Patients' and medical practitioners' approaches to the use of prescribed steroids in asthma: the potential for informed choice.

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LIST OF ABBREVIATIONS EMPLOYED

BMA	British Medical Association
BSA	Bovine Spongiform Encephalopathy
CJD	Creutzfeldt Jakob Disease
FDM	Fear Drive Model
FHSA	Family Health Services Authority
HBM	Health Belief Model
NHS	National Health Service
TRA	Theory of Reasoned Action

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ABSTRACT

Recent changes in legislation and access to information, through sources such as the media, may have influenced peoples' expectations for information about their prescribed medication. As a result, health care professionals may perceive an increased pressure to provide information.

A case study approach was employed to examine the sources and scope of information patients draw upon when they are prescribed oral steroids for asthma. The aim was to examine the extent to which patients can be said to exercise an 'informed choice' when they take prescribed medication. The role and importance of GPs (general practitioners) in informing the choices patients make was also examined.

Both qualitative and quantitative methods were employed. Interviews conducted with both patients and GPs indicated 'gaps' in understanding. Although the GP was the preferred source of information, patients reported that the choices they made were based on information from a range of sources. General practitioners justified not providing information to patients so as to 'protect' patients from knowledge of side effects. However, there was some awareness of the range of sources of information used by patients. A vignette technique was employed to further investigate GPs' recognition and understanding of the range of sources of information patients' use to inform the choices they make. Approximately half of the GPs who responded to the vignette recognised the influences presented. General practitioners who had been practising for a shorter period of time were significantly more likely to recognise these influences.

The conclusions draw on the literature of the sociology of the professions. In spite of the way in which the Government has sought to encourage patients to act as consumers, the state has also continued to endorse GPs right to make decisions concerning the level of information to provide. If GPs do not believe it is in the interests of patients to be provided with information to make choices about their medications then the information available to patients may be limited. This will have an impact on the ease with which patients may make 'medically' informed choices about their prescribed medication. Only when the communication between patients and GPs improves, will it be possible for a

relationship to develop where patients may be assured of gaining information from their GP at the level they feel is appropriate to enable them to make informed choices about their medication.

FORWARD

This section provides a description of the area of study, the disciplines drawn upon to provide explanatory theory and the key points from the research conducted.

The thesis is concerned with an aspect of the relationship between general medical practitioners (GPs) and patients. It stems from the idea that there have been recent changes in legislation and access to information, which may have affected the relationship between GPs and patients. Specifically, it examines the perceptions of patients and GPs concerning the provision of information about prescribed medication and the role and importance of GPs in enabling patients to make informed choices. This thesis adds to existing knowledge in the area by providing an in-depth understanding of the choices patients make about prescribed medication.

The research is located in the growing body of health services research. This is a recent literature which is yet to develop specific theories and understandings relevant to the research conducted for this thesis. For this reason, the disciplines of sociology and psychology were used to provide explanatory theory.

The sociology of the professions was employed to provide a historical and theoretical understanding of the position of both patients and medical professionals in society. The notion of 'career' (Goffman 1991), which was used to organise the findings from interviews with patients, is also drawn from sociological theory. Therefore, although the research is located within the area of health services research, the conclusions are informed by theoretical ideas drawn from sociology.

The value of sociological insights for health service research has been endorsed by Turner (1995) and by Metcalfe (1986). Thus, Turner (1995) argued that in illnesses where there is no known-cure, and in particular chronic illnesses, biological skills become less relevant and care informed by sociological insights is more effective in providing patient care than that based purely on biomedical perspectives. This argument is of particular relevance for this research which focuses on the treatment of a chronic illness, namely asthma. Moreover a series of seven articles in the British Medical Journal (Pope and Mays 1995, Mays and Pope 1995, Mays and Pope 1995, Britten 1995, Kitzinger 1995, Jones and Hunter 1995, Keen and Packwood 1995), describing the methods employed in social science studies and their appropriateness for research into issues concerned with health, demonstrate the increasing support for both the explanatory theory and the research methods traditionally associated with the social sciences. Research using these techniques has also been accepted by medical journals (Britten 1994b, Britten 1994c, Donovan et al 1989).

The thesis also considered three models drawn from psychology, which were developed to explain the way in which people balance the risks and benefits of complying with health directives. These models provide a framework for understanding the importance placed on specific types of health information. It was hoped to use these models to provide a structure for both understanding patients' beliefs about prescribed medication and for predicting their behaviour.

In the first chapter evidence of changing influences which have a bearing on the relationship between GPs and patients is provided. The influences noted are; legislative changes, alternative therapies, self-help groups and the influence of media coverage of health and illness. A key point is that patients have arguably never had such a range and diversity of influences on the choices they make about prescribed medication. As a consequence, health care professionals may perceive an increased pressure to provide information.

Patients' choices may be organised and understood using the concept of risk. However, patients' and medical practitioners' perceptions of risk draw on different sources of knowledge. It is argued that reaching a shared perception concerning the risks of treatment is likely to prove problematic. This may impede patients' attempts to make informed choices about their medication. Three models from psychology, the; health belief model, theory of reasoned action and fear drive model, were considered, but did not appear to be useful in the context of this research. In particular, they failed to take account of the individuality of people's experiences, or their current social situation; issues which are central to developing an understanding of the basis for the choices people make about their medication.

It was therefore considered necessary to broaden the theoretical constructs in the thesis and to introduce the notion of 'informed choice'. This central theme of the thesis was used to encapsulate the understanding of the choices patients perceive to be available to them, and the sources of information which they employ to make such choices.

In Britain, the provision of information by the medical practitioners has been presented in terms of informed choice, the 'rights' of patients to be informed (Collier 1989). This contrasts with the legal notion of informed consent in the USA, which dictates that information about any medical intervention, and its potential consequences, must be provided (Rees 1993). It is noted that such legal interventions do not necessarily ensure that patients are provided with information (Taylor 1984).

It is implied by the nature of informed choice, that the quality and quantity of information received by patients from GPs will vary. Potential difficulties during the process of communication between patients and GPs are examined. It is argued that these are likely to make it difficult for GPs to usefully inform the choices patients make about prescribed medication.

Whereas the first chapter is principally concerned with changes in the availability of information about medication which have the potential to alter the relationship between patients and GPs; the second uses the sociological literature on the professions to provide a more theoretical understanding of the influences on GPs.

An idea key to chapter two is that relationships between GPs and patients are also influenced by Government. It is argued that this relationship with Government underpins the position of the medical practitioner in society. The position of medical practitioners is likely to remain strong while they continue to have a monopoly over the provision of medical resources, and in particular to control the supply, and to a large part, the education, of medical labour (Turner 1995). This view has a major implication for this thesis. If GPs recognise that their position is supported by government, and not dependent on maintaining a knowledge differential, then they are more likely to provide information to patients.

It is noted that the relationship between government and medical practitioners is itself changing. Government is against the 'social closure' practised by professions and has increasingly intervened to control professional behaviour, for example, through changes such as the National Health Service and Community Care Act 1990, which gave effect to the white paper Working for Patients. These legislative changes encourage patients to act as consumers and make choices concerning their health care. This may be perceived as a challenge by medical practitioners. Despite these changes, it is argued that medical practitioners still occupy a powerful position in society, therefore, their perceptions of their role as a provider of information are a key area for investigation.

Sociologists have also considered the relationship between patients and medical practitioners. Jewson (1976) and Foucault (1991) documented shifts in the historical position of medical practitioners in their relationships with patients. They suggested that the patient has become less important as the medical profession has developed, and the success of the practitioner has become less reliant on the satisfaction of their patients, and more on recognition by their peers (Jewson 1976). If this is so, then it is not necessary to suit the individual requirements of each patient for information. From this literature, it is surmised that patients may not be provided with sufficient information by their GP to enable them to make informed choices about their medication.

Changes in legislation, in the availability of information on medical matters, the prevalence of chronic illness, and the role of alternative medicine and self-help groups, all noted in chapter one, are likely to have an effect on the relationship between GPs and patients.

On closer examination, it is argued that the changes promised by legislation have been more apparent then real. For example, few people have taken advantage of the measure which increased the ease with which it is possible to change doctors (Klein 1995). Information is available to patients through self-help groups (Kelleher 1994), the media (Karpf 1988), friends and family (Freidson 1961). However, sociologists would argue that the availability of information from outside of the consultation may not discourage people from consulting their doctor. This is demonstrated by the fact that people still consult medical practitioners with chronic illnesses, about which the patient is likely to have more knowledge than the medical practitioner (Williams 1984).

In contrast, the role of alternative medicine may be perceived as a challenge to the role of medical practitioners, as the use of alternative medicine is often associated with chronic illnesses, where solutions provided by 'traditional' medicine may have failed, or may not exist (Sharma 1992). Yet it is also suggested that alternative therapies offer proper personal contact and engender in the individual a sense of control over their body and health (Coward 1989). Thus alternative therapies may be perceived as not merely a challenge to the extent of the knowledge that medical practitioners have, but also to the type of relationship which exists between patients and medical practitioners.

What is also clear from a consideration of the relationship between patients and medical practitioners is that medical practitioners are in control of the surroundings in which a consultation takes place, and of diagnostic practices. However this control is only exercised during the consultation. Patients make the initial decision to consult the practitioner, and they also decide whether or not to adhere to any treatment which is prescribed. As noted in chapter one, there are a number of influences, such as the media, which inform patients about their prescribed medication once outside of the consultation. This makes it difficult to ascertain the exact sources of information which inform patients' decisions about their prescribed medication.

Chapter one describes changes in the availability of information about medication which have the potential to enable patients to take more control over their medical care and make informed choices about prescribed medication. However, the arguments presented in chapter two suggest that informed choice does not fit well either with GPs' professional culture, nor with the traditional role of the passive patient. General practitioners have the power to limit the information they provide to patients, thus affecting patients' capacity for making informed choices. Clearly, there are competing influences on patients when making choices about prescribed medication. It is the examination of these influences which forms the impetus for the research presented in this thesis. The fieldwork, as described in chapter three, sought to investigate the choices patients make about their prescribed medication and the provision of information to patients by GPs. It also considered the use by patients, and recognition by GPs, of sources of information other than the GP.

The aims of each stage of the research were determined and refined with reference to the findings from the previous stage. In line with the thinking of Kuhn (1970), the decisions taken concerning the methods to be employed were justified with regard to their appropriateness to address the questions being asked. Qualitative and quantitative methods were combined in order to maximise the breath of data and understanding (Silverman 1985, Roter and Frankel 1992). Initially, the research question focused on the information on which people base their choices about their medication, and the role of the GP in providing relevant and appropriate information. For this the chosen methods were in-depth interviews. Issues concerned with GPs' recognition of influences on patients were also raised through the interviews conducted with GPs. These issues were then further investigated through the construction of a vignette, based on the data from interviews with both patients and GPs.

Acknowledging that the subject of information about medication is vast, the research evolved to focus on perceptions of the side effects of steroid medication. A rationale for this approach is provided. The final conclusions were based on life history interviews conducted with patients who had been diagnosed as suffering from asthma and had received a prescription for oral steroids, interviews conducted with GPs and a vignette sent to all the GPs in Derbyshire. The research as a whole provided insights into potential communication problems between GPs and patients, and the construction of personally meaningful explanation by patients, upon which they based their choices. That patients perceived GPs had failed to provide information, and the variation in the extent to which GPs considered patients would seek and accept information from other sources, were key findings presented in this thesis. These findings support the literature, which is strengthen by the research conducted and presented in this thesis. The impact of these findings on informed choice is the substance of the final chapter.

Chapter One

SOCIAL CHANGE AND THE PATIENT - PRACTITIONER RELATIONSHIP

The aim of this research is to examine the possibility of patients making an informed choice about the use of their prescribed steroid medication. There is no general agreement in the literature as to the exact meaning of informed choice, however, for the purposes of this thesis, informed choice considers the information which patients use to make choices about their prescribed medication, with particular reference to the provision of information by general practitioners (GPs).

A case study approach involving people who had been prescribed oral steroids for the treatment of asthma is employed. Specific attention is paid to the kind of information people are given about the potential adverse effects of prescribed medication. GPs' attitudes towards providing information are also considered.

A number of changes in society have increased the availability of information about medicines and encouraged people to be better informed about their rights and their medicines. However, the idea that patients take on the responsibility for their medical treatment may challenge the traditional role of the medical professional.

Traditionally, medicine is seen as a high status profession. This status is partially maintained by the possession of esoteric medical knowledge. Legislative changes, together with the increase in the number of self-help groups, and the media coverage of health and illness, have increased patients' access to information about health issues. This increases the likelihood that patients will expect to be informed, rather than take advice on trust. Elston (1991) expanded on this point, and suggested that people have become more willing to take control of their medication, and are seeking information in order to achieve this end.

In recent years, concerns have been raised about non-adherence to prescribed medication regimens, and the resultant financial cost to the National Health Service (NHS) in terms of wasted medication (Audit Commission 1994). One explanation mooted is that there is a communication problem between patients and professionals (Britten 1994a).

This chapter considers the literature on the increase in the availability of medical information to patients, and the way the risks and benefits of medication are assessed by both patients and practitioners. As the fieldwork concentrates on people who have been diagnosed as suffering from asthma then the literature concerning the experiences of people who suffer from a chronic illness is explored. This is followed by a consideration of the debates surrounding the provision of information to patients by professionals. This involves a discussion of the reported communication problems in the relationship between medical practitioners and patients, and how this relates to the idea of informed choice. Changes which may influence patients will now be discussed.

Changing influences on patients

From the literature, four major influences on the possibility of patients adopting a more active role with regard to making an informed choice about their medication, were identified. These are:

- the introduction of legislative changes,
- the increase in interest in alternative therapies,
- the increase in the number of self-help groups,
- the possible influence of media coverage of health and illness.

All of these influences are now considered.

Legislative changes

Legislative changes in the last twelve years have generally worked to make medical practitioners more accountable to patients. The Patient's Charter, which was introduced on 1st April 1992, gives patients the right to have any complaint about National Health Service (NHS) services investigated, and to receive a full and prompt written reply from the chief executive or general manager (Department of Health 1991). The Patient's Charter also accords individuals the right to be given information about their treatment, including the risks and alternatives.

In addition, the 1989 White Paper entitled *Working For Patients* (Secretary of State for Health, Wales, Northern Ireland, and Scotland, 1989) simplified the procedure for changing doctors, by removing the requirement for the signature of the existing GP on the application for change. Both of these changes may be seen, in part, to increase the power of the patient in the medical encounter.

Importantly, although the provision is limited and records may prove difficult to access in practice, patients' right to see their medical records have improved. Under the Data Protection Act 1984, on written application, patients may see any records held on computer. Under the Access to Health Records Act 1990, patients have the right to see their written medical notes. Patients can request to see medical records made in, or after, November 1991. The initial procedure to see a manual record involves an informal request to the record holder, for example their GP, or consultant. Access may be granted to all or part of the record. For example, access may not be granted to records made by persons other than the record holder, such as those made by a previous GP. The stages become increasingly formalised, and the final place of appeal is the High Court. Although the procedure may prove complicated, it does acknowledge that patients have a right to see their records. However, because of the lengthy formalities, it is likely that the procedure will only be carried out in matter of dispute between patients and practitioners. Therefore, although it serves to increase access to information, it is unlikely to encourage a general increase in the amount of information provided by GPs to patients. Moreover, it may lead to more guarded note writing on the part of doctors.

European legislation has also increased the information available. Article 14 of the Council Directive 92/27/EEC of 31 March 1992 on the labelling of medicinal products for human use and on package leaflets, states that, from 1st January 1994, Member states of the European Community shall refuse an application for authorisation to place a medicinal product on the market where the labelling and the package leaflet do not comply with the requirements of the Directive. Article seven of this Directive lays down the regulations specifically for user package leaflets, of which, section (e) states that there should be:

> a description of the undesirable effects which can occur under normal use of the medicinal product...

Therefore, from 1 January 1994, patients in Britain had information about side effects on any new, or re-licensed, product, provided with the package. This increases the likelihood that patients will have some knowledge of the potential side effects of their medication. Furthermore, by December 1998 patients must be provided with detailed written information about all dispensed medication (Drug Therapy Bulletin 1995).

There have also been attempts to reduce over-prescribing and non-adherence. In 1993, the Annual Report of the Prescription Pricing Authority stated that over 400 million prescriptions written by GPs were dispensed annually. It estimated the cost to the NHS, for the years 1992 to 1993, to be over £3.5 billion in England and Wales alone (Audit Commission 1994). General practitioners have also been encouraged to prescribe alternative generic medicines which are cheaper than branded products. Moreover, on 1st April 1985, the Government produced a limited list of medications which, when prescribed, would be paid for by the NHS. The prescribable list of drugs was published along with a black list of drugs and preparations which are no longer available through the NHS. This was in an attempt to reduce the 'drugs bill', by not paying for items thought to be of little therapeutic benefit, such as cough medicine, and through stating how much the Government was prepared to pay for certain products.

The original proposal created a great deal of opposition from practitioners who felt their clinical autonomy was being infringed (Stacey 1991: 224). However, it did succeed in reducing the drugs bill by £75 million in the list's first year of operation (Secretary of State for Health, Wales, Northern Ireland, and Scotland 1989). Information on the cost of individual drugs, and their own prescribing costs, has also been provided to GPs with the aim of increasing their awareness of these costs. Yet, as more recent figures indicate, the costs of prescribing are still a matter for concern, and attempts have been made to find a social, as opposed to a solely legislative, solution.

An area of particular concern, is the financial cost of non-adherence to medication regimes. Over sixteen years ago, in 1980, Walton et al estimated that in the UK, the hoarded or wasted drugs that result from non-adherence, cost well in excess of £3400 million per year. The problem could stem from the idea that the giving and receiving of a prescription is a way of closing the consultation for both patient and practitioner. This suggests that there may be communication problems between patients and GPs. Moreover, Britten (1994b) challenged the idea that patients expect a prescription, and argued that GPs tend to overestimate patients' expectations, and subsequently many prescriptions are not cashed.

In summary, the consequences of legislation are firstly, that the level of information available to patients is increasing. Secondly, GPs are under pressure from the Government to reduce the drugs bill. Taking up the suggestions of Britten (1994a) and Elston (1991) presented earlier, that patients want more control over their medication, the current focus is on improved communication to reduce the amount of medication wasted through non-adherence to medical advice.

The increase in the availability of information about medication due to legislative changes has been considered. The availability of alternative therapies also provides a source of information for patients about health complaints. The possible influence of this will now be discussed.

Alternative therapies

Alternative therapies may be defined as therapeutic practices based on understandings of the human organism, the disease process and its treatment, which are different to those held by Western scientific medicine (Jary and Jary 1991). Sharma (1992) pointed out that orthodox medicine never achieved a total monopoly of medical services in Britain. The alternative medicine sector has grown steadily over the past 20 years (Murray and Shepherd 1993). This increases the number of options available and may be especially attractive to people who have long term health problems (Sharma 1992: 4). This idea is particularly relevant for this research which focuses on the chronic condition asthma. However, Coward argued that patients are attracted to alternative therapies for reasons other than merely a discontent with conventional medicine. Her argument is that more often than not individuals are attracted to the new mythology about nature and health which surrounds these practices (Coward 1989: 6). She did however concede that dissatisfaction with conventional medicine has been important in fuelling the alternative health movement. The issue of side effects is an important focus of the criticism made by alternative therapists, in that not only has conventional medicine 'failed' in its promises to deliver good health for the population, but it is actually seen as endangering people's health (Coward 1989, Sharma 1992).

The critical idea is that the use alternatives challenges the presupposition that traditional medicine has the answer for all medical problems (Sharma 1992: 3). However although people may seek advice from alternative therapists, a study conducted by Murray and Shepherd (1993) suggests that the use of alternative medicine does not lead to a reduction in demand for general practice consultations. They found that users of alternative medicine were frequent GP attenders and suffered from chronic disorders. These results suggest that people use alternative medicine in addition to orthodox treatment, however any information or explanations that people receive when consulting alternative therapists is likely to influence the choices people make about their prescribed medicines.

The changes in legislation and the increase in interest in alternative therapies reported above, demonstrates an increase in the information people may have with which to make choices about their prescribed medicines. The amount of information available to patients may also be influenced by the reported increase in the number of self-help groups. This issue will now be explored in more depth.

Self-help groups

Self-help groups are often set up to provide information and support for people who suffer from a chronic condition. They provide a source of information for patients about both their condition and their medication. Kelleher (1990: 66) stated that a number of self-help groups have sprung into existence, and that the range of medical conditions and social groupings with which they are associated, seem to be evidence of a range of needs not adequately met by either the health services, social service provision, or existing lay networks. This is not surprising considering the reported increase in the numbers of people suffering from chronic conditions (Gerhardt 1990). Kelleher's (1990) conclusions were based on an observational study of the way in which a self-help group for people with diabetes was started. He suggested that, in terms of their role, self-help groups defy simple categorisation, and that they merely exemplify some of the contradictions inherent in modern society. Therefore, the increase in the number of self-help groups may not necessarily be linked to the desire for more information on the part of the patient, it may be associated, for example, with the need for support from fellow sufferers. The role provided by a support group is likely to vary according to illness with which it is associated.

With regard to the reported increase in growth in support groups, and the focus of this research on asthma, the Campaign for Asthma provides a good example. *Asthma News*, their magazine, reported that the number of branches of the Campaign for Asthma have grown from 24 in 1979, to 189 in 1993. What is of particular interest, however, is that in 1994, the head office responded to more than 60,000 requests for information, and the Asthma Helpline handled 17,796 telephone calls (Asthma News 1995). This suggests that the Campaign for Asthma is involved in both supporting people and providing information.

In summary, self-help groups provide additional sources of information, as well as offering mutual support. Members of self-help groups may also learn of, for example, a range of treatments available, including 'alternative' therapies. As a result, it seems reasonable to assume, that the patient may be more likely to question professional advice, and possibly challenge it. In the next section, the discussion moves to consider another source of information for patients, the role of the media.

The Media

There is a long tradition of self-medication based on guidance provided by books, newspapers, magazines, the radio, and more recently, television. In certain circumstances, for example in the case of minor illnesses, such as colds, for which the medical profession have no cure, this tradition of self-medication is positively encouraged. Taylor (1984) suggested that, in the context of an 'information revolution', medical knowledge has become a burgeoning industry. She stated that consumers from every social class are bombarded with 'medical facts' from popular magazines, from self-help books and from television programmes, which range from consulting doctors as an integral part of radio or television programmes, to documentaries. Moreover, Karpf (1988) pointed out:

> Time and time again, researchers cite television as a major source of viewers' health information, secondary only to doctors and dentists, and sometimes overtaking them. Television and radio documentaries also rated highly as trustworthy sources of health information (P. 220).

The media may perform a similar role to that of a support group. One example of this was the coverage, in 1984, by the consumer affairs programme *That's Life*, of the experiences of people who had been using tranquillisers over an extended period of time (Lacey et al 1985). This provided an arena in which people could express their experiences, and it attempted to call to account the pharmaceutical companies who produced the tranquillisers, and the doctors who prescribed them. This demonstrated the power, and ability, of the media to recognise and publicise the experiences of 'ordinary people'. The coverage produced an environment in which people could describe and share their experiences in a manner similar to that provided by a support group.

Yet it is a contentious issue whether the media actually initiates of merely reflects public concerns. Brown (1989: 5) concluded that it is more likely that the media consolidates, rather than changes views. This argument suggests that the media does not alter peoples' beliefs about medication, but merely reinforces existing beliefs. The literature which examines peoples' beliefs about medication is examined later (see P. 27).

Bury and Gabe (1994: 66) argued that it is the medical profession that has come to dominate the media's coverage of health and illness. Thus media coverage on medical issues may differ from consultations more in terms of the quantity of information provided, than in actual content. Nonetheless, in the case of newspapers, magazines, and television, there may be a temptation to sensationalise the risks of medication in an attempt to gain more readers / viewers. Patients' perceptions of their medicines may reflect concerns raised by such sensationalism.

This idea that risk associated with medicines may be sensationalised was presented by Inman (1986: 44). He stated that compared with the risks of smoking, drinking or travel, the risks involved in drug treatment are minimal, yet risks continue to receive publicity from the media. In his opinion perceptions of risk have been distorted by 'horror stories' presented by the media, which in turn has caused public opinion to swing too far in the direction of excessive concern about rare side effects, while common benefits are ignored.

However, Inman's argument fails to appreciate the distress and suffering which may be experienced on an individual level, due to side effects. Inman's argument is concerned with the statistical balance between risks and benefits of medication, yet the statistical balance is meaningless to an individual who suffers a side effect which is personally devastating. This is generally the type of story which receives publicity from newspapers and television. An example of this is provided by the people fighting for non-fault compensation for the side effects they have experienced after taking corticosteroids (Gray, Daily Express, 23rd Nov. 1994, *Here and Now*, BBC, 23rd Nov. 1994).

Nelkin (1989) suggested that it is not only medication risks which are subject to media coverage. She stated:

> Every day we are deluged with warnings about "invisible hazards" ... We worry about dangers in the workplace, in our homes, and in the very food we eat (Nelkin 1989: 95).

The notion of risk is explored in more detail later (see P. 25)

The content of media presentations of risks to health vary in the extent to which they support, or challenge, the medical profession. Although it is impossible to assess the effect of the media coverage of issues of health on each individual, this coverage is likely to be incorporated into the process by which patients decide to consult their GP. This process was described by Friedson (1961), is known as the 'lay referral system'. This idea will now be explored.

The idea of a lay referral system for patients

As early as 1961, Freidson argued that a 'lay referral system' operates which in some ways mirrors the professional referral system. This was said to start within the nuclear family, and subsequently involve consulting people further removed from the immediate family until finally a medical professional is consulted. It has also been suggested that what is said in the actual consultation is likely to be remembered, interpreted and evaluated within the context of the 'lay referral system' (Tuckett et al 1985, Calnan 1987).

Freidson (1961) suggested that the significance of the 'lay referral system' may be underestimated. He believed that commiseration and helpful suggestions, trading symptoms and experiences, as well as gossip about doctors and medical institutions, are a ubiquitous part of everyday life. Therefore, to study interpersonal influence is about as difficult as studying such routine and unwitting behaviour as coughing and yawning. It is only the marked influence that stands out in the memory. The patient may, therefore, be unable to determine the exact origins of their information, and beliefs, about medication. Moreover, advice provided by the medical profession is likely to be interpreted within a patient's existing beliefs so the same piece of advice may have a different effect when given to different people, depending on their existing knowledge.

The idea of the lay referral system is important because it suggests that any information provided to patients has the potential to be interpreted differently depending on the existing knowledge and social networks of the individual patient concerned.

Legislative changes, alternative therapies, the increase in the number of self-help groups, and the influence of the media, have increased the availability of information to patients. The lay referral system demonstrates how information from these sources may be disseminated. All of these sources of information have implications for the choices people make with regard to their prescribed medicines.

The discussion will now move on to further consider the idea of patients' beliefs with reference to the choices people make with regard to their prescribed medicines. As the research focuses on the provision of information about the potential adverse effects of prescribed medication, then the notion of risk is used to provide a framework within which the beliefs of patients and practitioners may be examined and compared.

The risks and benefits of medication: patient and practitioner beliefs

The idea of risk has recently risen in prominence (Douglas 1994: x), and is relevant to this research which focuses on the information upon which patients' decisions about medication are based, with particular reference to the provision of information about potential side effects.

Risk is a concept with different meanings according to who is using the term (Lupton 1993:425). In it's original usage, 'risk' is neutral, referring to the probability or mathematical likelihood, of an event occurring, however this is no longer the case (Douglas 1990). Thus in Lupton's (1993) opinion understandings of risks differ according to social and cultural circumstances, and are laden with meaning.

Short (1984) supported Lupton's belief and argued that the analysis of risk is driven by the hazards associated with advances in science and technology, and risks have been conceptualised in terms of costs and benefits. However, what has been ignored is how people live with these risks and how living with risks affects their perceptions and behaviour (Short 1984). Lupton (1993) argued that the research methods used to assess risk perceptions fail to take account of respondents' belief systems. Au understanding shared by the Royal Society (1992) who stated one of its aims to be to consider and help bridge the gap between what is said to be scientific, and capable of being measured, and the way in which public opinion gauges a risk and makes decisions. Thus idea of a 'gap' between expert and public accounts of risk will now be examined.

Differences in perceptions of risks by experts and the public has been highlighted by Douglas (1994). She suggests that experts attempt to be objective, while the public draw on a range of conflicting sources, such as friends and family. An area which she perceives to be of specific interest is in defining how a consensus is reached (Douglas 1994).

With specific reference to medicine, the argument, in general terms, is that patients give subjective meaning to both the experience of their illness and the effects of the medication, while practitioners, in contrast, are likely to perceive the risks and benefits of medicines from a professional, emotionally detached standpoint. This reflects their training, their belief in the medical model, and the expectations placed on them. In the next section, these different perceptions will be examined, with reference to the existing literature.

The basis for patient's decisions about medication

Handwerker (1994: 670) argued that the interaction between patients and practitioners is problematic. Practitioners draw on language that is resolutely scientific and medical, while patients deal with personal experiences and feelings. In particular, the expression of risk in terms of a statistic of probability, may be especially meaningless. Probabilities are generalisations. Each patient's experience of illness and of medication is an individual experience; therefore, probabilities are not particularly relevant in this context as it fails to take account of all the other factors which will also influence decisions taken about the medication (Handwerker 1994: 673).This suggests a potential for a 'gap' in understanding between patients and practitioners, which may make communication between patients and GPs problematic.

People's beliefs about risks may well diverge from the medical 'reality' due to, for example, myths, or cultural beliefs, or even personal experience. Individual constructions of risk may be shaped by biographies and bodily knowledge, by cultural models and by ongoing experiences as patients in the health care system (Becker and Nachigall 1994: 510). This idea is examined through the use of life histories in the fieldwork. Peoples' perceptions of risk are also likely to be influenced by media coverage of particular risks.

Handwerker (1994) further informed the debate with her suggestion that even when interpretations of medical risk between practitioner and patient are compatible, there are other structural factors which impinge on a person's ability to seek or follow medical advice, such as physical access to health care. Decisions about risks and benefits are not taken in a vacuum, but are affected by a number of social factors.

Becker and Nachigall's research pointed to the complex nature of lay constructions of risk, which may encompass both gains and losses. The women and men in their study of the cultural construction of risk in treatment for infertility in the U.S. weighed the danger of taking action against the danger of inaction, in this case continued childlessness, and rarely viewed the risks as outweighing the potential benefits (Becker and Nachigall 1994: 516). Forrest (1995) also suggested that people weigh up the risks and benefits of treatment carefully. She interviewed women who had decided not to have their children vaccinated, and suggested that their objections centred around the possibility of vaccine damage, vaccine effectiveness, and concerns about the effects of vaccine on long term health. Moreover, they also refused vaccinations on the grounds of a lack of information concerning the risks and benefits of vaccination, and the lack of informed debate on the subject. This suggests that people may make decisions not to have medical treatment on the basis of inadequate information, as well as because of concerns about the potential risks. Both these studies point to a sophisticated weighing up of the risks and benefits in each situation, suggesting that although practitioners and patients may act differently, this cannot be taken to imply that patients are not making a carefully considered decision.

Hence, the 'risks' that people take may make sense when related to their lifestyle. Graham's (1994) study demonstrated how women living in difficult circumstances may consciously use cigarettes to cope with the stresses and strains of daily life. The sample did not lack knowledge about the health damaging potential of smoking, yet they choose to continue smoking on the basis of their beliefs about the benefits in their particular circumstances. McKeganey (1992: 112) added to this with his suggestion, based on fieldwork, that a woman might know and understand the risks of unprotected sex; nevertheless, the social stigma often attached to carrying condoms can mean that condoms are not used and sexual risks are taken. It is therefore apparent that patients use their own judgements at key points in the medical encounter, for example in deciding to consult the doctor, and having done so, then deciding whether to adhere to the prescribed regimen. Moreover, individual patients differ in their evaluation of risk (Hellinger 1989). The beliefs behind patients' conceptions of risk are now considered in more detail.

Patient's beliefs about medicines

Ley (1988) suggested that people may have their own ideas and attitudes about illness and the use of medicines, and interpret information within a framework of their own ideas. These ideas are often termed 'lay beliefs' or 'lay knowledge'. Such beliefs are likely to influence patient's judgements both within, and outside of, a consultation.

Donovan et al (1989) suggested that people's beliefs are internally consistent and rational in their own terms. They are not static, but change in the light of new experiences and the availability of believable information. Gabe (1994: 214) supported these ideas, and argued that work on the nature of people's beliefs has indicated that although they may suggest a lack of knowledge of anatomy and physiology, and may be based on strong emotions, they can be both coherent and logical, and may provide an effective narrative reconstruction of the relationship between illness and the individual's perception of his or her place in the world. Moreover, Herzlich and Pierret (1987: 107) suggested that people need to relate a given illness to their environment and their life as a whole, in order to give it meaning. These ideas are explored in the fieldwork through the use of life histories in interviews with patients.

Stacey uses the term 'people knowledge' rather than 'lay knowledge' to describe peoples' ideas and attitudes about illness and medication (Stacey 1994: 89). She expressed her belief that the term 'lay' suggests the absence of something valuable or prestigious, and may imply less competence, or even less moral worth. Following this reasoning, the term 'people knowledge' has generally been adopted here in place of 'lay knowledge'.

Any advice, either medical or non-medical, given to patients, has to pass through the filter of their own beliefs. Donovan et al (1989: 60) explained this with the suggestion that illness is abnormal to patients, and so they make use of both their own beliefs, as well as those of conventional medicine.

By it's very nature, sickness is a profound threat to the social and personal existence of the individual. Patients must therefore have some way of interpreting the nature of the threat that illness poses, in addition to means by which these effects may be mitigated. In other words, a belief system must imbue illness experiences with meaning and provide alternative courses of action (Blumhagen 1980: 198-199). This idea is taken up by Mechanic (1992: 1347) who stated that initially people explain their symptoms by applying common sense conceptions which may be idiosyncratic, or taken from socially prevalent conventional explanations such as stress, lack of sleep, overwork, or intense strenuous exercise. Such lay explanations affect subsequent appraisal of, and decisions to, seek care, self-medicate, or rearrange one's daily regimen.

The idea of the value of patients' knowledge moved one stage further with their presentation of the notion of lay experts (Tuckett et al 1985, Popay and Williams 1996). Thus:

> through a more or less systematic process whereby experience is checked against life events, circumstances and history, lay people acquire an 'expert' body of knowledge, different from, but equal to that of professionals in the public health field (Popay and Williams 1996: 760).

The term 'lay expert' implies that patients have knowledge which may be used by them in the consultation process, as opposed to being passive recipients, as implied by the biomedical model of health. They continued:

> Like professionals, lay experts may on occasions be 'wrong' ... On other occasions there will be no simple 'answer' - no right or wrong - and lay and professional knowledge will both have a contribution to make to understanding. While lacking accreditation in any formal sense, lay experts can be accorded recognition on the basis of relevant extensive experience (Popay and Williams 1996: 761).

They (Popay and Williams 1996:760) described how the question of the meanings that people attach to health and illness has emerged as an important theme within the social sciences and humanities in the last twenty years. However, these meanings are commonly described as 'lay beliefs'. They also point out that only recently have these understandings begun to be accorded the status of knowledge, and then only within the social sciences and humanities. This highlights an additional complication to the assessment of patient's knowledge, in terms of the status of knowledge, and the fact that assessments may vary between groups of people. In Britain, the GP is the primary point of contact in the NHS, and as such is the main interface between biomedical concepts of disease and lay beliefs about illness. They are therefore in an important position with regard to the status of these beliefs, and the level of credence they gain.

Popay and Williams (1996: 760) argued that if research in the field of public health is to develop more robust and holistic explanations for patterns of health and illness in contemporary society, then it must utilise and build on new knowledge such as the meanings health, illness, disability, and risk, have for people. This was investigated in the fieldwork for this project, which is presented in Chapter Three.

However, Blumhagen (1980: 198) argued that it can not be assumed that either individual or expert belief systems are of a uniform structure, and unaffected by the individuals themselves. What should be examined is how a particular lay person interacts with a particular expert, and from these interactions conclusions may then be drawn about the whole system. For this reason the fieldwork incorporated understandings from both patients and health care practitioners.

Having examined patients beliefs, the discussion will now move on to consider medical practitioners' beliefs concerning risk.

The practitioner's beliefs about medicines

Handwerker (1994) stated that in the medical literature, risk is defined in terms of medical probability translated from epidemiological studies. Epidemiology seeks to develop predictive models for an entire population, so from an epidemiological perspective, risk refers to the estimated excess frequency of occurrence of an event in a population, and is usually presented in the form of a statistical probability, or as a statement of relative risk (Becker and Nachigall 1994: 507).

The assessment of risk and benefit, with regard to medicines, has generally been seen as a matter for professional judgement. Becker and Nachigall (1994) stated their belief that physicians view risk, from within their biomedical ideology, as an intrinsic part of the practice of medicine. The assessment of risk on the part of a medical professional must balance the responsibility for the health of the patient, against the patient's right to make decisions about their own lives, and to make their own assessment of the risks and benefits of treatment. However this may differ between practitioners, particularly between GPs who have built up a relationship with their patients and may therefore be more flexible on the basis of knowledge of a particular patient's social and medical circumstances, and consultants who by the nature of the organisation of their work generally do not have the opportunity to develop such relationships.

Decisions about treatment with medicines present the medical practitioner with the problem of weighing up the risks and benefits of a particular medication, and of making the decision about the amount of information to provide to the patient. This is further complicated by the fact there are implications in terms of the time spent explaining the risks and benefits of medication, and the possible need for counselling, both of which may operate as a constraint on practitioners who wish to provide information.

Practitioners may not always provide information about medicines, because of their concern that it may make patients anxious, with the result that they will not adhere to their suggested treatment (Morris 1982). This is despite research evidence to the contrary (Lamb et al 1994, Kerrigan et al 1993). Moreover, medical practitioners may be faced with a difficult dilemma if a patient, having been informed about a range of treatments and their possible risks and benefits, then opts for a treatment which the practitioner feels is less effective then the recommended one, or even refuses treatment altogether (Brock and Wartman 1990).

It was suggested earlier that the idea of risk has become more prominent in society, as this research focuses on medicines, then it is useful to examine the issue of medical risks. In one of her examples Douglas (1994) argued that:

> doctor knowing they may be sued for giving the wrong advice have to practice a more cautious medicine, their manners have to be formal and distant, they watch their words and resort to objective probabilities to explain the choices that face their patients. They must not advise in these choices, as they may be sued for wrong advice. The scientific language of risks allows them to let the patient choose for themselves (Douglas 1994: 15).

The example she gives concerns a woman given the probability of having a baby who has Down's Syndrome and having to decide whether to have an amniocentesis test, which itself is associated with the risk of miscarriage. Patients may now be encouraged to make choices about their medicines based on the relative objective risks, as presented by their medical practitioner. This is not because there is a belief that patients should be allowed to make decisions about their medical care, but instead is because along with the increasing prominence of the idea of risk, has gone the notion of blame (Douglas 1994). In this situation the practitioner may feel forced to make the patient make a decision based on objective risks factors, regardless of whether or not the practitioner feels this is appropriate.

In the light of this discussion it is logical to conclude that the increasing availability of information concerning medicines discussed in the first section, together with increased publicity about risks in general, has the potential to influence patient's beliefs, and hence their assessment of the risks and benefits of their medication. Patients who are informed, from any source, medical or non-medical, are likely to be in a stronger position to make choices about their medications, and this may appear to threaten the established relationship between the patient and the practitioner. The basis of the relationship between patients and practitioners is explored in chapter two.

Nelkin (1989) highlighted the presentation by the media of 'health scares', what is perhaps more crucial is the way in which these issues are then dealt with by 'experts' in society. With reference to this, Giddens (1991) stated:

> In the face of such complexity, it is not surprising that some people withdraw their trust from virtually all medical practitioners, perhaps consulting them only in times of desperation, and stick doggedly to whatever established habits they have formed for themselves (Giddens 1991: 121).

'Health scares' are generally associated with a failure to provide consistent information about the safety, or otherwise, of the item in question. This has been highlighted recently with the scares concerning the safety of beef, with reference to the alleged link between Bovine Spongiform Encephalopathy (BSE) and Creutzfeldt Jakob disease (CJD). If information is not provided both confidently and consistently by 'experts', then the general public will remain confused, in addition to being concerned. This is likely to have an influence on relationships between 'experts' and the public, such as the relationship between doctors and patients. A reduction of the faith in 'experts' in society may also mean that alternative, less formal, sources of information may be actively sought. This is likely to have an effect on the relationship between patients and GPs. All of the ideas presented above will now be further explored through examination of the models which have been developed in an attempt to predict peoples' behaviour in risk situations.

Models used to predict peoples' behaviour in situations which involve risks

Two models, the health belief model (HBM), and the theory of reasoned action (TRA) have been used to consider beliefs about treatment and the effect of these beliefs on adherence to medication regimens. In addition, the fear drive model (FDM), has also been used to predict peoples' behaviour in risk situations. These theories are now considered in turn.

The variables of the HBM, conceptualised into the context of health-related behaviour, are: the desire to avoid illness, or to get well if ill, and the belief that a specific health action will prevent, or ameliorate, illness. The HBM contains the following four dimensions.

- Perceived susceptibility; the subjective perception of the risk of contracting a condition.
- Perceived severity; this includes evaluations of both medical or clinical consequences, and the possible social consequences of a condition.
- Perceived benefits; this depends upon beliefs regarding the effectiveness of the various actions available in reducing the disease threat.
- Perceived barriers; that the potentially negative aspects of a particular health action may act as an impediment to undertaking the recommended behaviour. For example, the possibility of side effects.

