

Negotiating the management of chronic non-malignant pain:
the perspectives of general practitioners and patients

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Declaration

I declare that I have made a substantial contribution to the research presented in this thesis. A statement of the nature of this contribution is included within the thesis. None of the contents have been used in support of another degree or professional qualification.

Abstract

This thesis presents a study of the views and experiences of general practitioners and patients of the management of chronic non-malignant pain. The study used qualitative methods, based on initial and follow-up semi-structured interviews with general practitioners (n=29) and patients (n=60) recruited through general practices and through specialist pain centres in the local area. The aim of the study was to incorporate general practitioners' and patients' views in the development of local services.

The methodology of the study was based on the ethnomethodological and grounded theory traditions of sociological research. Data analysis was inductive, with analyses of initial interviews informing the topic guide for the follow-up interviews. The overall approach to the data was substantially informed by the phenomenology of Schutz, though within this broad understanding of the data other theoretical positions emerged as offering relevant interpretations. The analysis of the interviews with general practitioners and with patients were carried out separately and are presented as such.

The analysis of the interviews with general practitioners produced a heuristic model of their accounts of their work which revealed that this was inherently problematic, comprising a number of conflicting tasks. The analysis uses Schutz' description of practical knowledge and the importance of considering motives, means and ends as a basis for elucidating the limitations of formal knowledge and the nature of hidden work of clinical practice.

The analysis of the interviews with patients emphasised the fundamental difficulties of establishing the legitimacy of their experience of pain in the context of everyday life and in the context of health services. The analysis used theories of intersubjectivity, self and threatened identity from social psychology and sociology in order to interpret their accounts of their experiences.

The thesis makes both practical and theoretical contributions to the understanding of chronic pain and reflects critically upon the methodological issues of using qualitative methods to provide user perspectives in health services research.

Acknowledgements

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I am also greatly indebted to my supervisors John Howie and Kathryn Milburn for their stamina, patience and support as well as their intellectual guidance.

I wish to acknowledge Kathryn's contribution to this endeavour outwith her supervisory role. Kathryn's involvement in an earlier research project meant that I benefited greatly from her expertise and insight in qualitative research methods. It also meant that I ate too many cakes. However her greatest contribution to this thesis has been as a loyal friend who has supported me through the many personal difficulties and crises with which have beset me throughout.

Chapter One: Introduction

This introduction to the thesis has two purposes. Firstly, it describes the history of the research project upon which the thesis is based. The study which forms the basis of this thesis was funded by the Scottish Office Chief Scientist Office (CSO) Public Health and Health Services Research Committee entitled: “The management of chronic non-malignant pain in a local health board area: general practitioners’ and patients’ perceptions of specialist services and the potential for primary care.”

Secondly, it provides an overview of the structure of the thesis as a whole. As such this chapter sets the context of the difficult balance between the applied health services research agenda of the original research project and sociological agenda of theoretical exploration based upon this research. The thesis attempts to reflect both of these agendas.

The chapter begins with a natural history of the development and preparation of the original research proposal, drawing together a number of interests which shaped the research project and which have influenced the structure of the thesis. It describes the background to the project in terms of the emergence of pain in primary care as an area of interest within a developing research programme and the placing of the topic of chronic pain within local and national health policy. A brief description of the research in terms of its project management provides a statement of the author’s role in the research project.

The chapter ends with a summary account of the analytical and theoretical

development of this thesis as a basis for a description of the structure of the thesis. This is followed by an introduction to the content of each of the chapters.

A natural history of the research: background and policy context

The emergence of pain management in primary care as an area of research interest can be traced to three previous pieces of research carried out by the author.

The earliest of these was an analysis of an existing data set which contained self-reported data on patient satisfaction and health status (Hopton et al. 1993). Respondents scoring positively on the pain scale used were significantly more likely to report dissatisfaction on three of the seven most discriminating satisfaction items. This association was independent of other process variables (characteristics of the consultation) and respondent characteristics. This analysis did not yield specific findings about the management of pain in general practice consultations. The principal conclusion drawn was of the need to consider the experiences of different patient groups as a basis for understanding the lay evaluation of primary care. However, it did point to pain in general practice as an area of potential interest.

A later project which involved a postal survey of a stratified random sample of patients registered with five general practices in the local health board area provided data on reported health status and perceived needs for different kinds of help (Hopton and Dlugolecka 1995). The analysis identified pain management as one of two areas (the other being advice about welfare benefits) of substantial

perceived need.

However, the principal impetus for a qualitative research project on the management of chronic pain in primary care was an earlier CSO funded project entitled "Patients' Perspectives on Primary Care" (Hopton et al. 1995). This project was based on semi-structured in-depth initial and follow-up interviews with people with rheumatoid arthritis and with asthma.

An important theme which emerged from the interviews with people with rheumatoid arthritis, was that of their experiences of pain and its consequences both in everyday life and in the context of health services. Although the research had anticipated that the experience of spells of continuing pain would be an important difference between the groups of respondents, the study provided detailed descriptions of the impact of pain. Respondents described the problems of the invisibility of pain in the social context of everyday life. They also described the problems of health services and health professionals focusing on the management of the disease process rather than the pain per se.

As well as identifying chronic pain as a substantive area of interest in primary care, this project influenced the development of the current study in two other ways. The primary purpose of this project was to develop a conceptual basis for the lay evaluation of health care. The emergent analysis can be seen to have formed an important part of the researchers' received knowledge which informed the current study. The project also provided relevant methodological experience. These aspects

of the formative influence of this work upon the current study are discussed further in chapter six on the study design, methodology and the fieldwork process.

Taken together, the findings from the three studies pointed to the potential for a study of pain management in primary care and prompted a preliminary review of the clinical, epidemiological, sociological and anthropological research on pain. The review indicated that there was little clinical research on chronic pain in primary care, that services and approaches to management of chronic pain were characterised by diversity; and that, in epidemiological terms, there was no single agreed and useful medical categorisation of chronic pain patients (Davies et al. 1992). Although there was substantial sociological and anthropological research on the experience of chronic pain, its management and its social and medical consequences, again there was little work set in the context of primary care.

The feasibility of a study of chronic pain in primary care was further explored in terms of likely policy and health service interest. In the early stages of preparing the proposal, the researchers learned that the Scottish Office Working Group of the Medical Advisory Committee were preparing a national review of services for chronic pain management (Crombie and Davies 1991), that the national (UK) Clinical Standards Audit Group were preparing guidelines on the management of back pain and that the local health board were reviewing services for pain management and had recently undertaken a needs assessment of existing services (Duncan and Webb 1993). The local review of services for pain management was undertaken with a view to commissioning a new integrated service.

At the time of preparing the proposal, the context of service development and planning was underpinned by the following structures and policy themes introduced by the 1990 health service reforms (Department of Health 1989). These reforms had introduced the internal market, with NHS trusts as independent financial provider organisations, general practitioner fundholding and commissioning by health boards¹ or general practitioner fundholders. One of the major policy themes was that of developing a 'primary care led NHS' and this in turn served to emphasise the importance of general practitioners' views in development and planning processes. General practitioner fundholding incorporated general practitioners' views directly in purchasing decisions. Where purchasing or commissioning was undertaken by health boards, there was thus an imperative to incorporate the views of general practitioners in their specifications for services.

A second theme was that of a renewed emphasis on incorporating the views of patients and the wider public in the planning of health services. These two themes combined to produce an argument, which for the most part went unquestioned, that general practitioners could act as proxy reporters of patients' views.

The opportunity to link a potential study on chronic pain management with local service development emerged from a series of discussions with the consultant in public health medicine who was leading the local commissioning exercise, giving

¹ Health Authorities in England and Wales

the study clear application to health services and serving to fulfil the policy imperatives of including both health service users and general practitioners' views in service development. Thus an explicit aim of the project was "To assist (name of Local health board) to incorporate consumer² views into purchasers' specifications for contracting". There was also the potential for the research to examine the assumption that general practitioners' views could act as proxies for patients views.

In summary, the key issues emerging from this exploration of feasibility for the current study were as follows. Firstly, that the management of pain was high on both national and local health service agendas suggesting that there would be policy interest and a reasonable likelihood of obtaining funding. Secondly, that focusing on chronic pain would be one way of narrowing the scope of the research agenda and would allow the potential for the research to be informed by the wider sociological literature on chronic illness. Thirdly, that given the lack of clinical and epidemiological research on chronic pain in primary care, a study which used qualitative methods was most appropriate for opening up this area of enquiry. Finally, that a design based on semi-structured interviews with general practitioners and patients offered the opportunity to link with local service development.

Project management and description of the author's role in the research

The proposal was written by the author on the basis of the preparatory work carried out jointly with Kate Smith, who had also worked with the author on the study on Patients' Perspectives on Primary Care. At the outset the project was led by the

² In this context the term 'consumer' refers to both service users (patients) and general practitioners

author, with Kate Smith and Judith Scott employed as half time researchers. Half way through the project, Kate Smith left to take up a lectureship and was replaced by Linda MacLeod.

All the interviews were carried out by Kate, Judith and Linda. The management of field work at the outset of the project was that it be divided equally between Kate and Judith who would both interview general practitioners and patients and each would follow-up the respondents they had initially interviewed. Linda joined the project before the first stage of fieldwork was completed, carrying out some the initial interviews with both general practitioners and patients. Kate wrote to the people she had interviewed before she left, explaining that Linda would be contacting them instead to carry out follow-up interviews.

As lead researcher I had jointly managed the project with Kate until she left, carrying out some pilot interviews, developing the topic guide, establishing project administration and providing training and support in interviewing to Judith. Although the intention was that Kate would continue to have an active involvement in the research in her new post, this was practically not possible. The overall effect was to change the level of seniority of the team substantially. Instead of two experienced researchers with relevant methodological and theoretical backgrounds (one of whom had a half-time commitment to the project) working with one much less experienced researcher, there was one experienced researcher working with two very much less experienced researchers. The overall effect was that there was insufficient time to develop the analytical skills, the substantive and theoretical

knowledge of the researchers in order to complete the analysis within the time limit of the project. Although there had been regular team meetings throughout the project to discuss themes and issues emerging from the data, these discussions were very preliminary. As both Judith and Linda had to take up other jobs, the analysis has been carried out by the author after completion of the fieldwork.

Introduction to the structure of the thesis

The main influence on the structure of the thesis is the study methodology. As such, a brief introduction to the methodology is required here. More details are given in chapter six on the study design, methodology and the fieldwork process.

The study drew on a number of inter-related methodologies, including that of grounded theory, that is, developing middle range theory or explanatory concepts from inductive analysis of the data (Glaser and Strauss, 1969). An important aspect of this approach is the inter-relatedness of inductive data analysis and theoretical exploration in an iterative and reflective research process, termed by Blumer (1969) a process of theoretical inspection. A consequence of this approach is that the scope of the relevant theoretical literature cannot be specified at the outset. This has implications for the scope of literature review, for the presentation of the literature reviewed and for the presentation of the development of theoretical perspectives and applications.

In terms of the scope of the literature reviewed, the effect of this iterative process

has led the review through four distinct but related areas. As indicated above, the literature review process started with a preliminary review of health services research on chronic pain and of the sociological and anthropological research on chronic pain. The work on the sociology and anthropology of chronic pain was seen to be based upon two distinct, but methodologically related, strands of sociology: the sociology of chronic illness and the sociology of medical work. Thus in the in the coming thesis, chapters on the sociology of chronic illness (which is a sociology of lay experiences of living with chronic illness) and the sociology of medical work precede the chapter reviewing the sociology and anthropology of chronic pain, setting the wider theoretical context for this work.

The study methodology has also influenced the presentation of the literature reviewed. The overall aim of the reviews contained in these three chapters is to map the theoretical and conceptual terrain for the analysis of data which follows, not to build an argument for using specific theories or concepts in analysing the data. Within the reviews of these areas attention has been given to themes and perspectives which emerged from the process of interaction between theoretical reflection and inductive data analysis as being of potential interpretative value.

A final effect of the process of theoretical inspection has been to influence the presentation of the development of theoretical perspectives within the thesis. The usual style of presenting the full theoretical context in the chapter or chapters reviewing the relevant literature at beginning of the thesis is arguably inappropriate in this methodological context. The strategy adopted in this thesis has been to

introduce the relevant theoretical perspectives in broad terms prior to presenting the analysis of the data, but to expand on key theoretical perspectives in the final chapter, following the presentation of the analysis of the data. This is intended to reflect the iterative process more accurately and should mean that reader is able to see the relevance and application of the theory more clearly once familiar with the data.

The overall structure of the thesis is as follows. Chapters two to five review the relevant literature. Chapter six contains a description of the study design and methodology. It also describes how the process of data analysis and methodological considerations led to separate analyses of the interviews with general practitioners and patients. There is further theoretical reflection upon this issue in the final chapter of the thesis. It is mentioned here to introduce the structure of the four chapters presenting the analysis of the data: chapters seven and eight present the analysis of the interviews with general practitioners and chapters nine and ten present the analysis of the interviews with patients. The final chapter revisits the main theoretical perspectives used in the interpretation of the data and draws together the methodological issues and the implications for the provision of health services. A description of the contents of each of the chapters is given below.

Chapter two reviews the literature relevant to understanding health service management of chronic pain. It begins with an overview of the problems that chronic pain presents for the health service, including the problems of defining chronic pain and of the problems of the current structures of service provision for

people with chronic pain. A history of physiological models of pain describes the aspects of the experience of pain, or presentation of pain, which these models sought to address and the implications of these models for treatment and intervention. The principal interventions or treatments are described in sections on the pharmacology of pain and psychological approaches to pain management.

This 'health services research account' of chronic pain formed the basis of the original research proposal and sets the context of 'received medical or clinical knowledge' which health professionals, if not lay people, may draw upon in discussing their experiences. The presentation of the data in later chapters assumes some knowledge of aspects of this account, as did the respondents themselves. Thus, for example, the summary of the pharmacology of pain is intended to provide the reader with relevant background to the analysis of general practitioners' accounts of prescribing. It may be helpful to re-read this short chapter prior to reading the chapters presenting the analysis of data.

Chapter three contains a theoretical survey of sociological studies of medical work in order to set the relevant theoretical context for the research on medical work in chronic pain management reviewed in chapter five. It reviews theoretical analyses of the epistemology of medicine as well as empirical research on the nature of medical work carried out in a range of health service settings, including general practice.

Chapter four reviews work on the sociology of chronic illness and on theories of self

and identity. This provides an introduction to the methodologies and concepts within this field which have informed both the research on the experience of chronic pain and the lay evaluation of health care reviewed in chapter five and the methodology and analysis of the interviews with people experiencing chronic pain in the current study. Particular consideration is given to concepts of self and identity in the context of the sociology of chronic illness as a basis for critically reflecting upon the potential of wider theories of self and identity to contribute to this area of work and to this thesis.

Chapter five reviews research on the sociology and anthropology of chronic pain. The chapter comprises two main sections structured to parallel the areas of work reviewed in chapters three and four respectively, setting work on chronic pain in the wider contexts of the sociology of medical work and the sociology of chronic illness.

It is perhaps worth highlighting one of the main conclusions of the literature review as a whole here: that there has been no sociological research on general practitioners' and patients' experiences of chronic pain management in the context of primary care.

The study design, methodology and research process are described in chapter six. It addresses the following aspects of the research process: the local health service context and sampling sites; the process of sampling and recruiting respondents; the

characteristics of participating respondents; the methodology of the study and the theoretical and substantive interests informing this; the development and content of interview topic guides, the process of interviewing and, finally, an overview of the process of analysing the data.

The analysis of the interviews with general practitioners is presented in chapters seven and eight. Chapter seven contains an analysis of general practitioners' accounts of the overall process of working with people with chronic pain, describing the development of a model or 'ideal type' of general practitioners' accounts of their work with people with chronic pain. The analysis draws attention to the construction of chronic pain and people with chronic pain as part of a process which is represented analytically in terms of two phases, indications of transition between the two phases and areas of work which are on-going throughout. Chapter eight explores two aspects of accounts of this process, referral and prescribing medication, in more detail. The analysis of each of these areas is underpinned by the analysis of accounts of the process as a whole presented in chapter seven.

The analysis of the interviews with patients is also presented in two chapters. The first of these, chapter nine, presents an analysis of the experience of chronic pain in everyday life, the experience of chronic pain in social context and the processes of self-management including an exploration of respondents' understanding of terms such as coping, accepting, getting on with things. Taken together these form the analytical framework based on concepts of management of self and threatened

identity for interpreting respondents' accounts of their interactions with the health care system. The initial task of chapter ten is to illustrate the application of these concepts in the interpretation of respondents' accounts of their experiences of health services. The themes raised in this section of the chapter are revisited in the two later sections which consider respondents' views of general practice and hospital services.

The concluding chapter of the thesis seeks to place the analyses of the interviews with general practitioners and patients in wider theoretical context and to draw out the methodological and health service implications.

Chapter Two: Chronic pain management in the health service

Introduction

This chapter presents a 'health services research account' of the management of chronic pain. Its purpose is to contextualise the health services research agenda of the thesis by providing the reader with a summary of received knowledge about chronic pain management within the health service.

This 'health services research account' reflects the content of a substantial number of introductory texts, review papers and the structure of more in-depth specialist texts or collections of papers surveyed (Fairley 1982; Chapman 1984; Keefe et al. 1992; Working Group of National Medical Advisory Committee 1994; Large 1996; Williams et al. 1997; Hopton et al. 1997; Horn et al. 1997; NHS Technology Assessment Programme 1997; Nurmikko et al. 1998; Smith et al. 1999). As such it introduces some of the 'formal' ideas and understandings of pain, chronic pain, its clinical management and treatments which a range of professionals and lay people can draw upon. Within this account chronic pain is constructed as fundamentally problematic in terms of clinical practice and in terms of service provision and delivery.

The chapter begins with an overview of the problems that chronic pain presents for the health service, including the problems of defining chronic pain and of the current structures of service provision for people with chronic pain. This is followed by a historical review of models of the physiological basis of pain, the

aspects of the experience of pain, or presentation of pain, which these models sought to address and the implications of these models for treatment and intervention. The principal interventions or treatments for chronic pain are reviewed in the two subsequent sections on the pharmacology of pain and psychological approaches to pain management. The chapter concludes with a summary of the implications for chronic pain management in primary care.

Chronic pain: the problem

Chronic pain is known to be a common problem bringing substantial individual, social and socio-economic costs. Establishing how much of a problem it is, even in simple terms of prevalence within the population is problematic, with estimates of the number of people affected ranging from 7.6% to 45% (Smith et al. 1999).

Chronic pain is seen as presenting medicine with a fundamental challenge, the subjective experience of chronic pain often being resistant to objectification either in terms of its visibility, classification or explanation. Although the experience of chronic pain is associated with many diagnosable chronic illnesses, it is also experienced by people when no identifiable physical cause can be found. The resistance of chronic pain to classification and to measurement is problematic in clinical practice and in terms of service management and administration.

Defining chronic pain

Defining chronic pain has been problematic. Some research has used site of pain as

a means of classification. The commonest sites of chronic pain in the community are: limbs and joints, which account for around half of all cases, and the back which accounts for around a third (Smith et al. 1999). Classifications based on diagnosis are inherently problematic, as there is often no detectable underlying pathology. A further problem with both site and diagnostic classifications is that patients often experience pain in more than one site or may have more than one diagnosis.

Other attempts to define pain have been based on understandings of the underlying physiological mechanisms of pain described below. Thus early attempts at defining pain were related to understandings that there must be a cause of the sensation of pain, whether this be physical or psychological, or in definitional terms organic or psychogenic (Large 1996). With the advent of the Gate Theory of pain, there came recognition of the problems of this classification, principally that it led to unhelpful concerns in clinical management about whether the pain was a result of depression or the cause of depression.

Current formal definitions of pain seek to construct pain as an experience rather than a sensation and regard the patient's report of pain as fundamental. Thus the definition of the International Association for the Study of Pain (IASP) of pain is "an unpleasant sensory and emotional experience associated with actual and potential tissue damage, or described by the patient in terms of such damage" (Merskey 1979). This definition is followed by a note that pain is always subjective. Chronic pain is described as "pain which has persisted beyond normal tissue healing time",

taken to be three months in the absence of any other criteria, a definition which seems anomalous in the context of the explicit recognition that pain is not always associated with tissue damage.

Service provision for people with chronic pain

The development of specialist services for people with chronic pain is relatively recent. Pain clinics were very rare until the 1950s when the management of intractable pain emerged as a ‘natural extension’ of the specialty of anaesthetics (Kugelmann 1997). The development of specialist management of intractable pain was based on the administration of narcotic and analgesic drugs along with ‘new’ interventions such as nerve blocks and nerve sections which lay within the field of anaesthesiology. Nerve blocks and nerve sections were indicated by developments in the physiological understanding of pain, though as described below, the concept of ‘stopping pain signals getting to the brain’ by severing the relevant nerve, has come to be seen as somewhat naïve.

In the UK, as in the US, specialist services for the management of chronic pain developed rapidly during the 1970s and 1980s (Davies et al. 1992). Though the changing physiological models of pain, described below, can be seen to have opened up the field of pain management to a range of disciplines and therapies, the development of services within the UK National Health Service (NHS) has been, and remains, predominantly anaesthetist led.

Moreover, much of the development of specialist services for chronic pain can be seen to have emerged incrementally, without a significant program of investment and often dependent on the interests, enthusiasm and ability of specific individuals to appropriate marginal resources. The history of service provision in the local health board area of this study, described in chapter six, provides concrete illustration of this pattern.

As a consequence of this incremental development, the services which emerged are characterised by diversity in terms of structure, resources, range of treatments offered and the range of health service disciplines involved the overall approach to pain management (Crombie and Davies 1991; Csordas and Clark 1992). Moreover, research in the UK has shown that amongst hospital specialists there is little consensus on broad approach or on the effectiveness of specific clinical interventions (Davies et al. 1991).

Although within the health service specialist chronic pain management is still predominantly based on the work of anaesthetists, multi-disciplinary pain management programmes are now an integral, if not the preferred, mode of care provision. These programmes typically combine a range of therapies including psychological techniques, physical therapies (physiotherapy and occupational therapy) if not complementary therapies such as acupuncture, hypnotherapy, osteopathy or chiropractice. Access to such programmes is restricted as the number of programmes in the UK is relatively small (Working Group of the National

Medical Advisory Committee 1994).

Although there has been a recent upsurge of interest within the health service on the management of chronic pain, the problems of definition described above means that there is little basic epidemiological information upon which to begin to assess the adequacy of service provision. Most people seeking medical help for chronic pain will be seen in primary care, although what proportion of the community population seek help is difficult to determine. It is likely that only a small proportion of people who seek help from primary care for their chronic pain go on to receive specialist intervention, there is no routine information available to assess this (Potter 1989). Similarly, little is known about the pathways patients take to receive specialist treatment for chronic pain, although it is known that before referral to specialist clinics many people have been referred to a variety of medical specialties.

The history of physiological models of pain and chronic pain

The following historical account of physiological models of pain and chronic pain is presented to familiarise the reader with some formal understandings of pain and chronic pain which may have become part of the applied clinical and social knowledge (Moscovici 1981) which professionals and lay people can, and do so in this study, draw upon.

It also forms the background for the social constructionist analyses of theories of

pain and its management considered in the forthcoming chapter on the sociology and anthropology of pain. These include the discourse analyses of Vrancken (1989) who describes how the different models and theories are used in accounting for practice. It also includes that of Kugelmann (1997) who examines the metaphors and symbolism of one aspect of this account, the Gate Theory, and its social and professional uses which “put an array of professionals at the gates to subjectivity, to colonize and reform it”.

The development of the understanding of the physiology of pain can be summarised in terms of three principal inter-related theories or models (in chronological order): specificity theory, patterning theory, and the Gate Theory.

Specificity theories of pain can be seen as being based on Descartes’ descriptions of pain responses, and related to this, the Cartesian dualist philosophy of body and mind. Descartes’ observation that pain is evidenced by bodily withdrawal from a noxious stimulus led him to suggest that receptors at the point of stimulation passed information via a pathway to a pain centre in the brain, leading to experience of pain and thereby to movement away from the stimulus. Modern specificity theories were dominant between the middle of nineteenth century and the beginning of the 20th century, however even until the mid-1960s much work on the neurophysiology of pain was based on neural analogies of this model. Research tried to isolate neural receptors and pathways via the spinal cord that were specific to pain, that is, pathways which did not transmit other kinds of sensory information such as warmth. There were also attempts to ascribe even greater specificity, by considering

different receptors and pathways for different types of pain and a differentiation between A-delta fibre pain and C-fibre pain (sharp versus dull) as opposed to simply A-delta transmission.

It is important to delineate some of the basic assumptions implicit in this model. The model implies the presence of a noxious stimulus and related to this that the experience of pain has a signalling function that produces an adaptive response. It is also a spatial model in that it assumes that pain is felt at the anatomical site of stimulation. Moreover it assumes a direct and invariant relationship between a type of stimulus and the sensation felt, with no consideration of how the pain or experience of pain might be modulated, let alone interpreted, by other factors. In particular, the model was exclusively physical and thereby produces the possibility of a distinction between real and 'unreal' pain, or in clinical terms, organic versus psychogenic pain.

In these respects there are several types of cases of pain that this model could not easily account for. It could not account for 'phantom limb pain' or any persisting pain without injury or organic cause. The construction of a category of pain, that of pain of psychogenic origin, accommodated this apparent discrepancy. More problematic discrepancies were cases of people who did not feel pain despite obvious severe injuries, such as soldiers injured in battle, and people with a clinical condition which meant that they were incapable of feeling pain although with apparently normal nervous systems.

Pattern theories of pain can be seen as attempts to adapt specificity models in order to accommodate some of the 'anomalous' cases described above. Pattern theories proposed that the sensation of pain resulted from spatial and temporal patterns of neural transmission rather than transmission of information via pathways specific to pain. A central summation process of neural information was proposed such that information was only transmitted to the brain if the information at the dorsal horn in the spine exceeded a threshold. Thus, although these models made the important step of acknowledging that a simple linear causation model is inadequate, the models did not take account of evidence of receptor specificity and did not ascribe an active role for the brain. Neither did these models offer an explanation for how psychological factors might be important. Although early pattern theories were superseded by the Gate Theory described below, with some interpreters claiming that this led to a paradigm shift (Kugelmann 1997), the importance of neural patterns does form a crucial part of current thinking (Nurmikko et al. 1998).

The developers of the Gate Theory, Melzack and Wall (Melzack 1973) analysed the strengths and weaknesses of existing research and models. They identified that a comprehensive theory of pain must be able to account for a number of phenomena including clinical observations of the spread of pain and pain without physical cause and the influence of psychological processes on pain perception and response.

To accommodate these parameters they proposed a model that suggested pain fibre transmission is modulated at the base of the spinal column by a 'gate' that controls signals to the brain stem and cerebral cortex and thereby the degree to which pain

is felt. The crucial difference from existing theories was the suggestion that the gate may be opened or closed by descending signals from the central nervous system as well as from ascending signals from peripheral nerves. In proposing a role for descending signals, the Gate Theory was thus able to provide a basis for the impact of psychological factors such as anxiety, attention, memory, depression on the experience of pain. In doing so, it also provided a holistic model that legitimated a multidisciplinary approach to clinical practice in the management of chronic pain.

Over the last decade a new paradigm has emerged. Whereas previous models attempted to explain all pain, or pain generally, a distinguishing feature of current thinking is the emphasis on understanding the mechanisms of chronic pain in contradistinction to the mechanisms of acute, intermittent or continuing pain. A key element of this is new recognition of neural plasticity, that is that the nervous system is not 'hard wired' but adapts and develops. In particular chronic pain has come to be seen as an emerging process and neurological changes, which persist, can be seen to account for pain which persists after healing or with no apparent physical cause, as this recent summary describes:

"The most important clinical development in chronic pain during the past decade has not been new treatments but a thoroughly revised interpretation of the mechanisms that act to maintain pain. Pain is no more seen as a predetermined result of simple activation of certain neural structures. It is now understood to be a dynamic phenomenon due to myriad patho-physiological changes in the peripheral and central nervous system in response to disease, injury or loss of function. These changes reflect the surprising but indisputable fact that the human nervous system is adaptable and capable of substantial plasticity. Initially reversible, the changes tend to become fixed depending on the nature and duration of the original cause, as well as the age of the patient and perhaps the genetic susceptibility of the patient. In chronic pain the abnormal activity in the altered mediating afferent system continues irrespective of its original

causation.” (Nurmikko et al. 1998)

Within current understanding, some elements of previous models have persisted, for example the concept of descending factors has been supported and elucidated by the isolation of endogenous opioids produced by the central nervous system in response to painful stimulation, described below.

A key issue implicit in this historical account of the physiological understanding of pain foreshadows issues emerging in later sections of this thesis: the models are continually evolving and as such there remains some difficulty in providing a physical explanation of pain, particularly chronic pain, in a clinical context.

The pharmacology of pain

Much of the development of physiological models of pain can be seen to have trailed behind clinical evidence and practice in its attempt to provide explanations for ‘anomalous’ cases. In contrast, developments in understanding the pharmacological basis of pain can be seen to have followed expedience, seeking post-hoc explanations of the mechanisms underlying the treatments which were being used to relieve pain (Fairley 1982; Budd and Price 1994). To quote a recent clinical review of management strategies for pain:

“The standard analgesics are still variations on willowbark (non-steroidal anti-inflammatory drugs, NSAIDs) and poppy (opioids).”
(Justins 1996)

Opium is known to have been used for the alleviation of pain since the 3rd century

BC (Horn and Munfano 1997) and willowbark since the late 18th century. Thus much scientific and commercial endeavour has attempted to isolate the active compounds, to understand their action in pharmaco-physiological terms and to manufacture and market synthetic equivalents in order to reduce the side effects of natural products. The main concepts and developments in pharmacology which are relevant to understanding current clinical practice are described below.

The history of opioid use has been particularly interesting. Despite its long use, the underlying mechanism was not understood until the 1960s when endogenous opioids, produced by the central nervous system in response to painful stimulation, were identified. Compared with the use of NSAIDs the use of opioids has been controversial in the management of pain because of the risk of addiction, and a brief overview of some of the controversies follows.

The development of palliative care has had a major influence on the debate about the use of opioids. In terminal illness the primary goal of care is clearly seen as the relief of suffering, with the risks of addiction and side effects being secondary to this goal. Chronic non-malignant pain presents a different context for evaluating the relative priorities and risks associated with drug therapy and the use of opioids in this context has been much more problematic (Justins 1996; Williams and Erskine 1997; McQuay 1989; Portenoy 1990; Portenoy and Foley 1986). Research has shown that the risk and incidence of iatrogenic addiction to opiates is low, suggesting that an over cautious attitude to the use of opioids may deny some patients optimal pain relief (Morgan 1989). Moreover it has been suggested that

the unnecessary avoidance of addiction has led to 'under-prescribing' which in turn leads to 'pseudo-addiction' whereby the patient's behaviour and demands for increased medication appear similar to those made by opiate abusers (Weissman and Haddox 1989).

In terms of the general pharmacology of pain however, there remain two principal types of analgesic medication (opiates and NSAIDs) both of which have side effects, despite efforts to produce new compound variations which minimise these. There has, however, been substantial development in the use of co-analgesic medication, principally the use of anti-depressants and anti-convulsants. Again it could be argued that the paradigm shift which the Gate Theory brought also opened up the possibility for indirect pharmacological action on pain. That is, if the physiological model provided an explanation for how, via descending pathways, anxiety and depression as physiological states could influence or exacerbate pain, then this presents the possibility of pharmacological action to reduce anxiety and depression thereby reducing their effect of exacerbating the pain.

A further significant advance has emerged from the development of palliative care: the production of a formal framework for the pharmacological management of pain relief, 'the analgesic ladder', which comprises a systematic approach to progressively increasing levels of analgesia along with an active approach to the use of co-analgesia. A simple representation of this approach is given below.

Figure 1 The World Health Organisation analgesic ladder

Step 1	non-opioid +/- adjuvant therapy
Step 2	weak opioid + non-opioid +/- adjuvant therapy
Step 3	strong opioid + non-opioid +/- adjuvant therapy

Within current models of the use of co-analgesic medication, particularly the use of antidepressants and anti-convulsants, there remains some debate about the specificity of these treatments with different types of pain (anti depressants being thought to be more effective for burning types of pain and anti-convulsants for shooting types of pain) (Justins 1996), although this assumption has recently been disputed by a study which showed that both types of pain responded to tricyclic anti-depressants (McQuay and Moore 1997). The now routine use of anti-depressants in chronic pain has brought ambiguities in the clinical and social meaning of their use as the data from this study will illustrate³.

³ Though anti-depressants have an analgesic effect an important clinical issue is whether this is separate from the antidepressant effect as it occurs with lower doses. To put this the other way round, doses of anti-depressants appropriate for the management of pain may seem to be 'sub-therapeutic' for the management of depression. In this context then, anti-depressants may not simply alleviate pain by alleviating depression that might be exacerbating that pain.

Psychological approaches to the management of chronic pain

Given psychology's aspiration to be a science, with the term science referring to models of what constitutes science implicit in the natural sciences, there has always been a biological or physiological perspective within the discipline (Beloff 1973). As described above, the Gate Theory, with its emphasis on descending as well as ascending modulating systems can be seen to have opened the realm of clinical pain management to psychology (Kugelmann 1997) by offering a physiological perspective.

The impact of psychological approaches on the management of chronic pain have been substantial, leading one review in a health psychology text book to claim that “psychologists have contributed more to the understanding of chronic pain and its management than any other single medical specialty” (Williams and Erskine 1997). From psychology, two theoretical perspectives, behaviourism and cognitivism, have formed the basis of therapeutic approaches, broadly described as behaviour therapy and cognitive-behaviour therapy, to the management of chronic pain.

Behaviourist approaches to pain management can be seen to have had their most identifiable impact on the management of pain, particularly chronic pain, in the work of Fordyce (1976). In broad terms, behaviourist approaches emphasise the importance of studying patterns of environmental stimuli and the behavioural responses with which they are associated, and how these stimulus-response pairs come to be conditioned, that is, learned or modified by re-learning. Consideration of the nature of the physiological or cognitive mechanisms which underpin the

observable stimulus-response associations is not directly relevant to this model of behaviour although they are implicit in it. As such, a frequent summary criticism of behaviourist theory is that it treats individuals as 'black boxes' and, implicitly, all behaviours as unconscious reflexes. In this context it has been suggested that behaviour therapy of pain is merely 'a warmed over sensation theory' (Kugelmann 1997) implicit in specificity and pattern physiological models.

Another, but perhaps more positive, interpretation of this aspect of the behaviourist approach is its recognition of subconscious or unconscious learning and its ability to manage or shape unconscious behaviour. It is perhaps worth making explicit here that the term 'behaviour' can include social behaviour, illness behaviour (such as taking medication) and physiological responses such as the tensing of muscles in response to pain.

Within the broad approach of behaviourism there are two different models of conditioning (learning): classical and operant conditioning. Classical conditioning can be described as learning by association. In contrast, operant conditioning considers learning through consequences, such that responses followed by rewarding consequences will be strengthened whereas those followed by unpleasant consequences will be weakened. It is from models of operant conditioning that the concept of 'secondary gain', whereby indirect consequences of behaviour provide sufficient reward to sustain the behaviour is derived. In the context of chronic pain management then, the goal of behaviour therapy can be seen to be to reduce dysfunctional illness behaviours and to increase behaviours which enable a return

to more normal life without explicitly attempting to address the cognitive or affective aspects of the experience of pain.

In contrast, to the 'black box' approach of behaviourism, cognitive behavioural approaches attempt to change behaviour by addressing and changing attitudes, thoughts and feelings. Cognitive-behavioural models can be seen to have physiological equivalents in the recognition of the importance of descending signals and neural plasticity in neuropsychology generally, but here in the emergence of the Gate Theory of pain and in models of the mechanisms of endogenous opioids. The term 'descending' refers to neural signals originating in 'higher' levels of the central nervous system and the brain. Thus 'higher' mental processes were seen to have an impact on perception of the level of pain and a potential physiological basis for this could be seen to lend greater legitimacy to psychological approaches. Cognitive behavioural approaches therefore cover a range of 'cognitions' such as attitude, thoughts, beliefs, sense of self worth or self efficacy.

To make the application of these theories in clinical practice more concrete, behavioural approaches may include periods of activity and rest on specified or time contingent schedules as well as goal setting and pacing. They also include techniques such as biofeedback (feedback on measures of physiological responses such as electromyographic activity) to train patient to control apparently involuntary responses. Partners or family members are sometimes included in behavioural therapy on the grounds they may be maintaining or reinforcing certain behaviours. Cognitive-behavioural approaches would include education about the

mechanisms of pain, challenging the idea that pain necessarily means harm, developing positive thinking and avoiding negative thinking or 'catastrophising' and developing effective coping mechanisms, such as assertiveness training.

Summary: chronic pain management in primary care

This chapter has described the history and the current context of health service provision for people experiencing chronic pain. Most health service care for people with chronic pain takes place in primary care (Potter 1989). Specialist services are characterised by diversity in structure and clinical practice.

There has been little research on chronic pain in primary care, in part perhaps, due to an enduring methodological problem of the absence of an epidemiology of chronic pain. In this context there is a clear need to begin to understand how some of the complexities and uncertainties in formal knowledge and service provision are interpreted and managed in primary care. The qualitative research described in this thesis aimed to open up this area of enquiry by examining the negotiation of these issues by general practitioners and patients.

Chapter Three: Sociological studies of medical work

Introduction

This chapter presents a theoretical survey of sociological studies of medical work in order to set the relevant theoretical context for the research on medical work in chronic pain management reviewed in chapter four. It also sets the analysis of general practitioners' work presented in this thesis in a wider theoretical perspective.

Given the apparent diversity of the references reviewed in this chapter, it is perhaps worth considering the review process. The starting point was that there has been little sociological research on the work of general practitioners with particular patient groups (McKeganey 1989) and as such, locating the current study within an existing substantive literature would be difficult. This is in part because the scope would be too broad. There has, after all, been a vast amount of health services research on general practice, including, mainly quantitative, studies of clinical management of specific conditions. Alternatively the scope would be too narrow to constitute a 'review'. McKeganey cites just twelve sociological studies of general practice, and only two of these are studies of general practitioners' work with specific patient groups.

In this context, the overall direction of this section of the literature review has been guided by the imperative of including studies which are based on sociological theories about medical work which are of potential relevance to the current project

or that use relevant methodologies. The review process has been one of following up references from papers reviewed, supplemented by a manual search of all volumes of *Sociology of Health and Illness*, the last 4 years of *Social Science and Medicine* along with other relevant papers from general reading. The studies reviewed cover theoretical social science analyses of the epistemology of medicine and its disciplinary construction and qualitative empirical studies of medical and clinical work carried out in a wide range of contexts but which fall within broad paradigm of interactionist medical sociology (Gerhardt 1989).

The chapter contains three sections. The first section reviews three analyses of the epistemology of medicine. Taken together the three reviews illustrate two underlying theoretical approaches to the social construction of medical knowledge, the ethnographic or interactionist approaches of elucidating practical knowledge and the discourse analytical approaches of analysing disciplinary power. Both of these theoretical approaches are evident in the empirical work reviewed in the subsequent sections of the chapter. Between them they challenge the dominant epistemology of medicine as that of theoretical, or formal, scientific knowledge which is morally and ideologically neutral. As such they offer a means of reconsidering the problems of inexplicable wide variations in clinical practice, and the failure to follow evidence based clinical guidelines. Indeed, the rationale for several of the empirical studies of medical work reported in later sections of the chapter is given as seeking to understand how these variations, or failures to comply with guidelines, arise.

The second section reviews empirical analyses of medical work carried out in a wide range of clinical settings. This allows further exploration of the application of the theoretical perspectives described in the first section and introduces the range of concepts and themes which characterise this area of research.

The final section reviews sociological studies of the work of general practitioners. It begins with a review of the methodological issues before considering four empirical studies which illustrate theoretical and substantive issues of direct relevance to the thesis.

Analyses of the epistemology of medicine

Three analyses of the epistemology of medicine are described below. Two of them are closely related. The analyses of Gordon (1988a) and Schon (1987, 1992) are both set in the context of the debate about medicine as an art or science, or between clinical science and clinical expertise. The third analysis is Armstrong's Foucauldian analysis of changes to the disciplinary basis of medicine (Armstrong 1984, 1987).

Gordon set her analysis within the current emphasis on evidence-based medicine and calls for clinical practice to become more scientific. She describes "art" and "science" as the two metaphors of clinical knowledge, both of which can be seen to have acted as "shields" to the autonomy of individual clinicians and to the status of the medical profession respectively. As she puts it, "hiding much that is not very scientific nor very artful". Gordon's argument then is that there is a need to

understand better the strengths and limitations of both clinical science and clinical expertise, or of their metaphorical analogues, of art and science, analysis and intuition.

In considering in more detail the calls for clinical knowledge to become more scientific, she identifies two approaches to this. The first, described under the heading of clinical epidemiology, seeks to develop “clinical science” to form the basis of medical practice. The second, described under the heading of medical decision making, aims to subject clinical judgements to scientific scrutiny with a view to making them more rational, explicit and formal.

The attempts of medical decision making to make clinical judgement more rational can be seen as falling within an Enlightenment model (Strong 1980), one which reflects a particular approach to knowledge and a particular model of the person (Chapman and Dylan 1980), that is, cognitive and rational. Within this model, the assumption is that in clinical practice physicians behave like scientists collecting data, analysing it, and then making a diagnosis.

Gordon then develops her analysis of these scientific approaches to medicine by drawing out contrasts with paradigms which emphasise the importance of practical knowledge, skill and expertise. Practical knowledge is described as embodied know-how that derives from acting in concrete situations and learning from their outcomes and from skill acquisition. Thus whereas the rational-cognitive approaches imply that knowledge can be broken down into the component parts of

a decision making process, models of practical expertise emphasise that many skills, such as riding a bike, do not require thinking, calculation or reflection. Furthermore, practical knowledge is embodied, sensed through touch, sight, sound and smell as well as the emotions. Thus it can be seen to encompass intuition, feeling that something is right or not right such that situations are understood or grasped in an instant and as a whole. Following from this, practical knowledge is intrinsically linked to meaning and context.

Schon's (1987, 1992) analyses of the need to develop reflective practice and of the crisis of professional knowledge are similarly contextualised in the opposition between art and science. Schon constructs the crisis in professional knowledge as arising from the dogmatic pursuit of rational scientific practice and the consequential revelation of its inadequacies in necessarily complex and uncertain situations. He describes this as forcing clinicians to choose between the "high ground" of science and the "swampy lowland" of clinical practice. Schon, too, emphasises the importance of 'grasping situations' as whole and the irreducibility of skill to 'describable routines', noting that the process of constructing solutions is also a process of constructing the problem. His analysis of the artistry of clinical work is that of "trial and error reflection in action which is smoothly embedded in performance".

Schon's argument is more an argument from within clinical practice than from without, based much less on sociological or other theory than that of Gordon. As such his exploration and elucidation of 'artistry' is narrower, leaving him without a

means of incorporating the emotions, an aspect of 'art' which he sees as essential. However, his core argument is similar, that there is a need for a new epistemology of practice which does not leave clinicians having to choose between rigour and relevance.

In a series of related papers, Armstrong (1979, 1984, 1987) has used Foucault's genealogical account of the development of medicine to consider the relationship between power and disciplinary transformation, particularly in the context of general practice. Thus Armstrong refers to Foucault's account of the emergence of the clinic (Foucault 1976) in which the gaze of medicine shifted from its 18th century concerns with external, two dimensional patterns of tissues and symptoms towards a three dimensional map of the diseased human body. The person-subject featured little in this disciplinary paradigm, other than as a source of information about clues to the physical examination. The development of the social sciences and their appropriation by medicine can be seen to have introduced a further paradigmatic transformation, making the person a visible subject and extending medicine's disciplinary power (Widdicombe 1992) into psychosocial realms.

Armstrong (1979) suggests that this latter paradigmatic transformation has not occurred equally across medicine as a whole, leading to 'biopsychosocial tensions'. In particular, Armstrong argues that the rise of general practice as a specialty within medicine can be seen to have arisen through the construction of its interest in the 'biopsychosocial' patient, distinct from hospital medicine's emphasis on the objective bodies.

Armstrong's work has formed the basis for many discourse analyses of medicine, including several analyses of disciplinary transformation in the context of pain management which are referred to below (Baszanger 1989; Nettleton 1989; Dodier 1994; Kugelmann 1997).

The above analyses draw attention to two issues in the epistemology of medicine. Firstly, the dominance of models of medical practice based upon rational scientific decision making and, in contrast, the importance of theorising practical knowledge or skill which can incorporate routines and processes of trial and error, is embodied, emotive, intrinsically linked to meaning and context and not always accessible on reflection. Secondly, the importance of considering disciplinary power, particularly in relation to the power of constructions of the subject within the discipline of psychology, and of the disciplinary tensions which can exist between different areas of medicine. In short, that different disciplinary explanations within medicine have an ideological content.

Empirical studies of medical work

This section of the chapter reviews six observational studies of medical work carried out in a range of settings including ear nose and throat (ENT) specialities, community psychiatric nursing hospital casualty departments, medical specialties, coronary surgery and occupational medicine. All six draw on a range of theoretical perspectives contributing to the sociology of practical knowledge in everyday life.

The first three can be seen to emphasise the importance of routines, either directly in clinical practice, or indirectly in terms of the typifications of patients which in turn inform this practice. The second three, can be seen draw on a different aspect of the sociology of practical knowledge, emphasising the problematic rather than the routine nature of knowledge and adding analyses of discourse to emphasise the situational construction of practical understanding from diverse or patchy bodies of knowledge.

Routines and typifications in clinical practice

A study by Bloor (1976a, 1976b) used observational data gathered in outpatient clinics of 11 ENT specialties as a basis for exploring the wide variations evident in clinical practice. Bloor uses the phenomenology of Schutz to interpret his observations, drawing on Schutz' arguments that situations are determined by their relevance. In this context, the study focuses on the variations in observed routines used by different clinicians. Five parameters of variation were identified: the search procedures used to examine the patient, variation in decision rules about the importance put on examination findings as compared with the history, variations in the decision rules for history taking, variations in the decision rules pertaining to the history and variations in routines according to the age of the patient. Bloor makes the point that the variants of routines may be appropriate for each actor's purpose at hand. However, no explicit consideration is given to what these

purposes might be.

Bloor (1976b) also draws attention to the way that the routines, whilst serving the specialists' purposes, could serve to exclude clients from participating in decision making, such as inhibiting clients' agendas by closed questions and interruptions in the history taking. Bloor noted that where specialists did not use inhibitory routines in history taking, they tended to use reactive routines, forcing closure, in discussions about the treatment.

The work of Hak (1994), although not strictly within the scope of this review, is worth noting here. He explicitly challenges Bloor's and others analysis of dominance in terms of interactional structures, whether routine or otherwise. From his observations of interactions between psychiatric nurses and their clients, he argues that dominance resides in unequal access to each others objectives and perspectives rather than in access to conversational 'turns' or topics. However his overall conclusion, that whereas patients' knowledge of professional standards and objectives will vary considerably professionals have a "relatively complete understanding of what the patient attempts to achieve in the encounter", is to be considered with caution.

A number of studies have examined how doctors and other health professionals construct 'good' and 'bad' patients (Jeffery 1979; Strong 1980; Kelly and May 1982; May and Kelly 1983). In their review of the literature Kelly and May (1982) point

to the importance of interactionist analyses in understanding how patients come to be defined good or bad arguing that the process of definition arises from interactions between doctors and patients rather than because of anything inherent in patients themselves.

This perspective, along with the concept of typifications, informs their empirical study of psychiatric nurses' construction of 'problem' patients. They identified that "what is critical in determining nurses categorization of some patients as 'problem' is not so much the level or nature of patients' demands, but rather the patient's willingness to legitimate the nurses' therapeutic aspirations." May and Kelly also suggest that in the context of psychiatric nursing nurses do not possess readily available technical skills nor clear authority and as such interactions with patients are an important means of maintaining a viable professional identity.

An earlier study by Jeffery (1979) also illustrates these themes of analysis, examining typifications, or routine categorisations, of patients in an observational study carried out in accident and emergency departments. 'Good' patients were described by staff in terms of their medical characteristics, their symptoms or the causes of their injuries. Key criteria of being one of the good patients was that the patient, their symptoms or injuries either allowed staff in training to practice skills necessary for passing professional exams or allowed staff to practice their chosen specialty, or tested their professional competence.

In contrast, other patients were categorised as 'rubbish', though other terms could

be used to label this category. The rules broken by patients categorised as rubbish were as follows. Firstly, that patients must not be responsible either for their illness or for getting better. Secondly, that patients should be restricted in their reasonable activities by their illness or symptoms. Thirdly, that patients should see illness as an undesirable state and should co-operate in trying to get well.

Studies of knowledge construction and problem solving in clinical practice

Three studies draw on understandings of practical knowledge which emphasise the way that the process of knowledge construction draws upon a range a different types of information and theories.

In a participant observational study carried out as a houseman working in three specialties Berg (1992) begins from Knorr-Cetina's conceptualisation of scientists as practical reasoners, who "interweave cognitive, social and material elements on an ad-hoc, opportunistic basis". His primary interest is in the way that physicians solve ordinary problems and construct medical disposals, focusing on the transformation from patient problems to solvable problems. The term transformation implies a process in which the problem is remoulded, not so that the patient's problem is relieved, but so that the doctor has a limited set of actions which she perceives to be a sufficient answer.

Berg observed that the type of questions that physicians ask (of patients or of tests or examinations) are selected to produce the transformation that the physician has in

mind, thus pre-structuring the process. Where findings were contradictory, physicians were observed to put data aside as relating to a separate patient problem for which a different solvable physician problem has to be found.

Berg also observed the way that different kinds of information or data could be either down graded or up graded in the transformation process in relation to other influential sources of information such as patient characteristics, or availability of time. As Berg puts it “when time runs short during consulting hours, potentially time consuming historical or examination cues are often re moulded in favour of a more timesaving transformation.”

In general then, Berg suggests that there is no fixed hierarchy between different types of information and that structural and organisational factors can also lead to the reconstruction of medical criteria and disposal options. Whilst emphasising this transformational flexibility, Berg also reflects on the potential for medical practice to be in “utter chaos” and that physicians must have some frame of reference. Following Bloor (1976a, 1976b) and others, he suggests that the use of routines, would offer some order.

In a study of cardiac catheterisation case conferences, Hughes and Griffiths (1996) take an approach similar to that of Berg, drawing on the concept of clinicians as pragmatic actors rather than scientists. From observational and tape-recorded data, they describe the way that solutions (as to whether the patient is accepted for surgery) emerge from processes of negotiation amongst colleagues. A crucial aspect

of the study and the analysis is that it is set within the context of public debate about the denial of cardiac surgery to smokers and other patients with negative cardiac risk factors thus adding an explicitly socio-moral dimension to the problem solving process.

As such the processes of negotiation involved clinicians in reasoning within both clinical and everyday moral frameworks and drawing upon both technical assessments and social information. Hughes and Griffiths pointed to difficulties clinicians face in trying to reconcile themes and counter themes within the multiple discourses, including a wider socio-political discourse that ethnographic interactionist studies neglect.

Finally, Dodier (1994) carried out an ethnographic study of expert medical decisions in the field of occupational medicine. He used Goffman's concept of frames, as the means by which people organise their experience in social contexts, to analyse physicians' interpretations of their work with individual patients.

Dodier identified three basic frames: the clinical frame, the solicitude frame and the psychosomatic frame. In the clinical frame, the expert relies on her or his clinical viewpoint in judging the authenticity of complaints. In the solicitude frame, there are no medical proofs and as such the legitimacy of patients complaints is accepted unconditionally. The psychosomatic frame makes a division between the conscious and unconscious thus creating a new status for subjective complaints without any objective evidence, that is, that these subjective complaints require further

interpretation. In this frame doctors see psychological suffering behind physical complaints. There are, however, a number of different positions which doctors can adopt in relation to this. Thus, the clinical frame, in which the doctor distinguishes legitimate and illegitimate complaints according to diagnosis, can be introduced within the psychosomatic frame, with a psychiatric diagnosis indicating legitimacy. The solicitude frame can also operate within the psychosomatic frame.

Although the study was carried out in the context of occupational medicine, all the cases presented in the analysis are of people experiencing on-going pain. As such the study has direct substantive relevance to the thesis. The analyses of authenticity, subjectivity and objectivity within psychosomatic frames address key themes in medical work and chronic pain, reviewed in chapter five below.

Summary: the social construction of practical knowledge in medical work

The above studies provide concrete illustration of the processes of the social construction of practical knowledge in medical work and draw attention to the following key issues.

The studies illustrate the importance of considering medical work from the perspectives of routines and from the perspective of the construction of knowledge as negotiation and problem solving. The studies of routines in medical practice point to the potential importance of considering clinicians' motivations whether this be in terms of 'purposes at hand', therapeutic 'objectives' or 'aspirations', and the

importance of these professional motivations in constructing views of patients and the socio-moral status of patienthood.

The studies of problem solving illustrate that in practice clinicians draw upon a range of different types of knowledge, including both clinical and everyday common sense knowledge, and multiple discourses, including socio-moral and political discourses. The process of knowledge construction in problem solving is simultaneously a process of re-structuring or pre-structuring the problem. In this transformational process there is no fixed hierarchy of different types of knowledge, different types of knowledge can be used depending on the process of transformation, and on the structural, organisational and wider socio-political context. Though there is no fixed hierarchy of different types of knowledge, different explanations can have differential legitimacy and ideological content.

Sociological studies of the work of general practitioners

This section of the chapter reviews sociological studies of the work of general practitioners. As was noted at the beginning of this chapter, there have been few empirical sociological studies of general practitioners' work, fewer still of their work with particular patient groups and little attention has been given to general practitioners' understandings and perceptions of their own work. The first part of this section reviews the sociological neglect of general practice in terms of the wider debates within sociology and in terms of methodological issues. The second part of the section reviews four empirical studies, two are of the broad work of general practice and two of general practitioners' work with specific patient groups.

Sociology and general practice

This analysis of the sociology of general practice is based upon that of McKeganey who identifies two debates within the development of sociology which may have contributed to its relative neglect of general practice (McKeganey 1989). Firstly, he uses the analysis of Strong (1979a) to argue that sociologists have perhaps been more interested in studying general practice in terms of their own interests in the social processes of power, professionalisation, communication and social class. Secondly, he suggests that the commitment to developing an emancipatory sociology would mitigate against giving priority to work which could be seen to legitimate the position of powerful social groups. He notes that even sociological studies in medicine, which have sought to apply sociology to problems of general practice, have rarely considered general practitioners' work with specific patient groups. As McKeganey argues, there may be obvious methodological reasons for this.

The work of general practitioners is unplanned and diverse. As such observational work of care of specific patient groups would be difficult to schedule. Given the inability to predict which consultations would be relevant, the alternatives would be time consuming and costly, involving either waiting for opportunities or collecting data on a large number of consultations which would not be relevant. Moreover, an important element of general practice care is continuity, interactions with patients over a series of consultations and contacts.

Of the studies reviewed below, only that of Horobin and McIntosh (1983) which is concerned with general practitioners' management of time, is based on observational methods. The three remaining studies are based on interviews with general practitioners.

Empirical studies of the work of general practitioners

In an early study of general practitioners and communication, Comaroff (1976) carried out semi-structured interviews with 51 general practitioners and examined the common sense knowledge underlying their decision rules about choices of communication strategy with patients.

Comaroff sets her analysis in the context of practical knowledge or 'everyday decision making' in which actors assume future circumstances will be like those in the past and in which actors use 'rules of thumb' rather than 'rational' analysis. She also notes that in routine social situations actors may be equally concerned with justifying past actions as present and future ones.

Her exploration of decision rules highlighted the way that the general practitioners reconciled discrepancies between their behaviours and professional norms (medical text book statements) by referring to competing clinical priorities such as giving patients minimal facts in order to allay anxiety or because of pressure of time. She also noted that the general practitioners preferred to conclude consultations by telling patient's that their problem was something specific. She suggests (following

Scheff) that in the context of risk and uncertainty, the decision rule is that “to judge a sick person well is more to be avoided than to judge a well person sick.”

A further point raised by Comaroff was that of the variation in general practitioners' responses to the questions. That is, some general practitioners gave very short, straightforward or 'unelaborated' responses, whilst others went into considerable detail, or as she termed it, they gave elaborated responses. Her analysis of elaborate and restricted responses, with elaborate responses being those in which general practitioners described more varied types of patients, links two themes in the wider sociology of general practice. Firstly, the theme of general practitioners' different orientations to their work (Mechanic 1970). Secondly, their typifications or categorisations of patients. She concluded that general practitioners' communication strategies depended upon two factors: the complexity of their categorisation of patients and the range of potential courses of action they recognised.

In their study of the work of 50 general practitioners working in urban and rural settings Horobin and McIntosh (1983) explored the relationships between general practitioners' perceptions of time and risk and of the nature of routine medical work. Thus their study is set within the “complex economy of time and scarce resources” in which the work of general practice is accomplished. Their a priori analysis of risk is that, in contrast to Scheff (and Comaroff above), continuity of care in general practice means that it is plausible to gamble on the risk of something not being serious, that general practitioners can 'wait and see'. Their analysis

demonstrates the differences in the economies of urban general practice, where the relationship between time and risk is that of missing something in short, necessarily routine, consultations and rural general practice, where time is not experienced as a constraint but where limited access to immediate specialist help introduced a different meaning of risk.

The following two studies of general practitioners' work with particular patient groups are closely related. Both explore general practitioners' work with groups of patients with arguably social, as opposed to medical, problems. Strong (1980) analysed with general practitioners' accounts of their work with patients with problems of alcohol abuse and McKeganey (1989) examined general practitioners' work with opiate abusing patients. As McKeganey's analysis, like many of the studies of medical work described above, draws substantially on the earlier work of Strong, it is Strong's work which is considered in detail below.

Strong contextualises his study amid myriad research publications and strategy documents advocating rationalistic or Enlightenment approaches which argue that if only general practitioners were better informed about the nature of alcoholism they would feel less negative or reluctant about this aspect of their work. In contrast to these approaches he draws on Hughes' concept of 'dirty work' as work outside professional conceptions what the ideal or essential work of the occupation is or should be. Having confirmed, from his data, that general practitioners did see alcoholics as source of irritation, and noticed that they also saw alcoholism as a major social problem, he goes on to consider how they negotiate these two positions.

He describes how alcoholic patients can be seen to contravene the basic assumptions upon which general practitioners' ordinary relationships with patients were based. Firstly, the assumption of clinicians' having access to technical expertise did not apply in the context of alcoholism. Strong reflects that professional knowledge differs from lay expertise in terms of definitions of allowable ignorance, that is, that knowledgeable professionals should be able to define what they do not know as well as what they do.

Moreover, the social nature of alcoholism could be seen to contravene the assumption that the focus of medicine is on the 'natural sphere', that is, it deals with naturally occurring diseases in patients' bodies. Strong draws on his earlier comparative work on the ceremonial orders of clinics (Strong 1979b) to suggest that the assumption that medicine focuses on the natural is maintained by both patients and doctors in the traditionally 'bureaucratic mode' of doctor-patient interactions within the UK health service. In this context, moral issues of personal responsibility can be set aside. In the context of alcoholism, the issue of patients' responsibility, "defective will and good character" were core aspects of inspection.

Finally, defining alcoholism was problematic as it necessarily involved placing drinking in the context of other problems. Drinking patterns did not necessarily constitute alcoholism unless they were problematic. If they were problematic further consideration had to be given to other problematic aspects of patients' lives, and whether patients themselves considered their drinking to be problematic. As

such it was difficult to identify the 'real' problem.

As described above, McKeganey's (1989) analysis of general practitioners' accounts of their work with opiate abusing patients overlaps substantially with the issues identified by Strong. McKeganey describes the range of medical, commonsense and ethnographic knowledge which the general practitioners used in the identification and diagnosis of opiate abuse. The analysis identified the particular problem faced by general practitioners in enquiring about the possibility of abuse without offending the patients, referring to Strong's analysis of the 'bureaucratic mode' of medical consultations and clinicians' avoidance of moral or 'character work'. General practitioners' work necessarily involved the questioning the authenticity of patients' symptoms. This issue is of direct substantive relevance to this thesis as often patients' symptoms were of pain, and general practitioners needed to ensure that medication prescribed for pain relief was not being abused. As such, 'character work' could not be avoided.

Summary: sociological analyses of the work of general practitioners

The sociological studies reviewed above fall within the broad paradigm of the social construction of practical clinical knowledge. They draw attention to aspects of the structure of general practice and the content of general practitioners' work which have methodological and theoretical implications: firstly, the diverse and unpredictable nature of the work in general practice; secondly, the importance of interactions over a series of contacts or consultations; thirdly, the management of

time and the management of risk and finally, the problems of work which demands engagement with wider socio-moral issues and the distribution of responsibility.

Chapter Four: The sociology of chronic illness and theories of self and identity

Introduction

This chapter reviews work on the sociology of chronic illness and on theories of self and identity.

The review of the sociology of chronic illness is intended to serve two purposes. Firstly, it introduces the methodologies and concepts of the sociology of chronic illness which have informed the work on the experience of chronic pain and the lay evaluation of health care reviewed in the following chapter as well as informing the methodology and analysis of the interviews with people experiencing chronic pain in the current study. Secondly, the review gives particular consideration to concepts of self and identity in the context of the sociology of chronic illness as a basis for critically reflecting upon the potential of wider theories of self and identity to contribute to this area of work and to this thesis.

The chapter comprises three sections. The first section provides a critical review of the sociology of chronic illness. It begins with a survey of its broad themes, methodologies and concepts. The thematic emphasis on the importance of process is used as a basis for structuring a more detailed review of the field based upon four inter-related conceptualisations of processes: illness trajectories, biographical work, adaptation and, finally, identity work and management of self. The second section

provides a selective review of theories of self and identity drawn principally from discursive social psychology. The final section provides a summary which identifies outstanding issues and problems in the field of the sociology of chronic illness and points to the potential contribution of wider theories of self and identity to address these problems.

The sociology of chronic illness

Overview of the sociology of chronic illness: themes, methodologies and concepts

In order to condense a now extensive literature on the sociology of chronic illness the forthcoming summary is based primarily on a number of key review articles and text books: review articles by Gerhardt (1990) and Conrad (1990) in a special issue of *Social Science and Medicine* on qualitative research on chronic illness; reviews by Bury (1986; 1991); Kelly and Field (1996) and Williams (1996) with books by Anderson and Bury (1988) and Thorne (1993).

The sociology of chronic illness as a field within the sociology of health and illness can be characterised, and frequently is so, in terms of its origins and its dominant methodological approaches as well as some core concepts. The emergence of the sociology of chronic illness as a field of research has been linked to several key crosscutting themes, each of which can be seen to have had enduring implications within this area of work. Firstly, changing patterns of illness and medicine, with

more people living longer to experience chronic illnesses and to be offered or need medical care in relation to these problems place the political, economic, social and medical consequences within the realm of sociology. Secondly, critical responses to Parson's functionalist analysis of the sick role as a temporary state (Gerhardt 1990; Bury 1991) point to the need to take account of the emergent nature of chronic illness by placing it within a theoretical framework which is temporal. Thirdly, re-appraisals of the social responsibilities of sociology in debates about 'who is sociology for' can be seen to be linked to calls for the sociology of chronic illness to emphasise the importance of lay views and knowledge and the 'insiders' perspective (Conrad 1990). Thus a key feature of the field has been to describe the active role of people with chronic illnesses in managing symptoms, illness and medical regimens in the context of their daily lives and their active role in negotiating health, and specifically medical, care. Finally critical debates about the role of sociology in relation to medicine (Strong 1979) can be seen to have provided a source of courage to overcome sociology's reluctance to study specific medical conditions.

It is also possible to characterise the sociology of chronic illness in terms of its methodological approaches. Much of the sociology of chronic illness has used qualitative methods based on the theoretical perspectives of grounded theory (Glaser and Strauss 1967; Strauss and Corbin 1990); phenomenology (Heritage 1984); ethnomethodology (Garfinkel 1986); symbolic interactionism (Gerhardt 1990); social constructionism (Bury 1986) and the sociology of everyday life. The purpose of listing singly these inter-related perspectives is to make the point that

although there are overlapping premises and concepts, and although many studies (including this one) have their grounding in an eclectic mix of these (Charmaz 1990; Costain Schou and Hewison 1998), the methodologies are not simply interchangeable. This is an issue of particular relevance in the context of work on adaptation and self and identity considered below.

However, it is perhaps worth drawing attention to some of the links between these theoretical perspectives and methodological approaches and the key themes outlined above. The call for an insider's perspective or "authentic data on the experiential side of chronic illness" (Gerhardt 1990) has been interpreted as a call for a phenomenology of chronic illness. The perspective of symbolic interactionism offers, amongst other things, an emphasis on meaning and on the (active) role of individuals in negotiating meaning. Both phenomenology and ethnomethodology as underpinning the sociology of everyday life brought a focus on the mundane and on 'taken for granted practices', routines and typifications and the legitimacy of lay knowledge and rationalities (Gerhardt 1990). Finally, all five perspectives theorise micro-social processes. This point may seem somewhat self evident and uninteresting in and of itself, it is relevant here as a routine source of criticisms, primarily on the grounds that such research is apolitical and astructural (Annandale 1998). Again, this issue is returned to in relation to theories of self and identity below (Widdicombe and Woofitt 1995; Wetherell and Maybin 1996).

Given the methodological bases of much of the research on the sociology of chronic illness, in particular the influence of a grounded theory or inductive approach, the

empirical work can be seen to have generated a wide range topics of interest, concepts or 'middle range theories'. Thus from Conrad (1990) and Bury (1991) alone, the following topic areas and concepts can be identified: illness trajectories or careers; uncertainty; legitimation and explanation; adjustment, adaptation and coping; managing regimens, compliance and non-compliance; identity work and management of self, including stigma, disclosure, concealment; normalisation and finally biographical and narrative work. Conrad also notes that underpinning these topics is a concern with process. He suggests the following threefold typology of processes: patient career, narrative reconstruction and identity development.

Given the pluralism of concepts evident in this field, the following summary borrows Conrad's identification of the importance of process, although not his typology. It considers the following four processes: illness trajectories, biographical work, adjustment and adaptation and finally, identity work and management of self. As might be anticipated, the delineation of these processes is more pragmatic than real and the forthcoming summary struggles somewhat with the inter-relatedness of the concepts. Perhaps the best justification of this format is that it is structured in such a way to reflect the concept which the researchers or authors have used to anchor their own analyses.

Before considering each of these processes in more detail below, it is important to add an additional and not uncontroversial characterisation of the field of the sociology of chronic illness: that of its distinction from the less well developed area of the sociology of the lay evaluation of health care. This issue is of particular

importance in the context of this thesis where a primary aim is to understand users' experiences of health care. This issue is considered briefly below.

In her review of the sociology of chronic illness Gerhardt (1990) noted that the early work suggested that there was a need to move away from the study of interactions in medical settings (Goffman 1968; Strauss and Glaser 1975) towards understanding experiences in the wider context of daily life. That is, to move away from an implicit patienthood towards a personhood. The argument here is that the sociology of chronic illness has achieved this very well and the focus on the experience of illness in everyday life now dominates.

That is not to argue that work in the sociology of chronic illness does not consider the experience of treatments and health care. Much work has emphasised the impact and management of treatment regimes, particularly medication (Conrad 1985), and experiences of the 'merry go round' of investigations, treatments and diagnoses (Anderson and Bury 1988; Bury 1991; Fitzpatrick and Hopkins 1992). Rather, it is to note that much of the work on the lay evaluation of health care remains distinct from this field, being based upon the patient satisfaction tradition of research which is predominantly quantitative and, it has frequently been argued, atheoretical (Calnan 1998a; 1998b; Hopton et al. 1993; 1995; Williams and Calnan 1996; Coyle 1999). Thus although qualitative research on the experience of chronic illness in the context of everyday life can be seen to have implications for health care, there have been few attempts to integrate concepts, theories or methods from this field with attempts to develop a theoretical basis for the lay evaluation of

health care.

The emergent nature of chronic illness: illness trajectories

Much of the work on the sociology of chronic illness has acknowledged the importance of considering the emergent character of chronic illness and to place it within a temporal framework. Strauss and Glaser (1975) conceptualised such a framework as a 'trajectory'. Following Strauss and Glaser, the core concept has been used as a basis for empirically derived descriptions, such as Kotarba's description of the chronic pain career (Kotarba 1977) and as an organising concept, as in the case of Bury's review (1991). In broad terms the related concepts of career and trajectory can be seen to imply, if not explicitly suggest, a series of stages (Gerhardt 1990). These stages too have been assigned different labels and subtly different meanings by a range of authors, but can be seen to comprise an initial period of disruption; the search for explanation and legitimation usually in the form of seeking a diagnosis; initial reactions to the diagnosis⁴; then on-going care and processes of management and adjustment.

Biographical and narrative work in chronic illness

As hinted above, the concept of trajectory frequently implies a succession of stages. Theories of biographical disruption (Bury 1982) and narrative reconstruction (Williams 1984) can both be seen to examine this trajectory as a biographical

⁴ As much research on the sociology of chronic illness has considered specific illnesses samples have frequently been based on people with a diagnosis of the illness.

process. Thus Bury's concept of biographical disruption attempts to encapsulate the practical, social and physical processes of the onset of illness as well as the assault on sense of identity, self worth and meaningfulness of experience. Williams' analysis of the accounts of people with rheumatoid arthritis of the onset of illness and interpretation of the diagnosis described the process of constructing a meaningful biographical history. His analysis emphasised the importance of having an explanation for having the illness, or its genesis, in biographical terms in order to account for such questions as 'why me?' or 'why now?'. He described how people incorporated, or tried and failed to incorporate, aspects of their past into their accounts of the causes of their illness. From biographical disruption then comes the necessity of reconstructing a sense of order and for Williams an individual's account of the origin of illness in terms of biography was seen as a means of attempting to negotiate a sense of order between body, self and society.

Adaptation, adjustment and coping

The third conceptualisation of process described above comprises the processes of adaptation, adjustment or coping. As Bury notes, these concepts are difficult to distinguish empirically. He chooses to review these concepts within an analytical framework which considers adaptation as the generic term encompassing categories of coping, strategy and style (Bury 1991).

Bury suggests that the term coping is primarily used in the literature on chronic illness to refer to the cognitive processes of adaptation which would include

developing a sense of coherence or self worth or simply 'putting up with' or 'tolerating' the effects of illness. The term strategy is used to refer to what people do, for example their strategic interactions with other people and in health care settings. Finally he uses the term style, following the work of Radley (1989) described below, to refer to the cultural repertoires, symbolic meanings and discourses which people can draw upon in order to understand or account for their experiences.

