THE MANAGEMENT OF ELDERLY PATIENTS WITH PAIN:
A COMMUNITY NURSING PERSPECTIVE

Thesis submitted by

Janet M. Walker BSc., SRN, SCM, RHV

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Nursing and Health Care Research Unit
Dorset Institute

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The management of elderly patients with pain: a community nursing study

Janet M. Walker

ABSTRACT

This research project is designed to determine a plan of assessment and intervention, which can be used by nurses in the community to help elderly patients cope with painful conditions.

A theoretical model is developed, in which coping is defined in terms of the degree of control experienced over pain and other stressors. This model identifies emotional state as the indicator of coping at any particular time.

A study is described, in which subjects were 190 retired patients, who were being visited by a district nurse, and who identified that they had persistent or recurrent pain. Data on pain and coping was collected using semi-structured interview. Mood state was measured as the dependent variable. Independent variables for quantitative analysis included pain intensity ratings, pain duration, disability, health, personal and financial problems, age and locus of control. Qualitative data were collected to validate the quantitative findings. Questionnaire data were collected from nurses for purposes of verification and comparison.

Nonparametric correlations, and multiple regression analysis, identified that the variables which directly determined coping were feeling the pain to be under control, being occupied, feeling informed about the painful condition, having regrets and non pain-related personal problems (notably bereavement loss). Those who used active occupational and pain-relieving strategies coped better than those who adopted passive coping strategies. Patients generally valued supportive aspects of nursing care, particularly the provision of encouragement and confidence. Nurses systematically underestimated patients' worst pain and overestimated anxiety. There was a significant association between patients' pain complaints and perceived pain exaggeration. Few nurses used a pain assessment protocol, or had received formal education in the management of chronic pain.

These results are used to produce guidelines for the nursing management of elderly patients with pain in the community, with particular reference to assessment and intervention, based upon the nursing process.

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CHAPTER 1 INTRODUCTION

1.1 Background to the study

This thesis describes a research project which was initiated to investigate the nursing management of pain in the community. It originated from the premise that nursing theory must have direct relevance to nursing practice, in order to ensure competent nursing action (Akinsanya 1987a), and that nursing requires a distinctive body of research-based knowledge, based in the life and behavioural sciences (Akinsanya 1987b). In particular, the study was undertaken in response to concerns, voiced by nurses working in the community, about pain management in the home, and a realisation that there was a need to make better use of psychology in the nursing assessment and treatment of pain in the community (Akinsanya 1985).

The study itself represents in the region of 400 hours of interview time, during which 190 elderly patients provided detailed information about their pain experiences, their present and their past lives. These interviews could not take place without much preparatory work. This included introductory talks to groups of district nurses, briefing sessions with the nurses concerned at each stage of questionnaire distribution, and ultimately feedback and discussion of the preliminary results at group level. The process of data collection, for the main study alone, took a year to complete. The result is a rich mix of data about pain perceptions from the perspectives of the patients themselves, and the nurses who visit them.

Pain is almost always an unpleasant experience. We generally refer to the person who has pain as a 'sufferer', indeed pain and suffering are often regarded as being synonymous. We all think we understand the meaning of the word pain, yet it is primarily a subjective experience which others can begin to understand only by the way in which we communicate our feelings. In this respect it is both real and elusive. As nurses we so often share a sense of helplessness when patients' pain complaints remain unresolved despite our best attempts to help alleviate them. Alternatively, as Akinsanya (1985) pointed out, we may develop a resistance to so much suffering which helps us to cope with the situation but which leaves the patient to face their pain alone.

The nurse in the community faces a particularly difficult burden when confronted by patients in pain. Many of these suffer from chronic pain, and the nurse is often one of very few people with whom they have direct contact. There seem to be relatively few resources available to help combat pain in this situation. It is difficult to assess just how bad the pain really is when the patient's complaints are saved up from one visit to the next. Drugs may not work, or have side effects. The patient may be referred for specialist advice but, as is quite often the case, receives little long term satisfaction. Discussion with fellow nurses reveals that this scenario is not uncommon. Problem patients become a burden to their relatives, to nurses and general practitioners, to other supportive services and, not least, to themselves.

Past philosophical and scientific explanations of the pain experiences of patients whose pain persists have included pain as a means of manipulation, of expressing guilt or hostility, or of adopting the sick role (Bond 1984). These explanations appear generally unhelpful to nurses, since they offer little guidance in the management of persistent pain, and have tended to shape negative attitudes towards sufferers by increasing the tendency to label or blame the patient. The relationship between pain, emotional state, and behavioural response is complex, yet interventions may involve any of these three dimensions. How is the nurse to know which type of intervention is appropriate for a particular patient? It is often so much easier to try another prescribed drug, offer reassurance and hope that it will work this time. The price of failure is high for the nurse and the patient.

Melzack and Wall (1982) described pain as one of the most challenging problems in medicine. The challenge extends to the patient who tries to overcome pain, to carers who share the burden of pain, and to nurses who try to help in the management of pain.

This research was undertaken in the belief that community nurses have a significant role to play in improving the quality of life for patients who are elderly and in pain.

REVIEW OF THE LITERATURE AND RESEARCH ISSUES

1.2 The problem of the elderly with pain in the community

The number of very elderly people in Britain has increased dramatically in recent years (Rossiter and Wicks 1982). In 1981 those aged over retirement age accounted for about 15 per cent of the total population, of which 38 per cent were aged over 75. The latter proportion is expected to increase to about 45 per cent by the year 2000. Rossiter and Wicks reported that over 70 per cent of those aged over 85 suffer from some kind of disabling condition, while Masi and Medsger (1979) reported that as many as 85 per cent of those aged over 75 suffer from significant degenerative joint disease (osteoarthritis) and hence, it may be presumed, some degree of pain. They also recorded that rheumatoid arthritis was present in 10 per cent of persons aged over 65. Local inquiries revealed that other painful disorders common among the elderly include peripheral vascular disease, angina, neuralgias (including post-herpetic neuralgia), stroke and malignancy. The majority of these disorders involve chronic, rather than acute pain.