Thus, the combined levels of susceptibility and severity provide the force to act, and the perception of benefits, minus the barriers, defines the preferred course of action (Janz and Becker 1984: 2). However, it is also believed that some stimulus, or 'cue to action', is necessary to trigger the decision-making process. This could be internal, for example symptoms, or external, such as communications from the media (Janz and Becker 1984: 3). Unfortunately, as Janz and Becker point out, few studies have attempted to assess the contribution of 'cues', for example Health Education advertising campaigns, or documentaries on the television, in predicting health actions.

The HBM has also been criticised on the grounds that the theory analyses the structure of health beliefs, and thus health culture, yet fails to recognise that people have social constraints on their behaviour, such as family and work commitments (Good 1994: 42).

Furthermore, the complexity of the meanings with which people associate illness and the range of beliefs they have are simplified so as to be comparable to with the rationality of biomedical knowledge (Good 1994: 42). Therefore, the model is seen as too inflexible as it fails to take account of individual differences and thus to provide an accurate insight into what occurs in reality.

In the opinion of Tuckett et al (1985), while the HBM and the research it has inspired may have helped to place patients' beliefs on the medical agenda, they have done so in a way which confirms the stereotypical idea that patients' beliefs are a nuisance and an indicator of patients' ignorance. Moreover, the HBM provides little guidance about how to deal with patients' beliefs in a consultation situation, and has inspired little or no research which directly examines what doctors and patients say to each other.

The TRA has been developed by Ajzen and Fishbein (1980). The theory aims to predict and understand human behaviour. The idea is that people use whatever information is available to them in order to make decisions. This is not to say that their behaviour based on these decisions will always appear to be reasonable or appropriate from an objective point of view, but Ajzen and Fishbein (1980) argue that a person's behaviour follows logically and systematically from whatever information happens to be available to them. This theory is useful in that it highlights the idea that people may make decisions on the basis of whatever information they have, even if it may be deemed to be incomplete. This idea may be relevant in terms of this research, which is concerned with the information patients use in order to make choices about their prescribed medicines. However, it will not be employed in this thesis as the TRA attempts not only to understand peoples' behaviour, but also to predict it. The research presented here only seeks to explain, not to predict, therefore the model cannot be fully employed.

The fear-drive model provides an attempt to explain peoples' reactions to risk. The assumption made is that information about a threat and a means of protection from it are insufficient to generate behavioural change. Thus some motivating information must be combined with factual material about an illness for a person to act according to their fears (Leventhal 1980). According to the model, people with a limited understanding of the potential side effects of medication, experience anxiety, which provides the motivation to seek more information and reassurance from others. The more serious the perceived side effects, the stronger the motivation should be to ask for advice. The final part of the FDM suggests that once information has been obtained and fear is lowered, the coping response becomes permanent. Thus people may not recall having any fear about side effects as they may have 'coped' with the fear. Thus the model fails to fully take account of any fears experienced when the patient first received a prescription.

Both the HBM, and the FDM may be seen to present people as reacting to fears about their medication in an abstract way, and fail to take account of the individuality of peoples' experiences, or of their current social situation. If, as has been argued here, behaviour is more dependent on people's personal circumstances and how these affect their beliefs and the options they have, it may prove difficult to use them to predict peoples' behaviour with regard to their medication. An issue of particular concern here are the choices patients feel able to make in relation to their medicines, and the information upon which these choices are based. A person's knowledge concerning their illness and medicines is likely to differ for acute and chronic conditions. This thesis is concerned with the use of steroids for a chronic condition, namely asthma. For this reason the experiences of patients who have chronic conditions will now be examined.

The experience of chronic illness

Gerhardt, (1990), argued that modern medicine has greatly increased the life expectancy of people with chronic illness. This is largely due to the fact that secondary infections, which were the most frequent cause of death of the chronically ill until the 1940's, have virtually become extinct. The other factor is the improvement of drug treatment, as well as surgical intervention, which has dramatically improved the life expectancy of people suffering from chronic illness. What is particularly crucial about these developments is that a person suffering from a chronic illness may know more about their condition and its' treatment based on their own experience, than the medical practitioner does. This may affect the usual pattern of authority in the relationship between patients and medical practitioners. Furthermore, Taylor (1984) suggested that chronic illness may cause a problem to the medical profession, in that the efficacy of the physician is often measured according to whether they have done something, a feat which may not be possible with certain chronic diseases, such as arthritis. What is perhaps ironic is that advances in medical technology have allowed these diseases to be detected, yet there are no effective measures with which that may be treated (Beck 1992: 204).

The research documented in this thesis focuses on a chronic condition, asthma. In-depth interviews were conducted which considered people's experience of asthma, an approach also used by Snadden and Brown (1992) in their study of people's experience of asthma. The interviews adopted a life history approach which was used to gain a long term perspective on people's experience of their illness. This approach is in line with previous research concerned with the experiences of people who have a chronic illness (Charmaz 1983, Williams, 1984, Radley and Green 1987).

As the research was concerned with the choices people made with regard to their medication, and the basis for these choices, then general issues concerned with the idea of informed choice will now be explored.

Informed choice: the issues

The idea of informed choice, as employed here, involves the consideration of the provision of information by GPs to patients, and the information patients use to make choices about their medication.

The question may be presented in terms of the idea that doctors have a moral duty to inform patients about the treatment they are receiving (Collier 1989: 134). Alternatively, Todd (1983) highlighted the role of the medical practitioner using their judgement on behalf of the patient. He stated:

> This popular modern view that all patients should be told 'everything' is absurd and cruel ... if patients were given open access to their files they would be confused and worried but rarely, if ever, benefited (Todd 1983: 37).

Thus Collier (1989) presented the idea of informed choice by highlighting the 'rights' of the patient to be informed, while Todd sees the role of the medical practitioner in terms of providing patients with protection from information which they may not understand and may cause them anxiety. Pierce (1993) presented a more pragmatic view in which she stressed the individuality of patients, and expressed some reservations about providing the same level of information to everyone. She suggested that there is a need for more individualised interventions and support for patients who may have to make difficult decisions. This is because people make decisions differently, and react to situations where they have to make decisions in a different way. Therefore, patients may react differently, even if they are provided with the same amount of information. The implication is that an attempt needs to be made to 'tailor' the amount of information provided to the individual patient. Pierce (1993) advocated the GP determining the amount of information that the patient receives. However, if this is to be successful it requires that there is a good communicative relationship between patients and medical practitioners.

Faulder (1985: 33) argued that the elements of choice and voluntariness are essential to the concept of consent. Choice implies that we are aware of at least one alternative to the action proposed - that of saying no - but there may be several other positive possibilities which we can only know about if we are informed of their existence. Only if someone is 'informed' can a true choice be made. This, however, raises the problem of producing a standard definition of the amount, and level, of information which it is necessary to provide in order for a person to be 'informed' so they are able to make choices about their prescribed medicines.

Currently, case law indicates that if a patient requests no information, then a doctor need offer only minimal advice (Collier 1989: 134). A possible solution to this is that the current reliance on ethical codes, and the professional judgement of the practitioner could be replaced, with a legal requirement to disclose the risks associated with prescribed treatments. However, a legal requirement has its own problems and it is useful at this point to consider a comparable analogy in terms of the way the process of informed consent currently works in the United States of America. There, informed consent is legally defined as the procedure whereby patients consent to, or refuse, a medical intervention based upon information provided by a health care professional. Such information should cover the nature of the intervention and its' potential consequences (Rees 1993). Patient consent is usually provided in the form of a written declaration.

However, Rees (1993) was critical of the operation of informed consent and suggested that what passes as disclosure and consent may rather be viewed as a process whereby the patient legitimates the unilateral decisions of the doctor. While Katz (1984: 26) suggested that any disclosures have been limited to informing patients about the risks and benefits of proposed treatment, not about alternatives, and certainly not about the certainties and uncertainties inherent in most treatment options. Most importantly, conversations with patients are not conducted in the spirit of inviting patients to make decisions in partnership with their physicians (Katz 1984).

Taylor (1984) further informed the debate with his suggestion that the right to informed consent has made doctors cautious and led to them:

> hiding behind consent forms ... instead of talking to their patients (Taylor 1984: 211).

Thus, the ironic effect of a legal intervention intended to enhance the dialogue between doctors and patients, may have been to reduce it. The experience in the USA of using legislation as a tool to enable patients to make an 'informed choice' with regard to their medication, suggests that legislation may create inflexibility in the patient - practitioner relationship. More importantly, legislation could offer protection for doctors rather than patients. Practitioners who satisfy a legislative requirement to provide only a basic level of information could leave aggrieved patients, who find they were not fully informed of potential problems, with no legal redress if they experience untoward consequences from their treatment.

In addition to all the problems noted above, if such a measure were to be implemented in Britain, the first potential problem would be in drafting the legislation in broad enough terms to cover all eventualities. In particular, it would require a definition for a 'basic level' of information in particular cases, which in turn creates the problem of identifying a person or group to make such a decision. To be at least adequate, the information given on any prescribed medication, and its potential side effects, would need to be of sufficient depth, but at a level such that any particular patient would understand the options being presented. This would prove impossible to determine, given the individuality of each patient. Moreover, the blunt instrument of legislative power is unlikely to be able to discriminate sufficiently between the varying stages of severity of the range of medical conditions presented to GPs, nor could it cater for the wide variation in the personalities and wishes of patients. Ruling out a legislative solution completely, however, would leave the problem to the judgement of health professionals, a solution which may be equally problematic.

In summary, difficulties in providing a definition of either how much information is wanted by individual patients, or the amount of information about alternatives it is necessary to provide in order to present a choice, raises questions about whether it is possible to identify what constitutes an 'informed choice'.

The medical practitioner may possess knowledge about medicines, however the patient has access to many other sources of information and makes the final decision whether or not to adhere to the suggested regimen. Therefore the fieldwork will examine the information which patients have and the decisions that they take with regard to their medication. Following this GPs' perceptions of their role with regard to the provision of information will be examined.

The provision of information to patients in an attempt to enable them to make an informed decision about their medication may be seen by patients as a basic 'right' (Collier 1989). The argument is that a patient should be able to make decisions which directly affect their health on the basis of all the information that is currently available. It has been shown that if a patient feels involved in decisions, and in control, then this results in better health care outcomes (Frederickson and Bull 1995). Moreover, informing patients may benefit practitioners by preventing litigation in the event of negative or side effects.

The relationship between patients and medical practitioners with regard to the provision of information is examined in the fieldwork. This relationship is influenced by a long history in which is embedded the expectations each has of each other. The way in which the relationship between the patient and the practitioner works therefore requires further scrutiny. The historical basis of the relationship between patients and practitioners, together with general theoretical concepts as they relate to the relationship, will be presented in the next chapter. Here, studies which have adopted the relationship between patients and medical practitioners as their main focus, will be considered next.

Communication in the relationship between practitioners and patients

If, in line with the thinking of Pierce (1993), the judgement of the medical practitioner is to relied upon in order to establish the information which is provided to patients, then it is necessary to gain an understanding of this relationship. The changes which have already been documented may have created pressures on GPs to provide more information to patients. Research evidence suggests that there may be problems in the communication between patients and practitioners, which in turn affect the kinds of information GPs provide to patients. Tuckett et al (1986: 178) suggested that communication failures in consultations seem to result from the prevalent professional ethos which devalues the patient's contribution and so prevents an exchange of views. The ethos is part of an old stereotype of the patient, which may also have been responsible for the kinds of interpretation from previous research findings which blamed failures of communication on patients and their ignorance. Thus, Ley's (1988: 14) suggestion that it is likely that patients do not understand, or they misinterpret, much of what they are told may mean practitioners criticise patients, rather than considering whether the information they present to patients is appropriate and comprehensible.

The apparent reluctance of patients to challenge medical expertise directly, carries a legacy which means there is a long way to go to encourage patients to initiate discussion and play their part in insisting on information and choice. As recently as 1989, Collier argued that real changes in the therapeutic dialogue would not take place until the atmosphere between doctor and patient altered in the consulting room. This would only happen when they enjoyed mutual respect, recognised each others' needs, rights and limitations, and worked together towards a common goal (Collier 1989). The importance of good communication was also stressed by Maguire (1984), who suggested that many illnesses, and their treatments, may cause substantial practical, social and psychological problems. These can hinder recovery and seriously impair the patient's quality of life unless they are recognised and dealt with appropriately.

Stimson and Webb (1975) saw consultations as a process of negotiation between doctor and patient, whereby each tries to influence the other regarding the outcome of the consultation, the diagnosis given, and the treatment prescribed. Helman (1978) was critical of this and stated:

> What they [Stimson and Webb] fail to stress is that this negotiation is not only between two individuals, but between two systems of thought, lay and professional, folk and biomedical; that is, between two seemingly incompatible systems for the explanation and alleviation of misfortune (Helman 1978: 108).

Thus Helman (1978) believed the relationship between patients and practitioners was complicated by the fact that their ideas stem from different beliefs about the nature of health and illness. Williams and Wood (1986) supported this, and argued that the main difficulty in terms of communication between patients and doctors is the fact:

> that doctor and patient have different purposes: whereas the doctor's objective is to explain the aetiology of the disease, the patient may be more concerned to make sense of the disruption caused by the disease (P. 1435)

This suggests a 'gap' between the perspectives of the patient and the practitioner (Gould 1985: 33). If patients and practitioners differ in their objectives then trying to encourage mutual participation is likely to prove difficult.

Stacey (1994) expanded on this idea of a 'gap' between the perceptions of patients and practitioners. She believed that the main distinction between professional and people knowledge is that the latter is most often experiential knowledge. It derives from peoples' experience. The knowledge is not necessarily either simple or simplistic, however it is not the type of knowledge which is codified in books or taught in educational institutions. It is not systematised and generalised like professional knowledge. These beliefs and understandings about health and illness are modified and passed on, mostly by word of mouth, and offend against positivist canons by including the subjective along with the objective (Stacey 1994: 90). If people knowledge and medical views coincide patients may be happy to accept a doctor's advice or treatment. However if they clash and patients may be confused, dissatisfied and sometimes critical of medical staff (Donovan et al 1989: 60).

Although these studies are interesting, it might be expected that medical practitioners have some insight into these beliefs by virtue of the fact they live in the same society.

However, Popay and Williams (1996) suggested that although health professionals may recognise that lay people have opinions about the causes of ill-health, these opinions may be construed as interesting, but in some ways misguided, "ways of knowing" about health and illness. In the light of these beliefs, the problem is how to ensure effective communication between doctor and patient in the clinical encounter. A situation further complicated by the fact that each doctor and each patient is an individual, and therefore may have a different perception of the balance of risk to benefit.

Despite these difficulties, Blaxter (1983: 69) argued that unless the doctor's view of the disease process is reconciled with the patient's views, and the diagnosis makes sense in terms of the patient's models, then it may not be accepted. A view supported by Calnan (1991). Moreover, Williams and Wood (1986: 1437) argued that, it is not so much a question of examining lay beliefs as just another set of facts, but of recognising the place they occupy in a patient's life and thoughts. Weston and Brown (1989: 82) suggested the responsibility lies with:

> doctors to understand their patients' experience rather then hastily dismissing patients' idiosyncratic statements simply as evidence of their need to be better informed medically.

Yet, Collier (1989: 134) presented an alternative view with his belief that patients have obligations as well as rights; they needed to take responsibility for understanding their disease, and share with the doctor in the treatment. A view supported by Weijts (1994) who argued for a move towards more mutual responsibility and participation by patients in health care decisions.

Patients' beliefs have implications for practitioners who seek to educate patients (Donovan et al 1989: 61). Donovan et al (1989) claimed that education cannot be assumed merely to be a simple matter of transferring information from a knowing doctor to the ignorant patient. As the evidence presented above indicates, patients are not 'blank sheets', most have sets of beliefs that determine their understanding and behaviour. They suggested that there should be a shift towards more interactive information provision to allow the more active participation of the patient. This would enable information to be built both on to, and into, patients' existing beliefs, not imposed upon them. Therefore an improved clinical response may be sought through understanding and negotiation.

Yet, Davidson et al (1991) suggested that the division between scientific or professional knowledge on the one hand, and lay or public belief on the other was outdated. They continued:

> The two strands, though, are rarely if ever entirely separable, indeed the range of thought and belief in both the professional and public domains is so broad that the traditional lay/scientific dichotomy may well have outlived its' usefulness. The situation is not surprising if we consider that we are dealing with a society from which science has grown and to which science and scientists continue to belong, a society where the media of mass communication carry an enormous volume of up-to-date scientific information (Davidson et al 1991: 5).

These ideas are supported by Giddens (1991) who suggested that the development of professional medicine itself has led to the "sieving off" of knowledge and curative skills once held by many lay people. Moreover, he also believes that modern life is a complex affair, and consequently there are many "filter back" processes whereby technical knowledge, in one shape or another, is reappropriated by lay persons and routinely applied in the course of their everyday life (Giddens 1990: 145). Thus the 'gap' between the knowledge held by medical practitioners and patients may be reducing because of general changes in society.

Stevens (1986) suggested that changes in conventional medicine were related to changes in views of medical knowledge:

> Just as the notion of the patient's role is shifting from the legitimated dependency of the 'sick role' to more active involvement in clinical decision-making, physicians are seeking to develop roles and skills that allow for complexity and uncertainty, rather than assuming that scientific expertise lays down 'one best' way of proceeding in most cases. In turn, redrawing the doctor-patient relationship implies new definitions of medicine, diagnosis and disease (Stevens 1986: 84).

The arguments presented above suggest that the relationship between the patient and the practitioner is changing, particularly with reference to the status of medical knowledge.

Elston (1991) summed up the changes in the relationship between patients and practitioners with her assertion that:

> According to many commentators, the past decade has witnessed not only the end of an era of optimism about scientific medicine, but also, and not

> unconnectedly, the 'end of the era of the passive patient' and the beginning of the era of active 'consumerism' (P.77).

At its simplest, it is argued that an increase in 'people knowledge' about medicine, declining deference to experts in society at large, changing attitudes of doctors, and changing patterns of morbidity, are modifying social expectations about doctor - patient relationships in the direction of mutual participation. Rees (1993: 2) supported this apparent shift with his suggestion that patients have turned to other sources for information about health, although he saw this as a possible consequence of, rather than necessarily as a cause of, the degeneration of the unequal relationship between patients and GPs.

The theories that have been proposed with regard to the changing relationship between medical practitioners and patients suggest that the relationship may be moving in the direction of mutual participation. However, if, as has also been suggested, the beliefs of patients and of practitioners are based on different premises, then it may prove difficult to achieve mutual participation unless this 'gap' can be bridged. This may create problems for patients being able to make informed choices. Research evidence which presents patients attempts to gain information, and thus contributes to the idea of informed choice, will now be considered.

The provision of information by general practitioners: the evidence

This section demonstrates the difficulty of providing a definition of informed choice based on the literature. The research focuses on the choices patients make and the information on which these choices are based. Here, research which considers the information patients say they want about their medicines is presented, with specific reference to information concerning the side effects of medication. The issue of side effects has been identified as information about side effects is likely to affect the decisions patients make about their medication. The aim is to provide insights into the ways in which the changes in legislation, increases in alternative therapy, increases in the number of self-help groups, the influence of the television and newspapers, and the increase in chronic illness, may have affected patients' perceptions of their treatment. Keown et al (1984) found a discrepancy between the beliefs of medical practitioners and the expressed wishes of patients concerning the provision of information about side effects. Keown et al (1984), suggested that this may well leave patients dissatisfied.

Indeed, although GPs are widely considered to be the primary source of information on the risks and benefits of medication (Chapman 1988), studies have generally agreed that the advice GPs give is often inadequate. In a study by Ridout et al (1986), the authors concluded that most patients wanted more information about prescribed medication, especially their unwanted side effects, than GPs were offering. Two years later, Gardner et al (1988) conducted a study to determine patients' perceptions concerning the importance of information about medication. The results showed that patients rated precautions to be aware of, drug interactions, and adverse effects most highly. However, although patients rated information about medication-related problems to be of the highest importance, it was found that certain aspects of this information were communicated only seventeen percent of the time. The authors concluded that:

> Physicians, pharmacists, and others who provide patient education about medications should be sensitive to the fact that patients perceive information about adverse drug effects and interactions to be highly important. A heightened awareness, and provision of such information to patients may lead to improved patient satisfaction and compliance (Gardner et al 1988: 598).

Both of these studies indicated that patients wanted more information about their medication.

The work conducted by Boreham and Gibson (1978) may be seen to contribute to the insights provided by the studies detailed above. They investigated whether patients attempted to obtain the information during the consultation that they had stated, prior to the consultation, that they wanted. They interviewed a sample of eighty female patients about their views on, and expectations of, the provision of information concerning their illness. Patient behaviour during the consultation was then observed, focusing specifically on the means whereby patients gained information, how doctors responded to questions from patients, and the way both patient and doctor influenced the communication process. The resulting data indicated considerable discrepancies between patients' expectations and their subsequent behaviour. In general, patients did not attempt to gain the information which they had previously expressed a wish for.

Boreham and Gibson's (1978) results were supported by more recent work conducted by Beisecker and Beisecker in 1990. They found that patients expressed a strong desire to receive medical information in a wide variety of medical areas. However, on average, patients exhibited relatively low levels of information seeking behaviour when interacting with doctors. The authors provide a possible explanation for this occurrence relating to the fact that the study primarily included people with chronic diseases or disabilities, who may have obtained all the information they believed they required. However, the authors also found that patients placed responsibility for medical decision making on the physician. They suggested that patients wanted to be knowledgeable about their medical care without necessarily becoming responsible for medical care decisions. Moreover, that patients wanted to be given information about their medical conditions, yet were unwilling to use that information to make informed decisions regarding their own health care. Both this study, and the evidence from Boreham and Gibson (1978), suggest that patients may state a wish to gain information, but may not obtain this stated level of information in practice. The conclusions of Beisecker and Beisecker's study also cast doubt on the idea that providing patients with information will necessarily lead to them making informed decisions with regard to their medication.

Collier (1989: xiii) provided an alternative explanation for these findings with his belief that patients believe themselves to be in a hostile environment and fear 'bothering the doctor' or 'wasting his time'. The stress patients experience may also account for Ley's (1988: 27) belief, based on a number of studies, that patients are given more information in the consultation than they report that they have received when questioned after the consultation.

Frederikson and Bull (1995) also challenged the conclusions reached by Beisecker and Beisecker (1990). They suggested that if patients are encouraged to adopt an active role in the consultation, then the outcome is beneficial for both patients and practitioners. In their study involving eighty patients, they set up an experiment using a patient information leaflet which emphasised the role of the 'good' patient as a provider of information, beyond the mere recitation of symptoms. The leaflet also suggested that patients should ask for more information on particular points of interest. The results showed that patients responded positively to the leaflet, and a comparison of doctors' ratings of the quality of communication in consultation, showed that the experimental group performed better than the control group. This suggests that encouraging patients to be more active in the consultation may be the key to improving communication between doctors and patients. However, it also suggests that patients may only feel comfortable with adopting a more active role if GPs indicate that it is appropriate. The major implication of this, is that the responsibility to improve the quality of communication in the relationship between patients and medical practitioners is seen to rest with medical practitioners.

A number of complex factors combine to construct the problem of communicating information between doctors and patients in the consultative relationship. A key issue is the practitioner's belief that informing patients about side effects is likely to cause problems with adherence to the prescribed regimen.

Lamb et al (1994) found evidence to suggest that only a quarter of physicians discussed potential side effects with their patients. This was explained in part by the belief that the suggestion of side effects could lead patients to believe they were experiencing them. Lamb et al's study investigated this by giving one group of people verbal instructions and a handout describing the name, purpose, dose, and three most common side effects of the medication they had been prescribed. Another group received the usual discharge instructions. Patients were interviewed fourteen to twenty one days later using a standardised questionnaire. The results showed no difference in the incidence of targeted side effects for specific medications between the groups studied.

Conrad (1985: 29) suggested that adherence was more complex than merely reliant on the provision of information by health care professionals. He argued that the meanings people attribute to medication in their everyday lives are more salient than doctor-patient interaction for understanding why people alter their prescribed medication regimens. An idea also supported by Britten (1994a). The issue is presented as primarily a problem of self-regulation rather than one of adherence. Conrad's idea, based on a study of people with epilepsy, is that in fact altering a medication regimen should be seen as an attempt to assert some degree of control over their condition. So, the quality of the information transacted between patient and doctor may not necessarily be the only factor that influences adherence.

Moreover, the idea that adherence is correlated strongly with the patient's understanding of their condition has also been presented (Carenini et al 1994). However, Wright (1993) argued that the problem was broader than this, and contended that both doctors' prejudices and patients' perceptions needed to be taken into account, since strategies for improvement must include educating the prescriber as well as counselling the patient.

Moreover, the usefulness of concept of adherence itself has been placed under attack. Donovan and Blake (1992) suggested that the concept of adherence was irrelevant to patients who weigh up their personal costs and benefits, taking into account their own particular social circumstances. Their study of patients who attended a rheumatology clinic suggested that this was the crucial element in defining whether or not they adhered to their doctor's medication advice. What might seem an irrational act of non-adherence to the GP, could be a rational decision from the point of view of the patient. Therefore, giving people information to encourage them to make a choice about their treatment, could therefore lead to non-adherence. Given these findings, Donovan and Blake (1992) have argued that the solution to wasted resources lies in a more open, co-operative doctor - patient relationship.

Studies suggest that decisions about adherence take account of a greater number of factors than merely the provision of information. Moreover, other studies suggest that the provision of information is beneficial to patients. Legg England and Evans (1992) suggested that in recent decades a large body of research has accumulated suggesting that the health of patients is favourably affected by the perception that they have some control over their treatment. Affleck and Tennen (1987) supported this with reference to their work with people who had rheumatoid arthritis. The patients who reported greater personal control over their medical care and treatment expressed more positive mood and were rated as exhibiting more positive adjustment to their illness. Savage (1986) also supported this view, with her argument that women need to have control over the birth process, and that professional advisers who are prepared to share information and decision making with women are essential to helping them to exercise control, and emerge as confident parents. Furthermore, Kerrigan et al (1993) found that, in men undergoing elective inguinal hernia repair, a very detailed account of what might go wrong did not increase patient anxiety significantly. This evidence suggests that doctors may give people detailed information about their treatment, including information about any possible side effects, without adversely affecting treatment by increasing anxiety. Moreover, information about their treatment may actually benefit the patient.

There is also evidence that patients actively seek information from sources other than medical practitioners, further suggesting that practitioners may leave patients unsatisfied. In 1981, Scrambler et al conducted a study of working class women, in which they found that 71 percent of the symptom episodes that led to a medical consultation were discussed with a lay-person before a visit to the doctor was made. Ten years later, a study conducted by Davidson et al (1991) noted the variety of influences on people. As an example they suggested that the development of ideas about coronary candidacy, or the 'kind of person who gets heart trouble', are not constructed on an entirely individual basis. They continued:

> Rather it is a collective activity with many different types of input. The mass media and official bodies are the sources of much processed scientific data: reports of illness and death are available from family, friends, work colleagues and neighbours, celebrities such as politicians and sports people suffer and die in the public gaze: individuals make observations of themselves and those around them. None of this cultural activity takes place in a vacuum ... Such is the cultural condition of individuals in mass society that the opinions, attitudes and perspectives they hold tend to be personalised modifications of generalised systems passed on from agencies of the wider society. (Davidson et al 1991: 7).

These sources of information and advice will be examined in the fieldwork with both patients and medical practitioners. Moreover, Davidson et al (1991) further suggested that lay theories of health may in some cases extend beyond medical expertise:

> 'Lay' theories may display a complex and thoughtful interest in the relationship between preventability and inevitability, an area sometimes glossed over by the confidence in control which pervades the ideology of modern Western medicine (Davidson et al 1991: 4).

These understandings may, in fact, be seen to inform the medical debates surrounding risk, with regard to coronary candidacy. While, in terms of the content of patients' beliefs, Baxter's (1983) interviews about health and illness with 46 woman, suggested that the models of disease process presented by the women, although often factually incorrect, were in principle no different to those of advanced medical science, and no less sophisticated. Thus information sources other than the medical profession, and the beliefs systems informed by these sources should not be degraded.

Summary

Evidence has been presented concerning the provision of information to patients by medical practitioners. Problems of communication between practitioners and patients, and the existence of a 'gap' in perceptions between the two parties may reduce the opportunities for patients to receive the information that they want. These ideas have been considered with reference to changes in the relationship between doctors and patients , in particular the idea that patients are becoming better informed, and that the relationship may be moving from a situation characterised by the patients' reliance on the doctor, towards a relationship characterised by mutual participation in the therapeutic encounter.

Conclusions and the way forward

The possibility of patients exercising an informed choice has been used here to consider information provided by GPs to patients, along with other potential sources of information for patients.. Changes in legislation, the growth of self-help groups, the increasing interest in alternative therapies, and changes in the nature of illness, all reflect a shift away from an all - knowing professional who prescribes treatment and expects the patient to adhere rigidly to prescribed regimens, and a shift towards the idea that patients should participate in decisions concerning medication therapy. This has been related to the presentation of information about health issues in the media, and to the idea of a lay referral system, which uses these sources of information, and is influenced by the changes detailed above. The literature suggests that patients construct sophisticated belief systems and use these when making decisions about their medication. These derive from a number of sources and take account of personal experiences over life histories and changing circumstances.

All of the ideas presented above are considered in the fieldwork, which adopts a case study approach focusing on the side effects of oral steroid medication prescribed for asthma, a chronic condition. Particular reference will be made to the way patients' perceive information concerning side effects, as information about side effects is likely to affect the decisions patients make about their medication. The provision of information and the choices patients make are assessed, although the difficulty of defining an 'informed choice' have been noted. General practitioners' perceptions concerning the information they believe it necessary to provide, the basis of the decision as to the information to be provided, and the way in which they believe this information is employed by patients when making choices with regard to their medication, are then investigated.

If patients are to make an informed choice then issues regarding the communication between patients and medical practitioners are of vital importance. An understanding of the relationship between patients and medical practitioners, based on sociological theory, is presented in the next chapter. This is used to consider the role played by the expectations of both patients and practitioners in the consulting room. The underlying idea is that changes which are evident in practice, represent a shift in both the character and the outcomes of the consultative doctor - patient relationship, away from the dominance of professional interest, and towards the interests of the patient. Before this may be assessed, the position of the medical professional in society is examined in order to gain a deeper understanding of possible problems in communication between patients and practitioners.

Chapter Two

THE RELATIONSHIP BETWEEN PATIENTS AND PRACTITIONERS: INSIGHTS GAINED FROM SOCIOLOGICAL THEORY

In Chapter One it was argued that legislative changes, together with increases in the number of self-help groups, and the media coverage of health and illness, have increased patients' access to information about health issues and that as a result patients may now be better informed about their medicines. These changes may also increase the likelihood of patients expecting to be informed by medical professionals, rather than just taking advice on trust. This chapter seeks to provide a background upon which these changes may be better understood by examining the history of the relationship between practitioners and patients, with particular reference to the idea of professionalism. The aim is to use sociological theory to provide an in-depth understanding of both the position of medical professional and patients.

Medicine is one of the oldest professions, and doctors have a high status in society. This status extends beyond the realms of their professional expertise, and doctors have traditionally been seen as respected members of the community. Lupton (1994) suggested that Western societies in the late twentieth century are characterised by increasing disillusionment with scientific medicine. Her view is that, paradoxically, doctors are criticised for abusing their medical power by controlling or oppressing their patients, while at the same time access to medical care is widely regarded as a social good and the inalienable right of every person. There is also an increasing dependence upon biomedicine to provide the answers to social as well as medical problems. Yet, in Lupton's opinion, despite an apparent disillusionment with scientific medicine, the mythology of the beneficent, god-like physician, remains dominant. Therefore, although medical professionals may be criticised, they are still seen as a legitimate sources of help and advice when people are ill.

The traditional model of the relationship between medical practitioners and patients depicts medical practitioners as professional experts with the knowledge and experience to know what is best for patients. Patients, in turn, are characterised by a passive acceptance of the advice provided by the medical practitioner. However, if patients are becoming more informed about their medicines, as suggested in chapter one, then this model of the relationship between patients and medical practitioners may be subject to change.

In this chapter, theoretical perspectives on the definition of a profession, and the debates surrounding professional practice, will be presented. This is followed by key theoretical ideas concerning the historical position of the medical professional in society, which demonstrate that the relationships between practitioners, and both the Government, and patients, has altered over time. The impact on the relationship between patients and practitioners of more recent changes will then be discussed. The changes under consideration are carried forward from chapter one, they are: legislative changes, the role of alternative medicine, the increase in the number of self-help groups, and the media. The reported increase in chronic illness is also considered. Information from these sources may influence patients through the operation of lay referral systems, and may affect their beliefs about health and illness.

The literature on professionalism

A key concept used in analysing the relationship between patients and practitioners is professionalism. The word profession conjures up images of security, public service, respectability, independence and prestige (Hurd 1986). However, professional practice has come under increasing scrutiny. Gabe et al (1994: ix) argued that until the late 1960's most sociologists accepted medicine's definition of itself as a profession, which used its expert knowledge and special skills rationally and benevolently. Subsequently, the growth of a more critical sociology encouraged an alternative view of medicine as a dominating profession, characterised either by its monopoly of the provision of health services, or by its response to the requirements of the economic system (Gabe et al 1994: ix). The literature on what constitutes a profession will now be examined in order to provide a context for the development of an understanding of the role of the medical professional.

What is a profession?

The medical profession is frequently cited as the archetypal profession (Harrison and Pollitt 1994: 5) However, since the mid-nineteenth century many other groups have claimed professional status and both the term and its application are still debated. Sociological attempts to define a profession, and to explain professionalisation have varied (Turner 1995). These debates will now be examined.

Freidson (1973: 30) claimed that once an occupation is accepted as a profession, then by definition it is knowledgeable. The 'classic' model of the attributes necessary to be deemed a professional include reference to controls over entry through mechanisms such as the requirement for certain qualifications, and a lengthy training. Until the late 1960's, the 'trait' model and the functionalist model held a position of ascendancy in the sociology of the professions (Saks 1995). Both of these models tended to view professions as being essentially altruistic occupations (Saks 1995). This view of professionals as knowledgeable experts which was current in the 1950s and 1960s, has since been challenged. However, these older models of professionalism still retain some currency, and are worth exploring in a little more detail. Initially, the trait model will be briefly described, and the criticisms made of it noted, then the functionalist model will be presented, together with the criticisms made of it. Following this, both the trait model and the functionalist model will be considered in terms of their implications for the relationship between patients and practitioners.

'Trait' models of professionalism tend to comprise a list of 'attributes' which are said to represent the common core of professional occupations. The traits listed commonly include altruism, and the adoption of certain codes of conduct, which may be enforced through professional associations. The practitioner is perceived to be acting in the interests of the patient, which suggests that the patient should listen and follow the instructions given. As the doctor is perceived to be acting in the best interests of the patient, and then the patient, knowing this, passively follows the advice given.

Johnson (1972: 23-26) presented a range of criticisms of the trait approach. He suggested that commentators do not agree on which elements should be included, and that the traits identified may be based on the idea that there are, or at least were, 'true' professions which exhibit certain essential elements. Moreover, the professionals' definition of themselves may be accepted without question. This may result in a partial, and even biased, view of the elements which characterise a profession. Johnson (1972) also stated that there is little attempt to theoretically articulate the relationship between the elements presented. Thus a list of apparently unrelated elements may be produced. As no clearly defined and generally accepted characteristics are presented, then the trait model does not provide a means by which professions may be distinguished from occupations. The model also fails to provide a clearly defined reason why the medical profession retains the status it does.

The functionalist model is more abstract than the 'trait' model, and is marked by a greater degree of explanatory intent. There are no attempts to present an exhaustive list of 'traits'; rather the components of the models are limited to those elements which are said to have functional relevance for society as a whole, or to the relationship between professionals and clients (Johnson 1972: 23). The functionalist perspective, promulgated by Durkheim, states that professionals are altruistic, and are motivated by public service rather than personal profit. Parsons (1964) also added to these generally accepted features of esoteric knowledge and altruism by stating that, by virtue of their expertise and knowledge, the professional has authority over the 'lay' person.

Parsons (1951) theory of the social organisation of medical practice is based on the assumption that, in most instances, patients could not be expected to consent to medical examination or treatment on the basis of an understanding of its' medical merits. Thus, a patient, by virtue of being ill, passes responsibility for their well-being to the doctor (Parsons 1951). In line with this, Melville and Johnson (1982: 17) contended that patients are ignorant of the real dangers of the drugs they take and are content to leave the judgement of the risk to the doctor. Therefore, according to this argument, patients may agree to the demands and suggestions of their doctors not because they understand the need for them, but because they have faith in the doctor as a person and a representative of the profession (Tuckett et al 1985: 3). This presents the model of a patient who passively accepts the authority of the practitioner, and is the basis for Parsons' 'sick role'.

As with the 'trait' model presented above, the functionalist model presents the relationship between practitioners and patients as one in which the practitioner, by virtue of their expertise, decides what is in the best interests of the patient, and the patient accepts this decision. Accountability is within the profession itself, not a matter between patients and professionals. The perspective does not allow for the situation in which either party does not fulfil their expected role, and where conflict may result. Yet, as Hurd (1986) pointed out, conflict is built into the professional - client relationship due to the expertise of the professional and the ignorance of the client. Thus, in practice, this model may be seen as flawed, as it fails to take account of situations in which the doctor may be challenged. However, from the perspective of the doctor, this model may make sense in that it allows them to practise their skills and expertise, to the benefit of people without these skills and expertise.

Hughes (1981) also criticised the functionalist model. He believed that professionals did not simply operate for the benefits of their clients, and that their organisation and practices also protected and benefited the practitioners. This criticism suggests that the authority of the practitioner may be exercised partly on the basis of self-interest, as opposed to altruism.

As demonstrated by the criticisms presented above, these models have lost credence sociologically. However, they may still represent the view of professionalism held by professional groups themselves. In certain cases patients, especially older patients, may also support these accounts of the attributes of professionals.

Two other views are relevant to this discussion. The first is the Marxist concept of professionals as controlling agents of the state. This view gained considerable currency in the sociological literature of the 1970's. The other explanation is a Weberian argument, and is concerned with the link between the organisation of the medical profession and their position in society. These alternative perspectives will be explored next.

Marx or Weber? Alternative perspectives on the patient - practitioner relationship

Marxist thinkers believe that the economy is a primary influence on the formation and development of social structures, and on the ideas that people hold about both themselves and their societies. Turner (1995) suggested that the:

> Marxist analysis of the profession denies the normative function of the professions and questions its ethical character, by emphasising the role of power and market control over the legitimising function of knowledge (P. 130).

The Marxist perspective presents professionals as agents of social control. Medicine is presented as a tool of the ruling economic class, and medical care seen as geared towards class exploitation. The power and privilege of the medical profession is said to emanate from its value to the capitalist class in maintaining the status quo. Indeed, the medical profession does exercise a role of social control, in terms of making legitimate the withdrawal from social responsibilities, through, for example, medical certificates which entitle people to time off of work (Hurd 1986).

Yet, medical professionals are not seen by Marxists to be in a position to exercise control over their own work, instead they are seen as puppets of the state (Hart 1985). However, in practice, evidence suggests that this is not true. Even under the NHS in Britain, where the state defines need on the basis of citizenship, the medical profession retains the authority to define the priority of treatment. Moreover, hospital doctors still conduct private practice outside of the control of the NHS (Hurd 1986). Therefore, doctors may be seen to have autonomy, even within a ‘national health service’.

The Marxist perspective has lost ground in favour of the thinking of Weber, who believed the source of medicine’s power to be within its political organisation as a profession, rather than through any allegiance to the ruling economic class. According to this perspective, it is occupational control which is the basis of the status position of medical practitioners in society, not, as is claimed by the functionalist model of medical practice, the inherently socially valued skills or expertise of the professional.

Arguing from a neo-Weberian perspective, Freidson (1970) claimed that knowledge itself does not give power; only exclusive knowledge gives power to its possessors. Therefore, in his opinion, it is not enough to merely possess esoteric knowledge, in order to have power, this knowledge must be made exclusive. This perspective sees professions as occupational groups who are primarily defined in terms of their monopolistic control over the market for particular services (Parry and Parry 1976). A privileged position in society is maintained through the granting of a monopoly by the state, and the guaranteed security of tenure to those allowed to practice (Lupton 1994). This position has also been noted by the feminist critique of the medical profession. Feminists view the medical professions as a:

> privileged occupational group exercising patriarchal authority and control over subordinate social groups, especially over women (Turner 1995: 130).

In the case of the medical profession, the Government provides official recognition of, and supports, their occupationally generated definitions of health and ill-health, and their beliefs concerning what constitutes acceptable therapy.

Daniels (1973: 39) claimed that it was generally agreed that one of the crucial characteristics of a profession is autonomy. In practice, autonomy exists when the leaders of a profession define or regulate the nature of the service offered, through, for example, control over recruitment, the certification of members, and the definition of standards of adequate practice. Autonomy is also demonstrated by a profession's ability to organise its own work and freedom from outside control (Freidson 1970, Blane 1991). Freidson (1973: 33) argued that the strongest professions have managed to preserve much of the right to be the arbitrators of their own work performance, justified by the claim that they are the only ones who know enough to be able to evaluate it properly, and that they are also committed to ensuring that performance measures up to basic standards. This is the case with the medical profession (Larkin 1983). A possible consequence of this is that medical professionals may be reluctant to encourage patients to make informed choices about their medication, as this may challenge their position. However, the claim to be sole arbitrators over their own work has been challenged over the past twenty years from a variety of sources, including the Government. This will be examined in more detail later (see P. 63).

