibly also of the legal authorities. He also insists that almost all contemporary psychiatric practice operates in a similar way.

The recent extension of psychiatry to include community care is therefore of fundamental importance. Indeed, Ewins concludes:

> ... as a result of the introduction of community care ... psychiatrists and mental welfare agencies could be increasingly integrated into the elaborate social welfare fabric (constructed largely by the Labour Party with the increasing acquiescence and support of the Conservative Party) behind which lay the belief that social problems could be eradicated by positive efforts to ameliorate social conditions.[34]

Labour Party policy-makers reciprocated by emphasizing the necessity of moving towards community care but at the same time, given their deference to expert opinion and their desire not to antagonize the medical profession, accepted the diverse nature of mental illness. Both sides benefited from this exchange – the medical profession gained prestige and power, while the Labour Party was able effectively to remove discussions of mental illness from the political arena, since mental illness merely became a 'social problem' which could be ameliorated; no longer was it construed as an endemic feature of a class society, which only a socialist reconstruction of society could attempt to eradicate in any fundamental way.

Ewin's argument appears to be rather programmatic (particularly as we have presented it here, owing to limitations on space), but it is well supported by the analysis he makes of the political background of the Mental Treatment Act and the Mental Health Act. He clearly demonstrates the Labour Government's role in ensuring that there was a radical break with the principles underlying the 1890 Lunacy Act, which had been preoccupied with defending the rights of the individual against unlawful committal to a mental asylum. For example, the Royal Commission on Lunacy and Mental Disorder (1924–7) had stressed the need to move towards a medical view of mental illness but had recommended the retention of the judicial authority in all cases of the detention of the mentally ill. The Labour Government, however, insisted on including a provision whereby 'non-volitional' patients (i.e. those judged to be incapable of expressing willingness to enter a mental hospital) could be detained on medical authority alone for a period of six months or a year. As the

Minister of Health of the time insisted, this provision was 'the heart of the Bill'. But it represented the first crucial move towards removing legal constraints on the activities of the medical profession with regard to detaining the mentally ill.

This provision was also important to Labour Party policy-makers since it enshrined a crucial element of their reformist thinking. The Government therefore not only ensured that any amendment that threatened the central provision of the Bill was defeated, but also effectively curtailed detailed discussion of many of its provisions by using the technique of closure motions. The Labour Government thus achieved its aim of granting increased power to the medical profession. However, the 1930 Act was clearly transitional – as Ewins remarks:

> ... at the medical level ... there was still a marked tendency to regard many 'lunatics' as incurable and suitable only for detention ... at the political level there was still substantial opposition to this movement away from the legalistic approach to the detention of the mentally ill.

By 1959, changes in therapy combined with changes in political attitudes to remove the obstacles to the general acceptance of the medical view of mental illness. The establishment of the National Health Service in 1949 contributed to these developments since it resulted in the first steps towards the integration of the mental health services with the general health services – a process that tended to reinforce the acceptance of the medical view of mental illness.

The Mental Health Act of 1959, like the Mental Treatment Act of 1930, was preceded by a Royal Commission; but whereas the previous Commission had been composed mostly of lawyers with only two medical representatives, the 1957 Commission was dominated by the medical profession. Irrespective of their political and professional background, both Commissions accepted the medical view of mental disorder, though they differed significantly in their actual functioning. The Report of the 1957 Commission shows that opposition to granting the medical profession increased powers was far more muted – only five organizations submitting evidence supported the retention of judicial powers.

Ewins also analyses the contribution made by the legal profession to the findings of the two Royal Commissions. The profession, as a whole, did not feel its interests threatened by a movement towards medical rather than judicial control of the mentally disordered, because of fundamental social and political changes. He argues that

> while the legal profession evinced great concern for the liberty of the subject with regard to the compulsory commitment of the insane in a period dominated by the ethics of individualism and laissez-faire ... it would not oppose the movement towards extending the powers of compulsory commitment in an era of increasing state intervention and social welfare, particularly since such opposition would become increasingly futile and inimical to the interests of the profession, as consensus between the political parties with regard to social welfare (including treatment of the mentally ill) became established.[35]