In a series of articles based on a study of coronary patients and their spouses, Radley and Green (1985; 1987) and Radley (1989) have sought to develop theories of adjustment. Radley and Green developed a two dimensional model of adjustment based upon the relationship between self and illness as one dimension or axis (self complementary to illness or self opposed to illness) and society or degree of social participation as the second dimension and perpendicular axis producing categories of adjustment in each of four quadrants.

Radley's (1989) later analysis used this model but sought to distinguish mode of adjustment, meaning the contextualisation of illness conduct and the co-ordination of bodily action and social conduct, from style, based on an analysis of the importance of discourse as sources of constraint or dilemmas to be resolved in this conduct. This brief overview of their work is presented here as the basis for noting two points. Firstly, that the work attempts to examine concepts of self in relation to processes of adjustment in both empirical and analytical terms. Secondly, that the focus on discourse of self and the body is seen, by the authors, as both a means of

overcoming the interactionist-structuralist debate and of deconstructing the implicit morality or legitimacy of particular modes of adjustment. In this construction then, adjustment has an ideological content.

Kelly (1994) has also proposed a typology of coping. His typology was based on a summary of three types of coping present in the existing literature: technical, intra-subjective and interpersonal and a fourth, not reflected in the mainstream literature, which refers to the way in which people make sense of their experiences. In this conceptualisation processes of narrative or biographical reconstruction can be seen as forms of coping. From this analysis he draws on his work on processes of self and identity management in people with ulcerative colitis and takes a reflexive step, suggesting and illustrating that the way people talk about coping can be seen as a form of identity management. It is important to note that his analysis was based on stories which he interpreted as being about coping and not respondents' consideration of coping, however they chose to interpret it, *per se*.

Taking these three explorations or expositions of adjustment and coping together, several issues remain. Firstly, as Bury identifies, the use of the constellation of terms such as coping, adapting and adjusting are not clearly defined in analytic terms nor empirically, in terms of how they are used in everyday language or as members' categories. Kelly's analysis of ways of talking about coping can be seen as beginning to address this issue, but not to explore understandings of the different terms.

Secondly, they point to the inter-relationship between theories of adjustment and theories of self and identity. Kelly's proposition that talking about coping can be seen as a form of identity management is an explicit statement of this inter-relationship, although his analysis contains no explicit reflection on the focus on accounts of coping as identity management as opposed to other aspects of his respondents' accounts.

Thirdly, related to this, they point to the need for greater theoretical and methodological clarity in relation to the concepts of adjustment. It is possible to discern beneath Bury's apparent substantive typology of coping, strategy and style the different theoretical traditions of individual cognition, social interactionism and postmodernist discourse analysis.

In conclusion, conceptualisations of adjustment can be seen to have drawn upon a broad range of theoretical and methodological approaches and have considered the importance of self and identity management. In contrast, work on self and identity in chronic illness, described below, has drawn primarily upon symbolic interactionist theories of self and identity. The suggestion here is that clarity in theorising the processes of living with illness (adaptation) requires explicit consideration of a broader range of theories of self and identity.

Identity and self in the sociology of chronic illness

Six analyses of self and identity in the context of chronic illness are reviewed below.

All are based on empirical work and, it is argued, can be seen to be explicitly or implicitly based on Mead's theory of self as social process⁵. A brief overview of Mead's theory of self is given prior to the descriptions of the studies.

Mead's theory of self borrows the concepts of the 'I' and the 'me' from the work of pragmatist William James, with self being a developmental process constituted from the development of ideational processes about how one's self is seen by others, or a generalised other (Hewitt 1984; Kelly 1992; Crossley 1996). Thus the self is a social and reflexive process, comprising the two aspects of the 'I' and the 'me'. Mead's precise definition of I has been controversial, though a representative interpretation is that of that which experiences the whole phenomenal field, the perceiving, acting, feeling body subject which can only know itself in retrospect (Crossley 1996). The me is the I's objectification, the I's external or outside view of itself which necessarily entails a sense of the perspective of the other.

In the most cited of all the forthcoming analyses, Charmaz (1983) proposed that loss of self be considered as fundamental form of suffering in the chronically ill. Her analysis is based on interviews with 57 severely debilitated or housebound people with a range of chronic illnesses. She uses a symbolic interactionist perspective, that the self is social in nature and maintained through social relations, along with the concept of self-concept as "the organisation of attributes that have become consistent over time". The sources of suffering, or losses of attributes of

⁵ It is important to acknowledge the asymmetry underlying this critique: namely that it has arisen from a process of comparison between work on self and identity across psychology and social psychology, with a relatively narrow field of the sociology of health and illness within sociology.

self-concept, were identified inductively. These were: leading a restricted life; experiencing social isolation, experiencing discredited definitions of self and becoming a burden.

In a later analysis (Charmaz 1987) she offers an elaborated, and more flexible or dynamic analysis of self and identity. Her analysis presents two 'new' interconnected concepts, firstly, preferred identities and secondly, identity hierarchies and in which self-concept is explicitly stated to be an emergent structure which can change. The identity hierarchy emerges over time and consists of levels labelled the supernormal, restored, contingent and salvaged identities⁶.

The identity process which Charmaz proposes is that people experiencing illness will pursue preferred identities that maximise leading a normal life, but may have to reduce their identity goals as illness progresses. The process is flexible such that people may move up and down the hierarchy. She notes that others can define whether or not a particular identity level is appropriate and that there can be difficulties where intimates may assume a different identity level. Charmaz points out that existing work has emphasised processes of identity or biographical reconstruction in terms of past and present identities and notes that identity can have a future orientation.

⁶ She defines these as follows: supernormal, an identity demanding outstanding achievement even in conventional terms; restored, a reconstruction of previous, pre-illness, identity or identities; contingent, an identity which is hypothetically possible but uncertain because of the possibility of further illness and the salvaged self, retaining a past identity based on a valued activity or attribute.

Kelly (1992) examined the problems of presentation of self and the negotiation of identity in research on the experiences of people with ulcerative colitis. He begins with an overview of theoretical concepts of the self and identity, but draws primarily on those of Mead and James, leading him to a summary which emphasises the self as mediating social structure and behaviour through the process of role taking and social identity as the label imposed by others on the self. However he also draws on the phenomenology of Schutz, suggesting that the self can be seen as “the locus of phenomenological life in which the natural attitude provides the means for dealing with the here and now”. Kelly focuses primarily on sexual identity, using his data to illustrate the precariousness of the interactive process between private and public self, the skills of impression management, the issues of concealment and disclosure needed to maintain a viable sense of self. Kelly’s analysis contrasts with the most often quoted earliest analysis of Charmaz (1983), emphasising loss of self, in its emphasis on the work of maintaining aspects of the self.

The uneasy pragmatism of structuring this section of the chapter in terms of different processes in the sociology of chronic illness was noted above and the following study by Corbin and Strauss (1987) could equally have been included in the earlier section on adjustment. Their study involved interviewing 60 couples, one of whom had a chronic illness. Their respondents included people with a range of chronic illnesses including cardiac disease, stroke, diabetes or who had suffered from accidents which left them quadriplegic or paraplegic.

Corbin and Strauss argue that action aimed at achieving a sense of control and balance over life, as well as giving it continuity and meaning, must take place not only in terms of illness management but also of biography. The focus on biography emerged from the observation that respondents always talked about their illness in a biographical context, and that whilst some people made chronic illness the focus of their lives, others appeared to “integrate it into the fabric of their being”. In this context they developed an analysis of the inter-relatedness of what they suggest are the three dimensions of biography: body, biographical time and concepts of self. They suggest that a range of illness trajectories, including, comeback, stable or downward, could be seen as partly underpinning biographical time.

Their conceptualisation of self follows Mead and Goffman. They define conceptions of self as personal identity, or self-classification of who I am in the course of biography. Conceptions of self are thus formed through the integration of various aspects of self into a more inclusive whole. Continual performance of aspects of self is dependent on the body as the medium through which conceptions of self are formed. Successful performance requires mind and body to work in harmony. Views of self are formed by reviewing performance. By performance, they mean action and its appearance to others. Thus body failure leads to changed or omitted performance and where this is the case there are then consequences for both self and biographical time and involves biographical work to re-align the three aspects of biography.

Corbin and Strauss propose four types of biographical work which are analytically

distinct but occur simultaneously, with each affecting the others. These are: contextualising, that is, incorporating the illness trajectory into the biography; coming to terms, that is, arriving at some degree of understanding and acceptance of the biographical consequences of actual or potential failed performances; identity reconstitution, that is, reintegration of the identity into a new concept of wholeness around the limitations in performance; and biographical recasting, that is, giving new directions to the biography. Two of these, coming to terms and identity reconstitution, are described in more detail below.

Corbin and Strauss suggest that coming to terms varies along a continuum through stages from non-acceptance, through acceptance to transcendence. By acceptance they mean that the person has found a way of biographically accommodating the illness by altered or changed performance and hence restoring meaning to their life. They suggest that the process of acceptance is a form of grief or depression which requires aspects of the self to be relinquished in order to embrace and be hopeful about the future. Acceptance requires hope or the perception of an exit or way out of the current situation. They point out that acceptance does not necessarily mean happiness and thus differs from transcendence wherein people have overcome their bodies and found real joy in living. Although the process is conceptualised in stages it is not unidirectional, they suggest that people can move back and forward along the continuum in response to the illness trajectory or biographical contingencies.

The process of identity reconstitution is described as having three steps: defining and redefining identity, refocusing of direction and re-integration. Redefining

identity consists of refamiliarisation with the body and a reorientation in order to establish new priorities. Refocusing of direction involves giving new salience to old and still intact activities and shifting the salience of action from body to mind or mind to body. Identity reconstitution can also involve the development or use of what they describe as 'helpful personal philosophies'. The extent of identity reconstitution required in order to regain a sense of wholeness of integration depends on the number of aspects of self which are lost.

Adams et al. (1997) used concepts of personal and social identity to examine the issue of non-compliance with medication amongst a group of 30 patients diagnosed as having asthma and being prescribed prophylactic medication in the past year. They carried out semi-structured interviews with 14 women and 16 men from a single general practice. Their analysis was initially set in the context of Goffman's work on stigma, discredited self and the related issues of disclosure. However they go on to argue that the concept of identity provides a more appropriate framework for their data, using concepts of personal and social identity and suggesting that the distinction mirrors Mead's distinction between the I and the me.

Their analysis of the data was based upon two groups of respondents, those who accepted the diagnosis of asthma wholeheartedly (accepters), and those who did not accept the diagnosis (deniers or distancers), although they noticed that a small group of respondents (pragmatists) did not fit into this typology. The authors pointed to the way that some respondents rejected the social identity of asthma sufferer whereas others managed to reconcile it with other social identities and their

personal identity.

Their analysis allows them to challenge the conceptualisation that chronic illness leads to a diminished sense of self (Charmaz 1983), suggesting that this will occur only if an individual cannot achieve rejection or reconciliation. In this context they suggest that pragmatists may eventually reject the identity or achieve reconciliation. The authors' explicit distinction between personal and social identity and their emphasis on identity work as a dynamic process offers a more critical exploration of self and identity than much of the work on the sociology of illness described above. However, there remains an implicit cognitivism and the related assumption of discrepancies or dissonances between identities which require to be resolved.

In a study of the narratives of cancer patients, Mathieson and Hendrikus (1995) begin with a theoretical review of narrative, self and identity. They cover a wide literature, referring not only to the above work based on symbolic interactionist theories of self reviewed above, but to recent work which can be seen to be part of the linguistic turn in social psychology emphasising the textual and discursive basis of self and identity which is reviewed below.

The study was based on semi-structured interviews with 37 purposefully sampled respondents (with most respondents having breast, head or neck cancer). Interviews were specifically designed to elicit identity issues. From the analysis of the interviews the themes of feelings of fit, including signals of threats to identity,

biography and biographical work, illness trajectory, stigma and voice emerged. By voice, they meant the process of negotiating as a patient. In this respect their study, like that of Adams et al. (1997) above, can be seen to cross the fields of the lay evaluation of health care and the sociology of chronic illness, giving explicit consideration to issues of identity in health care settings.

Their conclusions are framed within the context of the lay evaluation of health care and they claim to have generated an alternative vocabulary to that provided in more traditional psychosocial research. They argue that when patients try to communicate what they are living through it will take the form of a narrative as an on-going set of attempts to evaluate the meaning of this experience. However, despite the wider scope of their theoretical background, it is not clear that their analysis of data is in any way methodologically different from the work described above, albeit with some thematic differences.

In conclusion, research on self and identity in the sociology of chronic illness has been primarily based upon Meadian theory of self, often without making the theoretical basis explicit and rarely distinguishing personal and social identity. Several issues require further consideration.

It was noted above that the initial analysis of Charmaz (1983) on loss of self remains the most frequently cited of the studies. The other studies reviewed above can be seen to have sought to offer a more dynamic conceptualisation of the process of management of self and identity, to consider past and future self concepts as well as

present and to emphasise the positive and constructive nature of identity work. However, these analyses remain relatively neglected in the field.

Secondly, although all the studies referred to above emphasise the self as an interactional micro-social or interactive social process, as dynamic and contextual, the analyses convey a strong sense of individualistic cognitivism (Crossley 1996) frequently presenting a series of stages with different structures of self. Though they imply that the process of self occurs over a time span, this time span is not unspecified. However, it is unlikely that the implicit time span is that of one moment to the next. Thirdly, many of the studies emphasise, and therefore assume, the necessity or centrality of wholeness, integration or reintegration of different aspects of self, giving little critical consideration to the theoretical status of this assumption. Moreover it is an assumption which can be seen to parallel too closely for comfort, individualistic theories of dissonance amongst cognitive structures driving change (Potter and Wetherell 1987). Taking these two issues together, the analyses can be seen to struggle to find a sufficiently flexible conceptualisation of the process of self.

Finally it is important to consider a potential counter argument to the above criticism that the theoretical basis of the work has not been sufficiently explicit. That is that the studies have appropriately derived concepts of self and identity inductively from the data. The argument here is that the eclectic mix of methodologies which characterises the overall field of the sociology of chronic illness has led to the failure to distinguish between the ethnographic or even

phenomenological exercise and the analytic exercise, as Young (1989). In short, research on self and identity in the sociology of chronic illness failed to distinguish between analytical theories of self (such as Mead's), empirical descriptions of the process of constructing self and respondent's own experiences or theories of self.

Self and identity: alternative theoretical perspectives

The purpose of the following section is to establish a framework of broader theories of self and identity. The argument here is for the need to give explicit consideration to postmodern accounts of discourses of self from social psychology (Sampson 1989; Shotter et al 1989; Wetherell and Maybin 1996; Widdicombe and Wooffitt 1995; 1997) and to sociology's growing attention to reflexivity in thinking about self and flexible identities (Warde 1994; Wetherell and Stevens 1996).

It is beyond the scope of this thesis to present a complete review of theories of self and identity in social psychology. As such the review is selective considering three analyses of self and identity which illustrate key aspects of recent social psychological approaches and address the issues which the work on self and identity in the sociology of chronic illness has neglected or struggled with. The first of these is an empirically based textual analysis of self in the context of a medical encounter (Young 1989). The remaining two analyses revisit the distinction between personal and social identity and explore the social construction of theories of self.

The work of Young (1989) is based on the text of a recorded encounter between a doctor and patient in an intimate medical examination. As Young argues, "whatever

the medical business of the examination, its phenomenological business is to displace the self from the body” or “threaten the embodied self”. Where such objectification of the body is perceived as depersonalising, there may be a need to reconstitute a self, achievable either by breaking the framework of the realm of medicine or by maintaining the framework but inserting what Young describes as an ‘enclave of the self’. In the course of the encounter in which there is an interchange about the medical process of explaining the examination procedures and taking a medical history, the patient narrates three (irrelevant) stories about his time in Auschwitz. The stories have some link to the medical dialogue in that they include reference to parts of his body, though not the same parts of the body as the doctor is examining and discussing, but are much more broadly autobiographical

The importance of Young’s analysis is as follows. Firstly, it illustrates a textual approach to identity. Secondly, it explicitly acknowledges the distinction between “discovering the structures of narrative in discourses about the self must be distinguished from imputing narrative structures to discourses about the self”, the first being an ethnographic exercise, the second an analytic one. Thirdly, as something of a distraction from this description of theories of the self and identity, it inadvertently illustrates the scant relevance, or discrepancy in motivational relevance, to use Schutz’ terminology between the social action of doctors and patients in medical encounters. That is, that they are doing different things.

In contrast to the work on self and identity in the sociology of chronic illness, social psychology has long distinguished social and personal identity. Breakwell’s edited

collection on threatened identities (Breakwell 1983), for example, was structured around the division of threats personal identity and threats to social identity with chapters by Harre (1983) and Apter (1983) exploring this theoretical difference in some detail. Both arrive at similar conceptualisations of personal identity, though through subtly different arguments and ultimately using these conceptualisations to different ends. Both arguments are summarised below.

Harre begins his chapter by distinguishing the fact of identity from the sense of identity. He demonstrates, by a philosophical analysis of theoretical scenarios, that the body serves as the primary fact of identity for self and for others. By similar means he demonstrates that, in contrast, sense of identity involves subjective and psychological components. He then presents what can be seen as a phenomenological analysis of self, drawing on the argument of Hume, that in an important sense the self is never experienced but must be presupposed as necessary for the form of experience comprising a definite hierarchy of awareness. The hierarchy of awareness is illustrated by the possibility of reflexive consciousness, that is, being aware of being aware. Interestingly, Harre uses the example of experiencing pain, being aware of experiencing pain and of attempting to distract one's self from that awareness.

Moreover, sense of identity, which is only partly bodily identity comprises both a sense of personal identity and of social identity, though personal identity can be seen to have constituents which are social as well as those which are individual or private. In order to make sense of this somewhat bewildering distinction between

social identity and social constituents of personal identity it seems crucial to note the specificity of his term social identity, that is social categorisation theories of social identity, which Harre points out are, by definition, clear and categorical. His conclusion is that sense of identity depends upon a socially enforced theory of self. This theory of self has two components. Firstly, it comprises a continuous co-ordination of point of view and action within a spatio-temporal material system. Hence the theory of self is embodied. Secondly, it comprises the association of exercise of agency with a point of action, that is, a sense of self as agent and the person at the focus of only one field of consciousness. The argument is difficult to follow, but his later work on the grammar of self and identity perhaps clarifies why this is the case (Harre 1991).

In considering the grammar of self and identity, Harre's work can be seen to address one of the key themes in discursive psychology, that of the cultural relativity or socially constructed nature of psychology's subject, the individual, self or identity. He constructs an argument from two sources that problems and misunderstandings arise from the use of inadequate grammatical models for understanding person talk. His first source is an exploration of grammars of self in other languages, the second a therapist's account of his work with a woman whose talk was uninterpretable. Only after an in-depth grammatical analysis was the therapist able to see that the woman's talk comprised three selves. By applying a similar deconstruction of grammar to theoretical work on the self and identity, Harre distinguishes between the self-1, the philosopher's concept of self, from self-2 the type of self which Goffman referred to in his studies of self-presentation. He argues that both concepts

are essential for understanding personhood and for living as persons, albeit a distinction which ordinary language fails to make. Harre also demonstrates that there must be a transcendental sense of self which is not simply Mead's or Goffman's me.

In a chapter which is much easier to summarise than those of Harre, Apter (1983) also distinguishes between personal and social identity and draws on James' rather than Mead's, distinction between the I and the me. He suggests that a complete phenomenological account of a sense of identity would have to refer to at least three component characteristics: personal distinctiveness, a sense of personal continuity and a sense of personal autonomy, by which he means the feeling that one is in control of one's own thoughts and actions. He makes the point that sense of identity is different from self-concepts, that the categories of sense of identity are different in kind from those of concepts of self.

Apter illustrates this difference in kind in an analysis of negativism, that is, individuals who appear to have an intense negative attitude to aspects of their life. Using examples of individuals whose self-concepts may be changing or threatened, such as adolescents or older people, he illustrates that a clear, integrated self-concept comprising different aspects of self is not necessarily the basis for a strong sense of identity. In this context then, a teenager may prefer to be laughed at rather than ignored, because this may make him feel distinct. The need for a strong sense of personal identity (an I) then is different from, and in some respects more basic than, the need for a positive self-concept (the me). Apter translates this distinction

into clinical terms as a weak or threatened identity at the level of the me (neurosis) being more serious than at the level of the I (psychosis).

In summary, the key features of this theoretical area, in very broad terms, are the acknowledgement of the importance of sense of self and theories of self along with the process of self-presentation (or identity work) in social context whilst questioning, in theoretical terms, the notion of a unitary self. Thus analyses of the experience of chronic illness which emphasise 'loss of self' can be seen as only telling part of the story, and whilst some aspects of self are 'lost', other aspects are being maintained or developed despite the threats to sense of self from social relationships, medical treatments and interactions from with health services (Young, 1989). The suggestion here is that it may be helpful to understand the management of different selves in micro-social interactions within the context of a socially constructed theory or theories of self.

Summary: critical reflections on the sociology of chronic illness, self and identity

The literature comprising the sociology of chronic illness is now substantial and is largely based upon qualitative research (Gerhardt, 1990, Conrad, 1990). This area of enquiry can be summarised as follows. It has sought to explore the experience of illness and symptoms in everyday life and has emphasised the active role that people have in managing their own illnesses and health problems. It has pointed to the importance of considering illness trajectories (Bury 1992), and has described the difficulties and importance of making sense of the experience of illness (Williams

1984; Bury 1988; 1992).

It has identified the complexity of the task of self-management in terms of the unpredictability of illness and symptoms, the experience of good days and bad days (Wiener 1975), exploring ways in which the management task can be conceptualised using terms such as coping, strategies or style. Finally, it has considered the impact of illness of self and identity, frequently emphasising chronic illness as leading to loss of self. Despite these achievements three important criticisms of the field require to be addressed.

Firstly, despite the explicit emphasis on the active role that people themselves play in the management of illness and symptoms, it has been suggested that research has tended to focus more on the problems than the solutions (Bury 1991). Some of the studies and analyses reviewed above can be seen to have a 'solution' focus, for example the work on narrative reconstruction (Williams 1984), processes of adaptation (Bury 1991) and on constructive processes of identity management (Charmaz 1997; Kelly 1994; Adams et al. 1997). The argument here is that the theoretical integration of the concepts which these analyses draw upon may provide a more critical solution-orientated approach.

Secondly, it was noted earlier that the sociology of chronic illness can be seen to have overcome medical sociology's reluctance to study specific medical conditions. It is argued here that a consequence of this has been a relative neglect of the fact

that health and illness are not simple opposites (Radley and Billig 1996) and that people can have other health problems, and for those with an interest in the lay evaluation of health care, use services for other problems. Thus the experiences of a specific illness are rarely placed within the context of broader self-definitions and experiences of health and illness.

Thirdly, much of the work within the field of the sociology of chronic illness has theorised micro-social processes and as such is open to the criticism that it is apolitical and astructural (Annandale 1998).

From the surveys of the sociology of chronic illness, the analyses of the self and the wider review of theories of self and identity above it is possible to see that a reconsideration of work on the self and identity might offer the potential to address some of these criticisms, offering the potential for an analysis which can accommodate positive and negative identity work in the context of everyday life and in the context of health care as well as placing this identity work within a wider socio-structural and ideological context.

Chapter Five: The sociology and anthropology of chronic pain

Introduction

The forthcoming chapter reviews work on the sociology and anthropology of chronic pain. It begins with an overview of themes and methodological issues before providing a review of research in this area in two sections which parallel the areas of work reviewed in chapters three and four respectively, setting work on chronic pain in the wider contexts of the sociology of medical work and the sociology of chronic illness. The first of these considers the social construction of knowledge about chronic pain and studies of chronic pain management in clinical practice. The second considers the experience of chronic pain and lay experiences of health care. The studies are presented in simple, albeit summarised, narrative form, with brief details of the methodology and the main theoretical and conceptual points raised. A summary of the main issues, themes and concepts at the end of each section.

Overview of the sociology and anthropology of chronic pain: themes and methodological issues

The substantive scope for sociology and anthropology in studying pain is considerable. From the early anthropological work of Zolbrowski on the cultural relativity and the expression of pain, there has been considerable broadening of the field (Encandela 1993). Throughout the research reviewed below there are several recurring themes or arguments for a substantive interest in chronic pain.

Firstly, chronic pain is seen to either to present medicine with a major challenge, or to confront it with its own failure, in both practical and epistemological terms. As such, it can be seen to offer a magnifying glass through which to examine the social processes of medicine (Baszanger 1992). Secondly, much of the research refers to politico-economic arguments about, what is sometimes portrayed as the epidemic loss of days of work due to chronic pain, particularly back pain; the costs of welfare associated with this; both these given further impetus by the apparent upward trend. In this context chronic pain can be seen to “highlight the fault lines of society” providing a starting point for considering the processes and distribution of welfare (Kleinman et al. 1992). Finally, almost so obviously as to be forgotten, chronic pain is a source of individual and social suffering.

Not only is the substantive scope for social science immense, but so is the theoretical scope. Kleinman et al. (1992) point to the diversity of theoretical interest in chronic pain from within the same anthropological research group, to illustrate “pain’s sheer exhaustibility as a subject for conceptualisation and empirical study”. Fortunately for this review, the potential for the anthropological and sociological study of chronic pain has not been realised. Narrowing the scope of this review to consider studies of people’s experiences of chronic pain and studies of the provision of health care and medical work, leaves little work to be considered, though the theoretical perspectives and concepts drawn upon are indeed diverse.

There are also a number of methodological issues which need to be highlighted. Chapter two of the thesis drew attention to the difficulties in developing a medical

classification of chronic pain, and identified this as pointing to the need to consider chronic pain from a social science perspective. There is strong argument made by Conrad (Conrad 1990) and followed by the research presented in this thesis, that social science should study the experience of chronic pain per se, regardless of the underlying medical conditions. Nevertheless, the importance of cause or type of chronic pain is of practical relevance – how to recruit a sample of people with chronic pain – and arguably of some substantive relevance, particularly in terms of respondents' experiences of health care.

In short, research on chronic pain appears unable to avoid some engagement with medical conditions or classifications. This review has included both studies of the experience of chronic pain per se and studies of people with problems which are characterised by chronic pain and may have a medical classification or diagnosis (e.g. low back pain, musculoskeletal problems) where the researchers' interest is the experience or management of pain.

There are two reasons for making the scope of the review explicit in this respect. Firstly, as prior explanation of the relevance of including this methodological information in the summary descriptions of studies. Secondly, as an explanation for why several important pieces of work in the sociology of chronic illness, on the experience of rheumatoid arthritis, a disease characterised by the experience of pain (Wiener 1975; Locker 1983; Bury 1988), have not been included.

A second methodological issue is that the majority of the studies described below have been carried out abroad, with most based in the US. Whilst the discipline of medicine (formal medical knowledge and clinical practice) may be assumed to be similar to that of the UK and other European or Western countries, the medical systems, structures of provision of care and their ideologies are different.

Studies of the social construction of formal knowledge about chronic pain and of pain management in clinical practice

The social construction of formal knowledge about chronic pain

Five studies, reviewed below, have examined the social construction of understandings of chronic pain. That is, they consider the theories and formal knowledge of pain and chronic pain outlined in chapter two and place them in a critical social science perspective.

The first of these is a theoretical social constructionist analysis of physiological models and medical knowledge of pain (Kugelmann 1997). Kugelmann offers a Foucauldian interpretation of how the physiological model of the Gate Theory can be seen to have acted as a symbol which allowed the transformation of clinical practice to include a wider range of disciplines. He argues that the Gate Theory of pain did not create new forms of treatment but made them legitimate. His analysis draws on Armstrong's⁷ general description of the emergence of a biopsychosocial model of medical practice to include the disciplinary perspective of psychology, its promise to overcome Cartesian dualism and of its promise of "emancipation".

⁷ See description of Armstrong's work in Chapter 2 on the epistemology of medical practice.

Kugelmann argues that the Gate Theory has reconstructed pain as a process as opposed to being spatially located within the body and he traces the history of medical reclassification of pain to include the patient's subjectivity, such that the patient's report of pain is seen as fundamental. However, he argues that, by legitimating greater psychotherapeutic treatment of pain, and attempting to objectify this subjectivity, it has also led to "a new morality of biopsychosocial treatment", shifting responsibility from the practitioner to co-management between patient and practitioner. As he puts it "helplessness or passivity has no place in the gate control flow chart".

Kugelmann concludes that, as in other areas of medical practice, the disciplines of medicine, and the justification for intervention in patients' lives, have no limit. He suggests too that this has two major consequences. Firstly, it eliminates the possibility of shame, or a sensibility to being exposed, as everything is potentially visible to medicine's disciplinary, if not technical, ways of seeing. Secondly, in constructing pain as individual suffering, it serves to "silence pain as social protest" and detract from the social structures which may produce it.

Priel et al. (1997) also offer a theoretical analysis of chronic pain, based on the application of semiotic theory. They emphasise that, despite advances in psychological therapies, a major dimension of chronic pain therapy, namely the patient physician relationship, remains problematic in many instances. They argue

that the accepted meaning of pain in medical and human relationships changes for the chronic pain patient. In extreme this transforms pain into an incoherent and poorly understood experience which both patients and physicians may come to view as meaningless experience of suffering. Medicine is premised on links between signs as indexes to a causal relationship with illness and in this context pain generally is an index. This is not necessarily the case with chronic pain where the meaning of pain is often hidden to both patients and physicians and requires further interpretation. This, they argue, may force physicians to become “interpreters” rather than “translators” of the pain necessitating a psychotherapeutic rather than a biomedical approach. Thus, whilst they are arguing for consideration of the issue of meaningfulness in the healing process, they are identifying potential difficulty that this may present in the context of biomedical practice.

Vrancken (1989), like Kugelmann, offers an analysis of the practice of medicine as a discourse, but bases her analysis on empirical work. From interviews carried out with physicians and psychologists from eight specialist pain centres in the Netherlands she proposes five ideal types or discourses of chronic pain. The five ideal types are labelled the somato-technical approach, the dualistic body oriented approach (an apparent paradox which is explained below), the behaviourist approach, the phenomenological approach and the consciousness approach. These are summarised below⁸.

⁸ Although Vrancken identified her ideal types empirically a cautionary note is required. Only two of her respondents used discourses which she includes in the ideal types phenomenological and existential and both of these are linked directly to the theories of two identified anthropologists.

The somato-technical approach is described as being characterised by a pragmatic approach to pain based on neurophysiology. The paradoxically labelled ‘dualistic body oriented approach’ acknowledges that pain can be the result of organic, psychological or social factors, yet in practice maintains a methodological dualism, insisting on knowing the relative importance of these factors in causing the pain. As preferred treatment is based on causes, Vrancken describes an effect echoed in many of the forthcoming studies, of patients being ‘yo-yoed’ between therapies and therapists.

The behaviourist approach conceptualises chronic pain as a learning process and aims to re-habilitate and re-socialise the patient. Vrancken notes the tendency for this discourse, through concepts of operant conditioning and secondary gain to introduce a moral dimension whereby pain is seen as a mistake or bad habit. With the exception of Vrancken’s discussion of the importance of cause in her analysis of the dualistic body orientated approach, these discourses closely match those in the received knowledge of clinical practice described in chapter two.

Vrancken’s consideration of the remaining two types of discourses can be seen as a critical theoretical review of the work of the theorists she identifies them with. Both address the phenomenology of the body. As such there is considerable overlap. Their distinctiveness as ideal types appears to lie in their therapeutic means. Thus both theories point to the impact of pain making the body the centre of the lifeworld or of consciousness. In the phenomenological approach, pain coming to the centre of the lifeworld pushes everyday life into the background, interrupting

intersubjectivity and leading to isolation. This perspective is implicitly processual, that is, that pain causes this disintegration of the lifeworld which in turn interrupts the healing process, hence pain becomes chronic. In this context therapy seeks to reintegrate the person with the lifeworld by means of biographical work. The consciousness approach sees pain as a problem of consciousness which becomes filled with pain and awareness of the body. In this approach the problem is addressed by existential means, encouraging understanding of the pain, reflection on self and personal philosophies.

Vrancken then uses her theoretical explorations of the phenomenological and consciousness models to reflect on the residual metaphysical problems. Firstly, the problem that pain cannot be separated from the perceiver, by which she means the person experiencing pain. Secondly, she draws on the work of Scarry (1985), which highlights pain's defiance of language and its fundamental unshareability. Thirdly, she uses theories of the body in everyday life, drawing on the distinction between the lived body as subject and self, as opposed to the body as object to offer an analysis of the inherent psychophysical dualism of experience. In phenomenological terms, pain feels physical. As Vrancken observes, from this analysis, the patient might force the physician into a dualistic framework.

Finally, Eccleston et al. (1997) used a Q-factor analysis to examine the structure of ideas or attributions of causes of pain. Eccleston places the Q-sort technique in the context of social constructionism, as a method in which people construct their own

accounts or understanding of an issue⁹. In this context then, the aim was to maximise the range of possible accounts by including statements drawn from a wide range of discourses involving a wide range of participants. The participants included people experiencing chronic pain, a range of medical practitioners (e.g. anaesthetists, general practitioners, nurses, orthopaedic surgeons, physiotherapists, psychiatrists, psychologist) and some 'self defined' pain therapists, including complementary therapists. The final Q-sort used 80 statements and was completed by 60 people.

The factor analysis produced four accounts, labelled as follows: (figures in brackets are the number of people whose individual accounts exemplified the shared account and their designations): the patient's account (9 people, 8 people experiencing chronic pain); the professionals account (11 people, 5 anaesthetists, 3 clinical psychologists, one physiotherapist, one academic psychologist and a nurse); the scientists account (3 people, one clinical psychologist, one health psychologist, one complementary therapy practitioner) ; finally the alternative practitioners' accounts (one complementary practitioner). The differences between the accounts are described in terms of implicit understandings of blame and responsibility¹⁰. Thus the profile of statements making up the patients' accounts are reported as: support for statements which asserted a physical cause for the pain; strong disagreement

⁹ It involves each participant in ordering a wide range of statements about an issue, in this case causes of pain. Each individual account is then compared statistically using factor analysis to produce a set of shared accounts which best fits all individuals accounts. These statistically derived accounts are then elaborated by using other sources of data from individuals whose account loads strongly or is most congruent with the particular shared account or a key item within the shared. Other sources of data might include comments added during the sorting process or responses to open-ended questions.

¹⁰ The items are not explicitly about blame and responsibility, rather it is the researchers interpretation that statements imply issues of blame and responsibility.

with items which could be seen as discounting a physical cause; strong support for items which apportion blame to the medical profession and strong disagreement with items which suggested any blame on the part of the sufferer or suggested individual weaknesses such as personality or laziness.

In contrast, the professional account was summarised as deflecting blame or responsibility from medicine, countering the idea that pain must have a physical cause but giving prominence to explanations in terms of dysfunctional reactions to pain events, learned behaviour and habits. The researchers note however, that items in this account did not attribute cause to individual characteristics, such as personality or laziness and conclude that there was “considerable effort not to portray patients in a negative or dismissive way”. They also noted that physical explanations of pain were less prominent than in the patient account and that a key theme was that chronic pain is not amenable to medical treatment.

The researchers’ overall interpretations of their findings are based primarily on these two accounts, considering what each account achieves. The patient account is seen to deflect blame away from the self and to place an emphasis on the importance of diagnosis to provide meaning for the pain and as such legitimacy for the patient. Similarly, the professional account, in its resistance to accepting responsibility, is seen as a means of protecting a threatened professional identity.

Studies of the clinical work of pain management

This section describes four studies of the clinical work of pain management. Three of the studies are based in specialist chronic pain management clinics, two of them focusing on the culture of the clinics with the third, of particular relevance to this thesis, examining the nature of clinical work. The fourth study is a qualitative study of general practitioners' views of low back pain patients.

In one of the Harvard studies on chronic pain, Jackson (1992) conducted participant observation research in a residential pain centre. Over the eight-month fieldwork period she carried out 196 interviews with 136 patients and 20 staff members. The majority of the centre's patients suffered from lower back pain. She described the focus of the study as an "investigation of cognitive restructuring in patients". Her reporting of the study provides a rich description of the programme's culture, which she labels as being one of "tough love", of staff patient interactions, interactions amongst patients themselves and of "patient encounters of the ideology of the clinic". It is her description of the latter which is summarised here.

In setting the context for her analysis she draws on three underlying issues. Firstly, the fundamental ambiguity about the nature of the pain itself, its invisibility, its subjectivity and, as such, its challenge to Western mind-body dualism. Secondly, she identifies two contradictory ideas about the locus of responsibility for pain within the ideology of treatment. Finally she considers issues of stigma and demoralisation which derive from these.

One of the key themes was the problems of meaning and communication about “real” pain and the psychological and emotional elements of pain. Jackson observed that though the term “real” pain was used frequently by patients and staff, neither ever used the term “unreal” pain. In this context she notes that one of the main areas of patient’s complaints about clinicians was that of their doubting that the pain was real, from a real cause. She also notes, echoing the work of Vrancken (1989) and Bates et al. (1994) that many patients were initially deterred by the programme’s emphasis on psychological techniques and describes the staff’s “selective attention” to patients’ problems and different treatments, prioritising patients with real causes. As a consequence, patients for whom staff were not seeking to find a diagnosis interpreted this as there being an assumption that the pain was all in their heads.

In this context, she described how patients can be placed in a double bind by the unconventional approach of the pain programme as they struggle with the biomedical model of pain which does not espouse that changes in attitude can bring about changes in pain, and the need to acknowledge that attitude can make a difference in order to engage with the treatment programme. Jackson argues that the programme forces people to accept to some extent that the pain is in their head and that in some sense then they can ‘will’ its reduction. This admission of responsibility violates what she describes as a “cardinal rule determining legitimacy in Western cultural notions about illness, that one is in no way responsible for one’s condition”. Moreover, she argues that admitting that pain is connected to mental or emotional problems may be seen to invite the stigma of mental illness. She

summarises the central message of the clinic which emerges from the negotiation of these ideological dilemmas as being that “until now you have not been responsible for pain until now, but now you know how to control it you are responsible”.

Finally she offers an analysis of how the majority of patients who have come to take on the ideology of personal responsibility have assimilated this in one of two ways. Her analysis is based on the three different groups of patients, all of whom leave saying the programme has been a good experience for them. The first group, often people who had pain as a result of accidental injury, are described as seeing pain as not their fault but as having come to accept responsibility to get on despite the pain, feeling that they now have more control over it. The second group is described as coming to see the pain itself as their responsibility, saying that have come to terms with this and know they know they must get on with their lives. The third group who leave having benefited have done so on the basis that the program has changed their experience of pain such that it is substantially less problematic.

Research by Bates et al. (1994) sought to explore the cross-cultural differences in the provision of care for people with chronic pain using two studies conducted in outpatient chronic pain control centres, one in the US and the other in Puerto Rico. The research considered the two centres, both described by the researchers as biomedical, as ethno-medical systems. Its broad aim was to address the overall gap in existing research of the role of cultural beliefs, values and standards of health care providers and how these may influence patients responses to chronic pain,

their abilities to cope and to treatment and care. Both studies included both qualitative and quantitative data. Qualitative data was gathered from 110 Anglo-Americans, 44 Latinos, and 28 Polish Americans who participated in the US study and a comparative group of Puerto-Ricans using formal and informal interviews. Interview data was supplemented with case study materials for six patients from each ethnic group selected to represent a range of ages, gender, diagnosis, duration of pain and pain coping style and observational data on interactions between patients and staff.

Their analysis identified five cultural factors, which could be seen to affect the type and quality of health care and the responses of patients. These were: cultural differences in the expression of pain; differing mind-body worldviews; health provider-patient relationships and views concerning pain responsibility.

The researchers suggest that cultural differences in standards for expressing pain could explain their observation of differential reaction to expressions of pain by staff in the Puerto-Rican centre, who tended to evaluate the seriousness of pain on the basis of the outward expressiveness of patients, in contrast to the US where expressiveness by patients was often seen as patients being overly emotional rather than the pain being severe. The researchers also suggest that the different world views of the mind-body relationship of the two centres could be seen to underpin patients differential reactions to suggested therapies, particularly psychological treatments. They noted that in Puerto Rica providers and patients generally shared a holistic view of mind-body integration and emotional, psychosocial and biological

factors interact in the chronic pain experience. In this context, patients generally accepted suggestions for psychological treatment without displaying anger and did not interpret inquiries about psycho social factors as indications that the doctor viewed the pain as exclusively stemming from psychological factors. In contrast, patients in the US were frequently angered by these suggestions, considering inquiries into psycho-social matters as evidence that the doctor thought the pain was due to psychological factors and not real.

They, too, echo Vrancken's (1989) analysis of the dualistic body oriented approach, that although providers expressed their belief and commitment to a multidisciplinary multi-causal approach, their actions showed clear preferences for using biomedical procedures such as nerve blocks. They also note that psychological therapies were only offered after failure of physical treatments

The study also noted differences in the doctor-patient relationships between the US and Puerto-Rican centres. They describe the usual basis for the relationship in the US as professional, with patients not consistently being treated by the same physician, although with some personal recognition of long-term patients. Relationships in Puerto-Rican centre were much less formal, friendlier and based on the assumption of the importance of knowing about the patient's feelings, their family and their social relationships.

Finally the researchers note the differences in attributions of responsibility between the two centres, arriving at a similar analysis to that of Kugelmann (1997), that in

the US centre the use of behavioural and cognitive techniques depend upon the patient assuming responsibility and an underlying ideology of individual autonomy. In contrast the Puerto Rican centre placed greater emphasis on the role of others, providers and family members as advocates and supporters.

Perhaps unsurprisingly, given their analysis of these differences, their overall conclusions are that culture is one of the major factors affecting the way that people perceive and respond to chronic pain in themselves and in others, that as long as cultural background of patients and providers are ignored expensive treatment programmes are likely to remain relatively ineffective.

Baszanger's (1989;1992) study of the management of chronic pain, provides the most detailed description and theoretical analysis of professional work. She picks up the challenge of how professionals manage pain as a private sensation which cannot be objectified or reduced to facts, that is, of work which is necessarily "fragile". Her work based on a grounded methodology used observation of consultations, participation in group work and conversations with physicians and nurses. The study was based in two hospital centres in France, chosen to represent the two poles of the specialty of pain management, designated by Baszanger as "curing through techniques" (Centre 1) versus "healing through adaptation" (Centre 2). The professional structure of Centre 1 was that of core staff consisting of one neuro-surgeon and two anaesthetists with other disciplines providing support. Patients at this centre received an average of three consultations. In contrast, Centre 2 is described as offering an extensive integrated patient care programme by a team

of physicians skilled and interested in using behavioural techniques for treating pain with a range of other specialists (including a psychiatrist). In this Centre cases are followed up for between eight to fourteen months.

In the paper from the study reviewed here, Baszanger's explicit aim is to look at practical knowledge, how clinicians tap what she describes as "almost incompatible resources", meaning different scientific theories, discourses as well as the information that patients contribute in consultations. As such, her work is of two-fold relevance to this thesis. Firstly, in terms of the substantive issues about work in pain centres which emerge through the empirical data. Secondly, in terms of the theorising about practical clinical knowledge and its relationship to formal clinical or scientific knowledge.

Baszanger describes the work of Centre 1 as being primarily orientated towards deciding whether the pain was "something" or "nothing", with "something" being an organic cause of the pain. To this end, the work could be seen to follow a logic of "look for", "eliminate", "verify" possible causes, whilst seeking to assess whether the pain could be projected onto a body map. This in turn involved looking for congruity between different sources of information including physical examination, clinical interview, and referral letter. Although reference to the gate control theory opened up the possibility of both physical and psychological processes influencing the pain, the process of interpretation in this pain centre minimised psychological processes, thus pain that was "something" was more important than pain that was "nothing". That is, in this context, "something" was the marked pole of the

dichotomy (Billig et al. 1988). She also describes the “rupture in continuity” when the physician seeks to refer a patient to a psychiatrist, observing that many patients are not ready for the shift. Where this is the case, she notes that, in contrast to Centre 2 where the emphasis would be on understanding the pain, physicians sought to prove to the patient that the pain was psychological.

In contrast, although the work of Centre 2 acknowledged the distinction between somatic and psychogenic pain, this did not influence how decisions were made. The basis of medical work was the patient’s experience of pain and illness and Baszanger describes the work as following a logic of explanation: “understand”, “ponder”, “analyse” and explain, with the emphasis being on integrating information from the patient into a global judgement about the person and the pain. Along with the work of explaining, Baszanger describes the work of conviction wherein the physician works to convince the patient to change, to develop “mutual involvement” and agreement, to agree a therapeutic goal and strategy. A key element of the basis of the work of conviction is that the physician has to guarantee that he believes in the patient’s pain, to close off other therapeutic opportunities (such as surgery) and to develop a universe of shared work in which the patient is clearly implicated in the treatment. This conviction has to be sustained, which may mean that the physicians have to continually reconstruct goals and the temporal framework for the shared plan, for example, by revising the understanding of what would be the normal time for a given change.

Baszanger also describes the set of “clues” which were seen to point to psychological

malfunction. These were common to both centres but given differential weight in each. They included: wandering pain; a pain that stops when the patient is asleep but starts with maximum intensity on waking, spontaneous pain, pain that cannot be explained by examinations, exaggerated presentation, and excessive use of health care and medication.

Baszanger's analysis of her observations is framed within Armstrong's (1987) analysis of two historically differentiated ways of conceiving clinical work, in broad terms the old biomedical approach and the new biopsychosocial approach. A core argument is that there is tension between theory and practice raising the question of how social science can bridge the gap between analyses of theories of practice and analyses of medical action in operation, or to use terminology borrowed from other research, how to explain the relationship between formal and operational knowledge. Baszanger suggests that her description of the work of managing pain has illustrated the cognitive context or frameworks into which clinicians fit their clinical experiences. As she identifies, her analysis can be seen to fit with a range of situationist analyses of medical practice which conceptualise the situation in different ways, in this case a cognitive conceptualisation. Thus clinical work is not about physicians dispensing knowledge and patients receiving it, but about how "given practical arrangements of theoretical facts open the way to specific regimes of doctor-patient relations".

The following study is the only qualitative study found on general practitioners' work with pain, here low back pain specifically. Skelton and Murphy carried out

semi-structured interviews with 10 general practitioners in the UK (Skelton et al. 1995). They asked general practitioners about their general approach to the management of low back pain and about the process of managing specific patients. The analysis presented is based on what the researchers describe as the key issue of the way in which general practitioners differentiated between patients during the management and treatment process.

They identified six different ways in which general practitioners differentiated amongst patients. These were: in terms of the patient's psychological constitution; on the basis of the patient's clinical condition; on the basis of the patient's approach to management; on the basis of the patient's help seeking behaviour; on the basis of the patient's social class; and on the basis of the patient's sex and occupation (with sex and occupation being linked in a single category). The authors' also describe general practitioners' concerns about patients with low back pain and psychological distress, where the edges between cause and effect often became blurred.

Summary

A core theme of the studies in this chapter is that of pain and the challenge that it presents to assumptions about the mind and body. Many of the studies either refer directly to, or imply, that dualism is an ideological assumption of medicine. Though the ideology of medicine can be seen to have been transformed by the introduction of the discipline of psychology, the transformation is not complete in ideological or practical terms. Thus as many of the studies indicate, though the biopsychosocial

model may not be dualistic in theory, methodological dualism persists in practice in terms of seeking a physical cause for the pain, distinctions between ‘real’ or ‘unreal’, and ‘something’ or ‘nothing’, with primary attention being given to the ‘real’ and the ‘something’. Moreover the introduction of psychosocial models of chronic pain (and other illnesses) bring the related ideological assumptions of individualism and self-responsibility which constitute a new morality. Whilst the various forms of the metaphysical problem of mind-body dualism can be analysed in theoretical terms, as they have been in this summary, there remains the phenomenological dualism, that is, that pain feels physical.

The experience of chronic pain and the lay evaluation of health care

The experience of chronic pain

This section reviews qualitative studies which have explored the experience of living with chronic pain. In broad terms, these studies can be seen to fall within the sociology of chronic illness reviewed in the previous chapter, drawing on similar methodologies and concepts. The first two studies, of Kotarba (1977; 1983a; 1983b) and Hilbert (1984), focus primarily on the issue of making sense of and accounting for suffering, seen by both as being a fundamental problem for people with chronic pain. The section then reviews a collection of analyses of the experience of chronic pain by the Harvard anthropology group (Good et al. 1992), considering three of these to illustrate the key themes of the collection as a whole.

One of the earliest studies of peoples' experiences of chronic pain is that of Kotarba (1977; 1983a; 1983b) carried out in the US. His study involved interviews with 110 lay people and health care workers supplemented with 90 hours of ethnographic observation in natural settings where, Kotarba suggests, chronic pain was likely to be a primary topic of interaction. These settings included chronic pain centres, YMCA healthy back classes, professional athlete's locker rooms and working class bars.

The theoretical context of the study is that of existential sociology which, like symbolic interactionism, argues that the world does not have intrinsic meaning but that social actors in everyday situations negotiate meaning. Existential sociology, however, can be seen to place particular emphasis on the problematic nature of meaning and the feelings of meaninglessness, which are understood to permeate social life. Kotarba argues that the existentialist framework is appropriate in light of "the tremendous difficulty pain afflicted people have in making sense of their suffering" (Kotarba 1977).

One of the central constructs in Kotarba's work, is that of the chronic pain career. Kotarba's concept of career can be seen to be derived from the concept of trajectory from the sociology of chronic illness, in particular from Glaser and Strauss's work on the dying trajectory, adapted by Fagerhaugh and Strauss in their analysis of pain trajectories in in-patient settings (Strauss and Glaser 1975). Kotarba's choice of a different term, career, is based on his observation that the trajectory of chronic pain

is different from other chronic illnesses, in that there is not usually an underlying deteriorating pathology. Kotarba points to the implications of the distinction between the inevitability of suffering as opposed to its worsening in both experiential and clinical terms.

In experiential terms, Kotarba conceptualised the process of adjustment to chronic pain, the career, in three stages. In the onset stage pain is perceived to be transitory and able to be dealt with by diagnosis and treatment. The second stage, the “emergence of doubt”, is the stage at which treatments are not working but people continue to seek medical help, focusing on getting the best specialist care. Kotarba labels the third stage the chronic pain experience where, confronted with the ineffectiveness of medical treatments, people may give renewed attention to lay approaches to managing pain and seek help within a chronic pain subculture. Kotarba describes the patient’s view of the career as being marked by a “variably effective struggle to maintain a sense of control over one’s pain”, either by seeking pain relief or by seeking to normalise enduring suffering within a frame of reference of beliefs.

In clinical terms, Kotarba describes the process as progressing linearly from the initial stage where pain is seen as being transitory and acute, through to the chronic stage. He identifies that medical workers initially react to pain as a symptom of treatable pathology. The reality of chronic pain only becomes apparent after considerable medical failures and as such, chronic pain is constructed as “pain that

is medically unsuppressable”.

Returning to the experience of chronic pain, in particular how people attempt to manage and find meaning in their suffering, Kotarba offers two kinds of analysis of this process. The first is based on the concept of chronic pain sub-cultures (Kotarba 1983a). The second (Kotarba 1983b), which he describes using an unfortunate psychologism as the “cognitive control of chronic pain”, draws upon Weber’s analyses of the importance of theodices of suffering.

Kotarba’s analysis of chronic pain sub-cultures is anchored in his work with professional athletes and with working class men. He describes the importance of normalising constructs available within the sub-culture, for example, both groups could be seen to be working in occupations at high risk for experiencing chronic pain. He also describes the availability of social expertise in the management of chronic pain, exemplified by shared awareness of the meanings of concealment or disclosure. He uses the example of the awareness amongst athletes still striving for peak performance and success that disclosure could damage their prospects.

In a paper on death, belief systems and coping with chronic pain, Kotarba (1983b) reviews the belief systems which can serve as “emotional support and spiritual strength”. Within his sample he notes that Christian belief systems were most prominent, but others such as meditation, were used. He concludes that “the ability to cope with chronic pain is enhanced by the availability of a viable belief system as

a resource either for meaning or for instrumental therapy” and that “Regardless of the types of belief systems used, their adherents display an overall sense of comfort with their affliction, a strength to continue coping and a distinct absence of hopelessness or depression as clinically defined” (Kotarba 1983a).

In contrast, in a context of meaninglessness or ‘loss of cognitive control’ he describes, through a case study of one of the participants in his study whom he notes appeared to have not ‘normalising belief system’, how suicide can be constructed as the “ultimate resource for pain management”. He suggests that his ‘naturalistic’ exploration of the breadth of cognitive resources, social and cultural dimensions of the experience of pain contributes to the debate about depression as cause or effect of pain. He argues, citing the work of Pinsky, that the modal response of people experiencing chronic pain is best described as demoralisation, “a situational sense of hopelessness and meaninglessness”.

Hilbert's study reported in 1984 (Hilbert 1984), in which he argues that chronic pain defies cultural construction, is one of the most frequently cited and is rich with theoretical interpretations. As such his empirical work and his theoretical analysis is described in some detail below. His study is based on interviews with 22 people experiencing chronic pain recruited from 2 pain clinics in the US.

His introduction to the study begins with the observation that most folklore about pain includes the implicit belief that it will go away or can be treated, except when

pain is associated with specific illnesses. As such, resources for understanding and making meaningful the experience of pain which persists despite treatment have to be found outwith this realm. He argues that Kotarba's demonstration of how athletes and blue-collar workers constructed meaningful interpretations of their experiences was a description of the process of social interaction within chronic pain sub-cultures within which pain could be normalised. In contrast, Hilbert bases his work on isolated sufferers, people without the possibility of creating a chronic pain subculture. The key themes emerging from the interviews were: the different natures of acute and chronic pain; the role of diagnosis; social isolation; the management of pain in social settings, disclosure and concealment and the unavailability of private knowledge.

Hilbert argues that chronic pain is not just "normal" pain which continues. Observing that none of the people he interviewed had thought that the pain might continue, he reflects that chronic pain cannot be experienced as on-going normal pain precisely because normal pain is expected to end. As the resources for understanding pain are those of normal pain, he suggests it was both inevitable that respondents would invoke concepts of normal pain in their attempts to understand their experience and inevitable that they would fail. Related to this, he argues that it is also inevitable that chronic pain is not recognisable from the outset, but only by a "gradual dawning of awareness".

Hilbert's analysis of respondents' motivation to search for a diagnosis found that this

was based on three reasons. Firstly, that diagnosis would lead to treatment and cure. Secondly, as a means of describing the condition for others. Thirdly, he suggests that the fact of finding a location in medical classifications and in the body of medical knowledge generally can also be seen to mean that others share the condition, and in particular, that one is not mad. The latter reason, he suggests, can be seen to underpin people finding the label of 'chronic pain' helpful after initial diagnoses led to treatment, but to treatment which was unsuccessful.

In the absence of any cultural or medical constructions of the pain he suggests that:

“the experience of chronic pain includes the emerging suspicion that one is like no other, that one is suspended in an on-going experience which makes no sense, that no one else can share or comprehend this experience just as one cannot comprehend it oneself, in short that one is socially isolated.”

In this context, he reflects on clinicians' views of people as being unwilling to live with pain or being unwilling to accept the pain, pointing out that any means of normalising it is unavailable to them. That is, they are not unwilling but unable.

Placing this cultural isolation in everyday social context, he suggests that people experiencing chronic pain are faced with the insoluble dilemma of reducing social isolation by disclosing the pain, with no means of managing this disclosure, or of remaining isolated by concealing it. Hilbert suggests that managing chronic pain is uniquely problematic as, again, cultural folklore governing the expression of pain only applies normal pain. Methods such as withdrawal, concealment, moaning, confiding are not appropriate all the time. Thus whilst there are pressures to

disclose, such as the imperative to be open and not hide one's feelings in intimate relationships, there are contradictory pressures to conceal, such as not initiating depressing discussions or continually complaining. These contradictory pressures exist simultaneously. Hilbert also notes that in a sense the invisibility of pain, in both literal and cultural terms, makes pain management a "self-concealing activity" and as such, classic notions of social passing and stigma are not appropriate.

Finally Hilbert turns to his analysis of peoples' descriptions of searching for patterns in their experiences of pain to correspond with their personal philosophies, searches which they experienced as frustrating and leading them to the conclusion that pain is too random and complex to describe. He constructs the data analysis, and theoretical analysis, in the context of the question as to why, given the absence of cultural constructions of pain, people do not organise their pain experience on their own?

Hilbert's analysis of this draws on the social constructionism of Berger and Luckmann (1967) and Garfinkel (1986), using the argument that the constraints upon one's understanding or accounting are imposed by society not by an objective external world. However, society also constructs a view of objective reality such that any account is not necessarily socially sanctioned as adequate or correct. In a sense Hilbert is arguing that there cannot be a private account, analogous to Wittgenstein's argument that there cannot be a private language. The next step in his argument is to point to what he describes as "trendy notions of pain as private",

a consequence of which is that, if pain is private and unavailable to others, nothing can count as verification or correct description. In other words he is arguing that pain is socially constructed as being private. Here Hilbert invokes Wittgenstein's argument that to argue that pain is a private experience entails "eliminating precisely that about language that is meaningful and can be used, reducing the philosophical question to one for which nothing counts as an answer". Wittgenstein himself used pain to illustrate this argument, and Hilbert quotes Wittgenstein's conclusion that pain "is not a something, but not a nothing either."

In summary then, Hilbert argues that the everyday assumption of the privacy of pain constructs the isolation of people experiencing pain, suggesting that this lack of means of social accountability is a possible reading of Durkheim's original meaning of anomie. This theory would predict the symptoms of depression observed in people with chronic pain. Finally, he argues that the lack of a culture of chronic pain is treatable.

A series of studies by a group of anthropologists at Harvard (Good, Brodwin et al. 1992) sought to develop an ethnography of the experience of chronic pain. The studies, conducted in the US, yielded a series of analyses of people's experiences of chronic pain (summarised below) and an analysis of the work of a specialist pain centre (reviewed in a later section). The three studies included a study of the impact of chronic pain on working Americans, based on in-depth interviews with 38 people with a range of pain conditions over a two year period; study of the

experiences of people with jaw, neck and back pain which involved interviews with 40 people (32 of whom suffered jaw pain) drawn from volunteers recruited from support groups and finally the ethnography of a single residential pain clinic.

The introduction to this chapter noted Kleinman et al.'s (1992) comment on the immense potential for theorising pain. The volume of collected analyses reflects this, providing rich description, primarily based on case studies and using a wide range of concepts, theories and theoretical perspectives. Only three of these analyses are described in detail below as they can be seen to illustrate the key themes of the volume. Before describing these analyses it is worth considering the key messages of the volume as a whole (Good, Good et al. 1992). In many respects, these arguments echo those of Bendelow and Williams (1995) call for a sociology of pain. These are: the need for a phenomenology of pain; the need redress the neglect of the voice of those experiencing chronic pain; the need for consideration of chronic pain embedded in the broader relations of the body and society and the need to consider chronic pain in the context of social suffering in its widest sense.

The first of these analyses to be considered in more detail is that of Good (1992) based on accounts of people experiencing temporo-mandibular joint disorder (TMJ). Good presents his analysis in three parts: firstly, considering the origin myth and history of the pain and its narration, secondly, using the phenomenology of Schutz as a basis for an examination of the impact of chronic pain on the lifeworld and thirdly, the struggle for a name or symbolization. His analysis is of the impact

of pain as “unmaking” or “shattering the world”. In this respect, as Kotarba (1983b) and Hilbert (1984), the central issue is constructed as being that of intersubjectivity.

Good’s analysis begins from Scarry’s (1985) description of pain as “shattering” language and being characterised by doubt or “unshareability”. He notes, however, that language is not shattered in its literal sense, with many people being “frighteningly articulate” yet still unable to express their suffering through language feeling that others could not possibly understand their world. Using the phenomenology of Schutz (1972), Good explores the ways in which the world of people in chronic pain is unshareable.

Good argues that the body in pain has special primacy, dominating consciousness and breaching the natural experience of an undivided self which acts through our bodies such that the body is experienced as ‘object’ and the locus of agency against the self. Although the body is experienced as object, pain resists ‘objectification’ and localisation in medical tests and in language, hence Scarry’s juxtaposition of the absolute certainty of experience and the inevitability of social doubt (Scarry 1985).

Whilst much of the work on chronic pain reviewed above emphasises its destructiveness, two other analyses are mentioned here which offer insight into constructive or re-constructive processes of living with chronic pain.

Good (1992) used case studies of two professional women from the study of

working people with chronic pain to counteract the more prevalent emphasis on work as a source of stress and to examine the positive aspects of work: firstly, as a “haven” from pain and secondly, as an arena for self-realisation wherein work can offer “a context for meaning making and self constitution”. In particular, she concludes that the narratives of the two women can be seen to construct a divided self, a “competent professional self and a personal self in physical and psychic pain”. Similarly Garro (1992), on the basis of work with 32 people with TMJ, argues that in the face of the “ontological assault of chronic illness” that there is almost always a reaction to preserve one’s identity.

Lay experiences of health care

Only four studies of lay experiences of health care for chronic pain were identified, though the work of Jackson on the culture of a specialist chronic pain centre could perhaps also have been included in this section. Two studies have explored experiences of diagnostics tests in the context of low back pain. The third, a study of people reporting pain in the muscles or joints, was an exploration of the meaning of ‘wear and tear’, though it specifically considers interactions between patients and general practitioners. Finally, Bendelow and Williams (1996) carried out a study of lay experiences of a chronic pain clinic.

Both the studies of the meaning of diagnostic tests to people with chronic pain (Rhodes et al. 1999; Garro 1992) are placed in the context of the social construction of the anatomical understanding of the body. Rhodes et al. draw on Foucault’s

exposition of the emergence of anatomical space as a basis for medical practice. Garro describes the two related assumptions that inform both medical and lay understanding: firstly, that the inside of the body corresponds to visual images of it which are objective and show the body as it really is and secondly, that variations in people's bodies can be measured against norms that show what is typical and what is deviant. The studies showed the important role of medical tests in providing legitimation for people with chronic pain, where tests could be constructed as factual evidence of a match between the body as object and the experience of pain. Conversely, where tests provided no visible explanation for the pain, people were left with the disjuncture between objective tests and their own experience. In the context of this discrepancy, Garro argues that people are often left in a position of alienation, with the certainty of their own experience being threatened.

In a study of people reporting pain in the muscles or joints, Busby et al. (1997) explored lay understanding of musculoskeletal disorders using the concept or 'wear and tear' as a focus. They interviewed 80 respondents sampled purposively from a larger survey to include people who had not consulted about their symptoms and those with very intensive patterns of using health care. The relationship between lay and clinical knowledge is explored by comparing the lay perspective emerging from the interviews with people with joint or muscle problems with the clinical perspective, drawn from the professional literature, dialogue with professionals during the course of the research and interviews with a rheumatology consultant and three academic general practitioners.

The study illustrated that lay accounts about joint pain were grounded in detailed descriptions of the nature of work, not only in terms of its constituent activities, but also in terms of the economic and social processes which act to constrain “the body in labour”. In their discussion of lay responses to professional expertise they describe the difficulty of negotiating with general practitioners, particularly in terms of access to specialists (specialist knowledge) and specialist technology. A further issue was the interpretation of explanations in terms of ageing, which lay respondents interpreted as a way of saying that nothing could have been done differently and nothing can be done now.

In contrast to the detailed “contextualisation”, as the authors put it, in lay accounts, the professional accounts were less contextually based, frequently emphasising the inevitability and blamelessness of the ageing process. The two key issues emerging from general practitioners’ accounts were general practitioners’ recognition of the threat to the doctor-patient relationship associated with their limited capacity to intervene and of the importance of specialist tests in providing physiological evidence to account for the origins of wear and tear. The researchers also note that general practitioners can be seen as the point at which lay knowledge comes into contact with the world of professional expertise. Their overall conclusion however, is that in practice the reification of lay and professional knowledge is not helpful.

Finally, in a study of the lay evaluation of a pain relief clinic, Bendelow and Williams (1996) interviewed 34 people immediately after their treatment at the clinic. As the only sociological study of a UK pain clinic, it is considered in some

detail below. Their analysis is framed in the context of the suggestion that “the chronically ill may come to view medicine as both “the fountain of hope and a font of despair” describing their main aim as assessing the extent to which this is true of chronic pain patients. Their findings are reported in terms of the two broad themes: firstly, the inter-relatedness of respondents’ expectations and their pain careers and secondly, their evaluations of the consultations, management and treatment offered at the clinic

Using Kotarba’s conceptualisation of the chronic pain career and Radley and Green’s description of types of adjustment they describe two different groups of patients. The first group, the largest, they suggest “displayed classic features of resignation” feeling that their lives were totally dominated by the pain and that there was no hope for the future. In Kotarba’s (1983b) terminology they had reached the chronic pain stage of their career, but could envisage a “pain free future”. The second group is described similarly in terms of the stage of career but as more often expressing a different style of adjustment, akin to that which Radley and Green termed accommodative (1985). In this style, pain is incorporated into their lives, as Bendelow and Williams somewhat judgementally put it, “adjusting to it (pain) in a more positive manner”.

Having described these two groups Bendelow and Williams use the concept of styles of adjustment as a way of interpreting reactions to the clinic. The reactions of the resignation group are summarised in terms of having high expectations of a cure or of treatment which relieves pain and as feeling despondent when treatment failed.

In contrast, for the accommodation group, attendance and treatments at the clinic are only part and parcel of a broader strategy of coping, not solely dependent on the biomedical concept of cure. Overall they conclude that the overarching feeling of the people that they interviewed was of medicine having failed them.

Summary

Earlier in this section, it was noted that much of the work on the experience of chronic pain emphasises its destructiveness. The above literature review fails to capture and convey the pervasiveness within this work of the construction of the experience of chronic pain as 'destructive', 'shattering', 'unshareable', 'isolating' and 'alienating'. Scarry's analysis of pain in the context of war and torture, of pain defying language, being unshareable, unmaking the world and by virtue of all these constituting self-certainty and fundamental doubt in others, is quoted in most work and often used as a starting point (Scarry 1985). Though there are constructive analyses of the importance of pain cultures, of personal philosophies or theodices and illustrations of identity reconstruction pain, the sociology of pain begins from the premise that chronic pain is fundamentally problematic. It draws attention to the fundamental problems of intersubjectivity, meaninglessness, hopelessness and threats to identity and absence of means of cultural construction.

The studies of the lay evaluation of health care echo similar themes. Thus the studies of the meaning of diagnostic tests and of wear and tear can be seen in terms of the failure of health care to provide a legitimating cultural account of experience

as pain. Although Bendelow and Williams (1996) consider processes of adjustment in their study, their overall emphasis is on the failure of medicine and lack of hope.

Conclusion

This review of the sociology and anthropology of pain has identified a number of key conceptual and theoretical issues. The cultural resources available to interpret pain and particularly chronic pain are limited. Medical cultures¹¹ have, in social terms, appropriated the experience of pain and suffering yet chronic pain particularly defies both the practice and some of the fundamental propositions of Western medicine¹²: namely that there is objective knowledge knowable apart from subjective experience (Gordon 1988b). Two recurring philosophical problems are those of mind-body dualism (Kirmayer 1988) and intersubjectivity.

The understanding of pain and the ways available to talk about pain are based on mind-body dualism (Bendelow and Williams 1995). Approaches to understanding pain based on neurophysiology and psychology perpetuate this dualism and dichotomous thinking. Although there has been a move away from this dualism in thinking about best clinical practice which now emphasises multidisciplinary (described in chapter two), difficulties remain because language sustains the dualism as does the experience of pain itself. That is, pain feels physical.

¹¹ Including those of complementary therapies

¹² This term is used with acknowledgement that medical practice (particularly in primary care and in relation to chronic pain) is not a single culture, but nevertheless there are some key assumptions which are identifiable

Moreover, many of the analyses reviewed above have suggested that the experience of chronic pain calls into question the sense of intersubjectivity and thus fractures the 'social fabric' (Crossley 1996) through which one's sense of self and others is constituted.

There have been recurring calls to address these problems by developing a phenomenology of chronic pain, based on the experiences of chronic pain sufferers (Bendelow and Williams 1995; Good, Good et al. 1992). In particular, Bendelow and Williams emphasise the potential for the sociologies of the body and the emotions to inform this phenomenology (Bendelow and Williams 1995). Overall however, the sociology and anthropology of chronic pain, like the sociology of chronic illness (Bury 1991), can be seen to have focused more on problems than solutions, both in philosophical and practical terms.

Chapter Six: Study design, methodology and the field work process

This chapter describes the process of conducting the research. It begins with a brief overview of the study design and methods, before considering each of the elements of the research process in more detail including: the health service context and sampling sites; the process of sampling and recruiting respondents; the characteristics of participating respondents; an overview of the methodology of the study and the theoretical and research interests informing this; the development and content of interview topic guides, the process of interviewing and, finally, an overview of the process of analysing the data.

As has already been indicated, the data from interviews with general practitioners and with patients were analysed separately. More details of the process of analysis of each data set are given in following chapters which present the findings.

Overview of the study design and methods

The broad aims of the study were to describe general practitioners' and patients' experiences of chronic pain management within primary care, their perceptions of existing specialist pain services in the local health board area and their priorities for development.

The study used a qualitative methodology based on initial and follow-up semi-

structured interviews with general practitioners and patients who had been experiencing chronic pain for at least one year. The fieldwork was carried out over a two-year period, with follow-up interviews taking place approximately one year after the initial interview.

Patients and general practitioners were recruited from four specialist pain centres in the local health board area and directly through general practices in order to include respondents with diverse experience of health services. Patients were interviewed in their own homes. General practitioners were interviewed at their workplace. All interviews were tape recorded and transcribed verbatim for analysis. Themes and issues which emerged from the analysis of the initial interviews formed the basis of the topic guides used in the follow up interviews.

The study had the approval of the local research ethics committee.

Overall 29 general practitioners and 60 patients participated in initial interviews, with 28 general practitioners and 52 patients taking part in follow-up interviews.

Summary description of the history and structure of services for people with chronic pain in the health board area

At the time of developing the current study, a needs assessment for chronic pain had been recently completed by the local Department of Public Health. This provided

both an impetus for the work and a description of current services which served as a basis for the design of the sample. The needs assessment identified that there were four local specialist services based in four different trusts for people with chronic pain: three chronic pain clinics and a pain management programme. The structure and content of each of these services, designated in this study as specialist pain centres, are summarised below.

These summary descriptions provide a concrete illustration in local context of the key features of NHS provision for chronic pain, namely that services are diverse and have often evolved in response to individual or trust initiatives rather than being planned as area wide integrated services.