A further explanation for the medical profession's place in society was presented by Parry and Parry (1976). On the basis of their study of the medical profession, they argued that the 'producer - consumer' relationship is a less important consideration than the wish to establish a monopoly of practice in order to get rid of rival medical approaches. The basic strategy employed is the doctors' claim to unique competence, which is legally supported. This explanation is in agreement with the idea that occupational control over the provision of medical certain resources is the basis for the position of the medical practitioner, not the inherently socially valued skills or expertise of the professional.

If professionalisation is regarded as an occupational strategy in which social groups attempt to control their place within the market, then it is necessary to remember that changes in the market may result in de-skilling (proletarianisation) and de-professionalisation (Turner 1995: 139). Proletarianisation and de-professionalisation are two ideas which have been developed to explain the changes taking place in medical power and authority in the United States of America (Gabe et al 1992). These ideas will now be briefly explored.

Elston (1992) argued that the proletarianisation and the de-professionalisation theories share some common features. Both claim that medicine is a victim of general social trends affecting the claims of all occupations to privileged status on the basis of technical expertise, and therefore that medicine may be losing its status. The specific claims of each of these theories will now be examined.

Advocates of the proletarianisation idea, which draws on Marxist theories, believe recent challenges to the British medical profession's freedom from managerial accountability to the state as a buyer of medical services to be significant as a sign of de-skilling. Traditionally, de-skilling is occurs when conventional skills and expertise are replaced by new technology (Elston 1992). However, in this case it is taken to include the freedom to exercise certain skills. In terms of exercising specific medical skills, Turner (1995) argues that although the medical profession has a systematic body of knowledge, which could make it subject to de-skilling, as the use of this knowledge requires considerable interpretation, the medical profession is not likely to be subject to de-skilling. The ability to withstand the processes of de-skilling will be to some extent a consequence of the cohesion of a professional group, its level of government support and its location within the hierarchy of professional skills (Turner 1995). With specific reference to the medical profession, doctors may be seen as relatively cohesive and to present a united front in the form of the British Medical Association (BMA). Yet, they are also fragmented by the division into a number of specialities, who are likely to fight each other over, for example, scarce resources. In terms of government support the medical profession in Britain is supported by legitimisation for biomedicine through the NHS. However, the government has increasingly challenged the medical profession through the 1980's and 1990's. The changing relationship between the government and medical practitioners is considered in more detail on P 63. Yet, if Coburn's (1992) view of the medical profession as the single most powerful occupation in health and health care is adopted, then it is likely that it may well be able to withstand any pressures of de-skilling.

The position of medical professionals in society has also been challenged by the idea of deprofessionalisation, the idea that medicine's status has been undermined as the 'knowledge gap' between physicians and consumers has diminished (Gabe et al 1994: ix). As with the notion of de-skilling, this is also based on the suggestion of challenges to the skills and expertise of the medical profession. Gabe et al (1994) stated:

> Within the general backlash against professional society, lay people have been less willing to accept uncritically the judgements of doctors (P. ix).

Arguments suggesting that people may be becoming more knowledgeable and thus may be more prepared to challenge the medical professional were explored in Chapter One. This idea also forms part of the rationale for the research conducted for this thesis.

Of relevance to the ideas presented above concerning the idea that patients may be becoming more knowledgeable about medical matters is Giddens' (1990), challenge on the notion of an 'expert'. He suggested that knowledge passes between professionals and non-professionals in both directions. Doctors, and many other types of professional expert, derive power from the knowledge claims which their codes of practice incorporate. Yet, the specialisation inherent in expertise means that all experts are themselves lay - people most of the time. In turn, no-one can interact with abstract systems without mastering some of the rudiments of the principles upon which they are based: interacting with those people who are designated experts in society demands at least some element of expertise. Therefore, following the ideas presented by Giddens (1990), occupational control over resources may be seen as more important than expertise as expertise is not exclusive. Yet, occupational control over resources may be perceived as expertise because it ensures that people may only obtain those services from people who have certain designated skills, for which they have state-legitimated credentials. The argument is that it is social closure, the process by which groups try to maintain exclusive control over resources by limiting access to them (Giddens 1989: 214), which ensures this authority. This explanation appears to ignore alternative therapies. This may be because such treatment is not free of charge from those practitioners under the terms of the National Health Service. The position of alternative therapies, including the way in which they may inform the decisions patients take with regard to their medication, will be discussed in more detail later in this chapter (see P. 75).

Therefore, professionalisation may be seen as an occupational strategy to maintain certain rewards and privileges. Turner (1995: 151) argues that a sociological approach to the professions can combine the perspectives of Weberian and Marxist sociology. Thus, in order to understand the position of medical professionals in society it is necessary to consider both the class structure and the economy, but it is also necessary to consider a profession's relationship in the market. Turner (1995) summed up the position of medical professionals with the statement that:

> The possession of a knowledge base and access to patients as clients leads in the workplace to considerable privileges in the form of occupational autonomy and control over the process by which the service is delivered (Turner 1995: 152)

By these means, the exercise of social closure, the maintenance of autonomy and the development of bodies of knowledge which permit sufficient scope for interpretation with a result that the patient remains relatively ignorant, and thus subordinate, the medical profession has maintains its position in society (Turner 1995).

The argument presented above has implications for the ideas presented in chapter one that to patients may become more informed about their medicines. They suggest that even if patients are provided with more information, this alone will not necessarily challenge the position of the medical professional. However, it may be perceived as a challenge by medical practitioners themselves.

Chapter one documented shifts in legislation, changes in the availability of information about medicines and treatment, the increase in chronic illness, and the interest expressed concerning alternative medicine. These changes suggest that the 'gap' in knowledge between the expert medical practitioner and the patient may be decreasing as information becomes available from a number of different sources. The implications of these changes in terms of the relationship between patients and practitioners will be examined later (see P. 70). First, the changing role of the practitioner will be presented, as it is necessary to gain an understanding of the position and role of the practitioner in order to fully assess the implications of the changes detailed in Chapter One.

The changing role of the medical practitioner

The position of the medical professional both in terms of the relationship with the Government, and the relationship with patients, has altered considerably in the last two centuries. Initially, an examination of legislative changes, and their implementation, dating from the last century is presented. The evidence demonstrates the way in which the relationship between medical professionals and the Government has altered over time. This will be followed by a consideration of shifts in the relationship between medical practitioners and patients.

The influence of Government policy and legislative changes on the position of the medical practitioner

It has been suggested above that the government's legitimisation of the position of medical professionals helps them to maintain their status in society. The twentieth century has seen the Government increasingly intervene to control professional behaviour. The return for this control has been Government supported legitimacy for specific, accredited professional practices. The arguments above have considered the idea of expertise to explain the position held by the medical practitioner, however the weight of argument comes down in favour of the idea that their status depends on social closure and their occupational control of health care resources. The most significant piece of legislation, which underpins the closure of the medical profession, is the 1858 Medical Registration Act. This laid the foundations for autonomous self-control. This autonomy is provided, supported and sometimes challenged by the Government.

The Medical Registration Act determines the medical profession's legally privileged position in Britain (Saks 1995: 73). A key provision is that the Act forbids non-qualified persons representing themselves as registered practitioners. Qualifications and registrations are sanctioned by the General Medical Council (Harrison and Pollitt 1994). Therefore one particular view of medical practice and knowledge is defined as legitimate. Although other sources of medical help may be sought, the existence of Governmental support for one particular view of medical treatment legitimates that particular system.

As a result other systems become marginalised. The very term 'alternative' medicine demonstrates the status of this form of medical practice. However, the increasing interest in 'alternative' medicine documented in Chapter One suggests that, despite Governmental support for traditional biomedicine, people are interested in other approaches.

Larkin (1983: 113) also noted the monopolistic power of the medical profession such that it subordinates adjacent and related occupations. Hurd (1986), considered the 1961 Medical Act which continued the trend to legitimate the bio-medical model by giving practitioners such as physiotherapists, radiographers, dieticians and occupational therapists, formal recognition and a measure of control over internal discipline and training. However, in return for Governmental - recognition they may only accept patients who are referred by doctors, and the treatment should be along the lines suggested by doctors. A consequence of this Act is that certain practitioners, such as osteopaths and chiropractors, refuse to enter the NHS as this would mean their practices would be restricted to those defined under the 1961 Medical Act. Moreover, it would imply a change in their beliefs about the causes and treatment of medical conditions (Hurd 1986).

The National Insurance Act of 1911, and the introduction of the NHS, which came into existence on 5th July 1948 (Klein 1995), also demonstrated the Government's continued support for biomedicine.

The National Insurance Act introduced provisions for health and unemployment insurance. The health side of the Act provided a system of panel practice whereby every worker below a certain wage was insured with contributions paid by the worker, the employer and the Government. For GPs, the Act provided an assured clientele and better fees (Stacey 1991). Stacey (1991: 114) argued that throughout the inter-war period, proposals for the reorganisation of health care provision were made, many edging towards universal and publicly funded health care. What was clear was that it would be a service organised by, and for, biomedicine. By the mid-twentieth century, the medical professional was firmly entrenched at the head of an increasingly complex division of labour. It had subordinated to its own service a variety of other health-care workers, and was served by an increasingly stratified nursing profession. All these factors were to greatly influence the structure of the emergent NHS (Stacey 1991: 114-115).

When the NHS was being developed, the medical professional had a great deal of influence. One example of this was the concession gained by GPs, who did not want to become 'salaried servants'. They argued successfully to remain independent entrepreneurs, using a system of payment by capitation. In 1974 the NHS underwent reforms with the aim of creating an increased responsibility to managerial authority, and providing an integrated service. However, doctors as a whole insisted on retaining their clinical autonomy, thereby resisting managerial authority. Moreover the 1974 reorganisation created a three-tier health service administered at regional, area and district level. While nominally in this structure, in practice GPs avoided integration by continuing to work with Family Practitioner Committees. This demonstrates the power of the medical profession at this point in time, even within a state-run system (Stacey 1991: 127 - 128).

However, the 1974 reorganisation did mark one important step towards integration: the prestigious teaching hospitals lost their special independent status, and were integrated into the administrative structure of the NHS. Although Ministers were lobbied hard, it was to no avail. This demonstrates a contrast with 1948. While extensive concessions were made to the leaders of the specialisms in 1948, this was not so in 1974 (Klein 1995). Therefore, the influence of the medical profession, in their relationship with Government may be seen to have diminished between 1948 and 1974. However, it was to diminish still further, as shown by the reforms of the NHS in the early 1990's.

Klein (1995) suggested that the publication of the Conservative Government's White Paper, *Working for Patients*, in January 1989, brought about the biggest explosion of political anger and professional fury in the history of the NHS. The subsequent insistence of the Government on driving the White Paper proposals through Parliament, with virtually no concessions to the critics, crystallised both the anger and the fury. By the time that the legislation was formally implemented, there was a wide spread perception that the NHS, as conceived in 1948, had been transformed in ways that betrayed the principles on which it had been founded (Klein 1995: 131).

The BMA used advertising hoardings, newspaper advertisements and pamphlets to oppose the proposals laid out in the White Paper. In this instance, the medical profession had been excluded from the policy process. Few concessions were made during the passage of the National Health Service and Community Care Act 1990, which gave effect to *Working for Patients.* The new legislation came into effect on 1st April 1991.

Specifically, two major and contentious reforms were proposed. First, the separation of the purchaser and the provider roles: health authorities would in future be responsible only for buying health care from providers. The providers, both hospitals and community services, would be transformed into autonomous trusts, whose budgets would depend on their competitive efficiency in getting contracts from purchasers. Second, general practitioners were given the option of becoming fundholders. This created the notion of an internal market; the NHS was to mimic those characteristics of the market that would promote greater efficiency within the framework of a public service committed to the non-market value of distributing access to resources according to need (Klein 1995: 184).

Consultants' contracts became the responsibility of local management. As a consequence managers could be explicit about what was expected of professionals. Moreover, the quality of professional practice would in future have to be demonstrated, rather then being taken for granted; all consultants would be expected to take part in medical audit, reviewing their own practices, the use of resources and the outcome for patients. These changes challenged the position of the medical practitioner and are the basis for the arguments mooted by advocates of the proletarianisation theory (see P. 60). Yet, in spite of these changes, consultants displayed only "fitful and erratic interest" in audit (Klein 1995: 196). They, therefore demonstrated their ability to modify, if not subvert, the Government's intentions.

The medical profession's general suspicions of the reforms were reinforced and fuelled by specific grievances about the proposals for primary health care. The battle over general practice demonstrated with particular clarity that they had lost their ability to veto change in the NHS. In April 1990, the Secretary of State for Health imposed a new contract on GPs. Apart from winning some minor and marginal concessions on points of detail, general practitioners, as represented by the BMA, suffered a humiliating defeat (Klein 1995).

The Government claimed that the twin aims of their proposals were to give patients greater choice of the services available, and to secure greater satisfaction and rewards for those working in the NHS who successfully respond to local needs and preferences (Klein 1995: 192). GP fundholding was one way in which these aims were to be met. Fundholding became one of the most contentious parts of *Working for Patients*. (Klein 1995: 191).

Although the rhetoric claimed that the idea was to make doctors more accountable, and to provide patients with more choice, in practice neither has happened. The consumer's only right under the NHS is to have access to the health care system, once that has been achieved, it is for the professional providers to determine what treatment is appropriate. In a sense, therefore, the scope of the NHS's services, and the degree of its' comprehensiveness, remains a matter of professional convention and local decision making. However, in the light of the recent reform, the separation of the purchaser and provider function means that the former have to be explicit about what services they propose to buy on behalf of their populations. They have to publish an annual purchasing plan, in which they set out what they propose to buy and from whom (Klein 1995: 232). In practice this has not always happened, therefore doctors have not been made accountable to the extent that was intended.

Klein (1995) summed up the changes documented above with his statement that:

> the centre of gravity has shifted from paternalism to consumerism, from need to demand, from planning to choice. But as we have seen, in no case has the shift been complete. Markets have been managed; choice has been constrained by worries about costs; priorities follow need as well as demand (P. 249).

The legislative changes of the 1990's have demonstrated an increasing diminution of the influence of the medical profession, compared with earlier in the century. However, the beliefs and practices of biomedicine are still legitimated by the Government, despite the increase in management by non-clinicians. Therefore, although the influence of the medical profession on the Government may have reduced, medical practitioners still occupy a powerful position in society.

A brief history of the changes in the position of medical profession in relation to the Government has been provided. This is important as it demonstrates the changing position of the medical profession in the wider political arena, and in terms of Government policy. It has also highlighted government's wish for patients to act like consumers and make choices concerning their health care. This idea is now further explored by examining the historical position of the medical profession in their relationship with patients.

The history of the relationship between the medical practitioner and the patient

Johnson (1972) stressed the historical specificity of professions. He saw the professional - client relationship as rooted in the conditions of the societies in which they are found, specifically he argues that the nature of client control changes as societies change. Indeed, there is evidence of shifts in the historical position of the medical practitioner in their relationship with patients. These will now be presented and assessed.

Jewson (1976) and Foucault (1991) both provided accounts of changes in the relationship between patients and medical practitioners. Jewson (1976) presented this in terms of a shift in the mode of production of medical knowledge from beside medicine, to hospital medicine and finally to laboratory medicine. Hurd (1986) described how, in the seventeenth and eighteenth century, the patrons of medical professionals were the rich aristocracy and they dominated the relationship. This had the consequence of preventing advances in medical knowledge, as it was not acceptable for a physician to experiment upon a person of social position. Moreover, the medical profession was not organised (Jewson 1976). It was only with the founding of hospitals for the poor, and thus the shift to hospital medicine, that experimental medicine began to make headway.

In Jewson's (1976) terms, the position of the 'sickman' became subordinate to the medical practitioners, and investigations shifted away from the person.

Foucault (1991) also documented the changes which occurred in medical practices in the late eighteenth century. One major change was the introduction and routine adoption of physical examination, in which the practitioner exerted power over the patient's body. In this way: "the patient is the accident of his disease, the transitory object that it happens to have seized upon". (Foucault 1991: 59). Interest in the unique qualities of the whole person was no longer seen as relevant. Disease became a precise and objectively identifiable event occurring within the tissues, of which the patient may themselves be unaware (Jewson 1976). The patient was therefore treated as an object. These changes show how practitioners were gaining control in the relationship, initially on the basis of their superior class position in relation to the people they treated in hospitals, and then on the basis of new knowledge and expertise which was gained from treating these people.

Thus by the nineteenth century, the relationship between medical professionals and their clients had shifted to one in which the professionals dominated. This was illustrated, according to Foucault by the change whereby the question; what is the matter with you? was replaced by the question; where does it hurt? (Foucault 1973). The growth of the urban middle class, as a result of the industrial revolution, created a new client base. This affected the relationship between medical professionals and clients, with regard to the increase in the number of clients treated. As the technical expertise of the medical practitioner increased, partly through the practice of examination, and hospital based experimental medicine, so did the social distance between professionals and their new middle class clients (Hurd 1986).

The focal point of the medical career shifted from the primary relationship being the relationship with the sick, to the importance of the relationship with other clinicians. This happened as control over the occupational group became centralised in the hands of senior members, and a 'collegiate' system of occupational control emerged. Posts were obtained through a system of selection which was in the direct control of the senior members of the occupational group. Thus the position of a medical professional relied less on the satisfaction of their patients, and more on the recognition by their peers (Jewson 1976). The final stage was the move to laboratory medicine. This required emotional detachment and the complete removal of the importance of the individual patient (Jewson 1976).

The ideas presented above suggest that the patient, as an individual, has become less important as the medical profession has developed. The current position of medical professionals in their relationship with patients will now be examined. Of particular concern, are the implications for this relationship of the changes documented in Chapter One which suggest that patients may now attempt to exercise more control in their relationships with medical professionals.

The patient - practitioner relationship

Medical practice intrudes into areas of social taboo relating to personal privacy and bodily functions, as well as areas of culturally defined ritual significance such as birth and death (Johnson 1972:43). This is likely to have an effect on the relationship between patients and medical practitioners. The greater the social distance and the greater the helplessness of the client, then the greater the exposure to possible exploitation and the need for social control. Control may be exercised through a professional organisation. In the case of the medical profession, the British Medical Association (BMA) lays down a professional code of conduct. Yet, if diagnosis or treatment of a condition involves an intrusion into areas which are normally kept private, then any resultant embarrassment may make it difficult to encourage patients to make choices about their medicines.

Johnson (1972), developed the argument on the relationship between client and practitioner by emphasising the power which professionals have to define the needs and treatment of their clients, and to resolve any disputes in their own favour. It is only where an occupational group shares wider resources of power, by virtue of its membership of a dominant class or caste, that it is able to impose its own definitions of the producer - consumer relationship. Such an imposition is only likely to be successfully achieved where the actual consumers or clients provides a relatively large, heterogeneous, and fragmented source of demand (Johnson 1972: 43). These conditions are met by the relationship between medical professionals and patients. Moreover, doctors tend to originate from the middle classes, and their long training socialises them into the 'values' of the medical community, where they learn to speak a common language. A language which is only partly understood by outsiders. This creates a unified front against the typically unorganised patients.

However, chapter one documented five major influences on the possibility of patients adopting a more active role with regard to making an choices about their medication. The influences are re-presented below.

- Legislative measures which are designed to increase the accountability of medical practitioners, through for example, the introduction of easier complaints procedures and the simplification of the process to change GPs.
- The availability of information about medical matters.
- The increase in the prevalence of chronic illness. In these cases patients develop a longer term perspective, and have the chance to accumulate knowledge and expertise.
- Increasing interest in alternative medicine, which suggests a loss of faith in science, and in the medical model.
- The increase in the number of self help groups.

The implications of each of these changes for the relationship between the medical practitioners and the patients will now be discussed.

The influence of legislation in giving patients 'rights'

Together with the changes to the structure of the NHS documented earlier, measures have been introduced to allow patients to exercise choices, and to raise their awareness of their 'rights'. *The Patient's Charter* explicitly sets out a range of rights. These range from the "right to receive health care on the basis of clinical needs, regardless of ability to pay", to the right "to be guaranteed admission for treatment by a specific date no later than two years from the day when your consultant places you on a waiting list". (Klein 1995: 212). Although this appears to be of benefit to patients by speeding up waiting time, in practice, strategies such as the construction of a waiting list to get onto the consultants waiting list are employed (Klein 1995).

More generally, the Government has presented the rhetoric of a well informed consumer who is able to make choices on the basis of performance indicators. However, although doctors, particularly if they are fundholding, may be able to exert pressure on NHS Trusts, there is nothing the consumer can do directly; there are no decisions to take, informed or otherwise (Klein 1995: 213). Moreover, in terms of the increased ease with which a patient can now change doctors, Klein (1995) suggested that in practice patients have not done so. A possible explanation lies in the fact that it may not be practical to change doctors for a number of reasons ranging from the geographical location of alternatives, through to a lack of information about the service a 'new' doctor will provide. 'Glossy' brochures do not guarantee an approachable GP. Therefore, although patients may be aware that they have certain rights, the idea of the passive patient and the paternalistic doctor is still very strong. Moreover, with increased pressure on doctors from the reforms which have directly affected them, patients may not feel comfortable about exercising their 'rights'.

Although the Government has provided means by which patients may complain against the medical profession, Klein (1995) pointed out that failures on the part of the NHS are often blamed on politicians as opposed to the medical practitioners. This suggests that although patients may complain, they may also blame the Government for failures of service. Such criticism is often based on a perception of the NHS as underfunded.

The problems with legislative measures designed to increase the accountability of medical practitioners have been highlighted. Changes which have increased patients' access to information are likely to have had an affect on the relationship between medical practitioners and patients. The impact changes which have increased patients' access to information will now be explored.

The availability of information

The literature presented in Chapter One, demonstrated that patients are exposed to information about medical matters from a range of sources.

Self-help groups vary in the extent to which they are supportive of the views of the medical profession. Kelleher (1994) suggested that:

> self-help groups are complementary to medicine in that they are a way of making good one of its shortcomings, the failure to address the expressive needs of people. But, as part of a new social movement, they are important because they retain the possibility for seeing things differently, creating the opportunity for medicine to be challenged and interrogated (P. 116).

The very existence of self-help groups suggests that traditional medicine may fail to provide the support and information people feel they need. Moreover, self-help groups may encourage patients to exert control over their condition and their treatment, and to seek information in order to make informed decisions about their treatment.

Information from articles in newspapers and magazines, and from friends and family is widely available. It is likely that even if patients do not seek it, they may still be influenced by it.

Boreham and Gibson (1978: 409) suggested that throughout much of their history the professions in general, and the medical profession in particular, have fostered and maintained a knowledge gap between practitioners and clients or patients. Thus, in prescribing, the doctor has effectively taken the decision for the patient, as many health professionals believe that patients are not capable of judging the hazards involved in the use of medicines. Calnan (1991) placed a slightly different slant on this and suggested that the perspectives of the doctor and patient are in many respects different. Therefore, medical professionals may not believe it is necessary to provide certain information, yet patients may express a wish for information.

However, the failure to provide information to the patient has also been presented as an attempt by practitioners to increase social distance, their own autonomy, and their control over practice, by engaging in a process of 'mystification'. As Johnson (1972) suggested, uncertainty is not entirely cognitive in origin and may be deliberately increased to serve manipulative or managerial ends. This argument is taken further by Katz (1988), who argued that the lack of acknowledgement of uncertainty to patients is reinforced by the traditional authoritarian relationship that governs interactions between physicians and patients, and that doctors seek to foster. Professional certainty serves purposes of maintaining professional power and control over the medical decision-making process, as well as maintaining an aura of infallibility (Katz 1988: 558 -559).

Therefore, Katz believed that information has not been provided to patients on the basis of the historical development of the profession. Withholding information protects the notion of medical practitioners status as 'expert'. The major flaw, which is critical to this thesis, is that, as has been demonstrated, the medical practitioner is not the sole source of medical information.

Katz (1988: 554) provided another explanation as to why medical practitioners may not provide information to patients. Thus, great importance has been attributed throughout medical history to faith, hope and reassurance, and this seems to demand that doctors be bearers of certainty and good news. The idea of acknowledging the implications of treatment to patients is opposed by an ancient tradition, and the practitioner may fear that by doing so they will breach the accepted bounds of the relationship. Yet, if doctors acknowledged uncertainty, then they could reduce the existing gulf of inequality between physicians and patients (Katz 1988). This appears to be sensible in the light of the general availability of medical information, and of legislative provisions which aim to make medical practitioners more accountable to patients.

The two arguments presented above explain the current position of medical professionals in terms of the historical development of the profession. The argument favoured in this thesis is that the position of medical professionals is likely to remain strong while they continue to have a monopoly over the provision of medical resources and in particular to control the supply, and to a large part the education, of labour. Thus, the availability of information from outside of the consultation is unlikely to present a serious challenge. The reported increase in chronic illness will now be examined in terms of the possible effect on the position of the medical professional in society.

Changes in the character of illness

Boreham and Gibson (1978) suggested that the present position of medical practitioners in society is linked to the history of the nature of illnesses, and the expertise of medical practitioners. This image of the medical practitioner who believes their knowledge and skills to be so esoteric that the patient is seldom in a position to understand or to raise questions, is derived from an era in which the major afflictions with which the practitioner had to deal were acute, infectious illnesses. This created a clearly defined differential in power and status, and established Parson's (1951) idea of the active doctor and the passive patient.

However, the prevalence of chronic as opposed to acute conditions, has altered the balance of knowledge between the patients and the practitioner. A patient who has a long-term chronic illness is likely to accumulate knowledge and information over a long period of time, and may develop intimate knowledge with regard to their particular illness and the type of treatment which is effective in their own particular case (Williams 1984). In these circumstances the practitioner will be at a disadvantage, as even if they are an expert in this particular field, they are unlikely to possess the patient's level of knowledge without personal experience of the condition. As patients with chronic illnesses continue to consult medical practitioners, then the idea that the position of medical practitioners relies solely on their expertise may be seen to be flawed. Gabe et al (1992) suggest that the question as to why people consult their GP is not clear. However possible explanations include the requirement for continued legitimisation of their illness in the form of a sickness certificate, or as a 'check' on any new developments in the treatment of a particular problem.

Belief in the expertise of medical practitioners may be perceived as challenged by the increasing interest in alternative medicine. This idea will now be considered.

The role of alternative medicine

Continuing the theme of expertise, Coward (1989), suggested that the image of the 'expert', the rational scientist who could diagnose through scientific knowledge and in whom patients had absolute trust, has gone. This may have been influenced by recent 'health scares', such as the possible risk of contracting Creutzfeldt Jakob disease (CJD) from eating beef originating from cows infected with Bovine Spongiform Encephalopathy (BSE). In particular, the provision of conflicting advice may have affected confidence in experts. Coward (1989), believed that discontent has grown with the lack of time or interest shown in the patient. She presented the doctor as a professional with vested interests, who is as much concerned with his or her position in the hierarchy as with the comfort or rights of the patient, and as someone who occasionally covers up mistakes (Coward 1989: 8).

Furthermore, Coward (1989) presented the argument that, in conventional medicine, attention is rarely given to the patient's feelings or emotions. That doctors neglect any real human contact with their patients. They regard human bodies as their possessions, over which they can decide the course of treatment. This may be linked to the earlier discussion of the use of physical examination for diagnosis (see P. 69). Alternative therapies, on the contrary, offer proper personal contact and engender in the individual a sense of control over their body and health (Coward 1989: 9). Moreover, the status differential between patients and alternative therapy practitioners is different (Sharma 1992). This may attract patients to these therapies. It is for these reasons that patients are said to be seeking solutions from alternative medicine. The use of alternative medicine may also be explained with reference to the increase in chronic illness, where the solutions provided by 'traditional' medicine may have failed, or may not even exist. What it does suggest is that, for whatever reason, faith that traditional medicine has all the answers may be diminishing (Sharma 1992).

This section has considered changes in society which help to explain the position of the medical practitioner in the relationship between patients and practitioners. Various challenges to the 'expertise' of the medical profession have been presented. The conclusion reached is that the position of medical professionals in society are most accurately described with reference to their position as the state legitimated source of health care provision.

Although the medical profession may be under pressure by the challenges discussed above, there are still material and prestige rewards associated with being a member of the medical profession. The next section will present the position of both patients and practitioners, and demonstrate the complexity of attempting to assess the relationship between the two parties.

Perceptions of patients' and medical practitioners' roles

Doctors have considerable autonomy in the organisation and development of their work, and power in their relationship with clients, by virtue of the fact that they possess what is wanted and needed by clients. They also decide how, when, and for what reason these resources are to be granted to the patient (Lupton 1994). This authority is underpinned by the fact that a medical practitioner's judgement may not only be sought with regard to medical matters, such as an individual's fitness for work, but also in terms of being authorised to sign official forms, such as passport applications, by virtue of the position as a respected member of the community.

Hillier (1991) used Foucault's ideas to highlight the consequences of consultation practices. It was suggested that what is normally seen as very personal contact between two people becomes a matter of routine in the doctor - patient relationship, where doctors take for granted that the most intimate areas of the body are legitimate phenomena for examination. In Hillier's account, simple matters such as palpating the patient's abdomen may be dehumanising, rendering the patient a passive object of study. Thus, for a diagnosis to be obtained, the patient may have to allow the practitioner access to their body and explain symptoms which may not be repeated to any other person. This places patients at a disadvantage, as they are likely to be embarrassed. Studies on consultation practices have suggested that doctors are aware of this and do attempt to avoid causing the patient embarrassment. Thus strategies may be employed such as suspending verbal interaction, or referring to body parts by using 'the' as opposed to 'your' (Radley 1994).

The ideas presented above suggest a 'doctor-centred' view of the relationship between patients and professionals, where practitioners, by virtue of their control over the knowledge required by patients, dominate the consultation. The patient is, in most cases ill, and may not feel capable of challenging what has been said. Moreover, even if a patient does try to exert their influence, the notion that there is a competence gap between the two parties may influence the response made (Tuckett et al 1985).

Yet, in spite of the resources of the practitioner, the patient experiences the effects of the medicines prescribed, and has to 'make sense' of both the illness and the medicine. Moreover, the ultimate decision whether or not to take the medicine prescribed rests with the patient, as is evident from concerns expressed with respect to the amount of medication wasted through non-adherence (Audit Commission, 1994). Patients may also challenge the authority of the medical practitioner by, for example, changing GPs, or requesting a second opinion. What is clear from the discussion presented here and in

Chapter One, is that relationships between patients and practitioners may vary, and may also be subject to change.

In the patient - practitioner relationship, medical practitioners are in control of the surroundings in which a consultation takes place, and of diagnostic practices. However, this control is only exercised within the consultation. Patients make the initial decision to consult the practitioner, and they may also decide not to comply with the prescribed treatment. The personalities of patients and practitioners also influence the outcomes of the consultation.

Summary and conclusions

This research considers the possibility of patients making an informed choice about their prescribed medication. Therefore, the provision of information to patients by GPs, the choices patients say they make and the information on which these choices are based are all considered. This chapter has presented a range of theoretical approaches concerning the position of medical practitioners both in general terms, and in terms of their relationship with patients. These suggest that informed choice does not fit well either with GPs' professional culture, nor with the traditional role of the passive patient.

On examining the arguments, the position of medical practitioners appears to be best described with reference their control over the provision of medical resources. As this does not rely solely on the notion of 'expertise', then the position of the medical practitioner will not be adversely affected by patients requesting information so they are able to make an informed choice about their medication. Yet, practitioners may perceive their role to be challenged by such requests and may therefore resist attempts by patients to make informed choices.

A historical view of the changing relationship between the Government and the medical professional, and between patients and practitioners, has been considered. This demonstrated how the Government has increasingly sought control over medical practitioners. It also suggested that the influence of medical professionals over patients has increased throughout history, yet may now be diminishing as a result of patients gaining certain 'rights', as well as access to medical information. A number of sources of information for patients have been detailed. The increase in chronic illness, which may have the consequence that patients become more knowledgeable in certain areas than their doctor has also been considered. These factors, suggest that patients may challenge their doctors. All of these elements suggest that shifts may be occurring in the relationship between patients and practitioners, leading to the possibility of a greater demand by patients to exercise an informed choice with regard to their medication.

The literature presented both in Chapter One, and Chapter Two, demonstrates the increase in the availability of medical information to patients, and has been examined in terms of the persistence of traditional status differences between medical professionals and patients. In Chapter One, evidence was presented to suggest that patients do not get all the information that they want from medical practitioners. It also suggested that patients and GPs have different beliefs about health and illness which may render communication problematic. A difference or 'gap' between the perceptions of risk expressed by patients and practitioners was also shown to exist.

Chapter Two built upon the ideas presented in Chapter One and examined the relationship between patients and practitioners using the concept of professionalism. It considered the influences from outside of the consultation which had previously been highlighted in Chapter One with specific regard to the relationship between patients and medical practitioners.

The potential availability of information to patients from outside of the consultation, and the position of patients and medical professionals in terms of both their individual position in society and their relationship with each other has been considered. On the basis of the literature, the fieldwork sought to assess the provision of information to patients by GPs, and the choices patients made in relation to their prescribed medicine, on the basis of the available information. In particular, the literature suggests that medical practitioners may be reluctant to provide information to patients. In order to consider these issues it is necessary to examine what actually happens in, and beyond, patient - practitioner encounters. In the fieldwork the patients' perspective was initially focused upon. The following issues were considered:

- the way in which patients make their medication decisions,
- patients' awareness of making such decisions,
- the sources of patients' information,
- the role of the professional in providing information,
- and whether the way in which patients make decisions about their medication may accurately be described as an 'informed choice'.

The subject of information about medication is vast. The issue of side effects was identified for study, as knowledge of side effects is likely to influence the decisions patients take with regard to their prescribed medication. The fieldwork conducted is discussed in detail in the following chapter.

Chapter Three

THE FIELDWORK

This research uses the idea of informed choice to examine the influence of the information available to patients about health and medicines, and the possible effect on the relationship between patients and medical practitioners. It seeks to ascertain the basis for the choices patients are currently making about their medication, and the kinds of information on which these choices are based. Chapter One documented the range of information sources available to patients and the relationship between patients and medical practitioners. Chapter two considered the position of medical practitioners in society, with particular regard for their role as prescribers of, and therefore advisers about, medicines. This chapter describes the fieldwork conducted. The research involved both patients and medical practitioners, as any exploration of issues concerned with communication between patients and practitioners needs to take account of the meanings that both parties ascribe to the situation.

In this chapter, initial consideration is given to the philosophical principles which underpin the knowledge claims made in this thesis. This incorporates a discussion of what constitutes knowledge. The interpretative, and the positivist approaches, are then presented, followed by the more recent approaches which researchers have adopted. A discussion of the importance of the chosen research methods being appropriate to the research problem, is then presented. This is followed by a discussion of ethical considerations. Finally, the methods employed in the fieldwork, and the reasons for these decisions, are documented and discussed.

The philosophical principles underpinning the approach to knowledge

Kuhn (1970) argued that there could be no one objective true theory, but that knowledge can only be understood as a historically and socially-located product. He argued that science operated in terms of successive paradigms, with a paradigm being defined as a model or pattern. Furthermore, he believed that a paradigm:

> like an accepted judicial decision in common law, ... is an object for further articulation and specification under new or more stringent conditions (Kuhn 1970: 23).

Therefore, paradigms are subject to change and may be challenged. They gain their status:

> because they are more successful than their competitors in solving a few problems that the group of practitioners has come to recognise as acute (Kuhn 1970: 23)

Thus, they are judged on their ability to answer questions which are seen as timely. Therefore, paradigms represent:

> the source of methods, problem-field, and the standard of solution accepted by any mature scientific community at any given time (Kuhn 1970: 103).

Kuhn (1970) argued that reality could not be observed independently from these values, beliefs, and basic empirical assumptions, and furthermore that an investigator's epistemological stance; their beliefs about what constitutes valid knowledge, determines what kinds of research problems are studied and the type of theories which result from the research. Thus the researcher becomes part of the research, as the choice of the original problem, and the methods which are chosen as appropriate to address this problem, are subject to the values and beliefs of the individual researcher.

Historically, social inquiry has broadly been influenced by two major paradigms, often seen as incompatible because they are based on a different understanding of the relationship between the subjective meanings and values that people give to events, and objective facts. The two differing methodological approaches derive from different ideas as to the way in which it is possible to collect valid knowledge, namely the positivist and the interpretative approaches. These will be considered in turn, then the challenge of post-modernism, and its consequences for applied research, will be briefly considered.

Positivist approaches

Researchers who adopt a positivist stance, the posture of which is the archetype of the detached scientific observer, assume that there is an objective world, the truth of which may be discovered through observation of facts and the construction of laws which define the relationships between them. These laws not only govern the physical sciences, but also govern the way in which the social world operates. Social behaviour and events, it is argued, result from structural features of society. Social structures create pressures on people who are relatively passive in their response (McNeill 1985: 108).

Interpretative approaches

One way of distinguishing the interpretative approach from the positivist is to argue that there is an important difference between the subject matter of the social sciences and the subject matter of the natural sciences. Unlike natural phenomena, people are active, conscious beings who are self-aware, and actively engaged in a social situation. They are, for example, capable of reflection and of acting strategically according to circumstances. Key developments in the interpretative approach came with the work of Berger and Luckmann (1967), which outlined the development of a new paradigm of sociological enquiry. Berger and Luckmann (1967: 35) argued that if we are to explain some event in the social world, a detailed analysis would uncover the various layers of experience, and the different structures of meaning involved in this event. Moreover, social reality is not merely the sum total of individual thoughts and actions, it is 'intersubjective' because it exists in the shared consciousness of the actors (Berger and Luckmann 1967: 34). That is to say, it is a construction of shared meanings and interpretations of physical and social phenomena and their interrelationships. It follows that to explain social actions, they have to be understood in the way that the participants understand them. The task of the social researcher is to describe these shared meanings, which may in turn, make it possible to understand why people behave as they do (McNeill 1985: 113).

The challenge of postmodernism

In the mid-1980's a crisis of representation and legitimisation became evident through the developing discourses of post-structuralism and post-modernism (Denzin and Lincoln 1994). The ideas mooted suggested that claims to capture lived experience also represent the experience of the individual researcher in trying to document that particular experience. Moreover, the traditional evaluation and interpretation of qualitative research is problematic and the issues of validity, generalisability and reliability require further consideration. In simple terms, any understandings gained are filtered through the lenses of characteristics such as language, gender, social class, race and ethnicity. There is no objective observation, as any observation is socially situated in the worlds of the observer and the observed (Denzin and Lincoln 1992). Thus, in order for research to be seen as valid, studies should be small scale, and the researcher should be reflexive about their position in the research, and their biases.

The debates have been very briefly described. It is necessary however to be aware that there is no consensus, and debates about the merits of various approaches continue.

The association between philosophical principles and favoured research methods

With regard to research methods, positivists are likely to favour laboratory experiments where the variables can be controlled, and / or, quantitative survey methods. These have generally been used in ways that reflect a more structured approach to the study of society (Bryman 1988: 98). In contrast, interpretative researchers are likely to employ qualitative techniques, with an open-ended approach to the gathering of evidence. These enable social life to be studied in its natural setting, using for example, participant observation, and in-depth interviewing. As noted above, researchers who favour the ideas of post-modernists are likely to favour small scale studies within which they may reflect on their place in, and influence upon, the research.

Combining qualitative and quantitative approaches

As quantitative and qualitative methods tend to be associated with the positivist and interpretative approaches respectively, then a researchers choice of method may appear to stem merely from their epistemological stance. However, Silverman (1985: 17) suggested that choosing a method is more than a choice between polar opposites, it is a decision about balance and intellectual breath and rigour (1985: 17). Silverman (1985) provided a number of illustrations of research in which the use of quantitative data provided additional insights to qualitative studies. Moreover, Roter and Frankel (1992) argued that presenting the use of quantitative and qualitative methods as mutually exclusive, is wrong. They argue that respect for different methods should not preclude combining methods to maximise discovery and insight.

In broad terms, quantitative researchers may be seen as being concerned with theory testing, while qualitative researchers are concerned with theory generation. Epistemologically, this may be seen to be related to differing views on the nature of reality. However, Bryman (1988: 98) pointed out that in practice these 'ideals' often do not operate, consequently the contrast between quantitative and qualitative research, in terms of the verification of theory against preferring theory to emerge from the data, is not as clear cut as is sometimes implied.

Bryman (1988: 125) argued that the tendency to associate particular methods with any particular epistemological position is little more than a convention which has little to recommend it either as a description of the research process or as a prescriptive view of how research ought to be done. Bryman's (1988) alternative standpoint is that the research issue determines, or should determine, which style of research is employed. This means decisions are based on 'technical' issues regarding the suitability of a particular method in relation to a particular research problem. He further argued that this is generally the case with regard to applied research where the problem not only determines the method, it also provides the philosophical standpoint (Bryman 1988: 106). However, in line with Kuhn (1970), I would argue that any decisions taken concerning the methods to be employed will also reflect the views and beliefs of the individual researcher in terms of the appropriateness of different methods. The reasoning behind the decisions taking concerning the methods employed for this research will now be presented.

The methods chosen for the fieldwork

The argument underpinning this research is that despite the availability of information about medicines, the persistence of traditional status differences between patients and GPs may make it difficult for patients to believe they are able to make informed choices about their medicines. The research question focuses on the way patients make choices about their medicines and the role of the GP in providing relevant and appropriate information. The chosen methods were in-depth interviews, and a larger scale survey in the form of a vignette, for which quantitative methods of analysis were used.