The legal members of both Commissions therefore typically accepted the medical view of mental disorder and accepted that members of the medical profession should play the key role in committal procedures. But the most clear-cut indication of the acceptance of the medical view is the lack of opposition to the recommendations of the 1957 Commission, which removed the necessity for the automatic review of the grounds upon which patients were detained in hospitals. Automatic review was replaced by the proposal that patients should only have a right of appeal to a tribunal, since it was argued that a formal procedure might harm the welfare of a patient. The same argument was used to justify two further recommendations of the Commission concerning the functions of the tribunals. These were concerned with whether continued detention was necessary – not whether the original period of detention was justified or not. They were also to be given discretionary powers, which meant that they could decide whether proceedings were to be publicly reported, whether medical reports would be made available to the patient, or whether the reasons for particular decisions would be made available to patients and their relatives.

The 1957 Royal Commission Report (and the 1959 Mental Health Act which translated its recommendations into law) therefore represents the final victory of the medical profession in securing its claims to prime responsibility for the mentally disordered.

Our argument explaining why this victory was so long in being achieved has been long and somewhat tortuous, so it is worthwhile making one or two points by way of summary before once more commenting on the contemporary scene in Britain. The essence of Scull's argument is that the medical profession won control of the mad business for reasons that related to the needs of the profession, not the patients they sought to treat. As Ewins argues, the profession's final success was related to the economic and political changes that occurred as the Labour Party was emerging as a major political force. Psychiatry's claim to legitimacy has always been related to its pedigree as an offshoot of 'scientific medicine' – however, the conceptualization of medicine as 'science' is also highly problematic, being politically and historically determined.

At this point, the 'efficacy' issue also enters the argument. Most spokesmen for psychiatry will insist that it is entirely just that psychiatrists should have a unique and special role in terms of their relationship with their patients (and hence in terms of the law) because it is only psychiatrists who can administer the forms of treatment which are 'effective'. Of course, the issue of the nature of the 'effectiveness' is never really debated (and we have no space to enter into it here), but our reading of the history of psychiatry leads us to the conclusion that major changes both in health policies and in legal states of patients always takes place in a context in which the actual efficacy of the therapeutic methods of psychiatry has never been seriously explored. This will no doubt sound like heresy to many readers, but elsewhere we have reviewed evidence demonstrating that the policy of establishing psychiatric work in general hospitals did not stem from any major research programme.[36] Equally, both we and Scull,[37] in an entirelv independent piece of researching, have attempted to demonstrate that the so-called 'drug revolution' involving the new psychotropic drugs introduced from 1954/5 onwards is highly questionable. The claims of this 'revolution' need to be confronted on a very broad basis, but a critical reading of the literature on the 'revolution' reveals some singularly contradictory findings. For example, Wing and Brown's meticulous study[38] of the chronic wards of three different hospitals showed that drug treatments were of no significance in contributing to the quality of life of the patients on these wards.

With the benefit of hindsight, it is possible to examine with more critical eyes the euphoria created by this so-called 'drug revolution' which was associated from 1954 onwards with a steady fall in the number of psychiatric beds occupied by patients. Clearly psychotropic drugs are 'effective' in relieving and controlling symptoms, but this does not mean that they develop a patient's ability to deal with his or her problems in any fundamental sense. In addition there is, of course, no logical reason why psychiatry's claim to be effective needs to impinge on the basic human rights of patients. After nearly twenty years' experience of the Mental Health Act, there is now both increasing concern about the way that the psychiatric profession has been a party to undermining the rights of patients[39] and increasing lay scepticism about the claims of the profession to really provide effective help.[40]

The way we have presented these issues here is very programmatic, and further research work is obviously required, but nevertheless in order to conclude our main argument we shall now raise some further issues concerning the implications of psychiatry's final victory. This victory occurred in a period when the state increasingly intervened to regulate and control more and more aspects of everyday living. The extension of the sick role, to encompass many forms of deviancy which reflect the basic conflicts in a class society more clearly and openly than issues relating to general health or illness, has obvious advantages to the ruling groups within that society. The psychiatric profession, operating from the standpoint of self-interest, has been a willing tool in this process of mystification, but there is a very real sense in which the profession creates and perpetuates the very problems which it claims to be able to solve. Ivan Illich[41] has been primarily responsible for drawing attention to such issues in relation to general medicine, but it is worthwhile spelling out some of the subtleties of the relationship between the psychiatrist and his clientele. There is a real sense in which the sick role can be exploited by the individual who enters it. The role absolves the patient from responsibility for his 'illness', and hence carries with it the implication that the patient is no longer the agency determining the therapeutic changes that occur. It is the doctor who performs this function, and in doing so he tends to engineer passivity in his patients. Passivity can, of course, cause immense difficulties when entrance to the sick role is the result of physical illness, but when entry occurs as a result of mental disorder the situation becomes much more problematic.