Centre 1

The anaesthetist led pain clinic (centre 1) is the only medical service for which 'pain management' was explicitly included in contracts with the health board and for which there was specific funding, though this was not that straightforward and the contracts are not that specific. The focus of the clinic is on physical interventions including nerve blockade, transcutaneous electrical nerve stimulation TENS, and pharmacological management. There is no multi-disciplinary assessment. People who are assessed as needing physiotherapy have to be referred on, as there is no direct physiotherapy input into the clinic. At one time there was an unfunded arrangement for clinical psychologist input into the pain clinic, but this was withdrawn and, as with physiotherapy, patients have to be referred on to the

generic clinical psychology service based at the trust. Approximately half of the patients are referred directly from general practice, the other half from other medical specialties.

Centre 2

The service at Centre 2 comprises a weekly pain clinic provided by a single anaesthetist with input from senior registrars. Half of the referrals are from general practitioners. Again the focus is on physical interventions, with no direct access to physiotherapy or psychology and patients thought to be in need of these services have to be referred on. There was no specific funding for this service and there have been periods when the clinic has been unable to accept any new referrals and has closed its waiting list.

Centre 3

This service at this centre was initially set up on short-term funding in order to see patients referred with medical as opposed to surgical orthopaedic problems. The service is provided by a consultant orthopaedic physician (full-time) with a background in general practice and general medicine, seeing patients referred with medical rather than surgical orthopaedic problems. Again, the designation of this service as a specialist pain centre can be seen as somewhat problematic. It was included in the needs assessment and in the study as a specialist pain management

centre as the majority of referrals were for pain as the main complaint, with people with low back pain constituting the largest identifiable group of attenders. The physician is able to perform osteopathy and acupuncture and there is direct access to physiotherapy but not psychology.

Centre 4 (Pain management programme)

The hospital where the pain management programme is based runs a range of rehabilitation programmes and has access to a range of rehabilitative treatments and professionals. The multidisciplinary pain management programme involves a detailed initial assessment based on an interview of prospective patients carried out by a small multi-disciplinary team (rehabilitative medicine, psychology, physiotherapy and occupational therapy). It is primarily based on group work with some input on an individual basis. The course incorporates education on the physiological basis of chronic pain, cognitive techniques, assertiveness, goal setting and pacing and relaxation as well as advice about physical exercise and practical activities. The course is led by a psychologist with input from other professions, principally physiotherapy.

The needs assessment also considered other locally available services of high relevance to people with chronic pain including complementary therapies, voluntary and self help groups. It did not review the level of provision and role of other generic primary care services which are worth noting here such as physiotherapy, community psychiatric nursing, occupational therapy and clinical

psychology. The availability and accessibility of these services vary from practice to practice. However, an issue of particular relevance is that across the health board area the availability of clinical psychology was seen to be poor and waiting times for clinical psychology were estimated at least three months, in effect, precluding the use of generic clinical psychology services as a management option.

It is perhaps worth drawing out several other issues which are implicit in this overview and which quickly became part of the researchers' assumed knowledge about services and about how they were perceived and discussed by the respondents in the study. Firstly, that, with the exception of centre 3 as an orthopaedic medicine specialty service, many patients were likely to have been seen by other specialties prior to being referred to a specialist pain centre per se. As such they could be referred to any of the specialist pain centres by their general practitioner or from another medical specialty.

Furthermore, as the centres were diverse, patients could be referred to more than one of the specialist centres. The degree of similarity between centres 1 and 2 was such that it was less likely that patients would visit both these centres. However it was relatively common for patients who had been referred to the orthopaedic specialty to also be referred to either centre 1 or 2, then to the pain management programme at centre 4.

In this context then, although some attempt was made to ask patients specifically

about their views of the centres, their descriptions often did not distinguish 'specialist centres' in this way. The pain management programme at centre 4 was exceptional in this respect. Patients who had attended an interview for the course as well as those who undergone the programme described this as a distinctive experience. On the whole, however, patients described their experiences at the named hospital in which the centre was based and did not distinguish between their experiences of the pain clinic and other medical specialties. Even more commonly they described their experiences in terms of their meetings with, and views of, specific clinicians or, less frequently, specific treatments.

In this context then, it was inappropriate to analyse the patient interviews either by making comparisons between patients recruited from different centres or by attempting to summarise views and experiences of particular centres. Whilst the latter issue is not problematic in analytic terms, it can be seen to present some difficulties of application of the research in a health service planning environment and is relevant to the broader methodological issue of the use of qualitative methods in this context.

Sampling of respondents: general practitioners and patients

As described above, the broad aim of the research was to inform the development of local services. As such, the primary purpose of sampling was to include people with a wide range of experience of chronic pain, or in the case of general practitioners, its management, and of services. In order to achieve this diversity, it was decided to

recruit both general practitioners and patients from general practice as well as from specialist pain centres.

A further parameter of the study was that it be a study of the experience of chronic pain per se, regardless of site of pain or diagnosis. This was not a particular difficulty from the point of view of recruiting general practitioners, nor of recruiting patients from pain clinics, who would naturally comprise a group of people experiencing chronic pain for a wide range of reasons. However, given the absence of any existing categorisation or registration of people with chronic pain problems in primary care, further consideration had to be given to how to achieve a diverse sample without asking general practitioners to select them.

Sampling of general practitioners and patients from specialist pain centres

All four centres described above agreed to help with the study. Lists of patients referred by their general practitioners and seen within the previous twelve-month period were obtained via computerised and manual case-note searches. The proposal was to interview twice as many patients as general practitioners. As such the overall sample was achieved by a) randomly sampling from general practitioner and patient pairs b) randomly sampling patients from each list c) and randomly sampling general practitioners. Letters of invitation to participate in the study were sent from the pain centres to patients and their referring general practitioner independently.

Table 1 Recruitment of general practitioners and patients through specialist pain services

	Number contacted	Number interviewed	Number re-interviewed
General Practitioners			
Centre 1	7	4	4
Centre 2	5	3	2
Centre 3	9	4	4
Centre 4	5	3	3
TOTAL	26	14	13
Patients			
Centre 1	12	8	8
Centre 2	19	7	6
Centre 3	12	7	6
Centre 4	11	8	7
TOTAL	54	30	27

Sampling of general practitioners and patients from general practices

General practitioners were selected at random from the area directory of general practitioners and invited to participate in the study. When a general practitioner declined to take part, they were replaced with another general practitioner chosen at random until the quota of 15 general practitioners was reached. As one of the purposes of sampling was to achieve a diversity in use of services amongst both patients and general practitioners, an attempt was made to try to include some general practitioners who had not recently referred patients to specialist pain

centres. As such, general practitioners who were known to have referred a patient to one of the four specialist centres within the previous twelve months were excluded from the sample. Participating general practitioners were asked to be interviewed twice and to help with the sampling and recruitment of patients.

As described above, the method of sampling of patients from general practices required some consideration. Given that the study was explicitly not of pain associated with specific medical conditions, morbidity registers would have been inappropriate sampling frames even if available.

In the developmental phase of the research, two sampling methods were explored with the assistance of the practice based in the researchers' department. Firstly, consideration was given to the possibility of using registers of repeat prescribing to sample from patients receiving analgesic medication. This was time consuming, there was difficulty in achieving consensus on the types of medication to include as criteria and lists produced too many ineligible patients. A second feasibility exercise was carried out, asking general practitioners to prospectively identify all patients attending over a three week period whom they knew were experiencing chronic pain, irrespective of whether this was the reason for attending or not. Patients to be invited to take part in the study were then selected at random from these lists. Having discussed the feasibility of both methods with general practitioners, the latter method was chosen for the main study. Despite the potential criticisms of this method, principally that it depended upon the general practitioner being aware that the patient was experiencing pain and that it allowed general practitioners to select

or deselect patients, it was felt to be most feasible and appropriate to the aims of the study.

Table 2 below shows the numbers of general practitioners and patients approached to take part in the study, the number who agreed and took part in initial interviews and the number who were re-interviewed.

Table 2 Sampling of general practitioners and patients through general practices

	Number Contacted	Number interviewed	Number re-interviewed
General practitioners	23	15	15
Patients	36	30	25

The recruitment process

Recruiting general practitioners.

Letters introducing the study to general practitioners contained a brief description of the study and what participation would involve. They explained that a researcher would telephone within the coming two weeks to either arrange a short introductory meeting which would give them the chance to find out more about the

study and to ask any questions, or to discuss the study over the telephone, before deciding whether or not to participate. General practitioners who were willing to participate in the study were interviewed in their workplace at a time suitable for them.

Recruiting patients.

Letters introducing the study, with a patient information sheet summarising the project, were sent to patients recruited from pain centres and from general practices from the lead clinicians and their general practitioners respectively. The letters, composed by the researchers, gave a suggested time at which a named researcher would visit them at home to explain about the study and to answer any questions that they might have before they decided whether or not to take part. The letters also explained that if they were not interested in taking part in the study and did not want to be visited that they should return the tear off slip in the stamped addressed envelope provided or telephone the department carrying out the research. Patients who agreed to take part were interviewed in their own homes.

Characteristics of the respondents

Characteristics of participating general practitioners

Of the 29 participating general practitioners, 21 were men and 8 were women. They were asked at interview how long they had been in practice. Within the sample there was a wide range of length of time in general practice, between 1 and

31 years (mean=13 N=24). The 29 general practitioners were based in 28 practices, and the practice settings were also wide ranging. The table below, based on the analysis of routinely available data, shows the diversity in terms of practice (list) size and socio-demographic characteristics of the practice population.

Table 3 Characteristics of the participating general practitioner's practices

Average list size (range)	8177 (3425-13225)
Practice in area of high deprivation	3
Practice in area of medium deprivation	9
Practice in area of low deprivation	16

Characteristics of participating patients and their practices

Sixty patients participated in the study, including 24 men (12 recruited through specialist centres and 12 recruited through general practices) and 36 women, (18 recruited through specialist centres and 18 recruited from general practices). The age range of respondents was wide, between 21 and 82 (mean=51.1). There was no difference between the mean age of respondents recruited through specialist centres and those recruited through practices.

The participating patients were registered with a total of 39 general practices, again from practices in diverse socio-economic settings, as table 4 illustrates.

Table 4 Characteristics of participating respondents general practice populations

	Number of patients recruited through pain clinics	Number of patients recruited through general practices	All
High deprivation	9	3	14
Medium deprivation	6	13	19
Low deprivation	14	13	27

- **Employment status of respondents**

Asking structured questions about respondents' socio-economic status was felt, on the basis of previous research, to be too intrusive and to interrupt the conversation. Respondents were asked only a single question specifically about their socio-economic position, whether they were working or not. Asking about whether respondents were working or not seemed a natural question to ask at the beginning of the interview, or emerged as relevant at other points. Full details of respondents' work status are given in the table below. Almost half (47%) of respondents were not working because of ill health. In all cases, the primary reason for not being able to work was because of the problem of pain.

Table 5: Employment status of respondents

	Patients recruited through pain clinics N=30 (%)	Patients recruited through general practice N=30 (%)	All N=60 (%)
Not working due to ill health ¹	17 (57)	11 (37)	28 (47)
Retired due to ill health	5 (17)	2 (7)	7 (12)
Not working (temporarily off work due to ill health)	1 (3)	0 (0)	1 (2)
Working part time	1 (3)	2 (7)	3 (5)
Working full-time	0 (0)	5 (17)	5 (8)
Retired	2 (7)	4 (13)	6 (10)
Not working	3 (10)	6 (20)	9 (15)
Unemployed	1 (3)	0 (0)	1 (2)

- Respondents' problems with pain

Respondents were also asked as early in the interview as possible, how they would describe their health, and whether they had any particular illnesses or on-going health problems, other than the problems with pain or causing the pain. Very few respondents (n=9) had specific medical conditions which were the cause of their pain. For the remainder of the respondents an attempt was made to classify the origin of their pain on the basis of their story which emerged during the interview. The classification and number of patients in each category is given in table 6. Sixteen people could not be classified on the basis of the origin or cause of the pain.

Sometimes this was because they themselves had no idea, but more often it was because their explanation consisted of a number of possible causes or incidents which may have contributed.

Table 5 Overview of respondents' ' problems with pain

	Patients recruited through pain clinics N=30 (%)	Patients recruited through general practices N=30 (%)	All N=60 (%)
Time in pain (mean years) (range)	9 (2-30)	11 (0.5-40)	10 (0.5-40)
Origin of pain			
Unclear/not categorised	10 (30)	6 (20)	16 (27)
<u>Back problems</u>			
Sudden onset	2 (7)	1 (3)	3 (5)
Gradual onset	6 (20)	4 (13)	10 (17)
<u>Accidental injury</u>			
Work	3 (10)	3 (10)	6 (10)
Home	1 (3)	2 (7)	3 (5)
Road traffic accident	3 (10)	3 (10)	6 (10)
Continuing pain following surgery	3 (10)	4 (13)	7 (12)
Osteoarthritis	1 (3)	2 (7)	3 (5)
Rheumatoid arthritis	0 (0)	3 (10)	3 (5)
Scleroderma	0 (0)	1 (3)	1 (2)
Endometriosis	1 (3)	0 (0)	1 (2)
No longer in pain	0 (0)	1 (3)	1(2)

Overview of the study methodology

A number of methodological and theoretical positions and formative research interests and perspectives contributed to the methodology of this study. These are described below.

The theory of the method

The theoretical location of this project at the outset was within the related sociological traditions of phenomenology, symbolic interactionism, ethnomethodology and grounded theory, a location similar to the eclecticism described for the sociology of chronic illness reviewed in chapter four. Overall, these theories have informed the broad approach to the data rather than the details of its interpretation. The phenomenology of Schutz has found more particular application and relevance for the interpretation of the data and its key points are summarised below.

- **Schutz' phenomenology**

Schutz' phenomenology (Schutz and Luckmann 1974) provides an interest in the sociology of everyday life (Altheide 1977), of taken for granted knowledge (Douglas and Johnson 1977), mundane reason (Pollner 1974, 1987) and intersubjectivity (Schutz 1972; Heritage 1984). The key aspects of his theoretical position are

summarised below. Schutz' theory of practical relevance was used in more detail to analyse and interpret the interviews with general practitioners and as such is described more fully in the forthcoming chapter (Schutz 1970).

In attempting to find a solution to the debate about objectivity and subjectivity, Schutz took the phenomenological stance of 'bracketing out' concerns about reality, seeking to understand the structure of consciousness within what he termed 'the natural attitude'. In the natural attitude, reality is taken for granted, that is unlike philosophers, people in everyday life do not find the nature of reality and what is objective problematic. From this position, the key to understanding social life and developing a sociology of meaningful social action is to study what people take for granted. Schutz describes other aspects of the 'taken for granted' including the natural attitude of knowing that if something can be done in certain circumstances, it can be done again in similar circumstances, which Schutz termed recipe knowledge or action. Schutz also described the importance of processes of typification of knowledge. The process of typification consists of ignoring what makes a particular object unique and placing that object in the same class with others that share the same trait or quality. Types are formed in relation to a particular purpose at hand.

Social actors are seen to have a 'stock of knowledge at hand', formed by processes of sedimentation and determined by practical interests. This knowledge, made up of 'typifications', is biographical and unique to each individual as the accumulation of past experiences and of knowledge 'handed down' by society. This stock of

knowledge is patchy, contradictory and incomplete, though the patchiness is not necessarily problematic. The relationship between what is taken for granted and that which is problematic is determined by the practical interests of the actor, practical interests in turn constitute actors' spheres of relevance.

In developing his theory of social action and of social knowledge, Schutz also provides a theory of intersubjectivity, again within the natural attitude. Schutz' interest in analysing the problem of intersubjectivity, or finding its mundane solution in everyday life, is both philosophical and methodological. It is methodological in the sense that he is concerned to demonstrate the meaningfulness and appropriateness of social science interest in understanding other people. Schutz draws attention to two principal 'taken for granted assumptions' which underpin intersubjectivity in everyday life. Firstly, the assumption of interchangeability of standpoints, that is the assumption that others in the same position would see the world in the same way and conversely that disagreements about 'reality' can be explained in terms of different perspectives. Secondly, that intersubjectivity demands congruence between systems of relevance.

- **Grounded theory**

The methodology of this study also drew on grounded theory approaches (Glaser and Strauss 1967; Strauss and Corbin 1990, 1998), that is approaches which seek to develop 'middle range' theory based on inter-relationships between themes and categories which emerge from a inductive process of analysis. Grounded theory

approaches therefore stand in contradistinction to deductive approaches which use a particular theoretical framework to collect and analyse the data.

This study drew on grounded theory approaches in a limited way, taking explicit account of existing criticisms and debates about the approach. Firstly, this study took explicit account of the continuing debate about the extent to which any analysis of qualitative data can be carried out without some, though perhaps not a single, theoretical framework to draw upon in a flexible rather than an imposing way (Strauss and Corbin 1998). In this respect, as has been discussed in chapter one of the thesis, the analysis described below has involved a dual process of theoretical exploration of existing research on the sociology of medical work, the sociology of chronic illness and the sociology and anthropology of chronic pain alongside an inductive approach to the data analysis. The end result is that the analysis of current data is located within an existing body of knowledge, though quite what this location would be was not determined at the outset.

Secondly, the analysis and reporting of data in this study can be seen to illustrate criticisms that, rather than producing middle range theory or a plausible set of relationships amongst concepts, grounded theory researchers produce 'rich description' which is not necessarily theoretical. In the context of the health services research agenda of this study, explicit priority was given to producing rich description on the grounds that this may have particular educational value with the potential audience of clinicians. Thus although the study attempts to place rich description in a theoretical context, it gives equal priority to the processes of

description and theoretical development.

Thirdly, this study used some grounded theory techniques for analysing and reflecting upon the data through processes of constant comparison, constant questioning or different readings of the data, and open coding to identify key themes, elaborate concepts and describe categories (Strauss and Corbin 1990). The use of these techniques in this study is discussed in more detail below in the section describing the process of analysing the data.

Formative research interests

Within the broad methodological approach of the study, several of the author's existing and developing research interests or sensitivities can be seen to have had a formative influence on the processes of data collection and analysis. These interests can be summarised collectively as a 'focus on solutions', a focus which guided the development of the topic guides, the interviewing process and the process of data analysis.

As mentioned previously, this research developed from an earlier project on patients' perspectives on primary care, which had examined the lay evaluation of health care. This project highlighted two issues which the current study explicitly attempted to address. Firstly, that patients often appeared reluctant to criticise health professionals and to react negatively to repeated questions about whether they had experienced any problems or difficulties. This research adopted the

strategy with both patients and general practitioners of asking specific 'positive' questions in order to seek solutions rather than dwell on problems, for example about what had been particularly helpful, what they themselves had learned. Researchers introduced follow-up interviews with a re-statement of the interest in solutions and the way that people themselves had solved problems. The topic guides included questions based on problems which emerged in the first interviews and respondents were asked if they had any ideas or suggestions about how to manage these difficulties. In feeding back identified problems to respondents, general practitioners were asked to consider the problems identified by patients and vice versa. More details on the topic guides used in both initial and follow-up interviews are given below.

A second issue identified as problematic in previous research is that of asking people about existing services or the potential for development. It has been termed the problem of "deferential responses" (Porter and MacIntyre 1984), that is, "what is must be best". As respondents only know about the services they have experienced they have little basis for comparing and evaluating these services or for considering how things might be different. In order to address this issue, respondents were asked generally about how things could be changed for the better, but they were also given some more concrete suggestions to consider and comment upon.

The analysis also used, and highlights the use of exceptional cases as pointing to solutions. The use of the term exceptional is not to imply a (strongly positive) value judgement. Thus, for example, some respondents' detailed descriptions of what they

found helpful about (usually their own) general practitioner and his or her approach 'stood out'. These often included positive aspects of care which the general practitioners who were interviewed did not describe and in some instances described how some general practitioners have found 'solutions' to issues which other general practitioners raised as problems. In short they can be seen to illustrate that 'it can be done'.

A final research sensitivity which influenced the process of interviewing patients can also be seen as 'solution focused', but derived from concerns about the impact of the interviewing process on respondents rather than the more practical concerns outlined above. There were two identifiable strands to this concern. Firstly, that some respondents found the process of being interviewed about what is, by definition, a problematic area of their life emotionally distressing. The inclusion of questions about how they managed or had solved problems was seen to resonate with recent trends towards solution orientated therapy (O'Connell 1998), which in turn draw on social constructionist positions and emphasise the therapeutic value of constructing narratives.

Secondly, the research explicitly recognised one of the basic contradictions or double binds which confronts people living with illness: that of obtaining acknowledgement (in human or resource terms) of their suffering whilst maintaining the positives about themselves and their lives. As the analysis below will describe, sustained management of this contradiction, especially in the context of making claims on health and social welfare services, is in itself a considerable

demand. From the researchers' perspective, the contradiction is difficult to manage in that attempts to convey other peoples' distress and suffering risk 'summing up' people in terms of their problems or conversely understating or trivialising their problems.

The field work process

Overview of the interviewing process

The overall approach to interviewing both general practitioners was informal. As described above, the researchers had planned to make introductory visits to respondents to explain the study in more detail to them and to introduce themselves. Whereas patients were sent a time and date upon which the researcher would visit, appointments were made with general practitioners in advance either by speaking to the general practitioner directly or through the practice managers. Many general practitioners, and some patients, were expecting to be interviewed at the introductory visit and the researchers quickly learned to go along prepared to carry out the interview there and then, or to conduct the 'introductory visit' over the telephone.

The study was introduced to both general practitioners and patients as being about chronic pain, and that the researchers wanted to understand their experiences and views. The researchers explained that the interviews would be tape-recorded so that they could concentrate on what was being said rather than having to take

notes, that the interview would be transcribed and read over as part of the process of analysis and that the tape recordings and the transcripts would be confidential to the research team. The researchers reinforced that respondents should feel free to say as little or as much as they liked about any of the topics raised, and should at any time feel free to ask questions or bring up points that they thought were important even if the researchers had not asked about them.

The development of the topic guides for the initial interviews with both patients and general practitioners were based on exploration of the relevant literature, informal discussions and pilot interviews. Topic guides for follow-up interviews were based on the analysis of initial interviews.

The follow-up interviews were also introduced similarly to general practitioners and to patients, that in these interviews researchers would ask about ideas and issues which had emerged from the first interviews for discussion with them, that the purpose was to explore these issues with them, and that they should feel free to agree or disagree or add anything. As mentioned above, the researchers also explained that the first interviews had uncovered a lot of problems, and that a particular interest was in whether respondents had any suggestions or ideas about how these problems arise or what might be done about them. Details of the issues which were followed-up in the second interviews are not given in this chapter, but are considered in the chapters which present the analysis as and when relevant.

Although the broad approach to the recruitment and interviewing process was similar for general practitioners and for patients, the initial topic guides for general practitioners and patients were developed separately and there were some differences in the content and the 'feel' of the interviews and these inter-related issues are described in the following sections.

Development of topic guides and the process of interviewing general practitioners

As noted in the introductory chapters above, there has been little sociological research based on interviewing general practitioners about specific areas of their work and little work on lay (or professional) understanding of pain or chronic pain. The topic guide was developed primarily on the basis of a series of sensitising informal discussions and, as the topic guide developed, pilot interviews with general practitioner friends and colleagues who agreed to help with this stage of the fieldwork. The interview guide covered the following broad topic areas:

- general practitioners' professional background, length of time in general practice, length of time with the current practice, perceptions of the practice population and any areas of specialist interest within general practice
- their perceptions of their work with pain and approach to pain management in general, including how they would approach the management of a patient presenting with pain and what kinds of things would influence their decisions
- their understanding of chronic pain, their perceptions of their role and their approaches to managing chronic pain

- their perceptions and use of specialist services for people with chronic pain, including their reasons for referral
- their descriptions of 'ideal' and 'nightmare' chronic pain patients
- their perceptions of chronic pain management within primary care
- their perceptions and use of medications for chronic pain
- whether they had any personal experience of chronic pain, either having pain themselves or knowing friends or family with chronic pain
- their perceptions of the potential for service development, particularly within primary care

The summary above gives an overview but it is perhaps worth considering some of the questions and the overall composition of the initial topic guide in more detail. This more detailed consideration is, of course, given with the benefit of hindsight. Firstly, knowing where to start to ask questions about pain or chronic pain without making assumptions was difficult. The topic guide therefore tried to avoid assumptions about whether general practitioners had a definition of chronic pain, say, in contrast to acute pain. Thus the earliest questions in the interview asked about: how general practitioners might approach the management of a patient with pain (unspecified); what kinds of things might influence their decisions about management; whether pain was something they thought of in relation to specific conditions or in its own right; how confident they felt about assessing a patient's pain and whether this presented any problems. Only later were general practitioners asked about chronic pain; how they would define chronic pain;

whether they thought there was a difference between acute and chronic pain; how they would describe their role in helping people with chronic pain and could they describe their ideal and 'nightmare' chronic pain patients.

The decision to ask about ideal and very problematic patients arose from more general discussion in the research team about the potential differences between asking general practitioners about their work in general as opposed to asking them about specific patients. The latter, it was anticipated, might give more detailed descriptions of their work in practice as opposed to their work in theory. A number of different ways of asking general practitioners to bring specific patients to mind for discussion were considered. Asking about the patients participating in the study was problematic in that patients who were recruited through specialist centres were not known to be participating by their general practitioners. Also the researchers felt more comfortable about a study design and an interviewing process which did not allow direct comparisons between patients views and what general practitioners' views of individual patients were and vice versa. It was felt that this would reassure both general practitioners and patients about confidentiality and would ensure that researchers' reactions to respondents would not be influenced by the views of others. A further issue was that of avoiding guiding general practitioners to consider patients with particular illnesses or conditions.

From consideration of these issues questions about ideal and particularly problematic patients were used in the pilot interviews. The term 'particularly problematic' was in itself problematic, as general practitioners explained that

patients with chronic pain were often problematic. The term 'nightmare' was used after a general practitioner had used this term spontaneously in one of the pilot interviews. It appeared to discriminate particularly difficult patients effectively. However, some general practitioners were not at ease with the question and the question had to be delicately posed, that is the researchers had to convey their understanding that the question could be seen as problematic and as derogatory to patients but that it was a clumsy way of getting at recognisable issues. Furthermore, researchers were alert to instances where general practitioners talked about individual patients spontaneously in order to explore these in more detail.

Along with these very broad and exploratory topics described above there were questions which were relatively specific, but which were felt to be necessary, if not obvious, given the aims of the project. These were questions on prescribing, referral and management within wider primary care teams. Whilst it remained difficult to imagine a topic guide which had not included questions about these issues, in retrospect there was scope to reflect upon the way that these issues had formed the principal means of constructing general practitioners' work. Further reflection on this was carried out both in the process of analysing the data and in the follow-up interviews.

The initial interviews with general practitioners lasted about an hour. As there is little research which reports general practitioners' descriptions of their work, there was little background to serve as preparation for the kind of responses general practitioners might give, or their reactions to the process of being interviewed. A

clear effect of this was to generate some concerns for the researchers in the early stages of the project.

Firstly, an issue that perhaps could have been anticipated, was that general practitioners appeared to interpret the interview as a 'test' or 'assessment' of their practice. This had not appeared so obviously as an issue in the pilot interviews, probably because the pilot interviewees, by virtue of the process of recruitment, were more familiar with the researchers and with taking part in a wide range of research. It did emerge as an issue very early on once the fieldwork proper got underway. After discussion amongst the research team, it was decided to reinforce explicitly in the introduction to the interview that this was not the case, and that the project was about their views and experiences and was attempting to understand their work from their own perspective. Despite this attempt at 'reassurance' before the initial interviews, the experience of the research team was that one of the values of the follow-up interviews was that general practitioners appeared to feel able to be much more relaxed and discursive.

A further related issue, was the researchers' initial reaction to the interviews with general practitioners. Firstly, it seemed that the emergent accounts were relatively homogenous (that is relative to the interviews with patients), and that recurrent themes emerged clearly from very few interviews.

Secondly, the research team was concerned that the researchers' relative lack of

clinical knowledge might mean that general practitioners' responses were not as clinically detailed as they might have been had they been talking to a fellow clinician. Additionally, it might be the case that clinical issues which were raised by general practitioners were 'missed' by the researchers, that is not followed up during the interview or not picked up on during the process of analysis. For example, the researchers discussed concerns about not picking up clinical issues about one general practitioner's use of a particular drug in a particular circumstance.

Overall then, the process of interviewing general practitioners felt very different from the process of interviewing patients and the above areas of concern appear to have contributed to this. A further contributing factor was perhaps that the two principal researchers had already carried out a study interviewing patients about their care and had developed 'confidence' in the kind of data and issues that might emerge.

There are two reasons for recording these concerns. Firstly, simply to note the curiousness of these concerns, or more specifically, the curiousness of the absence of similar concerns about interviewing patients, especially since, as described below, patients frequently explained that people could not understand what it was like to experience chronic pain unless they had it themselves.

Secondly, they attracted the researchers' attention in the early stages of the project

and this in turn had consequences for later stages of the project. In particular a detailed analysis of the initial interviews with general practitioners had been carried out prior to the follow-up interviews. This raised a large number of issues to be addressed in the second interviews.

The follow-up interviews with general practitioners sought to:

- present a summary of the emerging analysis of the process of general practitioners' work with pain
- present particular themes and issues which had emerged from the initial interviews with general practitioners (for example, could they explain a bit more about what might be involved in some of the areas that general practitioners had described in the first interviews such as 'getting people to accept', 'helping people to get on with their lives')
- raise some of the issues or problems that had emerged from the interviews with patients, explicitly asking general practitioners about what their understanding of patients views were, for example in relation to medication
- finally, in the context of the researchers initial concerns, the second interviews with general practitioners gave the opportunity to re-examine some of the assumptions that had underpinned the initial topic guides

Given the detail with which the initial interviews had been analysed, the draft of the follow-up topic guide was very long. In order to cover all the topics identified, two follow-up topic guides were devised which prioritised different topics, although all

the topics were included in both schedules so that they could be covered if there was sufficient time. Half of the general practitioners taking part in follow-up interviews were interviewed using one of the guides and half were interviewed using the other. Follow-up interviews with general practitioners for the most part were longer than the initial interviews. As noted above the researchers' reaction was that the follow-up interviews with general practitioners were particularly helpful as general practitioners appeared much more relaxed and less as if they were being 'assessed'. Knowing the researcher (in some cases) or being familiar with the research process may have been important.

Other factors may also have contributed to this. In particular, by reflecting on the centrality in the initial interviews of the topics of diagnosing, prescribing, referring and asking about other aspects of their work which seemed less well defined, the researchers set a context which was outwith the areas of their work which could be formally assessed but introduced other topics directly, such as 'helping people to get on with their lives', which were not associated with formal assessment.

Development of topic guides and the process of interviewing patients

The development of the initial topic guide for patients drew on the work of the author's previous research project, on patient's perspectives on primary care (Hopton et al. 1995) as well as pilot interviews and a discussion group with people recruited through a local voluntary self-help group. In broad terms the topic guide covered:

- respondent's age, family background and whether they were working or not
- their perceptions of their general health and whether they had any specific long-term health problems or illnesses
- their contact with, and experiences and perceptions of hospitals
- how long they had been in pain, how the pain had started and its history
- their experience of general practitioners and perceptions of their relationships with general practitioners and general practitioners' roles
- their use of medications and other therapies and treatments
- their priorities for the development of services
- their experience of pain in the context of daily life

The interviews with patients were long, with most lasting an hour and a half and many lasting longer. Although a quite detailed topic guide had been prepared, most respondents talked in great detail about their experiences with very little prompting, many recounting the history of the pain and their experiences of health services without waiting to be asked anything. Thus, most topics were covered without prompting, or when raised by researchers were spontaneously covered in detail. An overall effect of the spontaneity of respondents and the fact that they seemed willing to spend considerable time being interviewed was that the interviewers were able to probe issues raised by respondents themselves in some detail. In summary then, the interviews with patients appeared to be naturally detailed, and autobiographical such that an initial reaction to this data was that of heterogeneity as researchers attempted to grapple with different causes, sites and effects of pain in diverse

biographical contexts. This was a very different researcher reaction from that to the general practitioner interviews as discussed in the previous section.

An important concern was that the process of being interviewed was physically and emotionally distressing for respondents, and sometimes for the interviewers. The researchers discussed the importance of sensitivity to these issues. In particular, interviewers explained at the start of the interviews that respondents should say if they were in discomfort, wanted to finish, take a break or move around. Similarly in response to the effort that respondents were making, interviewers were prepared to be flexible in the time spent with respondents, spending time chatting afterwards if this seemed appropriate.

The process of interviewing patients immediately felt more familiar and less problematic than the process of interviewing general practitioners. The amount of rich data collected immediately instilled greater confidence, though first readings and discussion produced some concern that it was so diverse that analysis would be difficult.

There were some exceptions to this, again, these are described in more detail in chapter nine which reports the data and analysis, in that one of the interviewers felt strongly that the topic guide was not appropriate for use with people with particular medical conditions (in this case rheumatoid arthritis).

The broad content and purpose of the follow-up interviews with patients were similar to that of general practitioners (see above). A distinctive and particularly important purpose of the follow-up interviews with patients was to catch-up with what had been happening since the initial interview, whether there had been any changes in their health, treatments or daily lives. Interviewers asked very generally about what had been happening and followed up specific issues that had been raised.

Although the interviewers had felt confident about the data when conducting the interviews and on initial readings of the transcripts, later reflections of the author were, on the contrary, that so much data had been collected that the process of analysis was too time consuming. To be more concrete, about a third of the interviews could be described as exceptionally long (up to three hours) and with follow-up interviews of similar length, simply reading the transcripts from a single respondent could take a whole day. Issues about the over-collection of rich qualitative data are just as important to address, for analytical, ethical and project management reasons, as the more common observation that the data is under detailed or superficial.

The process of data analysis

Data analysis was on-going throughout the fieldwork, with the research team meeting regularly to discuss issues and emergent themes. The interviews with general practitioners and patients were carried out simultaneously, with both

interviewers interviewing general practitioners and patients.

Nevertheless the process of analysing the data from interviews with general practitioners quickly became distinct from the process of analysing the interviews with patients. That is not to say that discussions amongst the research team did not consider their emerging understanding of the same issues from general practitioners' and patients' perspectives, but that the data set was analysed in two sections rather than as a whole. Thus at a very early stage, the analytic process had diverged towards producing analyses of the two data sets with the idea that these two analyses would form the basis for an integrated analysis at a later stage. However, as the separate analyses became more detailed so the appropriateness of such an integrated analysis became more questionable.

Some issues which have already been mentioned can be seen to have contributed to this divergence. The interview topic guides were constructed differently, though with areas of overlap, and were seen to be necessarily so. Moreover, the interviewing process felt different and generated different concerns. The data sets appeared different, and the apparent homogeneity of the data from interviews with general practitioners perhaps served to draw the researcher's attention to the inter-relationships between the readily apparent themes within this data. Had the general practitioner data perhaps appeared as diverse as the data from interviews with patients, the task of analysing both sets of interviews as a single data set may have seemed more 'natural'. However, in retrospect, the approach of producing two analyses can be seen to have taken explicit acknowledgement of the issue of

relevance (Schutz 1970) in that general practitioners and patients could be seen to have different 'practical interests' in terms of what they talked about in the interviews and in terms of what each group was 'doing' in the context of the interviews.

Alongside this theoretical justification of the separate analyses, runs a justification in terms of the explicit research interest of providing a rich description of the data as whole, a consideration which also pointed the analysis in different directions. To make this point more explicit, had the analysis sought common themes across interviews, perhaps to examine discourses of mind and body, this would have served to distort the presentation of the data and to neglect the fact that general practitioners talked a lot about medication and the problems of medication and patients did not. More fundamentally still, patients presented their own direct experiences of pain in autobiographical context, whereas general practitioners talked about their experiences of their professional work and of working with a range of people with pain, but without direct experiential knowledge of what it was like to be in pain.¹³

More detailed analysis of both sets of data was carried out by the author. All analysis was carried out manually, consisting of a number of different readings of the transcripts. The initial readings of both sets of interviews, read as separate data sets, was informed by the preliminary identification of themes in the research team

¹³ Although as noted above, general practitioners were asked about whether they themselves had experienced pain or whether they had personal experience of chronic pain from family or close friends. Very few general practitioners had either direct experience or personal experience through family or friends.

meetings, but returned to consider the salient themes or issues in the context of each individual interview. These themes, the researcher's reactions and theoretical ideas as they emerged by comparison with other interviews were noted to give an 'audit trail' of the initial exploration of the data. Later readings produced summaries of each interview in relation to identified themes, such that broad themes could be compared across interviews for elaboration or reformulation.

The analysis also made use of exceptional cases. As indicated above, some exceptional cases were used in consideration of 'solutions'. Other exceptional accounts have also been used as a comparative basis for reflecting on what was missing or noticeably absent from the majority of interviews.

As indicated in chapter one, the introduction to this thesis, although the author conducted some pilot interviews with general practitioners, led the field work process and carried out the analysis of the data presented in forthcoming chapters, the interviews were carried out by other researchers. In this context then, the analysis is not based on face to face interviews but on an analysis of text. It is perhaps worth considering this issue in more detail.

The following observations are offered on how the process of analysis felt. The process of analysis felt similar to that of a previous study¹⁴ in which the author had carried out face to face interviews. In the previous study, as was the case in this

¹⁴ The author has experience of carrying out similarly constructed interviews with people with asthma and rheumatoid arthritis and in interviewing general practitioners about the health needs of their practice populations

one, the researchers had kept field notes of their observations about the interviews. These did not form part of the analysis in either of the studies as the author's overwhelming feeling was that there was more than enough data to try to consider within the transcripts themselves. However, the author was fully aware of many of the issues in these notes as they had been raised and discussed in team meetings throughout the project. The main difference that the author was aware of in analysing the current data as text was that it was more difficult to remember who had said what, and hence to retrieve data and to place themes in their context within the interview as a whole.

The main impetus for addressing the issue of analysing disembodied data is a purely academic one, highlighted by reflection on the emergent themes from the interviews with patients of emotionality and issues of the visibility/invisibility of pain and discomfort. In relation to the former, the research team had discussed their own feelings of emotional distress and those of the respondents. However, reading the interviews carried out with patients was often distressing, with the author often having to take breaks. Respondents' descriptions were often very vivid and the interviews as a whole very dramatic as the stories unfolded, often as monologues, even on paper. The author's audit trail of the initial readings of the interviews contains many observations on the strong feelings invoked. It is interesting to note that re-reading these initial reactions in the very latter stages of analysis drew the author's attention to the development of immunity to this emotional content and to some of the horrors that patients recounted.

In relation to the issue of visibility or invisibility of pain some acknowledgement of the fact that the data analyst did not 'see' the respondents seems appropriate, though attempting to reflect upon what the impact of this might be is perhaps something of a hollow exercise. On the one hand, the interviewer analyst might have experienced the task of interpreting people and their accounts of invisible pain at first hand. On the other hand, the analyst of text is not 'distracted' by this task and focuses directly and necessarily on peoples' descriptions of their experiences of this issue.

Summary

The study is based on initial and follow-up semi-structured interviews with patients and general practitioners recruited from four specialist pain centres in the local health board area and directly through general practices. The study was explicitly a study of the experience and management of chronic pain per se, regardless of site of pain or diagnosis. The methods of recruiting respondents sought to ensure that the sample included respondents from with diverse experience of health services, and, in the case of patients, diverse experiences of pain.

Twenty-nine general practitioners participated in the study of whom 21 were men and 8 were women. They had been in general practice for a wide range of length of time and the practised in diverse settings in terms of practice size and the socio-demographic characteristics of the practice population.

Sixty patients participated in the study, including 24 men and 36 women. The age range of respondents was wide, between 21 and 82 (mean=51.1). Almost half (47%) of the respondents were not working because of ill health. In all cases, the primary reason for not being able to work was because of the problem of pain.

Several methodological approaches and formative research interests and perspectives contributed to the methodology of this study. The related sociological traditions of phenomenology, symbolic interactionism, ethnomethodology and grounded theory have informed the broad approach to the data. The phenomenology of Schutz has found more particular application and relevance. In keeping with grounded theory methodology the process of data analysis has involved a dual process of theoretical exploration of existing research alongside an inductive approach to the data analysis. Within the approach of generating grounded theory or concepts, equal priority was given to producing rich description.

The process of analysing the data from interviews with general practitioners quickly diverged from the process of analysing the interviews with patients, producing analyses of the two data sets. It had been intended that the two separate analyses would be eventually be integrated. However as the separate analyses became more detailed so the appropriateness of such an integrated analysis became more questionable. In retrospect, the approach of producing two analyses can be seen to have taken explicit acknowledgement of the issue of relevance (Schutz 1970). Thus the forthcoming section of the thesis which reports the analysis of the data from the

interviews with general practitioners separately from the analysis of the interviews with patients.

Chapter Seven: General Practitioners' accounts of the process of managing chronic pain

This chapter contains an analysis of general practitioners' accounts of the overall process of working with people with chronic pain.

The first section of this chapter details the methodology and process of data analysis, describing the development of a model or 'ideal type' of general practitioners' accounts of their work with people with chronic pain. The analysis draws attention to the construction of chronic pain, and people with chronic pain, as part of a process which is represented analytically in terms of two phases, with some areas of work being on-going throughout. The second section of the chapter outlines this model, describing the two stages and the indications of transition between them. Some aspects of general practitioners' work were continuous throughout the process and these are detailed in the third section. The final section presents a reflective summary of the analytical model in the context of issues emerging from the analysis of follow-up interviews.

Methodology and process of data analysis

As outlined above, the analysis of interviews with general practitioners is based on an 'ideal type' or a composite representation of general practitioners' accounts of their work. It is important to remember that the term 'ideal' refers to the fit between the analytical representation and the data, not to 'ideal' in terms of 'best clinical practice'. The representation is of general practitioners' accounts of the process of

managing chronic pain, not the actual process or the researchers' interpretation of that process. The original intention was not to develop an 'ideal type' representation of the data, rather the feasibility or appropriateness of this approach emerged only in the later stages of analysis, carried out after the fieldwork was completed. This section of the chapter describes the process of constructing the data, beginning with a description of the theory of the method

The theoretical approach to the data

As described in the previous chapter, the phenomenological tradition of research in sociology is one of the main methodological influences upon this project, particularly the work of Schutz (1970, 1972). Two aspects of Schutz' phenomenological approach are important to highlight in relation to the analysis of general practitioners' descriptions of their work. Firstly, the practical knowledge of everyday life is patchy and incomplete. Secondly, that "perception and understanding of the world cannot be separated from practical interest, one's own practical interest and sphere of relevance" with the implication that "motives, means and ends, as well as causes and effects are strung together without clear understanding of their real connections" (Heritage 1984).

These principles guided the analysis of the interviews with general practitioners in three ways. Firstly, they indicated the need to develop an understanding of the practical context in which general practitioners' work. Secondly, they identified that practical knowledge can contain logical contradictions which may or may not

be experienced as problematic. Thirdly, they locate the analysis within a sociological perspective on medical work which seeks to examine the relationship between ‘formal’ knowledge and practice and which stands in contradistinction to ‘rational decision making’ models which characterise much of the research on evidence based clinical practice.

This theoretical approach explicitly guided the author’s attention through initial readings of the data, in which the general practitioners’ accounts ‘appeared’ to be about what they do, prescribe medication for example, to consider their explanations of why they do things. In the terms used in this thesis, the analysis moved from considering core work to consider the work hidden behind these core activities. The terms reflect differences in the ways that general practitioners talked about different aspects of their work, with core work being recognisable “chunks” of work that they appeared confident in describing (and doing) in contrast to hidden work, for which there appeared to be no shared account.

The importance of the analytical distinction between core and hidden work is twofold. Firstly, the analysis indicates that different areas of hidden work can be seen to conflict with each other and secondly, that core work can serve a range of hidden functions.

The process of data analysis

The process of data analysis involved reading of transcripts from the initial

interviews to identify key themes and to produce an intermediate analysis. An outline of this analysis and key elements within it were fed back to general practitioners in the follow-up interviews for comment or elaboration.

A short summary of this intermediate analysis and thus the issues that general practitioners were asked to comment on is as follows. Firstly, that much of the work that general practitioners described seemed to consist of what is termed here core medical work of assessment, diagnosis, prescribing and referral. Secondly, that general practitioners described work such as providing support or helping people to get on with their lives. This seemed much more vague, appeared to emerge only after the core work had not resolved the problem. Finally, there was a phase of care which was patient-led and appeared to lack strategy.

The responses of general practitioners broadly confirmed this analysis, whilst identifying some important cautions and prompting a closer look at the nature of 'vague psychological' work. The follow-up interviews allowed critical reflection on the aspects of work identified as core work, such as prescribing and referral.

To give a specific example, the intermediate analysis was that much of the first interviews were taken up with discussion of medication, suggesting this was the major area of work. When this analysis was discussed with general practitioners for comment in the second interviews, most general practitioners agreed that the areas of work of diagnosis, prescription and referral were their main roles or "bread and butter" work, as one general practitioner put it. However, most added that

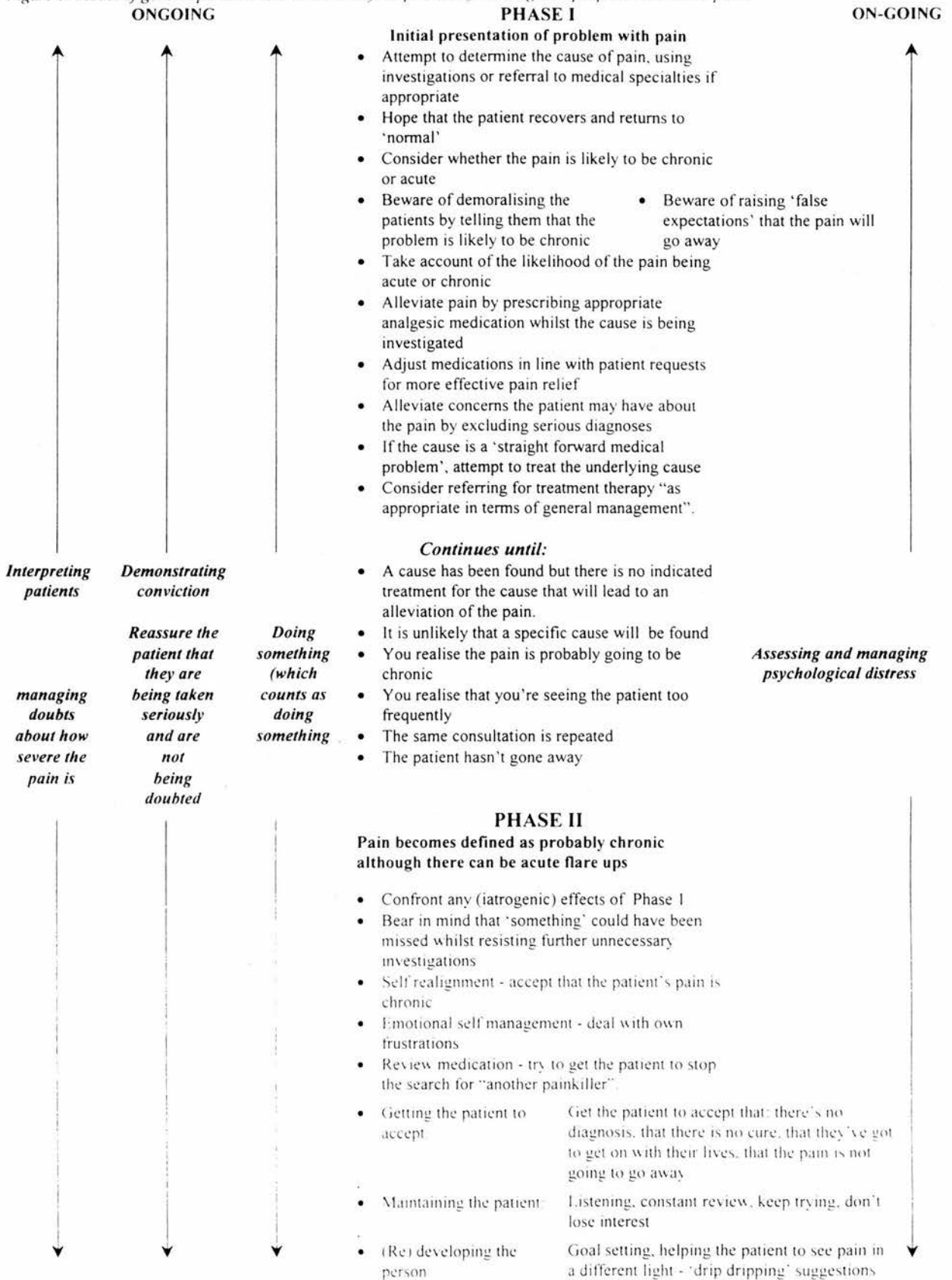
psychological work and on-going support were also important aspects of their work.

Re-analysing the data, the apparent dominant role of discussion of medication in accounts of general practitioners' work appeared to have emerged from the fact that they could spontaneously describe an approach to prescribing medications which was detailed, comprised a number of identifiable sub-problems, and was an indicator which formed a range of functions in their accounts of the process of work. In other words, there was a lot that general practitioners could say about medication, as described in chapter eight below. This contrasted with, for example, helping people to get on with their life, which most general practitioners did not discuss, even when prompted, to the same level of detail.

- **Constructing the model of general practitioners' accounts of the management process**

The overall structure of general practitioners' accounts of the process of work with people with chronic pain and the different elements it comprises is represented in figure 2.

Figure 1: Model of general practitioners' accounts of the process of working with people with chronic pain



The model was developed as follows. Each individual general practitioner's account of their work, from both initial and follow-up interviews, was analysed in terms of process and content. The composite representation in figure 2 was based on the elements of all individual general practitioners' accounts. It attempts to be comprehensive and thus to represent all aspects of the work which general practitioners mentioned explicitly or which was implicit in their accounts. In other words, not all general practitioners described all these elements of work. For example, very few general practitioners described work labelled in the figure and below as 'helping people to get on with their lives'.

Although the interviews were explicitly about chronic pain, the initial interview schedule actively sought to make no assumptions about what general practitioners' definitions of chronic pain, or patients having chronic pain, might be. Indeed, to pre-empt the description of the analysis which follow, the definitions of chronic pain can be seen as implicit in the accounts of the process of management rather than as a category or categories (or diagnosis) which informs management from the outset.

In order to avoid assumptions about definitions of chronic pain or about the process of management, general practitioners were asked early in the initial interviews how they approached the management of someone presenting with pain. General practitioners' responses to this question were very similar and comprised an account

based on some of the elements included in what has been termed phase 1 of the analytical model¹⁵. However, it is important to state that the analytical model of general practitioners' accounts of the process of management, in particular the two phases, is not based solely on responses to this question. Throughout the interviews general practitioners' accounts placed different aspects of their work in sequence with an implicit time course and the model reflects the overall sequential accounting process or narrative structure.

The following extract illustrates the implicit time course of once/then and the construction of chronic pain in terms of process rather than category. The general practitioner explained that his understanding of chronic pain is "pain which is on-going and which has no realistic hope of solution, cure" and was asked when does pain become chronic:

"Once you seem to have exhausted every avenue or have discovered the cause of the pain and discovered that it's not amenable to any form of treatment, at that point I think I would have a chat to the patient and say we're not now trying to get rid of the pain, we're trying to make life easier with the pain. Perhaps a different emphasis on things at that point."

(jsgp14)

As indicated in figure 2, general practitioners' accounts implied two identifiable phases of work. Accounts of work in the first phase implied a purposeful and linear process, with some consequential or "if-then" elements, though there was no strict order and the listing (in figure 2) of these elements should not be taken to imply either an order of sequence or importance. Many of the elements of the first phase

¹⁵ There was one notable exception to the two-phase narrative structure. The general practitioner specialist in pain management began his description of his work with people with pain at the stage labelled here as phase 2.

could be described as ‘recognisable aspects of medical work’ such as diagnosis, prescribing, and referral.

The construction of the process as consisting of two phases was supported by general practitioners’ descriptions of ‘doing’ (elements of phase 1) ‘until’ certain things or indications (such as realising that the patient is not going away). There was considerable consensus amongst general practitioners as to the ‘indications of transition’.

In contrast the second phase was characterised by less shared language, less stability and repetition, a lack of a sense of purpose or strategy and as being inherently problematic. The emphasis in this phase can be seen to have shifted from the pain to the patient and the patient’s perceptions of the pain, though this is an analytical interpretation and not one necessarily made by general practitioners.

The process and content of general practitioners’ work with people with chronic pain

This section of the thesis describes the model of general practitioners’ accounts of the process of work with people with chronic pain in more detail.

Phase 1: “bread and butter work.”

As indicated in the model the elements of phase 1 can be seen to comprise the basic building blocks of the clinical method including:

- attempt to determine the cause of pain, using investigations or referral to medical specialties if appropriate
- consider and try to take account of whether the pain is likely to be chronic or acute
- hope that the pain goes away naturally (that it is self-limiting)
- alleviate pain by prescribing appropriate analgesia whilst the cause is being investigated
- adjust medications in line with patient requests for more effective pain relief
- alleviate concerns the patient may have about the pain by excluding serious diagnoses
- if the cause is a 'straightforward medical problem' attempt to treat the underlying cause
- consider referring for treatment therapy as appropriate in terms of general management

It also included balancing two contradictory tasks: that of being wary of demoralising or labelling the patient whilst being wary of raising false expectations that the pain will go away.

As indicated above, not all general practitioners mentioned all these elements of work and different general practitioners placed different emphasis on different elements. However general practitioners organised their description of these

elements of work in terms of order and priorities and overall there were shared characteristics. Firstly, that this phase of work formed a sequential matter of fact account of a process which was straightforward and not inherently problematic. Secondly, that this phase of work was delineated as ‘a phase’ in retrospective accounts of problems which emerged from it (see below confronting the effects of phase 1).

General practitioners were asked in very general terms how they would approach or manage a patient with pain. The following extract (extract 1) exemplifies several of the key elements of the pattern of responses and important themes (underlined) which emerged from the analysis as a whole. These are described below.

- I: How do you approach or manage a patient with pain, what sort of things influence your decisions?
- R: I have to make a diagnosis. Why have they got pain, what’s the appropriate ... you know ... why are they here, what’s the cause of the pain. Once you’ve made a diagnosis or attempted to look for a diagnosis then you treat that once you decide what’s causing ... you don’t ... you’re treating the patient and their problem and once you’ve got that sorted out then say, well what can I do for this. Easy for someone with an osteo-arthritic knee then you’ve got certain groups of drugs that you use and that’s easy. So you make a diagnosis or you say look I don’t know what I’m doing here, I’ll have somebody else take a look at it but in the meantime I’ll give you something to try to control the pain.
- I: So if you don’t know what sort of things might be in the back ground, what would influence your decision as to what you do after that?
- R: Well I think it depends how long the pain’s gone on for. Hopefully pain is self-limiting, whatever the diagnosis is it will maybe just get better. You hope for that. If you think you can’t imagine it’s anything too serious from your clinical story then you usually just try and relieve the symptoms, to let nature take its course. The it’s what if it’s a brain tumour, what if it’s angina, should we not be doing such and such, maybe we should be looking in to blood tests, try to make a diagnosis. You’ve done the ‘what if’ and you try and find out what’s wrong there.’ Then there’s the other patients that have the long ...you think well there’s probably not much going on here, how am I going to

manage this and then you decide what's available. Should somebody who's got pain ... if you look back in the notes, they've had this pain in the head for 18 years, I'm unlikely to resolve that problem by giving 2 paracetamol every 6 hours. Is that awfully fuzzy?

(jspt17)

It is important to note that although the researchers were concerned about how to ask such a question, the responses indicated the question did appear to be meaningful and was not fundamentally problematic despite some respondents' concerns about having given "fuzzy" responses.

- The importance of finding a cause

The extract illustrates the primacy of trying to find a cause or diagnosis for the pain and with that, the assumption that pain should have an identifiable cause, as this general practitioner explained:

"The first thing that goes through my mind is what's causing this pain, can we do something about it".

(ksgp4)

Most general practitioners explained that "the first thing has to be to make the diagnosis and then treat it as appropriate", many implying the necessity of knowing the cause in order to treat: "You've got to link it in to whatever's causing it to try to see if you can do something about it". The primacy of knowing the cause was also linked to the hope of finding a treatment which could cure the problem as this general practitioner explained:

"In general it's (pain) a symptom of something else. If you treat the condition with a bit of luck you'll handle the pain as well."

(kgpc1-2)

Knowing the cause was also linked to feeling able to access a view of what this might mean for patients as this general practitioner explained:

“You’ve got to know why they’re having the pain. It’s easier to advise on the treatment. If you know the course of pain then you can give the patient a degree of reassurance about the likely course of the pain and what they can expect.”

(jsgp7c3)

The importance of the cause was evident throughout the interviews in general practitioners’ responses to other questions. For example, when general practitioners were asked whether they treat pain in its own right, most general practitioners explained that they would do so only if a cause could not be identified as the following quotation illustrates:

“I suppose the first thing you could try and find out is what’s causing the pain and cure it, thereby solving the problem. I appreciate that can’t always be done in which case the second stage we would try to control the pain is as sensible manner as possible.”

(jsgp14)

A few general practitioners struggled to discuss pain outwith the context of a diagnosis. As one general practitioner explained:

“I don’t actually look at the pain. Perhaps I look at the patient and say they’ve got X and associate it with X as the pain”

(jsgp7)

A cause could be either physical or psychological, however most general practitioners implicitly or explicitly (as in the following quotation) gave initial priority to trying to find a physical cause:

“I wonder if we get a bit over the top about that at times. I think it is important to make the right diagnosis and the right diagnosis could be a psychological upset and could well be in chronic pain. That is sometimes more common than you think. It’s having the boldness to

go down that route. I think most of us probably have the need to know that the physical side is all right before we go down that and yet if you wound it back you were probably fairly sure in the first place and you do the rest just in case.”

(jsgp6)

The imperative of finding a cause for the pain often led to the construction of psychological issues as (pathological) cause or causes, particularly where no sufficient physical cause had been identified.

- **The emergence of chronic pain**

Extract 1 also illustrates the implicit assumption that new pain (or perhaps new pain patients) will hopefully be self-limiting or treatable, and hence acute, and that therefore chronic pain and chronic pain patients emerge from these assumptions over a period of time. The cause of pain could in itself be an indication that the pain was likely to be chronic (e.g. osteoarthritis), though the cause was not always apparent initially and, as indicated in the quotation below, was not always a guide to long-termness. Knowing the patient and the patient’s history was also seen to give some possible indication of the likely long-termness. Most general practitioners described trying to take account of whether the pain was likely to be chronic, although some suggested that this was a ‘subconscious’ process.

Thus most general practitioners defined chronic pain as pain which has gone on for a period of time:

“You tend to give yourself your own time limit as to what you’d expect that condition to resolve in and if they don’t resolve within that time that’s when you’re starting to look at them being a different kettle of fish.”

(jsgp12)

Whilst sometimes pain could turn out to be chronic by virtue of finding a certain cause, pain could also become chronic as the general practitioner in the following quotation explains:

“I think you have to be honest with people and say that you’re going to have pain for some weeks but it will gradually get better and it’s really important that you keep mobile and do all these things. So you have to constantly try and think of ways that you’re going to stop this patient from becoming chronic.”

(jsgp13)

Overall, knowing whether pain was going to be short term or long term appeared problematic and this in turn had implications for working with patients. In particular, trying to balance not wanting to create too high expectations which might have to be addressed later while not wanting to demoralise the patient by “giving them a life sentence”, as the following quotations illustrate:

“Right at the very beginning you can make real problems for yourself by saying I’m going to get rid of your pain for you which is quite unrealistic. You might be able to but the chances are that you won’t be able to get rid of the pain totally and completely. The patient would say if they go to the doctor, they’ll get a prescription and that will be the end of it.”

(ksgp4)

“You don’t know at the start that it’s going to be chronic. There’s no point in saying to people you’re not going to get better because you’re going to be wrong a lot of times and its disheartening.”

(jsgp8)

Alongside the issue of not wanting to demoralise the patient was that of not wanting to create or sustain a sick role for the patient, as this general practitioner explained the difficulty:

“A problem has occurred 2 or 3 months down the road, it’s just not getting better, the patient’s starting to say, well things aren’t going

well, what's going on here doctor. The doctor goes down the line of having diagnostic doubts, doing more tests. Because of that maybe just failing to address what the patient's fears are. Sometimes they're not real fears, they're just I suppose if you'd say to them, look there are so many people who just don't get better quickly from condition x and unfortunately this is the way it's going. More pro-actively stating that this might be a long-term problem. I suppose there might be other issues that doctors are wary of and we don't like creating a sick role for people."

(lmgp1nr)

- **The immediacy of medication**

Most general practitioners' responses to the question about how they would approach the management of someone presenting with pain placed prescribing analgesia early in their account, as was the case in the extract 1 above, where medication for pain relief whilst the pain is being investigated is implicated immediately. However, although the above extract illustrates the immediacy of consideration of medication, it is important to note that it contains relatively little detail of prescribing decision making compared with most general practitioners' responses.

- **The need to rule out anything more serious**

Extract 1 also illustrates the recognition of the need to rule out anything more serious, by investigation or referral for investigation. General practitioners explained that this was often important in order to reassure patients, and themselves, as this general practitioner explained:

"Being confident about the cause of the pain allows one to concentrate on relieving it by using appropriate methods and allows one to explain why the pain is there better. It frees one from the

worry that one's missing something. I think that's why it's important."

(jsgp19-2)

Thus even for general practitioners who explained that knowing the cause of the pain was not necessary from their perspective, there was the corollary that

"as long as I know I'm not missing some other disease"

(jsp8aa).

- **Responding to patients requests for analgesia**

Finally, one further aspect of general practitioners' accounts of the management in phase one which is not illustrated in the above extract, was that of responding to patients' requests for analgesia. Many general practitioners described the process of finding appropriate analgesia in terms of patients' return visits. There were two principal characterisations of this. Firstly, that this was a necessary and legitimate part of finding the appropriate level or strength of analgesia with tolerable side effects. Secondly, as implying that patients' understanding of their pain was that there would be a painkiller to take the pain away. In the latter context, such repeated consultations were seen as problematic and a frequent characterisation of a nightmare chronic pain patient was that of someone demanding increasing levels of painkillers. However, a more detailed exploration of general practitioners' views revealed a more varied description of the range of views held by patients, as this general practitioner explained when asked what patients spring to mind in the context of chronic pain:

"the ones who attend us most frequently. The ones who come back time and time again and say I'm back about that pain doctor. The pills you gave me the last time are not really helping anymore, these are the ones."

(ksgp4)

Indications of transition

General practitioners' accounts of the process described above as phase 1, or elements of this process, sometimes indicated an approximate time interval for this phase. Indications ranged from several weeks, as in the following quotation, to as long as "a year or two" for example, for some patients to be reassured that there was nothing serious wrong with them.

"You basically are telling them to put up with it because it's going to go away. When you're getting to when it goes beyond a short time, again a couple of weeks perhaps, you're going to have to say well look this isn't going to go away or you're going to have to put up with this for a long time. I'm going to have to try and help you."

(jsgp9)

Thus there was no specific length of time for phase 1, or correspondingly for pain to become chronic. Rather there was implicit acknowledgement that the time interval varied from patient to patient.

General practitioners' accounts constructed the process of phase 1 by delineating it in terms of it going on 'until such and such' rather than specifying a length of time. There was considerable congruence amongst general practitioners' accounts as to what constituted the 'such and such', that is, in the terminology used here, the indications of transition. These indications were: that a cause had been found but that there was no treatment for the cause (which, by removing the cause, would alleviate the pain); that it was unlikely that a cause, or a definite cause, would be found; that the patient was consulting too frequently; that the consultations were repetitive; that the patient hasn't 'gone away' and, finally, an indication which can perhaps be seen to subsume all the others, the (general practitioner's) realisation

that the pain is probably going to be chronic.

The following quotations illustrate the frequency of consultations as an indicator the pain or the patient is chronic:

“Again there are so many variables and its going to depend on the patient, how much they nag you, how frequently a patient comes back. So if somebody comes back more frequently and bothers you on a frequent basis you’re perhaps going to put them into the chronic pain category much sooner than somebody who doesn’t, who’s perhaps a bit more stoical about it.”

(k1gpc3)

“perhaps it would be wrong to say chronic pain but they’re chronic complainers.”

(kgp1c4)

Throughout general practitioners’ descriptions of the elements of their work designated as phase 1, they conveyed a sense that the patient as a person was secondary to the process, with more detailed descriptions (more than the passing reference in the extract above) of trying to take account of the patient as a person - their ideas, history and personality - emerging as time went on and the pain or the problem or the patient emerged as chronic. Their accounts most frequently placed work like helping people to cope with pain “further down the line”, though not always as explicitly as in the following quotation:

“You may go through the whole gambit of investigation, x-rays, physiotherapy, specialist referral and find that nothing you’ve done improved their position and it might be at that point that you move on to pain management”

adding however that this point would be

“fairly well down the line.”

(jsgp7c3)

Phase 2 “a different kettle of fish”.

General practitioners' accounts of the work placed in phase 2 appeared to be much less of a shared account, with different general practitioners using different terms to explain work with the same implicit functions or meaning. Moreover all the elements of phase 2 were constructed as being inherently problematic. These were: the problems of confronting the legacy of earlier approaches, managing the risk of missing something, accepting that the patient's pain is chronic, managing emotional impact of the work, getting the patient to accept, keeping the patient going, actively helping the patient to get on with their life.

It is perhaps worth noting again here that this analytic representation aims to be comprehensive and, as such, not all general practitioners described all these areas of work, for instance very few general practitioners described work of actively helping patients to get on with their life.

- **Confronting the legacy of earlier approaches.**

Many of the problems that general practitioners described in working with patients could be seen to have arisen from earlier approaches. As described above, general practitioners explained that they often felt they had a sense of the likelihood that a problem would be acute or chronic. This depended on a number of factors such as the diagnosis, if any, the site of the pain, what was known about the patient, and the

patient's age. Nevertheless they could still get this wrong and get caught out, principally by having assumed that the problem would not become chronic.

One of the principal difficulties that general practitioners described was in terms of then getting the patient to accept that the problem was chronic as described below. Other problems were in terms of medication, in terms of the length of time waiting for appointments with other services and in terms of the process of investigation and referral for investigation.

Several general practitioners described the problem of prescribing analgesia high up the analgesic ladder in the belief that the pain would be acute and with the intention of trying to avoid setting up a cycle of pain avoidance, inactivity or requesting further analgesia. In some cases they could then be faced with the prospect of people being on levels of medication which they, or the patient, felt to be inappropriate for long term or on-going use.

General practitioners also expressed concerns that long waiting times for pain clinics, for referral and investigation by other medical specialties or for investigations by the general practitioner themselves meant that patients, their problems and behaviours became chronic or entrenched during this time and harder to change in the longer term. For example, patients who interpreted pain as meaning harm may become increasingly inactive during this period with inactivity leading to loss of employment and income thus compounding existing problems.

Other general practitioners described how the processes of investigation often involved patients in a long process of referral from one specialty to another and this in turn could bring its own problems as this general practitioner describes:

“If you had to basically work round all the specialties and sometimes you don’t come out with an answer so you’re still left with treating a pain of unknown cause and that’s very difficult. Undoubtedly by the time the pain has done all that, even if they didn’t have a psychological component to begin with, they’ve certainly got one by the end”.

(jsgp15nr)

Other general practitioners emphasised that this process of investigation could perhaps perpetuate the patient’s view that there must be a cause in the end, as one general practitioner put it: “the more you investigate the more the patient is concerned about not finding the cause”.

- **Risking missing something**

Although the emergence of chronic pain was in part characterised by repetition, seeing the patient too frequently or going over the same consultation again, general practitioners described a potential problem which had to be guarded against, in broad terms, that they had missed something or were missing something.

One aspect of ‘missing something’ was in terms of having missed something serious, that is the signs of serious physical disease. General practitioners explained their wariness that repetition or familiarity would lead to complacency about patients, as one general practitioner put it: “One worry is that by crying wolf all the time one of these days I’ll miss something”, or as another explained:

“Again one tends to know these people quite well. I suppose there comes a point when you tend to accept that a lot of this is emotional or psychological. There’s a danger there of course that when new pains crop up they get ignored.”

(jsgp14)

Many of the general practitioners gave a specific example of having missed something in the past in order to illustrate their concerns:

“It was a lady who had a lot of back pain and we x-rayed and things and couldn’t find anything wrong with her. She seemed to be very variable. She was apparently histrionic and it turned out she had breast cancer but she thought it was in her spine and we had missed it completely. So I had to apologise profusely to her.”

(jsgp8c4)

In this context then, general practitioners had to balance their own concerns about missing something against the potential negative consequences of on-going investigations for the patient (as described above). As this general practitioner explains:

“So it’s very difficult to withhold investigation I think at times and often I think perhaps we’re forced to do more investigating than is necessary in order to reassure ourselves as well as the patient that there isn’t some sinister cause for this. So it’s a bit of a trap really because the more you investigate the more the patient is concerned about not finding the cause. If you don’t investigate then you’re worried that you’re maybe missing something more serious.”

(jsgp1nr)

Some general practitioners described feeling they themselves often needed the reassurance of a second opinion and would sometimes ask another general practitioner colleague to review the patient or explained that they were often reassured when the patient consulted another general practitioner themselves.

Some general practitioners described the problem of the risk of missing something

in terms of not feeling certain enough to reassure the patient and this might be a reason for referral as this general practitioner explained:

“It was often very effective, we needed somebody to tell them and a consultant in hospital was a very powerful way of doing that. I would admit not feeling powerful enough sometimes to be able to say to somebody, look I don’t think there’s really anything wrong with you. So if there’s a doubt we’ll send them on to more investigations and it becomes chronic pain sometimes.”

(ksgpc4-1)

Although most of the descriptions of missing something physical were in terms of missing something serious, others emphasised the more general issue of missing things by pursuing a particular approach as this general practitioner describes:

“Even then you can get too blinkered down the track of dealing with this psychological manifestation of the condition. Even 2 or 3 years down the line, somehow or other their pain is suddenly relieved, if it turns out that they do have something, a neuroma or something on a nerve that can be surgically treated. That’s rare but it turns out that they do have that and the treatment is given appropriately, all these psychological manifestations tends to vanish almost overnight, which is quite sobering.”

(ksgpreg2)

Another important area of missing something was in terms of having ‘missed’ or not fully appreciated the amount of pain, suffering or disability that patients were experiencing. Again many general practitioners described particular incidents whereby they had come to realise as the following quotation illustrates:

“That frequent method of learning which is really just understanding a bit more of what the patient is putting up with and it’s always embarrassing to us because you wonder how stupid you could be. It dawns on you what the problems are and how you hadn’t really addressed it before hand.”