In the light of the dearth of research into the issue of the information patients use to make decisions about their medicines, with particular reference to the issue of side effects, exploratory semi-structured interviewing was initially employed. This was an appropriate method through which it was possible to explore patients' and professionals' views on the provision of information about the effects of medication, and the reasoning behind these views. The interviews raised some particular issues, while allowing the research to develop into areas and directions which were previously unanticipated (Field and Morse 1985: 65). Moreover, the method enabled the issues to be presented in the way in which they were perceived by the patients and GPs who were interviewed (Taylor and Bogdan 1984). This approach has previously been employed to obtain insights into patients' perceptions of their medication, and their medical condition (Donovan et al 1989). Interviewing has also been used to consider the provision of information in the consultation (Boreham and Gibson, 1978, Beisecker and Beisecker, 1990). The results from the findings from interviews with patients were then used to construct a vignette, which was distributed to all the GPs in Derbyshire. This enabled easily comparable data to be collected from a larger sample of GPs.

Roter and Frankel (1992: 1103) expressed their belief that:

> Methods of research ... are open to description in their own terms, and should be judged on the extent to which they succeed in answering the questions which they raise in the context in which they were raised.

The research methods chosen for this research reflect this view, as the choice of methods took account not only of the suitability of the method chosen for answering the question raised, but also their suitability for use with the people being investigated. Therefore, patients were interviewed in their own homes with the aim that they would relax and feel comfortable on their own territory. General practitioners were interviewed in their Practices, so that they would be in 'role', and a postal form of data collection was also used with GPs as this minimised their time commitment to the research. It was believed to be of crucial importance that each step of the research process was justified, ethically, methodically, and theoretically. Dudley's (1992) work on ethical issues takes these ideas further. These will now be discussed, together with the ethical considerations which need to be addressed when considering how methods are employed.

Ethical considerations

Initially, the abstract ethical considerations will be presented. Following this, practical concerns, such as confidentiality and integrity, as they related to the fieldwork, will be considered.

Dudley (1992: 328) made ethical issues central to qualitative fieldwork with her idea of the paradigm of consciousness. At the core of this paradigm is the concept of relatedness, which states that we are all part of a larger whole. She suggested that the concept of relatedness calls for an ethic of responsibility in research endeavours, which encompasses respect, care, and compassion for all participants, which includes the researcher, participants, and the community of readers (Dudley 1992: 328).

In her opinion, ethical decisions are always grounded in some schema of values, and she believes that her decisions about the research process emerge directly from her system of values (Dudley 1992). Her belief is that the method employed must be congruent with both the researcher's world view and the subject to be studied. People investigate the types of questions in which they are interested. This creates a personal investment in the ideas to be investigated. Therefore, methodological appropriateness is a key to participating in research with integrity, because methods of seeking knowledge necessarily evolve from the beliefs one holds about reality (Dudley, 1992: 329). Altheide and Johnson (1994) also supported this with the suggestion that qualitative research is:

> carried out in ways that are sensitive to the nature of human and cultural social contexts, and is commonly guided by the ethic to remain loyal or true to the phenomena under study, rather than to any particular set of methodological techniques or principles (P. 488).

Ethical consideration may also address questions such as what is the purpose of the research, and whom will it benefit. Dudley (1992: 341) stated that a researcher writes for others; for those who need to have their stories told, and for those who need to hear those stories for their own empowerment. This highlights the responsibility that researchers have for ensuring that their research is valid, and is, as far as is possible, an accurate interpretation of what the participants say. It also provides a justification for research in that it allows viewpoints to be heard, that may not otherwise be heard.

Dudley's (1992) argument that the method employed must be congruent with both the researcher's world view and the subject to be studied is compelling, as the decision concerning the methods to employ will almost certainly be influenced by the researcher's personal view of the most effective way of gaining knowledge with reference to a particular set of circumstances.

The participatory ethic, as outlined by Dudley (1992), was not fully employed in the fieldwork presented in this chapter. Data was obtained from a range of people and one interview with each person was judged to be sufficient at each stage. Therefore, methods such as feeding back transcripts for comments and clarification to ensure that the interpretation is as accurate an account as possible of what the participants said, were not employed. To have done so would have had implications in terms of time, and would therefore have limited the overall breath of the data collected.

The interviews with patients were closer to achieving the participatory ethic (Dudley 1992), than those conducted with GPs. This was related to the balance of power in the interviewing situation. When interviewing patients, they looked to me to set the agenda. Patients were reassured that I was not 'testing' them on their knowledge, and would not report what they told me to their GP, the aim being to encourage them to talk as freely as possible. However, care had to be taken not to cause patients to suffer any undue fears about their medication by virtue of the fact that they had been selected for interview. Patients were discourage from trying to gain information from me about their treatment, or from trying to get me to sanction their views about their medications, by explaining that I was not a health care professional. In some cases this did not prevent patients from asking my opinion, but I was able to say that I was not qualified to know.

This position was adopted because I felt it was not ethical to provide my participants with answers to queries about their medication, as I was not qualified to assess why certain decisions had been made. Moreover, I believe that the role of researcher is not an appropriate position from which to express an opinion concerning decisions which have been made about the appropriateness of treatment. Another concern was that interviewing patients about their medication may have raised their awareness of the potential problems associated with it, which may in turn have caused them to suffer anxiety. However, none of the patients interviewed appeared to suffer any anxiety, and the interview transcripts suggest that a good rapport was established, as people were very forthcoming regarding their beliefs about their medication.

In the interviews with GPs, they, by the nature of their occupational status, and the constraints on their time, sought control over the interviewing situation. Moreover, I have experienced the role of patient, but not GP, therefore, it was even more difficult to even attempt to achieve the participatory ethic with GPs, than with patients.

It was necessary to address a number of practical ethical issues concerning the fieldwork. Ethical standards in medical research are governed by local ethics committees. As this research involved patients, then it was necessary to gain ethical approval. Before any GPs or patients were approached, ethical approval for the fieldwork was gained from the Southern Derbyshire Ethics Committee. The committee was particularly concerned with obtaining the consent of patients before they were interviewed. An assurance was provided on this point, and all the patients interviewed were asked to complete a consent form before they were interviewed. A copy of the consent form used may be found in the appendices (Appendix A). Approval was also obtained from the Local Medical Committee, as it was hoped that their approval may encourage the participation of local GPs.

An important ethical concern arose because I wished to speak to patients about their medication. This is potentially a sensitive area. A letter requesting participation was prepared, but addressed from, and signed by, the relevant GP. The intention was to avoid raising patients' concerns about the confidentiality of their medical records. The letter assured the patient that they were not obliged to participate, and that they could withdraw from the research at any time. Assurances were also given that the care they received from the GP would not be influenced by whether they agreed to participate or not. A copy of the letter is included in the appendices, (Appendix B). The reply slips were sent directly to the University, as this was felt to reduce the pressure on patients who may have felt obliged to co-operate because the request had come from their GP. However this may have meant that I was seen as associated with the Practices, and therefore the GPs. This was addressed to some extent by explaining to patients, before they were interviewed, that I was not a doctor, or a pharmacist, and that I was from the University and was not connected with their GP practice. I also stressed that their GP did not know that they had been chosen to be interviewed, and that nothing that they said would be reported to their GP.

This section initially presented abstract ethical considerations, including the concern that accounts given should be, as near as is feasible, a representative account of what is said. An explanation of the attempts made to minimise the risk of making patients anxious with regard to their medication has also been presented. This was followed by details of the practical concerns, such as obtaining ethical approval, the use of a consent form, and details of the letter sent to patients inviting participation. The next section details the research methods employed in the light of the epistemological, methodological and ethical arguments which have been presented.

The research methods employed

A brief review of all the stages of the fieldwork are now presented. Each stage is then explored in more detail. All the research concentrated on the issue of information about the side effects of medicines. Initially pre-pilot interviews were conducted with two pharmacists, one GP and two patients in order to explore the idea presented in the literature of a 'gap' between patients and GPs in approaches to the provision of information about medication therapy. From these interviews the decision was taken to concentrate on patients' perspectives, as their viewpoint is vital to gain insights into the information used to make decisions about medicines. Therefore eight interviews were conducted with patients to explore their beliefs about their medication, and the way they balanced their understanding of the risks and benefits of treatment in order to make choices. To reduce the number of variables, eighteen patients with asthma, who had received a prescription for oral steroids, were interviewed. From this, an understanding was developed of the information that patients used to make choices about their medication. As patients mentioned GPs as a favoured source of information, then the research moved on to explore GPs' perceptions of the information they provided to patients, with specific reference to the effects of medication, and their belief as to whether patients were able to make a choice about their medication based on the information they had. This involved ten interviews, followed by a survey of all the GPs in Derbyshire using a vignette technique to gain insights into GPs' understanding of, and feelings about, the range of influences on patients. The findings provided evidence of a 'gap' in perception between patients and practitioners, in terms of the amount of information that patients were in command of, the role of the GP in providing it, and the way in which this information was used to make choices about their medication.

The fieldwork employed qualitative methods to explore patients' and GPs' beliefs in depth, and quantitative methods to gain a more reliable and representative picture of the practices of GPs. Each subsequent stage arose out of the issues generated by the previous one. For ease of understanding of the methods employed, and their sequence, the table (Table 3-1) below details the main characteristics, and aim of each stage. This is followed by a detailed explanation of the process.

Table 3-1

The Methods Employed

Title	Method	Sample	Specific objectives
Pre-pilot interviews.	Unstructured exploratory interviews (untaped).	One community pharmacist. One hospital pharmacist. One GP. Two patients taking prescribed medication.	To explore the existence of a 'gap', identified in the literature, between patients' and practitioners' perceptions of the amount of information that should be provided about the side effects of medication, and to identify key issues at a general level.
Pilot interviews.	Semi-structured exploratory interviews (Taped).	Eight patients taking prescribed steroid medication.	To sharpen the focus and establish the range of information about side effects that patients who had been prescribed steroid medication had acquired, how they had acquired it, and the way in which this influenced their assessment of the risks and benefits of medication.
Interviews with patients.	Semi-structured life history interviews (Taped).	Eighteen asthmatic patients taking oral steroid medication.	To focus more specifically on a group of asthmatic patients who had been prescribed oral steroid medication. To explore, in-depth, patients' beliefs about their medication, and to establish the understanding that they had of side effects, how they acquired it, and the way in which this understanding may influence the choices made with regard to their medication.
Interviews with general practitioners.	Semi-structured interviews (Taped).	Ten GPs.	To examine the information generally provided by GPs to patients about steroid medication, and to explore GPs' understanding of the way patients' beliefs influenced their use of medication.
Vignette.	Vignette (Administered by post).	Sent to all practising GPs in Derbyshire.	To improve the reliability and representativeness of the GP data, and to establish the extent of GPs' recognition, and understanding of, and feelings about, influences on patients, as presented in a single case study.

The specific objectives of each stage were determined through theoretical sampling. Theoretical sampling demands that at each stage of the research, concepts are identified which are believed to add to the evolving theory. More research is then conducted using a sample which identifies and specifically tests these concepts (Strauss and Corbin 1990: 176). In terms of this research, the findings from each stage determined the composition of the next sample identified. The way in which each stage informed the next will now be elaborated on in sequence, with the relevant findings presented to provide a rationale for the next stage.

Pre-pilot interviews

The fieldwork concerned the information about side effects that patients use when making choices about their medicines. As research in this area is sparse, semi-structured, untaped, pre-pilot interviews were initially conducted with an opportunist sample comprising; one GP, one community pharmacist, one hospital pharmacist, and two patients taking prescribed medication. The sample of health care professionals provided one representative from the most common medical providers of information about medication. These interviews were designed to generally explore how much information about the effects of medication was provided by health care professionals, and how much was required by patients, together with their thoughts on this subject. Notes were taken throughout, and on the basis of the evidence from these notes, a number of issues were identified. These issues are presented next.

Both of the pharmacists interviewed were concerned about giving patients information which might make them anxious, and wished to identify a balance between informing the patient, yet not inducing side effects by mentioning possible reactions; 'too much' information was seen as dangerous. They appeared to see their role as one of mediation between the GP and the patient, and would refer patients back to their GP if the patient was unhappy with any aspect of their medication. Their accessibility, in comparison with the medical profession, was stressed, and they appeared constrained in their role by a concern not to interfere in the doctor-patient relationship.

The GP who was interviewed stressed the need to preserve trust in his relationship with his patients. He was, however, concerned with pressure on his time, and stated that the prioritising of information meant that side effects might not always be mentioned in a consultation. Discussing side effects was only a priority when it was expected that some minor side effects might occur, and he wanted the patient to continue to take the medication. In such cases, the patient would be informed of what to expect.

The two patients who were interviewed both stated that they often felt too ill to ask questions when they were first prescribed a medication. One stated that he was given information when he requested it. He had suffered side effects from one of his medications when he was in hospital, but felt that the doctors should have realised without him having to tell them. He believed that patients had a right to know about the possible side effects of their medication, but that it might be better if the information were to be provided in the form of a leaflet, with provision made to ask questions at a later date. This would allow patients to ask questions once they had had time to consider the information provided. Moreover, as their condition improved they were more likely to be interested in asking questions. The other patient felt it was her own fault that she had not been provided with information about side effects, as she had not requested it. She did, however, state that she felt pressured by time when in a consultation. She believed she had a role in weighing up the risks and benefits of her medication, and would consult her friends and family if she wanted any additional information.

From these responses, it was evident that all those interviewed were assessing the risks of medication in different ways, and that their particular views on this influenced their attitude towards the provision of information about medication side effects. There was evidence of the use of professional judgement, by both the GP and the pharmacists, in deciding whether or not to provide information to patients. The pharmacists were concerned about providing too much information, and interfering in the patient's relationship with their GP. The GP, stressed the constraints on his time, and stated that information was provided according to the situation and the medication that had been prescribed. Both patients indicated that information about medication was not volunteered, although one said he was provided with information when he requested it. The other patient suggested that if she required any additional information she would consult friends and family.

As the evidence suggested that situational factors affected GPs' judgements and practices, it was decided to focus on patients who were prescribed a particular form of medication. Steroid medication was identified, as a means by which the potential number of variables could be reduced. Moreover, because of its' association by both professionals and patients with known side effects, it was likely to encourage both the provision of, and requests for, information. The intention was to examine the information about side effects that patients had acquired, the origins of this knowledge and the way in which it influenced their assessment of the medication. The second set of interviews will now be discussed.

Pilot interviews

A set of eight semi-structured interviews was planned in order to investigate further the information patients were given by GPs, or acquired from other sources. This would include patients' assessment of the medication and its effects. The questions were designed to determine what medication patients were taking, what they knew about it, the origins of this information and how this influenced their medication behaviour. The questions also sought to uncover any anxiety that patients may have experienced in connection with the medication, whether they had any knowledge of the medication prior to it being prescribed, and whether it was possible to say that they were making an informed choice regarding their medication.

Lists, supplied by the two participating Practices, were used to select the study sample, as they provide a good source of patients prescribed a range of steroids. Names were identified from a list of patients who had been prescribed one of ten different steroid preparations in the previous calendar month. The drugs were identified using the British National Formulary (BMA and Royal Pharmaceutical Society of Great Britain 1991) and varied from very mild to very potent steroid medication [1]. The aim was to consider whether there was an identifiable point, relating to the risk of side effects, at which patients either received or requested more information about the possibility of side effects. Random number tables (Francis, 1979) were used to select a sample of nineteen patients (one surgery had no patients in one category).

The GPs involved were asked if there was any medical reason why any of the chosen patients should not be approached to request an interview. One name was withdrawn on

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[1] The drugs that were chosen for the purposes of identifying the sample were: Hydrocortisone cream or ointment (Non-proprietary), any Betnovate product (Glaxo), any Synalar product (Zeneca), any Dermovate product (Glaxo), Prednisolone (Non-proprietary) Dexamethosone (Organon), Becotide inhaler (A & H), Beconase nasal spray (A & H), Betnesol eye drops (Evans), Predfoam (Pharmax) (Prescribed in the last SIX months)

medical advice. The GPs knew to whom letters had been sent, but as all the replies were sent directly to the University, they did not know who was interviewed. This enabled the patient's identity, and their comments, not to be revealed to the GP. More details about how the ethical issues relating to this part of the project were addressed, are presented on P. 89.

Replies were received from seventeen out of the nineteen patients identified. Fifteen agreed, and two refused. Interviews were conducted with the first eight who replied. Following analysis of these eight interviews the parameters of the sample were narrowed to include only a single medicines and a single condition. The patients who had agreed to be interviewed, but had not been included in the sample of eight who were interviewed, were then sent letters thanking them for agreeing to be interviewed, but explaining that their participation was no longer required.

As may be seen in the table (Table 3-2), the sample interviewed comprised six men and two women, and their ages ranged from six to seventy six. The gender imbalance shown here was reflected in the replies received.

Table 3-2

The composite of the sample for the pilot interviews with patients

Number	Gender	Age	Type of steroid medication the patient said they had been prescribed[2]	Code[3]
One	Male	64	Dermovate ointment	1M
Two	Male	73	Becotide inhaler	2M
Three	Male	43	Steroid injections, prednisolone tablets, becotide inhaler	3M
Four	Male	41	Becloforte inhaler, prednisolone tablets	4M
Five	Male	46	None	5M
Six	Male	34	Prednisolone tablets	6M
Seven	Female	76	Beconase nasal spray	7F
Eight	Female (Interviewed about her daughter)	6[4]	Hydrocortisone cream (prescribed in error when her daughter's condition was misdiagnosed).	8F

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[2] Patients were not always aware that the medication was a steroid.

[3] The numeral in the code indicates the order in which the interviews took place. The letter in the code indicates the gender of the person interviewed.

[4] The interview was conducted with her mother.

Before the interview commenced, the project was explained verbally, and the patient was required to complete a consent form, a copy of which they retained. I stressed that I was not from the medical profession, and was interested in their views on their medication. I did this in an attempt to prevent the participants from feeling intimidated, or from feeling that they were being 'tested' on their knowledge of their medication. I felt it was important to try and gain their perspective, therefore the schedule was merely used as a guide to topics, and generally only referred to at the beginning, and then again at the end of the interview, to ensure that all the intended areas had been covered.

Powney and Watts (1987: 36) pointed out that interviewing is as complex as any other social interaction, and therefore factors that may influence interaction in everyday life such as; social class, gender, age and ethnicity, may also influence the relationship between interviewers and interviewees. It is inevitable that the patients interviewed would have made certain judgements about me and my position, based on the fact that I was at a University, my gender and my age. All the respondents were white, and of British origin, therefore there were no ethnic differences. My age and gender may have affected some of the answers I received from participants, however I believe sufficient rapport was developed such that these factors did not affect the validity of the responses.

In order to gain the in-depth understanding required, it was necessary to establish a rapport that encouraged the participants to feel free to say exactly what they thought (Powney and Watts 1987: 40-41). To further encourage this, all the interviews were conducted in the interviewees' homes, which was intended to encourage the participants to feel as relaxed as possible, as they were on their own territory and in familiar surroundings. It was also designed to minimised the disruption to their lives.

All the interviews, from this point on, were audio-tape recorded. Powney and Watts (1987: 145) have suggested that tape-based interviews are often skewed in favour of the most articulate. However, I felt I would lose a lot of data if the interviews were not recorded, and in line with Powney and Watts (1987: 124), decided that inefficient note taking can be more distracting than the presence of a tape recorder. The five exploratory interviews that were conducted initially, were not audio-tape recorded, and I found note-taking interrupted the flow of conversation, particularly as it was not possible to maintain eye contact and take notes at the same time.

Permission to audio tape record all the interviews was requested, and there were no refusals. Although patients may agree to the interview being recorded, they may still feel inhibited by it. This was anticipated, and the tape recorder was placed out of sight where possible, and a small microphone put between us. It is often suggested that patients become more talkative as the interview ends and the tape recorder is switched off. This may be because the pressure to 'perform' has passed. For this reason, having finished the interview I would put my notes away and then switch off the tape recorder, and in this way did sometimes gain some additional information. These additional remarks were made as patients relaxed, because the interview was over and they felt the situation became less formal, and do not raise any ethical dilemmas about the use of remarks made 'off the record'.

All the interviews were transcribed in full. With reference to transcription, Powney and Watts (1987: 147) pointed out that transcription is only an interpretation by a transcriber of what is being said. However, as I did the interviewing and the transcribing, the transcribed accounts reflect my experience of the interviews. This meant that I could ensure consistency between the interviews and the transcribed accounts.

The issue of side effects was not raised directly, as the aim was to construct an understanding of the patients' perceptions of their medication, the idea being that they would raise the issue of side effects themselves if this was one of their concerns. The flexibility of the interview structure allowed me to ask general questions with regard to side effects, for example, what do you know about your medication? As the participants were encouraged to discuss all aspects of their medication, I feel that the issue of side effects was raised by the participants if they were aware of them.

Participants were generally very willing to talk. I think this was largely due to the fact that the majority of them did not work outside of the home, and they appeared to welcome the opportunity for some company. Generally, participants asked questions at the beginning, and once they were satisfied about what I was doing, and what they were being asked to do, they were very forthcoming. This is demonstrated in the findings.

Participants were encouraged to talk freely, and the order of the points to be covered was varied to preserve the conversational flow. The general areas covered, based on the literature review and data obtained from the initial interviews, are presented below.

- The medication that participants were taking and / or prescribed, how long they had been taking it, and how much they knew about it?
- How participants had obtained information; whether it had been volunteered or they had asked for it?
- Who had participants asked; their General Practitioner or someone else?
- How much information had participants wished to have?
- Were participants more concerned about certain types of medication then others?
- What information had participants gained from the media?
- Were participants concerned about their medication when it was first prescribed?
- Who did participants think should assess the risks and benefits of medication?
- How did participants assess the risks and benefits of their medication?
- Did they think patients had the right to know all the possible side effects?
- Would they like to know all the possible side effects?
- What were participants' views of patient information leaflets?
- Did participants generally feel any pressure on time when they were in a consultation with their GP?

Ideas that arose were probed and expanded further as the interview progressed. The flexibility of the schedule allowed issues raised in individual interviews to be included in subsequent interviews, allowing a picture of what was occurring to be constructed by building on earlier information. These developments could be in the form of new questions, for example about the role of practice nurses in the treatment of asthma, or in terms of ideas such as differing perceptions of the media coverage of steroids. Thus, the categories were shaped, in part, by the participants themselves. The use of the flexible structure also allowed the wording of the questions to be related to the situation as it developed, and helped to generate and sustain a good rapport.

The key findings from the interviews will now be discussed in order to demonstrate the contribution made to the development of the next stage of the method.

Preliminary findings from the pilot interviews

Participants generally expressed views which suggested that they were aware of the problems of side effects, for example: "of course everything has side effects". It was also suggested that "no drug is completely safe" (5M[5]). Moreover, the idea that their medication could possibly cause problems in the long term, problems that were as yet unknown, was mooted (4M and 5M). Criticism was levelled at the amount of information provided by GPs. However, when patients where asked directly whether they had raised their concerns with their GP, it transpired that they had not. This suggests that GPs may not always provide the level of information about medication that patients would like, a finding which echoes those from the preliminary interviews. The idea that patients may not complain directly, even though they say they are dissatisfied, is supported in the literature (Stimson and Webb 1975).

A possible explanation as to why patients may have reported their dissatisfaction when interviewed, but not attempted to present their concerns to their GP is provided by the idea of story-telling. Stimson and Webb (1975) claimed that story-telling is a significant vehicle for complaints. They argued that:

> the story is a form of communication (1) which highlights a process by which patients make sense of past events, (2) in which certain standards of behaviour of doctors and patients emerge, are sustained or are changed; and (3) in which some redress is made for the inequalities in the relations between the client and the professional (Stimson and Webb 1975: 90).

Storytelling allows the complainant to appear more active in their recitation of events than might well have been the case in practice. This apparent exaggeration may lead to inconsistencies in the account that is given. In terms of this research, the flexibility of the interviewing technique allowed for 'stories' to be probed for clarification. This allowed for insights to be obtained into the level of, and basis for, patients' understanding of steroid medication.

Two patients (5M and 7F) were unaware that the medication they had been prescribed was a steroid. Even if they were aware that it was a steroid, this could not be taken to imply that they were aware of any risk of side effects. No patient reported actually asking either their GP or their pharmacist for information about possible side effects. Two patients reported experiencing some side effects. However it was only after this had happened, and was reported to the GP, that they were informed of the potential for adverse effects (1M and 4M). Indeed, one participant felt he had experienced a side effect, yet it was not recognised as such by his GP (6M). Only one person from the sample had sought information about potential side effects (6M). He was taking oral steroids, on a long term basis, which carries a greater risk of systemic side effects than the medication taken by the other patients who were interviewed. Of particular interest, is the finding that he asked a friend who was part of a support group for information about his medication, rather than consulting his GP.

In all the interviews, the notion that medication was necessary in order to control the symptoms and to maintain a certain quality of life was seen as important. Thus, the general consensus was that there was little option but to comply: "If you need to take them you have to take them whether they've got side effects or not" (5M). This suggests that patients were not balancing the risks and benefits, as they felt that non-adherence was not an option. This sentiment was supported by a comment made by a married couple: the husband said "I don't know what would happen if I went off them" (2M), to which his wife said "Oh no, he would be no good without them". Neither of them had ever experienced any side effects, and he was not concerned about any of his medicines. However, she said that she "liked to get to the bottom of things", suggesting that she would have liked to know more about the possibility of side effects. Yet, despite the negative points, the medication was seen as effective. This idea was strongly supported by the comment that: "It's a wonder cure in a way" (1M).

All the participants expressed the view that patients have the right to know about their medication, and all said they believed they could ask for any information from their GPs if they wished. However, on further investigation, this response did not necessarily mean that they had ever asked for information. Thus, a discrepancy between perceived interest and actual behaviour was exhibited. A partial explanation for this came from two patients who expressed their reluctance to 'trouble' the GP. The expression of the pressure on time was also made by both the GP, and one of the patients interviewed in the exploratory interviews. However, when probed further, the general view was that

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[5] Please see Table 3-2 for an explanation of the code.

doctors should volunteer more information. Yet when asked whether doctors should list all the possible side effects, the fact that 'some people' may not be able to cope with a lot of information about the potential side effects of their medication, was mentioned in all but one interview (3M). Furthermore, the use of the doctor's judgement to 'control' certain information for some patients was suggested. All but one (5M) of those interviewed were prepared to rely on the judgement of the GP to provide appropriate information about the side effects of their prescribed medication.

Although the idea of patient information leaflets was fully supported, none of the participants expressed outright dissatisfaction with the level of information that they had received, raising the possibility that they were reluctant to appear too critical of GP practices. However, even those patients who at first appeared well informed were not necessarily so. One person who appeared to be well informed knew that he was receiving steroid injections, and that the short courses of prednisolone he had received were classified as steroids, yet he was not aware that his Becotide inhaler was classified as a steroid (3M). Another, admitted he did not know what the actual side effects were, he just did not like the idea of taking steroids (4M).

There was some variation in the views expressed about steroids. In some cases concern was voiced in comparison with other medication: "they are not aspirins are they?" (4M). In another case they were seen as 'safe' because they had been prescribed by the doctor (3M).

Participants were also asked about sources of medication information. They stated that they 'picked things up', both from the media, and from other sources generally, but could be no more specific about the information that they had obtained. Other than this, the media was dismissed as being about body-builders, and, as such, irrelevant to a person whose medication was under the supervision of the doctor (3M, 6M). The steroids discussed in the media were also described as a different form of steroids, and as such, the information was of no interest (1M, 6M).

Summary of the themes that emerged

- There was a general willingness of participants to accept the medication as the only solution for controlling their symptoms and as a means to maintain a certain quality of life.

- There was an awareness that medication may cause side effects in the long term.

- A gap was observed between patients' stated wish for information and their reported attempts to obtain it from GPs.

- GPs appeared not to provide information routinely, or to invite questions.

- Participants reported using sources other than the GP, and sometimes in preference to the GP, for information about their condition, and their medication.

The aim of this round of interviews was to further develop insights gained from the initial round of exploratory interviews. Specifically, the interviews aimed to establish the range of information about side effects that patients who had been prescribed steroid medication had acquired, the source of this information, and the way this influenced their assessment of their medication.

In spite of these findings, one weakness of the interviews was that they took account of a wide variety of conditions, and strengths of steroid medication. As a consequence, patients' concerns about the medication also differed considerably. In order to address these problems, the parameters of the sample were narrowed further to include only a single medication and a single condition. The sample included patients who had received a diagnosis of asthma, and had been prescribed an oral steroid, prednisolone, in previous calendar month. Prednisolone was chosen as it is prescribed in both long and short courses, and has a range of identifiable side effects. Definitions of both asthma, and the possible side effects which may result from a prescription for the oral steroid prednisolone, are presented in the next chapter (see P. 121).

A finding of particular interest from the previous set of interviews, which required further investigation, was the belief that the risk of side effects increased over time. This suggested that it was necessary to further explore how patients' understanding of their medication was built up, and the role the GP played in this. The intention was to explore the points at which information and knowledge was both sought and provided and how this related to patients' experiences. This included an understanding of informal sources of information used by the patient, and how these sources either changed or developed according to the severity of the condition for which the medication was prescribed. The aim was to explore how patients' changing understanding of their medication might influence the decisions taken concerning their medication, and whether these choices could be deemed to be 'informed choices'. By concentrating on patients' actual experience, rather than using abstract questions about what they felt they might do, it was hoped that patients' would feel more comfortable when answering, with an associated improvement in rapport. For these reasons, a life history approach was adopted for the next stage of the research. A brief explanation of this method is now provided.

The life history method

Armstrong (1982) described the life history method in the following terms:

> The life history method attempts to locate individuals in their overall life experience as well as the broader socio-historical backgrounds against which they live ... There appear to be two main alternatives ... [The] complete life history ... [or] the alternative ... multiple biographies within the same or similar areas of research ... the multiple biographies approach (P. 7, 9).

The multiple biographies life history approach was employed to encourage participants to recount the 'story' surrounding their situation. Graham (1984: 119) suggested that stories provide a vehicle through which individuals can build up and communicate the complexity of their lives. Stories can be used to illuminate the uncertain dynamic quality of the experience, as stories themselves are part of the process by which individuals make sense of past events and present circumstances. But they may also be a source of exaggeration, as suggested on P. 100.

The intention was to relate any concerns patients had about their medication to the development of their condition, its severity, and possible changes over time. Evidence was therefore sought concerning the information sources, both formal and informal, which were accessed during the course of the illness. It was anticipated that this technique would increase the 'richness' of the data obtained. The practical concerns associated with this stage of the research are now addressed.

The final patient sample

Two more GP Practices were recruited at this point. This increased the number of surgeries involved to four, thereby increasing the potential range of responses, along with the size of the available sample. One was recruited from contacts in the Family Health Services Authority (FHSA), the other from a personal recommendation. One of these was based in North Derbyshire, so ethical approval was obtained from the North Derbyshire Local Research Ethics Committee. A contact at each surgery was established, and the sample of patients was obtained in the same way as for the previous set of interviews (See P. 93).

The patients who were approached were chosen randomly from a list of patients who fitted the criteria; they were asthmatic, and had received a prescription for prednisolone in the previous calendar month. A list of thirty prospective participants was prepared from three surgeries. The aim was to identify an initial sample of twenty patients. As for the previous interviews, the selected list of patients was then presented to GPs to check that there were no objections on medical grounds to these patients being contacted. A standard letter was used, and was signed by the relevant GP. A reply slip, and a freepost, self-addressed envelope was included. Patients who sent a positive response were then contacted by telephone to arrange a suitable time for the interview.

One practice insisted that they identified the patients to be approached. They also used their own letter, although they were supplied with a copy of the standard letter. This may have affected the willingness of patients to take part, as only two replied. The use of their own letter may also have affected patients' response to both myself and the project. In particular, the participants from this surgery appeared unsure about the project, and required more explanation than patients from other surgeries.

It was only after responses were received from this Practice that the extent of the problems related to it were realised. I was led to believe that letters, in the format sent to patients from the three other Practices, had been sent out, and not wishing to antagonise the members of the Practice felt it was necessary to wait for a while before following this up. By the time that replies had been received from patients who were part of this Practice, all the other interviews had been conducted. The two patients who had responded were interviewed, and the findings from this stage were based on a sample size of eighteen, as opposed to the originally intended sample size of twenty.

A tables of the characteristics of the patients interviewed at this stage, organised according to whether they were prescribed oral steroids on a regular, or an occasional, basis, is now presented (Table 3-3 and Table 3-4):

Table 3-3

The demographic characteristics for interviews with patients who take oral steroids (prednisolone) on a long term, regular basis

Interview	Gender	Age	Condition (as described by the patient)	Length of time for which the condition has been diagnosed	Surgery
A	Male	62	Asthma / emphysema	56 years (asthma)	2
F	Female	47	Asthma	25 years	1
H	Female	48	Chronic obstructive airways disease	6 years	3
I	Female	69	Asthma	3 months	3
K	Male	58	Asthma	2 years	2
L	Male	50?[6]	Asthma	7 years	3
O	Male	53	Rheumatoid arthritis	5 months	2
P	Female	18	Asthma	12 years	3

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[6] This patient's age was not confirmed, but he was judged to be approximately 50 years of age.

Table 3-4

The demographic characteristics for interviews with patients who take oral steroids (prednisolone) on a short term, occasional basis

Interview	Gender	Age	Condition	Length of time for which the condition has been diagnosed	Surgery
B	Male	81	Chest complaint	10 years	2
C	Male	69	Asthma	4 years	1
D	Female	63	Asthma	39 years	1
E	Female	62	Asthma	3 / 4 years	1
G	Female	71	Asthma / bronchitis	5 months	1
J	Female	78	Asthma	5 / 6 years	3
M	Female	20	Asthma	10 / 11 years	2
N	Male	68	Emphysema	5 years	3
Q	Female	58	Asthma	42 years	4
R	Male	50's	Asthma	Since childhood	4

The name of the patient with rheumatoid arthritis appeared in error on the list of patients provided by the Practices. However, the transcript of the interview contained themes similar to those found in the other transcripts, possibly because this is also a chronic condition. For this reason, the findings from this interview have been included in the final analysis.

As with the previous set of interviews, the format was loosely based on an interview schedule. The following areas were covered, but the order varied to maintain the conversational flow.

- What medication did they take?
- When was the medication first prescribed?
- What information had they been given about the medication?
- How, and whom, had given that information?
- Had they been warned of any possible problems, and if so, at what stage?
- What sources of information did they have; friends, neighbours, newspapers, television?
- Did they receive repeat prescriptions?

- Did they feel the medication had positive/negative effects?
- How would they describe their relationship with their GP?
- Had they asked about steroids?

These areas of interest are similar to those used in the previous stage of interviewing, which are presented on P. 99, however, the underlying interest was to gain a long - term perspective on patients' beliefs and actions with regard to their medication, and seek understandings of the possible influences on their beliefs and actions, with particular reference to the idea of informed choice. The way in which the analysis was conducted is now presented.

Finding themes in the interview data

Notes were written after each interview, and later added to the bottom of each transcript (Burgess 1984). These helped in the interpretation of data, as they provided a wider picture of the participant and the interview itself than could be obtained based on the taped conversation alone. All of the interviews were fully transcribed.

The life history interviews aimed to ascertain the choices that patients were making about their medication, and the basis upon which these choices were being made. The idea of a 'gap' between the perceptions of patients and GPs, with regard to the amount of information ideally provided, was also considered.

The method of analysis used was charting, which is a technique for selecting and reorganising the transcript material according to themes (Bryman 1994: 182). Themes were identified from several thorough readings of all the transcripts. This is illustrated in the appendices, (Appendix C), by the presentation of a single transcript and the themes which were identified within it. The existence of these themes was validated by a second person reading a selection of the transcripts, and through discussion a number of key themes were agreed. The example also indicates how the use of the interviewing method, and the life history approach in particular, allowed for clarification of particular aspects, and for the development of an in-depth perspective.

The evidence suggested that patients' medication decisions involved attempts to 'make sense', of both the effects of oral steroids, and the problems associated with asthma. The information on which these beliefs were based originated from the way personal experience was understood in terms drawn from both medical and non-medical sources. Most importantly, this range of patient beliefs, expressed both explicitly and implicitly, appeared to be a major influence on the way in which patients used their medication.

Examples of verbatim quotations from the interviews, which support the idea of 'attempts to make sense' of both the medication and the medical condition, are discussed in Chapter Four.

Although patients may construct their own beliefs, about the effects of medication on the basis of a range of sources of information, GPs were the common link in the provision of information. However, information from GPs generally appeared only to be provided at the request of the patient, either in asking about the medication or expressing fears or a reluctance to take the medication. This reinforces the earlier findings that GPs do not volunteer information. It also suggests that patients were open to advice from GPs, but also either sought, or simply acquired, information from other sources. This use of a range of sources of information supports the idea of a 'gap', as mooted by Keown et al (1984), between the amount of information that health care professionals, in this case GPs, feel it is appropriate to provide about side effects, and the amount of information patients wish to have at their command. This raised questions about the professional side of the 'gap', for example, were patients' perceptions of the provision of information accurate? Did GPs' believe they were providing adequate information?

The purpose of interviewing GPs was to examine how they perceived their role as a source of information about side effects, and to assess their awareness of the operation of patients' beliefs in relation to steroid medication. Interviews were conducted as a means by which GPs could explain their perceptions concerning the provision of information, and their understanding of the sources of information available to patients when making choices about their medicines. The use of interviews meant that GPs were able to present their beliefs, and were not forced to fit their responses into predefined categories. These interviews will now be discussed.

The interviews with general practitioners

Interviews with patients identified GPs as the most constant source of information about medication. So, ten interviews were conducted with GPs in order to develop themes concerning the way in which they saw their role with regard to informing patients about the side effects of medication. It was expected that insights might be gained into the professionals' perceptions of the 'gap', identified by Keown et al (1984), between health care professionals and patients, in terms of the provision of information about side effects. The 'contact' GP from each of the four surgeries involved in the patient interviewing stage of the research was interviewed. The remainder of the sample came from a list of names supplied by a colleague in the University, who was also involved in a project with GPs.

All the interviews, except one which was conducted at the GP's home, took place at the interviewee's surgery. Interviews varied in time from twenty minutes to an hour. All, except one, was on a one-to-one basis. One was conducted as a focus group, involving all the GPs in one practice. This produces a different type of data from one-to-one interviews. Therefore, the findings from the focus group are reported separately from the findings from the one-on-one interviews.

Briefly the data from focus groups may be richer as the group situation may stimulate peoples' thoughts and by doing so encouraging different ideas to emerge. Alternatively, the dynamics of the group may interfere with individual expression and people may feel intimidated (Fontana and Fry 1994). With regard to the focus group I conducted I believe the former is a more accurate description. This is likely to be as all the GPs were from the same Practice, and are likely to have previously discussed issues within practice meetings.

General practitioners were asked to comment with specific reference to asthma and prednisolone. As with the interviews conducted with patients, the interviews were loosely based on a schedule. The schedule covered the questions presented below, however the order was varied to maintain the conversational flow.

- What information do you give to patients?

- To whom do you give information?
- Do you vary the type of information you give, and does it vary according to whether patients have experienced side effects?
- What reasons do you have for this?
- Do you provide information according to a framework?
- How do you feel political changes, and other changes in society, have affected the demand for information?
- How do you feel about patient package inserts?
- Does the severity of someone's condition affect your behaviour towards them in terms of the information you provide?
- Do you believe that patients comply with their treatment for asthma?
- Do you have an Asthma Clinic, and if so, how does it work?
- Do you refer patients to the Campaign for Asthma support group?
- How do you feel about the media, and how it portrays both asthma and steroids?

Questions were not directly asked concerning patients' beliefs about medication, as I wanted any evidence of an awareness of these to emerge naturally in the course of the interviews. All the interviews were audio-taped, and then fully transcribed. The findings were then discussed according to GPs' perceptions of their relationship with patients, the information they provided to patients about the side effects of steroid medication, and GPs recognition of patients' beliefs. These results are presented in Chapter Five.

General practitioners were asked to comment generally on the information they would provide to patients, and on the way they felt this information was utilised. This meant the answers were often very broad, as GPs tried to answer with reference to a range of patients, situations and experience. They often said that they would tell patients the medication was a steroid, and maybe mention a few common side effects. However in some cases they would not tell certain patients that the medication was a steroid for fear of causing them undue anxiety. These fears, they claimed, were often based on previous experiences with that patient. Thus, certain patients were perceived by their GP to be particularly anxious. This indicates that GPs may base their decisions about the provision of information about medication on their previous experiences with patients, and on their beliefs about how patients generally react to this information. Interviews with patients had suggested that their beliefs influenced decisions concerning both their medications and condition, however interviews with GPs suggested that the importance of these beliefs may not always be recognised, or may be misinterpreted. This lack of recognition of patient beliefs further informs the idea of a 'gap' in understanding between patients and GPs.

The evidence presented from the fieldwork conducted so far has indicated poor communication between patients and practitioners. Patients appear to be making decisions about their medication on the basis of information from a range of sources. Yet, interviews with GPs suggest that they are either unaware of the way patients seek information to 'make sense' of their condition, or alternatively may misinterpret patients' wishes. In order to investigate the 'gap' further, a vignette was constructed with the intention of gaining insights into GPs' recognition and understanding of, and their feelings about, patients' use of a range of sources of information when making choices about their medicines. The aim of gaining an understanding of GPs' awareness of, and feelings about, the way patients construct their understandings, was to provide an account of the possible communication problems between patients and GPs. The use of a vignette, and its specific application here, will now be described in more detail.