The process of becoming mentally ill involves crucial personal and interpersonal conflicts and adjustments which are clearly of a different order from those involved when the diagnosis is of physical disorder. Peter Sedgwick has, of course, argued a diametrically opposed view,[42] but in our opinion his analysis is largely spurious since it fails to take account of the meaning of illness for individuals who become 'ill' either physically or mentally. Admittedly the terms 'physically' or 'mentally' are arbitrary societally-derived labels, but to fail to see that they profoundly influence both the subsequent career of the individual and the way that he or she conceptualizes the problem is peculiarly myopic. (We have no space to explore this issue here although David

Morgan's article 'Explaining mental illness'[43] does much to clarify the many vexing theoretical issues in this area.)

Fortunately some recent work by the psychiatrist, R. D. Scott, has also provided many crucial insights into the processes of becoming mentally ill.[44] The process whereby an individual becomes 'mentally ill' typically begins within family settings which are, of course, particularly difficult to study.[45] By studying the families of his own patients, Scott has provided us with a rather different perspective from that offered by sociologists, such as Scheff. His studies have demonstrated that many patients are able to use their 'madness' not only to control and influence their close relatives but also to manipulate the psychiatrists, social workers and other professionals they encounter. Scott's work, therefore, provides a rather different picture of the psychiatrist/patient relationship. The psychiatrist certainly has great power in this relationship – powers of detention, powers of providing compulsory treatment, etc. – but the patient is often in a position to exploit the situation to his own advantage. Moreover, this ability to exploit some features of the sick role can turn into an inability ever to leave the role. The patient becomes trapped in the role and uses his manipulative skills to maintain the *status quo.* Any new therapeutic initiative taken by the psychiatrist or other member of staff is dislocated and eventually negated because neither the patient nor his family can tolerate any fundamental change.

Scott has coined the useful term 'treatment barrier' to describe the obstacles to effective therapy which are created by the culturally prescribed view of mental illness prevailing in Western society.[46] A central feature of this view is that the mentally disordered are ill and hence lack responsibility for their actions. Through his painstaking research work, and through his crisis intervention methods which flow from his research, Scott has attempted to confront these obstacles directly. In doing so, he has begun to open up many exciting new avenues for a contractually based therapy which avoids the social control dimension implicit in traditional psychiatric therapies. But, nevertheless, we cannot help pointing out the historically derived paradox in his work – Scott has made a significant contribution to confronting the medical model, but he has done so from the most unlikely base – namely Napsbury Hospital, a typical example of the kind of mental hospital to be found on the outksirts of any large city – which still reminds us that the medical model still dominates British psychiatry a hundred years on. Ironically, Scott has recently moved from

Napsbury to a psychiatric unit in a general hospital. Such units are, as we have argued elsewhere,[47] an even clearer reflection of the domination of the medical model within the mental health services. And yet it is from such a base that Scott will be continuing to operate his crisis intervention approach which is, of course, aimed primarily at preventing people in crises from entering the sick role as an opportunist solution to problems which are usually embedded in their interpersonal relationships.

Scott's work has been little recognized or valued within the psychiatric profession as a whole, but this is not surprising given the reactionary nature of the profession which we have documented in this chapter. So, in order to end our contribution in a way which validly reflects this history, it is necessary to turn away from Scott's innovations and consider the future of the profession as it is articulated by its main spokesmen. We have space for only one of these – no less a personage than Sir Keith Joseph who, in introducing the 1971 White Paper 'Hospital Services for the Mentally Ill', made the following observations:

> Psychiatry is to join the rest of medicine . . . since the treatment of psychosis, neurosis and schizophrenia have been entirely changed by the drug revolution. People go into hospital with mental disorders and they are cured, and that is why we want to bring this branch of medicine into the scope of the 230 district general hospitals that are planned for England and Wales.[48]

Given the history of psychiatry which we have outlined in this chapter, need we say more?