(jsgp19)

- **Accepting that the patient's pain is chronic**

General practitioners frequently constructed their own realisation that the pain, or the problem, or the patient, was probably going to be chronic (however they defined this) as an indicator of a transition from one phase to another. Their accounts of working with patients with chronic pain (after their own realisation) described a process of adjustment or acceptance. Thus, although many general practitioners described how they had borne in mind that the problem might turn out to be chronic, they also described the difficulties that this realisation brought and continued to bring, both in terms of their own thoughts and feelings and in working with patients to try to change the patient's approach. This latter aspect is described in a separate section below, though it is important to note that general practitioners' descriptions of their own difficulties were often linked to their descriptions of their difficulties in changing patients' approaches.

As implied above, there appeared to be two strands to general practitioners' adjustment and continuing acceptance of the patients as having chronic pain; a realignment of thinking and the on-going management of their emotional reactions to this work and the patients with chronic pain.

- **A realignment of thinking**

Many general practitioners described the difficulties that they faced in terms of knowing when to stop investigating or referring patients in the hope of finding a cause, cure or intervention that would alleviate the pain. Sometimes explanations of

this difficulty were in terms of their concerns not to miss anything and also not to remove patient's hope or "give them a life sentence." As this general practitioner explained that one thing that was difficult to do was to:

"admit to ourselves that we have exhausted all the possibilities, that you're not doing the patients any favours by going round the same merry go round two or three times"

(jsgp16)

Many general practitioners described this process in terms facing up to the failure or limitations of the approaches or treatments that they had been trying or were available and thereby what they could achieve for the patient in the future, as the following general practitioner describes:

"I think just as you try and get the patient to get realistic about their symptoms often the doctor has to force himself to be realistic about his expectations of treatment for the patient."

(jsgp16)

Many summed up the change in their thinking in terms of coming to realise that there was nothing, or nothing else, that they could do. Although as described below, such descriptions were based on an implicit distinction between what constituted 'doing something' as opposed to 'doing nothing', with doing something most often being alleviating or curing the pain by prescribing, investigating or referring.

General practitioners also described or implied a general change in their approach to patients, or as this general practitioner put it, "style of working".

"Well I think you adopt a style of working and accepting people, accepting that people have got problems and none of us are going to cure them. Sometimes accepting that they don't want to be cured anyway."

(kgp1c4)

Although most general practitioners implied a change of approach, there was no shared account of what the approach became. Many general practitioners used terms which directly conveyed their difficulty of giving an account of this, such as to “guddle along”. There were, however, a number of themes which emerged from the analysis.

There appeared to be more of a focus on the pain in and of itself. For example one general practitioner described this as “later on beginning to look at the pain per se” in contrast to “having tended to look at it as part of a symptom complex or a disease”

Although general practitioners described beginning to look at the pain as a problem in its own right, the imperative to find an explanation for the pain remained. Thus, many general practitioners described thinking about the patient’s perception of pain, whether there was a “psychological component” or a “psychological overlay” or whether the patient had “psychological problems” which would explain their pain.

Related to this, many general practitioners’ accounts focused on the issue of frequent and continuing consulting by patients, either constructing this as problematic in its own right or as an indication that there was a continuing problem. As this general practitioner explained:

“If the patient is continuing to attend there is a continuing problem. It may not be a straightforward one for pain control but it certainly is still a problem and therefore it is appropriate that the patient should

continue to attend and discuss the pain. Obviously if I doubted the actual nature of the pain... I wouldn't doubt the pain if they're telling me they've got. You invent pains but the pain may be psychological but that's obviously something you're addressing at that stage."

(jsgp14)

Taken together, consideration of whether there was a psychological explanation for the patient's experience of pain or for their continuing attendance brought close scrutiny of patients. General practitioners "wondered if there was something else going on". This work is described in more detail in the following section on general practitioners' interpretations or assessments of patients. In summary though, this work of interpreting patients, assessing their "personality" looking for "hidden agendas" or "ulterior motives" can be seen to have an implicit moral content.

- **Emotional self-management**

General practitioners' accounts of their work with people with chronic pain included descriptions of the negative feelings, primarily inadequacy, frustration and failure they experienced and the effort involved in managing these feelings.

The sense of frustration was often linked to their perceptions of their not being able to do anything, or of the limitations or failure of what they could do.

"The feeling of helplessness for yourself. If you feel that you've come to the end of your therapeutic armentarium and that are still having none and you think what else can I possibly do."

(kcp1c3)

"doctors as individuals are willing to try and help people, make them better. Someone comes along and you can do none of these things people are obviously still in the same situation and need support, you feel you've failed them in that you can't bring any of your

conventional skills to bear”.

(jsgp14)

Throughout the interviews general practitioners emphasised the importance of their relationship with individual patients, in particular the importance of having a good relationship or building a good relationship, particularly with patients with chronic problems. Many general practitioners described the importance of liking patients and the impact of not liking them. However, they also described the negative impact that frequent or long term contact or repetitious consultations could have, as one general practitioner put it “It’s only as familiarity breeds contempt that any little bits and pieces that might indicate they’re not suffering as much as they say they are will come through” and another explained:

“There’s no doubt that any chronic patient is the one that keeps coming back time after time and there’s no doubt you lose enthusiasm and its difficult to keep yourself enthusiastic and still looking for problems or different areas to treat.”

(jsgp6)

As indicated above, ‘over familiarity’ or prolonged frequent contact appeared to be linked to general practitioners’ growing concerns that “there must be something else going on” and in turn to growing doubts or ‘difficulty believing’ the patient or, as the following general practitioner put it, “loss of sympathy” or “loss of faith”

“Again if you find somebody who is apparently, in spite of everything you do, not responding, it becomes very difficult to maintain not only your own sympathy but actually belief in them. Both the individuals I’ve talked about at length fall into that category from time to time. Essentially I have to take absolutely their words for it and I ...there are moments when I say to myself, why on earth am I dealing with this in this way. There’s something else, there must be something else going on here. Why is my only option to go on giving these people dihydrocodeine or temgesic? At that point what I’ve had to do is grit my teeth and say well it doesn’t matter because there’s nothing else I can do. It’s keeping them satisfied, it’s keeping them happy ... happy is not the word, but keeping them content for the moment. There’s

nothing else I can do about it but yes there are points when you begin to lose your faith as it were.”

(jsgp9)

General practitioners also described their frustration when patients appeared unwilling to do anything for themselves, “not responding”.

In describing their emotional reactions, several general practitioners (cautiously) made reference to the term and concepts of ‘heartsink patients’. The following quotation described the process that many general practitioners described, that of trying to manage their own emotional reactions and the effort that this involved.

“You could be very negative about it. You could say that a patient with chronic pain is beginning to feel as you see them for the nth time. You’re beginning to feel inside that you’re turning them into a heartsink patient, you’re getting anxiety every time they come in. I think you have to then stand back and say ok I’m getting anxious, angry, whatever reaction it’s producing within me, why is it doing that? What can I do then positively to try and counter that? I think you have to take that on board as a positive thing not as a negative one.”

(ksgp4)

Other general practitioners alluded to the theory that “a heart sink is simply your perception of them”. One general practitioner went on to illustrate that the theory did not always work in practice, and described his feelings about a specific patient

“I just cannot deal with her emotionally because she doesn’t seem able to make any impetus herself and make any effort herself. She just wants life miraculously back to normal and be well. Every time I see her name in the book I just die and I positively go out there, build up to it for a good five minutes before, try and smile but I know at the end I’m going to feel devastated.”

Concluding

So she keeps coming back but still has faith that I’ve got something else to offer her but I don’t”

(jsgp12)

Thus despite what can be seen as attempts to rationalise or use their own feelings, many general practitioners were left with contradictory emotions or ‘mixed feelings’ as this general practitioner describes:

“My attitude there is on the one hand I’m intensely sympathetic and think I wish I could do something for this woman. On the other hand I think bloody hell why do you keep bothering me and what the hell do you want me to do about it, you’ve had this for yonks, why do you keep calling me every time it happens again.”

(jsgp9)

- **Getting the patient to accept**

The problems of getting the patient to accept were frequently mentioned. General practitioners often described this problem in very general terms, that is without necessarily being explicit about what the patient should accept or what they were trying to get the patient to accept other than in very broad terms as the following quotation illustrates. This general practitioner is describing nightmare patients:

“It’s people who haven’t accepted their case. So far as I can see, from a medical point of view we’ve done the best we can and they’ve had a proper service and yet they still can’t accept things”

(ksgpw2)

At other times general practitioners were more specific in their descriptions of what they were trying to get the patient to accept. These encompassed getting the patient to accept that there was no cure, no way of alleviating the pain completely, no diagnosis or identifiable cause of the pain, that the general practitioner could not do anything else and that they have to live with the problem.

As indicated from the analysis above, a critical part of getting the patient to accept depended upon the general practitioner's own acceptance¹⁶ as this general practitioner explained:

“Yes you've got to have realised that it's not going to get better before you start. I mean your initial expectation is that you're going to treat them, they're going to get better and they will be back doing what they were before. They expect that as well so most people can tolerate the pain if they think it's going to get better. The real change comes when everybody realises that it's not going to get better. My initial treatment of people I haven't seen before is arriving at a diagnosis, prescribing for them, giving them advice about how to help their pain but it's not really the psychological, it's usually some aspect of helping them with their pain. Coming back to backs, exercises and posture, care of the back. It's only when you realise it's not going to get better that you have to start saying to them well I think we're going to have to learn to live with this. Subtle ways through the consultation.”

(ksgp8c4)

General practitioners described some ways of trying to actively manage the problem of getting patients to accept themselves such as “subtle ways through the consultation”, or explaining that although the problem cannot be cured or treated “things won't always be this bad”, or reassuring the patient that you were “not telling them to go away, that you would still be there to help”.

Where general practitioners described actively trying to get the patient to accept, this was a process which extended over a period of time and a number of consultations. Some general practitioners explained that an important advantage of general practice in this respect was that patients were seen over a period of time,

¹⁶ That is not to imply that patients could not have accepted prior to the general practitioner accepting. In such cases though, general practitioners would not have problems getting patients to accept. As one general practitioner explained, there may be a tendency to forget about the people who have adjusted on their own and to focus on the ones that are problematic.

allowing general practitioners to try to ‘pace’ this work, or the amount of information that they gave patients in any one go as this explanation implies:

“Well there’s a limit to how much people can take in at one go anyway even if they seem keen to know everything. You may in any case, if you try and tell them everything the first time, find yourself telling them the same things two, three times over at separate consultations. And sometimes I think they, if they keep asking the questions it’s because they don’t like the answers so it’s actually denial.”

(gp18js)

The problem of getting patients to accept was one of the key reasons that general practitioners gave for referring to pain clinics or other specialties, explaining that their intention was that this would confirm there was no treatment, no identifiable cause or that the patient would have to live with the problem.

Alternatively, some general practitioners described a process of having to wait until the patient comes to accept over time as this general practitioner explained:

R: “With any luck we grow into physical disabilities and begin to accept them and work round them. So time is very important and I think often it is playing for time. That may well be why we’re so free with the analgesics and non-steroidals and things.”

I: “In order to play for time?”

R: “Yes, to buy a bit of time until the patient comes to terms with it and hopefully then begins to relax and not see it as the major problem in his life.”

(jsgp13)

Some general practitioners described other problematic aspects of actively trying to get patients to accept, in particular their unwillingness to “rob people of hope”, to explain the importance of waiting for the patient to realise in their own time.

“No I suspect that you have to wait because people always like or hope that things will improve and get better. I think if you say its not, you’re going to rob them of that hope and it’s only after it slowly dawns on them that you then put them there.”

(jsgp7c3)

- Keeping the patient going

Alongside the work of trying to get patients to accept or waiting for patients to accept, general practitioners frequently described an important aspect of their work in terms such as “jollyng” or “chivvying” the patient along, providing support. A wide range of terms or categories were used to refer to this process, which some general practitioners explained was difficult to describe:

“It’s not something that’s easy to measure or even to describe. It can be nothing more than a friendly pat and saying stick in there or a full blown half hour session of talking over anxieties, fears, disability. Then there’s the option of referral to psychological services such as pain management clinic.”

(jsgp5)

An underlying theme in all the terms used was that of ‘stability’ or of work which was not intended to bring about any change. This general practitioner explained that helping people to cope or come to terms with pain was a large area of work which involved “letting people moan. Perhaps not changing anything but just talking to people and listening.” Or as another general practitioner put it:

“Seeing them from time to time, more just to act as a sounding board for how they’re getting on, the problems they’re experiencing knowing full well at the end of it that you may not be able to offer them anything new in terms of giving them something or doing something for them. Simply allowing them to express the problem.”

(jsgp5)

Other descriptions of this process emphasised the motivational aspect of keeping people going as this general practitioner described:

“You do actually get quite involved with them. It is difficult, are you just jollyng them a long and giving them a moral boost every 2

months to keep them going. I think there's a fair element of that and whether we're the best people to do that I'm not quite sure."

(jsgp6)

This area of work can be seen to contrast with the work of getting the patient to accept, which implied getting the patient to change approach or thinking, and the work described below of getting the patient to take a more positive approach.

Although general practitioners described this work of keeping the patient going as being an important part of their role, their accounts often implied that this should not go on too frequently or continuously, that is, there remained an assumption that this could not be a role which continued indefinitely.

Alongside general practitioners' constructions of this aspect of their work as valuable and important, there were also frequent negative constructions of this, such as not "getting anywhere", "not being able to see a way forward" or as this general practitioner explained "getting stuck in a rut".

"It's very easy to get stuck in a rut and you've started a drug that's reasonably satisfactory then the tendency is just to keep going and providing everything's alright and continue it. I'm sure that isn't always helpful."

(jsgp6)

As described above, general practitioners' descriptions of getting 'stuck in a rut' often combined concerns about missing something or becoming complacent with explanations of their feelings of the need sometimes to step back, reassess the situation or take a fresh look. In this context one possible solution was to refer the patient:

"I think the actual referral and giving us a break from it at least

feeling we've got the responsibility off our shoulders for a while is sometimes quite useful and allows us to reassess the situation."

(jsgp19)

- **Helping people to get on with their lives**

A third area of work which general practitioners described, again often very non-specifically, was that which is designated here as helping people to get on with their lives. General practitioners' descriptions of this work were underpinned by a sense of trying to bring about positive change, either in the patients thinking or in the patients behaviour, "helping people to see that there is light at the end of the tunnel", "trying to involve the patient in more positive aspects of coping". Thus this analytical category of work appeared distinct from the categories of getting the patient to accept or keeping the patient going, though 'getting the patient to accept' was often constructed as the necessary pre-cursor to this work of "where they're going next" as the following quotation illustrates:

"It's the acceptance of it, can they accept it and are there mechanisms to help them accept it, that this is them and life is not all doom and gloom just because they've got this. It's acceptance but acceptance is just the bouncing board for where they're going next."

(jsgp6c4)

Again general practitioners described this as an on-going process: "constantly drip dripping suggestions" over a number of consultations. These suggestions were often related to trying to get patients to be more physically or socially active, for example, "stopping them sitting at home brooding about it (the pain)". They sometimes involved setting goals or giving advice about how to make practical adaptations. The following general practitioner's explanation was unusually detailed and specific

about this area of work:

“I think one of the things that you often find yourself doing is trying to persuade the patient to do things but by a different route. Often the patient who has limitation because of pain then finds frustration creeping in because they are reluctant to do things differently because it seems like giving in. There’s often an all or none response, if they can’t do a thing the way they used to then they can’t do it full stop. Certainly one of the things I often find myself doing is trying to persuade people to look at alternatives or perhaps accept that they can still do things but maybe not as quickly or take two days to do the garden or one day, that sort of thing.”

(jsgp16)

Other general practitioners described, again in often very broad terms, trying to change patients’ attitudes or their perception of the pain and its impact to “allow them to see it in a different light.” or to be more positive as this general practitioner describes:

“I think some people ... I think I would try to be more positive and say well if you’re managing to get out with this pain then it can’t be quite as bad as it was because you told me that you couldn’t manage to do this, that and the other. But I think that’s different, that’s turning it round and using it positively.”

(lmgp10)

The work of getting patients to be more positive or more active, “turning it round” appeared to be difficult, not least because it was difficult for general practitioners to describe other than in terms of their general motives, but also because it could easily conflict with the necessity of maintaining conviction or reassuring the patient that they are believed and taken seriously. In the above quotation, for example, the approach could be seen to involve contradicting the patient.

Moreover, as with the work of ‘getting patients to accept’ and ‘keeping patients going’, general practitioners’ motives of getting the patient to take responsibility for

their lives or getting patients involved in “more positive aspects of coping” were often linked to the underlying assumption that patients should go away or consult less frequently as this general practitioner explained:

“I try and involve the patient in more positive aspects of coping and, as I’ve already said earlier, part of that is reducing the number of times she comes and tells me about it.”

(jsgp1)

The continuing work in the process of managing chronic pain

The previous section of this chapter described elements of general practitioners' accounts of the emerging process of managing chronic pain. Throughout their descriptions of these aspects of their work, there was an implicit sense of an unfolding process with two phases. This section of the chapter describes those aspects of work which were continuous throughout general practitioners' accounts: the detection of psychological distress and depression; the process of assessment or interpreting patients and managing the doubts that this could engender; the process of maintaining conviction or reassuring the patient that they were seen as genuine; the imperative to do something which counts as doing something.

The reporting of these continuing aspects of the process of management in a separate section is not to imply that these areas of work are distinct or unrelated to other elements of the process.

It is perhaps worth restating that the analysis is seeking to be as comprehensive as possible and to reflect the scope of general practitioners' work. General practitioners did not talk about all these aspects of work with the same frequency or with the same amount of detail, thus there is considerable difference in detail amongst the subsections.

Detecting psychological distress

General practitioners' descriptions of the importance of recognising the

psychological distress or depression associated with pain formed a clearly identifiable aspect of their accounts of the process of chronic pain. In other words, this area of work appeared to form part of a recognised clinical account and was discussed in a clear matter of fact way.

General practitioners described the importance of detecting psychological distress or depression from a very early stage indicating a recognition or assumption that this could be associated with pro-longed pain - that is, pain that perhaps might still turn out to be acute but had lasted sufficiently long to have a negative impact on a person's life. They also indicated their awareness that psychological distress or depression could occur and re-occur in people with chronic pain over a number of years.

For the most part, general practitioners described this area of work as unproblematic. There was an apparent difficulty of knowing whether the distress or depression was causing or exacerbating the pain or was caused by the pain. However most general practitioners explained, or conveyed the sense that, the main thing was that they knew how to manage depression whether this was cause or effect. Many general practitioners implied that the use anti-depressants for depression and for pain relief meant that the cause-effect distinction was thus less relevant in practical terms. There was, however, a difficulty of negotiating the use of anti-depressants with patients. General practitioners described the care that they felt they needed to take in order to avoid the patient thinking that a prescription of antidepressants meant that their general practitioner thought they were imagining

the pain. That is, in the terminology of this analysis, the suggested use of anti-depressants could conflict with the work of maintaining conviction.

Interpreting patients: “Doctors like things to fit together”

As indicated above, throughout their accounts of working with patients with chronic pain general practitioners described processes of interpreting patients, continual processes which involved piecing together evidence or information about patients over time. This could involve more formal or discrete elements such as history taking, clinical examination or investigations such as scans or x-rays. It also involved informal observation, drawing on information from other sources, trying to find an explanation for the pain or the patient’s behaviour, taking account of general practitioners’ own feelings and reactions to patients and making comparisons between patients. That is, the overall process of interpretation, or in formal terms, assessment, can be seen as involving a search for patterns amongst various kinds of information:

“Well it’s like looking at a painting. Get too close all we see is the brush strokes, stand far away and you see a picture. Occasionally the only way you can see a picture is actually by standing away from the individual and just fitting them into the pattern. Occasionally this is a bit of a thump. That’s the only way you can do it because if you look at every individual then you cannot practice medicine because medicine is a matter of patterns.”

(jsgp9)

As the overview of social scientific approaches to medical work on chronic pain anticipated, the process of interpretation can be seen to involve a number of different ways of seeing, or trying to see or to objectify, the experience of pain and the person in pain either in terms of observable or visible evidence or in terms of the

disciplinary tools of interpretation such as those based on pathophysiology or disease or theories of psychology or psychopathology. Unsurprisingly the analysis of general practitioners' accounts of this work reveals the contradictions of practical reason and sets up an implicit either/or or dualistic thinking which characterises lay and professional discourses of pain. It reveals the influence of a range of structural or broader social factors which influence these ways of seeing and of interpretation. Related to this, it is thereby imbued with moral content, which can be seen as a form of 'character work' which involves an interpretation of the person in pain, particularly their motivation.

The above outline of the different means of interpretation which general practitioners could use has an important implication for the nature of general practitioners' accounts and for the analysis described below. In particular, the subject of interpretation changes with the means of interpretation, from pain as the subject, to the person's problems as the subject, or the person themselves as the subject.

This interpretative work can be characterised by 'fragility', 'doubt' (Scarry 1985; Baszanger 1992) or ambiguity (Schutz 1970). The term doubt is used throughout this analysis. The choice of terminology is based on the following reasons. Firstly, to make an explicit distinction from the term 'uncertainty' which forms part of the recognisable and familiar discourse of professional practice in medicine, particularly general practice. The term uncertainty can be seen to imply that ambiguity is resolvable given more information or greater knowledge, that is it

implies knowing what it not known (Strong 1980). The use of the term doubt is intended to imply fundamental ambiguity and to indicate that the process of interpretation is being considered here within a social constructionist paradigm. Although the term ambiguity, as used by Schutz (1970) for example, would achieve this location within a different paradigm, the choice of the term doubt is preferred to indicate the ideological and moral aspects of the process of interpretation. Thus 'character' work and the interpretation of motivations are seen as integral to the concept of doubt.

Throughout general practitioners' descriptions of this aspect of their work were two implicit assumptions. Firstly, that it was possible to know when someone was in pain. Secondly, that there was room for doubt in that not all pain was 'known' to be genuine. General practitioners frequently used the term 'genuine' in the context of genuine pain, genuine problems or genuine people. Whilst some general practitioners did refer to malingerers, this reference was very rare. On the whole, the primacy of genuineness meant that the construction of non-genuine in general practitioners' accounts had to be implicit and was achieved by contrast with the 'genuine'. The following quotation illustrates both these assumptions:

"I think the patient's attitude and whether or not they seem genuine. If you've been in contact with people who are in genuine pain, you soon learn what somebody in pain looks like."

(jsgp4c2-2)

All the general practitioners made the point that pain has to be what the patient says it is, that often all there is to go on is what the patient says and that it could be dangerous to disbelieve patients or even to miss-categorise them, as this general

practitioner explained:

“Yes and there’s a risk that patients think that you’ve put them in a different category from what they are and get very upset if they think they’re not being taken seriously.”

(ksgp1reg)

However they frequently went on to describe the problems of this, constructing the room for doubt, explaining that patients descriptions required further interpretation. The following quotations encapsulate the juxtaposition of the importance of the patient’s verbal account with an immediate statement of the problematic nature of this as a basis for practice. The quotations also illustrate themes referred to later in the analysis.

“Well of course you can only go on the basis of what people tell you and some people overplay their symptoms and other people underplay their symptoms. I think generally people are really quite sore. If you ask them directly they will generally tell you. Some people obviously have different levels of pain threshold and some people put up with things that you wouldn’t believe and other people you wonder... but that’s life. If you ask very specific questions you can usually get a measure of how much pain people are in. Of course that is an impression.”

(jsgp2)

“I mean why people get pain and the back pain is a classic one. You see people with what appears to be an extremely bad back, very stiff, lots of x-ray changes and yet they’ll tell you it’s not that bad. Now whether that’s their perception of the pain or whether they are actually getting this pain I don’t know. The problem is we have no objective measure of pain we only have people’s ratings of it.”

(jsgp19)

“There’s a number of patients that seem very genuine, they’ve got obvious disease process going on and they really try and make light of it and try and function as best they can within whatever disability they’ve got. There’s another group of patients who seem to be big moaners, everything’s sore and you’re not really sure what’s going on. There’s a certain number of patients who are obviously looking for other benefits related to ... either they want to give up work or get disability allowances. You’re not quite sure if they’re just after a high off the DF’s that they’re trying to get from you.”

(ksgpreg1)

Thus even in the context of the fundamental tenet that “anyone who tells you they’re in pain is in pain” there was still room for doubt about “accepting they have pain at face value but not necessarily accepting the severity at face value. Then the very difficult thing is, I have pain you have discomfort.” As this general practitioner explains:

“there are a small number of people but I think it’s a very small number of people who are coming along and tell you they’ve got pain and you really don’t think they’re in pain. That’s a very small number. It’s usually people who you suspect are wanting drugs. I think the much more difficult thing is to assess how much pain they’re getting, not whether they’re in pain or not. I don’t know there is any absolute way to do it. You’ve got to think why would they want to mislead you and that gets you back on to are they wanting more drugs, is there something else going on in their life that’s bothering them and making them tolerate the pain much less. I mean that’s not just true of pain, that’s true of all illnesses. Is there some hidden agenda? It’s a dangerous game to doubt patients because you’ll get your fingers burnt if you start saying this patient’s saying they’ve got a lot of pain and I don’t think they have. You’ve got to take people very seriously. You’ve got to have some very good reason for thinking they’re not in pain when they tell you they are. Judging the degree of it is much more difficult.”

(jsgp8c4)

In the context of these problems with (some) patients’ accounts, general practitioners used a range of means of searching for objectivity. However there was always room for doubt. Such doubts remained problematic, because of the necessity of the work of conviction, described in a separate section below, of assuring the patient that they were seen as being genuine. As the general practitioner quoted above recognised and as the analysis of the interviews with patients confirmed, patients “get very upset if they feel they’re not being taken seriously.”

- Having a causal explanation for the pain

As the analysis of the process of management of pain indicated, one of the key first steps was often to determine a causal explanation for the pain, either a definite event, such as an accident, or a “definite disease process” as one general practitioner put it. Both these could be an important source of objectivity or genuineness, although again, even where definite pathology could be diagnosed or observed this did not always explain the severity of the pain as these general practitioners explained:

“the same disease in two different people can have vastly different effects.”

(jsgp10nr)

“Sometimes it’s impossible to predict (whether pain is acute or chronic). Shingles is the characteristic one. You get some people with very nasty facial shingles and who seem to have no pain whatsoever after it and others who have in comparison a very mild form of it and have chronic pain for years after it.”

(jsgp6)

Another sense in which doubts about causal explanation could arise was in terms of the mind-body dualism. For instance, as described below, once general practitioners looked at patients psychologically they could begin to wonder whether the pain was causing psychological distress or whether the psychological distress was contributing to the pain. Again even when there was a definite disease process, the question of whether psychological factors were contributing to the expressed severity of the pain could arise.

- Observation

Most general practitioners appeared to engage in a search for some ‘objectivity’, of which visible or observable evidence, whether visible by medical imaging or visible to the general practitioner in formal examination or in informal observation, was one aspect. As this general practitioner explains:

“I go through all the things that you’re taught as a student. You take a good history first and hopefully well quite a lot of things you can get fairly strong patterns as to what’s wrong before you’ve ever laid a hand on the patient. Observation as well. They come to me down quite a long corridor so I can sometimes learn quite a lot by observing how they get out of their seat in the waiting room and walk down the corridor. Then you’d go on to the examination and during the examination you’d probably be asking about other factors, occupational factors, social factors, stress and that sort of thing which may alter their perception of pain or how they actually cope with pain as well.”

(jsgp16nr)

The importance that general practitioners placed on formal examination varied. Some general practitioners were confident that a physical examination could provide an objective judgement, as this general practitioner explained somewhat incautiously:

“Again with arthritis, squeezing the joints and seeing what sort of reaction they have to that. Looking at them in the face and giving them a jolly good pummel and if there’s no reaction there’s obviously not much tenderness and if they pull their hand away then it’s very obviously sore. That sounds a bit unkind but ...you can make a fairly good objective judgement.”

(jsgp7)

Most general practitioners described the importance of observation during informal ‘tests’ such as observing any differences in the patient’s behaviour when entering or leaving the consultation (as the general practitioner quoted above described), in

getting on and off an examination bench or, if the consulting room was (un)fortunately placed with a view of the car park, watching patients walking and getting into their cars. Observation could extend beyond the consultation and the medical centre into the community as one general practitioner explained

“When you’re out on house calls and you see them marching up the street. You challenge the next time they come in and again in a small community like Braidtown we’re very fortunate, they’ve got to walk past the health centre to get to the shops so if they want to lead any kind of life in the community they will be spotted.”

(jksgp1)

Or as another general practitioner who was also based in a relatively small community explained:

“They (the patients) know we all drive around here seeing people.”

(lmgp1nr)

None of the general practitioners discussed any problems of interpreting such informal observations. In particular, there appeared to be no acknowledgement of the need to take account of the effort that patients might be going to in “order to lead any kind of life”. Implicit in general practitioners’ accounts of their observations and interpretations of such observations is a contradiction or delicate balance between their work in encouraging people to be active yet being ‘inappropriately active’ being a source of doubt.

Whilst most general practitioners made use of informal or semi-formal observations, a few general practitioners explicitly used formal examinations suspiciously as a test of genuineness as this general practitioner explained:

“There are a number of tricks that you learn like ... I can’t possibly get down to my toes doctor. Then if you actually put their back against a wall and ask them to bend over it’s amazing how far they

can bend sometimes when they're actually ... so you're trying to trick the people who are actually conning you. You'll always get a few of those."

(jksgp2)

An alternative view on the use of observation and examination was given by the general practitioner specialist in pain management who reflected with shame on his use of formal techniques of detection:

"I can recall, much to my shame now, no more than about three or four years ago, standing up teaching groups of students about how to detect malingerers or patients who didn't have or were over elaborating their pain and we spent a great time talking about tests for inappropriate pain signals and disguised straight leg raise tests. Pain behaviours and pain signals and all of these things. It really is with some shame now that I've got into it deeper I realise that we deal in a much more complex area and it's not nearly as simplistic as that."

(ksgpreg2)

Only a few general practitioners described that a potential problem with informal observations was that patients can become aware of this and get upset.

Although most general practitioners described a search for some observable objective evidence, descriptions were frequently followed by a description of its inadequacy or meaninglessness and a different level of objectivity seemed to be demanded. This general practitioner explains the inadequacy of 'objective' x-ray evidence:

"Some people seem to have very little in the way of organic disease but complain a lot of pain for the amount that you can see on the x-ray."

(ksgpreg1)

Thus pursuit of objectivity moved from visible or observable signs, with an

extension of the visual metaphor, to a task of putting together a picture or discerning a pattern, tying things up, in which the observable needed to match the patient's account or description:

“I suppose you're always looking for objective signs. If you're coming across somebody in the examination that seems to fit in with what they're telling you ... for example I suppose examining an abdomen would be a good one. You will get people who will tell you what dreadful tummy pain they're having yet when you lay a hand on their tummy it seems to be completely soft and non-tender, One would wonder about other factors other than abdominal pathology there. Likewise examining joints, the objective functional impairment you're coming up with often doesn't tie up with the story you're hearing. So trying to tie things up is one step in trying to assess it.

(jsgp16nr)

Sometimes patients' accounts or general practitioners' observations did not fit with an implicit model or anatomical explanation that general practitioners appeared to hold, though they did not make this model explicit. This general practitioner explained that doubts could be raised when a patient's description:

“bears no relation to the anatomical distribution of one's nervous system. It puts the question mark in your mind as to whether this pain is of neurological (as opposed to psychological) origin.”

(jksgp2)

Part of the difficulties that many general practitioners had with people who described moving pains, or pains which appeared to move from one part of their body to another may be related to an implicit model of identifiable pathology in a specific anatomical location:

“There are some things with chronic pain and it usually lends itself to be the chronic abdominal pain, the shifting pain, the one that doesn't fit with any of the text books and you're fairly sure there's a major psychological element.”

(gpjks1)

Despite the imperative, or perhaps instinct, of the search for objectivity, many general practitioners reflected on whether there was any point pursuing ‘objectivity’ in such a subjective area. As the general practitioner quoted above added:

“In some ways that’s not that useful in that at the end of the day you’re still trying to deal with the patient’s perception of the pain and how you then deal with that is largely down to listening to the impact that it’s having on their daily lives.”

(jsgp16)

- **Tying everything together about the patient**

General practitioners also described the ways in which information about individual patients could form patterns which they could piece together, or not, in some cases. This information included observable behaviour, an assessment of the impact of the pain on the patient’s life, prior knowledge of the patient, knowledge of the patient gleaned from other professionals or from members of the patient’s family as well as from a psychological interpretation of the patient.

As described above, statements about the primacy of the patient’s verbal account of pain were often followed by a statement of the doubts associated with this. Asking the patient detailed questions about the impact of the pain appeared to be seen as one way of objectifying the patient’s account. For example some general practitioners explained that although patients described pain as agony, close questioning about its impact, such as was it affecting their sleep, could reveal whether it was really agony or not.

Many general practitioners explained that knowledge of the patient was important as the following quotation illustrates:

“It can be difficult to assess but I think that’s where being in general practice is an advantage because you may know that patient from other conditions and you form some sort of opinion of how they cope with other conditions and therefore whether they’re likely to.. if Mrs Jones comes down and tells you there’s something wrong, well there really is something wrong because she doesn’t very often complain. Whereas if Mrs Brown comes down you think oh no not her complaining again.”

(jsgp18)

Whilst much of general practitioners’ interviews emphasised the importance of the relationship with individual patients, paradoxically this relationship could be constructed as a lack of objectivity as this general practitioner explained:

“It’s difficult for you to be properly apart from the patient as a really objective measurement of pain.”

(ksgpc1-2)

Earlier sections of this analysis have drawn attention to the importance of general practitioners’ emotional reactions. General practitioners’ own feelings about individual patients were often included in their interpretations of patients, as the following quotation illustrates:

Again a lot of it depends on your sympathy for the individual. If it’s a patient who you know, respect, like even, you’re more likely to take them seriously than someone who you consider a bit of a time waster and who has been wasting your time or tends to come in with trivia or suddenly presents this out of the blue as an addition to something else which has been going on for ages which is what sometimes happens. Again it’s a very individual response to the individual.”

(jsgp9nr)

These feelings were also an important aspect of knowing the patient, and appeared to one of the implicit reasons as to why it was difficult to be ‘objective’ or be ‘apart from’ them.

Psychological interpretations of the patient

An important part of the process of working with patients with chronic pain was to consider the role of psychological factors in patients' presentations of pain.

Some general practitioners explained that consideration of 'hidden agendas' was an integral part of their 'consultation skills'. General practitioners also referred to concepts which can be seen to parallel the psychological concept of secondary gain, that is, that apparently dysfunctional behaviour can be sustained because it provides alternative gains. The following extract from an interview illustrates the doubt which consideration of secondary gain (a line) or the contribution of 'psychosocial factors' (how is the marriage doing) could create:

R: "I've been asked to do a report on a patient about a knee injury that happened in 1991. I think the lad has probably got some disturbance in his knee from this accident at work but he has been off work steadily since then and I cannot logically see any way of not giving him a line and yet it's always at the back of my mind. I think"

I: "What is it that makes you wonder?"

R: "The sort of emotional overlay I would say, but its not a sort of clean, objective kind of situation, it's all sorts of things like how is the marriage doing and lots of things."

(jsgp7)

General practitioners' discussions of possible "hidden agendas" did not appear to lead to doubts about whether the patient had pain. As one general practitioner explained in the context of doubts about objectivity:

"You tend to think, well the pain itself is not a great problem, what's the problem is the patient's perception of it or is there a hidden agenda that I'm unaware of. So these are the ones that you would perhaps hold off a bit or go digging deeper for other things going on, other factors. The sort of pain that's not borne out by any physical signs like the x-ray or whatever, again I suppose it would just make you look a wee bit harder for other compounding factors but it wouldn't make you say that this patient hasn't got a pain." (jsgp16)

Whilst the fact of the patient's pain remained unthreatened, where general practitioners did speculate about the ways that the patient's pain might function to serve their motives, such as attention seeking within the family, these motives of secondary gain were always implicitly constructed as less worthy and the patients as less genuine.

Interpreting patterns of patients: the experiential epidemiology of general practice

Another source of patterns or misfit which general practitioners described in trying to interpret individual patients was how they compared with other patients. Davison et al. (1991) used the term lay epidemiology to describe the way that people interpreted the patterns of health and illness they perceived in the people that they knew or were aware of. This included the way that they described known individuals to challenge the conclusions of population or scientific epidemiology. This section of the analysis focuses on the way that general practitioners constructed comparisons between individuals and patients or people in general, or simply between individuals.

There are key features of a general practitioner's role and the health service structure within which they work which can be seen to impact on the way that general practitioners' construct their understanding of the population of patients. General practitioners described some of these, often in contrast to the view from hospital medicine. These were that general practitioners only see people who choose to consult and continue to consult. In this way people who consult too frequently can be seen as 'problems' or as representing the failure of medicine or

the general practitioner's failure. This was most clear in responses to a question we asked in the first round interviews - could you describe your ideal patient with chronic pain? - where many general practitioners explained that this was somebody who went away happy with medication, or if they continued to consult then this was to tell the general practitioner that they were happy and doing fine.

The comparisons between people were often interpreted in the context of general practitioners' own motivations and emotions. The quotation above, in which a general practitioner explains the importance of having sympathy for patients, illustrates the importance of general practitioners' emotional reactions to patients. In terms of general practitioners' motivations, the observation that some people seem to cope or "put up with" tremendous illness and distress with minimal medical input raised a question about people who appeared to need much more medical attention for (apparently) very little as the following quotations illustrate:

"But at the same time you kind of say well hang on, other people can cope with this."

(jsgp9)

"As I say there must be a whole lot of them who actually do the adjustment themselves. They realise, who don't actually wait and come back and see me, they just say well it's not got better, the doctor's not doing anything for me, I'll just get on with it".

(jsgp8-c4)

There were several strands to general practitioners' accounts of how individual differences that they observed made their work with people and pain difficult. These were that people have different pain thresholds, that people react differently,

that people present their pain very differently, that people use language very differently, that people interpret their pain differently and that people have different personalities. Several of these, patients having different pain thresholds, using language differently, are illustrated by quotations in earlier parts of the analysis on the process of interpretation.

As indicated above, comparisons along these dimensions could be made between types of patients that the general practitioner has known, as in the following quotation:

“Patients who we have over the years felt have because of their pain adopted a pattern of behaviour dictated by their pain which possibly we feel isn’t entirely necessary because we see other people with similar problems who aren’t as limited because they view it differently.”

(jksgp5)

Comparisons were also constructed between individual patients and the ‘average’ patient:

“I suppose you’ve got your rough idea of what you’d expect from the average person with that problem and if you’re getting away from your expectations or if you’re getting inconsistencies then you’d maybe look at that person slightly differently from the average.”

(jsgp16nr)

Finally, general practitioners also compared individual patients. In the following quotation the general practitioner has been asked to describe an ideal patient. He describes a specific patient, rather than responding as most general practitioners did, by describing a generalised ideal patient, and he spontaneously goes on to draw a comparison with another problematic patient:

“She’s very uncomplaining, if you ask the questions she’ll say yes

she's in a lot of pain and she's very limited. Yet presumably because of her underlying personality, she will not let it get her down but her sleep is disturbed and she does have a lot of problems. Well this other lady that has ME, which I'm not disputing, who tends to refuse some of the treatment on offer because I think she's got a lot to lose from losing the potential sick role that she's taken up. She's worked her environment round to such that she gets a lot of attention from people. Obviously if she physically was a lot better then she would lose a lot."

(ksgp1-c2)

One further example of inter-relationship between the structure of general practice, in this case, the diversity of patients in a surgery, and the construction of comparisons between patients, emerged from a chance conversation with a general practitioner colleague, recorded in the author's field notes. The author mentioned that she was reading a transcript of an interview with someone with back pain. The general practitioner colleague groaned and explained that she'd just finished a surgery in which she'd seen a patient who keeps returning with backache. She elaborated on why she was so dismissive of him (in talking to the author), explaining that the patient before him was somebody who hardly ever comes to the doctor, but had come for advice because his legs were weak and he was having trouble getting up, if he knelt down, for example. She explained that she'd examined him and found serious muscle wastage, and that he had been having problems for some time before 'bothering someone'. She was concerned that he had a serious degenerative disease and referred him immediately. As she explained, it was hard to have that much sympathy towards someone who was basically healthy even if complaining of backache.

Interpreting patients in wider social context

General practitioners' accounts contained three main areas where the social context or social factors could contribute to doubts: the social problems of drug abuse and addiction, the social policy construction of financial claims and the social censure of accounts of pain. That is not to say that general practitioners explained these issues as being sociological, this is an analytical interpretation which is important to make because of the absence of a sociological perspective in most general practitioners' accounts.

All general practitioners made reference to the issue of the potential for medications prescribed for pain to be abused, although a small number of general practitioners raised this issue in the context of explaining that it was something that was not a real concern. General practitioners who identified themselves as working in small communities often expressed confidence that they would know if drugs were being abused. Very few general practitioners had direct experience of being "caught out" by patients, but most expressed concern about the possibility that people might be after "a high off the DFs¹⁷"

The overview of the sociology and anthropology of chronic pain in chapter five described chronic pain as an issue which exposes the fault lines of society because of the way that it can function in terms of income redistribution, either in terms of claims for financial compensation due to the cause of pain or in terms of the

¹⁷ DF118 was the former brand name for an opioid analgesic (dihydrocodeine preparation) used for moderate to severe pain.

entitlement of financial subsistence of people unable to work. Although changes in the administration and allocation of disability payments have meant that general practitioners are no longer in the position of deciding entitlements, the possible financial implications of pain could raise doubts.

As the above analysis has suggested, patients ‘underplaying’, or failing to admit to symptoms, or being too ‘stoical’ was also a constituent of the problem general practitioners faced in interpreting people and pain. Whilst most of the accounts given of this were in terms of individual differences, some general practitioners did reflect on the social meaning of pain and of the societal difficulties that people face in giving their accounts of pain. For example, whilst some general practitioners described people with low back pain as being well known for “swinging the lead”, others, most often general practitioners who experienced back pain themselves, described this general view, and the culture of humour surrounding back pain as placing patients with back pain at a double disadvantage. As this general practitioner explained:

“It doesn’t bother me but I’m aware for people who do get severe back pain that they often have a curious relationship with it in that they are aware that no one can see it. ‘ My bad back’s almost a joke but it isn’t particularly to the person who’s got it. Just because they haven’t got a plaster on, it’s not obvious to anyone else.”

(jsgp19)

Intuition and gut reaction

Although, as the above analysis demonstrates, general practitioners were often able to articulate the origins of any doubts, and to reflect on their processes of interpreting patients, there remained a category of explanations which by its very

nature, could not be made more specific or reflected upon in any more detail. This category of explanation included “instinct”, “gut reaction”, “a combination of intuition and logic”, “getting a feel for patients” or thinking “there’s something funny going on here” as these general practitioners described:

“I think this is one of the troubles about this aspect of care. It’s this gut reaction of, are they leading you a merry dance or a straight story. There’s always the two levels, the stoic who won’t tell you and you know there’s something wrong but they won’t admit it, to almost the histrionic end ... for every one that we think, wait a minute there’s something funny going on here, there will be one that will be hypersensitive and we have to cope with that.”

(jsgp1)

“Sometimes you think why has this person come to see you. You get a gut feeling, there was something funny about that consultation, it just didn’t all fit together. It can be as none specific as that.”

(jsgp8-c4)

- **Summary: managing doubts**

General practitioners’ accounts of their work interpreting patients implied a process which left considerable room to have doubts about patients and their motives. Such doubts could rarely be managed directly with the patient because of the necessity of the work of conviction. The analysis suggests that these doubts could not be avoided, merely bracketed out as the account of the general practitioner pain specialist revealed. Throughout most of the first and second interviews he had explicitly maintained the following position:

“I’ve yet to come across a patient who is genuinely making it up. If they say they’ve got pain then I would take that at face value.”

and later,

“I think the true malingerer is so rare as to not be worthy of worrying about detecting. If the patient says they’ve got pain then that’s it for me.”

(ksgpreg2)

However this degree of conviction could only be sustained by ‘bracketing out’ the doubts as a comment towards the end of the interview revealed:

“I’m not lumping in my diagnostic group of the chronic pain patient the patients who are using back pain as a means of getting a sick line or who are cynically manipulating. There are a small group like that, who may be attempting to use back pain to get opiates which they then sell.”

(ksgpreg2)

Work of conviction

Throughout their descriptions of working with people with chronic pain, general practitioners emphasised the importance of reassuring the patient that they (the general practitioner) believed them and were taking them seriously, as this general practitioner explained:

“First of all you have to get the patient to believe that you believe what they’re telling you.”

(jsgp5)

This section of the thesis describes general practitioners’ accounts of the difficulties in achieving this. It is noted here however, that this analysis of general practitioners’ understanding of the problems of this area of work revealed subtly different issues from the analysis of patients’ descriptions of the problem, that of thinking that doctors think they are imagining a lot of the pain.

General practitioners frequently described the problems of getting patients to believe they were being taken seriously. Thus the importance of the work of conviction was implied rather than stated directly and positively. The problem of getting patients to believe that they were being taken seriously was sometimes described as inexplicable as this quotation illustrates:

“I don’t know what it is that you put out. I really don’t know why it happens either because you seem to do the consultation the same as you’ve done with other people and yet it’s quite clear at the end that they’re unsure and the uncertainty arises. You might not get it at that consultation. They’ll come back at the next one or the one after and say do you believe me. Some of them will come out with it and say, do you think I’m making this up.”

(jsgp8-c4)

Most often, general practitioners described the problem in relation to specific areas of their work. One strand of difficulties was in terms of patients’ expectations, or their interpretation of patients’ expectations, of being treated physically. As one general practitioner explained:

“There are some people who somatise and it probably is emotional and if you mention it to them they won’t come back to see you. So you have to treat them very physically.”

(ksgp1-c4)

Overall, the most frequent difficulties that general practitioners described could be seen as the converse of this, trying to discuss psychological aspects of pain or psychological approaches to pain management with patients. As one general practitioner put it: “using the word psyche in it and people begin to think you so distrust them.”

The following quotation illustrates several of the recurrent themes in general practitioners' understanding of their difficulties. Firstly, that (some) patients view their pain as physical and that this is often a too narrow, or blinkered, view. Secondly, that asking questions about the emotional aspects of pain is often interpreted by the patient as suggesting that it is all in the mind and that the patient is not suffering physical pain at all, or that they are being written off as malingering. Thirdly, that patients need reassurance that the general practitioner is not suggesting that there is no pain at all. The quotation also illustrates the implicit assumption that the issue from the patients' perspective is absolute, that is, that they are not suffering pain at all whereas from the general practitioner's perspective the issue is of how much, that it's not all in the mind.

“The other aspect is the patient who's come very much with blinkers on that this is physical and you start probing the emotional side they get very upset because I think what they're really deep down feeling is that he thinks it's all in the mind and that I'm not suffering physical pain at all. Of course one has to be sensitive to that because the pain they're experiencing is real to them and I think they've got to be reassured about that. That we're not just saying it's all in your mind and there's no pain at all. I think that's a fear some people will have. Some people are quite happy to open up about it and others would be fearful of that. I think their fear is being written off, that we would say to them go off and we don't want to see you again, you're just malingering and having us on.”

(jsgp15nr)

Related to this issue, as described earlier, general practitioners explained that they had to be very careful to explain the (potential) use of anti-depressants for pain management as opposed to managing or treating depression. Some general practitioners explained that this could work in reverse, that is, they could explain that the antidepressants were to help the pain when their (undisclosed) intention was that this would help with associated depression.

“The difficulty with some pains is depression can be part of it and I think you can treat depression effectively. The interesting bit is that anti-depressants will also help the pain as well particularly if it’s nerve pain. I think they can be a useful treatment just for the pain itself. Sometimes some patients are very reluctant to be treated for their depression because they think that you’re really saying it’s all in your mind but if you can say to them, look I would really like to see what effect of the antidepressant is on the pain and there’s good evidence that antidepressants work on the nerves, then you might get a dual approach and you might get them eventually to say I’m actually feeling a lot better and I realise I was quite depressed. You can get that out of it as well. So again it’s how you approach it. You can use antidepressants for both.”

(jsgp6aa)

In the context of these difficulties, many general practitioners explained the importance of an on-going open and honest relationship with patients, where there was sufficient trust in order to negotiate these problems constructively. Again general practitioners emphasised the importance of developing this relationship over a period of time. Some general practitioners explained that this could be achieved in one go in the hospital setting if consultants set time aside to do this at the beginning of a consultation.

The three issues above: the importance of treating patients physically, the difficulties of discussing psychological approaches to pain management and the importance of the doctor-patient relationship can be seen to have important implications for the overall process of care. Moreover the work of conviction, or the motive of reassuring the patient that they were being taken seriously, could be seen to underpin other aspects of medical work such as prescribing, referring and investigating, as one general practitioner explained:

“You would hope that if you were still offering them different kinds of treatment then they will be assuming that you believe them.”

(jsgp12nr)

As described in the section on referral below, one of the motives for general practitioners referring a patient or continuing to refer and investigate was in order to demonstrate to the patient that they were being taken seriously. Conversely, desisting from this approach and trying to get the patient to accept that there was no diagnosis or no treatment could jeopardise the imperative of maintaining conviction.

Thus in relation to the problems of getting patients to accept, general practitioners explained that there was a limit to how soon they could suggest to patients that there may be no cause or treatment. One aspect of this was that general practitioners had to go through physical treatments in order to develop any relationship with patients. A second aspect was that the appropriate level of understanding between patients and their general practitioners was needed and this took time to develop. The following general practitioner explained the timing of introducing the idea that there may be no cure:

“I develop it over years and then when I’ve got it and hit them with the hard fact they accept it, if I’m being honest with them all the way through”

(jsgp18nr)

Some general practitioners explained that an important part of their role in this context was to always have “something up their sleeve” or different alternatives to offer the patient, that is to be seen to keep trying, to never be seen to give up. Most importantly, as described in the section below, implicit in the concept of keeping trying was keeping trying to do something.

A further important implication of this aspect of the work of conviction was that it can be seen to underpin general practitioners' feelings of "getting to the end of the rope" or "the end of the line". As described below, this was one of the reasons that general practitioners would refer a patient.

The imperative to do something which counts as doing some thing

Throughout general practitioners' accounts of the process of working with people with chronic pain there was an implicit assumption, often made explicit, that their role was to do something to help. As one general practitioner explained: "We are trained to do something".

This statement, of the need to do something, can be seen to be self-evident. However, alongside statements of the need to do something general practitioners frequently made statements that there was nothing that they could do. The following description, in which a general practitioner is explaining that he has become better at dealing with the problem of getting patients to accept that there's nothing else he can do, can be seen to be based on implicit assumption that helping to minimise the symptoms, in this context, counts as 'nothing':

"I think I'm better now at saying there's nothing else I can do. You're going to have to accept that this is an on-going problem and the best I can do is to help minimise it for you in various ways. Again that's getting stuck with the problem and it goes back to the feeling of failure."

(jsgp14)

Throughout their descriptions of problems with their work, general practitioners frequently made statements that there was nothing more that they could do or, more importantly from the analytical perspective, “that there was nothing that they could do except”. It was therefore possible, in analytical terms, to construct the elements of work which ‘counted’ as doing something, in contrast to the elements of work which were bracketed out, the ‘nothing except’ elements.

The following extract illustrates how general practitioners ‘bracketed out’ elements of their work. It is taken from a follow-up interview with a general practitioner in the context of exploring an issue from the intermediate analysis, that much care in chronic pain was patient-led or reactive.

“I think it’s probably very true. Probably the major reason being that we probably feel impotent in being able to do anything. If there’s something you can do then you’re much more likely to initiate action where you feel that nothing you can do is going to make any difference then initiating anything is difficult because what are you going to initiate. The only way you can be said possibly to initiate things is to give the patient set intervals to return and report to you. Once you’ve reached the stage of establishing your chronic pain state where everything that can be done has been done, then it’s a case of an on-going unchanging situation. Then there’s very little probably that most GP’s would feel they could do by taking the lead in that there’s nothing they can lead into’.

(jksgp5)

This general practitioner went on to explain, that the best they could do would be to set small goals and get patients to report back at set intervals, but in the context of his previous explanation, this strategy was constructed negatively.

Other general practitioners drew comparisons with other areas of work with patients with chronic problems in order to illustrate that there was little or nothing

that they could do with people with chronic pain as the following extract illustrates. Again, the general practitioner is commenting on the suggestion that on-going care for people with chronic pain is patient led and perhaps without a strategy.

I: So in terms of taking a strategic or proactive approach, is that something that you ever feel is appropriate for some people?

R: I feel it's appropriate for things like heart disease where you know you can actually make a positive difference to someone's life expectancy and quality of life. So if you know someone has heart disease they may not be approaching you but obviously when you get the repeat prescriptions you will look through, check things like are you aware of the smoking status. Is there something that I can actually manipulate to make their quality of life better? It's known that for those people you can dramatically improve their heart disease, their quality of life and their long-term life expectancy. So in that situation yes I think there's a positive reason for doing it because there's a positive goal to be achieved".

He goes on to describe similar things that can be done in continuing care for asthma before concluding:

"So in those situations you would be proactive because you know you can actually make a difference to that person. In chronic pain where you don't have a way of making things any better than I've not come across a case where I'm positively seeking someone out to say here come and have a go at this."

(Jsgp12nr)

Throughout the interviews as a whole, the elements of work which were constructed as 'doing something' were, unsurprisingly, the core elements of medical work: referring, prescribing, investigating and diagnosing. Other elements of work that general practitioners described as important aspects of their role, such as 'keeping the patient going', along with other aspects of hidden work described above, tended not to count as something.

The interpretation offered here is that this implicit division of work which counts as something as opposed to doing nothing arose from the absence of a shared or formal professional account of key elements of continuing general practice care. Whilst this is an analytical interpretation, it can be seen to underpin the sense that some general practitioners described, again negatively, as leading to collusion:

“I think there’s an awful lot of colluding goes on and we all want to try to help people in pain. I think it’s just I suppose one of our basic reasons for taking medicine in the first place, to relieve the world of pain entirely for some reason. So when we do see people in pain then it really makes us want to do something about it. So sometimes I think we do inappropriate things really and don’t help the patient and may give them too many drugs and this sort of thing. We have to be careful to look at our reasons for doing things if possible and the consequences as well.”

(jsgp13)

Reflecting on the process of working with people with chronic pain: towards the management of an insoluble problem

As described in the introduction to this section of thesis, issues which emerged from the initial interviews and which formed the basis of the analytical model of general practitioners’ accounts of the process of working with people with chronic pain were discussed with general practitioners in the follow up interviews.

The issues which were followed-up were as follows. Firstly, that work with people with chronic pain seemed inherently problematic¹⁸. Secondly, that general practitioners appeared to describe work like prescribing, diagnosis and referral in much more detail than work which seemed ‘vaguely psychological’. Thirdly, that

¹⁸ the question was phrased that we wondered if we had assumed in the first interviews that this area of work was problematic but perhaps this wasn’t the case

their descriptions suggested that work which could be described as ‘vaguely psychological’, such as getting people to accept their pain, keeping people going or helping people to get on with their lives, appeared to come only later in the process of care. Fourthly, that many of the problems which general practitioners described appeared to arise from earlier stages of care based on the process of diagnosing and prescribing and as such there appeared to be scope to bring in issues, like trying to get the patient to accept, earlier in the process. Fifthly, that much care for people with chronic pain appeared to be patient led and finally, related to this there appeared to be no sense of strategy in general practitioners’ on-going work. For the most part the follow up interviews confirmed this analysis.

Most general practitioners agreed about the tendency to be able to talk more about aspects of work such as diagnosis, prescribing, investigation and referral. Some explained that this was how they were trained, others that these were the areas that they felt they knew most about, or as several of the general practitioners explained, these elements could be seen to constitute the basic medical model:

I: Do you think that it seemed to us that this is what people described in most detail and do you think that’s because ... you say these 3 aspects ... the areas that most GP’s either focus on or do you think it’s just that it’s easier to describe?

R: I think they’re easy to describe and they are important bits of management. So if you want to sub-divide management then the bits that you look at are ... the medical model tells you that for everything you should come to a diagnosis by means of investigations and having formed that diagnosis, if you’re unable to form a diagnosis or unable to manage appropriately then you should refer to someone who can. So basically it was just reverting to the medical model. What I think is more important is that someone is able to manage the pain and that someone might be the patient well it should be the patient with a GP’s guidance or with the doctor’s guidance. I don’t think we’re very good at working out what the process of management is. So management’s too vague and if you ask us what

does management mean then we tend to go back to our medical model. That's probably not as accurate as it should be."

(jsgp112)

Another explanation used was that these areas of work were discrete and discernible as the following quotation illustrates:

"(We) don't described other areas of work well (as opposed to prescribing, diagnosis, referral) because you're doing it as part of giving them the information, part of the consultation. I suppose to some extent it's not actually a separate bit like the other bits are sort of separate little chunks. Part of the overall thing is to help them to adjust."

(jsgp8-c4)

Many general practitioners took the opportunity to reinforce their view that the other aspects of the work that were difficult to describe were as important or more important. Some general practitioners also explained that these were elements that they felt general practitioners should be introducing, and that they did introduce, right from the start although often acknowledging that there may be a shift in priorities over time as the following quotation illustrates:

"I think patients need support at all times and I think the whole picture needs to be taken into consideration at all times which is obviously the support at an early stage. Perhaps we don't concentrate on that when we're trying to elucidate the cause and we're grappling with the technical aspects of it."

(jsgp19)

In relation to the issue of trying to address problems earlier or avoid them all together, many general practitioners explained that they had learned to try to do this and to try to be more active in keeping in mind that the problem could be come chronic. Thus what the analytical model conveys less well is the extent to which general practitioners' approach was based on "trying not burn any bridges" with a

patient that they may have to come back to, or as another general practitioner put it: “not digging holes for yourself and the patient that you then can’t get out of”.

Other general practitioners described how they tried to engage the patient in this process of ‘keeping options open’, as this general practitioner explained (in relation to certain conditions):

“I try now with certain conditions to say at the outset that we may not get to the bottom of it and that these kinds of conditions are known sometimes to go on for a very long time. To say that from word 1.”
(jksgp5)

Interestingly, the best description of this process and account of its success came from one of the patients who was interviewed, a young woman (aged 36) with neck pain following a car accident:

I: Do you feel that your GP has a long-term strategy for you when you were dealing with your pain?

R: I think so.

I: I suppose in a sense that’s what you described last time when you felt that you were being led into how to cope?

R: Yes. She always said right from the beginning this isn’t going to just disappear. Which I suppose was just getting me adjusted to realising that.

I think that’s one of the things the GP very sneakily told me. Adapting to the pain rather than just saying, well maybe it’ll be gone tomorrow and then when it’s not you get more depressed because it’s still there.

(jspt8-2)

Thus although the follow-up interviews raised some cautions about the analytical model, general practitioners’ descriptions of having had to learn to avoid its pitfalls does lend support to its relevance.

As such, the composite representation of the process of general practitioners’ work

with pain does appear to have heuristic validity. As indicated above, the process appears to set up its own problems, for instance switching between the work of phase 1, which broadly represents a medical model, and phase 2. This was the view of the general practitioner pain specialist, expressed in this extract from a follow-up interview:

I: When we looked at the first set of interviews with GPs it seemed like there was a process of working through stages in a linear sequence. What do you think about that?

R: What sort of stages?

I: Well in terms of trying things, if that doesn't work it was another thing. There wasn't a sense of trying different approaches at the same time.

R: I think that is a fair comment. Much of the problem with the management of chronic pain stems from that underlying confusion of treating it as if it was going to behave in the same way as an acute condition would.

He adds later:

“You carry on along that logical A leads to B leads to C approach. That's fine for a condition that will behave in that logical manner but for a complex biosocial, everything all pumped into one thing like chronic pain, it doesn't work, it doesn't follow that pattern. It's a fundamentally different process that's happening. The patient with chronic back pain isn't getting the same biological phenomena as the patient with pain from a sore throat. So I think that linear aspect is a thing that leads on to more problems than it ever solves and it's almost applying the wrong model to the wrong condition.

(ksgpreg2)

Summary

“I suppose the further training would be in how we approach chronic apparently insoluble problems. We've got used to looking at and approaching people dying in a different way than was done say 10 or 15 years ago. Maybe we should learn lessons from that in the way that we look at ...for example someone dying is in a way we feel partly our failure or the failure of medicine although obviously it is a natural process, it has to happen at some stage. The same with

chronic pain that some people have got it and we cannot relieve them from that but we ought to be able to look at it from a slightly different viewpoint to help the patient's cope with it.”

(jsgp19)

The model of general practitioners' work with chronic pain which emerged from this analysis has drawn attention to chronic pain and chronic pain management as an emergent process which involves core clinical work such as prescribing, investigating, referring and detecting and managing psychological distress, along with hidden work. Moreover an important aspect of the analysis of hidden work is that it reveals a number of fundamental dilemmas. Both the process of working with chronic pain and its dilemmatic components have been shown to be shaped by the structural context of general practice and the wider social context.

From general practitioners' accounts, chronic pain emerges as a process. Whilst chronic pain can be indicated by finding a physical diagnosis or a physical cause, it is also indicated by patients continuing to consult and by consultations becoming repetitive. Throughout the emergent process the problem is transformed from being the pain per se to becoming the problematic patient and the person with problems. This in turn brings moral scrutiny.

The initial stages of the process of managing people with pain which may turn out to be chronic or may become chronic pain (or the patients may become chronic patients), involves the tasks of: being wary of demoralising the patient by assuming that the pain is chronic, or creating a sick role for the patient, whilst being wary of

raising false expectations that the pain will go away; bearing in mind that the pain could become or turn out to be chronic whilst hoping that it will go away; being wary of missing something whilst being wary of the negative or unhelpful effects of continuing to investigate.

As pain or the patient emerges as chronic the process of management involves the hidden tasks of general practitioners' own re-alignment of thinking and emotional work, getting the patient to accept, keeping the patient going and helping the patient to get on with their life.

Aspects of general practitioners' work which emerged as being continuous throughout included the core work of detecting and managing psychological distress and assessment or interpretation of patients but also included the hidden work of 'doing something' and of maintaining conviction. Again aspects of this work emerged as dilemmatic: the need to treat people physically in order to maintain conviction whilst considering psychological aspects of management and the need to assure that the patient that they were seen as genuine whilst managing doubts.

General practitioners' accounts of the process of managing chronic pain were complex and can be seen to be underpinned by a number of conflicting agendas or priorities.

The suggestion from this analysis is that the conflicts or dilemmatic aspects of this

process could in part be avoided by undertaking both approaches at once. This 'solution' is described in the following (exceptional) quotations:

"It does work very well to put the two things together. It works well to have somebody going for chronic pain management at the same time as waiting for their lumbar fusion operation or their dichotomy or whatever. It shouldn't be an either or thing. There shouldn't be anything in my book that says you can't send them to both simultaneously and treat both aspects of the condition at the same time."

(ksgpreg2)

Or as this general practitioner concluded:

"I think it needs both approaches. Not a choice between a very starchy drug based regime or essentially accusing the patient of being a nut case, which is the way they see it. And I think it needs to be lifted out of that idea that there is pain and there is not real pain."

(jsgp9)

Chapter Eight: Revisiting aspects of core work: general practitioners' accounts of referral and prescribing medications.

Introduction

This chapter considers two aspects of core work in more detail, exploring general practitioners' accounts of their work in referring patients to specialist services and in prescribing medication. The analysis of these two areas is underpinned by the analysis of the process as a whole presented in chapter seven.

The first section of this chapter analyses general practitioners' accounts of their reasons for referring. This analysis is used to address one of the aims of the research, that of describing general practitioners' views of specialist services and of the potential for developing chronic pain management in primary care; and to explore some of the methodological issues in using qualitative research methods as a basis for service development and planning.

The second section of the chapter analyses general practitioners' accounts of their work in prescribing medication, a subject they talked of extensively in the interviews. The analysis of this aspect of general practitioners' accounts illustrates well the processes of 'uncovering' hidden work and reflecting on initial readings of the data which had focused on aspects of core work. As was the case with referring, prescribing medication could be used to fulfil the imperatives of aspects of hidden work.

General practitioners' perceptions of services for people with chronic pain and their reasons for referral

One of the aims of the research was to describe general practitioners' perceptions of existing services and to explore the potential for development, in order to assist the Health Board in commissioning services for people with chronic pain. This section of the thesis addresses this aim by analysing general practitioners' views of specialist services for chronic pain.

In doing so it illustrates some important methodological issues about using qualitative methods as a basis for incorporating the views of professionals as indirect users of services in service planning and development. As might be expected, many of these overlap with methodological issues in the lay evaluation of health care.

A summary of the argument underpinning the analysis in this section is as follows. The views of service users, here general practitioners, cannot be summarised in a simple, straightforward or descriptive way. Moreover although service users can (sometimes) identify problems with existing services, there is an additional difficulty in trying to explore the potential for service developments. That is, there is an important sense in which service users only have experience of existing services, making it difficult for them to know, and to make suggestions about, how things could be different.

In the context of these issues, the analytical approach taken here is to attempt to

extrapolate the potential for development from accounts of existing problems. This section of the chapter focuses on general practitioners' accounts of their decisions to refer patients to specialist services. The basis for this focus is that, in broad terms, though rather obviously, general practitioners can be seen to refer when they reach the limitations of their own approaches or resources, an argument captured in the following quotation:

“At the moment I don't even need to know why I refer you. I just need to know that I can't deal with this and vaguely in which direction to send you.”

(jsgp11c3)

The underlying analytical argument is therefore that it is possible to infer the development of skills and resources needed to underpin primary care based chronic pain management, at least in part, from general practitioners' descriptions of their reasons for referral.

The analysis of general practitioners' accounts of their decisions to refer can be seen to fulfil three purposes within the chapter as a whole. Firstly, as described above, general practitioners' accounts of their decisions to refer a patient to specialist centres contain the basis for an analysis of the existing limitations of primary care. Secondly, the analysis of general practitioners' explanations for referring patients presented below constitutes another means of reflecting on the analysis of the model of general practitioners' work presented in the previous chapter. Many of the reasons for referring mirror problems and difficulties faced by general practitioners in their work with chronic pain described in the previous chapter. Thirdly, along with the analysis of the general practitioners' accounts of their work in prescribing

medication in the forthcoming section, it illustrates the hidden work behind the core work.

This remainder of this section of the chapter illustrates the arguments above. The first sub-section introduces the methodological issues. The second sub-section describes general practitioners' views of the process of secondary care for people with chronic pain. This sub-section includes an analysis of general practitioners' views of the pain management programme at centre 4. The final sub-section describes general practitioners' accounts of their reasons for referring patients.

It is perhaps worth highlighting here that this section of the thesis assumes familiarity with the existing structure of service provision in local health board areas as described in chapter six which outlined the study design and methodology.

Methodological issues and the analytical approach

As outlined earlier one aim of the research was to describe general practitioners' perceptions of existing services and the potential for development.

General practitioners were asked specifically about secondary services for chronic pain, what services they were aware of for people with chronic pain and when and why they might refer to them. If general practitioners did not mention one of the four centres which had been defined as a pain clinic, then the interviewer would ask directly if they were aware of the service. In this way it was possible to obtain a

comprehensive picture of general practitioners' views and awareness of services.

Several readings of the data were attempted specifically to meet this aim and the process of data analysis raised a number of important methodological issues. In broad terms, general practitioners' views of the existing specialist services for chronic pain management could not be summated in a straightforward way which would allow the researcher to make direct statements about general practitioners' views of particular service units. More specifically, a simple content analysis would not have captured the complexity of the data or its meaning.

Three methodological issues can be seen to underpin these points. Firstly, not all general practitioners knew about all the centres and not all general practitioners had referred to all the centres. Secondly, general practitioners' reasons for referral to a service often framed their perceptions of that service. Thirdly, general practitioners' accounts, like those of patients, constructed their views of specific services or centres within the context of the process of care as a whole.

- **General practitioners' knowledge and understanding of existing services**

The following description of general practitioners' awareness of existing services illustrates the difficulty, if not impossibility, of appropriately summarising their views of specific centres.

All general practitioners were aware that there was a pain clinic at centre 1,

although some general practitioners explained that they were not confident about how much they knew about what the clinic did. Only a small minority had never referred a patient to this centre, although the frequency and recency with which general practitioners had referred to the clinic varied.

Similarly, all general practitioners knew about the orthopaedic medicine service at centre 3 and most had experience of referring a patient to the service. Most general practitioners did not mention this clinic spontaneously when asked about specialist pain clinics but discussed their use of this service only when prompted.

The pain clinic at centre 2 was less well known and use of this service appeared to be based on geographic proximity. Unsurprisingly given the ad-hoc structure of the clinic, some of the general practitioners who knew about the service thought that it had closed. General practitioners' accounts of this service suggested that they did not distinguish the nature of the service from the service at the centre 1, even though they did not give much detail about either of the services.

At the time of the first interview, only a few general practitioners appeared to be aware of the general pain management programme at centre 4 and even fewer had referred patients to it. Again, most general practitioners did not mention the centre 4 programme when asked about pain clinics and this appeared to be for two reasons. The few general practitioners who were both aware of the service and knew something of its content and ethos thought of it as distinct from a pain clinic and thereby appeared to classify it as something different. General practitioners

who were aware of the other rehabilitation programmes for people with specific conditions, were unaware of the general programme and thus thought that the programme was just for back pain or angina pain.

- **General practitioners' views of specific services in the context of the reason for referral**

General practitioners were often negatively critical when there was a mismatch between their purpose in making the referral, and by implication their assumptions about the functions of the clinic, and the work of the clinic. In some cases it was clear that the dissatisfaction of general practitioners was linked to the reasons they gave for referral to a specialist pain service which, as described below, could be in order to try to get the patient to accept that the pain was not going to go away, or to help the patient to get on with their lives.

The framing of general practitioners' criticisms of services by their motives in making the referral is illustrated by the following explanation from a general practitioner who explained that his view of the clinic at centre 1 had become more negative such that he has stopped referring there unless for something specific. The implication of this explanation being that centre 1 did not, or should not, just do specific things. Similarly, many general practitioners were very negatively critical of centre 1, particularly for the lack of psychological input and follow-up.

In contrast, other general practitioners explained that they found centre 1 less

useful than the pain management programme at centre 4. They were not negatively critical of the centre 1 pain clinic, arguably because they were not referring there in the hope of it providing a service which it does not provide. One general practitioner made this point explicitly, reflecting that it was not fair to criticise an anaesthetist led service for not being a psychological service.