The vignette technique

Finch (1987: 105) described vignettes as:

> short stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond.

The use of this format allows for features of the context to be specified, so that the participant is invited to comment on a set of social circumstances, rather than to express his or her 'beliefs' or 'values' in a vacuum. The method therefore acknowledges that meanings are social and that morality may well be situationally specific (Finch 1987: 106). It also allows qualitative information to be presented to a wide sample in order to gain more representative data for quantitative analysis.

As Finch (1987) further suggested:

> the vignette technique offers a way of studying complex issues while still capitalising on the strengths of the survey method, in that equivalence of answers can be assumed more readily and therefore the data can reasonably be used as the basis for generalisations about a given population (P. 111).

Thus the use of a vignette, as opposed to a survey containing a list of questions, enabled GPs' understandings concerning patients' medication behaviour to be explored in a way which approximates to the complexities with which such issues are surrounded in reality (Finch 1987). This may be seen to increase the validity of the data collected.

The vignette was based on a 'typical' case from the life history interviews with patients. It was administered to all practising GPs in Derbyshire to gain as representative a response as possible. One of the particular strengths of the vignette technique, in terms of this research, was the possibility of presenting a context, and therefore a more detailed background to the questions being asked, than would have been possible in a standard questionnaire. GPs were required to comment on one case as it developed. The use of a single case increased the reliability, as it meant the responses to questions were based on the same evidence, therefore GPs were not responding to questions purely on the basis of their previous experience with a variety of patients. It also allowed some scope for generalisations to be made. Finally, it could be argued that the use of a fictional case made the process of gaining the data less confrontational than may have been the case had a set of questions alone been presented. The way in which the vignette was constructed will now be examined.

The construction of the vignette

The scenarios presented were all based on experiences described by patients previously interviewed. General practitioners were asked to respond to questions as the 'story' developed. The case constructed involved a fifty-eight year old woman. The gender and the age were chosen as reasonably typical of the sample involved in the life history interviewing stage of the research. Each of the scenarios presented had been recounted at least once, and the 'events' represented how patients may incorporate information into beliefs systems to rationalise their actions. The validity of the vignette stemmed from the authenticity of the source material. However, the validity may be seen as compromised by the fact that a postal form of data collection does not allow for face-to-face clarification of any questions that may not be understood. It is also difficult to ensure that the questions are interpreted in the same way by all the participants. The vignette was piloted to minimise the likelihood of this possible problem (See P. 118).

The vignette developed as illustrated in the shaded areas of the table presented overleaf (Table 3-4). At each stage GPs were asked to comment on whether they felt the situations presented were realistic. A list of emotions also followed each of the scenarios, and GPs were asked to respond either yes or no, in answer to whether or not they believed they would experience these feelings. The descriptions presented were: supportive, sympathetic, resigned, frustrated, betrayed, angry, and that you had failed. The aim was to cover a spectrum of possible reactions. The vignette sought to establish whether GPs recognised the situation, and then to establish their feelings towards a patient who acted in that way. The composition of the vignette was such that the suggested influences became further removed from both the patient and the GP as the vignette progressed. Initially the patient's own beliefs were presented, then beliefs based on advice from friends and family, and the television, and finally beliefs based on information from the Campaign for Asthma.

The table below (Table 3-5) presents the scenarios presented in the vignette, together with examples of some of the experiences on which the vignette was based. A copy of the vignette is provided in the appendices (Appendix D). General practitioners were asked to respond either yes, or no, to a series of questions based on the scenarios presented below, and posed as the 'story' progressed. Some of the quotations do not correspond exactly to the statements in the vignette. This is because the vignette was designed to convey ideas that had been implicitly, as well as explicitly, expressed, therefore it was not felt necessary to duplicate them exactly.

Table 3-5

Examples of key findings used to construct the vignette

She says she has heard both 'good' and 'bad' things about steroids[7].

Did you know anything about them? Had you heard of them?[8]

I'd heard of them, yeah. I heard that they did you good. That was all that bothered me[9].

What made you concerned about taking them? (Oral Steroids) [10]

Well...I don't know really you, you hear things about them I suppose.. and I've got a sister that takes everything under the sun, you know, her doctor just hands everything out and she just thinks she's got to take everything. And um, I don't want to get like her...I think you can take too much.

On further examination of her records, you notice that she was prescribed an antibiotic a year ago. She suffered an adverse reaction which she attributed to the medication.

So you don't like taking tablets?

Well, no not really, it's not that I don't like taking tablets, it's that I think well, if you become reliant or you get side effects you get more problems. Now the best thing I find is an aspirin and yet of course I come from a family of stomach ulcers, and yet I'll take an aspirin. I've tried other things, paracetamol and things like that, I mean they're horrid to me..

Do you mean they don't work or..

They usually make me tummy hurt and all sorts, I don't feel, I don't like them, I don't like the reaction I get. Now an aspirin will settle me down a bit.

So would you say you worried about side effects when you are prescribed things.

Well, I must be worried, unless it's a natural thing. I mean I don't know that I'm worried, but tablets are tablets aren't they, drugs are drugs.

and er this is probably why, in fact this is why I don't take a lot, or I try and resist them, you know, because, I mean over your life you see people on tablets don't you and you see them become absolutely dependent on them and I think, no I don't want that. I'd rather have the one and screw it out altogether, you know.

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[7] The shaded area notes an extract from the vignette.

[8] The italics in the non-shaded area denotes an extract from an interview with a patient where the interviewer is speaking.

[9] The normal text in the non-shaded area denotes an extract from an interview with a patient, where the patient is speaking.

[10] The brackets contain additional, explanatory, information.

She thought the dose sounded a bit too high and she has not taken them as prescribed.

Do you worry about taking any of them. I mean are there any that you don't like more than others, or more concerned about?

Yeah, these steroids. I don't like them at all. I keep saying to them don't you think it's time you weaned me off of them? And 'cause I've been taking eight, at a time, you know. Well to start with me doctor just said to me take eight and he says he's sure that he told me to take eight all at once, but I can't remember him saying take eight all at once and I was just taking two at a time you see.

Ah ha, spreading it during the day

And it wasn't doing any good and I had to send for him because I couldn't breathe

Oh dear

And he says them steroid tablets should do the trick

ah um

He said I can't understand it, I said well I take two every, four times, ooh he said, I said take them eight at a time. I said I can't remember you saying that. Well I did, I know I did and 'cause I thought eight of them at one go, I said what are you trying to do, kill me. He said no you take eight at a time, well I was, I said to my husband I'm not taking eight of them at a time, you don't know what they'll do to me. He said you'd better do as you're told so I took them, but I was always a bit wary, eight tablets on one go seemed to me to be an awful lot and er just this last four weeks he said I'll try and cut you down and see how your asthma goes and that, and see how you go but he says I won't cut you down any lower than that until we see how the asthma is going to go, but they put me on them when I took hay fever and pneumonia, I was on them when I had pneumonia.

So is it the number you have to take you're not happy about or the fact that they are steroid tablets?

The fact that they're steroids, I've heard that much about steroids, but they say that that's not the same type of steroids

She has spoken to both her daughter and her neighbour and asked them what they thought about the dose that you had prescribed. They agreed with her that it 'sounded' a bit high.

So you said the pain in the bones and the thinning of the bones has come from, from the prednisolone?

Well, yes, I assume so

Did they suggest that this might happen, did you ever have any idea that er, that that drug could cause that?

Well, I mean I've been taking it all these years no-one said to me initially, this was the bit that really gets me, no-one when I first took it said to me it's got side effects, I mean I've virtually had to find all the side effects out myself, just through talking to people when I've been in hospital, whenever

What like other patients?

Yeah, but I seem to be, the ones I talked to I seem to be on higher dose than them, you know even when I last went in ( ) Everyone seems amazed the amount of drugs I am taking when I go in, especially the nurses.

She telephones the surgery a week later and says that she has seen a television programme about the side effects of oral steroids. She is upset and worried about the fact that she has taken them.
Now, you said you weren't worried about steroids until you saw this programme Yes, cause it said it could do something to your **bones** (Her emphasis) *Ah um* But er, it wasn't on, it was a programme I think that should have been on a lot longer, to let people know the full facts of taking these tablets, but it give you what about a quarter of an hour if that, then it changed onto another subject. But there was a group of people and all of those had put weight on, hence I said now I know where mines come from. But when I mentioned it to the doctor, he said well didn't anybody tell you and I says no. I'd heard about em, and I'd read, you know, different articles in the paper, in books and that about them, um, he said well you should have been told, they do give you an appetite, you are inclined to put weight on with them. Um, I said well it's a vicious circle for me then (Laughter)

A fortnight later Mrs X comes to the surgery and tells you that she has joined the Campaign for Asthma and has received some written information about the use of steroids in asthma.
That's why I believe a lot in asthma society. *Because it gives you full information?* It gives you full information and we have regular meetings at the City Hospital with speakers who demonstrate um nebulisers, who talk about various medications so you get the full facts, and you're able then, a lot of them are from the manufactures you see and you are able to ask the manufacturers what the side effects are if any and that.

Practical concerns relating to the vignette

The vignette was piloted with two GPs to establish the ease with which it could be completed. Minor amendments were then made. The Derbyshire FHSA were contacted, and a copy of the vignette was sent for their information, and for any comments. They agreed to the vignette being sent out, and provided lists of all the practising GPs in Derbyshire. The vignette was first sent on 31st July 1995. It initially gained a forty-eight percent response rate (n = 498). Another copy was sent, on the 11th September 1995, to GPs who had failed to respond. The last response was received on the 31st October 1995. Responses were finally received from sixty-nine percent of the practising GPs in Derbyshire.

The vignette was designed to be analysed using descriptive statistics. As demographic data on all the GPs in Derbyshire were available from the FHSA, then it was also possible to use bi-variate analysis to establish how representative, in demographic terms, the response was. This analysis is presented in Chapter Five.

Summary

The research set out to investigate the problematic idea of informed choice. The argument is that informed choice requires a participative relationship between patients and medical practitioners, and challenges the enduring traditional relationship. The idea of a 'gap' between GPs' and patients' perceptions of the level of information ideally provided with reference to the effects of medication was explored. The overall aim was to establish whether there was any evidence to support the view that patients are able to make informed choices about their medication.

This chapter has discussed the philosophical and ethical justifications for the methods employed. It has also demonstrated the way in which the methods employed and the groups studied were 'built' up stage by stage. Initially, exploratory interviews were conducted with a small number of patients and health care practitioners in order to define the issues. This led to the adoption of a focus on steroid medication, and interviews were conducted with eight patients. From these interviews, an appreciation of the variety of information sources accessed by patients began to develop. The focus was narrowed once again, this time to limit the sample to asthmatic patients who had been prescribed an oral steroid, prednisolone. A life history approach was adopted in order to consider how perceptions of the condition, and of the medication, might change over time, as well as to identify potential sources of patient information. From the analysis of these interviews, it has been argued that patients cope with both their condition, and the potential side effects of their medication, by employing personally meaningful explanations constructed around a variety of beliefs. Ten interviews were then conducted with GPs to explore their part of the 'gap' with regard to the information provided about the side effects of medication. The questions covered the range and type of information they provided about side effects when steroids were prescribed, as well as GPs' understanding of the way patients build and sustain personally meaningful understandings about their medical condition and its treatment. Finally, GPs' recognition of, and feelings about, patients' beliefs, was examined in more depth through the construction and administration of a vignette based on the findings from the life history interviews with patients. The research as a whole provided insights into potential communication problems between GPs and patients, in terms of the existence of patients' beliefs, and the failure of GPs to contribute meaningful information to patients, such that they felt able to make informed choices about their medications.

Having discussed the fieldwork which has been conducted, and the rationale behind each stage, the next chapter will present the full analysis and discussion from the life history interviews conducted with patients. The interviews conducted with GPs, along with a discussion of these results, will be presented in Chapter Five. Chapter Five also contains the results and discussion from the administration of the vignette.

Chapter Four

INFORMED CHOICE: LIFE HISTORIES OF PATIENTS WITH ASTHMA

The research uses the idea of informed choice to investigate the provision of information about side effects to patients, and to explore patients' perceptions of the choices they make, and the information upon which these choices are based. The evidence is then used to enquire into the possibility of a 'gap' between the information desired by patients and what is formally provided by GPs.

This chapter documents the results of the main enquiry. It involved eighteen life-history interviews with patients who had been diagnosed as suffering from asthma, and had received a prescription for oral steroids in the previous calendar month.

Asthma is defined as a condition marked by recurrent attacks of paroxysmal dyspnea, otherwise known as spasm or seizure of laboured or difficult breathing, with wheezing due to spasmodic contraction of the bronchi. In some cases, it is an allergic manifestation in sensitised persons; in others it may be induced by vigorous exercise, irritant particles, or physiological stress (Anderson 1982). The potential side effects of oral steroid medication which do not necessarily require medical attention are a false sense of well being, increased appetite, indigestion, nervousness or restlessness, and trouble in sleeping. Side effects such as decreased or blurred vision, decreased or slow growth in children and growing teenagers, frequent urination, and increased thirst should be brought to the attention of a medical practitioner. If the medication is taken long term then there are also risks of: abdominal or stomach pain, acne or other skin problems, bloody or black tarry stools, filling or rounding out of the face, increased blood pressure, irregular heartbeats, menstrual problems, muscle cramps or pain, nausea or vomiting, pain in the back, hips, ribs, arms, shoulders, or legs, swelling of feet or lower legs, thin, shiny skin, unusual bruising, unusual tiredness or weakness, unusual weight gain, and wounds that will not heal (U.S. Pharmacopeial Convention, Inc. 1986).

Patients were interviewed using a life history approach to discover how patients with a chronic condition develop their understanding of their condition and their medication over time, and any related effects on their relationship with their GP. As the interviews described here are life histories, the concept of career is useful for organising the data. Following a definition of the concept, a brief description of the way in which each patient's medical career developed is presented. This provides background information into the lives of the patients who were interviewed, and their key concerns. It also provides a context for the choices patients reported making with regard to their medication.

Other studies concerning the experiences of people with chronic conditions have adopted a life history approach and use personal narratives to explore the experience of chronic illness (Snadden and Brown 1992, Robinson 1990, Radley 1989, Williams 1984, Charmaz 1983). The presentation of each person's individual medical career is constructed from both the interviews transcripts and the fieldnotes made directly after the interviews took place. Claims to validity may have been increased if the personal narratives had been feedback to the patients who were interviewed. This was not done due to the pressure of time, however I believe the rapport which developed in the interviews ensured that the personal narratives represent valid accounts of patients' experiences of their illness.

The presentation of the interviews is divided according to whether the patient received a long or short term prescription for oral steroids. This is of particular interest with regard to the development of side effects. For a long term course of steroids a small dose will be prescribed, with the aim of maintaining the condition at a 'reasonable' level. Long term side effects such as thinning of the skin may develop. The life history approach allows an appreciation of how patients may cope with this change. A short term course will be administered at a higher dose than a longer term course, with the aim of treating a sudden worsening of the condition. The side effects in these cases are likely to be short term, visible effects, such as weight gain. Therefore the length of the course of oral steroids prescribed is likely to affect patients' perceptions of both their medical condition, and their medication. The interviews are also further organised according to the length of time for which the condition had been diagnosed.

The transcripts were analysed using the technique of charting (Bryman 1994). All the interview transcripts were thoroughly re-read, and themes were identified. The transcripts were then re-organised according to the themes. The key issues to emerge from the data are presented here. First, the relationship between patients and GPs is explored. The GP is the professional expert on the condition and the choice of treatment, and, as such, might be expected to be the key informant about medication. However, there are also other factors to consider, such as next patients' measures of quality of life. Patients' measures of quality of life are explored as themes, as they may affect the choices patients make with regard to their medicines. Finally, patient's perceptions of sources of information other than the GP, as noted and discussed in Chapter One, are explored in order to gain a more rounded picture of the information patients reported using when making choices about their medicines. Patient' explanations about the potential for developing side effects from taking oral steroids are also documented.

Brief case studies of all the patients interviewed are now provided.

The patient's medical career

The notion of 'career' was used by Becker (1953) to describe the 'deviant career' of the drug user, and by Goffman (1990) who described the 'moral career' of patients with stigma; the situation of the individual who is disqualified from full social acceptance (Goffman 1990: 9). Goffman suggested that people who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self - a similar 'moral career', that is both the cause and the effect of a commitment to a similar sequence of personal adjustments. In one phase of this socialisation process, the stigmatised person learns and incorporates the stand-point of 'the normal', thereby acquiring the identity beliefs of the wider society, and a general idea of what it would be like to possess a particular stigma. Goffman also suggests that there is another phase in which a person learns both that they possess a particular stigma, and the consequences of possessing it (Goffman 1990: 45).

Therefore, the idea of career is two-sided. It incorporates both the idea of self-development, and the context through which the self travels. The interplay of these two initial phases of the moral career form important patterns, establishing the foundation for later development, and providing a means of distinguishing among the moral careers available to the stigmatised. Here, the idea of 'moral career' is used to describe how patients manage their diagnosis of asthma, and the associated side effects of their oral steroid medication. The intention is to explore the changing meanings they give to the strategies they develop for coping with an asthmatic condition which requires prescribed medication for its relief, and with the side effects associated with the medication. In particular, attention is paid to the specific choices patients have made, and in what sense these could be referred to as 'informed' choices.

Table 4-1 presents the age, the medical condition, and the length of time for which the condition had been diagnosed, of each patient who had received a prescription for a long term course of prednisolone. This is followed by a fuller description of each of the patients in terms of their medical career. This process is then repeated for patients who had received a prescription for a short term course of oral steroids.

Table 4-1

The demographic characteristics for third stage interviews with patients who take oral steroids (prednisolone) on a long term, regular basis

Interview	Age	Condition (as described by the patient)	Length of time for which the condition has been diagnosed
Mr A	62	Asthma / emphysema	56 years (asthma)
Mrs F	47	Asthma	25 years
Ms P	18	Asthma	12 years
Mr L	50?[11]	Asthma	7 years
Mrs H	48	Chronic obstructive airways disease	6 years
Mr K	58	Asthma	2 years
Mr O	53	Rheumatoid arthritis	5 months
Mrs I	69	Asthma	3 months

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[11] This patient's age was not confirmed, but he was judged to be approximately 50 years of age.

Mr A was 62, and had suffered from asthma for most of his life. He set a 'benchmark' of being able to "get out", as his marker of quality of life. Taking a long term course of oral steroid medication allowed him to achieve this benchmark. He had gained information over time. The source of this information varied from the GP and practice nurses, and hospital doctors and nurses, to talking to other patients while in hospital, and the asthma society. When Mr A was sent for a bone scan he reassured the doctors that he was aware that taking oral steroid medication may cause him to suffer damage to his bones. Because Mr A was aware of this risk, the necessity for the test did not surprise him. He did not believe he had any choice but to take the medication prescribed. This sentiment was strongly expressed throughout the interview, together with his belief that the improvements in the effectiveness of medication over time outweighed the side effects of the current medication.

However, although Mr A took his steroid medication regularly, he reported leaving a larger time gap between his nebulisations than had been advised by his doctor. He believed this made the treatment more effective. This suggests that despite the faith he expressed in the medical profession, he still disregarded professional advice in favour of his own beliefs. He had previously suffered adverse effects from a prescription for tranquillisers, however, he blamed the practitioner who had prescribed that medication, and did not believe this had made him wary of other medications.

Mrs F was 47, and had suffered from asthma for the past 25 years. She was on a long term course of oral steroids. She was first prescribed oral steroids in the 1970's. She was annoyed that she wasn't warned of the side effects of oral steroids when they were first prescribed, and believed that information had been withheld by the medical profession ever since. She had gained information from a variety of sources, including from other patients when she had been admitted to hospital. She believed she has no choice but to take oral steroids, however she also believed that any medical problems which have developed since she was prescribed oral steroids have been related in some way to the fact she takes oral steroid medication.

Mrs F listed the side effects of oral steroids as diabetes, heart attacks, ulcers, hair loss, and bruising. She said her ankles had swollen up, she had bruises on her legs, and a skin problem. She was angry as she said she had trusted the doctors, and now she is on a medication which is causing her side effects. However, she has to continue to take it. She was told this by a GP other than her own. He told her that she would die without it. Her comment on this was that she appreciated the fact he was honest with her.

Recently, her doctor tested her for diabetes. However, she says that until that point she was not aware that diabetes was a possible risk. She feels she should have been informed about this.

Mrs F was aware of the necessity of her medication, and the fact that she would probably be dead if she had not been prescribed it. However, she said that she would like to have been informed about the potential side effects, and then at least she might have felt that she had had an option about whether or not she took it. Her lack of confidence in her ability to gain information from the medical profession even extended to the fact she believed she will not get access to her medical notes. She was not aware of the terms of the *Access to Health Records Act 1990.*

Mrs F had become distrustful of the medical profession, and the information provided, and said she constantly sought new information.

Ms P had suffered from asthma since she was three. She was on a long term course of oral steroids, which she said the doctors were trying to wean her off. She expressed a wish to stop taking the steroids because she had experienced weight gain as a side effect, and felt that at her age she should be slim. She said she did not need to seek information about her condition or her medication, as she felt she gained all the information she needed by just living with the condition. Her concerns were the weight gain, which she attributed to taking a long term course of oral steroids, and the embarrassment of the 'shakes'. She was unsure whether this was caused by her steroid medication, or one of her other medications that she took for asthma. In fact, this is a known side effect of the drug salbutomol. She had told her GP of her concerns about her weight gain, and they had discussed the need to reduce her current dose of prednisolone while avoiding a deterioration in her medical condition.

Mr L was in his fifties, and had received a diagnosis of asthma about ten years ago. He had been informed about the side effects of oral steroids after experiencing thinning skin, and bruising. He said that he suffered from pains, but was not sure whether this could be attributed to taking oral steroid medication. He had also read in a leaflet that he could suffer heart trouble as a result of taking oral steroids. He took the steroids because they were the "best of two evils". He said that he monitored his condition, and went to the doctor when he felt he needed oral steroids. However, when his medication had been changed, he had not been given an explanation. He had said that he had not queried the change as he thought the doctor must believe the change was appropriate.

The main way in which Mr L convinced himself that his medication was safe to take, was because children take them. Moreover, he felt that he was fortunate to have only recently developed asthma, as children also suffered from it.

Mrs H was 48 and was taking a long term course of oral steroids for the treatment of chronic obstructive airways disease. She had been diagnosed six years ago. The medication had caused her to gain weight, and she said her skin had become thin. She was also aware that oral steroids could make her blind, and cause brittle bones. In an attempt to reduce the likelihood of brittle bones she had increased her consumption of milk. Her daughter, who is a nurse, had enquired about the side effects on her behalf. Mrs H had also sent away for information. Both her and Mrs E reported requesting information from support groups. Mrs H also collected newspaper cuttings. She believed her GP was happy to answer her questions, although she said he teased her about her requests for information. She also suggested that doctors may not know all the side effects. Although Mrs H actively sought information, she expressed the continuing theme that with her symptoms there is no choice but to take the medication.

Mr K, was also aware that there were possible side effects. However he believed that he should take his medications, unless they caused too much aggravation. He was 58 years old, and had received a diagnosis of asthma two years before the interviews. He said that previous to this he had always been fit. He too believed that he had no choice but to take the medication. He had gained weight, which he attributed to taking oral steroid medication, but had not discussed this with his GP. Although he was on a long course of steroids, he did not believe that he was taking enough to cause him too many problems. This was based on his wife's experience of taking oral steroids in large quantities, which had caused her to suffer side effects, in particular to gain a great deal of weight.

Mr K said he was happy to ask for any information he required. He believed leaflets provided a good, and easily accessible, source of information. He also expressed his belief that side effects could be eradicated, and blamed the pharmaceutical companies for not doing this.

Mr O was 53 years old and had been diagnosed with rheumatoid arthritis five months before the interview. He had been taking oral steroids ever since. Although he did not fit the criteria as he was not asthmatic, it is interesting to note that the ideas expressed by him about oral steroids are similar to those expressed by the patients with asthma. He did not know what the steroids did, or how they worked. He said that he took them because he had been prescribed them. Mr O was concerned about "after effects", but said when you are in a lot of pain you'll take anything. He had asked his doctor about the side effects after he had seen a report in the newspaper about a young girl who had died after taking the same medication that he had been prescribed. He said the GP had said he should not worry, as he was not on anabolic steroids. However, Mr O was aware that he was not taking anabolic steroids, and was concerned about his particular prescription. Yet he dismissed his concerns by restating his trust in his GP.

Mrs I was 69 years of age, and recently developed asthma after having pneumonia. She said that she had been in good health up until the last 6 months, and found it hard to accept her condition. She felt that her doctor had failed to provide a satisfactory explanation as to why she should have developed asthma, and she had borrowed medical books from her daughter in order to try and understand her condition. However, she did not feel that her symptoms warranted her contacting the Asthma Helpline for advice. Her uneasiness about her condition also affected her feelings about her steroid medication. Her doctor had suggested that she should not suffer any adverse effects from her medicine, as she would not be taking it for very long. She was now anxious for the doctor to "wean" her off them. She even expressed concern that her GP had gone on holiday, therefore the process of reducing the tablets would stop while she was away, and she would be on them for longer. Her main concerns were that she did not want to get fat, and she did not want to get addicted. It is interesting to note that Mrs I expressed concerns about the future consequences of her medication. However, Mrs I had a friend who was asthmatic, and very ill, who she helped to nurse. She also knew people who had gained a lot of weight while taking oral steroids. This information had affected her attitude towards both her condition, and the medication prescribed for its' treatment.

Summary of the life histories of patients who take oral steroids on a long term, regular basis.

All eight of the patients' life histories presented here involved a long term prescription for oral steroids. According to these accounts, information provided by the GP to patients concerning the risks of side effects was either provided as a result of the occurrence of side effects, or following a direct request. It was not volunteered. Sometimes it was not given even when requested. Three patients, Mrs F, Mrs H and Mr O, reported attempts to gain information about potential side effects. Mr O described a failed attempt to clarify the risk of side effects. He did not gain the information he required, but said that he trusted his GP so was not concerned. Mrs F was dissatisfied with the amount of information she had been given, and believed that information was being withheld from her.

A common thread, expressed directly by six of the patients is the belief that they had no choice but to take the medication. Two patients, Ms P and Mrs I, expressed a desire to stop taking the medication, although both acknowledged that the medication controlled their condition. In the course of their medical career, all the patients had come to accept that they had a serious condition, and had found the medication helped in controlling their symptoms. In spite of the problems they had experienced, all the patients had found a way of 'making sense' of the treatment, although the form that this took varied with the individual.

The next section examines the ten patients who were taking short courses of oral steroid medication.

Table 4-2

The demographic characteristics for third stage interviews with patients who take oral steroids (prednisolone) on a short term, occasional basis

Interview	Age	Condition (as described by the patient)	Length of time for which the condition has been diagnosed
Mr R	50's	Asthma	Since childhood
Mrs Q	58	Asthma	42 years
Mrs D	63	Asthma	39 years
Ms M	20	Asthma	10 / 11 years
Mr B	81	Chest complaint	10 years
Mrs J	78	Asthma	5 / 6 years
Mr N	68	Emphysema	5 years
Mr C	69	Asthma	4 years
Mrs E	62	Asthma	3 / 4 years
Mrs G	71	Asthma / bronchitis	5 months

Mr R said he accepted the necessity for oral steroid medication. He was in his fifties, and had suffered from asthma since he was a child. He was concerned to gain more information about the side effects of oral steroids, but concluded that he was not on the medication often enough to be affected by side effects. This was despite being unsure of any potential side effects, except weight gain.

Mrs Q was 58, and had suffered from asthma since she was 16. At the time of the interview she had just been prescribed a short course of oral steroids. She had recently seen a television programme which discussed the side effects of oral steroid medication. The two side effects which she recalled to have been discussed on the television programme were weight gain, and damage to the bones. Although she had been frightened at first, she had started to rationalise the information to suit her own situation. She said she was pleased because she could now relate her weight gain to the steroid medication, and felt she could cut down on biscuits in order to prevent this occurring in the future. She was more concerned about problems with her bones. She had spoken to her GP, who said she should have been told that her appetite might increase while taking oral steroids. However, with regard to the question of damage to bones, he merely said this had not happened to her.

Mrs Q presented a number of reasons why the side effects presented in the programme might not be relevant to her case. She said the patients presented were on higher doses than she was. She also believed they probably also had something else wrong, other than just asthma. She reported experiencing mixed feelings about the programme. It had informed her about the origins of her weight gain, however she said she had been receiving treatment with oral steroids for so long now and it had not affected her like that, therefore she concluded that it must affect some people more than others. She also believed the medication was so efficacious that she had no choice but to take it.

Mrs Q believed that doctors differed in the amount of information they provide, but based on her own experience, believed that younger doctors were better at providing information. She said that in the future she was going to try and consult young doctors.

Mrs D was 63, and had had asthma since childhood, however said that now it was only occasionally bad. She didn't like to take medication because "you hear things". She spoke of her sister who she believed took medication too readily. She also believed that taking medication too often reduced its effectiveness.

Mrs D had been prescribed tranquillisers in the past and this had made her wary of taking medication in the long term, for fear of addiction. She felt she was not fully informed about what she was prescribed, and she believed her experience with tranquillisers had made her more likely to question doctors.

Ms M was first diagnosed with asthma when she was ten, but her condition had deteriorated in the last three years. She had just received a short dose of oral steroids after having a cold. She was embarrassed by the "shakes" caused by her salbutomol inhaler. When she took oral steroids she experienced aching and felt restless. Her main concerns were of day-to-day problems, such as the fear of an attack if she was in a smoky environment. She said she had not sought information, but the practice nurse had given her literature about both asthma and her inhalers.

The most uninformed patient interviewed was an 81 year old man (**Mr B**), who described his condition as a chest complaint which the pollen aggravates. He had suffered from this condition for twenty years, and believed his condition was caused by his previous employment in the fire service. He was prescribed short courses of oral steroid medication, and took it without question. He described his medication as a "tonic" and a "booster". He did not perceive a direct connection between steroid medication and his condition, instead he saw the medication as a means by which his general well being was improved.

Mrs J was 78 and had suffered with acute asthma for the past five or six years. She took short courses of oral steroids because she believed they did her good, but did not believe in taking medicines "willy nilly". She would rather avoid taking any medication, however at certain times her condition dictated taking some. She said that she could ask for information as and when she needed it.

Mr N used his own benchmark in order to maintain his medicines at a 'reasonable' level. Mr N was 68, and had suffered from emphysema for the previous five years. He received short courses of oral steroids, which he believed the doctor used as a "bang". He perceived his medication as necessary, however he used his ulcer as a 'benchmark' by which he could judge whether his medication was likely to cause him any problems. He was very frustrated that his condition limited what he wanted to do, in particular the gardening. This caused him more concern than the potential side effects from the medication. He was not interested in potential side effects, and although his daughter was a nurse, he had not asked her about his condition or his medication. He had faith in the efficacy of the medication, and appeared to believe that the fact he did not receive a "big dose", and that his ulcer would warn him if he had taken too many, protected him from side effects.

In **Mr C's** case, the hospital and his GP disagreed over the diagnosis. Mr C was 79 and reported being diagnosed as asthmatic for five or six years. However, the hospital told him he didn't have asthma, while his GP said he had a condition allied to asthma. He had been prescribed two inhalers which he believed to be ineffective. Although he had discussed this with his GP, his GP insisted he took them, so he did. He also received prescriptions for oral steroids. He believed them to be very effective, and said he always made sure he had an adequate supply. He had developed his own way of taking them. Instead of taking them as prescribed, when his breathing became tight he reported that he took six tablets and went to bed. Originally, he said he was concerned about being on steroids, however their effectiveness had reassured him, as had the fact that he had not gained weight as he had seen other people on steroids do. He also had not developed an increase in muscle bulk, like an athlete. He rationalised this by suggesting that the steroids must be a different type to the ones that cause those side effects.

Mrs E, was 62, and had had asthma for the last five years. Occasionally her condition deteriorated to the point at which she required a short course of oral steroids. She tried to "resist" taking medicines and talked as if she were resisting a great temptation. She said it was easy to become dependent if you got a "good effect". Yet, she suggested that it was all right to take medication as long as you "weren't on a thing forever". Mrs E also discussed how easy it was to say you will resist medication when you are not in pain.

Mrs E talked of the "good old days" and "Mother Nature". Despite this she suggested that doctors should be respected because of all the time they had spent learning their skills.

Mrs G was unsure of accepting a diagnosis of asthma. She was 71, and believed she had previously experienced the same symptoms, however at that time they had been diagnosed as bronchitis. She linked her diagnosis to the shock surrounding the sudden death of her husband. Mrs G accepted her medication, despite having gained weight as a side effect of a previous course of oral steroids. However, her previous experience also told her that the medicine was very effective.

Summary

As with the patients who had received long-term courses of oral steroids, patients were asked what they knew about their medicines, and from where they had gained their information. None of these patients reported that information was volunteered to them by GPs. Both Mrs Q and Mr R reported that they had requested information from their GP, but that the GP had failed to provide the level of information that they had requested. In both cases they had constructed their own explanations to address their concerns. Mr N and Mr C, also addressed their concerns by using their own beliefs.

Mrs D was wary of medication, and criticised the failure of GPs in general to provide information. This section also included the least informed patient interviewed, Mr B. He did not make a connection between a prescription for oral steroids, and his condition. In his opinion the medication was prescribed to give him a "boost".

Certain common themes were identified in the life histories of patients and these are now considered. First, the relationship between patients and GPs is discussed. Then patients' wish to maintain a certain quality of life, and the implications of this for the choices patients then make about their medicines, is considered. Finally, the explanations that patients developed about the potential side effects of oral steroids, and the information upon which these are based, is presented.

The relationship between patients and GPs.

Despite a belief in the necessity of treatment, patients wanted to be informed about potential side effects, and to have the side effects they experienced confirmed. Because the GP is the key professional informant, the relationship with the GP is a crucial determinant of informed choice. However, the findings from interviews with patients suggest that GPs may not be providing the information that patients perceive that they need in order to make an informed choice about their medication.

No patient remembered being provided with information about side effects when they received a prescription for oral steroid medication, although the idea that they might have been informed when they received their initial prescription was mooted. Mrs I, the only patient for whom it was an initial prescription, was not informed about side effects, but told by her GP that she would not be on them long enough to develop any side effects. The consequence of this was that she was very anxious to stop taking them. In two cases, Ms P, and Mr A, the initial prescription had been issued when they were in hospital.

Eight patients said that they were happy to ask for any information that they required. This cannot be taken to imply that they were well informed about their medication. It merely meant that if they were unsure of anything they felt that they could approach their

GP. However, this is more suggestive of a belief in the expertise of the GP, than representative of the amount of information that patients had received from their GP.

Even when specific information was requested, two patients expressed the view that the GP did not provided sufficient information. The first of these was Mr R, whose GP refused to give him information on the potential side effects of oral steroids, except to say there was a possibility that he might experience weight gain. His wife had previously been prescribed oral steroids, so he was aware that there was a risk of side effects other than merely weight gain. He said:

> since I've been on them, I don't know whether it's just coincidence or, I know I've different bones really aching and cracking, and God knows what. I don't know what to put it down to, whether it's age or [12].
>
> *Have you thought about asking your doctor?*
>
> I've asked him and he says could be your age, you know, he kind of brushed it off.

Mr R said that he wanted to be informed about the side effects of oral steroids, however, reported that his GP just said:

> could be putting on weight, and left it at that.

He continued:

> I don't like asking for too many of these tablets if there is side effects, you know. I would like to know what the side effects was of them really.

The wish for more information about side effects was expressed throughout the interview, however, Mr R said the only information his GP provided about the possible side effects concerned the risk of weight gain. Therefore, the GP did not provide the information Mr R wanted, even in response to a direct request.

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[12] This key explains the symbols used in the quotations from transcripts.

SYMBOL	MEANING
[ ]	Material omitted.
( )	Clarification of material.
Normal	Interviewee speaking.
Italics	Interviewer speaking.
...	More than one person speaking at the same time.
New sentence	Different person speaking.

Another example was Mrs F, who believed that information had been deliberately withheld. She thought the GP did not believe that she could cope with the information. She said:

> [ ] Unless they think you're going to jump out the window or something, or what ... But I mean I've put up with it for twenty five years so

She was annoyed about what she saw as a paternalistic attitude which prevented her from gaining information about her medication.

Five patients also discussed incidents which suggest that they may not have received the information that they wanted. Mr L, was unsure of why his medicine had been changed, as this had not been explained to him. A similar case of a failure to explain was presented by Mr C. He reported a disagreement about the diagnosis of asthma between the hospital and his GP. He did not understand why this discrepancy existed, and believed the inhalers he was prescribed were ineffective, however he appeared unable to persuade his GP of this belief.

Mrs D expressed the belief that GPs generally do not fully inform patients. This was based on her experience of being prescribed tranquillisers in the past. One patient (Mrs H) reported that her GP teased her about asking questions, a practice which may well discourage her from requesting information. Both Mr O and Mrs Q asked for information about the side effects of the oral steroids they had been prescribed, having seen reports in the media about the potential side effects. Mr O received an explanation about anabolic steroids, which did not relate to his original concerns. Mrs Q, had her fear of weight gain from oral steroids confirmed, however, with regard to her concern about possible damage to her bones, she was only told this had not happened to her. Finally, the fact that Mrs I did not understand her condition, is also an implicit criticism of the format of the information provided by her GP. These accounts suggest that patients do want information, and that this information is not being provided by the GP.

With regard to providing information about serious side effects, an interesting 'role reversal' between the expected roles of the patient and the practitioner was presented by

Mr A. The doctor wanted him to have a bone scan, but this necessarily requires informing the patient why this is necessary, and therefore about the possible risk of damage to bones associated with the long term use of oral steroids. In this case the situation was diffused by Mr A himself:

> And I saw Dr. B. And he said I want you to go for a scan.
>
> *Uh uh*
>
> And he said are you worried about it? Don't worry I said if you're going to tell me it's a bone scan because of prednisolone I'm not worried I've known for ten years, you know so that's alright then [ ]

The GP was able to send the patient for a procedure without the need to have a discussion about the long term risks of taking oral steroids. A discussion which may have caused Mr A to suffer some distress. When Mrs F was tested for diabetes she was only told it was a possible side effect of the steroids she was taking when she asked why the test was necessary. She was upset that she hadn't at least been warned about this possibility. This demonstrates that screening for side effects may force GPs to provide information to patients about potential side effects. This point is raised later in the interviews with GPs, and is discussed in the next chapter.

Only Mr B, expressed the traditional belief that the GP should make all the decisions, and did not see the need for information. This may be seen to fit with the model proposed in the 1950's by Parsons (1951) which is discussed in more detail on P. 56.

Despite an apparent acceptance by patients of the information provided by GPs, patients may use other sources of information in order to fill any gaps in their knowledge. A good example of this was Mr N. Mr N followed the directions given to him by his GP, yet believed his ulcer would cause him problems if he took too much medication. Therefore he accepted the advice of his GP, yet also had a 'safety net' to ensure that he did not take 'too much' medication. He appeared to accept the role of the 'passive' patient, however this was not so in practice. This provides additional evidence of a 'gap' between the understanding of patients and of GPs. The examples of Mrs Q and Mrs I constructing their own explanations as to why they had not developed side effects further illustrates this point. More details of this is provided in the section entitled Patients' construction of beliefs, on P.142.Patients' construction of beliefs

Summary

The findings from the interviews demonstrated that:

- Patients did not generally recall receiving information about their oral steroid medication and the potential side effects from their GP.
- Patients who asked for more information about side effects did not always get it.
- If the patient has access to other sources of information, then they may use these to construct an explanation with reference to their experience, or failure to experience, side effects.

Some patients' expressed certain limitations to their individual definition of an adequate quality of life. These will now be explored, with particular reference to the way in which individual patients said they coped with these limitations.

Patients' definitions of a reasonable quality of life

Mr A measured the control of his condition in terms of whether he could "get out". He was aware of the necessity of the medication, and its potential side effects, however was prepared to take it if it allowed him to "get out". He said:

> I mean with the medication I've got at the moment I can manage to do most things I want to do [ ] as long as I can get out I'll put up with the condition.

Mr N expressed a different perspective with his frustration at no longer being able to work in the garden as he had done previously. The difference between these two patients could be due to the fact that Mr A had suffered from asthma for most of his life, however Mr N had only recently developed it, and therefore was not used to living with it. This demonstrates the usefulness of the concept of 'career' in examining peoples' experiences with regard to their illness, with the aim of gaining a more informed understanding.

The two youngest people interviewed, Ms P, and Ms M, also expressed views about their lifestyle, and how it was affected by their condition. Ms P expressed a wish to stop taking oral steroids because she had gained weight, and "you're supposed to be quite slim at this age". Ms M was concerned about the "shakes", which she experienced after taking her medication. She also worried about going to parties where there were smoky rooms which could cause her to suffer an asthma attack.

These examples demonstrated how patients tried to integrate their medical condition, and their prescribed medication into their particular lifestyle. They also highlight examples where limitations were placed on what patients want to do, and examples of patients' experiencing anxiety about possible attacks. In this way it is possible to gain an understanding of the background to the choices patients made about their medications. The main sources of information patients reported using were friends and family, the media and self-help groups. All of these influences were described in Chapter One. They will now be explored in more detail.