- **General practitioners' perceptions of the process of secondary care for people with chronic pain**

In broad terms, general practitioners' views of the overall process of secondary care for people with chronic pain matched those of the patients themselves often using the same metaphors of being passed from pillar to post or being on a roller coaster ride as this general practitioner explained:

“It is very easy for patients with chronic pain to get gobbled up in the system or go on a roller coaster ride from one department to another. I think it's because as doctors we don't really like patients that don't get better. That's very inconsiderate of them to spoil our day by not responding to our treatment. So they often do end up getting shunted on and referred sideways and backwards. I think that can be a big problem.”

(jsgp16)

As described in chapter 7, general practitioners often described the difficulties of trying to prevent or limit the problematic consequences for patients in the context of their own or patients' concerns to exhaust all avenues that might lead to treatment.

General practitioners described one effect of the process of being referred to different specialties was the compartmentalisation of patients into different bits,

often explaining that their role was then to try to piece all the different bits back together again. Some general practitioners explained the inevitability of this in terms of the structure of medicine and the problem of chronic pain not fitting within this structure as in the following quotation:

“You do often find a situation where yes referrals are going round but that’s a fault of medicine in a sense. Specialism works and for most people who fit a pattern it works very well but for people who don’t fit a pattern it can be difficult to know just what to do with them or where to send them”

(jsgp1)

Other general practitioners were less accepting of this:

“I did feel there was something lacking because I mean we have headache clinics for people with headaches and all kinds of headaches go to that and they sort them out. There doesn’t seem to be a pain of unspecified origin sort of thing.”

(gp15nr)

Views of the pain management programme at centre 4

General practitioners’ views of the pain management programme at centre 4 are considered in detail below. There are three principal reasons for analysing their views of this centre or programme specifically. Firstly, as indicated above, views of this centre or programme formed a separate and identifiable part of general practitioners’ accounts. Secondly, from an analytical perspective, there appeared to be the potential to explore general practitioners’ views of their own ‘vaguely psychological’ work with their views of this formal programme. Thirdly, the analysis had drawn attention to the way that psychological approaches, including the formal programme, appeared as part of the process of managing chronic pain only after ‘physical’ or ‘medical’ approaches had been tried. As such an explicit purpose of this part of the analysis was to try to understand why this was the case.

As indicated above, not all general practitioners were aware of the programme or knew much about it. Those who were able to explicitly contrast the approach of the centre 4 programme with the more 'traditional' approach of clinics based on physical interventions were very positive about the idea of the service. As one general practitioner, who described himself as having "leapt on the pain management service", explained "I wished we'd had this for years."

Again there was evidence of potentially conflicting priorities on general practitioners, with the general practitioner described above as having leapt on the service adding that he was trying to resist referring too many patients because he didn't "want to give them all the really bad ones." In contrast to other general practitioners who welcomed the centre 4 programme because:

"It's taken the real headaches away, the ones that really made me think ... the rest I can cope with but these are the ones that I thought I was going to go mad if I see this person again and do this consultation again."

(jsgp8c4)

By the time of the follow-up interviews, many more general practitioners had become aware of the centre 4 programme, had referred patients to it or were considering referring patients to it, and appeared to know much more about the ethos and content of the programme. Most general practitioners were explicitly positive about the approach of the programme, summarised as not trying to cure or alleviate the pain but helping people to get on with their lives and to change their perception of the pain. In general, the programme was seen to be much needed and

filling an important gap in relation to both secondary services and in relation to general practitioners' perceptions of their own skills or lack of skills.

General practitioners' concerns about the service were twofold. Firstly, that demand was such that it would become over subscribed and secondly, that they were making appropriate referrals. The latter of these concerns was in part related to the former issue of general practitioners explaining that there were many patients who would benefit from this approach but that they tried to resist over referring by, for example, waiting until people had run the full gamut of other things.

A second important explanation for waiting until they had 'reached the end of the line' before referring to the pain management programme was the issue of maintaining the conviction of some patients. In order to avoid threatening this conviction, some general practitioners explaining that they would wait until the patients themselves had become so desperate that they would try anything.

Overall, however, both these issues appeared to mitigate against the possibility of using the programme as an early intervention.

The problems of waiting times

All general practitioners raised the issue of waiting times which were universally perceived to be unacceptable, with nine months being the most common estimate. A universal view amongst general practitioners was that there was no timely specialist support.

The principal arguments for this being problematic were as follows. Firstly, that by the time patients reached the stage of being referred to the pain clinic waiting a further nine months was unacceptable from the patient's perspective. Secondly, that the long wait contributed to the chronicity of the problem, the implication being that patients became more entrenched in chronic pain behaviour throughout. Thirdly, that the wait gave people the opportunity to raise their expectations to an unrealistically high level.

General practitioners described the impact of waiting times on their approaches to working with patients. Some general practitioners suggested that anticipating a long wait might make them refer earlier, as this general practitioner explained:

“If your patients were seen right away, you might be able to delay your referrals. If you could get people seen when you want them to, you might not refer people so quickly. Some of your referrals you make frankly because you're hedging your bets.”

(jsgp12nr)

Other general practitioners explained that the knowledge that a patient could be seen quickly might make them more willing to try to manage the patient themselves:

“If they know that within a reasonably short period somebody will be seen they may have the confidence to take the problem on a bit further themselves before they actually make the referral.”

(ksgpreg3)

Other general practitioners explained that the long wait meant that they would put off referring unless the situation was desperate.

“I wonder at times do we actually continue down the more physical or traditional medicine approach with these individuals with chronic pain simply because we know that we have access to the services. It might be that we would admit to this being chronic pain sooner if the

service was available.”

(jsgp1-2)

Although general practitioners emphasised that the long wait was a problem, some general practitioners explained that, from their perspective, a positive aspect of this was that this got the patient “off their back” for a while.

General practitioners’ accounts of their reasons for referral to specialist pain management services

As described above detailed consideration was given to general practitioners’ accounts of their reasons for referring patients to specialist services in order to explore the limitations of primary care and to illustrate the hidden work behind elements of core practice. A brief description of the data makes this latter point more explicit, illustrating how general practitioners typically constructed their accounts of why they referred patients.

Although most general practitioners gave some clinical reasons as to why they would refer a patient to specialist services, not all general practitioners did so. Even when clinical reasons were given, these were not the only reasons. Thus a substantial group of general practitioners were explicit that they would not refer to clinical specialist pain management services unless they had a specific procedure or technique in mind. Joint injections, nerve ablation or advice about other physical interventions such as tens being the most commonly specified clinical reasons. However they also added other reasons as in the following quotation. This general practitioner was exceptional in saying that he would refer for advice about

analgesia:

“I think I would refer patients there because I would want advice on the particular analgesia we were using. Have we got the pain killer right, is there any other drug that we might be able to use for this particular pain. Another reason for referring to the pain clinic is to see if there are any other techniques that could be used, like injections into joints and that sort of thing which I’m not specialised to do and they are. Very helpful they can be so that’s two different reasons. Thirdly there’s this patient where you’re beginning to get to the end of the rope and not quite sure what to do next.”

(ksgp4)

Analysis of general practitioners’ accounts of their reasons for referring to specialist pain management services revealed that general practitioners’ motives for referring could be seen to mirror the range of problems identified in the analysis of their accounts of the process of their work as a whole. As such, referrals could be seen to serve a range of functions, including those implicit in what has been termed hidden work such as managing doubts, maintaining conviction, getting the patient to accept and managing their own emotional reactions. These reasons are described below. They are in no particular order.

- **Generally not being able to manage**

As indicated in the introduction to this section and in the above quotation, general practitioners frequently explained, in very general terms, that they referred when they ‘weren’t quite sure about what to do next’. An earlier section of this thesis emphasised the importance that general practitioners placed on giving the patient hope, or the feeling that there was always something else to try. In this context, referral could be ‘something else to try’ when general practitioners felt that they

were “beginning to get to the end of the rope”.

- **To demonstrate conviction**

General practitioners explained that referring a patient to a pain clinic could be an important demonstration of “the fact that somebody has taken them seriously”. The somebody could be the general practitioner themselves or the specialist. However, as many general practitioners explained, a frequent problem for them was that encounters in specialist pain clinics sometimes had the opposite impact on the patient, that is, it made them feel that they were not being taken seriously and as such general practitioners were left with additional work in trying to reassure people.

- **In order to do something**

The thesis has emphasised the importance of doing something that counts as doing something and this included referring a patient. Thus a reason for referring was because general practitioners felt they had to do something.

- **To manage doubts: for an ‘objective’ assessment of the patient**

General practitioners described a range of problems they faced in assessing patients and their pain and as such, referring a patient was often seen as a way of getting another, more objective assessment. The problems of assessing patients could lead general practitioners to begin to doubt their own interpretations, particularly to

wonder about how bad the pain was, whilst being aware that they might be being unfair. Again, referring the patient was constructed as a possible means of resolving these doubts:

“There are good programmes up at (name of centre 4) where people can go to be assessed, watched and maybe their perception of what their abilities are can be better monitored in that situation where I’m getting a bit cross. I would say, stand back here, this isn’t a good situation for anybody, let somebody else have a look. Make sure your assessment actually is correct because it might not be. This poor person might not be managing to do these things and you’re just getting the feeling the gut feeling that they’re a bit of a time waster.”
(jsgp17)

- **In order to confirm that there’s nothing seriously wrong**

Many general practitioners described the on-going process of resisting further investigations and referral whilst managing their own and/or the patient’s concerns that there may be something seriously wrong. As described earlier, in this context, general practitioners often felt that they needed someone ‘stronger’ or more ‘powerful’ to confirm that this was the case and hence would sometimes refer.

- **In order to get the patient to accept or get on with their life**

As described earlier, when general practitioners described their problems with getting patients to ‘accept’, this encompassed trying to get patients to accept a range of different things. These included trying to get patients to accept that there was no cause or explanation for the pain, that there was no cure or treatment or that the pain was not likely to go away. General practitioners’ reasons for referring to specialist pain clinics often included getting the patient to accept any one or more of

these issues. Referrals in order to get patients to accept different things were not linked to particular pain clinics, rather there was an implication that the purpose was to get someone else to reinforce whatever issue the general practitioners felt that they were struggling to get across. However some general practitioners did differentiate between specialist pain services in relation to trying to help patients to get on with their lives, in this context referring patients to the pain management programme.

- **Escalating use of medication**

The final section of this chapter describes general practitioners' views on prescribing medication. A particular concern was of escalating use of medications, that is, the sense of going up the analgesic ladder too quickly which in turn could lead to problems of addiction or abuse or a feeling of running out of options too quickly. In this context a referral might be a way of "putting the brakes on" as this general practitioner explained:

"When you're working through a pain management regime with a patient and you know you're heading quickly down the list of pain killers and you haven't known them for very long, you haven't built up enough information about what's going on. You do start to think, oh my goodness I'd better put the brakes on here which is almost a guess... what you're philosophically trying to do. So that can be a problem sometimes of doing more harm than good. What you often need is just time to get to know the situation a bit better. Often at that point if I feel I'm losing control, I will then look for help from an outside agency or tertiary referral to see a specialist or something like that, when I don't feel comfortable with it."

(lmgp1nr)

- **For own reassurance and support**

Many general practitioners explained that even when pain clinics were unable to do anything different or help the patient at all, the referral was still helpful from their perspective as a source of reassurance. An outcome of no change implied, or the discharge letters made explicit, that the general practitioner was doing all they could, not missing approaches or interventions that might be of benefit or “not making a complete mess of it”.

Some general practitioners explained that contacts could be a source of support, explaining that it was helpful to know that the specialist found some patients similarly difficult to cope with as this general practitioner explained:

“I think the advice and also to sympathise with us that we can’t cope and if we’re not coping they say the same. I think that can be quite helpful”

(jsgp3)

- **For own respite**

As indicated above, although waiting times for specialist pain management services were problematic, some general practitioners explained that this wait could form welcome respite from patients. Whilst general practitioners emphasised the benefits of this in terms their own emotional work and sense of relief, the break could also be constructed as having potential benefits for the process of care. In particular, general practitioners explained that it could allow an opportunity to reassess the situation and thus guard against complacency or ‘getting stuck’ with patients as this general practitioner explained:

“I think the actual referral and giving us a break from it, at least feeling we’ve got the responsibility off our shoulders for a while is sometimes quite useful and allows us to reassess the situation.”

(jsgp19)

- **In response to patient demand**

As the analysis above suggested, much of the process of working with people with chronic pain could be described as ‘patient led’. In this context, another reason for referring was in response to patient requests either for a specific referral or for the general practitioner to ‘do something’ as the following quotations illustrate:

“I think to be honest if they requested it.”

(jsgp15)

“I think that really comes when I feel that the patient is saying to me that they are not prepared to tolerate the situation any longer. The patient will occasionally say that out loud, you’ve got to do something. Or I feel that I am getting nowhere. I suppose the point will be when you feel that the consultations are becoming repetitive, when you’re saying to people when you’ve tried everything you know and you’re saying I can’t really do anything else, lets try this again or just keep taking the tablets. At that point I either start looking at another diagnosis or else refer them on to, it has up to now been the pain clinic at Centre 1, the anaesthetists pain clinic.”

(jsgp9nr)

- **Intuition or gut feeling**

As described above, general practitioners’ use of intuition, instinct or ‘gut reaction’ appeared to be an important part of interpreting or assessing patients. This could also be given as a reason for referring:

“pain you can’t make head nor tail of but you don’t think needs investigation by another specialist and you think it’s going to be chronic. I think nothing scientific but just a gut feeling.”

(jsgp3)

General practitioners' accounts of their use of medication in their work with people with chronic non-malignant pain.

Introduction

Whilst lay perceptions of medication has been an area of research interest for sometime, there has been relatively little research work on general practitioners' perceptions of their role in prescribing in the context of work with specific patient groups.

Recent qualitative research on general practitioners' perceptions of their work in prescribing has contrasted the 'formal rationality' of the received knowledge about best clinical practice with the 'professional rationality' or practical reason based on experience and the realities of everyday practice (Weiss and Fitzpatrick 1997). This theme is echoed in the following analysis. As was the case with the previous section on general practitioners' accounts of their reasons for referring patients to specialist services, general practitioners' accounts of their use of medication also revealed hidden work.

A brief overview of the received or 'formal' knowledge about drug therapy was given in chapter two as background to the forthcoming analysis.

Process of data analysis

The issues of medication were salient throughout the initial interviews. Although the topic guide contained a section asking general practitioners directly about their use of medication, the analysis of general practitioners' accounts of their use of medication actively sought to establish that the apparent salience of this theme was not simply a result of their being asked specific questions about this area of their work. The issues and problems of medication for chronic pain emerged spontaneously in the context of general questions about management and in relation to specific questions on other issues.

Further analysis revealed that although general practitioners had a lot to say about medication this did not simply equate to the use of medication being of greater importance as an area of work than other areas of work about which general practitioners had less to say. For example, much prescribing was done as routine repeat prescriptions and part of the reason general practitioners talked a lot about medication was to convey details of the many problems associated with this area of work as well as to describe their prescribing practice. In short, there was a lot that general practitioners could say about the use of medication. As one general practitioner commented on the interpretation of the data from the initial interviews:

“It probably quite fairly reflects general practice. A lot of people have in general practice ... we probably feel more comfortable talking about things we know more about. We know more about the effects of painkillers, we don't really know what the physio does, what an OT does. It's probably a reflection of both management and the fact that the GP's feel more comfortable talking about it.”

(jsgp4)

General practitioners discussed in some detail the problems of medication in the context of managing chronic pain. As described below, general practitioners' identification of these problems can be seen to be based on their assumptions of the principles of 'good practice' which appeared to be derived from an understanding of the analgesic ladder.

As chapter seven indicated, the use of medication in the management of chronic pain held a range of meanings and served a range of purposes for general practitioners. To be more explicit, in general practitioners' accounts of their use of medication, prescribing could be an indicator of the quality or appropriateness of their work with specific patients, an indicator or measure of the patient's pain and a means of negotiating their agenda with patients (such as maintaining conviction).

In the initial interviews general practitioners' accounts of their work in prescribing medication comprised descriptions of common prescribing practice, issues and problems and is described in the first section below. The term 'professional account' is used here, the term having been chosen to indicate that patients' views of medications were absent from this account and the appearance of patients was limited to those seen as 'problem patients'. In the follow-up interviews general practitioners were asked in more detail about these common issues and problems and were asked directly about their views on the importance of prescribing medication as part of their role. They were also asked explicitly about their views of patient's views of medication and a more complex picture than the 'patient as

problem' emerged as described below.

The professional account: general practitioners' views of medication in the management of chronic pain.

On the whole, general practitioners were confident about their knowledge of prescribing and reported having picked up many techniques from helpful discharge letters from the pain clinics. Often general practitioners explained that they were so familiar with the prescribing practice of pain clinics that they had often tried the range of 'drug cocktails' themselves rather than wait (too long) for the patient to be referred to the clinic. Some general practitioners also commented that this process had eroded the pain clinic's area of expertise, leaving them with even less that they could possibly do for patients who were referred.

Most general practitioners agreed that prescribing medication was an important aspect of their work with people with chronic pain, but many added corollaries which reinforced the point that there were limitations to this work, or that other aspects of their work were more important. The problems of using medication, principally analgesics, in the management of chronic pain were recognised by all general practitioners. In broad terms the problems were of the "spiral of iatrogenic things" potentially associated with the use of the medications, including side effects and the possibility of addiction and abuse.

There was also the recognition that painkillers may not be the answer and may not work, as one general practitioner explained:

“It’s trying to devise a regime of painkillers which doesn’t always work because you’ve got problems with side effects, the elderly and so on. The horrible fact is that pain killers aren’t always going to work.”

(jksgp3)

The view that ultimately pain killers do not work was shared by the majority of general practitioners and most explained that they were careful to explain to patients that painkillers may not take the pain away completely, that they merely take the edge off the pain. Some general practitioners appeared to be more confident and more proactive than others in suggesting to patients that tablets may not be the answer.

The view that painkillers may not work did not imply that painkillers were not helpful. As earlier sections of the analysis have indicated general practitioners’ descriptions of their use of medication could be seen to fulfil functions relevant to work such as that of keeping the patient going, maintaining conviction or “keeping something up your sleeve”.

These underlying functions appeared to underpin many of the non-rational or non-clinical approaches to prescribing which general practitioners described such as follows:

“Sometimes it is very much a matter of sticking a pin in MIMS to find one that works.”

(jsgp9)

More commonly these functions could be seen to underpin the reasons that general practitioners felt they had to give for prescribing combinations of analgesia which

were not logically indicated by the analgesic ladder.

“There’s no doubt that although co-proxamol and co-codamol are supposed to be more or less the same, some patients react better to one so I tend to go round the houses with the three of them.”

(ksgp1)

Within the recognition of the general problems of the use of medication in chronic pain, differences in general practitioners’ approaches to the use of medication remained. Despite the problems, for most general practitioners there appeared to be a pragmatic imperative to prescribe. Prescribing was something that they could actively do, as this general practitioner explained:

“I think there’s an awful lot of colluding goes on and we all want to try to help people in pain. I think it’s just I suppose one of our basic reasons for taking medicine in the first place, to relieve the world of pain entirely for some reason. So when we do see people in pain then it really makes us want to do something about it. So sometimes I think we do inappropriate things really and don’t help the patient and may give them too many drugs and this sort of thing. We have to be careful to look at our reasons for doing things if possible and the consequences as well.”

(jsgp13)

An earlier section of the analysis of general practitioners’ work in managing chronic pain described the need to do something, which counted as doing something. In this context, general practitioners’ perceptions of their role in relation to prescribing medication appeared to be linked to their perceptions of the relative importance and their competence in other things that they could do. A few general practitioners explicitly delimited their area of competence to prescription of medication, explaining that this was all they could do. As one general practitioner put it:

“My approach (to the management of chronic pain) would have¹⁹ to be pharmacological”

(jsgp9)

Another general practitioner was more explicit about how perceived limitations in the approaches to management could lead to an over emphasis on medications.

“The other danger with chronic pain is that it’s not actual pathological pain but it’s the patient who needs other treatment and that’s where I learnt this business of chronic pain management idea. I’m a great believer that quite often it’s not tablets they need, they need psychological and emotional support which we can’t give. So we tend to overplay the tablets.”

(jsgp2)

General practitioners frequently constructed the importance of medications in terms of the limited range of options for doing something. Alongside this construction of importance, there was also a general tendency to place prescription of medication first and foremost as a management strategy in general practitioners’ accounts, as the self-reflection of the general practitioner quoted below indicates:

“The frustration comes because of the inadequacy because .. often you feel that there’s nothing else you can do. I suppose at that stage one’s thinking more in terms of pharmacology and less in terms of psychology and support. I think that it’s always frustrating to us if our pharmacology cannot help patients to relieve their pain. Very frustrating”

(jsgp19)

The importance of prescribing medication as something that general practitioners could actively do was often implied indirectly, as in the following response to a question about what would be an ideal chronic pain patient:

“Probably somebody who has a condition which you can treat effectively with the minimum of medication, the minimum of side effects from their medication and who’s getting effective pain relief as

¹⁹ Researcher’s emphasis

long as they take it. May possibly be using self-help to ... might be using heat pads or getting their husband to do a bit of massage, aromatherapy. Any of these alternative things that can sometimes help. Having got them settled they then put in for a repeat prescription once in a while and you don't see them again. I'm joking there but I quite like to see what response you're getting, and see them from time to time. Largely they perhaps would still have their pain if they didn't take their medication but with their medication everything's nicely settled."

(jsgp18)

Taking the above issues together, perhaps the best summary of general practitioners views of medication in chronic pain management was as a necessary evil, as the following quotation illustrates:

"A certain amount of experimentation on my own part but even then I feel it is limited and it's often what I do I feel is inadequate. I often find myself prescribing strong analgesia because eventually I find that I cannot control pain without doing so. Which I find disappointing."

(jsgp9)

- **Shared principles of good practice**

The existence of the 'formal rationality' of the analgesic ladder presented general practitioners with a concept of good practice in relation to prescribing. It is important to realise however that the impact of the analgesic ladder on general practitioners' evaluation of their own prescribing practice appeared in terms of broad principles, described below. These broad principles were referred to directly by general practitioners, but were also implicit in general practitioners' accounts of their justifications for departing from these principles. In summary the principles were evident in all general practitioners' accounts, although individual general

practitioners' stated position in relation to these principles or their practical interpretation of them differed.

These principles were that: the use of analgesia for pain relief has to be balanced against side effects; that the use of the analgesic ladder in the management of chronic pain was intrinsically different to its use in the management of pain in terminal illness or for acute pain where there was a clear end-point; that there was a level on the pain ladder which was appropriate for patients and related to this that patients could be taking medication at an inappropriately high level; that the level of medication should be linked to the severity of pain, and as such the level of medication could be an indicator of the severity of pain

General practitioners' concerns to balance the potential benefits of medication against the possibility of side effects have been described above. The three remaining issues and their application in practice are discussed in more detail below.

The use of the principles of the analgesic ladder in the context of chronic pain as opposed to pain in terminal illness or acute pain

The indeterminate amount of time a patient could be in chronic non-malignant pain meant that it was possible to go up the analgesic ladder too quickly, reaching the top and leaving the general practitioner with nothing left to offer the patient. The notion of going up the pain ladder too quickly could be bad in and of itself, but many general practitioners linked this 'bad practice' to the implications for them of

not having anything left to offer the patient. Feelings that they (the general practitioner) were moving up the analgesic ladder too quickly were so disquieting that some general practitioners explained that they would refer a patient on at this stage, that this was one of the reasons that general practitioners would refer on to a pain clinic.

General practitioners explicitly contrasted prescribing medication for chronic pain with prescribing for acute pain, explaining that they were willing to prescribe strong analgesia for the limited time needed for the pain to resolve. An implication of this was that general practitioners could sometimes find themselves caught out, having prescribed strong analgesia for what they thought would be acute pain but which turned out to be chronic, thus leaving the patient at a level too high for continuing use, for the patient or for the general practitioner. This was problematic as moving down the ladder could potentially be difficult because of the effects of withdrawal.

The problems of patients being at an inappropriate level on the ladder

Although general practitioners described the problems of patients being on too high a level of medication, the problems with this were rarely made explicit. That is, general practitioners appeared to see this as self-evidently a problem. However the implicit reasons for this being problematic could be seen to be: the issue of running out of options; of the patient experiencing side-effects or becoming addicted; or 'getting stuck' as the following general practitioners explained:

"I think there is this underlying fear with the chronic pain that you keep going up stronger and stronger things you will end up with

somebody who has an addiction problem. Or lots of serious effects of the treatment that they're taking and that becomes a bigger problem than actually the original problem for which they were being treated".

(gp18js)

"if another treatment option becomes available then you're stuck with the opiate as well."

(jsgp14nr)

Many general practitioners used specific patients to illustrate their problems with people being on medication too high up the analgesic ladder. Most often these were patients who had been adopted from other practices or had been prescribed medication in hospital which general practitioners thought was inappropriately strong. This was one of the ways that general practitioners implied that hospital care (referral to the secondary sector) could disrupt their on-going management of a case.

Medication as an indicator of pain

The problems that general practitioners described in interpreting patients and assessing pain have been discussed in chapter seven. Some general practitioners described the ways that they would use medication to 'interpret patients' or assess the nature or severity of their pain:

"I think you just have to assess it on response to medication and what you see in examination."

(jksgp3)

Thus patients' level of self-treatment, particularly on initial presentation, was used by some general practitioners as an indicator of severity of pain, as the following general practitioner described:

"If they're taking analgesics themselves, if they're self-treating and

it's still coming through.. again if it's perhaps affecting their lifestyle, affecting sleep then you'd certainly take it pretty seriously.”
(kgp1-c3)

Some general practitioners explained that not having taken any medicines or not taking any medications would lead them to question the severity of patients' pain or, in some cases whether the pain was genuine or not:

“If they're in that amount of pain I don't think if non compliance is a problem then I don't think they're suffering from genuine discomfort or pain.”

(lmgp1)

- **The problems of addiction and abuse**

In the initial interviews all general practitioners mentioned the potential problems of addiction and drug abuse in relation to their work in prescribing medication.

In general, general practitioners constructed the problem of addiction in a way which emphasised professional culpability or responsibility in the context of the possible iatrogenic effects of medicine. In contrast general practitioners' concepts of abuse appeared to hinge on people who may not have any pain, or people who may be selling drugs on. Whilst there was acknowledgement from most general practitioners that monitoring the prescribing of drugs and the scrutiny of individual patients was part of being a responsible general practitioner, the responsibility for the problem was not seen to be medical in the same way as the problem of addiction was.

“I think addiction is almost.... implies that this isn’t necessarily of the patient’s own free will. Whereas I think if they start abusing medication it implies a certain knowledge of what they’re doing and a culpability within that”.

(kgppmr1)

As this analysis has already suggested, concerns about the wider social and medical problem of the abuse of controlled drugs could cast doubt upon a patient’s presentation of pain, though the relevance of this contextual issue varied amongst patients.

Whilst some of the general practitioners explained that in practical terms the risks of drugs being abused were small and too small to influence their prescribing, none of the general practitioners were able to avoid discussion of drug abuse as a potential issue. For example some general practitioners explained that some reflection on prescribing opiates was inevitable because of the awareness that prescribing of these drugs was being monitored centrally. Others alluded to the cultural meaning that these drugs had acquired because of their abuse, something which could make patients reluctant to accept prescriptions for, or ultimately, to take them.

As indicated above, all general practitioners had to locate themselves in relation to the potential problem of drug abuse. Some general practitioners explained that it was not such a worry for them as the problems of drug abuse were not high in their area, others explained that their knowledge of the patient and the patient’s family often enabled them to focus their concerns. That is, they did not worry about the issue in general but only in relation to patients with a known history of drug abuse,

to unknown, usually young, patients demanding strong analgesia and patients where members of the family were known or suspected to be involved in drug abuse.

General practitioners also had to locate themselves in relation to the potential problems of addiction such that some general practitioners described themselves as not frightened to use analgesics:

“A lot of people are suffering quite a bit of pain so I mean I’m not frightened to use analgesics”

(jsgp4)

General practitioners’ concepts of addiction were much more varied and were often linked to the concept of a physiological process. Sometimes this was made explicit as this general practitioner explained:

“I think it can be a straightforward physical addiction, things like dihydrocodeine”

(jsgp3)

General practitioners’ concerns about people becoming addicted were that there would be an increase in tolerance to medication, or problems of withdrawal. Some general practitioners used the term dependency to distinguish an ‘addictive effect’ which was based on psychological rather than physiological processes.

Some general practitioners were able to set aside concerns about addiction, explaining that the concept is irrelevant where the pain is continuing as this general practitioner described:

“If the pain by definition is chronic then I don’t think we can say that person is going to be addicted. They’ll be taking the drug but you’d have to then look at the scenario what would happen if the pain disappeared. You’re not looking at that, you’re looking at patients with chronic pain.”

(ksgp4)

Others set aside concerns by arguing that in the context of chronic pain, addiction might be a price worth paying:

“If somebody’s got some chronic pain and the only thing that helps is a drug of addiction then maybe that’s the price you’ve got to pay, that they are going to get addicted and become quite dependent on that medication. I think this should be discussed with the patient.”

(lmgp9)

In relation to both drug abuse and addiction, however the general practitioners defined these terms, the principal management strategy was of close scrutiny of requests for repeat prescriptions.

- **General practitioners’ views of patients views**

An apparent paradox which emerged from this research, and is touched on in a later section on patients views of medication, was summarised by one of the general practitioners:

“Patients get fed up just getting tablets all the time and yet GPs probably would say I get fed up with these patients asking for tablets all the time. Somehow or other there’s a block there, the relationship doesn’t work terribly well.”

(ksgpreg2)

Or as another general practitioner reflected on his own experience:

“It’s surprising how easy it is to take them off them. You wonder how it is they’ve come to be on these tablets which have significant side effects but significant pain relief as well. Yet you take them off them and they’re fine. They don’t complain. So there is an odd thing, it’s something to do with the patient and doctor and this build up and patient’s still complain so the doctor gives more. The other danger with chronic pain is that it’s not actual pathological pain but it’s the patient who needs other treatment and that’s where I learnt this

business of chronic pain management idea. I'm a great believer that quite often it's not tablets they need, they need psychological and emotional support which we can't give. So we tend to overplay the tablets."

Certainly, descriptions of patients returning for increasing medication were frequent in the response to an initial interview question asking general practitioners if they could describe a 'nightmare' patient with chronic pain and in descriptions of the range of problems that general practitioners faced in this area of work.

However, when general practitioners were asked in the follow up interview about patients' views of medication, the most common response was to explain that they varied. Often general practitioners made this point by referring to two extremes as in the following quotation:

"I think it's very varied. I mean there's some patients who absolutely hate taking tablets and I had someone in today who has terrible angina who refused to take anything in case he gets addicted to it. Then there are other patients who are desperate to get rid of their symptoms, would rather be slightly doolally from vast amounts of opiates and slightly out the box to get rid of all that pain. I think there's a huge variety. A lot of patients are actually quite reluctant to take tablets, or you prescribe them on a regular basis and they just take them intermittently."

(ksgp1)

Often general practitioners explained their reactions to patients (differing) views in terms of their own approach to medication, which as the following quotations illustrate, varied also:

"I suppose I also have sympathy with people who don't want to take too many analgesics because I personally don't like taking them regularly. I can take a non-steroidal for a couple of days and then my stomach starts to feel uncomfortable. So I'll take it on a bad day and then not take it for the next three days so I'd be a bad patient too. One will probably give me relief for a couple of days anyway so.... the others, ordinary analgesics ... I have sympathy with people who say

that paracetamol doesn't work because I think it's useless. It doesn't work at all for me and it's horrible to swallow so I have sympathy for that too. As I say, the side effects of medication .. if they complain of side effects well I suppose I tend to believe them because I've experienced some of them myself."

(jsgp18)

More often still, general practitioners described their reactions to patients' views in a way which gave an implicit indication of their own approach to managing chronic pain and areas of competence. The quotation above in which the general practitioner describes his realisation that it may not be tablets that patients need illustrates this. Some general practitioners implied a very narrow role, as in the following quotation. This general practitioner has just explained his "astonishment" at people who turn up in the surgery and have not taken any analgesics:

"If it's not a problem that's got serious consequences and they don't want to take analgesics, I'm really not sure why they're in the surgery."

(jsgp11-c3)

Summary

The analysis above has demonstrated how two aspects of core work, prescribing and referral, can be seen to hold a range of meanings and fulfil a range of functions within general practitioners' accounts of the overall process of managing chronic pain.

The analysis of general practitioners' views of specialist services for chronic pain highlighted several methodological issues pertaining to the use of qualitative methods as a basis for incorporating professional service users' views in service

planning and development. Firstly, general practitioners' perceptions of specialist services were often framed within the context of their reasons for referral. Secondly, general practitioners' constructed their views of specific services or centres within the context of the process of care as a whole. In the context of these methodological issues, the analytical perspective adopted was that it was possible to infer the need for the development of skills and resources in chronic pain management within primary care from general practitioners' descriptions of their reasons for referral.

A detailed exploration of general practitioners' accounts of their reasons for referring revealed that their motives for referring paralleled the problems identified in the analysis of their accounts of the process of their work as a whole and the functions of hidden work such as managing doubts, maintaining conviction, getting the patient to accept and managing their own emotional reactions.

This chapter has also explored general practitioners' accounts of prescribing in the management of chronic pain. As with referral, prescribing could be seen to fulfil a range of functions, being an indicator of the quality or appropriateness of their work with specific patients, an indicator or measure of the patient's pain as well as a means of fulfilling aspects of hidden work such as maintaining conviction. These underlying functions could be seen to underpin general practitioners' explanations of their non-rational or non-clinical approaches to prescribing

Though prescribing was constructed as being inherently problematic, because of the

need to balance the effects of treatment against side effects and the potential for abuse and addiction, there appeared to be a pragmatic imperative to prescribe. That is, prescribing appeared to fulfil the imperative to do something which counted as doing something. In this context, general practitioners' perceptions of their own role in relation to prescribing medication appeared to be linked to their perception of the possible other things that they could do, rather than to their perceptions of prescribing and its problems per se.

Two issues considered in this chapter are of particular relevance to the following chapters which present the analysis of the interviews with patients. Firstly, that general practitioners' accounts of the overall process of secondary care for chronic pain closely reflected patients' accounts. Secondly, the analysis of general practitioners' accounts of prescribing drew attention to their generalised view of patients and medication as the problem of patients returning for increasing medication. Juxtaposing this view with patients' generalised and critical view of general practitioners, described in a following chapter, as just prescribing medication, reveals an apparent paradox which is explored further below.

Finally, chapter seven drew attention to the importance of understanding the structural and wider social context in which general practitioners' work and the analyses of prescribing and referral further illustrate this issue. The analysis of general practitioners' accounts of their decisions to refer patients demonstrates how general practitioners place their accounts of decisions to refer a patient within the context of their perceptions of the health care system as a whole. General

practitioners' accounts of their work in prescribing medication are also contextualised by social issues of drug abuse and addiction.

Chapter Nine: The experience of chronic pain in the context of everyday life

This is the first of two chapters which present the analysis of the interviews with patients. It presents an analysis of the experience of chronic pain in everyday life, comprising three sections. It begins with an introduction to the respondents and a description of the process of analysis. The second section presents an analysis of the experience of chronic pain in social context. The third section presents an analysis of the processes of self-management and respondents' understanding of terms such as coping, accepting, getting on with things. Taken together these form the analytical framework for interpreting respondents' accounts of their interactions with the health care system, described in chapter ten.

Introduction to the people who were interviewed and the process of data analysis

The following description of the respondents is intended as both a reminder of some key methodological issues and as a means of placing the description of respondents within the context of the forthcoming analysis. It supplements the overview of the socio-demographic characteristics and health status of respondents given in chapter six.

Respondents were of a wide age range (21 to 82) and from a wide range of socio-economic and occupational backgrounds. The explicit intention of this research was to focus on the experience of chronic pain, rather than to try to focus on the experience of different types of chronic pain, as an epidemiological classification of

chronic pain in terms of diagnoses, causes or sites remains elusive. Indeed, the resistance of chronic pain to classification, medical or otherwise, was an important reason for carrying out in-depth qualitative research.

The interview schedules were based on the assumption that it was possible to ask people meaningful questions about chronic pain in general, regardless of how, in their own terms or in medical terms, the pain had come about. For the most part the analysis presented below focuses on the general experience of chronic pain. However, different origins of chronic pain were of relevance to some aspects of the analysis and these are indicated throughout the description of the analysis.

Despite the intention to set aside classifications in terms of origins or causes, it did feel important in analysing the data to keep in mind the different types of chronic pain that the respondents had. The following description of the respondents in the study seeks to describe some of the distinctions which emerged as important from the analysis.

As described above, the most frequent site/source of pain was back pain, often with pains in the neck, shoulders or legs. Many of the people with back pain had had at least one, often more than one, operation. Of the people with back pain, those who had experienced 'slipped discs' had, by definition, experienced major and sudden changes in their capabilities, though some had had some degree of back problems for some time. Other people with back problems had experienced a more gradual worsening of the problem over a number of years.

A second identifiable group was people who had an accidental injury such as sporting accidents, road traffic accidents or occupational accidents. Some of these people suffered obvious and considerable injuries, for example, one woman required major surgery in order to avoid amputation of her leg and had been unable to walk for some considerable time afterwards. Others developed pain later in different sites which they had not realised had been affected at the time of the accident.

A small group of people had experienced serious medical accidents. One woman had had nine abdominal operations, beginning with an operation for an ovarian cyst, but including one which accidentally perforated her bowel giving her septicaemia. Another woman experienced massive damage during childbirth which required her to have a colostomy for fifteen months and undergo reparative surgery. She was in the process of litigation at the first interview. Finally, a man developed a pressure sore whilst in hospital recovering from a road traffic accident. Despite plastic surgery, this left him with a 'big hole' and continual pain from his left buttock.

A small group of women had continuing abdominal pain and had had surgery for endometriosis or adhesions following hysterectomies.

Five people had specific medical conditions. Three people had rheumatoid arthritis, one person had Crohns disease and another Scleroderma.

From this brief overview it is possible to foreshadow a number of analytic issues. Firstly, that a large number of the respondents had experienced surgical interventions yet continued to be in pain and this in itself required management and interpretation, and frequently made on-going negotiation with health services additionally problematic. Secondly, that there were differences in the trajectory of pain, whether sudden or gradual, which were important in terms of the process of accounting for pain in social context. For example, the immediacy of the experience of a slipped disc presented an unmistakable crisis which left people in agonising pain, unable to move, needing instant medical help to relieve the pain, flat on their back somewhere, sometimes unable even to get to bed for several weeks. In contrast, more gradual onset appeared to leave more room for doubt.

There were also some exceptional cases which have informed the analysis. In general the interview schedule about chronic pain, as opposed to a specific illness or condition, worked well with respondents. However during the interview and during data analysis, it felt somewhat inappropriate for people with rheumatoid arthritis. That is not to say that whole interview schedule felt inappropriate, but that there was a strong sense that people with rheumatoid arthritis were different in respects that were difficult to define, although the analysis makes an attempt to do so.

The sample also included two people who were no longer in pain by the second interview. One elderly man had had an operation which had successfully alleviated

the pain. Another young woman, who at the time of the first interview had had pain in her shoulder for four years, saw a physiotherapist and, through exercise, had alleviated the pain. Although the overall analysis of the data has not integrated these two exceptional cases in any specific ways, they remain 'salutary' and resonate with the points that general practitioners made about the dangers of wrongly assuming that chronic pain cannot be cured.

The experience of chronic pain

Chapter four highlighted the tendency in existing psychological and medical approaches to chronic pain to concentrate on pain as a sensation, albeit a sensation which can have emotional consequences, rather than try to capture the totality (or multi-dimensionality²⁰) of the experience of chronic pain.

The following extract illustrates well the difference between pain as a sensation and the totality of the experience of pain. It is taken from a follow-up interview. In the follow-up interviews an attempt was made to explore in more detail with respondents some of the issues emerging from the initial interviews which appeared to imply mind-body dualism, such as mind over matter. It is included in full here as an illustration of the interviewing process, as a description of living with pain on a daily basis, but principally because the respondent very vividly captures how pain becomes life:

²⁰ The recognition of the need to take account of the multidimensional nature of chronic pain has formed part of the clinical/applied literature for some time. The use of the term totality of experience could be seen as representing this 'multi-dimensionality'. The reasons for avoiding the term multidimensionality are: to avoid any assumptions of familiarity and to avoid the implicit assumption that people with chronic pain experience it as multi-dimensional.

- I: When it comes to pain it seems difficult sometimes to understand what's to do with the mind and what's to do with the body. What do you think about that?
- R: You mean like how much of the pain is actually in your mind and how much is actually caused by what's wrong with you?
- I: Well we weren't really thinking of anything in particular when we're asking questions. It's just that a lot of stuff came up about that and it's one of these questions we want to understand a bit more. When thinking about pain it's hard to know what's to do with the mind and what's to do with the body. Do you feel that you can separate them?
- R: I'm not really ...I'm not getting what the question's all about.
- I: I'll try and ask something more specific. It's just that when people talked about their pain, it seemed that a lot of aspects of it were to do with the mind as well as the body ... the thing about when you're down the pain seems worse...those kind of things, the interplay between them. I'm just trying to understand that a bit more. It's really hard to ask the question actually.
- R: I see what you mean. There is a point where it's no longer just a pain in your leg, it's a whole thing, a whole body, mind, the whole view becomes the pain. There are times when it becomes like that. What was wrong with me was there were different stages of... you'd get up in the morning and there was virtually nothing at all and by the time you come downstairs and get set up for the day, it was just different stages and different points where you had to rest. Like getting up in the morning, getting washed, coming downstairs was taking it to about as much as I could stand. It became a sort of.... if you hurt something, say you hurt your finger, that's a pain in your thumb. But when you've got something wrong with you for a few months it does become more than just a pain in your leg, it becomes a thing. It becomes you. I don't know how to put this. It just becomes part of your whole day if you like. I'm not a clinical psychologist.
- I: Neither am I so
- R: That's the best way I can describe it. It just takes over and becomes part of your life."

(Impt13)

Many other respondents described or implied the totality of the experience of pain in terms of being them or being their life, although often indirectly as this respondent explained:

"I just felt if this was life I didn't want it."

(kspt2)

The remainder of this section of the chapter considers different aspects of respondents' accounts of this experience, whilst recognising that these may not, or do not, constitute the experience. These aspects are: a summary description of the impact of chronic pain, the constancy of pain, the experience of sudden and unpredictable acute incidents and the emotional context of the sensation of pain. Although each of these broad areas forms part of the existing literature on the experience of chronic pain, they are included here as integral parts of the analysis of the experience of chronic pain in social context.

The impact of chronic pain

Much social science has described the impact of chronic pain on people's lives. The respondents in this study gave very vivid and moving descriptions of the consequences. Rather than reiterate, albeit with illustrations from the data, the many ways in which chronic pain has an impact on people, the main points are reported in summary form.

Respondents described how chronic pain gave them difficulty sleeping and tired them out. Many of the respondents described that the pain meant that they were no longer able to continue working, as it seriously affected their ability to do things. They described how it affected their moods, making them feel down or depressed. Several respondents had attempted suicide or had thought about committing suicide. Family and social relationships were also affected and meant that outings

and activities had to be carefully planned.

Two aspects of the impact of chronic pain appeared to have a stronger profile in this study than in existing research: the impact on people's weight and their sex life. These issues are described below, to be noted, rather than as an integrated part of the analysis.

Many respondents explained that they had put on weight as a consequence of being less active because of the pain. This brought an awareness of a 'vicious circle': that the extra weight could be exacerbating their pain as well as being distressing in and of itself in terms of their body image:

"Of course if I could lose weight it would help but I'm in a vicious circle. I can't even walk any great distance."

(Impt9)

Many of the respondents described feeling that health professionals were judgmental about their weight and appeared not to take account of the 'vicious circle' as this respondent explained:

"I can remember going to this other doctor because my own GP wasn't there. This was maybe after the second operation and I asked for painkillers. He said oh yes. He looked at my notes and said, do you not think... he was another on about my weight ... maybe if you lost some weight, on your back especially carrying all this weight. See for ages I didn't want to go back. I hate when people say that"

She added later that:

"It was like he didn't know what to do. Not that he didn't care, I wouldn't say that but that was his first impression of why I was suffering pain. I had a bad back because I was overweight."

She also described a similar experience in relation to getting invalidity benefit, having to explain that:

“I was never overweight before I had back problems because you exercise and I can’t do that any more. It went to an appeal. I had to write and let them know the kind of life I’d led before I got the pain. I was really active, I mean you are with three kids.”

(kspt2-c1)

The interview schedule did not ask directly about the impact on sex, but offered the opportunity for respondents to raise this by asking about the impact on relationships. However this was not an issue which was explored in depth, in part on the basis of managing the interviewing process sensitively. As was the case in relation to the issue of putting on weight, this issue is simply noted rather than analysed here.

Most of the respondents with partners explained that their sex life had been badly affected, if not stopped completely, or become “non-existent”. Most appeared reluctant to talk to health professionals and rarely did so. On the rare occasions that the topic was raised in health care settings it was not dealt with fully or helpfully as the following quotations illustrate:

I: “Do you ever find it difficult to explain to people how you’re feeling?”

R: “Once, only once. After I had that operation in 1968. I went back into Centre 1 to see the doctor that had performed the operation. He asked the same question, is everything all right? There was a ... you know the chaps, he was a right garrulous ... he said it’s like this, if you can’t do something about my sex life there’s going to be a divorce. I think we were all sitting the same way. I wouldn’t have said it but we all burst out laughing together because this man ... he was all right after the operation. That was about the only time really.”

I: “Is that something anyone’s offered to help with or you’ve been able to...?”

R: “Well when I was in seeing about the prostate I said to the doctor

what about sex and all that. I said it's non existent. He just smiled and that was it."

I: "What about your GP?"

R: "I've never discussed it with him. I thought the doctor in the hospital would have understood that better than your GP."

(jspt26)

R: "You've not mentioned sexual satisfaction. That is a horrendous bit too."

I: "Right. Has that been raised by any other ...?"

R: "It was interesting, (name of centre 4) ducked it too and I raised it with them and discussed it with (name of professional). She gave me some notes, this was at the end I think. They were totally unintelligible. Diagrams, positions, arms and legs. I would suggest that is an area that all the Scottish niceties, other people don't want to talk about it, fair enough but it's not being discussed. One of the physios I went to, I raised this with her and she said I'll get on to so and so and find out.. she came back with, they don't know anything about it. I noticed that in the (name of centre 1) they had a questionnaire and the crossed out the bit about sex."

This respondent concluded:

"Nobody's talking about it."

(jspt17)

The constancy of pain

The majority of respondents described being in constant pain. Though the pain was always there, the intensity of pain varied throughout the day and from day to day. Only a handful of people in the sample felt that there were times when they had relief from any pain. Most people explained that they were always aware of the pain but there were some times that were worse than others were. The most common way of expressing the constancy of pain was to explain that it was there until falling asleep and with immediate awareness of pain on waking. Many

respondents explained that the pain would wake them from sleep, and others that even though they were not wakened that they cried out with pain in their sleep as this respondent explains:

“You waken up... I think I consciously waken up in the morning and you know the degree of pain that you’re in that day but it’s one of your first wakening thoughts. How is it today? Yesterday for example I woke up and before I could move my husband put his hand up and down my spine to help me turn over. He’ll say you cried out in the middle of the night.”

(jspt25)

Although the pain was “always there”, the experience of pain was changing. Respondents described acute spells when the pain could be “overwhelming” and that at these times there was nothing that they could do about it:

“The pain is in the lower half of my back. At times it feels like a nagging toothache, other times it feels as if it’s got a very sharp knife in that’s twisting it. The pain is constantly there. There is never a time that it is not. The extent of it is dependent on how you are in one particular day.”

(js10aa)

Many people, particularly people with back, neck or lower limb pain, experienced sudden critical incidents such as falls or spasms. Respondents emphasised the suddenness of these events which could occur without “rhyme or reason”. One woman with back pain explained that she had difficulty balancing and sometimes fell suddenly:

“This leg, sometimes when I’m out.. I can be going down the road and I can’t rush so I’m not hurrying. I can be going down the road or I’ve done it down this step here ... the next thing... I’m walking quite normal or as near normal as possible and this leg just folds under me.”

(jspt24)

Other respondents described these events as spasms:

“which of course once the leg is locked into that spasm it’s extremely frightening and I panic.”

(Impt9)

Living with the prospect of sudden, unpredictable events had both practical and emotional consequences. Some respondents described how this had prevented them from driving or going out alone, or had made them reluctant to do so. As one woman explained:

“Well I never go anywhere now without anybody. I’ve never ever been anywhere on my own for 2 years.”

(ksp2-c1)

These events often brought more severe acute pain, lasting between minutes and weeks. Descriptions of the emotional impact of the prospect of further events varied from extreme fear and caution through to a matter of fact sense of inevitability. Implicit in all respondents’ descriptions was the sense that these events were to be guarded against along with an emphasis on the difficulty, if not impossibility, of doing so. Respondents conveyed the lack of “rhyme or reason” very effectively in their descriptions of previous incidents, emphasising that they were not doing anything to cause it, as in the above quotation where the woman emphasises “walking quite normal” and “not hurrying”, or “just” doing everyday things such as “buttering toast”. Thus the juxtaposition of unpredictability and ordinariness appears to be an integral part of the nature of their distress or suffering.

The emotions of chronic pain

This part of the analysis attempts to capture the different emotions that respondents

experienced. This serves as an introduction, or sets the scene for, the forthcoming section on self-management which considers the emotional work or efforts that respondents described.

A very small number of respondents were reluctant to use the term pain to describe their main problem, explaining that it was more discomfort. For example, in one case the respondent described the problem with her leg as being a burning sensation with numbness in parts and another implied that although the sensation was 'pain like', it was not severe enough to merit being called pain.

"I don't think of myself as suffering pain because it's occasional or just quietly there like a bad headache or something."

(jspt29)

The majority of respondents experienced discomfort because of not being able to be still or remain in any position for very long or to be comfortable in positions which are ordinarily comfortable, such as sitting or lying, as the following quotation illustrates:

"I was in complete agony sitting for any length of time driving. I felt my back was literally breaking in two. It got to the stage where I was uncomfortable lying, sitting, standing. I just didn't know what to do. So I had to more or less stop the driving. Sitting too long in one position, it gets uncomfortable standing for any length of time and then I get very agitated and worked up about it and have to have a seat."

(jspt12)

Along with discomfort, the main emotions that respondents described were; anger, frustration, tiredness or exhaustion and boredom:

"It bores me. I can't do the things that I want to do."

(lmpt7)

"I couldn't explain that right to you. It's there all the time and some

days I'm just fed up with it. I get down some days with it, the way it's working me."

(jspt3)

"The lack of energy and tiredness is probably the most frustrating things. I get grumpy as well, really irritable."

(Impt4)

"The pain can be a bad thing right enough but its more annoyance than anything really. It just annoys me."

(kspt1-c3)

The experience of chronic pain in social context

As described in chapter four, a key theme in the sociology and anthropology of chronic pain is that of the way that chronic pain fractures one's sense of connecting with other people in a meaningful way. That is, it has been argued that chronic pain presents a challenge to intersubjectivity or in socio-psychological terms leads to anomie.

A recurrent theme in respondents' accounts which can be seen as encompassing this sense of the inaccessibility of their experience to others, was that only people who had experienced chronic pain directly themselves could really understand. The analysis which follows considers how respondents themselves constructed their sense of other people not being able to understand, and conversely, how some exceptional people do, at least partly, understand or know how they feel. The analysis can be seen, therefore, to constitute an account of mundane intersubjectivity.

There were several aspects of respondents' experiences which appeared to constitute

their sense of other people not being able to understand how they were feeling. These were: their sense of not being able to describe the experience of pain; their sense of not being able to describe the impact on daily life; the consequent impact of trying to explain; their awareness, in retrospect, of not having understood or realised what other people had been going through; their awareness of the ‘invisibility’ of pain and their awareness of the absence of any socio-structural acknowledgement or legitimisation of their experiences, particularly in the context of work and social welfare.

- **Difficulties describing pain**

The interviews contained what felt to the reader very vivid and discomfoting descriptions of the experience of pain as the following quotation illustrates:

“It’s just like somebody’s taken a knife and ripped open your body. It feels like an open wound. As if you had a poisoned finger and you can imagine that with a scar like that. Controlling right round your back, legs, hips.”

(Impt10)

However, such descriptions were usually circumscribed with a note that this was difficult or impossible to describe.

Respondents expressed difficulties in describing the sensation of pain. The following quotation illustrates the problem of being specific enough about the pain even to someone close enough to ‘see’ the pain. It also illustrates well how the difficulty of describing one’s direct experience of pain arises from implicit assumptions about what would actually constitute a valid description: in this case,

as frequently in other cases, that the pain be described in terms of coming from particular static sites.

“I don’t go oot my way to say I’m in pain. It is quite hard because you cannae explain what it is. Sitting here watching the telly and Sandra says to me, are you in pain? I say no. She says you are, I can see your face, it’s changing. I said it’s just shooting pains now and again. You can’t actually say the pain’s here or it’s there. It just seems it’s all round here. I cannae tell people what it’s like because it’s just too hard to explain to them. They say have you got a pain there? I say no. Well where have you got the pain? Well it is there but it’s there and there and sometimes it shoots up my leg. Oh aye. So they dinnae understand it and it’s quite hard to explain like.”

(Impt6)

As well as problems describing the sensation of pain, respondents explained the difficulties or impossibility of describing the emotional experience of pain:

“Sometimes I get ... I’m sometimes in tears with it. The emotions build up. Especially with the work I do. Some nights I come in here and you can’t sit down, you’re agitated and that lasts for a couple of days. You just get to the point where you’ve had enough but there’s nothing you can do. Trying to describe that to somebody.... you can’t.”

(Impt15)

Frequently respondents’ attempts to describe their experience of pain to the interviewer followed a ‘template’ of attempting to use common experiences of pain such as toothache, and then attempting to describe what these common experiences of pain did not convey or capture. The following quotation illustrates this structure, on this occasion emphasising the chronicity of pain as outwith common experience:

I: “Do you ever find it difficult to explain to people how you are feeling?”

R: “Most definitely. You feel they wouldn’t understand. They would understand you feeling miserable but if they haven’t known the pain they wouldn’t understand why you were so miserable. It’s like seeing a child and knowing that they’re crying, not knowing that they’ve fallen and hurt themselves two minutes earlier. You can say poor wee soul, what are you crying for. You’re sorry for the child but the child has hurt himself so he has pain, you don’t know the pain. I

would imagine it's something like that. It's all very well to say you've got a pain but you can't expect other people to understand it. You can expect them to sympathise with it but you can't expect them to understand unless they've actually suffered it themselves."

She concludes:

"So unless you've had a long spell of severe pain you wouldn't understand why you're being sympathetic."

(jspt24)

The analytical interpretation offered here is that although people can understand some different aspects of the experience of chronic pain, the totality of the experience of the pain is only available to people who have "actually suffered it themselves".

- "It's the wee silly things"

In describing their experiences of living with chronic pain, respondents frequently mentioned the "wee silly things" or "just little things" that they could no longer do at all, or no longer do without pain. The term was used frequently, with or without specification of what these "little things" were. The following quotations give specific examples:

"Stupid things like picking something heavy up, I couldn't grip it. Opening jars, fastening his babygros and things like that."

(kspt2-c3)

Descriptions of the impact of these wee things highlighted that by their very nature they were unanticipated and hence experienced as problematic within the course of

everyday life in a way similar to respondents' descriptions of the ordinary tasks that they were engaged in prior to acute incidents (above). Descriptions conveyed that it was the everydayness or trivialness of these things which meant that they were continuously unanticipated and, as such, served to reinforce the constancy of the experience of pain. As one respondent explained "It's just these little things", adding later:

"It's always there to remind you. You never get away from it. It changes your life because you can't do the things that you want to do."

(kspt3-c4)

Another respondent described the way that "silly things" "bring it to the forefront again":

" silly things, I can't play netball, I can't play tennis, I can't really do ten pin bowling either because I can't bend properly. I was trying to do grass bowls last week my husband and I. It was just a few days away with friends and I just couldn't do it. I did it but not properly so therefore you're useless because if you can't get to the level.... not that you're in the team anyway. Even if I forget and I do forget that I've had an accident and I forget that.... I don't always dwell on it, then it brings it to the forefront again."

(lmpt4)

A consequence of the ordinariness of these things was that this was another aspect of experience which was difficult to convey to other people, both in terms of conveying the meaning and in terms of lack of legitimacy of trivia or small things.

The following quotation draws together several of the above themes

R: "You can't explain to someone what it's like to feel pain, you can't."

I: "Have you met anyone ... I suppose have you met anyone else in pain who's been able to...."

R: "No. Most people have a few hours pain a couple of times in their life if they break a limb. I suppose childbirth is quite ...most of my friends have got children so they can say that was really sore. But if you go through that sort of pain every day for months, it soon wears

you down. There's no point in depressing other people by going on about it all the time. People don't understand pain. I would never have understood pain. When you talked about people, maybe your granny couldn't knit anymore because her hands were too sore ...it doesn't mean anything to you. All you think is, oh she's got sore hands, you don't think what it means to have sore hands and how you can't lift things or open things. You can't wear jewellery to feel nice. You don't think about it until it happens to you."

(jspt18)

- **The consequences of describing the experience of pain**

As well as the difficulty of describing pain in terms of putting it into words, or describing one's own experiences in terms which are understood to be socially valid, respondents described the problematic consequences of trying to articulate their experience. A common problem, that of boring one's self or becoming "sick of listening to myself", or boring other people stemmed from the chronic or persisting nature of difficulties. Other respondents described a reluctance to talk about their pain as part of the process of putting it out of one's mind or not dwelling on it, as this quotation illustrates:

"I prefer not to talk about my aches and pains because I think it magnifies them."

(Impt9)

A further difficulty for many respondents was that they could not account for their experiences in the sense of providing an explanation as to why they have pain, as the following quotation illustrates:

"It's unbelievable. I mean that's 10 years. And if somebody says to me "what's wrong with your back?" I canny tell them, I don't know. I'm in pain but don't ask me why I'm in pain because I don't know."

(jspt5)

- **Having not understood**

Alongside respondents' own sense of not being able to communicate their experiences to other people, was the awareness many respondents described of how they themselves had not understood other people's experiences.

"I'd always believe anybody when they say they've got a sore back now. I would never have before because I used to hear people saying I've got a sore back and I'd think they're only kidding on. Now if any one tells me they've got a sore back I'm the first to believe them."

(kspt4-c4)

Women respondents, more than men, often described having been in formal or informal caring roles in the past, but not having understood or realised what people were experiencing. The following quotation from an ex-nurse elegantly describes her new awareness of the distinction between sympathy and realisation which many other respondents expressed or alluded to:

"I sympathised with the patients, I was never.... oh come on get on with it. I was never like that. You don't realise that there's a big difference between sympathising and realising, there is a big difference. One of my patients was in a wheelchair that I used to deal with and she used to say, oh my back's sore. She used to get pain killers and I'd say right, what a shame I'll rub your back. I used to do that but until I started getting pains I didn't realised what pain she must be in."

(jspt4)

Another respondent also captured a similar distinction

"I think the fact that ... I suppose if you were talking to somebody that you felt was taking the whole thing seriously... seriously isn't the word. Somebody you could talk to about what's happening with you, that's not giving you the impression that... not a nurse because nurses at the hospital do that, they're trained to be sympathetic but they're like automated sympathetic, that's their job. A doctor or a psychologist, something along those lines. Again it's like everything else, it would have to be somebody who's suffered some kind of pain."

(lmpt13)

- Invisibility

Respondents described several ways in which they felt their experience of pain was socially 'invisible'. They described their awareness that there was nothing for people to see to suggest that they were in pain, often making comparisons with visible signs of problems associated with pain such as broken limbs, as in the quotation below:

"Because I know I look healthy, I know I can walk. As I say I'm very much better off than a lot of people. You can't put a stookie on it, you haven't got a sign that says honestly my back is killing me. It's acceptance within the other people and you'll find if somebody has been in pain them self, they'll appreciate it more than somebody that just thinks you look ok."

(jspt10)

They also described being aware that their inability to be able to do certain things was not indicated in any visible way either:

"Because they can't look at you and see things wrong with you. I mean if I had one of my legs amputated they'd think, that's a shame, she's not capable any more. But because they look at me and they can't see it, it doesn't register that I have some sort of disability so they don't understand."

(jspt18)

Younger respondents explained the additional difficulty of the invisibility of pain being compounded by their age, running counter to their own and other's expectations:

"Folk don't really see it because I'm young."

(lmpt15)

"I still believed, right until I finished work ... I didn't want to believe I wasn't curable, that I couldn't be made better to lead a basically normal life. I think having the doors closed and leaving you without

any hope, it is possibly because I was young when it happened, to find at that age that you're going to be left with a chronic problem that will get worse before it gets better, so you're getting old before your time. You expect with old age to get old and everything else like that. Ok you expect the knocks and bumps through the way but having been a very healthy person I think I took it very hard."

(jspt10)

- **The socio-structural invisibility of chronic pain**

As well as describing the problem of invisibility in the everyday social context of inter-personal contacts and relations, respondents described what can be conceptualised as the wider socio-structural 'invisibility' of their chronic pain and disability, particularly in the context of work and social welfare.

Work

In the context of work, many respondents had difficulties in legitimising their problems as the following quotation illustrates:

"I think my work thought I was away doing jobs somewhere else. I couldn't get it across to them what was going on."

(lmpt13nr)

Many respondents described wanting to carry on working, many because they needed the money, but there had not been sufficient flexibility in their roles, or the expectations of their employers or colleagues to allow them to make the adaptations that they would have needed to make in order to carry on in their existing jobs. For example, it was difficult for them to arrange to work part time, to avoid heavy work or to do things at a slower pace. Some respondents drew comparisons with the efforts made to integrate people with recognised disabilities in to the work force, explaining that their own problems were not given this status.

Other respondents explained that they had either considered, or actually had retrained, in order to try to change employment but had not been able to do so. For example, a young man with back problems who was employed as a grave digger had gone on a computer training course but remained trying to continue working as a grave digger as no alternative employment was available.

Welfare benefits.

An important issue which most respondents raised was of getting benefits that they were entitled to because they could no longer go on working in their job. The accounts of all respondents who had experienced this process were very distressing (to the author).

There were three key themes which underpinned their descriptions of this issue.

Firstly, that it was difficult to find out what benefits they might be entitled to. Unsurprisingly many respondents suggested that more provision of advice and information about obtaining benefits and access to non-health service supports and services (aids and adaptations around the home, access to transport) would be one of the ways in which health services could be more helpful to them.

A second issue was of the unpleasant, discrediting process of being assessed for entitlements. All respondents who had endured this process were highly critical of the validity of the assessment.

Some respondents were explicit about the feeling that they should not have to 'prove' themselves in this context, as this 31-year-old manual worker who had recently (6 months ago) been diagnosed as having rheumatoid arthritis explained:

"As I say I don't feel within myself that I've got to keep going to these doctors because I don't feel that I've got to prove myself to them. If you can walk to the shops you're all right. To me that's not right. At the end of the day I could probably do that but they don't know how much pain I'm in."

"My own doctors satisfied and I don't see what I've got to convince other people to satisfy them because I've maybe seen my own doctor at the football. How come you got to the football and that. You're in agony walking down the pitch ken. At the end of the day I've proved myself enough and I don't have to prove to anybody how much pain I'm in."

(Impt11)

This general feeling was implicit in most respondents' accounts, though the majority discussed specific problems with the assessment process in more detail. Several criticisms recurred in respondents' accounts. A common criticism was, as the above quotation illustrates, that though they may be able to perform certain tasks that this did not take account of the amount of pain that they experienced in order to do so.

A further strand of criticisms was that the welfare assessment panel does not always see them at their worst. Many respondents explained that they felt that the fact that they had good days and bad days was not taken in to account. Some respondents acknowledged themselves that there were days when they felt that they might perhaps be able to go back to work, but that they were not employable as they could not guarantee this from one day to the next. Related to this were concerns that the

panel would not actually 'see' them at their worst as this respondent explained:

"I've seen me lying on the floor and I could have been walking about and then maybe come to sit down, just turn. These men never see you like that."

(jspt26)

Many respondents described their feelings of anger and insult at being treated as if they were 'kidding on' as this 39 year old woman (who had had 3 back operations, including one as an emergency) explained in answer to a question about whether she had ever felt that people thought that she was imagining the pain:

R: "Oh yes. Definitely. I once went for a medical to get invalidity benefit. Honestly I came out of there ... I had tights on and this leg was just covered in blood from the chap pricking my leg because he would not believe I couldn't feel it. He kept pricking it. It was Davie Place and we were going to go up to John Lewis to look for a bed or something and my kids said mum look at your leg. I said we'll just have to get the bus home. I felt so ill after it. He was asking me to do things I knew I couldn't do and I wasn't doing them for him. It was like he thought I was kidding on, that to get on this benefit. Which I didn't I'd rather have worked. I swear this leg was covered in dry dots of blood where he'd pricked it. He actually said are you looking to see.. honestly he was a pig. He actually said to my GP he thought I could maybe get a job at the Road Bridge on the toll. That's when I couldn't sit for any length of time. My GP wrote back and I got my invalidity.

I: "Did he write back to him and tell him....?"

R: "Yes. He showed me the letter. He was the worst one. A few of them don't believe you can't feel anything. They can't understand how they can touch in here and I can feel that but I can't feel that bit."

I: "Do you think there's ways that can be avoided?"

R: "Well I think there must be an awful lot of people that are chancing it. They shouldn't make everybody feel ... they should have believed me."

(kspt2-c1)

The above extract illustrates that respondents feel the assessment is a test of their genuineness because they share the general view that some people do 'chance it'. It also illustrates the issue that many respondents raised of experiencing the

discrepancy between the application of some form of medical model, in this case the assumption of where anatomically the respondent should have been able to feel something and where she should not, and respondent's direct experiential knowledge. It also includes a reference to the possibility of getting a job on the Road Bridge at the Toll, which several other respondents had also encountered.

- **“Close people do know when there's something wrong. Not outsiders”.**

The difficulties that respondents described in explaining their experience to others and their strong sense that only people who had experienced pain themselves could really understand were salient themes throughout the interviews apparently resonating with the salience of ‘problem’ of intersubjectivity identified in the review of the sociology and anthropology of chronic pain.

However, many respondents also described how some people did understand, at least in some respects. Although not all people had ‘intimates’ who could understand, amongst those who did, the underlying issue appeared to be that they could be read without having to explain it, that is, that people just knew. That is, respondents’ descriptions of ‘unproblematic’ intersubjectivity implied that this was constituted by direct, rather than communicated, understanding. This was particularly valuable in the context of the felt the impossibility of communicating their experiences and the problems associated with this. The following quotation illustrates the value of not having to explain:

“My friends that were there ... I was still limping quite badly but you don't have to explain. Nobody was saying why are you limping and what's wrong with you. They just know. They know me well enough

and thought well she's here so she's not too bad, we'll leave her be and talk about other things.”

(jspt22)

Thus respondents' descriptions of people who understood were of people who could be assumed to understand or who needed no explanation, that is people who could 'read' and interpret visible, physical indications of pain or changes in the person themselves. It is important to note however, that the crucial issue is that of people being able to interpret or to 'read', not the indications themselves. This ability was constructed by respondents, implicitly or explicitly, in terms of on-going relationships or knowledge over time.

Thus respondents who knew that to some extent their appearance had changed over time or changed from time to time could sometimes assume that some people would see and be able to interpret this, as this respondent explained:

“Well most people do understand because anyone who knew me before knew that I was tall and able to get about and do everything for myself.”

(Impt14)

Many respondents' understanding of their own physical expression of pain was of smaller day to day changes, particularly in their face. People with whom they had on-going intimate contact were known to be able to read these signs as this respondent explained of his wife:

“She understands it because she lives with me. She kens when I'm in pain because she can see it in my face. It's easy enough to tell her.”

(Impt6nr2)

Some respondents described how some people knew them well enough to know

when they were different, or just “not the same”, though not in terms of specific physical expressions. The following quotation illustrates that although mood changes that appeared inexplicable to others were often problematic in terms of the social management of chronic pain, they could also be a clear indication of not being the same, or of being in pain, to people who were intimate enough to interpret this indication:

“Close people do (know when you’re feeling bad). My kids ... my kids .. this morning I was up early and I went back to bed and the wee one came in and said mum are you all right? They know when I’m not feeling right because I’m not the same. When you’re in pain you tend to be sort of ... you’re not a jolly person at all.”

(kspt2)

Other respondents described how some people had learned to ‘read’ them and to understand their experience of pain and its implication in terms of everyday activities:

“Right now I’m thinking I hope it’s going to be ok in Ireland because it doesn’t just affect me, it affects my husband. He’s marvellous. He controls me now. He’ll shout through, you’ve been sitting at that embroidery for far too long, move. I tend to got to bed a lot earlier now and he’ll say it’s time you were in your bed, you know what you’re like. He’ll take over the ironing and say I think you’ve done enough. So it’s just that he reads me now.”

(jspt25)

An analytical interpretation offered here is respondents’ descriptions of some people who could ‘read’ them in this way are description of people who have an understanding of the “silly wee things” which, by their very nature, are difficult to explain.

- From social doubt to self doubt: identity under threat

The analysis above has outlined the construction of respondents' accounts of their feelings about not being able to communicate their experiences or gain recognition for their experiences. As chapter four described, an important aspect of sense of self derives from perceptions of how others perceive us. The sense of not connecting with others can be seen as constituting a vulnerability of self.

In the following quotation the respondent describes her awareness of other people's difficulty in understanding pain without visible signs, and of how other people may think she is "malingering", affects her sense of self, making her "ashamed":

I think people understand about pain if they actually see you. If they actually see that to do this you go aah, that sort of thing. If it's not visible and if it's only because you're managing it yourself, I think that includes doctors too, I don't think... I think that's when it becomes difficult for me. There's also a queer thing that I'm almost ashamed of having it. I know that doesn't make sense but I am. It's all tied up with this feeling that people might think I'm malingering. I'm ashamed in a way that this is... it's not visible so I tend to keep it even more to myself and I find I'm even doing that for my husband at times. He knows because he can read me.....I think that's really where I find it difficult and I've got to explain to people. It's a difficult thing to explain.

(jspt25)

The social context of chronic pain, or the shared social concepts about chronic pain can be seen to contain sources of threat to an already vulnerable sense of self. In other words, respondents were aware of concepts of pain thresholds, of the importance of "mind over matter", of back pain, for example, as a common complaint with its associations of costs to society and of the concept of malingering or claiming ill-health for unjustifiable personal gain.

These concepts did not form core themes in the accounts of patients in the way that they did in the accounts of general practitioners. Patients, after all, had their own direct experiences to talk about and draw upon and these are the kinds of issues which emerge in discussions about chronic pain in general. However their occurrence ‘in passing’ in respondents’ accounts was sufficient to demonstrate that respondents ‘had access’ to them.

Many of the people experiencing back pain referred to its cultural construction as a source of amusement or a standard joke, both in terms of the physical comedy of people getting stuck in funny or ridiculous positions and in terms of humour based on the transparency of people claiming to have back pain as an excuse for getting out of things, being lazy or skiving. Respondents also referred to the media profile of back pain, in particular its presentation in terms of being a common problem associated with work loss and economic and health service costs.

In the following extract a respondent describes his perception of the need to visibly demonstrate his experiences of pain, “to put across how bad it was” in the context of taking time off work and how this reflected back upon his sense of self as “skiving”:

R: Yes I probably tended to put it on. When you’re in pain you don’t go about grimacing. When you’re on your own you don’t pull faces. I would say if there were people there, like my boss, you’d put on a face. As I say if you’re on your own you don’t go about twisted up. So that extent I would say I probably put on a bit of a ... not a show but certainly add to it a bit more, just to put across how bad it was.

I: How did you feel about having to do that?

R: It kept making me think I’m malingering, I should be back at work, this isn’t me. I just didn’t feel right, I felt I was skiving and I didn’t

like it. My wife and kids knew I was bad and had to be off work but everybody else treats you differently and they think you're skiving so you start to feel that way yourself. Even now it's still a big joke at work. When the warmer weather's coming round you'll be getting your bag ready to be off."

(lmpt13)

Alongside respondents' awareness of the issues of invisibility of pain and of the social construction of people with different types of pain, were two other important aspects of their social understanding of pain. These were: the way in which the experience of pain is affected by the mind and/or body; and the concept of pain thresholds. Both of these understandings led many respondents, implicitly, to question their own sense of agency or responsibility in living with pain. The following quotation is from a woman who has already explained how aware she is "that you have a lot of people on the television and newspapers who say that a lot of people who say they suffer from back pain are malingerers". It neatly draws together this wider social perception and her own awareness of the mind or the body, being tensed, having an effect on the experience of pain:

I: "How long have you felt that this aspect of malingering has been something ... what set up that?"

R: "I think it's because the pain varies. I think it's also because I am aware that the mind can have an effect and I'm also aware that when I'm tensed up it tends to be worse. People can say to me that's because if you are tensed up your holding your body more stiffly and I know that. It's a combination of the media saying that so many million people suffer from back pain that can't be traced and I think it's because I'm also aware how much your mind can influence how you feel."

(jspt5)

Other respondents mentioned the concept of pain thresholds or differential tolerance of pain. Whilst most respondents who mentioned pain thresholds or tolerance of pain did so in the context of describing themselves as having high

thresholds or high tolerance, for others these could be sources of self doubt as these respondents describe:

“That’s what I’m saying about our perception of pain. I think I’ve come to the conclusion that my perception of pain is different to someone else and they could cope with what I’ve got. I can’t cope. I still think I can’t cope with the pain very well. That’s what I feel now”

(jspt11)

R: “Then you think maybe I feel it more than somebody else would, You start to think is it because you can’t stand the pain, that you make it worse. If it was somebody else, say it was you that had the bad back, could you not have felt it as badly.”

I: “It makes you wonder about your own tolerance of pain.”

R: “The tolerance, that was the word I was looking for. If you could give 2 people the same pain ... but how would it be the same. See how both people cope with it. Yet I’ve always thought I had a.... like if I had a bad back years ago, say after the kids, I’d think oh I have to get on and yet never let it worry you. Then when I had this slipped disc and there was nothing you could do. It doesn’t matter what you try to do, turn or eat or get up to go to the toilet, the pain used to even make your teeth hurt. Sometimes when I think back I think, could other folk maybe have just got on with that and thought it wasn’t as bad.”

(kspt2-c1)

The concept of vulnerable sense of self has important implications for self-management, the process of living with chronic pain in everyday life. In particular managing a vulnerable sense of self can be seen as depending on conflicting imperatives. This is explored further in the following section.

Moreover it is of particular relevance to the analysis of respondents’ experiences of health services as a means of interpreting their descriptions of strong negative reactions to their encounters with health professionals. In this context, it is argued, that it is because people have self doubts that they find certain things that health professionals say to them as being unhelpful, upsetting or insulting, not because

they are 'certain' that the professional is 'wrong'.

The management of chronic pain in everyday life: self management and the processes of adjustment

This section of the analysis considers the ways that respondents actively live with pain and its consequences, termed here the processes of self-management, and their reports of how, if at all, this has changed over time, termed here the processes of adjustment.

Setting out this terminology for very broad terms at the start may seem pedantic. The purpose of this is to try to avoid, and sensitise the reader to avoiding, an uncritical use of other frequently used terms which fall within this broad domain: particularly the terms 'coping', 'accepting', 'coming to terms with'.

These terms were used spontaneously, frequently and unproblematically by general practitioners and by patients themselves. That is, both patients and general practitioners used the terms as if the meaning was self-evident and hence requiring no further explanation. However, in the analysis of the initial interviews with general practitioners, from the general practitioner's perspective getting patients to 'do' these things emerged as an important but problematic area. As a consequence of this, in the follow-up interview with patients, respondents were asked what, if anything these terms meant to them.

In summary, in order to forewarn the reader about what is to come, the data from

the follow-up interview with patients showed that the same term was used in very different contexts by different respondents and sometimes by the same respondents. A consequence of this was to direct the analysis to how the term was used and what it achieved or conveyed in the context of the interview.

Several important issues emerged from this 'redirected' analysis. Firstly, that the terms were not always simply interchangeable. Secondly, and most importantly, that the terms coping and accepting were used differently depending on the time frame of reference. That is, one could cope some days but not others, one could accept something on a day to day basis, but not for the rest of one's life.

However, returning for now to self-management or respondents' descriptions of the how of living with chronic pain and its consequences. The respondents described how which were practical and psychological, though overall there was much more discussion of the psychological aspects of living with and learning to live with chronic pain.

In the overall context of being very precise about terms, a comment on the use here of the term psychological is perhaps needed. Few respondents used the term psychological in describing how they lived with chronic illness. However, it seems appropriate to use this term to refer collectively to the processes they described in ways such as "getting the right attitude", "getting your mind right", "putting it to the back of your mind" or "taking one's mind off it" and to those activities which could be seen to have formal psychological equivalents such as having "wee goals"

(goal setting) or taking things slowly (pacing).

This analysis has already drawn attention to a key feature of respondents' descriptions of living with chronic pain, that of its constancy, both in terms of the practical activities of daily living and "the way it commands your mind".

In relation to the practical reminders of the constancy of pain, there appeared to be a variation in the extent to which respondents had learned over time different ways of doing things or not doing things automatically and thus avoided or reduced the frequency with which they were 'reminded' of the pain, as these respondents described:

I try to ignore it. I don't do certain things. Or I'd be careful how I turn. Again over time that becomes automatic, you just do it. Other people tend to say you've either got a headache or you back's sore today. My husband will tell me. I think it becomes an automatic response, you learn to live with it. The back in a way is easier to ignore because it's there constantly. That sounds stupid but it is (than the migraine). I think if you listen to your body and acknowledge that you have this the whole time, you could become very depressed. So you don't you switch off."

(jspt25)

"By the time you get to the years that I've had this problem it's second nature. It's just like you have this tooth that's kind of sensitive so you make sure you don't chew peanut brittle or whatever. Or your hands freeze up ... I think we've all got it as the years go by it just becomes so you never notice it."

"You just adjust. It's second nature after a while."

(lmpt9)

Alongside the adaptations that had become automatic, there appeared to be a different level, that of automatic ignoring, or as this woman describes it "mind over

matter”:

“It’s like a toothache. It’s always there, you can’t do anything.. it’s a pain but it’s not... like some days it’s hardly anything and other days it’s really bad. I think you’ve had it that long that it’s just part of your life now. I could go about moaning all day but I mean who’s going to benefit. You learn yourself it’s like mind over matter. You’ve had it that long that you just get on without thinking about it sometimes. It sounds silly but you can just get on and not think about it.

(jspt1)

Most respondents described the process of taking their mind off the pain by engaging in activities:

“I try to do things to take my mind off it, I’ll go for a walk or something like that.”

(js4pt)

Despite things becoming automatic, actively ignoring the pain or trying to take one’s mind off it, there were times when these efforts were not enough, their success varying from moment to moment and day to day as the following quotations illustrate:

“That’s right. You start to feel miserable because of the pain, you let yourself go and wallow in the fact that you’re in pain. Don’t get me wrong, there were days when I felt like that. Most of the time I just tried to ... not put a brave face on it, just go on as if it’s not there. You try and put it in a locked part of your mind, it’s not happening. There were days when it just got on top of you and you go into it. But for the most part it’s easy to say, maybe what I felt wasn’t as bad as some people felt but I was able to lock it away for the biggest part of the time. As I say I had times when I couldn’t and I did feel miserable. I’d be looking out that window day in, day out. It wasn’t so much the pain as everything else wasn’t. Not being able to do what you want to do, not being able to do anything. It gets on top of you.”

(lmpt13)

“So between the general pain which I can blank out when my mind’s occupied, we have the acute spells where perhaps if I’m walking or put my foot in a hole, the pain can overwhelm me at times.”

adding later

“So when it’s really bad the pain overwhelms me. Three quarters of the time I can keep the pain under control by keeping my mind off it, resting, not forcing myself to do too much but there are occasions when I just can’t help it. If I’ve got to stand too long, sit too long or whatever, so that’s the boring details of the pain.”

(Impt9)

Other respondents described how they managed to ‘keep going’ by making sure they kept particular activities going, or setting goals for the day, week or in the longer term such as going on holidays. Respondents with partners or young children often explained how their feelings of responsibility for them was an important positive motivation in ‘keeping going’ and made an important difference to how they managed their everyday life.

“Like the weans and that.. as I say I’ve got my wee goals at the end of the week, football on Saturday and that’s it. I go to football on a Tuesday ...I’m a lot busier now than I was when I was working, running after the weans. That’s what keeps me going.”

(Impt11)

The work involved in both the psychological and physical management of pain appeared complex, in terms of finding a balance, as one respondent put it “the balance of quality of life”, between not giving in to the pain, “not dwelling on it” but not fighting it so that one overdid activities and therefore suffered too much in the longer term. The following respondent describes this complex mental task of managing the pain, the effort of achieving being able to carry on “as if it wasn’t there”.

“Keeping the pain sort of.. I always say to the kids if something is sore and you cry it makes it worse. I don’t know if it scientifically does but it definitely happens. If you let yourself go into it, become miserable, it always makes it worse. Like wise you don’t want to fight it, I’m not going to give in to it. I always believe just to relax. Don’t let yourself go away into the pain but at the same time don’t fight it,

just relax and try and ... not ignore it, that's not the right word ...it's very difficult to explain. Don't fight it but don't become wallowed in it, just carry on as if it wasn't there."

(lmpt13)

The above description is typical of many respondents' explanations and could apply equally to practical tasks as to the psychological tasks.

Such descriptions convey the complexity but also the constancy of this task. Accounts also conveyed the fragility of this process in the following ways. Most respondents explained that there were simply times when they couldn't do it, as the above quotations have indicated, or as this respondent explained:

"There's times when I'm so tired I just want to curl up and say go away and leave me, let me die. I'm just after saying to you fight and you do but there's times when the fight goes, when it's really severe. I just go to my bed usually, curl up with a hot water bottle."

(jspt16)

The fragility of managing was also conveyed by descriptions which implied all one's 'resources' were already committed to it, that some days things demanded "pure determination". One respondent explained that she always felt she had to be feeling 110%:

"The thing is my psyche ... I have to be feeling 110% mentally everyday because if you feel really depressed and you get strong pain, it's soul destroying. You can't cope with anything. I feel as if I have to be on an up all the time to cope with it."

(jspt16)

Many of the respondents however conveyed this 'limit' with their use of the term coping. This in turn illustrates the importance of the time frame of reference for coping, as some respondents explicitly put it "coping a day at a time".

Throughout the interviews respondents talked about whether they were coping or not or coping well or not. Only a few people felt that overall they weren't coping and a few respondents described themselves as coping well. Most respondents' (spontaneous) use of the term coping was in the context of necessity: "you have to cope".

However, although most respondents were, in their own terms, coping, they frequently added a subscript that they did not know how they would cope 'if' something, the something being specific and often a very subtle change in their circumstances. Thus respondents who experienced more than one sort of pain, though not at the same time, often explained that they coped but they did not know whether or how they would cope with both types of pain at the same time:

"I just muddle on from day to day like everybody else. If I was ever to experience neck pain and back pain at the same time I'm not sure."
(jspt15)

Another young respondent (32-year-old man) explained his concerns that the reason that he was able to cope with the pain was because he was young:

"Maybe because I'm young I can cope with the pain I get just now. Maybe next year or five years from now I'll be worse off and where do I stand then."
(lmpt15)

Others explained their concerns about being able to cope in the future in very general terms:

"As long as it doesn't get any worse I can cope with it. I don't know how I would be if it got worse."
(jspt5)

The dynamics of self-management: ‘coping’, ‘accepting’, ‘fighting’ and ‘coming to terms with’

The preceding analysis has pointed to respondents’ descriptions of the fragility and effort of both the practical and psychological aspects of self-management. This section of the analysis examines in more detail the apparently conflicting use of frequently used terms such as ‘coping’, ‘accepting’, ‘fighting’ and ‘coming to terms with’. It highlights the importance of considering the ‘what’ (e.g. fighting what) of these terms, the implicit necessity of doing or trying to do these things, and integral to both of these, the time scale of reference.

For the most part, respondents did not specify a ‘what’ explicitly. The terms were used in general. When respondents were asked about their understanding of these terms in the follow up interviews, the questions were asked in general or in relation to pain generally. However, respondents’ use of these terms implied that respondents could accept some things and not others, or come to terms with some things and not others and that the process of coming to accept, or coming to terms with, had been different for some things and not others. Thus respondents could accept the pain, but not the stiffness of disability, or could accept that there were no medical treatments available but not that no help was available, or could come to terms with not being able to do some things but not others. For example in the following quotation the respondent is describing her experience of severely incapacitating seizures:

“That I refused to accept. When things are as bad as that and you can’t keep going like that ... that is what made me say, I’m not prepared to accept it. I wasn’t ready to accept that. Maybe I’m wrong, maybe I should have accepted things a lot earlier but what stage would I be at now if I had accepted it.” (js10-c4)

In the following quotation the respondent explains the difficulty of accepting no longer being an active person.

“I think it’s something you have to accept. Whether I will ever accept it I don’t know. I don’t think I will because I’ve been such an active person. The other way to look at it is you’re on your feet, you’re living.”

She concluded:

“Still positive thinking. You have to if you don’t its just going to drag you down. It’s rather difficult to accept. I would agree. I found it difficult. Very much so.”

(jspt7)

Most respondents described the necessity of ‘coping’, ‘accepting’ and ‘coming to terms with’, that is ‘you have to cope’, however this necessity and their achievement of these aspects of self management implied an active process managed on differing time frames: immediate, day to day or long term future time scale.

Thus as the above analysis of the use of the term coping indicated, many respondents explained that you have to cope, but expressed concerns about whether they would continue to cope in the future. Similarly, it was possible to cope overall by coping differently on a day to day basis, or cope with not coping some times. Thus in the following quotation the respondent describes learning to pace yourself, but by having a different pace on different days.

“There’s some days that you can get up and do more than others, others you are very limited in the amount that you can actually do. Some days you can work through this, other days you don’t get any respite out of it at all. There’s no real rhyme or reason, it’s not a case that you’ve done too much the day before, it’s your own stupid fault.” concluding “So you learn to pace yourself.”

(js10-c4)

The importance of this ‘different pace’ approach to pacing was highlighted by this respondent’s descriptions of her experiences of the pain management course, which she described as “trying to take away our freedom”, explaining that:

“I will attempt and challenge anything people give me to do. Unless you actually try something you can’t say whether it worked or not but I do not think that you should take away from the person the adaptability of something in their own life.”

(js10-c4)

The distinction between the present and the long term future in terms of accepting was particularly important in relation to respondents’ use of the term accepting as the following extract from a follow up interview illustrates:

I: "Right because em in our first interviews people talked about accepting pain and I mean, what we’ve got down here is then, we thought we were maybe wrong to assume that you can accept pain."

R: "No, you can."

I: "You can?"

R: "Yes it might be. I don’t know, it may only be a personal opinion but obviously I have."

I: "Yeh."

R: "Maybe not accepted it but I’ve learned to live with it. I mean I wouldn’t accept it as being in the sense that I still wouldn’t like to look forward 30 years and think this is how I’m going to be. But I’ve learned to live daily with it knowing that em, I’m only going to have another 6 hours and I can go to bed and take my tablets and I know I’ll get a good night’s sleep and then we’ll see what happens tomorrow morning.."

(jspt11)

Thus the different time perspectives underpinning respondents’ use of these terms explained many of the apparently contradictory uses of these terms such as having accepted the pain (in the present) but having to fight it (with reference to the future). In many cases concerns about how one’s body would be physically in the

future meant fighting the processes of physical deterioration

“Well I honestly feel if I don’t keep fighting it I’m going to end up in a wheel chair. Several times I thought that’s how I’m going to end up in a wheelchair.”

(kspt3-c3)

For most respondents the psychological management of the long-term future meant not accepting, or the converse of this, hoping. Thus many respondents who described coping, accepting and having come to terms with pain and its consequences explained, in reference to the long term future, that they could not accept this or were hoping that things would be different. As the following quotations illustrate:

“The fact that somehow I think to the future and think am I always going to be like this. You waken up in the morning and hope it’s going to be away but you know it won’t be. I feel healthy apart from this and if it’s like this just now what’s it going to be like when I’m older. I think that’s quite difficult.”

(jspt25)

I: How do you cope?

R: I just don’t know. I accept the fact that tomorrow I might be alright.”

(jspt15)

Self-management as management of self

Having described the complex processes of self-management, this section of the analysis offers an interpretation of these processes in terms of managing a sense of self. This analysis is based on respondents’ descriptions of the processes of living with chronic pain, their encounters with health professionals and their descriptions of their reactions to different kinds of therapy and suggestions about therapy, as

well as an analysis which sees the interview as a process in which respondents have to give an account of themselves (Kelly, 1992).

An earlier part of this chapter explored the vulnerability of sense of self. This section of the chapter can therefore be seen as an exploration of how respondents actively manage a vulnerable sense of self. In particular it explores the management of sense of self in two principal respects: in terms of continuity and sense of agency (Harre, 1983). In everyday terms, it is important to have a sense of who we are or what sort of person we are and there needs to be consistency and coherence to this, such that people can be seen to strive for continuity of self. It is also important to have a positive sense of autonomy, responsibility and capability for action and thoughts.

- **Consistency of self**

The analysis which follows illustrates the ways in which respondents could be seen to strive for consistency of sense of self. That is not to imply a lack of change or adjustment, but to consider the balance of the process of adjustment in terms of consistency of sense of self. Neither is it to imply that all aspects of self remain consistent, or that respondents could be grouped in to those striving for consistency and those with self-doubts. Rather it considers consistency of self as a process (or an aspect of an identity project) of negotiating, or accounting for, different aspects of self.

In the following extract, the respondent explicitly expresses the importance of not being different.

I: (following a break in recording) “You said that you didn’t like talking about it because you don’t want to be different. Has being in pain changed the way that you think about yourself then?”

R: “How do you mean?”

I: “You said you don’t want to be seen as different?”

R: “I don’t want to be different. I want to be able to do things and be me. This is me, that’s the thing, I’ve got to accept that and get on with it.”

(kspt2)

The placing of a consistency of self within the context of the interview is illustrated below. In this case the respondent has described in a lot of detail the growing social isolation of no longer being able to go out to work, or indeed to get out and about much, because of her back problems. She then returns to an earlier theme, of how much she ‘loves learning’. She explains that she has always spent considerable time in libraries, writing and studying, that “my main interests have always been creative and as a result I’ve been very isolated all my life”, concluding, “this is where I’ve always been isolated”.

Later in the interview she is asked explicitly: do you find that being in pain has changed the way you think about yourself?

“No I don’t think my personality has been damaged by it. I’ve always had good self-esteem despite everybody trying to”

She concludes later:

“Basically I’m quite a happy person.”

(jspt10)

In the above example, the respondent’s description of her self is directly linked to the problems of living with back pain. This is not surprising, given the topic of the

interview. However respondents also talked about themselves, what kind of person they are, what they do in ways not directly linked to the pain. In most readings of the data these statements would be ignored as irrelevant. This removal of irrelevant statements of continuity of self can be seen as part of the process of summing people up by their illness which this analysis has explicitly sought to avoid, if only by noting this process.

All the respondents could be seen to have ‘lost’ some aspects of themselves, or as this respondent put it, “you can’t be yourself”:

“I guess it all comes back down to the pain. You can’t be yourself, you can’t do the things you used to do. Your temperament changes because you get frustrated. At the moment what I feel is frustration. It gets me grumpy and I get narky when I’m like that. I have pretty much accepted it.”

(jspt27)

The experience of change in emotional response, moodiness, anger and snapping at people was one of the most frequent ‘losses of self’ that respondents described and is exemplified by the following quotation:

“I cannae handle pain. It’s actually changed my ... before I had this operation I didn’t bawl or shout. I lost the heid now and again but now I lose it like that. I’m more aggressive than I have ever been. Before I was happy go lucky, nothing really bothered me but now the least wee thing.”

(lmpt6)

Having argued against the idea that respondents had either ‘continuity of self’ or ‘loss of self’, there were however, noticeable differences between respondents in terms of the extent to which they emphasised continuity of self or loss. The interview with the respondent quoted above, who had recently attempted suicide,

noticeably contained no statements of continuity of self.

The process of maintaining continuity of self can be seen to have important implications in the process of adjustment. It can be seen as a demand which competed against the demands of pain relief and avoidance, particularly in the context of practical activity. Many respondents described the difficulties of adjusting to doing less as the following quotation illustrates:

“My back ... it’s like everything else, it’s there and you try to live with it but some days it’s ...I’m literally crying with it because it’s so sore. It’s very difficult to say don’t do this don’t do that. I was always quite and active person and it’s very difficult to say well I can’t do that.”
(jspt12)

Many respondents described the difficulties of changing pace, doing things more slowly:

“I’ve always been a person that was on top gear. That’s the hardest thing for me, to drop down into third. I find it awful hard.”
(kspt1-c4)

Many respondents who had made overall adjustments explained the particular importance of certain activities in maintaining key aspects of their sense of self, in the example below, being a housewife:

R: In a queer way sometimes... changing the bed for example is one of the activities that hurt and I’ll do it even though I know it’s going to bring the pain on because somehow that means I’m still the housewife which I quite like to be as well. So again I’ve taken the decision although I know it’s going to aggravate it. I’m proving that I’m still whole.”
I: So there’s all sorts of aspects.
R: Pride I think is what it’s called.

(jspt25)

Other respondents described what can be seen as a process of adjustment which has to involve overdoing it, as in the following quotation where the respondent explains “what will always be me”

“Well I just have a blow out, get angry and that’s it. I don’t know if I ever will cope with that. It’s maybe got to do with the fact that I put too many demands upon myself. I don’t see that I should have to change my personality because of my physical being. That is something that... I don’t think I ever will and I think I’ll always go through these wee bouts. They’re not that frequent to be honest. Maybe once or twice a year. In the early part it was terrible. I would often cry. First when I was in the wheelchair ... so I know that ...at least I’m not as bad as I was then. I think sometimes I get cross because I start something that I know I can’t finish and I shouldn’t have started it. That’s again me ignoring it. That’s me just thinking well no, I’ll do this. Then it hits you. Gosh I’ve taken on more than I can tackle. That will always be me.”

(Impt4-c2)

The project of maintaining a sense of self as consistent can be seen to apply to potential future self, possibly explaining some of the difficulties of accepting change or deterioration and the necessity of fighting this.

An additional complexity in the process of negotiating continuity of self was respondents’ awareness of how their behaviour would appear to other people in the context of social doubt. There seemed to be two aspects to this, to call their experience of pain or how much pain into question or to call into question their responsibility for self-care.

The following quotation is from a young man describing the importance of keeping fit (an aspect of continuity of physical self). As he notes, this may well appear to negate him having chronic pain:

“There’s certain exercises that I can’t do because of the back, putting

weight on my hips. Basically if I didn't go and do what I do at the gym just now, stretching and that well basically you put weight on and you can't get it off because you can't do sit ups and what have you. So I've got to try to do something else. I shouldn't be saying this on the tape, going to the weights and everything. They'll be saying how can he do that if he's got chronic pain."

(lmpt15)

"I refuse to be bound by illness and where I have been criticised for not accepting it, the only person that may suffer from me not accepting it in the end of the day is myself because I'm not going to hurt anybody else by this. You just do what you want. It may be a selfish attitude but it's my only self preservation."

(jspt10)

- Sense of agency

Many of the above quotations can be seen to illustrate the centrality of respondents' sense of their own responsibility and endeavour in the management of chronic pain and in the process of adjustment. That is, as the following quotations emphasise, how much is down to themselves, albeit in the context of necessity:

"The best person that knows how I can cope or not cope is me."

(jspt24nr)

I: "Has anything helped you to learn to live with it?"

R: "No. I've had so much pain in my life its just something I have to cope with."

(kspt3-c3)

"I think I've just come to the stage where I've learnt myself to live with it to be quite honest. Nobody else has helped. You just have to. It's either that or go off your head."

(lmpt10nr)

"For the first couple of years I used to get angry inside. Now there's no point. I must admit that over the years I have developed or found it easier as the years have gone on to handle it."

(lmpt5)

Along with the centrality of self-responsibility and autonomy, much of respondents' descriptions of learning to live with chronic pain emphasised the psychological work involved in these processes. Despite the importance of this endeavour, it remained fragile, as one of the respondents quoted above described, "three quarters of the time I can keep the pain under my control by keeping my mind off it" but that "there are occasions when I just can't help it". Respondents sometimes strong sense of psychological agency and other times sense of absence of this could become a source of self doubt as illustrated by an earlier quotation where the respondent is reflecting on what makes her feel as if she is malingering: "because I am aware that the mind can have an effect". To reinforce the point rather clumsily, if one can achieve mind over matter sometimes then why not all the time?

Summary

The analysis above has explored respondents' accounts of the experience of chronic pain in everyday life in four principal respects as follows.

It began by considering different aspects of the experience of pain, its impact on the tasks of everyday life, the emotional consequences of pain, the constant presence of pain and, for many of the respondents, the unpredictability of episodes of severe pain and sudden incapacity which could occur in the course of mundane activities. It suggested that the juxtaposition of unpredictability and ordinariness could be seen to constitute one aspect of the nature of suffering. Although analysis attempted to describe respondents' accounts of different aspects of the experience of pain, it

explicitly recognised that these may not constitute the totality of that experience.

Related to this, a second aspect of the analysis was the exploration of a recurrent theme in respondents' accounts that only people who had experienced chronic pain directly themselves could really understand. Exploration of how respondents constructed their sense of other people not being able to understand, and conversely, how some exceptional people did, at least partly, understand provided an analysis of mundane intersubjectivity.

The analysis of the problems of mundane intersubjectivity identified the following themes: the sense of not being able to describe the experience of pain; the sense of not being able to describe the impact on daily life; the problematic consequences of trying to explain; the awareness, in retrospect, of not having understood or realised what other people had been going through; the awareness of the 'invisibility' of pain in the context of inter-personal and face to face relationships and, finally, the awareness of the absence of any socio-structural acknowledgement or legitimisation of their experiences, particularly in the context of work and social welfare.

Although much of respondents' accounts, as much of the existing literature on the experience of chronic pain, emphasised the problematic aspects of intersubjectivity, many respondents also described how some people did understand, at least in some respects. That is, their accounts also contained descriptions of 'unproblematic' intersubjectivity. These accounts were underpinned by two themes. Firstly, the

accounts implied that ‘unproblematic’ intersubjectivity was constituted by direct, rather than communicated, understanding. Secondly, a crucial aspect of this direct understanding was the ability to interpret or read physical indications, rather than the nature of the physical indications themselves. This ability was constructed by respondents, implicitly or explicitly, in terms of on-going relationships or knowledge over time.

A third aspect of the analysis was to consider the implications of the problems of intersubjectivity and the wider social context in terms of self and identity. Thus whilst recognising that intersubjectivity was not always problematic, it was argued that the experience of the many problems of intersubjectivity could be seen to constitute a vulnerability of self and identity. As such, shared social concepts and understandings about pain and chronic pain were seen to contain sources of threat to an already vulnerable sense of self. These shared social concepts and understandings included pain thresholds; the importance of “mind over matter”; the association of chronic pain with costs to society and of the concept of malingering or claiming ill-health for unjustifiable personal gain. These understandings led many respondents, implicitly, to question the genuineness of their experiences and themselves, and their own sense of agency or responsibility in living with pain.

The concept of vulnerable sense of self had important implications for the processes of self-management or living with chronic pain in everyday life, explored in the final aspect of the analysis.

The work involved in the processes of self-management appeared to be complex, in terms of the constancy of the task and its fragility. It involved both practical and psychological work, though overall there was much more discussion of the psychological and emotional aspects of living with and learning to live with chronic pain. The analysis examined in detail respondents' often apparently conflicting use of terms such as 'coping', 'accepting', 'fighting' and 'coming to terms with', highlighting the importance of considering the 'what' (e.g. fighting what) of these terms, the implicit necessity of doing or trying to do these things, and integral to both of these, the time scale of reference. Having described the complex processes of self-management, the analysis offered an interpretation of these processes in terms of managing a sense of self in two principal respects: in terms of continuity and sense of agency.

The process of maintaining continuity of self was seen to have important implications in the process of adjustment, constituting a demand which could conflict with the demands of pain relief and avoidance, particularly in the context of practical activity. The project of maintaining a sense of self as consistent was seen to apply to potential future self, possibly explaining some of the difficulties of accepting change or deterioration whilst asserting the necessity of fighting this. An additional complexity in the process of negotiating continuity of self was respondents' awareness of how their behaviour would appear to other people in the context of social doubt, potentially calling into question their experience of pain or

their responsibility for self-care.

The importance of maintaining a sense of agency, or responsibility for one's own thoughts and actions was also explored. Respondents' accounts of the processes of self-management conveyed the centrality of respondents' sense of their own responsibility and endeavour in the management of chronic pain, particularly in relation to the psychological and emotional work involved in these processes. It was suggested that respondents' awareness of the fragility of this psychological and emotional work constituted a threat to their sense of agency.

The complexity of maintaining continuity of self and sense of agency whilst attempting to establish genuineness in the context of social doubt had particular relevance in the context of health care and is explored in the following chapter.

Chapter Ten: Patients' experiences of health services

Introduction

This chapter describes respondents' experiences of health services. It is in three parts. The first part, on the management of self in the context of health services parallel is the analysis developed in chapter nine. It uses the themes of the social context of doubt, management of self, continuity of self and sense of agency, to understand respondents' accounts of their experiences of health service. Whilst the exploration of these issues is primarily in terms of the problems that respondents described, later parts of the analysis seek 'solutions'. These consider the process of encountering health services as a process of constructing accounts of pain or of self and, by considering some respondents' accounts of 'solutions', how health services have contributed to the construction of a positive and valid sense of self.

Many of the issues raised in this section of the chapter are revisited in the two forthcoming sections which consider respondents' views of general practice and hospital services. Unfortunately this means that there is some degree of repetition for the reader. However, it seemed important to highlight the relevance of these themes and concepts in the context of health care generally, before placing these in more specifically defined and subtly different health care settings. The principal difference was the continuing contact with general practice, whether routine or an on-going relationship with a general practitioner.

Management of self in the context of health services

The analysis described in chapter nine described the social context of chronic pain, the difficulties respondents faced in providing a socially valid account of their experience and of themselves as genuine people with genuine pain. Moreover it suggested that their awareness of these accounting difficulties and the extent of social doubt was reflected in their sense of self, sometimes doubting themselves.

It also highlighted the difficulty of maintaining a sense of consistent, autonomous self in the process of having to adapt whilst seeking social legitimisation or acknowledgement of their experience. In short, that the sense of self was vulnerable and that managing one's sense of self and providing socially or medically valid accounts or presentation of self involved a complex balancing process. The following respondent describes such "a catch 22" situation. She explains the difficulty of trying to legitimate her experience of pain in the context of having made progress to accept, such that she no longer cries her heart out:

"The time I went to the pain clinic and he said how are you feeling. I said well you know and I smiled. He said I don't think it's a very funny matter, I'm pleased you can laugh about it. I said excuse me, it's either I laugh or cry. Whereas a few times when I've talked about this I could ... but you hold off. You have to start to learn to accept it because it's there. Say last year at this time I would have been crying my heart out and you probably wouldn't have got much out of me at all. It is hard to talk about it because it's something that really annoys you and hurts you. You've got to keep talking about it but everything's there. It's hard because you're trying to forget it in a way. It's like a catch 22 all the time."

(jspt32)

This part of the analysis demonstrates the implications of this context of doubt in health service settings. This context of doubt as a threat to identity and the

processes of managing a sense self can be seen to underpin many of respondents' accounts of their encounters with health professionals and their responses to suggestions about help and treatment.

Health care as a context of doubt

In the initial interviews, respondents were asked explicitly if they had ever had difficulties with health professionals not believing that they were in pain. With hindsight this question was somewhat crass, although perhaps this would not have been so obvious if it had not been asked.

Most respondents replied that they had never felt that they had not been believed (to be in pain). However in the course of the interview as a whole most respondents described incidents or encounters with health professionals in which they wondered if the professional thought they were imagining it or thought the pain was in their mind or that they were malingering. These descriptions can be seen to indicate that even in the context of the shared 'fact' of the sensation of pain, there remained considerable room for doubt about, for instance, how much pain, or how much of the pain was being imagined and the extent to which respondents were genuine, moral, self-responsible people or 'good' patients.

All the key aspects of respondents' difficulties in providing a social account of their pain, of their experiences and of themselves as genuine people described in the previous chapter could be seen to apply equally in health care settings. These

included, firstly, their awareness of wider socially held views on pain and people who have pain. Secondly, the difficulties of describing pain or explaining the origins of the pain. Thirdly, the problem of the lack of legitimacy of everyday activities; the problems of invisibility, the primacy of direct experiential knowledge (that only people who have experienced pain themselves can really understand). Finally, their perception of some health professionals as people who had not previously understood.

The social understanding of pain

Many respondents described their perception of doctors as holding the commonly held social views about kinds of pain and the people who have pain, as well as describing the problems with the practical techniques used to assess the patients, as the following quotation illustrates:

I: "I know you've said you don't really talk about it with other people but did you ever find it difficult to explain to people how you were feeling?"

R: "Yes to begin with. I found it kind of difficult to tell the doctor. I always have the feeling that doctors are the same with back pain and think... I think it goes back to the days when the miners were going to the doctor with a sore back and would make them bend down and touch their toes. The doctors were kind of ... we'll shove this a bit hard and see if it does hurt. If you scream well it hurts. It was hard at first to describe what you were feeling."

(Impt13)

Respondents also referred to other difficulties that doctors must face in assessing pain: that some people might be malingering or "swinging the lead", that people have very different pain thresholds and also that some people's pain could be psychological or psychosomatic as this respondent explained:

“It’s very difficult for them to know because for some people it can be psychosomatic and they don’t know what avenue to follow.”

(jsgp10)

Difficulties of describing pain

Accounts of the difficulties of describing pain to doctors, particularly within a short amount of time, were commonplace. Often respondents’ descriptions of the difficulties indicated their own assumptions about clinically valid accounts. Thus many respondents emphasised the difficulties of moving or non-site specific pain as one respondent explained “It’s very difficult to describe where the pain is coming from because it spreads”.

Many respondents described feeling that they had difficulty explaining the everyday activities and feelings about pain, “the wee things”, and that, correspondingly, doctors often seemed unaware of what it meant to live with chronic pain. It is important to acknowledge respondent’s implicit, or sometimes explicit statement, of their own part in this. The structure of respondents’ descriptions of the problems of discussing the “silly little things” can be seen to reflect their understandings of both the relative importance of chronic pain as a health service need and their assumptions of the role of doctors. Thus respondents often explained their difficulties in describing these details in terms of limited time available to them and their awareness of the (greater needs) of others, for example that other people in the waiting room might have breast cancer or heart disease.

Moreover, this issue was raised frequently in the context of discussions about

general practitioners but hardly at all in the context of talking about hospital doctors. This in turn can be seen to reflect an understanding that everyday difficulties of living with illness had even less (than in general practice) legitimacy in the hospital setting. Conversely, it can be seen to reinforce the importance of 'being known' by a general practitioner (see below).

One woman explained this difficulty in the context of talking to her general practitioner:

"You can't sit and tell him all these little things. I mean if you say to someone, I can't put my socks on because it's so sore. It doesn't mean anything to anybody. He doesn't understand how that depressed me."

(jspt18)

Invisibility

Many respondents described the difficulties of the invisibility of pain in face to face interactions, but particularly when the pain remained invisible to the more powerful scrutiny of medicine's 'new ways of seeing' such as x-rays and scans.

Again respondents described the difficulties that the invisibility of pain must present to doctors as this respondent explained:

"It's difficult when you haven't got any physical signs of being ill as well. It's difficult for them to believe you and I suppose it's difficult to be treated as well if they can't find out what's wrong."

(kspt2-c3)

Many respondents were aware that their physical appearance did not convey their pain and that this could present doctors with difficulties. Some respondents were

aware that their immediate appearance gave no indication of pain, but that closer physical examination did show signs of damage, sometimes illustrating this with accounts of the change in doctors who had eventually examined them. Other respondents were aware that although there was some visible indication of their pain or disability that other aspects of their demeanour made it difficult for doctors. In the following quotation the respondent is explaining that she has had difficulties proving that she was in pain:

“Yes. Even though I am the way I am I walk very fast. I sort of sidle along and this is deceiving to them. In actual fact I don’t think any of the doctors actually looked at my back for years until I was concerned about something.... I tried to explain to Dr Santer and she said I’ll have a look at it. She just went quiet and didn’t make any comment at the time but she believed me any time after that.”

(Impt9)

Respondents who had had x-rays or scans where nothing showed frequently wondered if doctors then doubted them or thought it was in their mind, as this respondent explained.

“We’re now at the stage where they’re saying that nothing’s showing but they do acknowledge that I’ve got pain. I’m still left thinking do they think it’s in my mind.”

(jspt25)

This respondent went on to explain that she had been greatly, though not entirely, reassured that this was not the case by the consultant’s explanations that pathways of pain could remain even after any anatomical damage or problem had resolved itself.

Respondents were also aware that not having an explanation or cause for the pain could compound the problems of invisibility as this respondent described:

“I think the way the doctor spoke to me like I was imagining it. He really didn’t want to listen to me and because I didn’t know what caused it, it’s like it doesn’t exist. Because nothing showed up on the x-rays, it’s like I’m a neurotic woman. I know it’s there and I’m definitely not imagining the pain.”

(ks2-c3)

People who haven’t experienced pain themselves can’t really understand

As described above, a re-current theme in respondents’ accounts was that people who hadn’t experienced pain themselves could not really understand it, as one respondent put it “There’s nothing you can substitute for experience”. This was the context for many respondents’ accounts of the difficulties in explaining to doctors and their concerns about “whether you’re getting through to them or not”.

Respondents’ descriptions of negative encounters with doctors were frequently underpinned by their awareness of doctors’ lack of experiential knowledge, and hence lack of understanding, as the following quotation illustrates:

“Again it comes down to individuals. I think the best person to deal with pain on a day to day basis is someone who knows what they’re dealing with. You can’t expect somebody to be sympathetic about something that they don’t know about. So maybe the doctor I didn’t like never felt any pain. Maybe he’s one of the guys who sails through life without ever having anything wrong and maybe that’s why he’s the way he is. Certainly if you knew the person that you’re dealing with has been through what you’re going through or something similar then you can certainly deal with them. I would think that they would be able to deal with you better. That would certainly be ... only have doctors in pain clinics that have suffered pain.”

(lmpt13)

Continuity of self in the context of health care

The previous chapter pointed to the importance of continuity of self, and the imperative of maintaining continuity could be seen to underpin many of respondents' descriptions of their experiences of health care.

Alongside the difficulties of the invisibility of pain and the difficulties of communicating the experience of pain was the additional complexity of managing the balance between continuity of self and genuineness as someone experiencing pain and needing help. Earlier parts of the analysis described respondents' awareness of the appearance of their behaviour to other people, including doctors and other health professionals, who might fail to appreciate the effort that this involved. In the terminology of this analysis, the dilemma of balancing management of self with what would be seen to be the (in)appropriate management of pain.

In the following extract the respondent is describing her experiences of the pain management course in the context of which she strongly identified herself as a rebel, explaining that the approach was not "allowing me to be me":

"We were shown easy ways round doing things which has helped. There was a lot of relaxation techniques which help you to relax and to relax yourself and to give yourself time for yourself. Things like that were very good. The rebellious part of me was the fact that they weren't allowing me to be me. Whilst I'll never say I'm a saint, nor will I say I'm a complete sinner. I'm a mixture of both. I like to have the reins rather than the reigns taken away from me."

(jspt10-c4)

The following quotation is also from a respondent describing his experiences of the

pain management course. It illustrates what was a frequent problem for respondents, that slowing down was 'not them' and thus they implied that this would need (too great) a change of sense of self.

“Well put it this way if you do what they tell you you’ll be keeping active, you’ll be doing things slower and you won’t be doing an awful lot. That is awful hard to learn. Especially for a person who is ... I do everything at 100 miles an hour and they wanted me down to 75. But in saying that I don’t know if I’ll ever be able to do that. Their theory is good but to put it into practice is pretty tough.”

(kspt1-c4)

Many respondents described their reluctance or refusal to take medication for the pain in terms of it threatening their continuing sense of self, often as 'not a tablet person', or in terms of the effects of the drugs which made them not feel like themselves as these respondents explained

“I felt a different person when I was on them (tablets)”

(jspt32)

“Partly its knowing that you’re taking drugs all the time but I don’t feel quite myself. So there’s side effects that are not major but without actually relieving the pain. If I had some of the side effects but was actually relieved of the pain then I may think it was worth while.”

(jspt31)

The complexity of maintaining continuity of self whilst attempting to establish genuineness in the context of social doubt had particular relevance in the context of health care. The following quotation illustrates what was a recurring problem for many respondents, that of conforming to broad concepts of how they ought to behave:

“And from the point of view of not being a good patient because I won’t slow down and sit down and do nothing, that, if I explain I don’t want to be a patient you know, I don’t want to have myself that I’m not able to do things.”

(jspt10-c4)

Perhaps more importantly still was the awareness that what they were seen to be doing in order to maintain a consistent sense of self may lead health professionals to question their level of pain. In the following quotation the respondent (above) who set himself 'wee goals' of going to the football reflects on how this might appear to his doctor whose child also plays football and is sometimes also there:

"I don't know how they can tell the level of pain you're actually in. It's like the walking carry on. Just because you can walk to the bottom of the road doesn't mean to say that you're not in extreme pain. I walk about the football pitch when I'm watching my boy playing football and nobody knows that I've just stuffed 3 of those tablets down my throat and I'm in agony every step. It's just the way it goes."

(Impt11nr)

Sense of agency in the context of health care

In the context of health services, as in wider social context, the fragile balance between self-management and sense of agency appeared to be easily threatened and disrupted. The issue of understanding this vulnerability to disruption appeared to underpin general practitioners' apparent difficulties in suggesting psychological or pain management approaches.

In their interviews, general practitioners emphasised their wariness of mentioning anything with the word 'psych' in it to patients, who would interpret this as a suggestion that they were imagining the pain. However, as described above, the analysis of the initial interviews with patients indicated the extent to which respondents themselves mentioned their own psychological approaches to self-management.

In the follow-up interviews with patients, respondents were asked directly for their response to general practitioners having difficulty in making these suggestions and about whether they would find psychological approaches helpful. Most respondents felt they could not explain the problem that general practitioners faced, implying that it would not be a problem as far as they were concerned but nevertheless appeared to understand the point of the question. However, most respondents described an encounter with a health professional where they felt that the professional was suggesting, directly or implicitly, that the pain was in their mind.

A closer analysis of these accounts revealed an implicit threat to sense of agency. In the following quotation the respondent can be seen to refer to the experience of the limits of sense of agency: “there’s a limit to how you get mind over matter” and when prompted further that it “does work a wee bit” can be seen to have to defend her self as “a determined person” and “quite strong willed” finally ending with her interpretation of this as “to say you’ve not got pain”.

R: “There’s a limit to how you get mind over matter as well”

I: “So it does work a wee bit?”

R: “Yes but the pain eventually takes over again. I hate when folk say it’s in the mind and this that and the next thing. Maybe that does apply to some folk but it depends what kind of nature you’ve got. I think if you’ve got quite a determined nature... it’s horrible is somebody says it’s in your mind. Your mind triggers the brain off.... your mind triggers the pain, we know that. I think if you’re a determined person and I’m quite strong willed, I think it’s quite hard for somebody if they turn round and say to you, try and forget about it. When you’re trying your damndest to say you’ve not got pain. Trying to just accept that things are normal when they aren’t, it’s horrible. It just reverts back to this thing again. People that don’t have pain don’t understand it.”

(Imp10nr)

Similarly, in the following quotation the respondent explains her reaction to the suggestion that the pain is stress related, linking her assertion that she ‘manages well’ and is a person that lives under stress and feels she can cope:

“I think one of my other frustrations has been that .. you’ve had it before where people immediately say oh well it sounds as if its stress related. You really don’t have this pain, it doesn’t exist, it’s state of mind etc. I have to say that I’ve recently gone back to a dentist that I used to use before I went down south and he ... I had a very long session with him before he decided to take me on. He had this attitude it really is just a matter of relaxing and the pain will go away. I almost bopped him one because I got so fed up with people saying that. I think yes I do live under stress, I do have a high-pressure job, I have many frustrations with the people I work for and people I work with but I believe that I can cope with that. I’ve lived with high-pressure job for years and know when I’ve got to stop.”

She concludes:

“I feel I manage that well and I do know my limits. So I do find it very stressful when people tell me that if I was relaxed I’d be fine.”
(jspt31)

Another respondent described a similar reaction to the suggestion that the Centre 4 Pain Management Programme might be helpful:

“My own doctor, when I approached him about seeing the orthopaedic specialist said to me, I don’t really think we’re talking about any cure for your back so I can send you to (name of centre 4) who have a pain management clinic who will help you to manage the pain. I did feel quite angry about that because I feel that I can manage the pain. I felt that again we were back to the scenario you’re making a fuss about nothing. That’s the feeling I got. I may be wrong but that’s the feeling that I got and it was only when I pushed him and said no I want to see an orthopaedic specialist and I’ll be happy that at least we’ll have exhausted everything and then I’ll manage it thank you very much on my own. I’m not normally an awkward person but that is just the feeling that I got.”

(jspt25)

However not all respondents appeared to experience such suggestions as ‘threats’ to their own sense of agency, although their responses implied sense of agency as the underlying issue. Some explained, for example, that “no, the pain is genuine” but that they wished “it was in their mind”. The following extract, in which the respondent describes her reaction to seeing a psychiatrist, illustrates the counter interpretation: that if it was in my mind I could do something about it. It also illustrates that sometimes researchers are unable to resist including some quotations in full, for no other reason than appreciation of a respondent.

“One of the doctors asked me why I was looking so miserable. Now to me that was a stupid question. I was in quite a bit of pain, I was feeling miserable. I’d gone into hospital and I didn’t want to. Then this young man comes and says why are you looking so miserable. As I said to the psychiatrist, supposing he had a nagging toothache, I wonder if he’d be smiling. I had a feeling that that was why they asked the psychiatrist to see me because this doctor was obsessed with me looking so miserable. I was miserable because I was in pain. You can’t be in pain and laughing your head off or even smiling. You can’t look happy. You can maybe fake a glimmer of a smile but you can’t actually look happy.”

Adding later:

“You can’t possibly look happy and be in pain. Unless you’re sick. To me then I would have needed a psychiatrist. So I begin to wonder if it was that young doctor that needed the psychiatrist. If he believed that anybody could be in quite a great deal of pain and look happy. So I don’t know. I mean you answer me that one.”

She concluded:

“I would have been quite happy if they’d found it was all in the mind because I would have felt then there’s a chance I might get rid of it. So it didn’t bother me in that respect.”

(jspt6)

Removing the threat to sense of self

A few respondents, though noticeably few, described their appreciation of not having to be concerned about how they or their behaviour might be interpreted in health care settings. Most respondents who had been on the pain management course explained how careful professionals had been to reassure them that their pain was not in doubt as the following quotation exemplifies.

I: Do you ever feel that you've not been believed?

R: Probably initially. You've got a wee feeling and it's obvious you're in pain. They make quite a deal about that at the pain management course. The first lecture is that we know you have pain, we believe you, we're not here to catch you out. We're here to help you, we just can't cure you but we'll help you. So that tucks everything away nicely at the start of the course."

(jspt13)

In the following extracts the respondent is describing the importance and value of her relationship with her general practitioner. She explains how she is able to not worry about her active behaviour being interpreted as suggesting that she does not have pain or, as she put it earlier in the interview, about conforming to the role of a 'good' patient:

"Because he does see me as an outside person. At times, I help running a Pony Club and his daughter's there, so he sees me in an outside situation not just sitting across a desk from him and he knows that I do more than I should and I'm perfectly honest and open about that and whilst he's good enough to say, "carry on, and I'll pick up the pieces but be careful of what you're doing" he will not try to say "you must not do it" or "you cannot do it" or "if you continue doing it then I'm not going to treat you."

"And that makes me a lot easier with the situation 'cos it's very difficult because I know that if I walked into an ordinary doctor's surgery looking the way I do and tried to explain to somebody I had chronic back pain, they would almost laugh you out of the surgery because I know that I seem healthy."

(jspt10-c4)

Health care as providing an account

The analysis has emphasised the threats to self experienced by people living with chronic pain, especially in the context of health care, which requires the establishment of legitimate need. The absence of a legitimate account of pain, such as a diagnosis or cause or description or explanation of the pain, as part of, or in combination with, some self-doubts can be seen to contribute to patients' vulnerability of self. This part of the analysis examines the role or potential role for health services in providing a socially legitimate, if not medically legitimate, account of pain and of self.

To give an example, a recognised, established, if uncomfortable role for health services is that of providing sick lines or evidence for claiming welfare benefits. Most of this is done on a routine or administrative basis. However, the motive of providing a socially acceptable or legitimate account for the pain could often underpin respondents' requests for consideration of further treatment, even though there was nothing that could be done as this quotation illustrates:

“I think since the operation I've taken the direct approach. I suppose it's to do with the DSS now as well. I want something done about it, but if nothing can be done about it I'm better having it on paper so I can produce it for evidence”

(jspt15)

Similarly requests for further investigations or examinations that were perhaps not clinically indicated could be explained in this way. Thus MRI scans or X-rays could provide the evidence upon which a sufficient account could be based and alleviate threats to self or self doubts as in the following quotation:

“He made me feel as if my problem wasn't in my shoulders but in my

head. Now I've had an MRI scan that shows the problem is in my shoulders. It may get me down and get me depressed but its certainly not stemming from my head."

(jspt32)

Where a visible account of the pain remained elusive, respondents particularly valued explanations of how this could be the case. Thus where hospital clinicians, the pain management course, and one or two general practitioners gave explanations of the establishment of pain pathways, these explanations were described as being particularly helpful.

A noticeable absence in respondents' interviews was their descriptions of being helped or given a positive view of themselves, particularly in relation to how they were coping. As was the case in other aspects of the analysis which follow, the absence was highlighted by 'exceptional' cases. Thus the positive support or feedback on this respondent's achievement of recovering from an accident which left her temporarily in a wheel chair and living with pain was 'remarkable' in the context of the interviews as a whole. She is describing her relationship with her general practitioner.

"I don't like talking about myself, that's one issue...I've never been able to come to terms with that. He's explained it to me and he actually thinks ...he said if he was writing a book about remarkable people, I would be listed number one. They didn't expect me to walk and sheer determination and all of that... I was slightly ... I think to be honest I probably was embarrassed because I don't think I've done anything special, I've just got on with it. That's just in your nature."

(lmpt4-c2)

Similarly, but in perhaps a less glamorous context, the following respondent described what she had learned on the pain management programme. Her

description of the very positive difference this had made to her life, emphasised a range of adjustments she had made to her thinking and the way she went about things. In the context of her new found understanding of ways of coping, she was able to construct her own sense of achievement:

“It took me 3 days to put on 5 strips of wall paper but I did it. I achieved it myself and I was pleased with myself. But before I would never have let it lie as long as that”

(kspt2)

The interpretation offered here of importance of this ‘exceptional’ case was not simply that she now felt she was coping well, many respondents felt that overall they coped well, but that she was now able to articulate why she was coping, managing or adjusting well and hence recognise her own achievements.

Experiences of general practice and general practitioners

Overall, respondents’ experiences of general practice, of different general practitioners and of their own general practitioner differed considerably. Respondents did describe negative incidents with general practitioners, although on the whole these were less frequent and less negative than descriptions of negative incidents with hospital doctors.

Most importantly, for most respondents, their overall views of their general practitioner or other general practitioners did not transfer simply to their views of general practitioners in relation to the management of pain. Thus respondents could be, in broad terms, positive about their general practitioner overall but critical of his or her approach in relation to pain.

This section of the analysis also describes patients' views and experiences of medication for pain. There are several reasons for including views on medication within this section. Respondents' descriptions of general practitioners, their implicit understanding of what general practitioners can do for pain and a principal reason for continuing, routine, contact with a general practitioner was in terms of prescribing. As such, medication was very rarely mentioned in the context of hospital contacts. Medication was also an area where there appeared to be a discrepancy between the analysis emerging from the interviews with general practitioners and the analysis emerging from interviews with patients. That is, as one general practitioner summarised, general practitioners seem to think that patients keep coming back wanting more and more pain killers to get rid of the pain and yet patients often criticise general practitioners for just giving out pain killers.

The importance of being known

As in previous work (Hopton et al. 1995), respondents described the importance of knowing their general practitioner and of being known. Sometimes this was described without further elaboration, that is, in such a way to imply that an on-going relationship with a general practitioner is self-evidently important. Respondents also described the positive implications of this on-going relationship; the value of not having to repeat oneself, the value of knowing that your general practitioner knew that you were not the kind of patient who consulted or called without good reason or would attempt to exaggerate problems - in short, that you

were genuine or could be trusted, and the value of being able to open up about problems and feelings:

“Again it goes back to the knowledge of the GP of the patient. Now a patient that the GP has seen more often than most is obviously to my way of thinking, going to have a better rapport with the GP as it were and there’s going to be a better knowledge between the two. the doctor can say to you himself I believe this patient. I can talk to this patient, I can draw him out. Whereas there might be an area if the doctor doesn’t know the patient he might sit back and be a bit suspicious or say I can’t really see anything wrong with him. They may for various reasons, whether its fundholding or expense, they may be reluctant to refer them. So the relationship between the GP and the patient is important but it’s so difficult to control.

(Impt5)

The importance of being known can be seen to have particular salience in the context of social and self-doubt of chronic pain. The context for doubt in relation to contacts with general practitioners paralleled that of the wider social and health care contexts (see previous section). Respondents also described their difficulties explaining their experiences to the general practitioner, and their own sense of responsibility for these difficulties. In the following extract a 31 year old man recently diagnosed as having rheumatoid arthritis explains how helpful his general practitioner has been:

“near the top (of the scale) ken. It’s the circumstances that stop him from being right at the top, time wise and me as a patient I suppose. When I go down there I probably don’t tell him half the things I should.”

He later explained

“It’s just me and that... sitting there and that you rattle off about six difference things ken that’s wrong with you and that. Christ what are you all about. I’ve never been ill before ken.”

(Impt11)

Other respondents described the problem of explaining the ‘wee things’ in the context of their relationship with a general practitioner:

R: “I think that a GP is able to understand if you say I have got this really severe pain that hits me here and goes down my arm. But if you say it’s the sort of pain that comes on when you’re doing the ironing or you’re having sex or I’m feeling on top of the world and walking across a school playground and before I get out of the gate my back’s spasmed 5 or 6 times. I don’t think they would be interested. Those are the details I leave out.”

I: “And those details are important to you.. how would you put those in relation to what you tell your doctor?”

R: “They’re important to me because it’s part of my life. It’s how my life is changing, how I’m doing things. But I have this perception that to a doctor somehow.. it’s an on-going level of pain normally but I have this perception that unless it’s the sort of pain where I’m rolling in agony, that they somehow won’t see it as important. And yet it’s this sort of label of on going way that’s affecting my life. It’s somehow not coming over as clear to a doctor I don’t think as a severe disabling heart pain or something like that. So it’s my perception versus a doctor’s perception.”

(jspt25)

This context of communication difficulties led many respondents to describe wanting to have an ‘outburst’ in order to convey ‘how much’ pain they were in and the extent of the difficulties that they were experiencing, whilst being aware that this might bring other problems, that they would be thought to be overplaying the situation, or to be labelled in other negative ways as the following quotation illustrates:

“Probably because I don’t go to them an awful lot with it and I don’t a lot of the time tell them exactly how I really feel. I go in there saying I’m going to and sometimes I want to scream and shout and bawl and burst in to tears. And say honestly I can’t cope any longer but I’m the type of person that just grins and bears it. So I don’t really ...my husband used to say well maybe if you do go in and say exactly how you’re feeling, let your guard down and let them see that it’s really sore, they’ll maybe do something. I said but then they’d probably just

turn round and say I'm a neurotic woman or I can't cope or stressed out and give me something for stress. Sometimes I feel that because I put this shield up that they don't really know how I feel."

(kspt3-c3)

Some respondents had taken the risk as this woman describes:

"I felt as though I've had to really shout to be heard. I can't really fault him because he's been ok but this thing with my back, I don't think anybody's taking any notice. I think that day I went in he suddenly realised how much pain I was in. They just seem to switch off when you say you're in pain. I think because I was almost in tears ... I've always put on quite a brave show up until then but I was genuinely scared and frightened. I said I really have to see someone, is there no machine... a pain machine even just to prove that I'm in pain. I said I'll do anything if someone will believe me."

(jspt27)

Other respondents described their experiences of general practitioners coming to a realisation about how much pain they were in. Respondents described their experiences of general practitioners being able to 'see' the extent of physical damage. In some cases respondents described doctors reactions upon direct physical examination or, as in the extract below, on the basis of scans or x-rays.

The extract below also illustrates other key features respondents' accounts of these 'breakthroughs'. Firstly, that there was no implication of neglect or criticism of the general practitioner before the realisation because 'it must be awful difficult for a doctor to know'. Secondly, that the issue was not that the general practitioner did not believe they were in pain but that there remained the issue of "how bad" and thirdly, that this legitimated the respondent's experience which was helpful in and of itself, and beneficial to the on-going relationship.

R: Dr Smith, as much as he's a nice doctor, it took him to see that x-ray to realise how bad my back was. He said I've known you've had a bad back but I didn't realise how bad it was until I saw this

x-ray. Even although he was nice to me about my back, he obviously still was under the impression that I was imagining a lot of it and it took the x-ray before he realised.

I: How did that make you feel?

R: "It made me feel good that he realised how bad it was and I hadn't been telling him lies, I wasn't imagining it.

I: "How did it make you feel about the fact that he'd maybe thought you were imagining it?"

R: "It's a thing that you've got to see, to prove how bad it is. You can say you've got a sore back and never have a sore back. I've heard of people pretending they've got sore backs and it must be awful difficult for a doctor to know who's imagining it and who's not."

(kp3-c3)

R: No I get on fine with all the doctors now. I'm surprised at Dr Brown because I never used to like him he's changed now."

I: How's he changed then?

R: He understands more. I think he thought that it was all in my mind my pain but when he saw me the other day he said my good god. Because I was lying out like that. I wanted to sleep because I never slept for 4 days. He said I'll be with you just now and I went into his office and was falling asleep. he checked my back and said I'll give you some painkillers. She (his wife) was worse than me. When I come out of there I was shocked by him. I said he's more closer to me now. he's realised that I'm in pain and he's helped me now. He's going to get me to the hospital."

(lmpt7nr)

An on-going relationship with a general practitioner was of particular importance in the context of having made such breakthroughs and in having the opportunity to make them.

Alongside the difficulties of the invisibility of pain and the difficulties of communicating the experience of pain was the additional complexity of managing the balance between continuity of self and genuineness as someone experiencing pain and needing help. The previous section of the thesis described respondents' awareness of the appearance of their behaviour to other people, including doctors and other health professionals, who might fail to appreciate the effort that this involved or, in the terms of this analysis, the dilemma of balancing management of

self with what would be seen to be the (in)appropriate management of pain. Most respondents described these issues in the context of concerns about how they were being perceived by their general practitioner. Indeed, the analysis of the interviews with general practitioners can be seen as confirming the appropriateness of these concerns.

Again it is worth noting here the one respondent, quoted earlier in the analysis, who was exceptional in explicitly describing the positive importance of her lack of concern about this issue, that, as she put it, of having “a licence to abuse ” in order to “try and lead a life”, with a general practitioner who saw her as an “outside person” and was “prepared to pick up the pieces”.

General practitioners and pain

As indicated above within respondents’ positive overall views of their general practitioner, descriptions of this relationship and contacts with general practitioners in relation to their problems with pain were less positive for the largest group of respondents.

Some respondents felt that their general practitioner, or general practitioners in general, were not interested in pain. The following quotations illustrates respondents’ awareness of general practitioners differential interest in different aspects of practice and patients:

“It seems to be everyday GPs its outwith their field. They can treat back pain as a normal muscular pain and they give you pain killers but when it’s an on-going thing it seems to be out with their

capabilities, it's not their field.”

I: “Do you think there are any aspects of chronic pain that you find it difficult to address with your GP?”

R: “Oh I just wouldn't bother. Sorry I know that's not a very good answer but I wouldn't bother discussing it with a GP. As I say I don't know what ... they like to be involved in cancer research and heart disease but I don't think they're bothered about the back so I don't bother them.”

I: “Are there any aspects of your experience of chronic pain that you feel your GP doesn't really appreciate or understand?”

R: “All of it. When I was down on Wednesday I had a small cyst on my chest which he and a sister operated on and removed it and put 2 stitches in it. He was over the moon. He enjoyed it. I mean he was very attentive and very good but I think that's the first time I've had my shirt off and I've had back pain for 5 years and he's never looked at me yet.”

(jspt15)

The obverse was also the case, that respondents were aware when general practitioners were particularly interested in pain generally or their particular kind of pain whether this was in a professional or a personal sense. Thus patients of the general practitioner in the study sample with a strong interest and training in chronic pain management, were aware of this.

Given respondents' feelings about the primacy of direct experience of chronic pain, that is that only people who had experienced it themselves could really understand, respondents particularly valued knowing that their general practitioner had also some direct experience of pain, or secondarily had a close family member who had experience.

“The same thing every time”: routine consultations

Many respondents explained that their continuing contacts with general practitioners were repetitive and not going anywhere, as this respondent explained:

“It’s like repeating yourself. Every time I go down there it’s how are you? Just the same, not any better. It’s getting slightly worse all the time. ”

(js14pt)

Many respondents explained that they now tended not to go to see the doctor, because of the feeling of “wasting his time” or this being no help, or because there is nothing more that can be done.

Amongst respondents describing this situation with their general practitioner, some respondents presented this positively as an indication of their own ability to get on with things and as their own choice, with the underlying implication of their own sense of responsibility. The following extract illustrates the habitual nature of the contact, this sense of choice and implicit responsibility:

R: “I think it’s just become a habit. I go along to get my painkillers, he says how are you and I say well everything is not too bad. That’s basically it.”

I: “Are you happy with that?”

R: “I think that’s all I know now. It’s become a habit. I suppose I wanted it to be different I could say I’m not pleased with this. If I was to really let him know how I felt I think I would end up on things like valium and sleeping tablets and I’m not wanting that. It’s all taken time to get to where I am and I’m quite happy.”

adding:

“It’s because I choose just to go along there and say look I just need pain killers and that’s it.”

(kspt2-c1)

The above quotation also illustrates several other important aspects of respondents' views of general practitioners and medications to be considered in more detail below. Firstly, that many respondents described general practitioners primary, if not only, approach to helping with pain as being to prescribe painkillers. Thus in the above extract, there is an assumption of the inevitability of stronger painkillers should she "really let him know how I felt". Secondly, that medication is the reason for continuing contact and hence, routinisation of the encounters. Finally that she is complicit in the assumption that her need (or needs) is 'just' for painkillers.

Other respondents described having learnt over time that there was nothing or little that general practitioners or the medical profession could do and that was why they had stopped going, as this respondent describes it, realising that there is no miracle cure:

"I suppose then the problem occurs because people still go down looking for a miracle cure and when there isn't one, "Ah useless" and it's the medical profession that get the blame and it's not, they just don't have the answer and I realise that now. I didn't realise it 3 years ago but now I do. And that's why as I said to you before, I didn't go and see him because the tablets I'm doing, that I've got at the moment, do take the edge off it, it makes me able to live with it so I dinnae see the point in going down and saying "I'm the same as I was", although he says to me I should come and see him more often, but I dinnae see the point."

(jspt11)

Other respondents described the repeated contacts in contexts which implied they were not able to get help or support. The following quotation is typical of respondents who were dissatisfied with the situation that "nothing changes" and illustrates several key themes, namely the inadequacy of approaches based on painkillers (or injections), the difficulties of managing sense of self in the social

context of “grin and bear it” when there are others worse off and other people’s (the doctors) potential negative reactions:

“It’s like you’re constantly going to the doctor.”

She added later:

“All they’ll do is increase the pain killers or give me an injection. I feel nothing’s being done, I’m just having to cope and that’s it. Sometimes I feel like screaming and saying you have it for a week and see how you get on. then on the other hand I say, well there’s a lot of people in more pain than me so grin and bear it. I just accept it but I hate constantly going back to the doctor because it feels like a broken record. He’ll say what can I do for you. I say I’m in pain. I just feel I don’t want to, it puts me off going because of it and if I have to go for something else it’s not so bad but then I think he’ll be thinking, oh here we go again, another problem with her. Then he’ll say how’s your back and I’ll say just the same. Nothing changes.”

(jspt12)

Other respondents described their awareness of the general practitioners’ own feelings (as opposed to general practitioners’ feelings about their patients). In particular that they would be frustrated about not being able to help or to do anything to relieve the pain, although as the following quotation illustrates this was not helpful:

“I think he gets quite frustrated himself when he can’t put his finger on what it is. I think he feels he’s there to do you a service and he can’t do it. It’s very unfortunate. It doesn’t help me though.”

(lmpt10nr)

Other respondents described the additional emotional burden that this could place upon them. The following quotation illustrates this. It also echoes the earlier theme of the limitations of sympathy as an uninformed and hence, unconstructive, response.

R: “He’s very sympathetic in the way he speaks to you, he’s got a really good bedside manner but at the end of the day he doesn’t give you anything. In fact the last two or three times before I went to the

(name of centre 4), I used to come out of there in tears because he felt so sorry for you and I'd get very depressed."

I: "Because he was being so sympathetic?"

R: "Being sympathetic but yet he wasn't doing anything for me."

(kspt2)

Whilst some respondents were able to simply 'stop going' in order to avoid repetitious consultations, some respondents, those requiring sick lines, could not. In these cases the necessity appeared to contribute to the burden as the following quotation illustrates:

" Well I just explain the same thing every time I go back. He asks me how I'm feeling and I say just the same. I don't think there's much Dr Brown can do. I just get the ... I go up for my line and that every 6 months. I wish I could stop"

(jspt3)

I: "I feel guilty if I have to go and ask for a sick line. This week I asked for a sick line, I self certificate myself for a week and then I went to the doctor."

R: "Why do you feel guilty?"

I: "Same again, because I'm young and you walk in, it's like what can I do for you. Oh, I've got a back problem. Oh I see. That's basically it. Do you want some painkillers? Well I'm not here looking for painkillers. So basically you're only looking for an answer. See then again a doctor can only do so much for you."

(lmpt15)

Views and experiences of medication for chronic pain

Overall, views and experience of medication for chronic pain formed a relatively minor part of the interviews with patients.

The vast majority of respondents could be described as having stopped taking medication for their pain altogether or as using medication very reluctantly. Most respondents appeared to implicitly hold the view that medication is to be avoided,

“that drugs are bad for you”.

This position seemed fundamental and unquestionable to many respondents such that having explained their reluctance to take medication for the pain, they were unable to understand a follow up question about why this was the case, that is they assumed that this was self-evident.

Respondents who appeared to be matter of fact or instrumental in their use of painkillers were very much in the minority and the majority of respondents who did take painkillers described trying to keep this use to a minimum. Thus respondents explained that they would try to do without medication until they had to and in general were trying to cut down. The respondents who described themselves as not wanting to have to do with out their painkillers were also reluctant tablet takers and often trying to minimise their use.

The following quotation illustrates several of these widely held views, although this respondent is unusual in her matter of fact response that taking tablets is “no problem”

R: “Well I’ve always believed that drugs are bad for you and the minimum is the best. Watching other people following doctor’s orders explicitly, I’ve learned that often enough you don’t have to take the full dose to get maximum benefit. you can get by with the minimum. I must admit there’s rarely a night when I’m not glad to take my co-didramol.”

I: “How do you feel about taking them?”

R: “I just take them now, no problem.”

(Impt9nr)

Almost all the respondents explained that painkillers do not kill the pain, that ‘they

just take the edge off it” or “take the sharpness off it” and “they fudd up” or “numb” the brain. As one respondent explained:

“There’s no such thing as a painkiller. It’s only a pain easer and it only eases it for a short time.”

(kspt3-c4)

The following respondent explained that she was hoping to be off all tablets in a month’s time

“I don’t want to be on tablets. If I go down and get painkillers they don’t take the pain away but they make you feel like just sitting about doing nothing. Maybe dozing but they don’t actually take the pain away so it’s no use taking them really.”

(lmpt6)

However it did seem that many respondents had reached this realisation only after some time and having been on many different medications, a “lot of trial and error with your tablets”, or as another respondent put it:

“I’ve had that many different kinds you wonder what one’s are helping you and what one’s aren’t.”

(jspt26)

Many respondents had been on ‘high level’ or ‘top line’ drugs such as dihydrocodeine /DF118s. As such a considerable number of respondents had had serious problems associated with medication use, including stomach problems requiring emergency hospitalisation and problems of withdrawal. Several of the respondents described severe reactions to amatryptolene.

Since pain killers did not ‘kill the pain’, respondents had to balance their ability to ‘take the edge off the pain’ with the other effects such as ‘feeling zonked’, ‘dopiness’ or feeling tired.