Patients' sources of information

The influence of friends and family, the media, and self-help groups will now be explored. These were all cited by patients as sources of information, and therefore are likely to have informed the choices patients took with regard to the medicines. Following this, possible explanations will be mooted as to why self-help groups and alternative medicine, two potential sources of influence which were previously discussed in Chapters One and Two, were not mentioned by patients.

The influence of friends and family

The lay referral system refers to the tradition of knowledge being both past down through, and across, generations. The findings for the life history interviews demonstrated that information was indeed passed in this way. For example, Mrs H reported receiving information from her daughter, who was a nurse. She had also been told of the link between dust mites and asthma by her hairdresser. Both Mrs F, and Mr

A had learnt about the side effects of oral steroids from other patients while they were in hospital. In the case of Mrs F, other patients provide a point of comparison. She was concerned that she appeared to take more medicines than any of the other patients. She was also angry that she should find out about side effects from other patients, as she believed this information should come from her GP.

What was evident from the life history interviews is that patients construct their own beliefs based on both their observations of the medication experiences of other patients and their personal experience of medication. A process which is also informed by information from sources such as the media, and self-help groups. Evidence of the use of these sources, and the extent to which they were referred to, are now discussed with reference to the findings from the life history interviews.

The influence of the television, books, newspapers, and magazines

There is a tradition of self-medication based on books, newspapers and magazines. More recently, sources such as the television, and even the internet have also provided information about health and medicines. The influence of these sources was evident in the findings from the interviews with patients.

Mrs I reported using medical books in an attempt to 'understand' why she had developed asthma. However, this non-medical source of information was only consulted when medical sources had failed to provide an adequate response to her concerns. She had spoken to both her GP, and the Practice nurse, yet she did not feel she had an adequate understanding of her condition. Therefore, she borrowed her daughter's book. The use of a 'medical book' was also reported by one of the patients interviewed in the initial exploratory pre-pilot interviews.

The principal example of information being obtained from the television was the case of Mrs Q, who saw a programme which outlined the possible side effects of oral steroids. She was the penultimate person to be interviewed, and the programme was shown after sixteen of the eighteen interviews had been conducted. She became concerned about the risk of side effects, and as a result spoke to her GP. He said that she should have been told about the risk of weight gain. However, her main concern was the risk of damage to her bones. He said this had not happened to her and she appeared satisfied with this explanation. The GP only appears to have dealt with the immediate risk. With regard to the risk of weight gain, she said she had cut down on biscuits to try and reduce her weight. However, in absence of a full explanation from her GP, she had constructed her own belief that the people featured on the television programme may have had something else wrong with them, not just asthma. In this way, she could allay her fears that she may develop the severe side effects illustrated.

Mr O reported seeing a newspaper article on the side effects of oral steroids. He also spoke to his GP about this. In response, his GP told him it was alright because he was not on anabolic steroids, yet the report in the paper was not about anabolic steroids. Mr O appeared to accept this explanation, despite the fact that it didn't provide an answer to his particular concerns. These last two examples demonstrate that people may not perceive that they are provided with an answer to their specific concerns, even when they specifically request one.

Finally, Mrs H kept newspaper cuttings about asthma and oral steroids. She did not report approaching her GP on the basis of any of the information she had gained from the newspapers. However, although she did not discuss this information with the GP, the fact she was interested and had access to this information, suggests that these articles may affect her attitude towards her medication. Mrs H also reported receiving information from both her daughter and her hairdresser.

Hence, the evidence suggests that books and the media provide a fruitful source of information for patients. The influence of self-help groups will be considered next.

The increase in the number of self-help groups

Kelleher (1990) stated that there has been an increase in the number of self-help groups. These groups offer both information, and mutual support. However, only one patient reported attending meetings of the Campaign for Asthma (Mr A). Both Mrs E, and Mrs H had sent for information, but had not joined. Moreover, Mrs I's belief that her symptoms were not severe enough to ring the Asthma Helpline suggests that the

Campaign for Asthma, was seen by her as providing a service for people with 'severe' asthma. She said:

> he (the doctor) gave me a number to ring (the Asthma helpline) for asthma if I needed it and I said I don't think it's that bad.

When asked if she had used the action line, she replied:

> No, I haven't been tempted to do that.

Mrs F reported having spoken to someone who was staffing an asthma information stall, in a shopping centre, but said the woman failed to tell her anything new. This is suggestive of a lack of confidence, on the part of Mrs F, in her knowledge about her condition. Indeed, she believed that the doctors were withholding information from her. In her quest for information, she was considering writing to an address she had seen in the newspaper for a support group for people who had taken, or were taking, oral steroids. As discussed earlier she had experienced a number of side effects, of which she had received no prior warning, and this had lead to her belief that doctors fail to provide information, and therefore it was necessary to use alternative sources of information.

It has been demonstrated that people gain information from a wide variety of sources. The next section considers the way in which patients may construct their own beliefs about their medical condition, and their medication, on the basis of these sources.

Patients' construction of beliefs

It has been demonstrated that patients construct beliefs about their medication on the basis of information provided by friends and family, and from media coverage. The way in which patients also construct beliefs based on their own experiences, and their observations of the experiences of other people, will now be explored.

Two of the patients, Mr A, and Mrs D, spoke about the way in which medication had improved over time, in particular it had become more effective. In Mrs D's case, she believed the medication she was now prescribed enabled her to continue to work when she was ill, whereas before she would have had to take time off. However, one patient, Mrs E, expressed an opposite point of view, and suggested that there was a general trend away from 'Mother Nature', which she presented in negative terms. She said:

> I think the doctors are so busy and everything is so technical and so ... that even they're losing sight of Mother Nature.

One possible explanation for the difference is that both Mr A and Mrs D had suffered from asthma since childhood, whereas Mrs E had only developed asthma in the last five years. Therefore, she lacked personal experience of the ways in which asthma had been treated in the past, and therefore did not have the same grounds for comparison. This demonstrates the importance of information about a person's medical career when considering their beliefs about medicines.

There was however differences in the way in which Mr A and Mrs D reacted to a negative experience with tranquillisers. Mr A blamed the doctor who had prescribed them, however the experience does not appear to have affected his attitude towards his medication. Yet, in the case of Mrs D, she believed the fact that she was given tranquillisers had made her more likely to question the GP, and to avoid taking medicines if possible. Thus Mr A attributed the blame to the behaviour of an individual GP, whereas Mrs D developed a more global concern about the trustworthiness of doctors and the safety of medicines in general. This demonstrates how two patients may have the same experience, yet interpret it in a different way.

The life history interviews also demonstrated how a person's observation of the experiences of others may affect their own attitude towards medicines. Mrs E said that she had seen people become dependent on medicines. While Mrs D, said that she did not want to be like her sister who takes "everything under the sun". She said:

> I think you can take too much.

Mrs I was concerned when she was diagnosed as asthmatic because she helped to nurse a neighbour who suffered from severe asthma. She was frightened of becoming like her. She said:

> I didn't mind the pneumonia, I felt they could cure that well enough, you know, I had no doubts that they would cure the pneumonia ( ) I was more worried about the asthma.

She was also concerned about weight gain and becoming addicted to oral steroids. Other patients also expressed a fear of weight gain based on their observation of other patients (Mr K, Mr R, Mr C). Thus Mr C said:

> athletes take steroids of a sort don't they, builds up muscle. Look at me I'm shrinking [ ] These, there must be several sorts of steroid, these expand the air passages, makes it better for me

He continued:

> I've seen people on steroids and their face has been blown up like balloons [ ] but it doesn't do that with me. I don't know whether it's a different kind of steroids or not, I don't know.

The important point is that these beliefs are likely to influence the choices patients make about their medication. If GPs are not aware of these beliefs then they may fail to provide information which may help patients to put their beliefs into a context. This may have the consequence that patients are not fully informed about their medicines, and may therefore be unable to make a medically informed decision.

Patients constructed their own explanations as to why they hadn't developed certain side effects. Mr C believed that the reason he had not put on weight, or experienced an increase in muscle bulk, was because the steroids he had been prescribed were "a different kind". Mrs Q found out about the more serious side effects of oral steroids through a television programme. However, as the only side effect she had experienced was weight gain, she came to the conclusion that steroids must affect some people more than others. Mrs I came to the conclusion that she had not been on oral steroids long enough yet to experience any side effects, however she was anxious to stop taking the medicine in order to prevent side effects from occurring. She said:

> I still don't like them, but I've had no side effects from them [ ] as yet, but they reckon you've got to be on them quite a while before any side effects really take place. Um, well, I'm trying to get my doctor to wean me off them before it happens.

Mrs I's belief that medicines should be taken for as short a time as possible was also echoed by both Mrs D, Ms P and Mrs E. Mrs E said:

> if you're not on a thing for ever, then your body's got a chance to fight it off.

Similar sentiments were expressed with regard to the dose that it was safe to take. Mrs I said:

> I said to my husband I'm not taking eight of them at a time, you don't know what they'll do to me.

It has been demonstrated that patients' experiences of side effects from medicines made them wary of medication in general. Patients also develop their own understandings, or beliefs, as to why they have not developed side effects. More importantly, experiences of side effects lead patients to raise questions about risk, and may motivate them to question their GP.

Mrs H asked her GP about the risk of side effects when she experienced weight gain and her skin became thin. The experience of side effects provided her with the motivation to ask questions. Mrs D also stated that she began to question her GP after she had been prescribed tranquillisers. She believed this experience had made her more cautious about taking any medicines. Finally, in the case of Mrs Q, a television programme concerned with the side effects of oral steroids provided the motivation for her to ask her GP for more information about side effects. These examples suggest that certain cues exist which encourage patients to seek more information.

Two models, the health belief model (HBM) and the fear drive model (FDM) have been developed in an attempt to predict peoples' behaviour in a risk situation. The relevance of these models to these findings will now be explored.

The HBM may be employed to explain the process through which people make decisions about their medication. It suggests that certain cues provide the trigger to the decision-making process. The HBM assumes a consensual model of doctor-patient interaction, in line with the idea of Parson's (1953). This reinforces a very medically-centred perspective, in which not following doctor's orders is seen as deviant (Conrad 1985).

However, the life history interviews demonstrated a range of perceptions concerning relationships with patients, and not following the orders of the doctor was not necessarily perceived by patients as an act of deviance (for example Mr C and Mrs I). This medical perspective fails to recognise that factors other than the influence of the GP affect people's behaviour with regard to their medicines (Janz and Becker 1984). A range of influences on people were demonstrated in the life history interviews suggesting that it is not possible to generalise about the way in which people made decisions concerning their medication. In particular, the influence of friends and family was shown to be very prevalent, an influence which Freidson (1961) suggested was almost impossible to assess. Moreover, in line with the criticisms expressed by Good (1994), the same 'cues' produced different reactions in different patients. Therefore, the HBM was perceived as too simplistic, in terms of its explanatory powers, to provide adequate explanations with regard to this data.

The fear drive model suggests that fears will be alleviated through information. In terms of the findings from life history interviews with patients, attempts to gain information about side effects varied. In particular, from the data it is difficult to assess whether patients gained a 'permanent coping response' as a result of information which reassured them about the medication, or whether they merely felt that they had no choice but to take the medication. Therefore, contrary to what the model predicts, patients did not report seeking information in an attempt to alleviate their fears.

The fact that these models were not useful in the context of this research is due to their inability to take account of differences between patients in terms of their desire for information and explanation. Although the models are useful in presenting the idea of patients beliefs, they fail to account for the individuality of patients interviewed and the range of beliefs expressed. Thus, the models are not really appropriate to the aim of gaining an understanding of the importance of peoples' beliefs when making choices about their medicines.

Patients reported access to a range of sources of information about medicines. In the next section, the information patients said they used when making choices about their medicines is considered.

The basis upon which patients made decisions about their medicines

By providing information, GPs may facilitate the process whereby patients can make choices, about their medication. The findings from eighteen life history interviews with patients suggested that patients differed in the amount of information that they had. At one extreme was Mr A who was aware of most of the potential side effects. He had gained this knowledge through a variety of sources, both medical and non - medical, over a large number of years. The least informed patients was Mr B, who was not even sure of the reason why oral steroids had been prescribed.

The source of patients' information also varied. It incorporated information from GPs and Practice Nurses, as well as the media, friends and family. Of particular interest was the idea that sources other than the GP were accessed when the GP was perceived to have failed to provide the information the patient required (Mrs I, Mrs H, Mrs Q).

The relationship between patients and practitioners is likely to influence whether patients believe themselves able to make an 'informed choice' about their medication. A range of relationships between patients and practitioners was demonstrated. The behaviour of Mr B was reminiscent of Parson's (1953) model of the paternalistic practitioner and the passive patient. He was not even aware of the reason why the medication was prescribed. He thought it was probably a tonic. Others, such as Mr N and Mr A, appeared to adopt the role of the passive patient, however, then discussed how they maintained some control over their medicines. This idea was also described by Conrad (1985) with reference to patients who suffered from epilepsy. The most extreme case of taking control was presented by Mr C. He took his steroids when he felt the need, and kept collecting repeat prescriptions to ensure that he always had a supply. He developed his own beliefs about the way in which the medication worked most effectively for him, and took it accordingly. He said:

> When the air passages get blocked I take half a dozen prednisolone when I go to bed and in the morning they've expanded and I can breathe.

Yet, he did not appear to see this as subverting what he had been told. In fact he was proud that he had never felt it necessary to take the amount prescribed, with reference to this, he said:

> the dosage is twelve at a time, but I never take twelve, I take six.

Oral steroids were chosen as the target medication because they have a range of identifiable side effects which, because of the likelihood of them occurring, patients are likely to be informed about. However, they are used for treating serious conditions, in this case, severe asthma. This means that patients are likely to comply, whether they are informed or not. The one factor common to all the interviews was the expression of the necessity for oral steroid medication. This was illustrated by Mrs J, she said:

> I can't say I'm happy about having to take them (oral steroids), but on the other hand I can't, occasionally my asthma is so bad that I just have to.

This was so for both long and the short term courses. The efficacy of oral steroids was also noted. However, this cannot be taken to imply that patients merely took the medicine without any further consideration of its possible effects.

The interviews demonstrated that patients generally did perceive themselves to be making choices about their medication, and wanted information about the risk of side effects. However, the findings also highlighted the fact that patients were not fully informed about their medication. This may result in misunderstandings, the most extreme cases of misunderstandings were descriptions of steroids as a "tonic" and as a means of "clearing up infection fast". In fact steroids mask infection. Therefore, patients were shown to be making choices which were not based on medical information. Thus choices were based on information, or knowledge, which was partial or even incorrect. In addition, patients were aware that they are making choices when they were not fully informed, but did not appear able to gain the information they want from their GPs (Mrs F, Mrs H, Mr O, Mrs Q, Mr R.) However, this does not mean that their choices were not medically safe, merely that they believed themselves unable to gain the information they wanted from their respective GPs in order to inform their choices.

In Chapter One four influences on the possibility of patients adopting an active role with regard to making an informed choice about their medication were highlighted. These were:

- the introduction of legislative changes,
- the increase in interest in alternative therapies,
- the increase in the number of self-groups,
- the influence of the television, books, newspapers and magazines.

It was also suggested that information from these influences may be disseminated through the operation of the lay referral system. The effect of the lay referral system, and the influence of the media, and self-help groups have already been discussed. However, the introduction of legislative changes, and the increase in alternative therapy were not mentioned by any of the eighteen patients interviewed. In the case of legislation, patients may not be aware of, or fully understand the changes. With regard to alternative therapies, patients may not be aware of this as an option for the treatment of asthma at the level of severity experienced by the patients interviewed. These potential influences will now be briefly explored.

A number of legislative changes have been implemented in the 1990's. These are explained in Chapter One (P. 17). The findings from the life history interviews with patients demonstrated no awareness of these legislative changes. In fact, Mrs F believed that she would not be able to gain access to her medical records. This demonstrated her lack of knowledge of the terms of the *Access to Health Records Act 1990*. The only other part of the legislative changes which were referred to were the leaflets which come with medicines. These were mentioned in passing, (Ms M, Mr L, and Mr K), but not directly referred to as a primary source of information. Therefore, evidence from the interviews suggests that changes in legislative have not helped the patients interviewed. In fact, they did not even seem aware of the changes.

The possibility of asthma therapy from alternative sources, other than the NHS, was not mentioned by any of the patients interviewed. This is despite Coward's (1989) argument that the 1980's saw a proliferation of so called 'fringe' therapies. A possible explanation is provided by Sharma's (1992) finding that the use of alternative therapies is 'supply led', and that people use them because they know other who have used them. In a sample of eighteen it is feasible that no patient knew another who had tried any alternative therapies. This conclusion is also supported by the fact only one patient (Mr A) attended meetings of the Campaign for Asthma, which is a possible environment in which information about alternative therapies may be available.

Conclusions and way forward

The findings from the interviews with patients are summed up by the following themes.

- Patients did not generally perceive themselves to be informed by their GPs about their oral steroid medication and the potential side effects.
- Patients who reported asking their GPs for more information about side effects did not report that they receive it.
- Patients have access to sources of information other than their GP, such as friends and family, and the media. These are used either to supplement, or in preference to, information from the GP.
- Patients construct their own beliefs based on the information that they receive from a variety of sources and from their own experiences, as well as those of other patients.
- Patients accept and use their prescriptions for oral steroids as they feel they have no other option.

Although these were recurring themes, each patient presented an individual and unique slant based on their own experiences. In particular, people integrated their experience of their condition into their chosen lifestyle, this demonstrates the relevance of the presenting the findings according to each patient's medical career. This was demonstrated by the life histories of each patient.

The findings from the life history interviews were suggestive of the existence of a 'gap' between the perceptions of patients and GPs with regard to the amount and content of information about the side effects of oral steroid medication that was perceived as necessary by patients to inform their choices. The most striking example was the view that information is not provided about side effects when it is specifically requested.

In their role as professional experts, and prescribers of oral steroids, GPs are in an important position as regards providing patients with information to inform their choices about their medicines. Therefore, GPs' perceptions regarding the provision of information about medication were also explored.

General practitioners were interviewed to provide an understanding of their side of the 'gap' presented above. The specific objective was to gain insights into their perceptions of their role as a source of information about medication, specifically with regard to side effects of oral steroids, and to consider their awareness of the range of sources through which patients gain information about their medication. Ten interviews were conducted with GPs. Following this a postal form of data collection, a vignette, was used to increase the number of responses and as a means by which the responses could be narrowed to take account of fewer variables. The results from the interviews and the vignette are discussed in the next chapter.

Chapter Five

THE CONTRIBUTION OF GENERAL PRACTITIONERS TO AN UNDERSTANDING OF INFORMED CHOICE

This research is concerned with the choices patients make and the information on which these choices are based. So far, the major question has been, on what basis do patients make choices about their use of oral steroids for the treatment of asthma? In their role as professional experts, and the prescriber of oral steroids, it might be expected that GPs would be key informants of the benefits and adverse side effects of medication for asthma. However, the interview data reported in Chapter Four illustrated the range of sources of information that patients use to inform the choices they made about their medication, and suggested that patients make choices on the basis of minimal information from their GP. In order to investigate these ideas further, ten GPs were interviewed. The interviews provided insights into GPs' perceptions of their role in providing information about medication, in particular side effects, and their awareness of the sources of information used by patients when making decisions about the use of their prescribed medication.

The findings from the interviews demonstrated that the amount of information provided is related to the consultation style favoured by the GP. Thus, some GPs believed that patients should be 'protected' from information about side effects if there was no other medical option but to take the prescribed medication. The alternative view expressed was that it was up to the patient to make their own decisions based on the information provided by the GP. There was some recognition of the influence of sources of information, other than the GP, and reactions to these varied from frustration to resigned acceptance.

A vignette, distributed to all the GPs in Derbyshire was also used to explore GPs' recognition of, and feelings towards, a number of influences identified from life history interviews with patients. About half of those who responded recognised the instances of patients seeking information from elsewhere. General practitioners who had been practising for a shorter period of time were significantly more likely to recognise the examples presented. These findings suggest that the 'gap' in understanding patients' needs varies according to the individual practitioner.

A brief summary of the characteristics of all the GPs interviewed is now provided. All the interviews but one were conducted on a one-to-one basis. One interview was conducted as a focus group, as was noted in Chapter Three, a focus group is likely to produce different data from a one-to-one interview. Therefore, the findings are presented after the findings from the other interviews. The interviews are presented according to the extent to which the GP reported acting in a paternalistic manner towards the patient, or alternatively, encouraged the patient to make their own decisions.

How do general practitioners perceive their role as the provider of information about medicines?

The evidence from interviews with patients points to a 'gap' between the information that patients want, and that which GPs provide. The question posed by this is, how do GPs see their role in terms of the provision of information about medicines, and in particular, with regard to the provision of information about side effects?

The perceptions that GPs have of their relationship with patients will exert a strong influence over the consultation. As discussed in Chapter Two, doctors have considerable autonomy in the organisation and development of their work, and power in their relationship with clients, by virtue of the fact that they possess what is wanted and needed by clients. They also decide how, when, and for what reason these resources are to be granted to the patient (Lupton 1994). Moreover, the notion of a competence gap between the patients and medical practitioners may influence any response to a request for information (Tuckett et al 1985). These comments suggest that the GP is likely to control the consultation.

The most paternalist ideas were expressed by **GP 3**. He was very concerned that patients should trust him. He believed that the use of steroids was "about right"; the benefits were obvious and complications were rare. He also believed that GPs were now better educated about asthma. He provided information to patients by means of providing three facts at each consultation, and believed that, in this way, patients absorbed information by "osmosis". These three pieces of information excluded particular questions asked by patients. Thus, he suggested that he was happy for patients to take the initiative and to ask questions. Furthermore, he believed that patients were generally well educated about the potential side effects of oral steroids. He was aware that patients did obtain information from the media. He also commented that some patients did perceive steroids as "bad things", and he linked this to the fact that a significant number had relatives or friends who had suffered side effects from steroids.

Although GP 3 was aware of patients' exposure to, and use of, non-medical sources of information, he did not fully support the provision of information leaflets with medications. He suggested that there is a fine balance between giving the patient enough information to enable them to use the medication effectively and safely, and listing so many side effects that the patient is afraid to take them. He would rather the medical practitioner explained to patients the important side effects, than see them provided with a list of all the side effects which have ever been reported. He believed that:

> Patients do tend to see things in black and white, whereas one of the things about medicine is that there's seldom a completely wrong answer, and seldom a completely right answer, it's often about weighing and balancing relative risks.

Furthermore, he suggested that it was very difficult for patients to make an informed judgement on the basis of what the GP told them. He said:

> if it's the only option left of keeping that patient alive, why burden them with the knowledge that there's a potential for side effects when they really have no other option. That may seem overtly paternalistic, but as I grow older, I know that if I was in the same situation I wouldn't thank anyone who thrust that knowledge down my throat.

Thus, his view was that patients should be informed, but that the judgement as to the level of information provided is best left to the judgement of their GP.

GP 1 stressed the necessity to adapt advice to the individual circumstances, and to the patient. However, he believed that when giving information it was necessary to balance the good that could be done against the possible harm; particularly as he believed that everybody is bad at assessing risks. His assessment of risks was very 'mechanical', and he suggested that even if you gave all the information to the most intelligent person, they still would not assess the risks properly. Moreover, both GP 9 and GP 2 said that they might not inform the patient that the medication was a steroid if they believed that it was vital for the patient to take the medication, as informing them might mean that they would not take the medication.

So far, the evidence is that GPs withhold information in the belief that are acting in the best interests of their patients. When compared with the data from patients, this further corroborates the existence of a 'gap' between patients and practitioners in terms of beliefs about the provision of information. Generally patients wanted to be informed about the potential adverse effects of their steroid medication. A realisation that patients want to be informed about their medication is shown by the next example.

GP 10, said that increases in the provision of information from sources outside of his control, such as information inserts in medicines, and the influence of friends and family, have forced him to provide more information. He reported that he could no longer prescribe anti-cancer drugs, and medicines for Crohns disease or ulcerative colitis, without informing the patient. As a result, he now tells patients that they are being issued with a prescription for oral steroids, as he said this saves time in the long-term. However, he also provided information because he believed that patients now want more information. His behaviour has become less paternalistic because circumstances have forced this change of stance. It is not motivated by a belief that patients should be given information.

GP 9 also discussed patients' requests for information. She suggested the need for a balance between the GP's judgement as to what they perceive to be in the best interests of the patient, and the patients' wish for information. With specific reference to the provision of information about side effects, GP 9 said:

> I think it's, again it depends on the person, um because there are some patients who are very suggestible and if you suggest side effects they're going to get them. Um, and, perhaps they're entitled to know what side effects they might get as well, but I think I might be a bit careful, um, but in general, I, because people sometimes, often look a bit um, oh steroids they're dangerous aren't they um, and I think because I feel that it is justified that they should have the treatment, that it is clinically correct to that I've got to then face the fact that they have heard a bit about steroids, and yeah, and they are entitled to know, or be given some information, perhaps some, I hope some fairly balanced information about what they're going to take.

These ideas expressed by GP 9 demonstrated her belief that patients differ. She reported that she had developed a benchmark with regard to the extent to which a patient should be encouraged to make their own decisions. She stated that the euphoria associated with steroid medication did make some patients want to take steroids inappropriately. On occasions, she said, this led to a compromise where a short course was provided. The ultimate decision, however, to issue the prescription had to lie with the GP. Although patients should be encouraged to make their own decisions, there were certain issues, such as considering the advisability of a prescription, where the ultimate decision rests with the GP. This is because, in certain circumstances, only GPs have the necessary expertise.

GP 9 supported the idea of patients being encouraged to make their own decisions. She said that by providing information and explaining things then the patient is more likely to adhere to the prescribed regimen. However, she believed that you cannot tell patients that they must do something, advice can only be given as to why they should do something.

Similar ideas to those above were also expressed by **GP 7**. He stressed the importance of patients having control over their treatment, and said that he provided patients prone to "challenging narrowing of the air vessels" with a supply of oral steroids. He also believed that the more education about medication that a patient received, the better the medical outcome. He saw a role for the media in the provision of information about medicines, as long as that coverage was balanced. However, his view of patients was that they wanted results, and at times their expectations were unrealistic.

GP 6 saw one of the problems of oral steroids to be that people were very ill at the time at which oral steroids are prescribed, and the initial effects of the medication are dramatic. He said:

> I wouldn't necessarily mention all the side effects at that stage (when they were first prescribed), but, especially if they did get a miraculous effect then, go on to telling them, right well this is, these have got lots of adverse problems. This is part, two reasons really, because otherwise people would take them like smarties, it's not knowing what's happening and they would tend to increase the dose as opposed to, or keep it, at a dose more like it.

Therefore, he prefers people to be worried about taking oral steroids. He further articulated this point by saying:

> In fact my preference is that the patient's worried about taking them and then if I've got to persuade them to take them then that sounds a good way of going about it.

However, he also presented steroids as a medication which certain patients had no option but to take, or they would not survive.

In terms of sources of information other than himself, he believed that television was a big influence on people, and moreover that the media could play a very positive role in terms of informing patients. However, he believed that, at the current time, information emanating from the media was sensationalised and negative. With regard to medication inserts, he believed they were written so as to be legally protective of the drug company, as opposed to necessarily informative to the patient. Finally, he believed the risk of being sued has increased the likelihood that information would be provided by health care professionals about side effects. Therefore, GP 6 presented a view similar to GP 10, that information may now be provided as a result of pressures from outside of the consultation. He also used information about side effects in order to discourage the use of steroids in cases in which he felt they were not necessary.

GP 2 said that he provided information in line with the concerns expressed by patients. He said that if patients do not adhere to the prescribed regimen, then this suggests that the information provided by the GP has not been understood. He believed GPs provide more information now than in the past, and that GPs are not so paternalistic. Yet, he qualified this by saying that he believed that patients probably regretted this change.

He said that information had to be provided to patients in a different, non-medical, language. However, he stressed the individuality of patients by stating that patient satisfaction relies on addressing their concerns, not merely on providing a certain amount of information. He suggested that anxieties were decreasing as oral steroids are used more, and patients have known people who have taken them. Despite this apparent tailoring of information, he said that if a patient was "twitchy" about taking oral steroids, then he would call it an anti-inflammatory medicine, and broach the subject again when they returned, and felt better. This suggests that his reported move away from paternalistic practice may not be strictly true in all situations.

One GP (**GP 4**) believed doctors were now viewed as health advisers, and that as a result patients were more prepared to ask questions. Yet, he also stressed that the patient also has to change their 'traditional' view and understand that the doctor does not know everything.

The GP who expressed the greatest commitment to patient autonomy was **GP 8**. He said he worked on the principle of providing enough information, and this would be judged by verbal and non-verbal cues from the patient. He believed in negotiating with the patient in order to persuade them to take the steroids, however, it was ultimately the patient's choice. He believed that the more patients know, the better. His views were summed up by the following statement:

> The patient owns their own life and condition, and choices, so my aim is to help someone to make their own choices and if they choose not to take the pills and get ill I feel that's the patient's choice, that's not a problem for me.

GP 8, and to a lesser extent GP 4, were the only GPs who reported a move away from a traditional paternalistic role for the GP, towards a relationship between patients and GPs characterised by the idea of a partnership. Therefore, the choices people make about their medicines may not necessarily be informed by GPs if the GP does not think it is appropriate to provide information. In particular, the provision of information appears to be largely determined through patients' requests and the judgement of the GP as to the appropriateness of the request. These ideas were summed up by the findings from the focus group (GP 5).

One of the main ideas expressed by **GP 5**[13], was that patients had a different understanding of steroids to that held by the medical profession. Patients were said to associate steroids with body-building, and weight-lifting, and with drugs' tests at the Olympics. All the members of the group stressed the seriousness of the decision to prescribe oral steroids. They also said that such a prescription is necessitated by the seriousness of the condition. In this context, they believed the balance of risks to benefits made the side effects insignificant. They questioned whether it was in the patients' interest to sit down and have a long discussion with them about the implications of long term treatment, if the treatment was, in their opinion, vital. The idea that patients differed, and that therefore information should be tailored to suit each patient was suggested. Thus, one of the GPs said:

> I'm sure it's bound to vary (the amount of information given[14]) [ ] some patients are more receptive and challenging and so you're bound to tailor your information according to what you perceive a patient's going to be able to understand.

However, generally, these GPs subscribed to the view that it was kinder to patients to act in a paternalistic manner, and protect the patient, than to inform them about side effects when patients have no other option but to receive treatment with oral steroids.

Summary.

General practitioners varied in their beliefs concerning the role they should adopt in the consultation. The variation ranged from GP 3 who did not believe that it was necessarily right to "burden" patients with knowledge when they had no choice but to take oral steroid medication, through to GP 8 who stated that a patient "owns their own life and choices". Three GPs, (GP 4, GP 8 and GP 9), suggested that patients have an obligation to take responsibility for their treatment. This is supported in the literature by Collier (1989) and Weijts (1994). All the rest, to some degree, reported that they withheld information in order to protect patients from information about potential side effects.

It appears that the GPs interviewed generally relied on their own judgement to determine the information to provide to patients. This is problematic if their are 'gaps' in understanding between GPs and patients. The idea of a 'gap' between the perceptions of patients and GPs with regard to information about medication has been a consistent theme throughout this thesis. In some cases GPs themselves identified a potential 'gap' between their understanding and that held by patients. A good example of this is the

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[13] All the interviews with GPs were conducted on a one-to-one basis, except 'GP 5' which was conducted as a focus group involving all the GPs in one Practice.

[14] ( ) indicates addition information provided for purposes of clarification.

belief that patients confuse anabolic and glucocorticoid steroids. Five out of the ten GPs interviewed referred to this link, and of those, four said that a link was made (GP 2, GP, 4, GP 5, GP 6), and only one, (GP 3), said that patients were surprisingly well educated, and did not confuse the two different types of steroids. In other cases the belief was expressed that the patient's behaviour was suggestive of a 'gap' in understanding. Thus, GP 8 stated that patients always got information when they wanted it. However, he then qualified this, and said that he did not look for gaps in patient's knowledge, and they may therefore exist. The existence of 'gaps' in understanding between patients and GPs has implications for the choices patients take with regard to their medicines, as any misunderstandings are likely to reduce the chance that the patient will gain the information they believe they need to make an informed choice about their medication. The idea of 'gaps' in understanding between patients and GPs will now be explored.

'Gaps' in the understanding between patients and general practitioners

An awareness of communication problems between GPs and patients was acknowledged. Thus, GP 6 suggested that failures in communication were a possible cause of patients' non-adherence to prescribed medication regimens, and GP 9 pointed to the actions of patients who took steroids inappropriately, which she believed were rooted in a failure of communication between the two parties. The most obvious case of a 'gap' in understanding between patients and GPs was demonstrated by GP 1. He admitted that he could not understand why patients sue the manufacturers of steroids for compensation for the side effects that they have suffered as a result of taking the medication. He said:

> we have a patient at the moment in this practice who is actually suing the manufactures for steroid induced problems, but without her steroids she would be dead [ ][15] and there is absolutely no doubt about that, er she remains alive and she remains in reasonable condition, not well, but reasonable, er and yet she still feels that she needs to sue the manufacturers.

This suggests a failure to understand why this patient should behave in this way when the medicine prescribed has saved her life, despite the fact it has also resulted in her experiencing side effects. This supports the views expressed by Helman (1990: 86) that

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[15] [ ] indicates material omitted.

doctors and patients view ill-health in very different ways, and that their perspectives are based on different premises, employ different systems of proof, and assess the efficacy of treatment in different ways.

Helman's (1990) ideas were also supported by the perceptions expressed by GP 1 and GP 9 that a short term course of oral steroids was safe and unlikely to cause lasting side effects. However, the findings from interviews with patients demonstrated that patients suffered side effects such as weight gain from short term courses of oral steroids, and that these caused patients to suffer distress. This suggests a failure on the part of GPs to understand the psychological effects on patients of their experience of side effects.

Some acknowledgement of Helman's (1990) idea was provided by GP 10. He suggested how the gap in knowledge between patients and practitioners may have reduced in recent years in response to the increased pressure, from both medical and non-medical sources, for GPs to provide information.

The suggestion was made that GPs judge the amount of information they provide to match their perception of the patient's level of understanding (GP 1, GP 2, GP 4, GP 5, GP 7 GP 8, and GP 9). However, GP 3 said he provided three pieces of information in each consultation, and additional information in response to patients requests. GP 6 and GP 10 said that they provide information about medicines to everyone in response to their perception that there is a general increase in expectations that information should be provided.

The idea that the amount of information provided by GPs is based on GPs' perceptions of their patients, may prove problematic if there is a 'gap' in understanding between patients and practitioners. Moreover, as discussed earlier, seven out of the ten GPs interviewed reported withholding information as they believed not providing information to be in the best interests of the patient. This suggests that relying on the judgement of the GP will not necessarily ensure that patients have sufficient information in order to make informed choices about their medications, if the GP was their sole source of information.

Summary

Having examined the information that GPs report they provide to patients, it is apparent that GPs may fail to provide information because of problems in communication between patients and GPs. The evidence suggests that GPs may, in some cases, be aware of possible 'gaps' in understanding between the two parties. This idea of potential sources of 'gaps' in understanding between the two parties is now further investigated by considering GPs' reported awareness of sources of medical information, other than the medical profession, which are used by patients.

Perceptions of the availability of information from sources other than the general practitioner

General practitioners' perceptions of the sources of information available to patients will now be examined. This provides an insight into GPs understanding of the information available to patients making choices about their medication. Initially, GPs' views on medication inserts, which may be perceived as medical sources of information, will be presented. This will be followed by an exploration of GPs' recognition of non-medical sources of information.

Medication Inserts

Views differed on medication inserts. They were criticised due to the 'flatness' of information, and the failure to grade side effects in terms of likelihood. The feeling that they were primarily designed to protect the pharmaceutical manufacturers, as opposed to inform the patient, was seen as a weakness. It was felt this could cause a patient to worry unnecessarily. However, some GPs appreciated the fact that they provided an additional source of information to support what the GP had said. This was seen as supplementary to the information provided by GPs, although one GP, (GP 10), did say that he suggested to patients that they read the leaflet, and said their inclusion with medication had forced him to become more open with his patients, by providing information he had previously withheld.

Therefore, medication inserts were generally seen in a positive light, but with some room for improvement in terms of the way in which information was presented. The discussion will now move on to consider GPs' perceptions of non-medical sources of information.

Non-medical sources of information

These sources of information have also been presented in previous chapters. They represent areas in which the potential for an increase in the availability of information to patients has been noted. These are as follows:

- legislation,
- alternative medicine,
- self-help groups,
- newspapers, and television.

Information from these sources may be disseminated via the lay referral system. Each of these areas will now be examined in turn to assess GPs' perceptions of these sources of information.

Legislation

Seven GPs, (GP 1, GP 4, GP 5, GP 7, GP 8, GP 9, GP 10) expressed the view that patients' expectations had increased. These expectations were seen by GPs as unrealistic. Patients were said to want more time and explanations. No GP reported any requests by patients to see their medical notes. Some GPs attributed the changes they had seen to the Patients' Charter, and GP 1 suggested that 1960's consumerism had developed into "People's Charterism" in the 1990's. Another GP, (GP 5), said that these changes were happening anyway, and that the Patients' Charter merely reflected this. Finally, GP 9 suggested that the Patients' Charter was not worth the paper it was written on because it gave people rights, without giving them responsibilities. It was implied that such a one-sided response was unlikely to lead to improvements in the quality of the relationship between patients and GPs.

What is particularly interesting about GPs' responses to the effect of legislation is that the life history interviews conducted with patients did not provide any evidence of them acting on the basis of any legislative changes. Some GPs attributed requests for information, and rising expectations to the Patients' Charter, yet patients may not connect the two in the same way. General practitioners' perceptions of the influence of alternative medicine will be assessed next.

Alternative medicine

The only GP to comment on the role of alternative medicine was GP 2. He said:

> obviously some people can be more irritating than others and come out with all kinds of cock-eyed ideas and ask all sorts of questions and might consult their homeopath or something. You know, people like that obviously you're not going to get anywhere, it's going to be more frustrating.

This generally supports the data from interviews with patients, that, although Coward (1989) has reported an increase in interest in alternative therapy, this was not apparent to either patients or GPs with regard to treatment for asthma. On the only occasion where it was noted, it was treated with hostility.

The next idea to be considered is GPs' perceptions of self-help groups, in this case the Campaign for Asthma.

Self-help groups

Little interest in the Campaign for Asthma was shown by any of the practitioners. On the whole, the day - to - day running of asthma care was delegated to the Practice Nurses, while GPs dealt with diagnosis, and the management of more 'difficult' cases. In line with this, the provision of information about the Campaign for Asthma was seen as a role taken on by the Practice Nurses. Thus, GP 1 said:

> our asthma clinic nurses are well informed about that (the Campaign for Asthma) [ ] they (patients) come and talk to her about the asthma and she will put them in touch with the support groups.

Hence, none of the GPs interviewed reported having any contact with the Campaign for Asthma. No GP reported any patient questioning their treatment on the basis of information gained from the Campaign for Asthma. Moreover, as the Derby group tends to work in consultation with hospital specialists, the information they provided is likely to supplement that provided by the GP, not challenge it.

Potentially more antagonistic sources of information are television programmes and newspapers. These will be examined next.

Newspapers and the television

In general, the media was seen in both positive and negative terms. It was said to confuse patients' understanding of the difference between anabolic and glucocorticoid steroids. Newspapers were also said to present steroids as associated with danger and disease.

The media in general were accused of raising peoples' expectations, and of over-simplifying information. The main objection concerned the sensationalist form in which information was presented, not the fact that information was presented. Thus GP 6 said:

> I think the media could have an extremely positive role to play and I think it's very interesting when there is a positive role played by the media how much response we get to it. Unfortunately, I think the media in general play a sensationalist and negative role and kill far more people than they've ever saved.

The influence of television was highlighted, particularly in terms of generally increasing requests by patients for information. This idea was supported by findings from the life history interviews with patients, in which a television programme detailing the side effects of oral steroids encouraged Mrs Q to ask her GP about the potential side effects of her medicine.

It was suggested that the media has been more effective than any political changes in increasing peoples' expectations. A GP from the group coded GP 5 said:

> I think the media had the most effect on the increasing, you know, things that people ask for, really because they're, everyday they'll sit down and watch something and I think that probably has the most effect, rather than any political changes really.

The general opinion about the media coverage of medical issues was summed up by GP 7, who supported the media providing such information, as long as the presentation was balanced in terms of presenting both the risks and the benefits of treatment.

Finally, patients may also be informed by friends and family through the lay referral system. General practitioners' recognition of, and perceptions about, patients' lay referral systems are now considered.

General practitioners' perceptions of patients' lay referral systems

An awareness of patients' lay referral systems was demonstrated by GP 3. He suggested that a significant proportion of patients prescribed oral steroids have relatives or friends who have taken steroids and have developed side effects, and that patients gain information from them. Neighbours were also cited as a source of information (GP 10). Moreover, the idea that health is one of the most common topics of conversation was also expressed (GP 10). GP 10 said:

> Asthma's very common, so a lot of people talk and I think that probably health is one of the most common topics of people talking in the outside world. It's very difficult for me as a doctor to recognise that, but I think that health is very important in the general population, so I think people talk

This suggests that GP 10 believes he has no choice but to accept influences from outside of the consultation, although he does not welcome them. This sums up the general attitude of the other GPs who were interviewed.

Patients' own beliefs were also referred to by GPs who said that they provided information about medicines in accordance with the beliefs and desires expressed by patients. However, the evidence presented earlier concerning the 'gaps' in understanding between patients and practitioners, and the evidence from the life history interviews with patients which suggested that patients generally wanted more information than was provided by their GP, indicates that GPs may fail to provide information in accordance with the beliefs and desires of patients.