“I was getting more tired but the pain was better. I couldn’t handle the dopiness, the being tired. My pain became more comfortable. You could read it, it was dead obvious. Nothing else changed. My well being didn’t change. Because I was tired I didn’t feel that well. Everything stayed static except ... it was the top line which was the pain control and the other line being how did I feel, tired or whatever. So this was getting greater and this was diminishing. So it’s up to me now. I can try and control the pain a bit better but I will be tired. Sadly that’s not an option for me. But sometimes ... it also makes me sleepy so we’ve got this bit to discuss again. Sometimes my legs are throbbing so badly that I can’t sleep and I won’t take sleeping tablets.”

(lmpt4-c2)

As indicated in an earlier section of the analysis, some respondents were reluctant or had stopped taking medication because it made them feel not quite themselves:

“Its knowing that you’re taking drugs all the time but I don’t feel quite myself. So there’s side effects that are not major but without actually relieving the pain. If I had some of the side effects but was actually relieved of the pain then I may think it was worth while.”

(jspt31)

Unsurprisingly in this context, most respondents explained that they took their medication in their own way. Most often this was in terms of minimising use, only taking medication when they had to as this respondent explains: “The doctor tells me to take them every so often and I don’t. If I’m in severe pain I’ll take them but only then”.

Some respondents described approaches to minimising their use of medication which involved going to considerable lengths to put off taking medication for as long as possible even when the pain got really bad, as this respondent described:

“I wait for the pain to get really bad and then I think I’m not going to last. If I feel the pain getting really bad ... sometimes I’ve got a couple of big pillows and if you lie on your stomach ... Whether it’s psychological and I think if I can lie on my stomach for three quarters of an hour, it does help, it takes the edge off it. You haven’t

immediately gone for the tablets. Sometimes I just go and lie down for a wee while. Probably 9 times out of 10 I have to get up and take the tablets but it has helped for an hour or so.”

(kspt2-c1)

Within a general imperative of minimising use of medications, some respondents explained that they would take extra pain relief on occasions in order to do certain activities, including being interviewed, or for relief from having had to ‘do too much’.

Respondents explained the reasoning behind wanting to keep medication use to a minimum in a number of ways. One frequent explanation appeared to be based on an implicit model of habituation, that is that over time the effect of the medication diminishes or the converse of this, as in the quotation below, that they have a greater effect then when you do take them:

“I’m not a tablet taker. I’m supposed to take them 4 time a day but I don’t. I’d rather not take them as take them. I like to do without them as much as I can. I’ve got a feeling the less you take, when you do take them they help you that bit more.

(jspt26)

The idea that the effectiveness of medication reduced with prolonged use formed the basis for some respondents’ concerns about reaching the ‘end of the line’ or being on morphine (that is, being on morphine based medication long term - a substantial number had experience of being on morphine for acute episodes of pain).

“I think short term the benefits would be well outweighed by the problems that you would have long term. I think you would become very much dependent on it as you would diazepam if they gave you it. Drugs aren’t the answer either. Plus the fact that you go... I tend to be on this sliding scale and my fear is... again back to the pain management clinic. An older chap who was there, he’s had the problem for about 35 years and he’s now taking morphine. He’s constantly going up the ladder from taking paracetamol and going

through the levels until he gets to this morphine tablets.. going through the whole range and once he's at that point, he can't go anywhere else. He's played his last card, or his doctor has anyway."

adding

"I wouldn't like to be taking morphine, that frightens the shit out of me."

(jspt11)

The above quotation illustrates another frequently mentioned concern, particularly amongst younger respondents, that of the long term effects of medication or as another respondent put it: "if the pain doesn't kill me the pills will".

Another important reason for wanting to minimise or not take medication was that this would block pain as a natural message from the body, that it was necessary to listen to one's body in order to prevent further damage as the following quotation exemplifies:

"I'm not a great one for taking pills because pain killers, depending on their strength, you're losing control. Physically pain is the body's way of telling you that something's wrong or that you're doing something wrong. You're maybe sitting in the wrong way or lying the wrong way. If you're taking the painkillers, you're suppressing the pain so that the message isn't really getting through properly. So if something is wrong you keep on doing it and there's always the chance that it's going to be worse in the long run."

(js11-c4)

The problems of negotiating help: "There's not much general practitioners can do"

Many respondents described that there was not much general practitioners could do except prescribe medication or refer on to specialists. A common criticism of

general practitioners was that “pills is the favourite thing” or:

“If they could give you other ways of dealing with it or other ways of relieving the pain instead of shoving tablets into you all the time.”
(kspt2-c3)

Many respondents described having had to find this out, or having arrived at this conclusion only after some time. This was not to imply that respondents expressing this view did not find their general practitioner helpful, although some of them did not. After all, as described below, many respondents continued to seek help from their general practitioner.

The apparent discrepancy between knowing that there was nothing that general practitioners could do but, in some cases, continuing to seek help parallels a similar discrepancy in general practitioners’ own accounts of their work. That is, that the underlying issue appeared to be that of understandings of ‘what counts as doing something’, with some things being more clearly identifiable than others. A further issue in relation to respondents’ accounts was that respondents rarely articulated directly and specifically what they were going for other than ‘help’, or they themselves reflected that they were unsure about why they were going. In the following quotation the respondent, speculates about why he goes:

“I hate going there because ... maybe I am looking for an answer but they’ve not got an answer for you. They can only do so much or refer you. Basically they’re there to refer you to somebody else.”
(lmpt15)

From respondents’ accounts, the process of negotiating help with general practitioners appeared to be complex for three principal reasons. Firstly, it involved negotiating outwith what general practitioners ‘just do’. As such, respondents had

to 'push' or initiate. The following quotations illustrate that respondents had to push for a range of different things including information and access to particular services, including referral.

"I find that doctors are good at doing things if you tell them and direct them. Do this for me, do that and they're quite happy but they're not very forth coming about giving you information."
(jspt27)

"To be honest I get the feeling that they're not that interested, not really. I don't consider that ... I had to ask for help, no one's ever said to me would you like to go to the pain clinic. I had to say this isn't going away what can you do about it. I had to prompt the doctors to do something. I really don't feel it should have to be that way and yet having said that how does someone know your level of pain. You expect more from the GP than was given. Although once I indicated it he said fine, that was OK. There's a bit of me saying they should be aware of that."
(jspt25)

"I'd have to push it to get referred somewhere but I couldn't exactly say where to go."
(jspt17)

Secondly, respondents appeared to have to negotiate general practitioners' assumptions about their reasons for seeking help. The following quotation comprises a frequently mentioned assumption, that of patients looking for a miracle or a cure for their pain. The respondent is describing her feelings about having to change general practitioners:

R: "Well it's hard to start all over again (with a new GP) because you don't know what to say. Especially when you go through it all and then they turn round and tell you they canny work a miracle. They've done that... would be wonderful but we can't, cannae work a miracle, and it's all written down in front of him, they've got all your records in front of them."

I: "How did you respond to that?"

R: "I says I'm not looking for a miracle. Just some help."

(jspt5)

Thirdly, both these issues can be seen to be compounded by respondents' own uncertainty about the type of help: having to push but not being able to say where to go, looking for "just some help".

Fourthly, where respondents did describe more specifically the things that they would find helpful, as they frequently did throughout the interviews, it appeared difficult for them to specify how this help could be given, particularly when this help was often assumed to be not what general practitioners do.

The problem of negotiating non-standard help, or help that was difficult to articulate, in the context of doubt and threatened identity, brought its own problems. The following quotation illustrates a number of these. The respondent is describing the difficulty of getting help from her general practitioner and has been telling the interviewer about some of the everyday things that she finds difficult, because of "how ordinary" these things are. Although she has, as she explained, been adjusting, there are "bad days". She also has concerns about how bad things could get in future. The suggestion of "help how to manage" can be seen to contradict her own sense of normally being able to adjust.

"It's how ordinary it is and how I'm learning to adjust my lifestyle to the pain which I normally do now. But there are days when I think this can't go on. I clearly remember saying to my doctor when I asked for the last referral, I'm only 50, what am I going to be like when I'm 60. He sort of looked at me. It's this sort of thing that on bad days you think I shouldn't have to put up with this. I said that and then the statement was, oh well perhaps we can get help for you how to manage. Somehow I felt it was because I had made the statement what will I be like when I'm 60. There was this woman who was paranoid and they were saying right I'll show you how to manage the pain and go away dear, you'll be fine. That's what I felt. I like my doctor, I'm sure he doesn't think like that way at all but sometimes that's the feeling I got."

(jspt12)

She went on to explain her negative reaction to his suggestion, drawing a conclusion that this research has drawn, that the context of such suggestions is important.

“The fact that the doctor said I don’t think there’s any more that can be done for you and here was I saying I want something done. So then because he offered me the counselling. It was somehow devaluing how I was feeling. So it was the context in which he was bringing in the counselling. It was the context that didn’t fit correctly.”

(jspt12)

Many of the respondents’ descriptions of their relationship with their general practitioner and what was helpful or unhelpful revealed implicit and subtle distinctions. Presumably these could easily be missed by general practitioners under their imperative to do something.

In the following quotation for example, the respondent explains that he has no problems coming to grips with the pain (per se) but needs help with particular consequences of the pain, that is, to not overdo things:

R: “The doctor knows all the things I’ve been through with my work and that. I know myself and I think he knows that if it’s just pain then that’s fine, I suppose you can come to terms with that. I’ve not got any problems with pain or coming to grips with it. It’s the professional help you need in not overdoing things to keep you mobile.”

I: “So learning what’s right for you?”

R: “Yes. Coming to grips with it.”

(lmpt11)

Many other respondents implicitly anticipated how their requests for help might be interpreted in order to try to be more specific. Thus in the following quotation the

respondent can be seen to anticipate the assumptions that she wanted help to make the pain go away, explaining that acknowledgement or a degree of relief from the pain would be helpful

“If they couldn’t give me something that would take the pain away then really all I want is someone to acknowledge it or make it better. I’m a difficult character.”

(jspt25)

In this respect, many respondents’ accounts contained examples of having to try to negotiate help other than medications. Often, as is the case in the following extract, respondents described trying to get advice and information about how to manage on a day to day basis or how to keep active:

I: “Do you think there are any short cuts in coming to accept the pain?”

R: “No not really.”

I: “There’s nothing that would have helped you to get through to that stage?”

R: “Probably if on the medical side of it. When I was with my last doctor it was a case of every time I went to him it was, oh there’s another different pill on the market, we’ll try that one. I suppose if they had sat down and said well we’ll try this or have you thought about doing that. It was just a case of, you’ve got the pain, we’ll give you tablets. It wasn’t a case of trying to talk it through with me and say well maybe you shouldn’t do that. Only on one occasion I said to .. not the GP I’ve got now, the other GP, I said I went to step classes and it was the first time he said to me, you shouldn’t have done that, that was stupid. I said well you didn’t tell me I shouldn’t do these sort of things. It’s common sense he said. I said well not really, I felt I needed to get some form of exercise and thought I’d try a step class. He said that was stupid. I felt like saying to him do you not think you should have told me that at he very beginning. So when I was going it was a case of, we’ve had a new rep in with new drugs, we’ll try these, maybe they’ll help. I think maybe if the medical side of it had been a wee bit advise you not to do that, be careful if you’re going to take light exercise or whatever you feel comfortable with.”

I: “So there was nothing of that?”

R: “No it was a case of trial and error. I did it and suffered. Then I said to them I did that and he said well that was stupid. So they suffer by me moaning at them.”

(jspt12)

The emotional consequences of pain

A major area of difficulty which respondents described was that of getting help or acknowledgement of the emotional consequences of pain, as the following respondent described in answer to a question about what in an ideal world would be helpful:

“Well even just talking to him (his general practitioner), just talking to him, just explaining to him actually what’s happening, the pain I’m going through. Try and let him understand what’s actually going through my head, the moods I take, all these different things ... ken moodies and I get angry, frustration really. As I say he’s not got the time and I’ve not got the time just to sit down ... it could take forever just to explain how the pain actually works and how it’s really like some days and as I say the moods I take, the changes ..”

(kspt1-c3)

There was one exceptional case, cited earlier as an example of how general practitioners could ‘sneak’ the fact that the pain may not go away in to consultations right from the start. In the following extract, the respondent describes the importance of discussing the emotional impact of pain:

I: “What do you think are the important things which doctors should know about someone who is in pain?”

R: “I think the psychological effect it has on them as well is a big thing because the pain’s there and they know they can’t get rid of it but then it can bring them down such a lot and cause a lot of problems. I know I get short tempered if my back’s really bad. I think explaining the psychological effects and discussing any problems that people have with it rather than just dismiss it as one of those things, you’ve got a bad back.”

She adds that

“I think I would have just got to the stage where I was so frustrated I’d be climbing the walls. I think maybe to point it out and say well you’re having these effects because of .. then it’s better than letting

them sit there thinking oh God, what am I going to do because I'm feeling this way. To have it pointed out you think, well it is a natural thing."

She concluded:

"I've been lucky because my GP is able to sit and recognises that there are other problems apart from the pain."

(jspt8)

From an analytical perspective the important issues in this extract can be seen to be the way that the emotional consequences of pain are implicitly normalised, "by having them pointed out to you" and the overall approach is implicitly proactive.

It is important to contextualise this extract in the context of general practitioners' descriptions of their work which emphasised considerable 'psychological work' such as detecting depression and looking for 'hidden agendas'. The analytical interpretation offered here is that such approaches are reactive and imply psychopathology, even when emotional distress is seen as a consequence of the pain rather than the cause, rather than the normal psychology of people experiencing pain, not just as an unpleasant sensation but part of life.

Patients' experiences of the process of secondary care

As indicated above, all but a few of the respondents had extensive experience of secondary or hospital services in a range of different departments, often including one or more of the pain clinics. This section of the analysis describes respondents' experiences of the overall process of secondary care.

From pillar to post

Respondents themselves naturally described their experiences of the process or system as a whole. Many respondents based their descriptions of services on the different hospitals and not the different departments within the hospitals. Their descriptions of pain clinics generally, or of a particular pain clinic, consisted of descriptions of pain clinics as part of the system, or of descriptions of critical incidents based on encounters with health professionals, or experiences of particular treatments.

Most respondents had been referred to a range of secondary services such as neurology, gynaecology, or orthopaedics as well as to pain clinics. Most respondents described going through a long process of different referrals, investigations and tests, often over several years. Overall, respondents viewed this process negatively.

Many explained that they had worries that the pain was 'something serious', by which most respondents meant cancer. Some respondents described only realising their concerns once they had had tests which finally reassured them that there was nothing serious, explaining that the worries must have been at the back of their mind. Other respondents explained that being given some tests or investigations made them think that there must be something serious and so made them worried. In the context of continuing pain and anxiety, the length of this process often felt frustrating.

Respondents' accounts included descriptions of the considerable emotional work involved in hoping that the particular test or referral might provide the answer only to find it unhelpful and in some cases changing from a feeling of relief that it was nothing life threatening to the realisation of the seriousness of continuing, possibly worsening, pain. The respondent below describes this "roller coaster ride".

"That touches upon something that I mentioned earlier. From the time that I first went to the GP, by the time that I'd gone through the process of being referred to physio and then to the different specialist departments, a considerable period of time had passed. That was a difficult period because this was the test period when everybody was trying to find out what was wrong with me. It's often very easy to slip in to the worst case scenario where you think have I really got something serious here or am I worrying too much, it's probably nothing. But then again if it was nothing would I have to go and see all these people and get these x-rays and scans poked and prodded .. oh God I must have something seriously wrong. You think have I got bone cancer. You don't know what to think, That is a hard... initially until eventually you get to the right specialist and you get your diagnosis. Initially you think is that all I've got. A bit later you think hang on a minute this is quite bloody serious. Because it wasn't as serious as you thought it might be, going back to the worst case scenario, you feel relief. But then you come back again and say hang on a minute this is serious, spinal arthritis. So it's a little bit of a roller coaster ride."

(Impt10nr)

"Before I was going down there I was thinking there must be something there. They build something up, leave you worried and then go on to the next patient. it's weird. Maybe they have a method of working or something but it's just weird to the patient."

(jspt16)

Many respondents emphasised the lack of progress made throughout the process, as going "back to square one all the time" or as in the following quotation "no further forward".

"It was all trotting along and you weren't getting anymore further forward, all you were finding out was what you didn't have. In the meantime I was just getting more and more uncomfortable and more and more pain."

(jspt18)

Another aspect of the process of drifting, which many respondents alluded to and some mentioned explicitly, was the sense of not being seen as a whole person, that each department would examine a particular part of the body, site of pain or type of pain in isolation. As one respondent summarised “Now in hospital of course it’s all compartmentalised. Everybody only deals with their own little area”. Another respondent explained:

“You were not seen as a whole person, what you’ve got is in compartments. So there was no transference of knowledge within that.”

(jspt25)

Several respondents, for example, experienced migraines as well as chronic on-going pain, particularly neck pain, and described being referred to neurology in order to investigate and manage the migraine first and in apparent isolation from the neck pain.

In this context then respondents had a sense of “drifting” or “floundering” in the system. Some respondents described feeling that they themselves had born the responsibility for finding the way round the system with the sense of “drifting” leaving them no alternative but to “push” or to “insist” as this respondent describes:

“Any of this moving on, whether its been my menopause, migraine or my back problem ... I mean I’m never ill but that’s the three things ... it’s because I’ve insisted on going back.”

(jspt25)

Many of the respondents reflected on the role, or lack of role, of general practitioners in this process. Thus one respondent described going to a general

practitioner who continually asked him “what do you want me to do?” adding that “I’d have to push it to get referred somewhere but I couldn’t exactly say where to go”.

In summary then, most respondents’ descriptions of their experiences conveyed an overriding sense of their being no system or process of care as such, but a series of disjointed encounters which engendered a lack of confidence as the following quotations illustrate:

“Yes, you feel as if you’ve fallen through the cracks. Because the people with the air of authority don’t acknowledge that there may be cracks, it takes longer before you realise you’ve fallen through a crack and then you don’t know where to go anyway because this authority figure hasn’t acknowledged that there’s a crack to fall through.

(jspt17)

“There isn’t a time line of intervention which would give the patient more confidence that something was being dealt with. When you go in, every time you feel you’re starting from square one again. Oh yes, right, let’s have a look.”

(jspt25)

The sense of there being no “time line of intervention” was particularly apparent in the context of the contrasting experiences of the few respondents with diagnosable medical conditions of rheumatoid arthritis, scleroderma and Crohn’s disease. The young woman with scleroderma and the young woman with rheumatoid arthritis both described the process of being referred and investigated prior to getting a diagnosis in terms similar to other respondents. However, having received a diagnosis they interpreted this unhelpful period as being an unavoidable part of getting to the right place. Both women described an instant feeling of relief and

reassurance that they had found someone who was going to help them (the consultant rheumatologist) and could explain things in detail.

“You start off going to your GP because you’ve got something sore and he tries his own little bit, if it doesn’t work he starts doing some tests. Then if they come back either showing something or not, he refers you to the hospital for what he thinks it is. I had to go to three departments before they finally whittled it down to what it was. It took a long time. It was a great relief to actually end up at the (name of centre 1) under the Professor and think, gosh here’s the person who’s going to try and help me. It was great and that was when the depression finally went.”

(jspt18)

The interviews with these respondents could therefore be used to reflect upon what was ‘missing’ from other respondents’ descriptions of secondary care including, as the above and following quotations illustrate: a sense of having got to the right place; a sense of on-going care and support; a sense of there being a recognised “route of care”; a sense of consistency between general practitioners and specialists and on-going communication between them in order to ensure optimal care; a sense of being able get help at any time if needed and being able to frame one’s own experiences within a knowledge about what is normal for people with rheumatoid arthritis.

“Normally people will say oh arthritis, you can’t do nothing about it, you’ve just got to live with it. Take the drugs and that’s but I don’t feel that they’re doing that with me. I don’t feel that at all. I feel they’re wanting to help me.”

(lmpt8)

“They’re looking after me”

(lmpt8)

“Once they get a hold of you that’s it, they make sure you’re ok. They work between themselves and the doctor and if you feel you’re not ... I just tell my doctor I don’t feel right and I have to go back and see him again, it’s right on the phone right away and make an appointment

for me to see them as soon as possible.”

(lmpt8)

“I couldn’t do without them (tablets). If I was stopping them I would be as bad as ever again. They’re the things that’s keeping me going. Of course everybody that’s got arthritis is like that.”

(lmpt8)

R: “The GP’s always backed up what the consultant said. In fact he said that the gold injection was probably what he’d put me on to and he did. They’re going along similar lines”

I: “So how do you feel about that?”

R: “Well obviously that’s the route you’re supposed to go down and that’s what happens.”

(jspt28)

“The GP’s explained there is a certain route they take.”

(jspt28)

Wondering if something could have been done sooner

The lack of a process of care and treatment as such, as well as the length of time respondents spent “drifting” appeared to engender retrospective doubts and uncertainties about whether something could have been done sooner. Most respondents described such doubts relating to either the incident attributed as causing the pain (such as an accident) or to the onset of problems. The time frame of these doubts could be as long or as short as the respondent’s relevant history.

“But I think, if you know early enough that there’s no much can be done, even if they said to you that 90% of sufferers don’t get better then I think you would expect the inevitable. But after having gone through 2 years of tests for them to say “no, sorry there’s nothing else we can do. Because you still say to yourself if they caught it in the beginning, could they have made it better.”

(js11pn)

Thus some of the respondents who had had an accident explained that they had initially not appreciated the extent of injury. Although they had had treatment for obvious or visible injuries, they only realised when the pain had developed some time after the accident that the injury had been more serious than they had thought or that other parts of their body had been injured, as this respondent described:

“Gradually over the years the back and the neck has bothered me. At the time they didn’t x-ray it in the hospital. They only asked me what was wrong with, what I felt was wrong. It was only the visible things that they attended to. Over the years these other things have gradually got worse.”

(kspt3)

Sometimes respondents explained that they themselves had perhaps been slow to seek help or could have ‘pushed’ for more help at an earlier stage. However most respondents’ stories conveyed the sense that the ‘system’ had let them down or been the principal reason for missing an opportunity for early intervention. The sense of omission was often compounded by the sense of it now being ‘too late’ as the following respondent describes:

“I think maybe the first 2 years would have been better because they say that the longer you’ve got a back pain the harder it is to get rid of it. It’s like you’ve had it for so long and ... even the physiotherapist said that, she said if your bones have been in a certain position for so many years it’s harder to get those bones to separate or move in a different road than if it was something that had just happened. Like maybe a year or 6 months. She said it’s a lot easier to deal with it then but it’s definitely harder to get rid of something that you’ve had for a long time.”

(jspt5)

The frustrating combination of having missed the opportunity for early intervention and reaching the stage of there being no more scope to do anything was particularly striking in respondents’ descriptions of being considered and turned down for

surgery. For some respondents the absence of timely intervention was epitomised by having been turned down initially because the problem was not bad enough only to be turned down again because there was now ‘too much damage’ as the following quotation illustrates:

“I think perhaps the only thing is in 1979 or 1980, when I first went about my neck complaint, something should have been done. Although it was pointed out that it wasn’t bad enough to do anything it was going to get worse. So I think if something had been done then it wouldn’t have got worse. Now it’s at a stage where it’s inoperable. That’s 20 years of my life wasted.”

(jspt15)

Never seeing the same person twice

“Well again you should be pointed in the right direction sooner than later. 5 Years is a long time drifting from pillar to post and you’re not meeting the same guy twice.”

(kspt1-c4)

An integral part of respondents’ negative views of this process was that of seeing different doctors all the time, sometimes as an unhelpful but perhaps understandable part of being referred to different departments or hospitals, but often as comprising their experience of the pain clinics. As this respondent explained

“Every time I went down to the (name of centre 1) it was a different doctor, different registrar. I was going down there roughly twice a year so what they’ve been doing with these poor registrars ...eating them up and spitting them out”

(lmpt5)

An important consequence of “never meeting the same guy twice” was the need to have to repeat their story over and over again and to be examined over and over again. As this respondent explained:

“You feel it’s a complete waste of time because you’ve to start and go through your history from day one again, every time you see somebody new they want to go right back to the beginning.”
(jspt5)

“Everybody keeps asking you over and over again, what sort of pain is it. It’s extremely difficult to describe pain.”
(jspt31)

As another respondent explained when asked what would be most helpful:

“Somebody that understands without asking. It’s almost too exhausting when somebody asks you a lot of questions.”

“As I say I’ve seen that many in there, you never see the same person and you have to start your story right from the start.”
(kspt3-c1)

Most respondents’ descriptions of this conveyed a sense of irritation or frustration about this process. Some respondents had finally produced a written history which they could take with them either as a prompt to easier to remember the information or simply to hand over to the doctor.

Earlier sections of the analysis identified respondents’ sense of their own difficulties in accounting for their pain, and thus for themselves as genuine people in need of help. In this context the process of repeating oneself can be seen as undermining or a threat to sense of self as well as simply irritating and frustrating. The following quotation illustrates the sense of being ‘tested’ in the context of having to establish genuine need or, in this case, real as opposed to imaginary pain:

“Each time I went to see him he asked me to describe the pain. Is it like a hot poker, what is it, what are the words. Eventually I said why do you keep asking me. The pain is the same as it was the last time and the time before. I actually found it quite distressing to be having to try and describe it because I thought what if I don’t have the same words to describe it. Is he then going to think I’m imagining it because I’m calling it something different. It’s an ache or it’s a...

using different words.”

(jspt31)

Thus from respondents' perspectives the process of verbal accounting appeared futile in the context of knowing that they could not describe their experience of pain but also because they perceived no impact on their care. Most respondents' descriptions conveyed a sense of this being a pointless ritual, some were more explicit about this as in the following quotation:

“It's non productive and time wasting. At the end of the day it's only the patient that suffers. What does the doctor care. He puts in his hours, gets his wage every month and the poor patient is still in pain, still in agony, still uncertain about what's happening, what's going to happen.”

(Impt5)

Previous sections of the analysis (especially the section on obtaining welfare benefits) have described respondents' views of the inadequacy and unpleasantness of physical examinations. In the context of secondary care, respondents' views and experiences of repeated physical examinations mirrored those of having to go over their history. The following quotation illustrates the experience of frustration and the respondents' awareness of the flaws in the interpretation of these tests being carried out in too short a time, compounded in this case by the respondent's (implied) view of an inexperienced doctor:

“A very young doctor. I'd say she was probably in her mid twenties.. 10 minutes and out, nothing we can do for you. Because the pain isn't visible from the outside, I go in and I look perfectly normal. They poke around my back and because I don't jump off the bed at that precise moment they just seem to think you're ok... because I've still got the movement as well but it's all pain inside. if it doesn't seem to show up nobody seems to care. I'm getting a bit frustrated with the whole thing.”

(jspt27)

The following respondent also explains a similar sense of unnecessary ritual:

“I think that’s just run of the mill to fill their time in. Justify their wages.”

(jspt12)

Managing being a medical success

As indicated at the beginning of the analysis of the interviews with patients, respondents who had had surgery appeared to face an additional complexity in negotiating their care and the legitimacy of on-going pain: that of having had clinically successful treatment which had left them with on-going pain or other problems. This presented some difficulties for most respondents left with pain after surgery, but appeared to be particularly problematic for respondents who had undergone surgery specifically to alleviate the pain as this respondent who had had his leg fused in order to alleviate the pain in his knee explained:

“The only reason I got this operation done to me was I definitely got told that this would take all my pain away. I don’t know what went wrong with the operation or what’s went wrong with my leg but I’m still in the same pain as I was before I got the operation.”

(lmpt6)

Other respondents who had been left with pain after operations, explained that they had been reassured at post-operative follow-up appointments that the pain would go away in time and described the difficulties of then beginning to realise that it was not going to do so and was not simply due to the immediate after effects of the surgery.

Some respondents described the difficulties that they faced in terms of on-going

pain running counter to their own expectations and to professional understanding of what should be the case as the following quotation illustrates:

“Once you’ve had your operation it’s (the pain) not really discussed. I never moaned but I used to say, I just can’t get rid of this pain. Its like once you’ve had your operation you should be well. They can’t seem to understand that sometimes you are left with pain.”

(kspt2-c1)

Other respondents implied greater omission, neglect or disinterest, hinting at the lack of on-going care once a treatment had been carried out:

“I don’t think they’re really bothering now. I felt after the operation, to me they feel as though they’ve done the job and that’s it, they don’t want to see you any more.”

(kspt1-c1)

Some respondents appeared to reflect doctors hopes and expectations back upon themselves, giving them “a feeling that I’m a failure” thus leaving them with an additional emotional burden similar to that described by some respondents in relation to their general practitioners:

“But it came through with him and in a way when it didn’t work, I felt somehow I had let him down. I can strongly remember thinking oh dear he’ll be ..because he’d actually written to my own doctor saying that he thought in my case there was such an obvious need for it that he thought it would work. My doctor was full of hope too and I do remember feeling that I’d let him down because it hadn’t worked.”

(jspt25)

Explanations for the pain

Earlier sections of the analysis described the importance of accounts of pain for respondents’ sense of self and, related to this, their social negotiations. This part considers respondents’ descriptions of their encounters in secondary care settings in terms of how these encounters can furnish them with explanations which make

sense, and thus enable them to account for themselves, or as was more frequently the case, challenge or discard their own accounts without providing an explanation. A crucial tenet of this analytical approach is that explanations are not simply helpful or unhelpful, plausible or implausible to people in and of themselves. Rather their interpretation, and respondents' reactions to these interpretations, can be seen to depend upon how they fit with respondents' understandings of themselves.

Overall respondents' descriptions were of disjunctures between the formal professional or clinical account and their own accounts. There were two principal different types or aspects of respondents' accounts, and thus different types of disjunctures.

Earlier chapters emphasised the fundamental phenomenological starting point of respondents' direct experience and the certainty of the sensation of pain and the feelings and emotions associated with this. One type of disjuncture was between clinical accounts and experiential knowledge. A second type of disjuncture was in terms of the history or origins of the problem, probably arising out of the fact that professionals were actually trying to help develop an account.

- **Clinical accounts and experiential knowledge**

There were two aspects to this sort of disjuncture: what things show, which touches on issues of visibility and invisibility and what people say. The discrepancy between the clinical account and experiential knowledge could operate in very broad terms

as this respondent indicates in his reaction to being told by the doctor that “everything is OK” juxtaposed with the fact that he was in pain:

“How the hell can everything be ok when I’m standing in pain.”
(ktp11)

Many respondents described the disjuncture between the clinical evidence, particularly sources of visible evidence such as x-rays and scans, which provided no physical disruption or abnormality to account for the pain and sometimes showed that the original injury had been remedied, and their continuing sensations of pain. In this context, many respondents found the physiological explanations for this discrepancy reassuring and helpful in terms of their ability to account for the discrepancy.

“He explained that the body can learn the pathways of pain so now when I have this pain it’s perhaps not my back that’s sore although I feel it is. It’s the fact that something’s triggered of the pathways and that’s what I’m feeling.”

“That made me feel better in a way.”

“It’s helped me to explain to people who are still very sceptical. It was all this thing about how come if my discs not out at the moment I can be feeling pain.”

(jspt25)

Other respondents were able to describe their physical sensations using very precise, often mechanical, metaphors, which appeared to reinforce the discrepancy between their experiential knowledge and the clinical evidence as this quotation illustrates:

I: “Do you think you have an explanation to yourself as to why, what might have happened?”

R: “No but I feel I’ve got this wee lump in my back, I can feel it. But every time I’ve says to somebody, even the physiotherapist, I’ve been to them, but it is like a wee ball and that’s really where I feel the pain’s coming from. So if I was standing somewhere and I was pressing my back against a flat surface that’s the bit that I can feel it’s the worst, that’s where it presses. And yet I’ve had CAT scans, the MRI scan and yet nobody’s come with anything.”

(jspt5)

In the following example, the respondent is discussing how helpful the osteopath was.

“She fully explained what was wrong and how it could be put right, how it could happen again.”

“When she showed me what was wrong I realised the telltale sign was the pain in my leg which had been preceded by a pin in the back. So it’s the back injury causes the pain in the leg but the back injury goes away and you’re left with the pain in the leg. So the whole thing made sense.”

(Impt13)

- **Negotiating the origins of the problem**

Secondarily to having a clinical account for current feelings of pain, or an account in terms of the physical body, it has been shown that an important part of accounting to self and to others is in terms of an explanation for the origins of the pain in historical or biographical terms.

To give a concrete example, a common, almost cliched explanation for the underlying cause of pain is “wear and tear”. Reactions to this explanation appeared to depend upon whether this explanation was seen to account for why some people would have more “wear and tear” (with the implication of sustained damage over a considerable time) than others. Thus this explanation appeared to make sense to older people or people who had been involved in strenuous work or activities as this 56-year-old agricultural worker explained:

“I think it’s the years of heavy lifting. Like I explained to you a wee while ago about the big boards I was lifting, that just brought it to a head. I was doing too much. It’s heavy lifting and the doctor said its just wear and tear.”

(jspt3)

In contrast, other respondents were generally dismissive of this explanation:

“Well they started off saying it was wear and tear but I mean how can it be anymore wear and tear than anybody else.”

(jspt24)

“They keep on saying you get wear and tear. If I hear that once more I think I’ll hit the next person that says it. The first time I had this problem I went to Centre 1 and I got a young doctor who just turned round and said, oh it’s wear and tear. I thought God, I’m only 40.

(jspt4)

Most respondents had clear ideas about this, particularly where the onset of problems was sudden and substantial as in the case of accidental injuries or ‘slipped discs’. Respondents who were less confident about their explanations, described the difficulties and tensions they felt in their encounters with health professionals, as this woman explains in the context of describing not being taken seriously:

“One doctor was trying to convince me that I’d actually fell and hurt it. I said I can’t remember even falling or doing anything even to strain it.”

(kspt2-c3)

Other respondents described incidents where, not only had their own possible explanations or concerns been dismissed, but also no other explanations had been offered either. In the following quotation a woman who had developed back problems similar to those of her father describes trying to explore her concerns that she had the same thing and therefore might also end up in a wheelchair:

“I just felt that he dismissed that as if it was rubbish, without even looking into the fact of what my father had. Especially when they didn’t know what it was. They just didn’t know what it was. It was not as if they could put an exact cause on it.”

(jspt12)

It's going to get worse through time and there's nothing I can do about it

As an earlier section of the analysis indicated, a recurrent theme throughout the interviews was that of what would happen in the future and an on-going concern or fear about not being able to cope with what the future might hold. Fears and concerns were about worsening pain and the consequences of worsening pain, increasing disability and dependency.

Although concerns about what will happen in the future have been noted as a feature of the experience of chronic illness in existential terms, from this interview data the link between these concerns and their encounters with health professionals, particularly hospital clinicians was particularly apparent. That is not to say that this aspect of communication generated these concerns, but that this was the clearest identifiable source of them.

Thus many of the respondents described having been told directly that they would get worse, that the underlying physical process was degenerative or as in the following example that arthritis would set in:

R: "What really frightens me is I know it's going to get worse through time and there's nothing I can do about it. Maybe in the next 6 or 9 months or whatever, arthritis will set in."

I: "Is that something you've been told?"

R: "Yes the doctor told me that through time I'll have arthritis"

Adding:

"I see it definitely is going to get worse. In a way I've got to worry about that because I see what it's like now and I'm getting a very moody man now, snapping at people so if it's going to get worse I don't know what's going to happen. I'll get even worse moods."

(ks1-c3)

Other respondents' concerns about the future appeared to be linked to explanations for the pain which can be seen as implying either 'unavoidable' or 'unnatural' deterioration. Thus for young people in employment involving strenuous manual work, having to work but unable to find alternative employment, problems of 'wear and tear' imply unavoidable accelerated deterioration. A substantial number of respondents reported having had explanations for the physical problems underlying the pain in terms of different part of their body having an extent of deterioration compatible with someone much older as this woman described:

“So when I went for the physio they told me I had the back of a woman of 70. I was only in my 40s then.”

(kspt3-c3)

Most respondents interpreted this type of explanation in terms of concerns for the future, in some cases appearing to interpret this in terms of deterioration of that body part continuing at a faster rate than the rest of the body as this young woman speculates:

“Already I've got 40 year old shoulders. Well that's what they told me 2 years ago when I was 18. So what age are they now? That's not even my choice and my shoulders are older than the rest of my body so obviously it's going to tell later on in life. What I hope is that it doesn't tell too badly. I don't want it to get really bad. I don't know what to do if it gets really bad. If it stays like this I can cope with it. It's sore but I can cope but if I ever got crippled with it that would really I wouldn't know what to do.”

(jspt32)

Some respondents described in detail encounters with specialist doctors who had told them that things would get worse. The following summary extract from an interview with a woman with severe curvature of the spine who had been experiencing incidents of extreme pain and immobility (once requiring

hospitalisation). Her story was perhaps the most moving of all such stories, but it does epitomise and bring together the basic elements or key themes underlying accounts of this type of incident. In summary that things would get worse without offering any help or advice in either preventing, slowing or managing this process or making unrealistic suggestions (the most common of these being to stop work altogether or to find another job).

One of the things which made her account of this encounter so moving was because she emerged from the appointment in tears only to bump in to a distant neighbour who had turned down heart surgery (and so could die at any moment). She recalls their initial conversation:

“He asked me what did they tell you in there because you just look shell shocked. I said I’m going to end up in a wheelchair and it never even occurred to me that I’d end up like that. I said it’s scary because he didn’t tell me when or if it would get worse. He told me it would get worse because I lived in a damp country. I told him what he had said about living in a hot country and we both had a laugh about it because it was pouring with rain that day.”

(jspt22)

Later in the interview she summarised her feelings:

“How many people have the options? Right lets just sell up and go away and live somewhere nice and hot because I have a problem with my back. When I asked him what I could do he said I don’t know. Sort of go away, I’m not interested in you because I can’t operate on you. That was how I felt. Go away to somebody else because I’m a neurosurgeon and I don’t know anything else. I’ve told you all I can tell you so off you go. Next please. That’s stuck in my brain for a long time because I felt as if he’d slapped me hard on my face. He didn’t seem to realise I was upset. He did say to me, you look upset. I said I feel upset and that’s when he said but you’re not the worst I’ve seen. That still didn’t help me. I just thought I pulled a short straw that day and got him. I’m sure there’s a lot better doctors I could have seen that would have explained it a bit better. I kept it to myself for a while and then said to my own doctor and he said that I should have complained about the way I was treated. I thought too

bad, it's done now.”

(jspt22)

Feeling dismissed

As described above, respondents' accounts of specialist hospital care emphasised their experiences of being referred from one service to another. These accounts also contained descriptions of the outcomes of their visits. Given that very few respondents were in on-going hospital care, the most frequent outcome was, in professional terms, to discharge the patient.

Respondents' descriptions were striking to the reader in two principal respects. Firstly, that respondents frequently described series of encounters or referrals in which they had been told nothing more could be done, or that they (the doctor) couldn't help, that they would just have to get on with their lives or live with it (the problem). Secondly, whilst some, perhaps most, descriptions of such concluding encounters were reported in a matter of fact or neutral way, where these encounters were described negatively the extent of negative feeling and distress was considerable.

It is perhaps important to note that respondents' descriptions of their reactions to these 'negative' encounters were not descriptions of the encounter, as this extract, in which the respondent describes his devastation to something that was 'put to him gently' cautions:

R: “The orthopaedic surgeon told me that, he said surgery can't cure it because its wear and tear of the bones. There's nothing they

can do about it. Surgery won't cure it so just get on with it."

I: "When you were told that, what did you feel about that?"

R: "I was just devastated to be honest like. I thought they could have done something. Sorted it out at least. Basically no. Just can't do it. I was absolutely shattered."

I: "Do you think there was any way that you could ... if someone's going to say that to you, do you think there is any way they could say it that could be helpful... make it a bit better?"

R: "Probably they could right enough. I just ... when he told me he was OK about it. Basically he sat down and spoke to me about it like. Just said well there's things that can be cured and things that can't be cured. Basically the type of arthritis you've got can't be cured, there 's nothing anyone can do about it. So basically you're going to have it the rest of your days. Days you'll be all right and days you wont. Basically he's been right up to now like. He was ok about it like. He put it to me gently like. He didn't just come out bluntly with it and told me that was it. He sat me down and spoke about it. He's been all right up to now like. He was ok that way like."

(kspt1-c3)

In this context, the remainder of this analysis uses the term 'dismissal' to refer to these incidents. It is intended that this term signal: the primacy of the patient's perspective (that is, how the patient felt, not necessarily what was intended); the importance of considering a meaningful process rather a bureaucratic event and the important status of these encounters as negative critical incidents.

Whilst it is important to include an analysis of respondents' descriptions of such incidents simply in order to reflect their salience in the interviews, these incidents also have analytical significance in that their construction was often based on an implicit comparison with ideas about what could have happened or be done instead. Thus they can be seen to reveal respondents' 'needs' in a way that direct questions often fail to do so.

Some respondents described the overall sense of their sequence of encounters with specialist services as a sequence of dismissals as the following quotations indicates:

“They’ve just been passing the buck from one to the other. Get rid of her.”

(kspt2)

“So everybody’s too easy on palming you off to someone else.”

(jspt32)

Many respondents described specific incidents in distressing detail. These took the form of encounters with a particular individual/professional. The following extract contains several of the key elements of respondents’ descriptions which together construct a very negative experience. Firstly, the lasting impact that the encounter has had. Many respondents explained that they could “never forget”. Secondly, the descriptions of the effort, discomfort and pain of getting to the hospital (either physically or emotionally in terms of having to wait or to negotiate the referral in the first place) Thirdly, the intensity of pain, and the lack of recognition of pain or of the person by the professional. Fourthly, the brevity of the encounter and absence of any examination. Fifthly, the additional discomfort of apparently unnecessary preparation (in this case, getting undressed). Sixthly, the sense of final denial of any further opportunity, care or help and the distressing emotional impact of this.

“I’ll never forget this guy. The most ignorant man I’ve met. I went down and he looked at me. He’s one of his guys with papers under the nose and the hand in the pocket. He just looked at me and said, well there’s nothing we can do for you, we’re just going to discharge. At that time it was agonising. From here to Centre 3 is a long way to sit. I was tight as a fiddle. I thought you rotten ... to be honest with tears in your eyes and you know the doors are closing. The nurse came in and said just go through there and get dressed again. You get undressed to walk out in front of this guy and he’s standing and just discharges you. Why not tell me before I took my clothes off.

That's my attitude. So she came back in and said, he wants to give you an injection. I said forget about it.

(kspt1-c4)

“Even the thought that somebody's going to try and help you. For somebody to turn round and quite bluntly say there's nothing we can do. They'd be as well saying to you go away and run in front of a car. It's devastating if you're suffering from horrendous pain and looking to them for help and you're not getting any. It's horrible.”

(lmpt10)

An underlying issue illustrated by both the above quotations is that from the patient's perspective the encounter is about trying to get some help. As indicated in the above section on having to push for referrals, respondents were rarely specific, or able to be specific, about what this help could be. In short, feeling in need of some help but not knowing what kind(s) of help. In this context then, merely being told that they were not eligible for a very specific clinical intervention appeared to be a neglect of their need which was much broader than this.

The following quotations construct the sense of being dismissed or ‘wiped off’ in relation to an implicit omission of trying to help, leading them to suggest what would have been more helpful. These suggestions were most often in terms of them being more sympathetic and understanding, offering advice about how to cope or get by on a day to day basis, or other suggestions for ways of relieving the pain (even temporarily) or even just a “clue” as the following quotations illustrate:

“Maybe being a bit more caring and a bit more interested in their jobs. Not being ... sort of explaining more to you, what your problem is and how to cope with it instead of just wiping you off.

(jspt32)

“...it's just I'm sorry I can't help you and not saying ... just basically saying that and leaving you to walk out the door. They know you've

got a problem so what they could have said was I'm sorry I can't help you, what you're going to have to do is try getting regular massages or giving you a rough idea or a clue."

(jspt5)

The sense of being 'wiped off' or dismissed, related not just to respondents' concerns about their current position but also in relation to their future health. In the context of having a problem which would get worse or deteriorate, where respondents accepted that they couldn't be made better, there remained room to help with preventing or slowing this process as this respondent explained:

"Well I can't turn the clock back. I'm in a lot of ways resentful for the earlier treatment if you like. The later stages have been mixed but the damage had been done.... I mean it's landed me up in a situation that I can't get out of. I still feel, although I'm supposed to accept the fact that nobody can make me any better, if there is still degeneration going on within your body, there should still be basic help to get you through that. If it was something that was static, that you were in basic pain, there were no other changes apart from age changes then fine but because there is still degeneration I still feel that there is something that can be done to help."

(jspt10)

In relation to the issue of feeling dismissed, there was one exceptional case which could be seen to bring in to focus the omission which most other respondents alluded to. The following quotation is (another) from a woman who was badly injured in a car crash. She required hours of surgery during which the surgeon just managed to save her leg. She is explaining how 'comfortable' she feels not to have been written off.

"Surgeon who operated is very helpful and she's always said to me, if you are ever in any doubt, any fears, go back to your doctor who will refer you back to me and we'll discuss it. So I've always had the support from the surgical staff."

"Certainly I can go back at anytime. I can go down to the doctor and say I'd like to speak to Miss McDonald because I've got this problem

with my knee. She anticipates that I will always have to be going back to be checked in that respect. That makes me feel quite comfortable because she's not writing me off."

(Impt4)

Summary

The analysis presented in this chapter began with an exploration of how the concepts of threatened identity, in the context of difficulties of providing a socially legitimate account of pain and of self as genuine, and of identity work, involving maintaining a consistent sense of self and sense of agency could be used to interpret respondents' accounts of their experiences of health care. All the key aspects of respondents' difficulties in providing a social account of their pain, their experiences and themselves as genuine people described in the previous chapter were seen to apply in health care settings. In this analytical interpretation, health care was seen to constitute a context of doubt.

The analysis highlighted the complexity of managing the balance between maintaining continuity of self and establishing one's genuineness as someone experiencing pain and needing help. It described respondents' awareness of the appearance of their behaviour to other people, including doctors and other health professionals, who might fail to appreciate the effort involved in managing this dilemma and may lead them to question their level of pain.

It also explored the ways in which the fragile balance between self-management and sense of agency appeared to be easily threatened and disrupted in this context

of doubt. The issue of understanding this vulnerability to disruption appeared to underpin health professionals' apparent difficulties in suggesting psychological or pain management approaches.

Although the analysis began from the perspective of health care as a context of doubt, and as presenting threats to identity, it ended with recognition that this analytical framework could form the basis of the converse interpretation: that health services could be seen as having a role or potential role in providing a socially legitimate, if not medically legitimate, account of pain and of self.

These concepts and themes were explored further in sections of the chapter, which examined their application, along with other emergent themes, firstly, in the context of respondents' accounts of general practitioners and general practice care and secondly, in the context of respondents' accounts of secondary care.

The analysis of respondents' accounts of general practitioners and general practice care explored four themes: the importance of being known, the experience of routinised consultations, views and experiences of medication and the problems of negotiating help.

The value of an on-going relationship with a general practitioner was implicit in many respondents' accounts. Its value was constructed in terms of not having to repeat oneself, in terms of knowing that the general practitioner knew that you were genuine and could be trusted and the value of being able to open up about

feelings and problems. The analysis also revealed the importance of an on-going relationship in terms of being able to overcome difficulties in the relationship, particularly in relation to the problems of establishing how much pain. Many respondents described their experiences of general practitioners coming to a realisation about how much pain they were experiencing, their accounts of general practitioners who understood their experiences paralleling accounts of unproblematic intersubjectivity through direct rather than communicated understanding described in the preceding chapter.

The analysis also explored respondents' accounts of routine consultations, a theme which echoed the theme in general practitioners' accounts of repetitive consultations described in chapter seven.

Although views and experience of medication for chronic pain formed a relatively minor part of the interviews with patients, exploration of this theme was driven by the apparent paradox between general practitioner's construction of patients returning for more painkillers as problematic and patients' construction of general practitioners only, and too readily, prescribing medication. The analysis confirmed that the majority of respondents held the view that medication was to be avoided and the construction of prescribing medication as the only thing that general practitioners did or could do.

It was suggested that this apparent paradox illustrated the more general problem of negotiating help from general practitioners in the context of the assumption held by

patients, and by general practitioners themselves (see chapter seven), that there is not much that general practitioners can do. That is, that the underlying issue appeared to be that of understandings of 'what counts as doing something', with some things being more clearly identifiable than others.

In this context, the process of negotiating help with general practitioners appeared to be complex in the following respects. Respondents rarely articulated directly their reasons for going to see a general practitioner other than for 'some help', often reflecting that they were unsure about why they were going. The process involved negotiating outwith what general practitioners normally do and as such involved having to 'push' them or initiate action. Furthermore it often required the negotiation of general practitioners' assumptions about patients' reasons for seeking help.

The analysis of respondents' accounts of their experiences of secondary care highlighted the construction of these accounts in terms of their experiences of the process or system as a whole with descriptions of critical incidents based on encounters with health professionals, or experiences of particular treatments. Overall, their descriptions conveyed the sense of their being no system or process of care as such, but a series of disjointed encounters which engendered a lack of confidence and consisted of unconstructive or 'negative communication'. The main themes constituting the overall sense of negative communication were as follows.

The absence of a structured process of care and treatment, as well as the length of

time spent “drifting” in the system appeared to engender retrospective doubts and uncertainties about whether something could have been done sooner. In direct contrast to accounts of general practitioner care which emphasised the importance of being known, an important negative aspect of the process of secondary care was of seeing different doctors all the time. A consequence of this was of having to undergo repeated verbal or physical assessments of the pain.

Earlier sections of the analysis identified the difficulties in accounting for pain and of self as genuine. In this context the process of repeated assessment could be seen to constitute a threat to identity. Consideration was given to the extent to which encounters in secondary care provided explanations which could be used in providing a socially legitimate account of pain and self, or as was more frequently the case, challenged or discarded respondents’ own accounts without offering any alternative accounts.

The analysis also examined the implications of concerns about the future and fears about not being able to cope with what the future might hold. Many of the respondents described having been told directly that they would get worse or having interpreted the explanations offered as implying an underlying physical process of degeneration. It drew attention to the juxtaposition of the interpretation that things would get worse with the frequent sense of being dismissed or told that there was nothing more that could be done.

Constructions of the sense of being dismissed were used to examine implicit

comparisons between what happened and ideas about what could have happened or what could be done instead. This analysis paralleled the analysis of the difficulties of negotiating help in the context of general practice indicating that from the patient's perspective the encounter is about trying to get some help rather than specific kinds of help. In this context, the narrow clinical construction of there being nothing that can be done based on non eligibility for a specific clinical intervention appeared to be a neglect or dismissal of a need which was much broader than this.

Chapter Eleven: Discussion: theoretical reflections, methodological and health service implications

This concluding chapter of the thesis seeks to place the analyses of the interviews with general practitioners and patients in wider theoretical context and to draw out methodological and health service implications.

The thesis has presented separate analyses of the interviews with general practitioners and with patients. The first section of this chapter summarises the analyses. The argument for carrying out separate analyses, made in terms of Schutz' theory of relevance (Schutz 1970), is revisited in the second section.

The third section of this chapter places the analyses in wider theoretical context. Each of the analyses used different theories in the interpretation of the data. The analysis of interviews with general practitioners used Schutz' theory of motivational relevance directly. The analysis of the interviews with patients examined the issue of intersubjectivity and used theories of self, identity and threatened identity. A consequence of this is that the discussion of theoretical issues below, namely relevance, intersubjectivity and theories of self and identity draw differentially upon the separate analyses. However, in seeking to set these 'grounded' themes and issues in wider theoretical and methodological context, in parts it draws these hitherto distinct analyses of data into a shared theoretical framework.

The remaining sections of this chapter consider methodological issues and implications for health services.

Summaries of the analyses of the interviews with general practitioners and with patients

The interviews with general practitioners were analysed to produce an ideal type or model of their accounts of their work with chronic pain. The model included two phases, with indications of transition between the two phases. The second, later phase was inherently problematic. Many of the problems of the second phase were described as emerging from the first phase. Some aspects of general practitioners' work were constructed as being continuous or on-going throughout. These included the detection and management of psychological distress, the work of conviction, the process of interpreting patients and managing the doubts associated with this process, and managing the imperative of doing something. The analysis described core clinical work as well as the hidden work implicit in accounts of this process, using Schutz' theory of motivational relevance to explore the hidden purposes and conflicting motivations inherent in this hidden work.

The model constructed chronic pain as process rather than a category. It also illustrated the emergence of moral scrutiny throughout the process as general practitioners' accounts changed from accounts of managing pain to managing the person in pain. Two aspects of core work, prescribing and referral, were analysed in detail in order to illustrate the hidden work involved.

The analysis of the interviews with patients described their accounts of the

experience of chronic pain in the context of everyday life, its constancy, its emotional impact as well as its impact on activities. It explored the issue of mundane intersubjectivity, respondents' construction of their sense of other people not being able to understand their experience unless they had pain themselves, as well as some respondents' accounts of people close to them whom they felt had a direct understanding. It was argued that the sense of other people not being able to understand constituted a threat to sense of self and that important aspects of self management were of managing threats to identity, maintaining a sense of consistency of self and a sense of agency. Respondents' descriptions of their experiences of health services were interpreted in terms of management of self, exploring how the threats to identity were constituted by health care and the potential for the removal of these threats and for the process of health care to provide a constructive account of self.

Respondents' descriptions of their experiences of primary care, general practice and general practitioners were considered separately from their accounts of secondary care, although within the shared theoretical framework. Respondents' accounts of general practice emphasised the importance of being known by their general practitioner and hence being seen as genuine and their perceptions of the process of general practice care, their experience of routine repetitive consultations, their problems of negotiating help and related to this, their sense that there was not much that general practitioners could do. Respondents' accounts of their experiences of secondary care emphasised their experiences of the overall process of care and critical incidents or encounters with individual clinicians, their experiences of being

lost in the system, seeing different clinicians and feeling dismissed.

Revisiting the separate analyses of the interviews with general practitioners and with patients

This section of the chapter revisits Schutz' theorising on structures of relevance. Schutz' theory is used in two ways. Firstly, Schutz' theory of relevance is applied to the analysis of general practitioners' accounts of their work with people with chronic pain, in particular to their accounts of interpreting patients with chronic pain. This serves to provide a detailed illustration of Schutz' theorising of the importance of relevance and its relation to his theory of intersubjectivity, serving as an introduction to the broader exploration of intersubjectivity in the subsequent section of the chapter. Secondly, the theory of relevance forms the basis for a broader reconsideration of the methodological step of analysing the two sets of data separately. This reconsideration is based on a comparison of similar or overlapping issues between each analysis, illustrating how these can be seen to be based on different structures of relevance within each analysis.

Schutz' theory of relevance

Chapter six introduced Schutz' phenomenology. This included consideration of the importance of taken for granted practices or routines and of the 'stock of knowledge at hand', which includes formal knowledge, knowledge derived from direct experience and knowledge handed down from others. This taken for granted stock

of knowledge is autobiographical, having been acquired or constructed over time. However, not all practices are routine and not all knowledge is taken for granted or unproblematic. In the context of this thesis, for example, the work general practitioners with people with chronic pain, particularly their work interpreting people with chronic pain was seen to be inherently problematic. Further exploration of Schutz' theorising of issues of relevance considers problematic knowledge or understanding and its relation to, or transformation into, taken for granted unproblematic knowledge and the converse of this, unproblematic knowledge becoming problematic.

Schutz recognises that “within the given field of our consciousness several configurations (perceptual or fancied or otherwise) compete with one another for our interpretive assent. They compete in the manner of problematic possibilities or alternatives” (Schutz 1970). Schutz considers how different aspects of relevance influence the perception of an ambiguous object. By ‘object’ Schutz means object of consciousness, although in the example he uses to illustrate his argument this happens to be a physical object, an object in the dark corner of a room which could perhaps be a coiled rope or a snake.

Schutz considers three aspects of relevance. Firstly, topical or thematic relevance, that is the aspects of an object which constitute its problematic nature in the midst of ‘unproblematic familiarity’ or the ‘taken for granted’. In the context of the data considered here, the patient presenting with continuing pain becomes problematic, or in Schutzian terms the topical relevance of the patient/problem is imposed upon

the general practitioner, when the patient fails to conform to the routine of consulting for a while and but then eventually going away.

Secondly, interpretive relevance, the aspects of the object or its context which are perceived to be relevant to reducing or removing ambiguity. Interpretive relevances could include past experience of other similar objects which are part of the stock of knowledge. They could also include theories, whether these be formal theories or 'lay' theories or 'rules of thumb'. Thus general practitioners could draw upon their past experiences with other similar individual patients, upon typifications of patients and their theories 'at hand' about patients, such as the theory of the derivation of secondary gain from pain.

Finally, Schutz considers motivational relevance, that is the importance of what the perceiver can do or intends to do, for the process of interpretation. The motivation to avoid 'missing something serious', for example, has different implications for the process of interpretation and demands different action from the motivation to 'avoid unnecessary investigations and referrals'.

Schutz notes that though the construction of the elements of relevance described above can sometimes be reflected upon, this is not always the case. This leads him to the distinction between knowledge that can be grasped polythetically, with reflection on the elements of relevance, and that which is monothetic, that is the process of interpretation or knowledge acquisition which is not available upon reflection. To set these two concepts in the context of this thesis, the interviews with

general practitioners can be seen to have encouraged them to reflect upon their (polythetic) interpretation or assessment of patients, revealing a range of interpretive relevances such as the anatomical distribution of the pain, patient's personality, or their history. General practitioners' assertions that sometimes their interpretation of patients depended upon 'gut instinct' or intuition can be seen to correspond to Schutz' identification of monothetic knowledge.

Schutz points out that his analysis is of a system of relevances which are necessarily inter-related, "concretely experienced as inseparable, or at least as an undivided unity" (Schutz 1970) and are not ordered in the 'processual way' that describing them suggests. In Schutz' theory action, interpretation and 'weighing of motives' are all inter-related and contemporaneous. As the analysis of hidden work in general practitioners' accounts illustrated, motives are rarely singular, but can be diverse and may be contradictory. Furthermore perceptions of the potential for action, in this case to do something which counts as doing something, are integrally related to motives and interpretations of the object upon which one seeks to act.

The importance of Schutz' analysis of inter-related systems of relevance can be illustrated in contradistinction to medical decision making or guideline approaches to clinical care which can be seen to assume that appropriate courses of action are derived directly from an objective, formal clinical interpretation and a motivationally neutral assessment of the patient, signs and symptoms (Gordon 1988). That is, they can be seen to neglect the entirety of the stock of knowledge at hand and its meaning in terms of structures of relevance.

Revisiting the argument for separate analyses: the importance of relevance

The argument for separate analyses of the interviews with general practitioners and the interviews with patients, introduced in chapter six, was as follows. Firstly, the nature of the data within each set of interviews appeared to be so different as to demand different analytical approaches. Secondly, from a methodological perspective it was argued that general practitioners and patients could be seen to have different structures of relevance and as such were doing different things, and giving accounts of doing different things, in the interviews.

However, there were issues or themes which emerged from both analyses. For example, both general practitioners and patients described the experience of routine or repetitive consultations in general practice and the difficulties of understanding another person's experience of pain. The argument here is that these 'overlapping' themes or issues were of different relevance in the context of each analysis and that they held different meaning for general practitioners and for patients. This argument is explored briefly below in terms of analyses of 'medication' and 'specialist services' and in terms of the difficulty of negotiating appropriate help.

The differential relevance of the topics of 'referral' and 'prescribing' for general practitioners and patients can be seen to be indicated from the outset by the relative (in)appropriateness of different terms used to describe 'similar' themes in either

case: prescribing and referral in the context of general practitioners' interviews, but use of medications and specialist services in the context of interviews with patients.

The analysis showed that the work of prescribing could be seen to hold a wide range of meanings and fulfil diverse functions in general practitioners' accounts, and as such much of the interviews with general practitioners included discussion of prescribing and medication. Thus, for example, for general practitioners' prescribing was a means of reflecting upon the appropriateness of their own clinical practice, an indicator of the level of pain that a patient was experiencing, or a means of keeping the patient going by trying to do something differently. General practitioners' implicit understanding of appropriate prescribing formed part of their construction of the problem identified by most general practitioners, that of patients asking for more painkillers.

However when general practitioners were asked in the follow-up interviews about their views of patients' views of medication, most of the perspectives and issues which emerged from interviews with patients (summarised below) were mentioned by one or more of the general practitioners. Although general practitioners appeared to have access to a range of different patient perspectives, these perspectives were not integral to their account of their work. Indeed the analysis of general practitioners' accounts of their work overall noted that references to the patients' perspective only emerged in the transition phase and in phase 2.

In contrast, patients' discussion of medication was much less and medication was an

issue that was rarely raised spontaneously. The analysis above (chapter ten) elaborated a range of themes and meanings from patients' discussion of medication. Examples of these included the predominance of the view that medication was to be avoided, the conflict between being themselves, maintaining a sense of consistency and agency and taking medication as well as their concerns that medication might be blocking signals from their body. Although these themes were explored, the analysis of patients' views of medication was driven by the emerging discrepancy between general practitioners' descriptions of the problem of patients demanding increasing medication and patients' perspectives that medication was to be avoided rather than from within the analysis of the patient interviews.

The apparent problem of the discrepancy between patients' and general practitioners' views could have emerged as a consequence of the difference between asking general practitioners about patients in general rather than asking about individual patients. However, the interpretation offered here is that it can be attributed to different motivational relevances. From patients' perspectives something, not necessarily medication, to relieve the pain versus general practitioners' perspectives of need to do something, from a limited range of things that count as doing something, including prescribing.

Similarly the analysis revealed similar areas of overlap in the analysis of general practitioners' and patients' views of secondary services. In contrast to issues of prescribing or medication, general practitioners' descriptions of this area of their work often spontaneously included references to patients' experiences of the process

of being referred. General practitioners often used the same metaphors such as a 'roller coaster ride' or being 'passed from pillar to post' and expressed similar issues such as never seeing the same person twice and being sent away and told that there was nothing that could be done.

The analysis of general practitioners' accounts of their reasons for referring patients revealed a range of motivations. Some of these motivations took explicit account of their understanding of patients' perspective or patients' motivations, such as referring in order to demonstrate that they were taking the patient seriously or because the patient asked them to do so. Others, such as getting the patient off their back for a while, were constructed in terms of general practitioners' own motivations.

Finally, the analysis of the interviews with general practitioners described the pragmatic motive of the 'need to do something' and the corresponding construction of a limited range of clinical actions or core work as constituting 'doing something'. The analysis of the interviews with patients could be seen to have identified a shared view of the limited work of general practitioners, that there was not much general practitioners could do, and as described above, that all general practitioners do is prescribe painkillers. It was argued that in this context, patients' motivations to seek help as opposed to seeking specific kinds of help, are likely to be interpreted by general practitioners in the context of their own motivation to do one of the things that count as doing something.

Conclusions: reflections of the theory of relevance

This section of the chapter has explored Schutz' theory of relevance. The detailed application of Schutz' theorising to the analysis of general practitioners' work interpreting patients illustrated the inter-relatedness of different aspects of relevance. As such it can be seen to provide a theoretical basis for understanding clinical work as practical knowledge involving the weighing of a range of motives, some of which may be seen to be conflicting, within the context of the possibilities for action. More specifically in the context of general practitioners' work with people with chronic pain, it was used to elucidate the problems of the ambiguity of interpreting pain or patients with pain. Further consideration is given to this process in the section on intersubjectivity below.

A comparison or meta-analysis of themes and issues in the hitherto separate analyses has illustrated the general point that general practitioners and patients may be acting within different systems of, particularly motivational, relevance. As such understanding the relationship between general practitioners' and patients' accounts is not a process of understanding two sides of the same story.

The practical potential of this theoretical approach for understanding interactions between clinicians and general practitioners is considered in more detail in the concluding section of the chapter on implications below. The issue is of further theoretical relevance in relation to the issue of intersubjectivity surveyed in the following section.

Intersubjectivity

As chapter five described, much of the sociological and anthropological work on chronic pain has emphasised the issue of intersubjectivity: the inaccessibility of the experience of chronic pain to others, the absence of social and cultural construction of this experience and the corresponding threats that this places upon identity. This section of the chapter considers the issue of intersubjectivity. It begins with a survey of theoretical and philosophical perspectives on intersubjectivity to set the context for considering the analysis of mundane intersubjectivity based on the interviews with patients. The analytical theme of intersubjectivity can also be seen to have emerged from the interviews with general practitioners, in terms of the problems of interpreting patients, in particular, the problem of knowing how much pain someone was in. This analysis is also revisited.

Theoretical perspectives on intersubjectivity

This survey of theoretical approaches to the issue of intersubjectivity revisits the Wittgenstein's linguistic analysis of pain (Hilbert 1984), before considering the phenomenological approaches of Merleau-Ponty (Crossley 1996) and Schutz (1972).

Wittgenstein used the example of pain in his argument that there could not be a private language. He argued that to say that one cannot know whether someone is in pain implies an inappropriate use of the term 'know', that there is a difference

between knowing another persons pain, which is possible, and having that pain which is not. In broad terms, to suggest pain is private is to suggest that language is not meaningful or useful.

His analysis also proposes that the statement 'I am in pain' be seen as a direct expression of pain, an exclamation not a description, and as such our relation to our own pain and to the pain of others is not one of reflection upon the knowledge of pain but one of a direct response to it. It is important to note that Wittgenstein's argument is against the fundamental privacy of pain and not against the understanding that pain can be private and that the privacy of pain may be socially and culturally constructed.

Merleau-Ponty's theorisation of intersubjectivity argued against the privacy of mental states by a phenomenological transcendence of mind-body dualism. He conceptualised intersubjectivity as fundamentally embodied and in this context mental states are inseparable from embodied performances which are equally visible from the outside as from within (Crossley 1996). Fundamental to Merleau-Ponty's theory of embodiment are affect and emotion which, transcending mind-body dualism, are corporeal outer and inner states. Intersubjectivity and relationships are mooded or emotional.

Schutz' theory of intersubjectivity shares a phenomenological basis with that of Merleau-Ponty (Schutz 1972). Fundamental to Schutz' analysis of intersubjectivity are the assumption of stand-point interchangeability, that is the assumption that our

experience would be the same as other people's in the same circumstances, and the assumption of congruence of structures of relevance. However, Schutz' approach is different in important respects.

In contrast to the theories of intersubjectivity described above, Schutz explicitly recognises that intersubjectivity can be problematic, mutual understanding is not guaranteed, but is continually being negotiated, sustained, lost and recovered. Schutz also recognises that intersubjectivity is differentiated and temporal. Schutz differentiates intersubjectivity in relation to consociates, contemporaries, predecessors and successors. Consociates are people in direct face to face interaction and intersubjectivity in this context is embodied in shared space and time. Contemporaries, as the term suggests, share social time, but are not encountered directly in face to face interactions. Successors and predecessors do not share the same social time.

Revisiting the analysis of mundane intersubjectivity

A central and recurring theme in the interviews with patients was that of their feelings that people who were not in pain themselves could not understand their experiences. In explaining the inaccessibility of their experience to others respondents described their difficulties describing the experience of pain, its emotional impact as well as its impact on daily life, the problematic consequences of trying to explain, their retrospective awareness of not having understood or realised what other people had been going through, their awareness of the invisibility of

pain and of the absence of any socio-structural acknowledgement or legitimisation of their experiences. In short their accounts emphasised that intersubjectivity was problematic.

However the analysis also demonstrated that though intersubjectivity was mostly problematic it was not fundamentally impossible and some respondents described some close people who had learned to read them, to interpret their moods and emotional reactions and to understand without explanation.

The theoretical interpretation offered here is that analyses of Wittgenstein and Merleau-Ponty fit the empirical analyses of 'best' or 'ideal' intersubjectivity achieved with some people in an embodied context. However Schutz' theory of differentiated intersubjectivity offers a means of integrating the analysis of the problematic nature of intersubjectivity and from this how 'ideal' intersubjectivity is achieved.

Schutz' emphasis on temporality and mutual tuning in offers the interpretation that intersubjectivity is acquired over time through various instances of 'recovered' understanding which take place in embodied context. It is important to note that respondents' perceptions of being read or understood, of course, do not imply that they are understood, but perhaps that they are not aware of being misunderstood or are understood 'for all practical purposes'. Such practical purposes could also be mutually negotiated over time.

The analysis also draws attention to the potential for further explicit differentiation

of intersubjective relations within Schutz category of consociates as people in face to face embodied interaction with shared spatio-temporal context. Such a differentiation may offer a theoretical perspective on the issue of intimacy which would counter the current theoretical emphasis on shared understanding through verbal disclosure (Jamieson 1999).

This analysis of intersubjectivity can also be seen to have implications in the context of health services. Respondents emphasised the importance of being known by their general practitioners and this can be interpreted as recognition of the importance of the development of intersubjectivity or intimacy over time, where there is sharing not just of context but of partial biography. The importance of an on-going relationship can also be seen as being implicit in the context of respondents' criticisms of the process of secondary care which frequently emphasised never seeing the same person twice as problematic.

In summary, the analysis of mundane intersubjectivity based on the interviews with patients demonstrated that intersubjectivity was problematic. However, this analysis, in contrast to much existing research, has identified that it was not always necessarily or fundamentally so, examining empirical and theoretical interpretations of how intersubjectivity is achieved. In this context, claims in previous research that the problem of intersubjectivity in relation to pain can be seen to constitute radical doubt or anomie need to be reconsidered (Kotarba 1983; Hilbert 1984; Scarry 1985).

Related to this, it is important to add a further theoretical note of omission in terms of the differentiation of intersubjectivity. The current analysis, like the analyses in the previous research reviewed has considered intersubjectivity in the context of chronic pain. That is they can be seen to have been based upon the implicit assumption that pain is the totality of life and of self and have not examined 'problematic intersubjectivity' in relation to the experience of pain in the context of other aspects of life (or self) which may not be problematic. Further research and analysis of mundane intersubjectivity would perhaps throw light upon these issues.

Intersubjectivity and interpreting patients

The analysis of the interviews with patients described above considered the problems of intersubjectivity from the perspective of people experiencing chronic pain. This section considers intersubjectivity in the context of the analysis of general practitioners' accounts of the problems of interpreting patients. There was an underlying assumption in both general practitioners' and patients' accounts that one could know when someone is in pain, and know 'what someone in pain looks like'. However this left room for doubt about how much pain.

The analysis of general practitioners' accounts of their work of interpreting patients and managing the doubts of this fundamentally problematic endeavour was used in the above section to illustrate the importance of structures of relevance. However it is perhaps worth giving a descriptive overview of the analysis here as a basis for further exploration of the issue of intersubjectivity in relation to general

practitioners' difficulties which explores the interdependence of intersubjectivity, interpretational and motivational relevance.

The analysis revealed the process of interpretation as drawing upon a diversity of resources, knowledge or theories at hand including formal physical assessments and informal observations, the process of tying everything together about the patient, their use of psychological interpretations of the patient, their use of comparisons with other patients and their interpretation of patients in the wider social context, specifically in the context of drug abuse and of financial or welfare claims associated with chronic pain. The analysis identified that through these interpretive processes the search for objectivity was also a process of moral scrutiny.

The starting point for theoretical reflection on this analysis is reconsideration of the problem of knowing how much pain someone was in. There was an underlying assumption in general practitioners' accounts, only considered by the author after the completion of fieldwork, that it is important or necessary to know how much pain someone is in. To put this the other way round, this assumption was so taken for granted that the research question "why do you need to know how much pain someone is in?" was never asked. In terms of Schutz' theory, the motivational relevance of this issue had not been considered or problematised. The analysis presented identifies two possible motivational relevances. The first, that this is an issue of 'risking missing something serious'. The second, that this is an issue of the need not to sanction drug abuse or illegitimate financial claims.

A further interpretation offered here is that the issue of how much pain someone is in is related to the importance of concerns about scarce health service resources, either in terms of referring on to specialist services or in terms of the economy of time in general practice. This motivational structure creates the need to objectify the amount of pain. That is, from clinicians' perspective, not only are they just as aware as other people that there are still areas of doubt about pain but their requirement to 'ration' leaves them the requirement to objectify, and fail to do so. An important aspect of this analysis is that it highlights the interdependence of social and organisational structure, moral scrutiny and intersubjectivity and that as such the economy of the health service is a moral economy.

Theories of self and identity

The main analytical theme used in the interpretation of the interviews with patients was that of the self and identity. In particular, it described respondents' accounts of doubting themselves in the context of social understandings of pain, chronic pain and people experiencing chronic pain. It also considered their efforts to maintain some consistency of self and sense of agency in the context of threats to identity in everyday life and in the context of health services. This part of the chapter places the emergent analysis in the context of theories of the self and identity in the sociology of chronic illness. In order to do so it is perhaps worth briefly revisiting the review of these theories given in chapter four.

The review argued that much of the sociology of chronic illness has used the term 'self' unproblematically. Firstly, there remains a strong emphasis on the impact of

illness on an (undifferentiated) self being lost or destroyed by illness. Secondly, most empirical research was seen to be based implicitly on Meadian or symbolic interactionist theories of self, that is, self as an interactive micro-social process, leaving the work open to the criticisms of being apolitical or astructural. Thirdly, the majority of the studies paid little attention to differences between personal and social identity. Fourthly, the studies did not distinguish between the ethnographic or phenomenological exercise and the analytical exercise and give little attention to respondents' own theories of self.

Related to this point, the review suggested that wider theoretical understandings of self and identity from postmodernist psychology and sociology which emphasise the social discursive construction of self and identity might offer the opportunity to counter these criticisms (Wetherell and Stevens 1996). In particular two analyses were considered which approach the issue of theories of self. Firstly, Harre's discourse or grammatical analysis which distinguished self-1, the theory of self, and self-2 the type of self implied in symbolic interactionist analyses (Harre 1983, 1991). Secondly, the analysis of Apter (1983) which distinguished the sense of identity comprising personal distinctiveness, a sense of personal continuity and a sense of personal autonomy from self as self-concepts. In Apter's terms, categories of sense of identity are different in kind from those of concepts of self.

The analysis of the interviews with respondents used theories of self and identity to interpret the data, seeing the interviewing process as a process in which respondents were 'doing' identity work as well as giving accounts of experiences

which reflected aspects of identity work outwith this context and, it is argued here, revealed respondents' own implicit theories of self.

The analysis described the construction of their accounts of feelings about not being able to communicate their experiences or gain recognition for their experiences of pain and this has been considered above in the context of theories of intersubjectivity. It was suggested in the analysis that this constituted a vulnerability of self or a threat to identity, particularly in the context of wide socio-moral understandings of pain and people who say they are in pain. From this, consideration was given to processes of self-management as processes of management of self in everyday life and in the context of health care.

Although the analysis used the concept of threatened identity and considered the threats to identity which the health care system presents (Breakwell 1983), it sought to present an analysis significantly different from the analyses of loss or destruction of an implicit singular self. Thus the analysis challenged the implicit conceptualisation of a singular self, and the corresponding tendency to sum people up by their illness, by noting the way that respondents inserted other consistent aspects of self or consistent selves into the interview. In this respect the analysis follows the work of Kelly (1994) and Charmaz (1987) in emphasising identity projects as positive social action similar to work on narrative of autobiographical reconstruction. However the argument here is that these analyses left the implicit concept of a singular self unchallenged and omitted to give an account of how or why these identity projects are undertaken.

Along with the work of maintaining consistency of self, a second aspect of identity work, that of, maintaining or managing a sense of agency was also described. That is, the work of maintaining a sense of self-responsibility and autonomy in the self-management of chronic pain. It highlighted that the processes of maintaining a sense of consistent, autonomous self were problematic in the context of having to adapt to the difficulties that chronic pain presented and in providing a socially valid account of their experience and themselves as genuine people with genuine pain. The theoretical interpretation of this analysis offered here is that sense of consistency and sense of agency imply theories of self. That is that they are different kinds of aspects of self, discursively constructed, akin to Harre's self-2 or Apter's sense of self.

This argument is expanded in the context of the analysis of sense of agency and the threats that respondents' failure to achieve mind over matter and suggestions of psychological approaches to pain management presented to their implicit understanding of the dualism of mind and body and hence to this aspect of their theory of self. The argument draws upon Kirmayer's theoretical analysis of the social construction of theories of self as based upon metaphors of mind and body (Kirmayer 1988). His analysis is summarised below.

Kirmayer argues that 'the contrast between wilful action and impersonal accident is central to both the private sense of self and the public concept of the person'. Tracing a number of contrasts or, to borrow Billig's term, ideological dilemmas

(Billig et al. 1988), which characterise Western thought he argues that mind and body are metaphors for the voluntary or intentional versus the involuntary or accidental. Within this theory of self, issues of mind and body are issues of agency, responsibility and blame.

As metaphors, mind and body are used to 'smuggle values into discourse', here the discourse of biomedicine, which is presented or assumed to be rational and value free. He places this argument within the context of psychosomatic medicine where the purported intent is to bring mind and body together. As other work has demonstrated, within psychosomatic approaches 'mind' and 'body' are not equal and the goal is to re-establish the mind's dominance and control over the body. Moreover in psychosomatic models, the patient can be blamed for diagnostic and treatment failures by attributing limitations of biomedical explanation and treatment to hidden motivations of the patient or be seen to be responsible for illness or recovery. That is, psychosomatic models present the "same dilemma over the boundaries of rational control and responsibility for doctor and patient".

Kirmayer summarises that from this social construction of self "the value of the person lies in his strength or will which is defined in opposition to the other – whether that other be society, nature or the body itself." As such this allows the cause of human suffering to be "held to be psychological and hence potentially under personal control." Furthermore "the psychologisation of distress is a move in this struggle over the distribution of power, responsibility and blame."

The distinctiveness of Kirmayer's analysis lies in his direct consideration of mind-body dualism as related to theories of self, that "the nature of mind, as interior world or agency of the person, and body, as the medium of sensation and action" depends upon the way that "social structure shapes the development of sense of self". As such "the moral dimension of medicine then, is not something imposed by doctors on patients, it arises from the cultural concept of the person." Though as Kirmayer points out "the choice of explanations in medicine is always a choice of values".

The analytical theme of sense of agency used in the interpretation of the data in this thesis can thus be revisited. The analysis described respondents' descriptions of the sometimes strong sense of psychological agency, for example, in keeping their mind off the pain and the corresponding construction of those times when this was not achieved as a source of self-doubt or loss of sense of agency. Further consideration of this issue in the context of health services suggested that respondents experienced suggestions of psychological approaches to the management of pain as threats to their own sense of agency and that the pain, or they themselves, were not seen as genuine.

The importance of this explicit attention to the social construction of theories of self is twofold. Firstly, as has already been noted, it places the management of self in broader structural and ideological context. Secondly, it was noted in chapter four that existing conceptualisations of management of self in chronic illness have struggled to theorise the processes of identity management, often using series of

stages with change being driven by conflicts of dissonance amongst concepts of self. The argument here is that theories of self offer greater flexibility than self-concepts for understanding, or doing, identity work.

The implications of this theoretical analysis in the context of health services in particular in relation to general practitioners' difficulties in maintaining conviction, are discussed below.

Methodological issues

The process of conducting the research reported in this thesis has raised a number of methodological issues. These were introduced in chapter six and elaborated upon at relevant points throughout the chapters presenting the analysis of the data as an integral part of a reflective research endeavour. This section of the chapter draws these methodological issues together and seeks to set them within the broader health service research context. In particular, it reflects upon the appropriateness of using semi-structured interviews to meet the aims of incorporating patient and professional views in service development and planning. An immediate point to make here, to be illustrated below, is that many of the methodological issues were similar for professionals (general practitioners) and patients.

Prior to undertaking this research, the potential problem of deferential responses in the lay evaluation of health care (Porter and MacIntyre 1984; Hopton et al. 1995) was noted. That is, respondents finding it difficult to be critical or to make suggestions about how service developments because of the problem of only

knowing what they have already have experience of. The analysis demonstrated that although general practitioners were able to be critical of existing services there remained a difficulty in relation to exploring the potential for the development of new structures of service provision directly.

Both the initial and follow-up interviews with both general practitioners and patients presented some suggestions for the provision of chronic pain management clinics in primary care for respondents to comment upon. However in the cases of both patients and general practitioners there was no simple and direct way of summing these responses and drawing straightforward conclusions from them. Rather their responses to these suggestions, by necessity, were typically constructed in terms of their experiences of existing services mirroring themes emerging from the analysis as a whole.

Furthermore both general practitioners and patients constructed their accounts of their views and experiences of specific services or specialist centres within accounts of their experience of the health service as a whole, though within this overall structure there were differences in the extent to which they described and commented upon specific specialist centres.

General practitioners' knowledge of the specialist centres in the health board area varied both in terms of their knowledge of whether services existed and of what the service offered. Moreover their views of the service or centre were often framed in terms of their stated reasons for referring a patient, such that general practitioners

were negatively critical of a centre which had not 'helped the patient to get on with their life' if this was their reason for referral. This analysis of general practitioners' accounts of their use of secondary services can thus be seen to parallel what, in the context of lay evaluation of health care, is frequently constructed as the problem of patients' unrealistic or inappropriate expectations (Locker and Dunt 1978; Fitzpatrick and Hopkins 1992; Williams 1994). However in this context, general practitioners' reasons for referral, which revealed a range of clinical and non-clinical motivations, were used analytically to infer their perceptions of the current limitations of primary care provision.

Patients' accounts of their experiences of secondary care were also structured in terms of their experience of the overall process of care and of being referred to a number of specialties, and this experience was frequently characterised as being 'passed from pillar to post'. Within their accounts of this overall process, respondents rarely described their experiences of specialist centres as such, focusing on their experiences of specific encounters with individual clinicians. Their accounts of these encounters or critical incidents were frequently negative and emphasised feelings of being dismissed and being given unhelpful explanations. The analysis considered the extent to which health services either contributed to the construction of a positive and valid self or threatened patients' identity. In contrast to the analysis of the interviews with general practitioners, the analysis of the interviews with patients did not focus on their understandings of the reasons for being referred or on whether they themselves had reasons for wanting to be referred. Rather it drew attention to the problems of the lack of specificity of their

implicit motivation of 'wanting some help'.

There are three principal implications emerging from this summary of methodological issues.

Firstly, the appropriateness of the assumption that general practitioners may act as effective proxy reporters of patients views of services by providing both a knowledge of patients' views and experiences and a greater knowledge of service provision and opportunities for service development requires critical appraisal. General practitioners' knowledge of services and ability to identify the potential for development cannot be assumed. The issue of differential relevance is of importance in this context, pointing to the need for explicit recognition that general practitioners and patients are doctors and patients are trying to do different things in their use of services and health services resources.

Secondly, the research has methodological implications in the context of recent attention given to considering the health care system in terms of patient care pathways, integrated and seamless care (Layton et al. 1998; Scottish Office 1998). The current research confirms the importance of a systems approach. However, the analysis of interviews with patients can be seen to point to the importance of patient centred approaches to defining and measuring these concepts. In particular, that a critical patient centred perspective on these approaches demands consideration of the communication pathway and the wider meaning of encounters with health professionals held by patients as well as the clinical and service or specialty

sequence of the process.

In summary then, qualitative research on lay (and professional) priorities for the development of services has the potential to clarify the principles and purpose of service provision but not necessarily the exact structure or operational details. From the researcher's work with local service planners, acknowledging these strengths and limitations is an important and positive step which may allay recurrent frustrations about the difficulties of incorporating users views in service developments.

In this context then, this thesis also outlines the broad principles and purposes of recommended service developments.

Conclusions: implications for health service provision

The final section of the thesis examines the potential implications of this research for the provision of health services.

Supporting the constructive management of self

The analysis has drawn attention to the processes of management of self in the wider social and health service contexts of doubt. It described the threats to self experienced by people living with chronic pain, especially in contexts such as health care, which require the establishment of legitimate need. The absence of a legitimate account of pain (such as a diagnosis, cause, description or explanation of

the pain) as part of, or in combination with, some self doubts was seen to contribute to patient's vulnerability of self. Moreover, it has examined the potential conflicts between management of self and establishing genuineness. Efforts to maintain consistency of self, by continuing activities despite the pain, could be seen to conflict with the need to establish the experience of pain and one's genuineness as a patient or as a person.

In this context, there appears to be the potential for more explicit recognition from health professionals (here general practitioners) of the dilemma that this presents to patients and for pro-active removal of the threat to the sense of self. That is, for health professionals to actively 'tuck away' the doubts in order to allow patients to try to be more active without feeling that this would cast doubt upon the amount of pain that they were experiencing.

A second aspect of the importance of maintaining consistency of self was in terms of future selves, and particularly patients' concerns about future deterioration. This concern appeared to constitute one of the areas where the negotiation of help was problematic. Many patients expressed their dismay, particularly in relation to hospital clinicians, at being told there was nothing that could be done and that things would get worse indicating the neglect of their concerns to slow or prevent further deterioration.

The analysis has also explored the importance of maintaining a sense of agency and how these understandings or theories of self could be seen to be threatened by

respondents' (sometimes) perceived failure to manage their pain, and particularly their failure in one aspect of this process, to exert mind over matter and to take their mind off the pain. It has been argued above that this perceived threat to the theory of self is intrinsically moral. Moreover it can be seen to underpin the communication difficulties between general practitioners and patients about imaginary as opposed to real pain in the context of psychological approaches to pain management noted in this research and the wider sociological and anthropological research on chronic pain (Jackson 1992; Baszanger 1992; Bates et al. 1994). In their discussions of the psychological aspects of chronic pain or their suggestions of psychological or other pain management approaches, health professionals need to be aware of how these suggestions may be interpreted as threats to patients' own sense of responsibility and sense of managing their pain. That is, to directly challenge the implicit assumption that if the pain were imaginary or in the mind that responsible, moral selves would be able to manage it.

A notable absence in respondents' interviews was their descriptions of being helped or given a positive view of themselves, particularly in relation to how they were coping. As was the case with other aspects of the analysis, the absence was highlighted by 'exceptional' cases. These exceptional cases pointed to the importance of demonstrating and explaining to respondents how well they were managing or coping in order to allow them to construct and articulate their own sense of achievement.

From patients' perspectives there appeared to be particular difficulties in negotiating

psychological or emotional help or support, although the interviews with the general practitioners emphasised considerable psychological work, such as detecting depression and looking for hidden agendas. The analytical interpretation offered here is that such approaches are reactive and imply psychopathology even when emotional distress is seen as a consequence of the pain rather than the cause) rather than the normal psychology of people experiencing chronic pain. Thus there appears to be much scope for proactive discussion and support of the emotional consequences of pain within a paradigm of positive mental health which emphasises the normality of these experiences.

Negotiating the health care system.

This research has clearly emphasised the importance of considering the health care system as a whole, both in terms of understanding patient's experiences of health care and in terms of general practitioners' management of patients.

Patients' descriptions of their experiences of secondary care for chronic pain emphasised a predominantly negative and ad-hoc process of being passed from pillar to post or lost in the system, often over a number of years, frequently seeing different clinicians on each occasion even when making return visits to a specialty or specialist pain centre, having to repeat their history, often finding the explanations for their pain unhelpful or unconvincing, frequently feeling dismissed having being told that there was nothing that could be done, sometimes in the context of being told that their condition would deteriorate. Moreover, the length of

the process often left them wondering whether something could have been done to help if they had had access to care sooner.

General practitioners' accounts of the process of managing chronic pain also referred negatively to this process, frequently describing patients' experiences in terms similar, if not identical, to the descriptions given by patients. Furthermore general practitioners described the problems that this process created for patients and for their management of patients, with part of the work of the on-going management of chronic pain being to try to resist continuing or restarting this process whilst trying to undo or manage its iatrogenic effects. However, this process was not perceived as wholly negative from general practitioners' own perspectives, with referrals performing positive functions such as reassuring the general practitioner about his or her management of the patient, giving the general practitioner respite from the patient, having someone new review the patient objectively and convincing the patient that they are being taken seriously.

Two potential implications can be drawn from this analysis. Firstly, that it may be possible to fulfil the hidden positive functions which the existing system of specialist secondary care provides in a different and more effective way within the primary care setting. For example, general practitioners' reasons for referring patients listed briefly above do not require access to clinical specialties or treatments although they may indicate the requirement for the development of specialist skills within primary care.

Secondly, there appears to be considerable scope to make the communication pathway more positive and constructive, raising awareness amongst all hospital specialties of patients' perspectives and feelings of being dismissed and of feeling frustrated or undermined by continually undergoing physical examinations or verbal assessments and reviewing the potential for more constructive assessment and discharge which emphasises what patients are doing well and could be doing for themselves.

Changing paradigms?

General practitioners' accounts of their work with people with chronic pain revealed a complex process which involved a number of conflicting motivations or priorities, many of which were shown to emerge from trying to change from one implicit and familiar model of care (the medical model) to another approach to management for which there was no available shared account and which comprised elements of work which appeared to have lesser legitimacy or were hidden. One of the areas of 'conflict', that of managing within an medical model and then switching to a different approach, can also be seen to encapsulate, in practical terms, the fundamental dualism between physical and psychological approaches.

The conclusion of this research is that a paradigm shift in terms of the legitimacy of this area of care is required. The development of the legitimacy of a new paradigm will depend on developing a recognised account of the elements of continuing care.

Accounts of some of these areas of work such as 'helping people to get on with their lives', 'getting people to accept' 'keeping people going' are available in other academic and primary care disciplines, principally psychology. Explicit recognition of hidden work, particularly the hidden conflicts it comprises is also required.

In practice, the thesis argues that the paradigm shift be encapsulated in service configurations based on the concept of twin track planning, such that pain is managed both as if it is acute and as if it (will be) is chronic from the earliest opportunity such that both phases of care run concurrently.

Service configurations should also take explicit account of the inherent problems and conflicting tasks which confront general practitioners. In short, that twin track planning may be difficult for one individual professional to achieve. The necessity of medical watchfulness and the context of doubt conflicts with the work of conviction which underpins helping people to get on with their lives. The development of pain specialists within primary care would be one way to address this issue and provide timeous support for general practitioners and on-going care for patients. One function of this service would be to provide support and case management through the process of investigation and referral.

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APPENDIX

APPENDIX 1: INTERVIEW SCHEDULES

Management of Chronic Non-Malignant Pain in Lothian : GP and Patient Perceptions of Specialist Services and the Potential for Primary Care

Interview Schedule : Patients

INTRODUCTORY STATEMENT

I would like to ask you some questions about your health, being in pain and your experiences with doctors and with health services.

While I'm going to go through a questionnaire with you, this is really only a guide for me, so don't feel that you have to stick too closely to the questions and don't worry about saying too much because we're keen to find out as much as possible about your experiences and what you think.

If you feel that I have missed out something important please tell me. Similarly, if there's anything you want to ask me, please do.

Also, please remember that I'm not associated with your general practice OR the pain clinic. Everything you say is strictly confidential. Only the researchers on the project will listen to the tapes and only I will know which tape is yours.

BACKGROUND

1) Before we start could you just tell me a little bit about yourself.....

PROBE : Age;
Lives with?;
Marital status;
Children;
How long at present address;
Occupation;
Qualifications;
Partner's occupation.

GENERAL HEALTH

You have been asked to take part in this interview because we understand that you have problems with pain. But, we are also interested in getting a broad picture of your medical history. Can you just tell me a little about your general health?

PROBE : How would you describe your general health at present?

Do you have any illnesses or health problems?

Do you have any other problems which you think might be affecting your health?

Family health.

Contact hospitals

PAIN

As you know we are really interested in hearing about your experiences of living with pain. Can you tell me a little about the pain and how long you have had it?

PROBE : initial experiences; What was it like at the beginning?
can you describe the pain?;
Is this the worst pain you have ever had?;
What do you think has caused the problem?;
What does the pain mean to you?
How are you affected?

Impact on life and relationships;
Periods when you have been pain-free;

What is the worst thing about being in pain?

**Do you feel that you have gone through different stages in relation to the pain?
What stage do you feel you are at now?**

CONTACT HEALTH SERVICES RE. PAIN

Tell me about going to the Drs?

Do you have one GP you think of as your own? What's s/he like?

What's the practice like?

How do you feel about going to the Drs?

Please will you tell me a little about your contact with your GP in relation to your pain?

PROBE : Did you visit your GP when you first thought something was wrong

What happened : tests; referrals;

Diagnosis : Have you been given a name for your symptoms?

How important has it been for you to know what is what?

What does your GP think the problem is?

IF HAS DIAGNOSIS : How do you feel about the diagnosis?

Have you seen anybody else in relation to your pain?

PROBE : Eg., Physios;
Nurses;
Contact hospitals;
Complementary therapists;
Social services;

FOR EACH : can you tell me a little more about your experiences?

Has anybody else been of help to you?

What or who has been of most help?

PAIN CLINIC

How did you come into contact with the pain clinic?

Tell me a little about your experiences?

How often have they attended/
What each visit involves; etc etc.

Have you learned anything in particular from your contact with the pain clinic?

Have they done anything which your GP couldn't have done?

Conflicting advice?

Has going to the pain clinic helped.

Have you ever had problems proving that you are in pain?

How do you feel that your pain has been handled by health professionals?

Looking back, how might things have been handled differently?

What do you think has helped you most?

Have you experienced any changes in relation to your care?

Have there ever been times when you have felt down because of the pain?

How did you manage?

What helped?

Anything more which could be done to help people when they feel like this?

Has being in pain changed the way that you think of yourself?

Have you come across anyone else who you think really understands what you are going through?

Have you ever had difficulties because people don't understand what it's like for you?

Have there been times when you have felt confused or unsure about any aspect of your care?

Do you feel that your questions have been answered sufficiently?

TREATMENT

Do you know much about different kinds of treatment for pain? What has been your experiences?

How much do you think your GP knows about different kinds of treatments?

MEDICATIONS

Are you currently taking any medications for the pain?

What about in the past?

How well do you understand what the medicines do for you?

What effects do they have on you?

Have you ever experienced any side-effects?

How do you feel about taking these medications?

Are you receiving any other forms of treatment at the moment?

Are there any other forms of treatment which you know about which might have helped you but which you haven't had?

Has having pain changed your view of medicine or the health service?

What have you learned about the health service and about dealing with health professionals?

Do you feel that you have got the hang of 'the system'?

People have different approaches to health care. Some people seem to be quite happy to let Drs/nurses organise their care, others seem to want to be more involved. What about you?

Have you always been like this?

What do your family feel about the care you have received?

What do you think it has been like for them living with someone who is in pain?

Is there any ways in which you think they could be helped?

One thing which might become more popular if the idea of a clinic to deal specifically with different illness or problems based in general practices. Such clinics might be run by specially trained nurses and people could go along to have tests or checkups.

Might something like this, dealing specifically with pain, be helpful to you?

Would it have been helpful in the past?

Can you see any advantages/disadvantages?

Finally,

This might be a difficult question, but we are looking for suggestions on how to make services better. Do you have any ideas?

How might things be improved?

What do you think are the major problems dealing with Drs/Health prof/NHS?

What do you think are the important things which Drs should know?

PATIENT QUESTIONNAIRE - SECOND ROUND

Introduction

Thanks for agreeing to be interviewed again. This interview will be roughly the same as the last one, with us keen to find out as much as possible about your experiences and what you think.

In this interview we'd like to explore some of the issues that came out of the first interviews in a bit more detail. To do this, we'll feed back to you some of the things that have come up in our interviews with other patients and also with GP's, to see what you think, and also to help us understand things a bit more.

As before, every thing you say is completely confidential.

GENERAL

1. Q1 First of all, can you just tell me a bit about how you've got on since I last saw you?

Prompts: changes in pain?
 pain clinics?
 new medications?
 any major events ?
 changes in circumstances in general?
 what has been happening with your GP?
 what have you seen your GP for?
 how many times have you been recently?

RELATIONSHIP WITH GP

Now I'd like to ask you a bit about you and your GP. I just want to say here that we're not trying to imply that there are always problems with GPs, but a lot of things about the GP-patient relationship came out of the first interviews, and we just want to understand them a bit better

- Q2 As you know we're interested in the relationship between a patient and their GP. In general do you think there any areas that can be particularly problematic between patients and doctors in relation to pain?

What aspects of chronic pain do you think are easiest to deal with with your GP?

- Q3 Thinking about yourself are there any areas that you find are difficult to deal with with your GP?

- Q4 Is there anything that's important to you that you haven't spoken to your GP about because you feel that it isn't the kind of thing that you talk to GPs about?

Is there something that your GP doesn't understand about you because you haven't found a way of explaining to them or haven't thought to explain it to them?

Is there anything that your GP hasn't asked you about that you wish s/he *would* ask you about?

- Q5 We asked people to describe their relationship with their GP in our last interview. Do you feel there has been any change in how you get on with your GP since you have had a chronic pain problem.

- Q6 To what extent do you feel that you and your GP are on the same wavelength?

Even though some people think their GP's are really good, there sometimes still seems to be a barrier, why do you think this might be the case?

- Q7 Are there any aspects of your experience with chronic pain that you feel your GP doesn't really appreciate or understand?

And are there things that you feel s/he does understand?

Q8 Do you think GPs, or health professionals, have an idea of what is really difficult for you - do you feel the questions they ask and the approaches they take are appropriate to how your pain affects you?

Q9 What do you think are the main things that GP's *should* do to help someone with chronic pain?

Q10 How do you find talking to your GP about pain?

How does your GP talk to you about pain?

(What sort of questions does s/he ask?)

Q11 Both GPs and patients have talked to us about lack of time as being a problem when a patient goes to see a doctor

What we would like to know is, if you had more time with the doctor, how would you like that time to be used?

How do you think the time available could be better used from your point of view?

Q12 Some people have talked to us about going through the same thing in each consultation with their GP.

Is this something that's happened to you?

How do you feel about this?

Q13 Many patients have said that they feel that they have had to make their own suggestions for treatment or services for chronic pain and that they have had to push for these.

Do you feel you have had to do this?/ What has stopped you?

How does your GP respond to this?

How do you feel you could be more confident in doing this?

- Q14 What would your ideal GP be like?
- Q15 What would your nightmare GP be like?
- Q16 Where do you feel your GP fits into this?

RELATIONSHIP WITH HEALTH PROFESSIONALS

- Q17 I've asked you whether there are any aspects of your experience with chronic pain that you feel aren't understood by your GP, what about with other health professionals - are there things you feel they do or don't understand
- Q18 Some people have told us about times when they have found that medical advice did not help them because it was a bit unrealistic given other things in their lives. (Changing job, family commitments) Have you found this?
- Q19 We've asked a lot about you and your GP. Have you had any help from anyone else at the practice apart from your GP?
- Q20 How do you find talking to (health professional) about pain?
How does (health professional) talk to you?

'Nothing more can be done'

- Q21 Some people have said that they felt that there's nothing more that can be done for them, and others have actually been told by health professionals that there's nothing more that can be done.
- Has this happened to you?
- What do/did you feel was meant by 'nothing more can be done'?
- How did you feel about it?
Was it the 'right' time for you?
Is there a 'right' time to be told?
- Do you think that there are ways you can be told this that are helpful?
What would have been helpful to you at this time?
- Q22 Do you think that there are still things that could be offered, even if it's not something that's going to take the pain away?
- Where do/did you find your information from?

Q23 Many people have talked about the psychological aspects of being in pain. Could you describe you 'psychological' approach to pain?

- for example, people talked about the importance of mind over matter, or keeping their mind busy.

Q24 On the other hand, many people felt that if a doctor or health professional suggested that psychological treatment would help they were implying that the patient was imagining the pain and they felt offended at this suggestion. This seems to be a dilemma for both patients and health professionals that we want to explore further.

Have you experienced this at all?

Have you got any ideas why this may happen?

What do you feel is the best approach for health professionals to take in this situation?

Q24 People talked about feeling down because they were in pain, and also that feeling down seemed to make the pain worse.

Has this happened to you?

How could health professionals help you with this?

Q25 There is a lot of uncertainty about what constitutes psychological help/treatment expressed both by GPs and patients and patients seemed to be wary about being referred for psychological treatment.

What do you think about psychological treatment?

Why do you think patients are wary of this kind of treatment?

Q Understanding what's to do with the mind and what's to do with the body seems difficult when it comes to pain. Do you have any ideas about this?

DIAGNOSIS/CAUSE

Acute/chronic distinction

Q26 We asked GPs what they thought were the differences between acute and chronic pain but we didn't ask patients. Do you think that there is a difference between acute and chronic pain?

Q27 Have you ever been told you have 'chronic pain'?

How was it explained?

What do you understand the term 'chronic pain' to mean?

Do you consider yourself to have chronic pain?

Explantations for pain

Q28 In the first interview we asked people if they had an explanation for their pain and many people seemed to have more than one explanation?

Have you had more than one explanation?

Who has given the different explanations?

Have you had a medical explanation for your pain?
who gave you that explanation?

Which explanation do you feel makes most sense to you, and why?

Do you have *your own* explanation for why you have got pain?

How do you talk to your family and friends about your pain, how do you explain your pain to them?

Do you always give the same explanation, or do you find you change what you say to people?

Issues of doubt/uncertainty

Q29 Many people have said that they felt their GP, or another health professional, thought they were imagining their pain.

How often have you experienced this?

Why do you think they would feel like this?

Do you have any ideas about how this could be avoided or tackled?

Is this something that you've discussed with the person concerned?

Q30 Some patients have expressed the feeling that they **themselves** sometimes wonder if a lot their pain is in their mind.

Is this something you have experienced?

How do you deal with it?

What do you think makes you feel like that/imagine your pain?

Does this feeling come and go?

TREATMENTS FOR CHRONIC PAIN

Medications

Q31 Both GPs and patients have expressed concerns about medications but we are not clear whether patients discuss their concerns with their GPs or understand their GPs concerns.

To what extent do you feel you understand your GPs concerns?

Q32 Do you take any medications that are not prescribed by a doctor/GP?

Do you have any concerns about taking these medications?

Do you ever ask anyone else's advice, apart from your GP's, on medications?

Does your GP know what other medications you are on, if any?

TALKING ABOUT PAIN

Experience of talking

Q33 A lot of people have said they find it difficult to talk about pain.

How do you feel about this?

[if find it difficult] What is it that is difficult?

Why do you think it is difficult?

Q34 When people have talked to us about their pain and how it affects them, one of the main things was the way they deal with it on a day-to-day basis with other people. Some people said that they find it difficult to tell people how they're feeling, and if people ask them how they are they find themselves just saying 'fine', so that they're not seen as a 'moaner'.

Is this something you have experienced? What do you think makes you feel like that?

Q35 Other people feel that the people around them know how they're feeling and don't feel the need to explain.

Is this something you experience?

What circumstances does this happen?

Was this something you negotiated or set up?

Q36 A lot of people have said that they feel if they talk about their pain too much they will be seen as a moan.

Is this something you feel?

Why?

Q37 People have also said that they can get fed up hearing themselves talking about pain. Is this something you feel?

Q38 As we've said, people find it difficult to talk about pain. We were wondering if you find any difference in talking to people in general about it and in talking to health professionals about it?

Talking to someone

Q39 A lot of people we talked to mentioned that they would find talking to someone about their pain helpful. Would you/do you?

What is it that's good about talking - how does it help?

Are there times when you want to talk to someone, and times when you don't want to talk?

Do you feel there is somebody you can talk to (about pain) when you need to

What is about a person that makes you feel you can talk to them - about being in pain or about how you feel? (*Try to get a sense of whether there is a difference between talking about pain and talking about feelings.*)

Q40 Lots of people have said to us that they do or would find it useful to talk to people who had experienced pain themselves. Do you feel like that?

What exactly is it that's good / bad about talking to other people who are in or have been in pain?

Who would you most want to talk to?

Q41 Do you find people talk to you about their experience with illness/pain?

How do you feel about that

Q42 Many people have talked about self-help groups, but didn't necessarily see them as being useful to them, even though many valued the thought of talking to someone about their pain. How do you feel about self-help groups? Why?

PSYCHOLOGICAL ASPECTS OF PAIN

'Getting on with it'

- Q43 One thing that seemed common to almost all our interviews was that people would tell us about how their pain caused them problems, but at the end of the day, they felt that they'd 'just got to get on with it'.

What does getting on with it mean to you?

Do you feel that you **do** 'get on with it'?

'Accepting' pain

- Q44 People talked in many different ways about 'accepting' that they had chronic pain. Some felt that for them to accept they had chronic pain was a good thing and it helped them with their pain. Others felt to accept the pain made them feel they were giving in to it. Some people said they accepted the pain but still hoped for a cure.

What is your experience?

What does 'accepting' that you have chronic pain mean to you?

Is this acceptance of chronic pain something changes over time?

- Q45 In our first interviews with people, we talked about coping with pain. Since then we've thought that maybe we were wrong to assume that people can 'cope' with chronic pain, and that it is perhaps something that keeps changing over time. What do you think?

Coming to terms with pain

- Q46 A lot of people talked about 'coming to terms' with their pain. What does coming to terms with your pain mean to you?

Are there things that have helped you do this?

- Q47 Again, we were wondering if coming to terms with pain is something that you either do or don't do, or if it is something that comes and goes. What do you think?

Stages

- Q48 We asked in the first interview about whether people go through stages with their pain. With some people, it seemed as though they hadn't noticed any changes, whereas with others it seemed to actually be more complex to them than just going through stages. What do you think?

EFFECTS OF PAIN

The Body

- Q49 One thing we didn't ask before was whether pain had made any difference to how people felt about their body and what is going on in their body, do you feel being in chronic pain has changed the way you think about your body?

Do you have your own ideas about how pain works - any theories of pain?

Do you feel differently about your body when you are in pain than when you are not in pain?

Has being in pain made you more aware of your body?
In what ways?

- Q50 We are interested in how people make sense of the pain they feel, and what it means to them. What do you understand that is going on in your body?

Do you feel that what is happening to your body matches the explanation of pain that you have been given by the doctors?

- Q51 What do you feel you have learnt about yourself through your experience of having chronic pain?

Change of plans for future?

Image of self?

Relationships

- Q52 People have talked about how being in pain has affected their relationships with partners, husbands, family, friends and neighbours.

Have you felt that your relationships have been affected, and how?

- Q53 A lot of people talked about how their pain affected their physical relationships with other people? Have you experienced this?

SERVICES FOR CHRONIC PAIN

These last questions are about services for people in chronic pain, and it would be helpful to us if you could give us suggestions, or tell us about things that you've found problematic or helpful in this area.

Q54 What does it feel like trying to get the help you need?

Q55 What do you think are the main problems you have faced in getting help?

Is there anything that would have made it easier for you to get help?

Is there anything that would make you more confident about asking for and getting help?

Q56 Most people seem to have spoken to a range of health professionals about their pain, and often more than one GP. Do you think it's helpful or not to speak to different people?

[if yes] What's helpful about it?

[if no] Why not?

Q57 One thing that came out of our interviews with GP's was that they started off treating pain at first as if it was going to go away, and then when it didn't, they ran into difficulties trying to change their approach. We're not sure whether patients experience this or are aware of this. How do you feel about it?

Q58 We've asked a lot of questions about your contact with specific services and with specific health professionals, particularly your GP. But what we don't have a sense of is what you feel about being in the middle of it all. We're asking this because a lot of patients said that they feel 'lost' in the system, with one referral after another. Is this something you feel?

What is it like to feel 'lost' like this?

Do you think there's any ways in which this can be avoided?

Q59 Has there ever been times after treatments or appointments that you've just been left not knowing what's going to happen next?

How important is it for you to know what's going to happen next?

Are there ways in which this being left not knowing what's happening next could be avoided?

Q60 People seem to have tried and be willing to try lots of different things to help them with their pain. It seems to us that although a lot of the things they've tried haven't worked, they're not given the chance to try them again at a later stage. Do you ever feel you would like to try a treatment again, for example physiotherapy, that you felt did not help at the time, but may help now?

Q61 It is easy to talk about health services in terms medications and treatments, but are there other kinds of help that you feel are important?

Q62 Do you feel that a GP is the best person to deal with your pain?
Why/why not?

Q63 One of the reasons GP's gave for referring to pain clinics was that they thought that patients would want to see an expert, but we weren't sure whether this is important to patients or not. What are your views on that?

Is there anyone who you see as being an expert?

Q64 [for people who have been to a pain clinic] Is there anything that was done for you at the pain clinic that you felt your GP, a nurse or someone else could have done just as well?

Q65 Finally, how would you feel about having a service whereby you could be referred to some kind of pain specialist, who isn't necessarily a doctor - they could be a psychologist, an occupational therapist, a nurse, or someone else. This is just an idea of ours and is open to suggestion from you, but we thought that this person would be someone who knew a lot about services for chronic pain and a lot about your particular case. You could see this person as well as, or instead of, your GP, and they could maybe act as a kind of 'case manager' and be able to take an overall look at your case and discuss it with you.

Is this something that sounds as if it could be helpful to you?

What kinds of things would you find it helpful for them to do?

Q66 How would you feel about keeping your own records, so that you would have all the notes from any consultations and you could take them with you to any appointments you had?

FINAL QUESTIONS

- Q67 Are there any practical things in general that you can think of that would change your life or make things easier for you, for instance anything to do with public transport, shopping, entertainment, hobbies, in your house, work ...
- Q68 What have been the main problems you've faced in trying to understand your situation?
- Q69 And what about health services, what have been the main problems you've faced in understanding them?
- Q70 How have you felt about being interviewed?

SECTION HEADINGS:

GENERAL

RELATIONSHIP WITH GP

RELATIONSHIP WITH HEALTH PROFESSIONALS

- testing

DIAGNOSIS

- acute/chronic distinction

TREATMENTS FOR CHRONIC PAIN

- medications
- complementary therapies
- other approaches

TALKING ABOUT PAIN

PSYCHOLOGICAL ASPECTS OF PAIN

- getting worse/nothing that can be done
- getting on with it
- issues of doubt/uncertainty
- 'coping' and accepting pain
- stages
- coming to terms with pain

EFFECTS OF PAIN

- the body
- relationships

SERVICES FOR CHRONIC PAIN

FINAL QUESTIONS

Management of Chronic Non-Malignant Pain in Lothian: GP and Patient Perceptions of Specialist Services and the Potential for Primary Care

GP INTERVIEW SCHEDULE

I would like to start by asking you a little about yourself and your background:

How long have you been a GP?

Where did you train?

Is this your first practice?

What attracted you to this practice?

Do you have any special areas of interest within general practice?

What do you see as the main health problems affecting the health of the patients at this practice?

What problems or groups of patients cause you the most work?

As you know we are interested in finding out about pain management within primary care

How much of your daily work is taken up with dealing with pain?

To what extent is pain something you think of in its own right, or do you think of it in terms of a specific illness/disease

How do you approach/manage a patient with pain?

What influences your decisions

(Age of patient/sex/working/non-working . . .)

How confident do you feel about being aware of a patient's pain?

How do you assess someone's pain?

**Do you have any consultation strategies which help you to assess the level of pain?
(Questions, pain scales)**

What do patients have to do to convince you that they are in pain?

Conversely, what makes you doubt that someone is in pain?

Looking back to your training, how was pain addressed/covered?

Do you feel this was adequate

What part of your training has been most/least useful to you

What do you feel would have been helpful

Do you feel your approach to pain management has changed since you trained?

Has anything in particular affected your views

Have you attended any seminars, or formal training in chronic pain management

We are particularly interested in chronic pain, and how it is seen from the GPs' point of view:

What do you understand by the term chronic pain?

Have you had any personal experience of chronic pain?

Perhaps among your family or friends?

When does acute pain become chronic?

How does the care you provide change?

and What are the major differences between treating someone who is in acute pain
someone who is in chronic pain?

**When someone first presents with pain do you have any ideas about whether it is
going to be chronic or recurrent?**

How do you manage a patient with chronic pain?

What influences your decisions?

(Age, sex, working, non-working)

**Thinking about the patients that you see with chronic pain, are there different types
of patients with chronic pain? (When we mention chronic pain what sorts of
patients come to mind?)**

How does this compare with the stereotypical or textbook chronic pain patient?

**How much of your work is taken up with dealing with people who are in chronic
pain?**

**Looking back over the last week, how many patients have you seen with chronic
pain?**

Tell me more

How did you deal with them

Do you ever discuss your chronic pain cases with colleagues?

To what extent do you find this helpful

**Are you aware of patients with pain who have seen different doctors within the
practice?**

How do you feel about this

**How much are other members of the primary health care team involved in the care
of people with chronic pain?**

Do you think there is the potential to widen this role?

To what extent do you feel chronic pain affects people's lives?

Do you feel it is important to assess this

Do you find this difficult/easy to assess

What is the hardest part of coping with people who present with chronic pain?

Do you have a nightmare chronic pain patient?

Tell me about a particular patient

What is your ideal chronic pain patient?

Tell me about a particular patient

To what extent are you involved in assessments for benefits?

There have been changes in benefit arrangements, how will this affect your work?

(Continuity of care - GP role in this)

Treatment

What sort of drugs do you prescribe for people in chronic pain?

What informs your decision to prescribe specific drugs?

How do you feel about prescribing drugs for people in long-term?

Pressured (by patient)/reluctant

Do you find you ever change preferred medication because of side effects

Are there treatments you would like to be able offer and would like to know more about

Can you think of any patients at the moment who are on drug therapies which you feel are unacceptable?

Do you ever feel caught in a catch 22 situation with patients drug-wise?

Do you ever get into pain management situations which you can't get out of?

What happens when you start treating someone who you think is in acute pain which then goes on to be chronic or long-term. Do you have to change strategies?

Services for chronic pain

How much do you know about specialist pain services in Lothian?

Which clinics would you consider to be 'pain clinics' within Lothian?

Which ones have you referred patients to

What influences your choice of clinic

How did you hear about them

At what stage might you refer a patient to a pain clinic?

What factors influence your decision to refer

At what stage would you like to refer patients

How confident are you about making referrals

Have you ever referred because you were desperate

What do you tell your patients about the reasons for referral and what they should expect to get out of it?

Do you think that you might raise people's expectations by referring them on?

What do you feel about the treatment your patients have received?

What have your patients felt about their treatment

Have there ever been conflicting approaches to treatment

How much have you learnt from the services

What aspect of the chronic pain service do you feel is most helpful to you as a GP?

What would help you most in providing care for your chronic pain patients

What do you feel your patients would appreciate most

What would be the ideal service (for chronic pain) from your point of view

What would you feel about having a chronic pain clinic within primary care

If there were services, which were perhaps easier to access, dealing with the assessment of pain, would you refer patients earlier?

Are there any services outwith the NHS which deal with pain management that you are aware of?

PROBE - What are your perceptions:

How might you like to see pain management services developed?

Finally,

What do you see as being your role in coping with a patient who has chronic pain?

Cure/alleviate symptoms

Management/coping

Do you feel that you have a role in the long-term care of a patient with chronic pain?

Are there any guidelines or other resources to managing chronic pain that you find particularly helpful?

For example do you have Dr Littlewood's guidelines

Do you use them

MANAGEMENT OF CHRONIC NON-MALIGNANT PAIN IN LOTHIAN: GP AND PATIENT PERCEPTIONS OF SPECIALIST SERVICES AND THE POTENTIAL FOR PRIMARY CARE

GP Schedule 1 - 2nd round interviews

Thanks for agreeing to be interviewed again. What we'd like to do in this interview is to feed back to you some of the things that have come out of the first set of interviews, and then ask you some further questions about some of the issues.

Basically the analysis that we've carried out has identified a lot of problems that GP's face in managing chronic pain, and we've based this interview schedule on a summary of all the issues that have emerged. What this means is that not every GP mentioned every issue, and also that there may be some things that were problematic for other GP's whereas they may not pose any problems for you. The important about this 2nd interview is that you feel free to agree with, disagree with or add to anything that we're saying.

The other thing is that we seem to have uncovered more problems than solutions in the management of chronic pain, so if you've found anything that's worked particularly well we'd like you to tell us about that as well.

In this interview we'll also be looking at some of the issues that patients' raised in the interviews that we did with them, and we'll explain what these are as we go through the interview. - it'll be interesting to get a GP perspective on some of these issues. Similarly, when we go back to interview the patients we'll be asking them about some of the difficulties that GP's face. So feel free to comment on any of the questions that we're going to ask and any issues that we raise. Before we start going through some of these issues, I'd like to summarise them to give you an overall view:

There seems to be four main aspects to what GP's have said about managing chronic pain:

- Firstly, investigation and diagnosis - trying to find a cause or an explanation for the pain
- Secondly, sorting out the appropriate medication
- Thirdly, managing patients in interpersonal terms - taking account of other factors that might be going on in a patients life or the fact that different individuals react differently to things. Also mentioned here was the GP's handling of their own frustration with the problem
- and finally, referring onto other agencies and their provision of services.

(We won't be discussing them in that particular order, but) would you agree that that's a fair summary or not? Is there anything that you feel we've missed?

INVESTIGATION AND DIAGNOSIS

- 1 If we talk about a bit more about the issue of investigation and diagnosis. Certainly patients have raised the importance of knowing the cause of the pain. Given that GP's also seem to invest a lot of time in trying to explain or reach a diagnosis or rule out possible diagnoses, how important is knowing the cause for the pain in terms of your management of the case?
 - How much of a difficulty is not having a specific cause for the pain from your point of view?
 - What do you think this means from the patient's point of view?

MEDICATION

- 1 Throughout the interviews, given the main aspects to managing chronic pain, the one which GP's spoke about with the greatest detail and usually with the most confidence was sorting out appropriate medication. It seemed to us that, although there was problems with this too, this was the area where GP's appeared to have their biggest role. How do you feel about this?
- 2 Although as we've said this seemed to be an area in which GP's were confident, there were still some problems. The main problems seemed to be: concern about side-effects of medication, concern about the possibility of the patient becoming addicted, concern that the patient was actually abusing pain drugs, and concern over the patient moving up the analgesic ladder too quickly, with nothing left to control their pain once they'd reached the top. To what extent are these the issues that you are concerned with, and do you feel they are particular to the management of chronic pain?

A further issue is the distinction between addiction and abuse. Is this a distinction you make?

i addiction

- 3 The first issue that GP's raised but didn't actually explain in much detail was their concerns that patients could become addicted to pain killers. Whilst on the one hand a straightforward explanation for this might be that people's tolerance to certain drugs over time becomes lowered, is that the main concern?

Do you think some people are more likely to become addicted than others?

Have you actually had any patients who you felt were addicted to drugs and what did you do about that?

ii abuse

- 4 The other issue that some GP's raised was the possibility of patients actually abusing pain drugs. Is that something that concerns you?

What would be your definition of abuse of pain drugs?

What circumstances cause you to be concerned?

Have you had direct experience of patients abusing pain drugs? How did you deal with that?

iv other medication issues

- 5 The other interesting issue that some GP's raised in relation to pain killers was that some felt that if a patient's pain is being controlled by drugs, then that patient wouldn't be classified as a chronic pain patient.

How do you feel about this?

- 6 In what ways do you think patient's views differ from yours on medication?

INTERPERSONAL RELATIONSHIPS

i assessing pain - sources of doubt

Going on now to talk about the other aspects of pain management, one of the questions we asked GP's in the first set of interviews was what do patients have to do to convince you that they're in pain. In some ways this was a leading question, and many GP's said basically that pain is what the patient says it is, but then went on to explain that there was a number of things that made them doubt this. Perhaps we could go through some of these sources of doubt and get your views on how important they are.

The sources of doubt were:

- the way that patients presented their pain. Some people would overstate their pain and some would understate it. This seemed to have the effect of making GP's either think that the patient was exaggerating their pain or of the pain going unnoticed.
- the way that patients' actions didn't match up to what they said. This doubt was raised either by chance incidents - maybe a patient would come to the surgery saying they're in pain, and then they would see them in the community doing something that they were told they shouldn't do - and also by deliberate testing on the part of the GP in consultations.
- that patient's actions didn't match up to what medical 'evidence' was available, eg the patient complains of pain in a particular site but x-rays don't show any physical damage.
- the site of pain. In particular, low back pain was frequently mentioned.

How do you deal with these doubts?

- 1 One way in which some GP's sorted out some of these doubts was to use some sort of informal test or observation, for instance watching a patient walk out of the surgery, or watching them get on and off an examining bench.
Are you aware of any problems in taking this approach?
How much do you think that patients are aware of this?
- 2 All in all it seems that presenting symptoms or problems is quite difficult for patients.
Is this issue of presentation ever something that you discuss directly with patients? Has that ever been helpful or not?
If you have any doubts do you every discuss them with patients?
- 3 Looking at all these sources of doubts, what realistically would patients have to gain by deliberately misrepresenting their own experience of pain?

ii psychological support

Moving on to some of the other problems in the management of chronic pain, if we can talk about the difficulties in managing the emotional distress that's sometimes associated with chronic pain, and the difficulties in trying to help people adjust or rehabilitate to their pain:

- 4 One of the difficulties that GP's faced was the relationship between chronic pain and other psychological problems like anxiety and depression. Sometimes GP's explained that they felt the pain had caused the anxiety and depression which had then become a major problem or conversely that the person's psychological health impacted on their pain.
How do you feel about that as a summary of the situation?
- 5 Sometimes GP's found it difficult to address this issue with patients, as in suggesting a more psychological approach to pain management, they might be seen to be suggesting that the pain was being imagined, with the result of alienating the patient.
Have you found this a problem?
Have you found any way round this?
- 6 The other thing that was raised to do with this issue was that it was felt that lack of time was something that hindered GP's in giving support. If you had unlimited time, what would you do with it?
- 7 Even given unlimited time there would still seem to be some specific difficulties in this area. For instance, there seems to be a dilemma between trying to help the patient adjust to their lives with pain whilst at the same time to be seen as being positive and to be trying to help them.
How do you deal with this situation, and how much of your work in trying to help patients get on with their lives involves working with their family or carers?

iv GP strategies

- 8 The other thing that struck us from the interviews with GP's was that it wasn't clear how much GP's had a strategic approach to patients with chronic pain. It seemed to be very much a case of reacting to the patient as and when the patient came in, so in other words, much of the care seemed to be patient-led.
Would you agree that that's the case or not?
How much of your role in dealing with chronic pain is pro-active or re-active, and do you have a longer-term strategy for patients with chronic pain?

If you do develop longer term strategies, how confident are you in how well these work. If you don't, do you feel it would be helpful to have a more structured approach - is this something that could be addressed in training? What would be involved in it?

- 9 GP's also mentioned problems with 'getting stuck' with patients and also the importance of working together with a patient towards particular goals. So if we think about these issues of developing a strategic approach, not getting 'stuck' with a patient, and working towards goals, if you had unlimited time to spend on these things, how would you use it?

v individual differences - personality

- 10 There are also other issues that were raised by GP's in relation to the importance of the doctor-patient relationship. There were certain issues that GP's talked about frequently, but didn't expand on. These issues were: different patients having different personalities and different pain thresholds, the importance of 'knowing the patient', and the use 'gut feelings' on the part of the GP when dealing with chronic pain.

To what extent are these issues important to chronic pain particularly?
Can you say what you would mean when you talk about these issues?

SPECIALIST SERVICES FOR CHRONIC PAIN

Gp's identified several problems with specialist services in Lothian. As part of our research we identified 4 pain clinics. Knowledge of these varied and GPs reasons for referring patients to these clinics were often based on factors other than what the services had to offer. So in the next stage of the interview I'd just like to go through in broad terms the problems and advantages that the pain clinics offered, and some of the reasons that GPs referred their patients there.

- 1 One of the main problems was in terms of the waiting times and some GP's were deterred from making a referral at all by the perception that the waiting time would be 9 months. There was several reasons why this was a problem. Firstly, it was felt that after 9 months the kinds of help in rehabilitation would be too late and patients would already be stuck in their behaviour patterns. Secondly, the wait tended to build up peoples expectations, and thirdly, it could slow down the process of people getting on with their lives. Which if any of these reasons would you agree with - would you like to add anything to them? Are there any ways in which the waiting time can be used helpfully?
- 2 The main things that GPs found helpful about pain clinics were: that they felt they learned a lot about different approaches, particularly about pharmaological aprooches to the managment of pain and therefore increased their own skill level; that the pain clinics reassured them they as GPs hadn't missed anything in terms of different approaches to managing the patient; and also that sometimes it was important from the patients point of view to have seen an 'expert' and for them to be reassured. Would you agree with these issues and are there any others that you'd like to add?
- 3 In relation to the issue of the importance to patients of seeing an expert, our interviews with patients suggest that this might not be as important as GP's think it is.
Is it something that you've discussed directly with patients?
What is it that makes you think that it's important for patients to see an expert?
- 4 GPs reasons for referral to pain clinics were wide-ranging. I'll go through some of them with you: for their own reassurance that they hadn't missed anything; because they felt that that's what the patient wanted; that the long waiting times could actually form some sort of respite care for the patients and gave GPs a bit of a break; that referral to a pain clinic was a means of addressing the issue that patients had to get on and live with their pain; some GPs said that they referred to give patients access to associated services, particularly psycholgocial services when they didn't feel that they could refer directly to a psychologist or psychiatrist because the patient would feel that they weren't being taken seriously or would react adversely to the stigma that mental health services can imply.
Can you add to these reasons?

- 5 If we think about GP's reasons for referral, and take into consideration that most aren't based on clinical medical reasons, and that GP's often aren't referring in order to access specific clinical treatments, how do you feel about a service based in primary care being developed?
Do you have any ideas about how this might be achieved?
- 6 The other thing that emerged was that a lot of gps felt that in Lothian services relied predominantly on physical treatments such as nerve blocks or injections when the psycholgocial element was relatively neglected.
What do you feel about this?
How aware are you of what psychological support is on offer to patients?
Do you think that there is anything more that could be done to develop psychological services in primary care?
- 7 One of the pain clinics that relatively few of the GPs knew about was that at the Astley Ainslie. As you may know, they offer an intensive psychological approach to the management of chronic pain, which is based on some individual counselling and some group work. What would be your initial reaction to that kind of approach?
How do you feel about group work - is this something that could be developed within primary care?
How aware are you of self-help groups for chronic pain? How do you feel about either informing patients about them or patients being involved in them?

TRAINING AND EXPERIENCE

- 1 The other thing we asked about was training in chronic pain management and most GPs felt that pain and chronic pain management wasn't well covered in training. In retrospect were there other chronic conditions that were covered more effectively in your basic training?
- 2 Most GPs felt that they'd learnt about pain informally, through experience rather than training. Are there any particular experiences or patients that you feel you learnt a lot from?
Have you made any 'breakthroughs' in terms of your knowledge of chronic pain and your approaches to managing it that others could maybe benefit from?

If you were offered the opportunity of a post-grad course in chronic pain management what would you like it to cover: would it be more in terms of medications or psychological aspects of managing chronic pain, different psychological techniques and would you be interested in multi-disciplinary training or not?

UPDATE ON CASES AND VALIDATORY QUESTIONS

- 1 In carrying out these interviews it appears that GP's are quite comfortable talking about pain up to a certain point, after which pain is talked about with reference to specific diseases, symptoms or sites rather than in and of itself. This point is not at any particular stage, and differs amongst GP's.
Firstly, what do you feel about this? Why do you think this happens?
Secondly, do you feel that when talking about pain it is useful to discuss it in terms of itself, rather than with any reference to specific types?
- 2 As we've just talked about, GP's tended to talk about pain in terms of specific types. The most commonly cited types of pain were back ache, arthritis, muscular skeletal pain, headaches, neuralgias, abdominal pain and neck pain.
To what extent is this list representative of your understanding of chronic pain?
- 3 In our previous interview you mentioned some patients ... how have these cases developed since we last spoke?
OR
Have you had any breakthroughs with particular patients since the last time we spoke? Tell me about them.
- 4 (To non-ref GP's) Can I ask how you picked the sample of patients that you gave us?

After the interview - One of the aims of this research is to develop ideas on post-graduate education and service development. Would they would be prepared to comment further on any ideas that we come up with? This could maybe be done over the 'phone and wouldn't involve another interview.

MANAGEMENT OF CHRONIC NON-MALIGNANT PAIN IN Lothian: GP AND PATIENT PERCEPTIONS OF SPECIALIST SERVICES AND THE POTENTIAL FOR PRIMARY CARE

GP Schedule 2 - 2nd round interviews

Thanks for agreeing to be interviewed again. What we'd like to do in this interview is to feed back to you some of the things that have come out of the first set of interviews, and then ask you some further questions about some of the issues.

Basically the analysis that we've carried out has identified a lot of problems that GP's face in managing chronic pain, and we've based this interview schedule on a summary of all the issues that have emerged. What this means is that not every GP mentioned every issue, and also that there may be some things that were problematic for other GP's whereas they may not pose any problems for you. The important about this 2nd interview is that you feel free to agree with, disagree with or add to anything that we're saying.

The other thing is that we seem to have uncovered more problems than solutions in the management of chronic pain, so if you've found anything that's worked particularly well we'd like you to tell us about that as well.

In this interview we'll also be looking at some of the issues that patients' raised in the interviews that we did with them, and we'll explain what these are as we go through the interview. - it'll be interesting to get a GP perspective on some of these issues. Similarly, when we go back to interview the patients we'll be asking them about some of the difficulties that GP's face. So feel free to comment on any of the questions that we're going to ask and any issues that we raise. Before we start going through some of these issues, I'd like to summarise them to give you an overall view:

There seems to be four main aspects to what GP's have said about managing chronic pain:

- Firstly, investigation and diagnosis - trying to find a cause or an explanation for the pain
- Secondly, sorting out the appropriate medication
- Thirdly, managing patients in interpersonal terms - taking account of other factors that might be going on in a patients life or the fact that different individuals react differently to things. Also mentioned here was the GP's handling of their own frustration with the problem
- and finally, referring onto other agencies and their provision of services.

(We won't be discussing them in that particular order, but) would you agree that that's a fair summary or not? Is there anything that you feel we've missed?

INVESTIGATION AND DIAGNOSIS

- 1 If we talk about a bit more about the issue of investigation and diagnosis. Certainly patients have raised the importance of knowing the cause of the pain. Given that GP's also seem to invest a lot of time in trying to explain or reach a diagnosis or rule out possible diagnoses, how important is knowing the cause for the pain in terms of your management of the case?
How much of a difficulty is not having a specific cause for the pain from your point of view?
What do you think this means from the patient's point of view?

MEDICATION

- 1 Throughout the interviews, given the main aspects to managing chronic pain, the one which GP's spoke about with the greatest detail and usually with the most confidence was sorting out appropriate medication. It seemed to us that, although there was problems with this too, this was the area where GP's appeared to have their biggest role. How do you feel about this?
- 2 Although as we've said this seemed to be an area in which GP's were confident, there were still some problems. The main problems seemed to be: concern about side-effects of medication, concern about the possibility of the patient becoming addicted, concern that the patient was actually abusing pain drugs, and concern over the patient moving up the analgesic ladder too quickly, with nothing left to control their pain once they'd reached the top. To what extent are these the issues that you are concerned with, and do you feel they are particular to the management of chronic pain?

A further issue is the distinction between addiction and abuse. Is this a distinction you make?

i addiction

- 3 The first issue that GP's raised but didn't actually explain in much detail was their concerns that patients could become addicted to pain killers. Whilst on the one hand a straightforward explanation for this might be that people's tolerance to certain drugs over time becomes lowered, is that the main concern?

What alerts you to the idea that patients are at risk of becoming addicted?

Some GP's mentioned that addiction was less of an issue with older patients - it was also implied that it didn't apply to the terminally ill. To what extent does life expectancy influence your approach to addiction?

ii abuse

- 4 The other issue that some GP's raised was the possibility of patients actually abusing pain drugs. Is that something that concerns you?

What would be your definition of abuse of pain drugs?

What circumstances cause you to be concerned?

Have you had direct experience of patients abusing pain drugs? How did you deal with that?

iv other medication issues

- 5 Relating to the issue of compliance or self-medication, GP's have expressed frustration that patients haven't taken any pain killers or aren't complying with their medication. How do you feel about this conflict between on the one hand worrying about patient's getting addicted and on the other being concerned that patients aren't taking medication?

- 6 From the patients point of view, they feel like their pain might be 'masked' by the painkillers, and that this might mean that their GP can't see how badly they're affected, or from their own point of view, that they don't know themselves any more if they still have the pain or not.

What do you feel about this, and is it an issue that you have tackled with patients?

INTERPERSONAL RELATIONSHIPS

i assessing pain - sources of doubt

Going on now to talk about the other aspects of pain management, one of the questions we asked GP's in the first set of interviews was what do patients have to do to convince you that they're in pain. In some ways this was a leading question, and many GP's said basically that pain is what the patient says it is, but then went on to explain that there was a number of things that made them doubt this. Perhaps we could go through some of these sources of doubt and get your views on how important they are.

The sources of doubt were:

- the way that patients presented their pain. Some people would overstate their pain and some would understate it. This seemed to have the effect of making GP's either think that the patient was exaggerating their pain or of the pain going unnoticed.
- the way that patients' actions didn't match up to what they said. This doubt was raised either by chance incidents - maybe a patient would come to the surgery saying they're in pain, and then they would see them in the community doing something that they were told they shouldn't do - and also by deliberate testing on the part of the GP in consultations.
- that patient's actions didn't match up to what medical 'evidence' was available, eg the patient complains of pain in a particular site but x-rays don't show any physical damage.
- the site of pain. In particular, low back pain was frequently mentioned.

How do you deal with these doubts?

- 1 Another way of looking at these doubts, and this is something that some GP's have raised and is if you like the opposite problem - that they sometimes feel that they have difficulty getting patients to believe that they're taking them seriously.

Is this something you've ever experienced?

Do you have any ideas why some patients might feel that their GP's aren't taking them seriously?

Are there things that you do to convince patients that you're convinced by them, and conversely, what would you do if you were a patient who felt that your GP wasn't taking you seriously?

- 2 Are these doubts peculiar to pain, or do they occur in other areas of general practice?
- 3 A lot of GP's mentioned that when assessing pain, factors such as the age of the patient, or whether the patient was in work or not, had implications for how they would treat the pain. For instance, if a patient presented with pain and they were in paid employment, GP's were more likely to treat the problem quickly. Do you find that factors like these play a part in your treatment of pain?

ii psychological support

Moving on to some of the other problems in the management of chronic pain, if we can talk about the difficulties in managing the emotional distress that's sometimes associated with chronic pain, and the difficulties in trying to help people adjust or rehabilitate to their pain:

- 4 One of the problems GP's faced was the problem of 'getting stuck' with a patient and feeling that there was nothing they could do. A lot of this seemed to be bound up with running out of medications.

Do you think there's anything that could be done to stop a relationship reaching this stage?

- 5 Many patients have said that if they had known earlier that the pain was not going to go away that they would have found it easier to cope.

Do you have any strategies for telling a patient that you think the pain is not going to go away - is this something you address directly with the patient, or is your approach to let the patient gradually work this out for themselves?

What do think the advantages and disadvantages are/would be in addressing the issue directly with patients?

- 6 In our patient interviews some people felt that pain is a sign of damage, and that increasing pain is a sign of increasing damage. How if at all do you take account of this issue when dealing with patients?

iv GP strategies

- 7 The other thing that struck us from the interviews with GP's was that it wasn't clear how much GP's had a strategic approach to patients with chronic pain. It seemed to be very much a case of reacting to the patient as and when the patient came in, so in other words, much of the care seemed to be patient-led.

Would you agree that that's the case or not?

How much of your role in dealing with chronic pain is pro-active or reactive, and do you have a longer-term strategy for patients with chronic pain?

If you do develop longer term strategies, how confident are you in how well these work. If you don't, do you feel it would be helpful to have a more structured approach - is this something that could be addressed in training? What would be involved in it?

- 8 The other thing that struck us from our interviews with GP's was that it wasn't clear how much of a strategic approach GP's had to patients with chronic pain. The problem of 'getting stuck' with patients also came up, the other side of that being that some mentioned the importance of working together with a patient towards particular goals.

How confident are you in developing the goals and negotiating them with patients?

How much do you do it?

What kind of goals would they be?

- 9 So if we think about these issues of developing a strategic approach, not getting 'stuck' with a patient, and working towards goals, if you had unlimited time to spend on these things, how would you use it?

v individual differences - personality

- 10 There are also other issues that were raised by GP's in relation to the importance of the doctor-patient relationship. There were certain issues that GP's talked about frequently, but didn't expand on. These issues were: different patients having different personalities and different pain thresholds, the importance of 'knowing the patient', and the use 'gut feelings' on the part of the GP when dealing with chronic pain.

To what extent are these issues important to chronic pain particularly?

Can you say what you would mean when you talk about these issues?

SPECIALIST SERVICES FOR CHRONIC PAIN

Gp's identified several problems with specialist services in Lothian. As part of our research we identified 4 pain clinics. Knowledge of these varied and GPs reasons for referring patients to these clinics were often based on factors other than what the services had to offer. So in the next stage of the interview I'd just like to go through in broad terms the problems and advantages that the pain clinics offered, and some of the reasons that GPs referred their patients there.

- 1 One of the main problems was in terms of the waiting times and some GP's were deterred from making a referral at all by the perception that the waiting time would be 9 months. There was several reasons why this was a problem. Firstly, it was felt that after 9 months the kinds of help in rehabilitation would be too late and patients would already be stuck in their behaviour patterns. Secondly, the wait tended to build up peoples expectations, and thirdly, it could slow down the process of people getting on with their lives. Which if any of these reasons would you agree with - would you like to add anything to them? Are there any ways in which the waiting time can be used helpfully?
- 2 The main things that GPs found helpful about pain clinics were: that they felt they learned a lot about different approaches, particularly about pharmaological aprooches to the management of pain and therefore increased their own skill level; that the pain clinics reassured them they as GPs hadn't missed anything in terms of different approaches to managing the patient; and also that sometimes it was important from the patients point of view to have seen an 'expert' and for them to be reassured. Would you agree with these issues and are there any others that you'd like to add?
- 3 In relation to the issue of the importance to patients of seeing an expert, our interviews with patients suggest that this might not be as important as GP's think it is.
Is it something that you've discussed directly with patients?
What is it that makes you think that it's important for patients to see an expert?
- 4 GPs reasons for referral to pain clinics were wide-ranging. I'll go through some of them with you: for their own reassurance that they hadn't missed anything; because they felt that that's what the patient wanted; that the long waiting times could actually form some sort of respite care for the patients and gave GPs a bit of a break; that referral to a pain clinic was a means of addressing the issue that patients had to get on and live with their pain; some GPs said that they referred to give patients access to associated services, particularly psycholgocial services when they didn't feel that they could refer directly to a psychologist or psychiatrist because the patient would feel that they weren't being taken seriously or would react adversely to the stigma that mental health services can imply.
Can you add to these reasons?

- 5 If we think about GP's reasons for referral, and take into consideration that most aren't based on clinical medical reasons, and that GP's often aren't referring in order to access specific clinical treatments, how do you feel about a service based in primary care being developed?
Do you have any ideas about how this might be achieved?
- 6 The sense that patients have of going through the health care system and trying to negotiate that is something that came out strongly from our patient interviews. Sometimes they felt a bit like a ping-pong ball, with one referral after another. Is there anything that could be done to reduce this, is this something that you ever discuss directly with patients. Is there anything that could be done to increase patients confidence in negotiating the system?
- 7 Some Gps felt nurses were important in providing information about a patients pain or problems that they were experiencing. Some Gps that it was helpful for patients to see a different GP in the practice. Taking these two things together suggests that there is scope for developing a team approach to the management of chronic pain. How much of this goes on informally and whats to be gained by perhaps addressing chronic pain management as a team issue more formally?

TRAINING AND EXPERIENCE

- 1 Most GPs felt that they'd learnt about pain informally, through experience rather than training. Are there any particular experiences or patients that you feel you learnt a lot from?

Have you made any 'breakthroughs' in terms of your knowledge of chronic pain and your approaches to managing it that others could maybe benefit from?

- 2 If you were offered the opportunity of a post-grad course in chronic pain management what would you like it to cover: would it be more in terms of medications or psychological aspects of managing chronic pain, different psychological techniques and would you be interested in multi-disciplinary training or not?

- 3 GPs mentioned their feelings of inadequacy and frustration when dealing with chronic pain and chronic pain patients. Is this something you identify with?

How much of it is an issue to do with chronic pain as opposed to particular types of patients?

How able are you to deal with your own reactions to problematic chronic pain patients - do you have a strategy for that and is this an area that could be developed as a team approach or which should be addressed in further training?

Are you aware that patients pick up on these feelings and that your own feelings of inadequacy have an impact on patients?

UPDATE ON CASES AND VALIDATORY QUESTIONS

- 1 In carrying out these interviews it appears that GP's are quite comfortable talking about pain up to a certain point, after which pain is talked about with reference to specific diseases, symptoms or sites rather than in and of itself. This point is not at any particular stage, and differs amongst GP's.
Firstly, what do you feel about this? Why do you think this happens?
Secondly, do you feel that when talking about pain it is useful to discuss it in terms of itself, rather than with any reference to specific types?
- 2 As we've just talked about, GP's tended to talk about pain in terms of specific types. The most commonly cited types of pain by GP's were back ache, arthritis, muscular skeletal pain, headaches, neuralgias, abdominal pain and neck pain.
To what extent is this list representative of your understanding of chronic pain?
- 3 In our previous interview you mentioned some patients ... how have these cases developed since we last spoke?
OR
Have you had any breakthroughs with particular patients since the last time we spoke? Tell me about them.
- 4 (To non-ref GP's) Can I ask how you picked the sample of patients that you gave us?

After the interview - One of the aims of this research is to develop ideas on post-graduate education and service development. Would they would be prepared to comment further on any ideas that we come up with? This could maybe be done over the 'phone and wouldn't involve another interview.