Summary

A number of general points may be made with reference to this work. Thus, the interviews suggested that GPs:

- may judge the information to provide to patients about side effects based on their knowledge of individual patients,
- believe that not informing patients may be in the best interests of their patients,
- have experienced growing pressure from patients to provide information and
- tolerate other sources of medical information.

Even within the ten interviews, GPs varied in their attitude towards patients. The variation ranged from GPs who acted in a paternalistic manner, through to GPs who stated the belief that the ultimate choice rests with the patient, and that the role of the GP is to act as a source of information, on the basis of which patients could then make their own choices. They also demonstrated that any information provided may vary according to the length of the prescription for oral steroids, and particularly with reference to the GP's assessment of patients.

The idea of a 'gap' between the perceptions of GPs and of patients was evident, in particular with regard to the assessment of risk. The impression given is that GPs do not always understand what the patient wants, and may try and 'guess'. This is borne out by the interviews with patients, in particular, the evidence that patients develop strategies to manage their medication, independently of their GP. Finally, GPs' recognition of the influence of legislation, the media and the lay referral system were all demonstrated.

Influences on patients were recognised, however there was also a sense of the individuality of patients, about whom it may be difficult to generalise. This suggests that these issues may be better explored using a technique in which the variables may be more easily set. In this way, evidence may be more concisely collected concerning GPs' recognition of, and feelings about, influences on patients and therefore a better understanding may be developed of the ways in which the relationship between patients and medical practitioners may be affected by the availability of information from non-medical sources. For these reasons a vignette was constructed.

The vignette was designed to address certain practical problems with using interviews. In particular, interviewing caused GPs to generalise about patients, while the design of the vignette required GPs to respond to questions concerning only one, hypothetical, patient. In this way, GPs responses were based on a particular situation, within a given context, and therefore responses could be more easily compared. The design of the vignette is outlined in more detail in Chapter Three.

The Vignette

The vignette was based on examples from the life history interviews with patients. A copy of the vignette may be found in the appendices (Appendix D). The findings upon which the vignette was based are presented in Chapter Three. The vignette aimed to provide an understanding of GPs' recognition of, and reaction to, influences on patients making decisions about their medication. It contributes to an understanding of the 'gap' between the perceptions of GPs and patients, by considering the extent to which influences on patients are appreciated by GPs. In this way, it is possible to assess whether GPs are able to tailor the information they provide, in the light of other possible influences on patients.

Initially, the representativeness of the response in demographic terms is presented. This is followed by those responses to questions which identify whether GPs recognised the influences on patients presented in the vignette. Then the feelings GPs believed they were likely to experience if a patient acted in the way described in the vignette, as these are likely to affect communication in the relationship between patients and GPs. Finally, an analysis detailing the demographic characteristics of the GPs who recognised the influences is presented.

The representativeness of the response to the vignette

As all the patients, and most of the GPs interviewed in the previous stages were based in Derbyshire, then the vignette was distributed to all the GPs in Derbyshire[16].

The first mailing was sent on the 31st July 1995, and it gained a 48 percent response rate. A second mailing was sent out on the 11th September, and from this the response rate increased to 69 percent. The last reply was received on 31st October 1995.

Responses to the vignette were initially analysed in order to establish how closely the response represented the demographic characteristics of GPs in Derbyshire. The variables identified were gender, practice type, and the number of years of practice.

There was no significant difference, with regard to gender, between those GPs who responded to the vignette and those who did not (Number of males who responded = 247, Number of females who responded = 81, Number of males who did not respond = 111, Number of females who did not respond = 36, $\chi^2 = 0.00231$, DF = 1, P= 0.96171). For an explanation of the statistical terms employed see Appendix E.

There was however a significant difference in the number of responses received from members of group practices compared with members of single practices (Number of members of group practices who responded = 309, Number of members of single practices who responded = 20, Number of members of group practices who did not respond = 130, Number of members of single practices who did not respond = 17, $\chi^2 = 4.26483$, DF = 1, P= 0.03891). In percentage terms, 70.4% of GPs who were part of a

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[16] Figures from 1994 suggest that Derbyshire is slightly over-representative of GPs from group practices (92%), than is the average in England (89%). It also has a greater proportion of male to female GPs, (75% and 25% respectively) than is the average in England (70% and 30% respectively) (Dept. Of Health 1995). Therefore the response may be judged not to be totally representative of England as a whole.

group practice responded to the vignette, as opposed to only 54.1% of those GPs who worked in single-handed practices.

In order to investigate the practical implications of this finding, the data were separated according to group practices and single-handed practices. The data were then examined, and the confidence interval for the differences were calculated (see Appendix F). By examination it is possible to appreciate that there was not a large difference, in percentage terms, in the way in which GPs from group practices and GPs from single-handed practices responded to the vignette. Therefore, the effect of this difference on the response may be seen to be minimal.

A Students t-test was used to establish if there was a relationship between whether GPs responded to the vignette and the number of years that they had been in practice (Table 5-1 and Table 5-2).

Table 5-1

The relationship between the variables response and number of years in practice

Variable	**Number of cases**	**Mean number of years in practice**	**SD**
Non-response	147	17.7483	9.012
Response	329	15.6413	9.365

Mean Difference = 2.1070

Levene's Test for Equality of Variances: F = 1.078 P = 0.300

Table 5-2

t-test for Equality of Means

Variances	**t-value**	**df**	**2-tail sig.**	**SE of Diff**	**95% CI for Diff**
Equal	2.29	474	0.022	0.918	(0.302, 3.912)

As demonstrated above, (Table 5-1 and Table 5-2) the GPs who responded to the vignette were significantly more likely to have been practising for fewer years than those who did not respond.

Summary

The response, therefore, was representative in terms of gender, and although GPs in group practices were more likely to respond, there was not a large difference in their actual response to the questions. Finally, the GPs who responded were likely to have been practising for fewer years than those who did not respond. Having established how representative the response was in demographic terms, responses to questions which identify the extent to which GPs recognised influences on patients, are presented.

Response to individual questions

The vignette was designed to explore GPs' recognition of, and feelings about, patients' attempts to get information about their medication from sources other than themselves. The idea was that if GPs are aware of influences on patients, then they may be able to identify, and therefore possibly alleviate, any fears that patients may have.

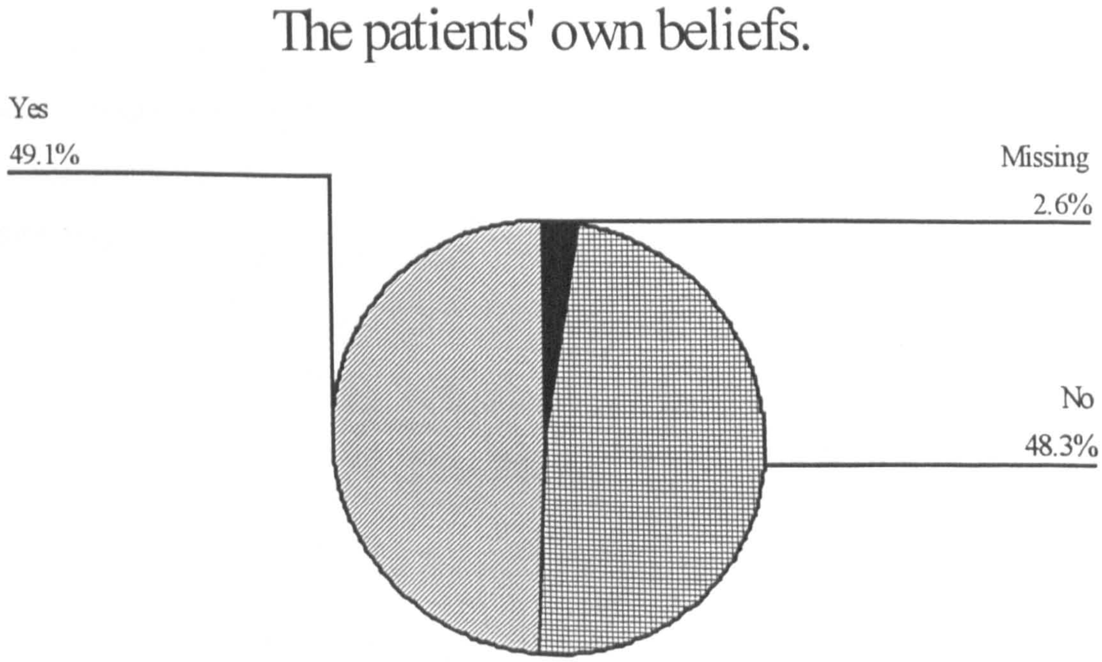
General Practitioners' recognition of influences on patients

Four different influences on patients were presented. The first question required GPs to state whether they would ask the patient, (Mrs X), whether she knew anything about oral steroids, as this was her first prescription for this particular medication. The majority of GPs answered positively (283, 82.3%). They were then told that Mrs X had heard both "good" and "bad" things about steroids, and asked if this would influence the way in which they might describe any side effects to her. The majority of GPs felt that this would make a difference to the information they provided about side effects (221, 64.2%). A comparison was then made to see if GPs who stated that they would not ask Mrs X if she knew anything about oral steroids (58, 16.9%), would attempt to take account of her knowledge when she volunteered that she had some ideas about the medication. Forty GPs (69%) who said they would not ask Mrs X if she knew anything about oral steroids, said that the fact that she volunteered that she knew something about this medication would influence the way in which they might describe the potential side effects. This suggests that the majority of GPs would try to take account of patients' knowledge, and even those who would not directly ask Mrs X if she had any prior knowledge, would try to take account of these beliefs when they were volunteered.

The GPs were then informed that Mrs X had suffered an adverse reaction to another medication a year ago. They were asked if they felt that this was likely to make Mrs X wary of the oral steroids prescribed. The majority of GPs (206, 59.9%) recognised that this might be a problem, however nearly forty percent of this group of GPs (133, 38.7%) did not feel that it would be a problem. They did not believe that previous experience of an adverse reaction would affect a patient's attitude towards the next prescription they received.

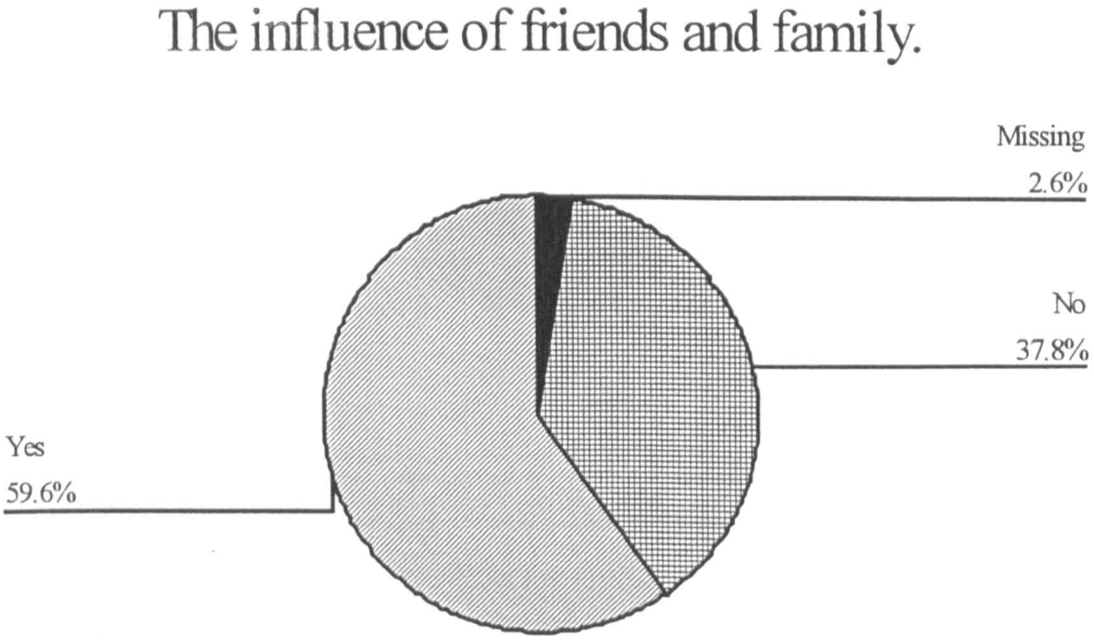
Four other situations were then presented that involved Mrs X using either her own beliefs, or non-medical sources of information, as the basis for her decisions about medication. General Practitioners were asked how realistic they felt each of the situations presented to be. The first situation involved Mrs X not taking her medication as prescribed as she felt the dose "sounded" a bit high. The response to whether it was felt to be a realistic situation was spilt, with 166 GPs (48.3%) saying that the decision, and her explanation for it, was not realistic, while 169 GPs (49.1%) felt that it was realistic (Table 5-1).

Figure 5-1



Mrs X was then said to consult her daughter and her neighbour to ask what they thought about the size of the dose. This was seen as realistic by the majority of GPs with 205 (59.6%) stating they felt it was a realistic situation, while 130 (37.8%) believed that it was not realistic (Table 5-2).

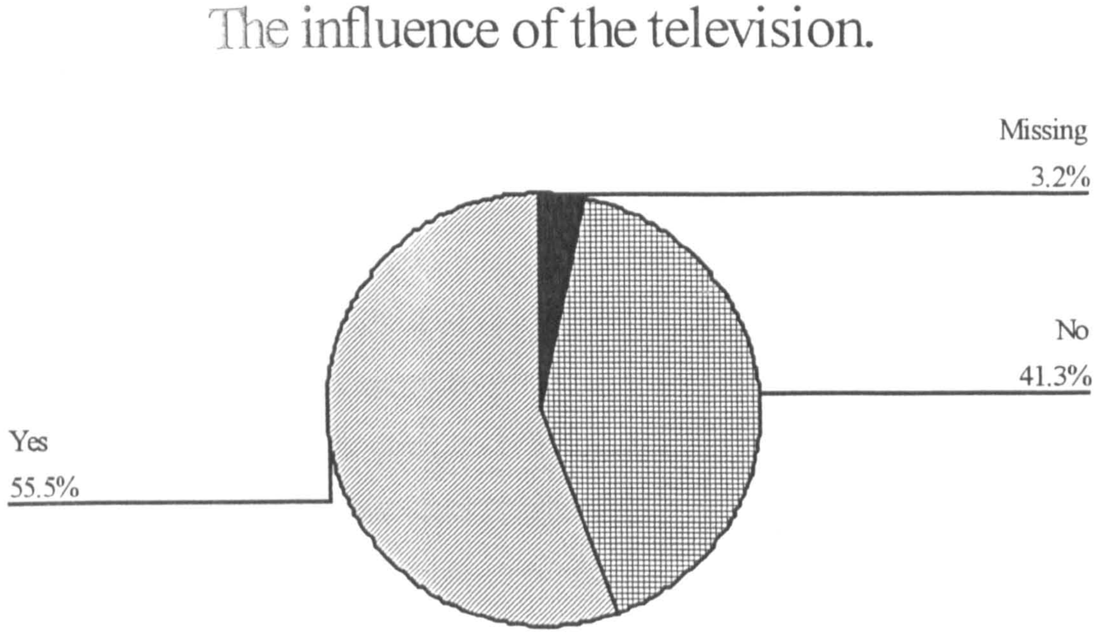
Figure 5-2



Seeking the advice of friends and family was seen as more realistic than making a decision without the support of others.

Mrs X then becomes worried about the side effects of oral steroids after seeing a television programme. Over half (191, 55.5%) of the GPs who responded felt that this was a realistic situation, while 142 (41.3%) did not feel that it was realistic (Figure 5-3).

Figure 5-3



GPs were also asked if they felt they could sufficiently reassure Mrs X of the safety of short term oral steroid medication, so that she would be happy to take oral steroids in the future. The majority of GPs (287, 83.4%) felt that they would be able to reassure Mrs X. This shows a great deal of confidence in their ability to deal with patients' concerns.

Finally, GPs were asked to comment on whether they felt that Mrs X's wish to discuss what she had learnt at a meeting of the Campaign for Asthma was realistic. Although the vast majority of GPs (314, 91.3%) stated that they felt this was realistic, the nature of the question differed from the previous three. In this question, Mrs X was said to want to discuss information from an organisation which may be perceived as supportive of the medical profession, whereas the other three situations posed a challenge to medical authority. It is therefore difficult to compare this response with the three presented previously.

In summary, as it was 'Mrs X's' first prescription, the majority of GPs would ask if she had any knowledge about oral steroids. Moreover, on volunteering some knowledge, the majority of those who would not previously have provided information would take this as a cue to provide information. Nearly forty percent of the GPs who responded did not feel an adverse reaction to a different type of medication would make Mrs X wary of the prescription which had just been prescribed.

In terms of how realistic the situations were judged to be, the most realistic was seen to be the influence of friends and family, then the television, and finally the patient's own beliefs. These results indicate that approximately fifty percent of the GPs who responded recognised non-medical influences on patients. They may, therefore, have an understanding of the way in which patients make decisions about their medication, and could potentially 'tailor' the information they provide in order to help patients make an informed decision about their medication. Having presented the extent to which GPs recognised the suggested influences, consideration will now be given to how GPs felt when Mrs X acted on the basis of these influences.

General Practitioners' reactions to the situations presented

There were four sets of questions in the vignette which required GPs to respond to a list of emotions, loosely based on those expressed in interviews with GPs, as the 'story' developed. The situations in which there was over 20% agreement among those GPs who responded, are presented here (Table 5-4).

Table 5-3

General Practitioners emotional response to the situations presented in the vignette.

Emotion	High[17]	Friends[18]	TV[19]	Campaign[20]	Count	Percentage
Supportive	✓[21]	✓	✓	✓	135	49.8%
	✓	x[22]	✓	✓	57	21.0%
Sympathetic	✓	✓	✓	✓	116	43.3%
	✓	x	✓	✓	50	18.7%
Resigned	x	x	x	x	98	38.3%
	✓	✓	✓	x	44	17.2%
Frustrated	✓	✓	✓	x	112	42.3%
Betrayed	x	x	x	x	212	81.5%
Angry	x	x	x	x	143	55.0%
Failed	x	x	x	x	163	62.7%

From the table it is possible to see that although the highest level of support was for all the situations presented, seeking the advice of friends and family receives less support from GPs than presenting ideas based on patients' own beliefs, television programmes, or the Campaign for Asthma.

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[17] High refers to the reaction of the GP to the situation presented that Mrs X did not adhere to her prescribed regime as she felt that the dose was too high.

[18] Friends refers to the reaction of the GP to the situation presented that Mrs X consulted her friends and family for advice about her medication regime.

[19] TV refers to the reaction of the GP to the situation presented whereby Mrs X sees a television programme which causes her to experience some concern about her medication.

[20] Campaign refers to the reaction of the GP to the situation presented whereby Mrs X attended the Campaign for Asthma, and wanted to discuss what she had learnt.

[21] x indicates that the respondent did not feel the emotion described.

[22] ✓ indicates that the respondent felt the emotion described.

The number of GPs who reported feeling sympathetic followed the same pattern as those who reported feeling supportive. Therefore, GPs are generally likely to be less sympathetic or supportive when presented with behaviour, or beliefs, based on information obtained from friends and family.

A possible explanation for the response to the whether GPs felt resigned in the situations presented, is that GPs may have responded to the general idea of influences on patients, to which they responded positively or negatively, as opposed to reacting to individual influences.

The highest level of agreement, to whether GPs felt frustrated, was to feel frustrated in all of the situations, with the exception of that in which Mrs X gained information from the Campaign for Asthma (112, or 42.3% of GPs). This may be explained because the Campaign generally provides information which is supportive of medical practice. The majority of GPs did not report feeling betrayed, angry, or that they had failed in any of the situations presented.

Although these responses do provide some insight as to the reaction of GPs when patients make medication decisions on the basis of non-medical influences, the missing values ranged from 21.2% to 25.6% and therefore these results must be interpreted with caution. A possible reason for this level of missing values is the design of the vignette. The question required GPs to respond either 'yes' or 'no' to a list of emotions, as many GPs only answered 'yes' then this may imply they wished to 'answer 'no' to the other possible emotions. However, this cannot be assumed so the responses to this part of the vignette are judged to be 'missing values'.

The results from the vignette as a whole suggest that approximately fifty percent of those GPs who responded recognised non-medical influences on patients. Interviews with GPs reported attempts to 'tailor' information to individual patients. The results from the vignette suggest that GPs may have an awareness of influences on patients, which would, therefore, help them to 'tailor' the information they provide to patients.

However, although the vignette showed that these influences are recognised when they are presented, this does not necessarily mean they will be recognised in a consultation situation. Of particular interest is that the influence of friends and family received the lowest level of support and sympathy. This suggests that the influence of friends and family is the most unpopular of the influences presented. It is, however, necessary to remain mindful of the low response to this part of the vignette (the missing values ranged from 21.2% to 25.6%).

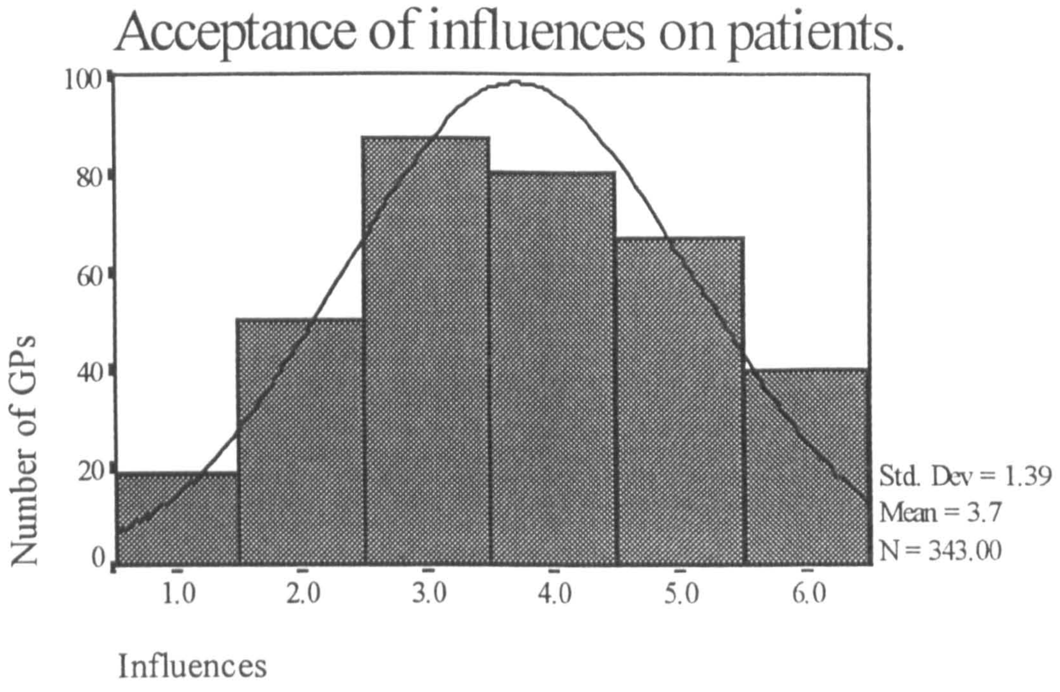
In order to further inform the points made here, the next section will present an analysis detailing the demographic characteristics of GPs who believed the influences presented to be realistic.

General medical practitioners' response to the influences

A multiple regression analysis was used to investigate the extent to which the variables of gender, practice type, and number of years in medical practice are able to explain GPs' responses to accepting the idea that patients make medical decisions based on influences other than the GP. The vignette was examined, and the questions which were felt to show a recognition of these influences were identified. These were questions 1, 2, 3, 5, 7, and 10, which when aggregated formed a new variable (acceptance). The maximum score, indicating a total acceptance of the possibility of patients acting on the basis of all these influences, was six.

A histogram of the variable 'acceptance' was produced with an overlay of the normal curve, and is shown in Figure 5-4.

Figure 5-4



The distribution of the variable 'acceptance' may be seen to be close to a normal distribution.

Before calculating the multiple regression, the Normal P-P Plot of Regression Standardised Residual was drawn. This varied with no specific pattern around the diagonal, indicating no untoward deviation from normality (Appendix G). Partial residual plots were also produced for all three of the independent variables against the dependent variable 'acceptance'. As the residuals did not form a pattern, it was deduced that there did not appear to be any other factor influencing the relationship between the dependent variable (acceptance) and independent variables (gender, practice type, and years in practice).

The regression analysis is now presented (Figure 5-4).

Table 5-4

Multiple regression for years in practice, gender and practice type on recognition of influences on patients

Variable	Variable type	Mean	B	SE B	β	β^2 ratio model	r^2 adj.	r^2 adj. change	t value	Sig. t
Years in practice	Interval	15.660	-0.029026	0.008252	-0.195155	3.25	0.02747	+0.02747	-3.517	0.0005
Practice type	"Dummy" group = 0 single = 1	0.61	0.629891	0.322658	0.108313	1.0	0.03583	+0.00836	1.952	0.0518
(Constant)			4.127540	0.147965		-			27.895	0.0000
Gender	"Dummy" Male = 0 Female = 1	0.248			0.014148	-	0.03304	-0.00279	0.257	0.7974

For the model using the variables years in practice and practice type F=7.03906, Sig. F=0.0010, n=326

The regression analysis showed that there was a very significant relationship between the variables of acceptance and number of years in practice. From this, it may be concluded that a significant amount of variation in the acceptance of differing influences on patients can be explained with reference to the number of years that a GP has been practising. The variable practice type also showed evidence of a trend in explaining the variation in the recognition of these influences.

The value of r^2 adjusted for change showed that the number of years that a GP had been in practice explained 2.7% of the variation in the recognition of the influences on patients' behaviour, while practice type explained an additional 0.8% of the variation. Gender detracted from the predictive value of the model, and therefore is not included in the model presented below. If the dependent variable of acceptance is plotted against the independent variable of years of practice than a negative slope is produced (B equals -0.029026). It indicates that as the number of years that a GP has been in practice increases, then the likelihood of them recognising these influences decreases slightly. The regression analysis also showed that the number of years a GP has been in practice is three times more able to explain the variation in the recognition of influences on patients than practice type (β^2 ratio).

The suggestion that influences on patients are likely to be recognised by GPs who have been practising for a shorter period of time suggests that these influences may be more readily recognised in the future. It may also suggest that not only are changes occurring in the information available to patients, as detailed in Chapter One, but also that changes may be occurring in the recognition of the range of influences on patients by GPs. Alternatively, these may be 'keen' GPs at the beginning of their career and are 'open' to the idea that the factors detailed in the vignette may influence the choices patients take with regard to their medicines.

The Students t - test presented earlier showed that GPs who responded to the vignette had been in practice for fewer years than those who did not respond. However, the mean difference in the number of years of medical practice between responders and non-responders was only two years. The confidence interval for the standard error of the difference between the two means at the 95 percent confidence level was calculated and showed that the maximum number of years difference between the two groups is four years. As the value of the means were 17.7 and 15.6 respectively, then this is unlikely to be of any practical significance. It may however mean that, due to the nature of the response to the vignette, the model presented here is more effective in describing the actions of those GPs who have been in medical practice for a slightly shorter period of time. Despite this, the value of the significance of F shows that the model is very significantly able to explain the variation in recognition of influences on patients.

Criticisms of the vignette

In hindsight, the list of emotions provided in the vignette could have been linked more tightly to the emotions expressed by GPs when they were interviewed, and fewer examples of emotions could have been presented. Therefore, the examples of 'betrayed' and 'you had failed' could have been omitted as they were not expressed in any of the interviews with GPs. This may have improved the response to this part of the vignette, as the emotions presented may then have been more familiar to GPs. The vignette could also have been designed to probe more deeply into how GPs respond to requests by patients for information. Finally, the wording of the question referring to the influence of the Campaign for Asthma required more careful wording as, when examined closely, the question did not collect the same type of information as was gained concerning the other influences presented in the vignette.

Summary

The response to the vignette was representative of GPs in Derbyshire. The analysis established that approximately fifty percent of the GPs who responded to the vignette recognised the influences presented. The most unpopular influence was that of friends and family, yet this was also judged to be the most realistic. General practitioners who had been practising for a shorter period of time were more likely to recognise the influences. This suggests that changes may be occurring in the ease with which GPs recognise influences on patients outside of the consultation, and that more GPs may recognise these influences in the future. This may mean that, as more GPs recognise these influences, they may attempt to discuss them with patients in the consultation, and thereby encourage better communication between GPs and patients. This idea is also loosely supported by the finding from interviews with both patients and GPs, that younger GPs were more likely to provide information. Alternatively, this could be an effect of the 'keenness' of new GPs and may not represent a potential change in the future.

Conclusions

This chapter initially detailed ten interviews with GPs. These interviews demonstrated a range of beliefs and practices. In particular, even within a sample of ten, views ranged from a paternalistic approach to their relationship with patients, to one where the belief was expressed that the patient should be provided with information, and then allowed to make their own choices.

Information was reported to be provided on the basis of the GP's judgement of the patient. However, the idea of a 'gap' in understanding between the two parties suggested that relying on the judgement of the GP was problematic, and that patients may not gain the information they believe they need in order to make informed choices about their medication, based solely on the information provided by GPs.

The idea of influences on patients from outside of the consultation has been considered throughout this thesis, with reference to their use by patients trying to make informed choices about their medication. The construction of the vignette was based on a number of influences suggested in interviews with patients. The vignette was distributed to all the GPs in Derbyshire. The results suggested that about half the GPs who responded recognised the influences presented. Moreover, a regression analysis demonstrated that those GPs who had been practising for a shorter period of time were significantly more likely to recognise the influences presented. If this trend continues, both with regard to younger GPs recognising influences on patients, and the existing level of recognition is maintained throughout GPs' careers, then there could be a potential for improvements in the future with regard to the relationship between patients and GP. Alternatively, if this represents the ‘keenness’ of newly qualified GPs then the proportions recognising the influences may remain roughly similar.

In the next chapter the findings from all the fieldwork will be considered, with reference to the literature, and recommendations for future work will be presented.

Chapter Six

PATIENTS' AND MEDICAL PRACTITIONERS' PERCEPTIONS OF INFORMATION ABOUT ORAL STEROIDS: IS INFORMED CHOICE POSSIBLE?

The research originated from the idea that recent changes in society may have influenced peoples' expectations with regard to the provision of information about medication. That patients may be informed, or may demand information, and health care professionals may perceive a pressure to provide information. The idea of informed choice was used throughout to consider the choices that patients make, and the information upon which these choices are based. A focus on the side effects of medication was adopted. Through pre-pilot and pilot interviews, a case study approach concerned with the side effects of oral steroids prescribed for the treatment of asthma was developed. The research explored the perspectives of both patients and GPs. The idea of a 'gap', or differences in perceptions, between GPs and patients was specifically considered. Particular reference was also made to non-medical sources of information on which patients' choices about their medication were reported to be based. General practitioners' recognition of these sources of information, and their feelings about them were also explored.

In this chapter the main findings from the fieldwork are appraised with reference to the research question. Initially, the suitability of the methods employed are assessed. Then the findings from all of the fieldwork are considered, according to three common themes. First to be examined is the general availability of information about medicines, and changes in legislation, as these may be perceived to create a pressure on medical professionals to provide information. Then medical professionals' perceptions of their role are considered, as these are likely to have an effect on the information they provide to patients. This is followed by a review of the idea of informed choice, with direct reference to the findings from the fieldwork. The final section presents recommendations for future research.

The suitability of the research methods employed

The research considered the possibility of patients being able to make an informed choice about their prescribed medication. A case study approach was adopted. This has its limitations in that the main findings relate only to the prescription of oral steroids for asthma. However, certain findings, such as views expressed concerning the provision of information about medication, the ways in which patients use non-medical sources of information to make choices about their medication, and GPs' perceptions of their role, provide new insights and present a foundation for further research.

In the light of the dearth of research concerning the information patients use to make decisions about their medicines, with particular reference to the issue of side effects, exploratory semi-structured interviewing was initially employed. In this way it was possible to explore the views of both patients and medical professionals concerning the provision of information about the effects of medication, and the reasoning behind these views. The interviews enabled a range of views to be presented, yet with a depth of understanding which would not have been possible had a larger sample been employed. The extent of GPs' recognition of, and feelings about, non-medical influences on patients' choices about their medication was also examined across a more representative sample. This was done using a vignette which produced comparable data from a representative sample of GPs in Derbyshire. This use of both qualitative and quantitative methods of data collection allowed for an in-depth understanding to be developed (Silverman 1985, Roter and Frankel 1992).

As discussed in chapter five, certain changes could have been made to the structure of the vignette, particularly to the questions concerning GPs' emotional response to patients use of influences from outside of the consultation. Despite this, the methods employed did address the questions raised at each stage of the research. The extent to which the findings addressed particular key issues will now be considered.

The availability of sources of information about medicines

The research initially stemmed from the idea that there has been an increase in the availability of information about medical matters in society, and that this may have affected people's knowledge of, and wish for, information about medication. Interviews were conducted with patients to determine the information that they said they wanted, and the information they used in order to make choices about their medicines. All the patients in the main part of the study had received a prescription for oral steroid medication. Oral steroids were identified as the target medicine because they have a range of common identifiable side effects about which patients are likely to be informed. However, they are also used for treating serious conditions, in this case, severe asthma. Therefore it is suggested that patients are likely to adhere to their prescribed regimens in order to relieve their symptoms. Indeed, the expression of the necessity for oral steroids was a factor common to all the patients who were interviewed. However, attempts to take 'control' were also noted. The most extreme being Mr C, who had completely altered his medication regimen to the way in which he felt it best suited him. This idea of patients with chronic illnesses acting to 'take control' has also been noted in the literature (Conrad 1985).

The amount of information patients possessed varied according to the interest of the patient, their GP, and their personal experiences. The fieldwork demonstrated that patients used a range of sources of information in order to make decisions about their medicines. Evidence was shown of the influence of friends and family, the television, newspapers, and in one case the self-help group, the Campaign for Asthma. What is of particular interest is that the influence of friends and family was not restricted to verbal communication, but patients observed the effects on other people of taking oral steroid medication, and made their judgements of the likely effects based on these observations. People also used their personal experience with both steroids, and other medicines, in order to judge the likely effect of their prescribed steroid medicines. The idea of 'career', drawn from the sociological literature, was used in order to gain an in-depth understanding of the way these various sources of information, together with any information gained from health care professionals, were used by patients to make decisions about their medicines. This demonstrates the usefulness of sociological insights in interpreting the results from these interviews.

The idea that patients make choices about their medication based on both medical and non-medical sources of information, and GPs recognition and feelings about these influences, were explored in interviews with GPs. Insights initially identified in the interviews were then examined using a vignette which enabled representative and comparable views to be obtained from a larger sample of GPs. In this way it was possible to demonstrate that approximately half of the GPs who responded to the vignette recognised the influences presented. The influence of friends and family was judged to be the most realistic influence, yet also the least popular. This may affect the way in which a patient stating a view gained from friends or family may be received by the GP. It is beyond the scope of the fieldwork conducted to comment on this, yet it does indicate an area in which difficulties in communication may occur between patients and GPs. These findings also demonstrate that combining qualitative and quantitative research methods allows a more complete understanding to be developed.

In the literature review, reference was made to the possible influence of changes in legislation, and of the reported increase in the popularity of alternative medicine (Murray and Shepherd 1992). Neither of these potential influences were mentioned by any of the patients interviewed. However, interviews with GPs suggested that patients expectations had increased in recent years, and in some cases GPs associated higher expectations with changes in legislation. One GP also noted the influence of alternative medicine, which he associated with causing problems in communication and adherence. Comments as to the perceived relevance of these influences were made in general terms and not specifically related to the characteristics of the case study under investigation. Moreover, with reference to the influence of alternative medicine, Sharma (1992) suggests that people often learn of alternative medicine through 'word of mouth', thus it is possible that none of the patients interviewed had knowledge of it, but that GPs, by virtue of the number of patients they have contact with, know people who use it. Both of these influences, legislative changes and alternative medicine, require further investigation in order to assess the possibility that they may influence the choices patients make with regard to their medicines.

Although patients constructed their own understandings about medicines, and used these understandings when making choices about their medicine, they all cited the GP as a preferred source of information. However, the findings suggested that even direct requests to the GP for information may not be answered (Mrs Q, Mrs I, Mrs H). A possible explanation for this is provided by the view expressed by a number of GPs that it is not always in the best interests of patients to be provided with information. This demonstrates how the GP's perception of their role may prevent them from providing information to patients, and therefore patients may not be able to make an informed choice, based solely on the information they receive from their GP. This is explored in more detail in the next section.

A number of GPs expressed the belief that if patients had no medical choice but to take the medicine prescribed there was no justification in causing them concern by informing them of the possible side effects. However, this demonstrates a failure to recognise the existence of other sources of information outside of the consultation through which patients may learn of side effects. The vignette demonstrated the validity of this view as nearly fifty percent of the GPs who responded failed to recognise the influences presented.

The idea that information about side effects may result in non-adherence was also presented in interviews with GPs. This argument is not generally supported in the literature (Lamb et al 1994). Moreover, informing patients may be of benefit to patients as they may feel they are able to exercise some 'control' over what is happening (Gardner et al 1988). In interviews, patients expressed a desire to exercise control over their medication. However, more fundamental is the fact that if patients experience side effects which they have not been informed about then this is likely to cause them to experience concern, which may in turn affect their trust in their GP. Indeed this was the case with Mrs F, who believed information about potential side effects had been withheld from her and said this had affected her trust in her GP.

Evidence from interviews with patients also suggested that failing to respond to patients queries about the potential for side effects may cause them to construct their own understandings in order to 'make sense' of the likelihood of side effects occurring and the reason for them. Thus people may develop explanations, for example that medicines affect people differently (Mr C).

The position adopted by GPs in their justification for not providing information to patients may be based on their perceived role as experts. These ideas will now be explored with reference to both the literature and the findings from interviews with GPs.

The position of medical professionals in society.

The position of the medical professional in society is an issue of particular interest, as it may be affected by changes in the availability of medical information. Thus the position of GPs may have changed as a result of shifts in the expectations of both patients and practitioners.

In the interviews with GPs, a number of references were made to their expertise. This suggests that they may see their position as maintained through their skills and expertise. However, the conclusions reached following an examination of the literature, suggested that their position is also determined by the fact they have a monopoly over the provision of medical resources, and in particular control the supply, and to a large part, the education, of medical labour. The perception presented by GPs in interviews does not contradict the conclusions drawn from the literature, it is merely that the basis for the conclusions drawn as to their position in society is less complex than that presented in the literature. However, the adoption of this more simplistic position may prove problematic for patients trying to make informed choices about their medication if GPs perceive that they should act to maintain this expertise, and as a consequence do not provide information to patients.

Moreover, if GPs feel that their position is maintained by their expertise, then they may feel threatened by the increasing availability of information about medicines, and by reported shifts to a 'consumerist' patient, which has been encouraged by Government interventions such as the Patients' Charter. As Anderson and Bury (1988: 1-2) point out, in an age of changing consumer demands and expectations, there is a need for providers to increasingly offer choices, not to make them. This is suggestive of a shift away from the idea of the professional as expert, towards the professional as offering an advisory service.

Indeed, interviews with GPs reported a perception that patients' expectations were generally increasing, and some GPs said that they now provided more information due to the impact of sources of information such as Patient Package Inserts. What is interesting is that patients did not associate their desire for information with changes such as the Patients' Charter, they merely wanted information at specific times in order to inform their choices about their medicines. Thus, some GPs may have noted a change in their role in terms of facing increased expectations concerning the provision of information. However, patients did not appear to have detected a shift in the role of medical practitioners.

Interviews with patients demonstrated that patients did not always receive the information they desired from GPs. Interviews with GPs demonstrated a range of beliefs from paternalism, through to the belief that patients should make their own choices, and the role of the GP is merely to provide information upon which patients' choices may be based. Reservations were expressed by GPs about the general increase in the provision of information, as patients were said not to have enough 'background knowledge' to be able to use the information provided effectively. Moreover, it was suggested that some patients did not want to be informed. A similar idea was also expressed in pilot interviews with patients, a number of whom said they wanted to be provided with more information, but that 'some people' could not cope with being informed. These patients suggested that GPs should judge the amount of information to provide. This fits with the idea expressed by GPs as to the differences between patients, which makes it impossible to provide a standard amount of information, and with the idea expressed by GPs that information about side effects is likely to be provided on request, as opposed to being volunteered.

However, a potential dilemma lies in the use of GPs' judgements to determine the amount of information to provide about the side effects of medicines. The fieldwork identified potential 'gaps' in understanding between patients and GPs, in particular it supported the literature which claims that people generally want more information about the side effects of their medicines than GPs perceive to be the case. In particular, a finding from the interviews with patients was that patients may wish to be informed about the side effects of their medicines, even if they have no medical option but to take the medicine. In this way patients perceive themselves to be 'in control'. However, certain GPs expressed the belief that it not always in the patients' best interests to be informed, particularly if they have no option but to take the prescribed medicine. This demonstrates a potential problem in the communication between patients and GPs, and thus a potential barrier to patients being able to make informed choices about their medications.

Informed Choice

The research considers changes in the availability of information in society and the possibility that these changes may inform the choices patients make about their medication. It is concerned with the provision of information to patients by GPs, and the influence of information from a range of sources, including the GP, to patients' choices about their prescribed medication. The role of GP is important as they are the official expert and potentially the major provider of information about medication to the patient. However, although the initial choice to prescribe the medication is based on their professional knowledge, the final decision to take the medication rests with the patient.

The problem of enabling patients to be able to make an informed choice about medication is more complex than merely mandating that a particular amount of information is provided by medical professionals to patients. Aside from the problems of determining the content and extent of information to be provided, mandating that a particular amount of information should be provided negates the idea that different patients may want differing amounts of information. It may also fail to take account of the existence, and the importance, of information from outside of the consultation, the accuracy of which cannot be challenged merely on the basis that it is not provided by a medical practitioner. Indeed, first hand experience from taking a medication is arguably more relevant than generalised facts about potential side effects. Moreover, there has been a blurring of the places from which advice about health matters may be obtained, as for example, medical practitioners now have 'slots' on daytime television, and columns in newspapers and magazines. In this way, medical and non-medical sources of information may be seen to converge.

The alternative to mandating that a certain level of information should be provided is to rely on the judgement of the GP. Pierce (1993) suggested that the information provided to patients should be 'tailored' to suit their individual needs. Yet, the findings from interviews and the vignette demonstrated that GPs are often unaware of patients' beliefs and the range of influences upon patients. Therefore, before patients may make informed choices based solely on the information from the GP, the communication between patients and practitioners requires improvement. In particular, patients and practitioners need to be encouraged to share their respective beliefs about health. This would be to the benefit of the patient as they may then be more readily able to combine all their knowledge. It would benefit the practitioner as it means the relationship would be more co-operative, and the patient is likely to adhere more closely to the prescribed regimen. It would also enhance the perceived role of the GP as the expert, as they would be responsible for helping the patient to integrate all their knowledge and beliefs.

The findings from the vignette suggested that GPs who had been practising for a shorter period of time were more likely to recognise the influences presented. Moreover, interviews suggested that younger GPs were more open with regard to providing information about medication. A possible interpretation is that the likelihood of patients being able to make an informed choice based solely on information from the GP may increase in the future. The chances of this happening will increase still further if measures are taken to improve the communication between GPs and patients. Possible suggestions for improving communication are detailed below.

The way forward

Research conducted by Frederikson and Bull (1995) suggested that if patients are encouraged to adopt an active role in the consultation, then the outcome is beneficial for both patients and practitioners. Encouraging patients to be more open in the consultation allows for the full range of patient reaction to the consultation situation, as patients who want the GP to make all the decisions would also be served in such an arrangement. The danger of this is that GPs may still ignore requests by patients for information. For this reason, concentrating on encouraging GPs to be more open in the consultation is likely to be more effective than a solution which places the onus on patients to request information.

If the communication between patients and practitioners does not improve, patients will continue to make choices about their medication, however, the information on which these choices are based may not be medically accurate. Improving the communication between patients and practitioners may be seen as the best solution as it does not rely on the blunt instrument of regulations or legislative powers, yet alternatively does not rely purely on the judgement of the medical professional. It is necessary to find a way in which patients and GPs may share the responsibility for the provision of information, and for enabling patients to make an informed choice about their medication. Moreover, GPs need to be flexible about their consultation style, and vary the information provided to suit the needs of the patient.

This idea of encouraging greater communication between patients and GPs through the development of a participative relationship may cause disquiet among GPs who hold a traditional view of the relationship between patients and practitioners. In such cases, the advantages of improved communication could be presented. The Government is concerned to reduce the cost of drugs and wastage from non-adherence (Audit Commission 1994). Encouraging a participative relationship between patients and GPs is likely to result in less medication being wasted, as it should encourage patients to feel comfortable about discussing any concerns they have about the medication or any adverse reactions they may experience. Moreover, improving the communication between patients and practitioners is likely to reduce the chances of consultations where the same symptoms are presented because the patient has not followed the medication regimen prescribed.

This solution aims to take the best from the other possible solutions that have been proposed. It maintains the position of the practitioner as the expert, thereby making use of their training and experience, yet it also emphasises the beliefs and experience of the patient. In the opinion of the Charmaz (1990), the recognition of patients' beliefs is fundamental to improvements in communication. It also highlights the necessity for the integration of these understandings into the decisions made concerning the level of information provided about the side effects of medication. In this way, the amount of information that individual patients want may be determined, and the wishes of all patients may be taken into account.

The findings from interviews and the vignette suggested that GPs may not be aware of the range of influences on patients when making choices about their medications. Informing GPs about these influences may improve the communication between patients and GPs. This, however, demands the co-operation of GPs and patients. Both of whom need to be involved in the development of the material to encourage a more participative relationship, and in the discussion of the form which the material should take. This could be done using focus groups of patients and practitioners in order to gain ideas about the most effective way to provide information to both patients and GPs.

Further insights into the provision of information about side effects, and the idea of informed choice, could be gained from practice nurses and pharmacists. Unfortunately time precluded the inclusion of these perspectives in any depth in this research. However, potentially, both have an important role in the provision of information to patients about the side effects of medication. These roles could be strengthened, possibly through the use of legislation. The role of pharmacists as a source of information was noted as long ago as 1975 by Stimson and Webb (1975), while Snadden (1992) suggested that practice nurses perform a strong support and information role for patients with asthma. Interviews with patients and GPs suggested that practice nurses sometimes play a large part in the day-to-day running of asthma care. Practice nurses do not have the same professional status as GPs, and may have fewer demands on their time, so they may be perceived by patients as more approachable than GPs. Therefore, practice nurses could fulfil a role of providing information to patients.

The extent to which nurses provide information, however, is likely to rely on the hierarchical structures within each individual practice. Interviews with GPs demonstrated a range of responses to the role of practice nurses with regard to asthma. In particular, the perception of the role of the practice nurses varied. One GP suggested that practice nurses provided a useful service in terms of performing routine tests on patients, as this saved time in the consultation between patients and the GP. At another practice, the practice nurse took almost total responsibility for asthma care, and would even initiate prescriptions for oral steroids. Focus groups with practice nurses would provide insights into practice nurses' perceptions of their role, and the way in which they believed patient care, and the ability of the patient to exercise an informed choice, may be improved through a possible enhancement of the role of the practice nurse.

The other group mentioned in the interviews were pharmacists, who may prove a rich source of knowledge about the side effects of medication. Patients may perceive pharmacists as more approachable than GPs because it is not necessary to make an appointment in order to consult the pharmacist. Alternatively, queues of people, and a lack of privacy, may discourage patients from asking the pharmacist questions about their medication. Pharmacists' perceptions of their role in providing information to enable patients to make informed choices about their medication could be examined, and any perceived barriers to providing information explored.

Focus groups conducted with practice nurses and pharmacists would identify their perceptions of their roles in terms of informing patients about the side effects of their medication. They would also provide useful insights into these practitioners' beliefs regarding the potential of their roles for enabling patients to make informed choices about their medicines.

The findings upon which the main conclusions are based concern asthma and its treatment with oral steroids. One patient was interviewed who did not suffer from asthma, but from rheumatoid arthritis. The prescription raised similar concerns to those expressed by asthmatic patients. A more extensive study could be conducted to ascertain the extent to which the findings are generalisable across different conditions and medications. For example, does the same 'gap' in perceptions between patients and GPs, with regard to the provision of information about side effects, occur when a prescription is issued for antibiotics?

The research presented in this thesis established general 'gaps' in understanding between patients and GPs. Further research could follow patients through the consultation process and identify the information they believed they received from the GP, and the information the GP believed was provided in that particular consultation. If the consultations were recorded, then the actual information provided could also be established. This would enable an understanding of the way in which the actual information provided by the GP informed the decisions taken. This may provide a useful understanding of the most effective ways of providing information.

With specific concern for the idea of choice, the patients involved in life history interviews had been prescribed oral steroids for the treatment of asthma. The condition dictated the necessity for the medication. If the sample had included patients who had only been prescribed inhaled steroids then more debate with regard to the necessity of the medication, and the choices patients perceived themselves to have, may have been apparent. However, if the medication was not perceived as necessary, then patients may not have debated the risks and benefits of it, and sought information. They may simply have failed to adhere to the prescribed regimen. For this reason inhaled steroid medication was not chosen for this study, however it may provide a useful comparison to the findings presented, and provide additional insights into the possibility of informed choice when the medication is not perceived by the patient to be a necessity.

Conclusion

Elston (1991) suggested that people have become more willing to take control of their medication, and are seeking information in order to achieve this end. Both the literature, and the findings from interviews with patients, suggest that patients gain information from a range of sources. Throughout this thesis, recent changes in society which have increased the potential for patients to be informed about their medication have been considered. An issue of key concern here is that, if GPs do not provide information about the potential effects of the prescribed medication, then patients may rely on other, 'non-medical' sources of information, and may use this information to make choices about their medication. This poses the question of whether a patient may be said to have made an informed choice if the choice was based on information which emanated from a source other than the medical profession. This is impossible to answer, as the medical accuracy of information cannot necessarily be determined merely with reference to its source. However, if information is more easily available from sources other than the medical profession then this raises questions about the position of the medical profession in society, and their role in helping patients to make informed choices about their prescribed medication. The GPs who were interviewed perceived their role as including the provision of information, however their wish to 'protect' patients by not providing information demonstrates a failure to recognise the existence of medical information outside of the consultation. It also suggests that GPs may not realise that patients often wish to make choices about their medicines, and even if they have no medical option but to take a medication this cannot be taken to indicate that they do not want information about the potential side effects.

The idea of informed choice has been used throughout this thesis. If patients are to be able to make informed choices about their medication, based on information which is medically accurate, then the communication between patients and practitioners needs to improve. Potential barriers lie in practitioners lack of awareness of the range of influences on patients, and failure to create an environment in which patients may express their beliefs comfortably. It unlikely that patients will feel comfortable about making choices about their medication if they do not feel comfortable about requesting information and about expressing their beliefs. Only when the 'gap' in perceptions between patients and practitioners decreases will it be possible for a relationship to develop where patients may be assured of gaining information from their GP at the level they feel is appropriate to enable them to make informed choices about their medication.

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APPENDIX A

THE CONSENT FORM USED FOR PATIENTS.

UNIVERSITY OF DERBY
MEDICINES RESEARCH UNIT.

PROJECT CONSENT FORM.

Title of the Project: Side Effects of Prescribed Medication: Dilemmas, Risks and Benefits of Informed Choice.

*** Patient's /**
Carer's Name:---
(Block Capitals)

*** Patient's /**
Carer's Address:--

Telephone Number:--

1. Details of the project have been explained to me and I agree to take part on the understanding that my identity is not revealed.
2. I am aware that a tape recorder will be used to record the interview.
3. I am aware that I am not obliged to take part and may withdraw from the project at any time.
4. I am over 18 years of age.

*** Patient's / Carer's Signature:** ---

Date: -----------------

(* Please delete as appropriate)

Appendix B

THE LETTER SENT TO REQUEST INTERVIEWS WITH PATIENTS.

Date

Dear [Name of patient]

The practice is currently involved with research which is being carried out by the Medicines Research Unit at the University of Derby. The research project is about patients' attitudes to their medicines. We have selected your name by chance from our records. The purpose of this letter is enquire whether you would be prepared to take part in the research. This would involve an interview with a Research Assistant from the University in your home. The interview will only last half an hour.

Everything you say will be treated in the strictest confidence and all records will be destroyed following the completion of the project.

You are not obliged to participate, and you may withdraw at any time. This will not influence the care you receive from your doctor in any way.

If you would be prepared to participate could you please reply using the slip at the bottom of this letter. A pre-paid, addressed envelope has been provided for your convenience.

If you have any questions you may contact Fiona Stevenson, the Research Assistant involved with the project at the University, by telephoning (0332) 622222 Ext. 2614.

Your Faithfully,

Name:
Address:

I **will / will not** be prepared to take part in the study. (Delete as necessary)

Appendix C

AN EXAMPLE OF A TRANSCRIPT, AND HOW IT WAS ANALYSED.

This shows an example of a transcript from which themes were identified. The questions asked by the interviewer are in italics, and the replies in normal text. Comments are made as to the developing themes throughout the transcript. These appear in brackets and are in bold type.

INTERVIEW(23) A. 27TH JULY 1994. 2:00PM MALE 62 NO.2

What drugs are you actually on, which drugs do you take?

(.)

Prednisolone, - alternate days, Phyllocontin (.) two tablets twice a day, (.) flixotide, that's an inhaler, steroid inhaler, that's everyday, morning and evening, then we have nebulisation with ventolin, atrovent and saline normally four times a day, can go up to six. Frusemide occasional, that's a water tablet.

---

(23) This key explains the symbols used in the quotations from transcripts.

SYMBOL	MEANING
[]	Material omitted.
()	Clarification of material.
Normal	Interviewee speaking.
Italics	Interviewer speaking.
...	More than one person speaking at the same time.
New sentence	Different person speaking.

Oh right, ok

Is there anything else, well I have ventolin inhalers which I carry about with me.

Are these all for the same condition?

Yes

Is that asthma ?

Asthma.

Asthma is the main condition, I'm told that I have emphysema?

Uh um

But I never think about that asthma is enough for me, I'll settle for that.

[This suggests that the condition from which he suffers affects his life, and the actual medical label is irrelevant. This fits in with the amount of time for which he claims to have suffered from the illness in line 14]

How long have you had asthma for?

Since I was seven years old and I' m now 63.

[He is a long term sufferer]

Has it always been as bad as it is now or has it got worse or...

Um, I would say that it has always been as bad as it is now

Uh um

Sometimes worse

Uh um

But with the medications that we have now, it's much more under control than it ever was

[This suggests that he believes that treatments have improved over time]

Uh um, yes

Now thinking about it the times when we use to have to go to the chemist and buy effagan?? tablets and hope that they would work

Um

You know, I mean with the medication I've got at the moment I can manage to do most things I want to do, I'm not allowed to work but I'm not restricted to the house which is essential as far as I'm concerned, you know, as long as I can get out I'll put up with the condition.

[The medication is seen in positive terms as liberating. This also illustrates how people may adapt their lives according to the severity of their illness, then they develop "measures" of quality of life, in this case being able to get out]

uh um

That's it as far as I'm concerned

How much do you know about the drugs that you take? I'm particularly interested in prednisolone but the others as well

Quite a bit actually, because whilst I don't dwell on the fact that I'm taking a lot of drugs, um, and I haven't really made it my business to find out a lot about them I have been told at various times what they are for, what they can do, what side effects there can be and all that kind of thing you know, but obviously you know if you take too many sprays you can make a mess of things, uh if you are taking too many nebulisations then don't carry on, you know see your doctor and see what can happen, With prednisolone I have known for what 10, 12 years cause I've had quite a few spells in hospital, but they can in fact damage bones

[Vague about sources of information. He says he has not tried to get information, but has gained information]

um hm

Uh, I take quite a philosophical view about it, they can damage bones but they've got a long way to go to get through mine.

[He appears relaxed about this. However, this could be seen in terms of denial, that he does not believe this is likely to happen to him. Alternatively this could be seen as an acceptance of the risk of side effects, alongside the condition and the medication]

So have you known about maybe the side effects of prednisolone for as long as you've had it ?

Yes

Yes, so I mean when you were..I'm quite interested in taking it back to when people were very first prescribed these drugs and if you can remember then.

Well, I think really um it would be about, lets see, possibly 12 years ago

uh um

When I first had to go into hospital

Uh um

And I was given prednisolone in fairly hefty doses you know 40mg a day and uh I don't think I was actually told at that time that it could do any harm I was told that there were side effects, um, one of the side effects was that you could put on weight fairly easily, you know it retains fluid, so it puts on weight and also (.) that it could have some detrimental effect on bone structure. But it never particularly bothered me, cause I mean uh if you got an illness you got to take some medication and as long as the medication is doing you good and keeping you going that's it as far as I'm concerned, you know.

[This shows the strength of the life history method, as he elaborates on the answer he gave in line 32, that he knew about the side effects when he first was prescribed prednisolone. Here he also presents his rationale for his apparent lack of concern about the risk of side effects. He appears to weigh up the positive effects of the medication against the potential risk of side effects and takes the medication, this may be seen in terms of a present time orientation to the treatment of his condition.]

Uhuh

Only, what 5 or 6 weeks ago I went to the chest clinic cause I'm a regular at the chest clinic you see

Oh yes

And I saw Dr. B. and he said I want you to go for a scan

Uh uh

And he said are you worried about it? Don't worry I said if you are going to tell me it's a bone scan because of prednisolone I'm not worried I've known for ten years, you know so that's alright then. I mean, you just don't have to worry about things, if you worry about everything's going to happen to you, well you'd make yourself feel worried so you might as well just let yourself be ill without everything else you know

[This "present time orientation" is continued]

You said that he said you know don't worry about it. Do you think he was, was worried about saying to you, you know this is because this drug could have caused this or..?.

No, no

No he wasn't

No I think I've spent a long time in, I've spent three , three month spells in hospital, and you get the patients who come along to you and say oh dear me, my steroids have gone up, I'm going to have this, I'm going to have that, you know. It never bothered me and I do know people who've had trouble with their bones but so be it. I'm living a fairly active life. I don't lead as active a life as a lot of people, but with the condition, I'm living a fairly active life and that makes me happy, so...I mean that thing there, that ventolin and atrovent, there is a side effect from that really, we call it ventolin shakes

[His quality of life at the present time is more important to him than potential problems in the long term]

Oh yeah

(.)

It's about 14 years ago when I first started on ventolin and I did get flustered by the shakes and I mentioned it to a specialist and now I was not very pleased with what he did, cause he turned around and said he's got shakes give him some um valium

oh

And uh it took me three years to get off valium

(.)

I didn't realise what valium could do to me.

[No evidence that this experience has affected his attitude towards medication in general - this is not so in other cases - EG (Mrs D)]

(.)

You said that you, were you actually told, you know a bit about the side effects of prednisolone. Were you actually told them at the time when, when you were in hospital or do you think you gained..

I were told that they could retain fluid, I was possibly told they could put weight on. I don't think at the time I was told about the bone structure thing. I think I think I learnt that from listening to various patients and what had happened to them

[Medication information from non-medical sources]

Have you picked a certain amount up from other patients?

Not a lot to be honest

I just wondered cause you'd said it and nobody else had mentioned other patients..

..no, no. I've not picked a lot up from, I mean possibly at the time I might have asked a question, well does it do any harm? As I said to you I just think it's got a long way to go to get through these so why bother. You know I mean there is no point in worrying about things like that to my mind. it might seem a silly point, of view, but if you are in this condition and there is a medication that will help you well you've got to weigh up the what you're told before hand, you've got to weigh up what will happen if something might happen in ten years time or fifteen time, you think to yourself well am I going to be alright in the fifteen years going up to that and am I going to enjoy myself cause I might pop off tomorrow anyway, you know.

[Present-time orientation for the assessment of risks]

uh ah

Life's too short to worry about things like that, in my opinion

[This could be seen as a coping strategy]

yeah, yeah...Do you feel you always have enough information to be able to make that decision?

Yes, I do really

Uh ah

Possibly because I never worry about my medicines, if it's something's doing me good then that's it

[Positive effects of medication]

Uh ah

So, I mean, do you think that you um?

Well, I could give you an instance in actual fact, this is long before I came to Derbyshire and this is where I wasn't told the side effects. I used to go a doctor who decide a certain medicine would be okay for me. It wasn't propriety or anything and he'd seen this work on another patient so he decided that it would be alright for me. I must have been about 18-19 at the time and he said , right I'm going to put you on this specialist prescription (.) and I had to have this made up (.) I went to the doctor who had taken over (.) I said I want a bottle of my medicine please. The prescription is underneath that pad there, he said is it?, So I said yeah (.). He took one look at it and he said you're not getting any more. He said if you carry on with this, with the stuff that's in it, I'll guarantee that you'll be dead inside 18 months.
Now that was a case in which I felt I should have been told what kind of stuff was in it. Cause I was a lot younger then and I didn't realise these things happened. But as far as I'm concerned at the moment everybody tells me enough. Because I am a member of the Asthma Society in Derby and we get uh excellent information and advice on anything. I mean most people will go to the chemist and will buy, is it ibuprofen, or something for headaches, if an asthmatic takes it, it makes them ill. Now we get all that kind of information you see so I'm not too worried about anything at the moment. I do feel that particularly at the chest clinic and in our own practice we get enough information about everything.

[This shows evidence of an incident which has affected his attitude towards medication. Although he professes not to be concerned about the side effects of steroid medication, in fact he does know the risks and can then assess them. This suggests he is interested in his medication, and uses non-medical sources of information, namely the Campaign for Asthma, in order to ensure that he is fully informed.]

Ah um. Do you tend to ask or do you not feel you need to?

No

I have enough confidence in the people I'm working with now to know that if there is going to be anything untoward I'll be told about it.

[Confident that sufficient information will be provided]

Is that confidence that's has been built up over the years?

Oh yes

(.)

The sister at the chest clinic will tell us anything we want to do. we only have to ring her up and ask her.

[Role of practice nurse]

So it's all very open?

> Oh yes Dr F. is the same. (.) She does tell you anything that's necessary, cause I don't think when you have that kind of relationship that it's necessary to probe and say well

is it going to do this, am I going to do this or do that. cause you are only getting yourself all tensed up. And in my condition, with the condition I've got tension is the one thing you don't want

[Shows confidence in the judgement of the GP, as regards information]

So, you are on, you said that you've been on, that you first took prednisolone about 12 years ago. Um, you never took it before that?

I can't remember taking it before that, no. I may have been given it on one of my spells in hospital and not realised, but uh, for at least 12 years I've had to keep daily records of what my peak flow output was and because of that I've had to keep a record of what medication I'm taking as well so it all comes automatic to me now. Possibly I may have been given it in hospital and not known .

How much do you know about your other medicines that you are on? (.) You said you were on another steroid inhaler as well

Yes, I don't know a lot about that one to be honest. This is why I say you have to accept some of it with a certain amount of confidence. Because I worked my way up really, from, presumably because of the condition, Becotide, becotide 50 to becotide 100, then they decide neither of those was strong enough so it was on to Becloforte and one of the side effects I did know about, possibly because I did ask about that one, um was that there is a form of thrush which you get from Becloforte. you know I

went to the chest clinic and I was talking to Dr. B. I said I keep getting sore throats can it be any of the medicines. He said Yes so he took a swab and he said yes it's your Becloforte, so we given, I was given tablets to counteract that. but since then we now have, for want of a better word the little torpedo things, the spacers.

Yeah, I know what you mean.

That not only helps you to get the drug rather than spray it about the room, they also cut out some of the effects of the thing hitting the back of the throat with any force and sticking there, you know. Ah, I went to the chest clinic a couple of months ago and this flixatide apparently is a new medication. I heard people talking about it saying it was a lot better than Becloforte. It apparently, uh, well I found this out in a roundabout way so I better not say too much about this one. But it is stronger than Becloforte, uh and I was asked first of all would I go onto a trial for it for some reason the trial didn't come about, but when I saw Dr, B. last, (.) He said I want you to try this one, see how you go with it and that was when he told me about having the bone scan.

[Information from non-medical sources]

Oh, yeah

I think what they are trying to do, and I'm quite in agreement with it, is if this flixatide proves to be better than Becloforte it might help me to um cut down on the prednisolone

Oh I see

Which is always a good thing. Um, we have cut down on prednisolone cause I was taking 6 alternate days and now I only have 4. Sooner get down onto 3, but we did try going down to 3 and I was not very well. So if we can get something to boost me the other way with an oral, with an inhaler so that I can cut down on prednisolone that will be me fine.

So, you'd rather have an inhaler than take the tablets?

Well, I'm not too bothered which way. Because the prednisolone works, and whilst I can't go below 4 at the moment If I can get below 4 that all helps with all the other kinds of problems that might come up you know

[Despite his apparent relaxed attitude towards the steroid medication he is keen to cut down on it]

Ahum

You said you'd heard about it from somewhere, Was that from the asthma group that you are in?

Yeah

Yeah

Patients do tend to talk at the asthma group and one chap said to me have you tried flixatide, its marvellous. It' the best thing I've ever had.

[Information from a self-help group.]

So you said you get information from your doctors and from the asthma group. Is there anywhere else that you've got information from?

Well, if I thought there was something I was taking and I wasn't too sure about it I'd ask the chemist, cause I'm on good relations terms with the chemist as well. I'd say what's this for, what's that for. If I want information I'll get it, but generally speaking I don't bother too much, now. As long as it's doing me good, that's the main thing.

[Asked the pharmacist, this shows a hierarchy of the providers of medical information.]

When you first went, I mean you've obviously been on steroids for quite a few years now. were you worried about taking steroids when you first were prescribed them?

No

Did you know anything about them? Had you heard of them?

I'd heard of them, yeah. I heard that they did you good. That was all that bothered me.

[Positive effects of the medication]

You hadn't heard anything bad about them?

No

(.)

As far as I'm concerned, the medication I've got keeps me going and if I was to look back on the times when I was first ill. Now I use to go along to the chemist and I'd buy a bottle of half-green ephadrine tablets over the counter and no-one bothered how many you took (.) Use potter's asthma cure.(.)
The information, the medication we get these days as far as I'm concerned is tremendous.

[An appreciation is shown of improvements in medication over time.]

So there has been quite a lot of changes even, obviously since you've started?

Oh yeah.

(.) Inject myself with adrenaline whenever I felt like it. (.) So the condition I've got at the moment are absolutely marvellous. I couldn't ask for more really.

Presumably you went to the doctor when you first developed asthma, you said you were 7 when you first developed it. Was there not very much they could do? It was mainly just over the counter stuff that you just went and brought?

That's right, yeah (.) (Discusses older treatments) Did start me off on the medihaler??? I think it was called and those things were supposedly pretty lethal, and I think the only reason they were lethal was that there wasn't enough information given out with them and people just kept puffing away, puffing away, puffing way. they gave a metered dose every time but no-one

said how many doses you got to take (.) (Had an inhaler with a bulb) but there again I was never told how much was the maximum or anything like that, whereas today you're given full information about how much you can take, how much you dare take.

What about information, maybe on the television about steroids or asthma

Not seen very much on steroids to be honest

You've not

No... If I notice them I do watch the programmes about asthma and I think some of them are very good, but I think there's a danger of just taking what they say on the television

[Wary of being too trusting of the media presentation of asthma]

(.)

Because, I think a little knowledge can be a dangerous thing, that's one example when it could be a dangerous thing

Ah um, If people get a little bit and then they get...

That's why I believe a lot in asthma society.

Because it gives you full information?

It gives you full information and we have regular meetings at the City Hospital with speakers who demonstrate um nebulisers, who talk about various medications so you get the full facts, and you're able then, a lot of them are from the manufactures you see and you are able to ask the manufacturers what the side effects are if any and that.

[Appears to find the Campaign for Asthma meetings useful, he also appears to give them additional credence because of the apparent links with the medical profession, for example where the meetings are held]

And do you find them very honest in that kind of situation?

Yeah, I think they've got to be really. I don't think they dare be anything else

You said that some of them just give a little bit of information, um, can you remember any examples where you might have seen this?

You mean on the television?

Yeah

Well, what I mean is that .. for anybody who doesn't know about the asthmatic condition the information that you get on there is only very very small really ,compared with the condition and you need to know a lot more about what can be done rather than just look at one thing.

Do you think that's maybe a problem of time?

Oh, yeah it is the time yes, yes. But I feel if they are going to put something on they should give you all the lot kind of thing, you know.

Do you think they are a good idea to have them on, to have the programmes.

Oh yes, yes

I mean as much as anything else my wife goes to the asthma meetings, so she knows as much as I do, well almost as much as I do, about my medication.

What about newspapers, do you find, have you ever seen anything in the newspapers?

Well, I've got to confess I don't read them very much. I haven't particularly, perhaps Win or her mother would find something that er was of interest and point it out to me, but I really don't spend a lot of time reading the newspapers so I wouldn't come across it.

(.)

(shows me magazine from asthma society - one every 3 months)

You pick up things like that (from the magazine). I suppose I've had the condition that long that I don't worry too much. I don't get that worried if I go into a spasm because I think I've always said that whilst asthma is a serious thing and there's more people dying with it now a days apparently. Em, I know how to control mine and I'm fairly happy with that. If it got to the stage when I thought I couldn't control It then I'd know I had to go to the doctor about it. I do get into trouble occasionally I must admit, because I leave it too long before I tell them. Because I think I'll try and see if I can get it a bit better before I ring her and then .. why didn't you ring me earlier. But asthma is a condition, in my opinion any way which is a lot worse for the onlooker than it is for the patient and it's bad enough for the patient. But, er, they think you are dying, you know because you can't get your breath. I'm rather surprised because one of the things that they do stress now at the, you know you were talking about information, one of the things they do stress about asthma at all the meetings is the amount of people dying from it. Now when I was younger, I was always told that people never died from asthma.

[One of the changes over time appears to be that asthma is treated more seriously. Although he has experience of asthma he trusts the doctors to be able to help him if the symptoms become too severe]

Do you think they are trying to make people take it seriously

Possibly, yes., yeah

May be the way it strikes me is by saying that people can die of it, you are saying to people, keep it under control

Yeah

So you have control of your treatment really? You control it. Do you feel that you are almost like an equal partner with the doctors, or..?

Well, I wouldn't say I was an equal partner, they obviously know a lot more than I do. But in terms of control of it, yeah.... Because I certainly have confidence in them and up to a point I think they have confidence in the fact that I will control it as much as possible. But I do admit, well it doesn't upset, it annoys my wife at times, if I am doing reasonably well, instead of doing the nebulisation every 4 hours I'll let it go to 6. Because I think if I can do that, stretch it out a bit, then that's going to have more effect

[Shows evidence of exerting control over his condition]

Ah um, yeah

You know my body is not as used to it as it...But that's only me.

(.)

Information, these days, in my experience is a lot better in terms of literature, in terms of people being open with you and having time to talk to you about it. I suppose I've been fortunate in a way because I had to give up work, the doctors always visited me here, which means they've got more time to talk to you anyway rather than a 5 minutes gap in a schedule, you know, and we have been able to talk about things and say well should I do this, should I do that, what happens if do and that's what happens if I don't

(.)

Do you feel pressure on you (in terms of time) if you go to the doctors

No

(.)

Any kind of research is good.

(.)

I've put up with it so long I tend to be a little bit slack about it, as long as I can get out I'm not really bothered.

[Lifestyle]

(.)

She understands and I think that's a very important thing about doctors.

(.)

If I wanted to ask her anything I feel confident she'd (the doctor) tell me.

(.)

Have you found that your attitude to both your drugs and your illness has changed as time has gone on.

Well not really, I've always felt they were a necessary, well not necessary evil, but necessary thing as far as my lifestyle went and... well it's just something I'd got to have and that was it.

[Here there is evidence of an apparent acceptance of his condition and the medication as part of his life. However evidence earlier suggests that this may be a coping strategy, and in fact his apparent acceptance is more complicated than this and appears to involve an assessment of the risks and benefits associated with the medication.]

Appendix D

THE VIGNETTE[24].

Please read the case study as it develops in the shaded boxes below. After reading each part please answer the associated questions (Q) in the manner indicated.

Mrs X., aged 58, has been on the practice list for five years, however you have never treated her before. She has recently been diagnosed as an asthmatic and her condition is deteriorating. In your opinion, she now requires a week long course of oral steroids. You have no record of her having had this medication before. She is already using both a salbutamol inhaler and a steroid inhaler. You tell her that the prescription is for oral steroids.

(Please circle your answer)

Q	As it is Mrs. X's first prescription for oral steroids, would you ask her whether she knows anything about oral steroids?	No	Yes

She says that she has heard both "good" and "bad" things about steroids.

Q	Would the fact that she already has some idea about the effects of oral steroids influence the way you might describe any side effects to her?	No	Yes

On further examination of her records, you notice that she was prescribed an antibiotic a year ago. She suffered an adverse reaction which she attributed to the medication.

Q	Do you believe this experience is likely to make her wary of the oral steroids that you have prescribed?	No	Yes

---

[24] Please note that the page breaks are not in exactly the same place as on the original copy of the vignette. The original was only three pages long. This is due to the size of the required thesis margins. The vignette was sent out on coloured paper in an attempt to distinguish it from the other mail received by GPs.

She calls you out two days later and tells you that the tablets are not working. You discover that she thought the dose prescribed "sounded" a bit high and that she has not taken them as prescribed.

Q How you would feel in this situation:

(Please circle your answer for each category)

supportive?	No	Yes
sympathetic?	No	Yes
resigned?	No	Yes
frustrated?	No	Yes
betrayed	No	Yes
angry?	No	Yes
that you had failed?	No	Yes

Q Do you believe her explanation for her decision not to take the medication is realistic?	No	Yes

As the conversation develops, Mrs X tells you that she had also spoken to both her daughter and her neighbour and asked them what they thought about the dose that you had prescribed. They agreed with her that it "sounded" a bit high.

Q How you would feel in this situation:

(Please circle your answer for each category)

supportive?	No	Yes
sympathetic?	No	Yes
resigned?	No	Yes
frustrated?	No	Yes
betrayed	No	Yes
angry?	No	Yes
that you had failed?	No	Yes

Q Do you believe Mrs X's action in seeking the advice of friends and family is realistic?	No	Yes

You explain the necessity of taking the medication at that dose. She appears convinced and says that she will follow the instructions you have given.

She telephones the surgery a week later and says that she has seen a television programme about the side effects of oral steroids. She is upset and worried about the fact that she has taken them.

Q How you would feel in this situation.

(Please circle your answer for each category)

supportive?	No	Yes
sympathetic?	No	Yes
resigned?	No	Yes
frustrated?	No	Yes
betrayed	No	Yes
angry?	No	Yes
that you had failed?	No	Yes

Q Do you expect to be able to sufficiently reassure her of the safety of short term oral steroid medication, so that she would be happy to take oral steroids in the future?	No	Yes
Q Do you believe that Mrs X's concern about her medication as a result of a television programme is realistic?	No	Yes

A fortnight later Mrs X. comes to the surgery and tells you that she has joined the Campaign for Asthma and has received some written information about the use of steroids in asthma. She has come to the surgery to discuss what she has learnt.

Q How you would feel in this situation:

(Please circle your response for each category)

supportive?	No	Yes
sympathetic?	No	Yes
resigned?	No	Yes
frustrated?	No	Yes
betrayed	No	Yes
angry?	No	Yes
that you had failed?	No	Yes

Q	Do you believe that Mrs X's wish to discuss with you what she has learnt is realistic?	No	Yes
Q	I would like to visit a sample of General Medical Practitioners to discuss the issues raised by this case study. This will **not** involve a discussion of your specific answers. Would you be prepared to take part?	No	Yes

Appendix E

THE STATISTICAL TERMS EMPLOYED.

In the analysis, the following statistical terms were used in the stated circumstances. The statistical range used for the probability of a correct decision to reject the null hypothesis was; 'statistical trend' less than 95% ($p = 0.05$) but not less that 90% ($p = 0.1$); 'statistical significance' greater than or equal to 95% ($p = 0.05$) but not greater than 99% ($p = 0.01$); and, 'very significant' greater than or equal to 99% ($p = 0.01$). Data and analysis were presented with the x axis as the independent variable, and the y axis as the dependent variable. In the 2 x 2 chi-square test the expected frequency in each of the cells was always greater than five. In the Students t-test the figures for the variances being equal were examined when P was greater than 0.05.

Appendix F

Confidence intervals for the difference in response between group and single practices.

Question No.	Answer	Group Practice (%)	Single Practice (%)	Confidence Interval (%)
1	No	18.6	5	13.5, 13.7
	Yes	81.4	95	13.5, 13.7
2	No	34.4	40	5.38, 5.82
	Yes	65.6	60	5.38. 5.82
3	No	38.7	30	8.5, 8.9
	Yes	61.3	70	8.5, 8.9
5	No	49.3	45	4.08. 4.52
	Yes	50.7	55	4.08, 4.52
7	No	40.1	33.3	6.58, 7.02
	Yes	59.9	66.7	6.58, 7.02
9	No	12.8	5	7.7, 7.9
	Yes	87.2	95	7.7. 7.9
10	No	43.6	30	12.79, 13.81
	Yes	56.4	70	12.79, 13.81
12	No	6.6	5.3	1.2, 1.4
	Yes	93.4	94.7	1.2, 1.4
Supportive		1.2	0	1.861, 1.214
		7.4	5.9	1.38, 1.62
		9.9	11.8	1.71, 2.09
		1.2	0	1.186, 1.214
		5.3	5.9	0.48, 0.72
		1.6	0	1.4, 1.8
		21	23.5	2.29, 2.71
		2.1	5.9	3.69, 3.91
		0.8	0	0.784, 0.816
		49.8	47.1	2.45, 2.95

Confidence intervals for the difference in response between group and single practices (continued).

Sympathetic		5	6.3	1.18, 1.42
		7.9	6.3	1.48, 1.72
		1.7	0	1.684, 1.716
		11.2	12.5	1.13, 1.47
		0.4	0	0.392, 0.408
		1.7	6.3	4.48, 4.72
		2.9	0	2.88, 2.92
		1.7	0	1.684, 1.716
		19.5	12.5	6.83, 7.17
		1.7	0	1.684, 1.716
		2.5	6.3	3.33, 4.27
		1.7	0	1.684, 1.716
		42.3	50	7.45, 7.95
Resigned		34.4	68.8	34.16, 34.64
		3	0	2.98, 3.02
		3	0	2.98, 3.02
		2.2	0	2.181, 2.219
		1.3	0	1.285, 1.315
		4	0	3.975, 4.025
		3.5	0	3.476, 3.524
		2.2	0	2.181, 2.219
		1.3	0	1.285, 1.315
		1.7	0	1.683, 1.717
		2.2	0	2.181, 2.219
		3.5	6.3	2.68, 2.92
		1.3	0	1.285, 1.315
		16.9	12.5	4.23, 4.57
		21.2	12.5	8.53, 8.87

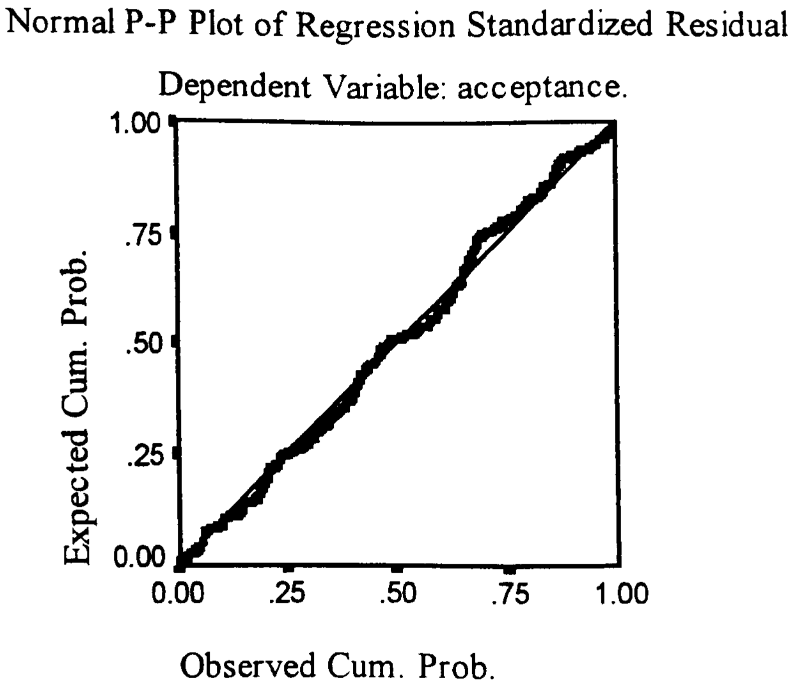
Confidence intervals for the difference in response between group and single practices (continued).

Frustrated		11.7	20	8.09, 8.51
		0.4	0	0.392, 0.408
		5	0	4.97, 5.03
		0.8	0	0.79, 0.81
		2.1	20	17.45, 18.35
		0.8	0	0.79, 0.81
		7.9	20	11.65, 12.55
		0.8	0	0.79, 0.81
		1.3	0	1.286, 1.314
		0.4	0	0.392, 0.408
		0.4	0	0.392, 0.408
		0.4	0	0.392, 0.408
		1	0	0.987, 1.013
		44.4	20	24.19, 24.61
		13.4	20	6.39, 6.81
Betray		82.1	71.4	10.42, 10.98
		0.4	0	0.392, 0.408
		4.7	7.1	2.26, 2.54
		0	7.1	6.97, 7.23
		6	7.1	0.96, 1.24
		2.1	7.1	4.86, 5.14
		0.4	0	0.392, 0.408
		0.4	0	0.392, 0.408
		3	0	2.93, 3.02
		9	0	8.96, 9.04
Angry		54.7	53.3	1.14, 1.66
		6.4	20	13.4, 13.8
		0.9	0	0.77, 1.03
		13.7	6.7	6.87, 7.13
		0.4	0	0.392, 0.408
		9	6.7	2.17, 2.43
		0.9	0	0.77, 1.03
		1.7	0	1.683, 1.717
		4.7	0	4.67, 4.73
		6	13.3	7.13, 7.47
		1.7	0	1.683, 1.717

Confidence intervals for the difference in response between group and single practices (continued).

Failed		67	62.5	4.26, 4.74
		0.4	0	0.392, 0.408
		3	6.3	3.18, 3.42
		0.9	0	0.888, 0.912
		2.6	0	2.58, 2.62
		0.4	0	0.392, 0.408
		0.4	0	0.392, 0.408
		7.7	12.5	4.63, 4.97
		0.9	0	0.888, 0.912
		0.9	6.3	5.28, 5.52
		9.4	0	9.36, 9.44
		0.9	0	0.88, 0.912
		8.6	6.3	2.18, 2.42
		1.3	6.3	4.83, 5.17.

Appendix G



Normal P-P Plot of Regression Standardized Residual

Dependent Variable: acceptance.