District nurses are involved in the personal care of at least 10 per cent of all elderly, chiefly for help with bathing (Potter and Hockey 1976). Potter and Hockey showed that more than 60 per cent of patients visited by district nurses were aged over 65, and that more than half of their caseload was made up of long-term sick, disabled or deteriorating. In some popular retirement areas, such as the location for this study, the proportion of those aged over 65 is particularly high at 23 per cent, compared to the national average of 15 per cent, while the proportion of those aged over 85 is double the national average (OPCS 1987). It is therefore likely that the percentages of elderly people being cared for by district nurses in such areas are much higher than those indicated above, and this is confirmed by local inquiry.

Hence the incidence of chronic and degenerative disorders within the caseloads of district nurses is also likely to be high.

Kratz (1978), in her study of the care of patients with long term illness in the community, found that nurses appeared to experience considerable difficulty in maintaining continuous levels of care for those long term patients who were not getting better. The number of visits decreased, and enrolled and auxiliary nurses were substituted for SRNs. This may well have been due to the phenomenon of burnout, as described Friedman (1980), in which feelings of inadequacy, frustration and depression occur in staff who have prolonged contact with the chronic sick, where suffering cannot be alleviated. Although pain was not a focus of the Kratz study, it is anticipated that such nurses' responses are relevant to situations involving chronic pain. Kratz suggested that nursing practices learned during hospital training may not always be appropriate for community care. Certainly nurse training in hospital mostly entails the management of acute pain, and this may not provide the knowledge and skills necessary for the effective management of chronic pain in the home.

There are very real problems which confront medical and nursing staff caring for elderly patients suffering from pain. Medical treatments for benign chronic painful conditions, so common in the community, often do not work effectively, nor are they all sufficiently widely available. Hip and knee replacements are usually highly effective in increasing mobility and eliminating or reducing pain, yet long waiting lists ensure prolonged periods of increasing pain. Meanwhile, general practitioners and nurses must endeavour to provide interim relief and support. Rose (1987) pointed out that the elderly are often vulnerable, lonely and anxious, but it is easier to give repeat prescriptions for pain and change the medication when the patient becomes 'a nuisance'.

The analgesics of choice in the treatment of pain in osteo and rheumatoid arthritis are aspirin and other anti-inflammatory agents. However gastrointestinal side effects are common and, once evident, preclude their subsequent use (BNF 1985). Mild painkillers, such as paracetamol, often have a limited effect in reducing arthritis pain, while stronger codeine-based painkillers cause constipation, especially in the dosages necessary to provide sustained pain relief. The continuous use of painkillers often leads to increasing tolerance levels and may prompt the search for more effective or stronger medicaments. Black (1980) suggested that where there is excessive or chronic use of sedatives, tranquillisers and analgesia there should be a complete evaluation of the patient's needs. In many instances withdrawal of drugs, or detoxification actually leads to a reduction in pain.

Many elderly patients are referred by their general practitioners to specialised rheumatology clinics for further medical help and receive such treatments as physiotherapy, hydrotherapy, wax and heat treatments which are of significant benefit in the short term. Few elderly people are referred to general pain clinics where nerve blocks, acupuncture, transcutaneous electrical nerve stimulation (TENS), biofeedback, hypnotherapy and psychological help are among the range of therapies used to treat a wide variety of disorders including osteo and rheumatoid arthritis (Marcer 1988). Harkins (1988) reported that less than 8 per cent of patients attending one multidisciplinary pain clinic were aged over 65.

These observations, together with the demographic figures given above, might lead to an anticipation of the presence of considerable suffering among the elderly in the community yet, while the prevalence of painful conditions is undoubtedly high, many old people seem to cope remarkably well in spite of considerable pain. Discussions with nurses involved in the care of elderly people have confirmed that the majority appear to cope well with life, in spite of significant pain and severe disability, yet others with similar physical problems seem to experience great difficulties. They become anxious, irritable, depressed, complain vigorously and make what appear to be unreasonable demands upon their carers and others who try to help. The needs of these patients deserve further investigation.

Akinsanya (1985) reviewed the role of the district nurse in the assessment and management of pain and identified the importance of knowledge of psychological considerations in the management of pain in the community.

She also highlighted psychological aspects of individual pain experience which, she felt, were likely to be misunderstood by nurses in the community, including coping mechanisms. There has been no research to date which has been designed to investigate pain management by nurses in the community. However information about the numbers of elderly people, the prevalence of chronic painful disorders and the problems faced by district nurses caring for patients with chronic diseases suggest that problems do exist and that research is required.

1.3 Pain research in nursing

Pain has been an important focus for research in nursing since the early 1970s. Among the chief areas of concern have been the management of acute post-surgical pain and the management of pain caused by malignancy. The majority of studies have been hospital-based.

1.3.1 Acute pain

One of the first nursing researchers in this country to demonstrate the importance of psychological management in acute pain was Hayward (1973). His classic study showed that preoperative information-giving could be very effective in reducing levels of post-operative anxiety and pain. Boore (1978) confirmed a physiological basis for this finding by showing that preoperative preparation reduces post-operative rises in the biochemical indicators of stress. Langer et al (1975) explored the nature of the information which was useful in reducing pain and anxiety and found that the teaching of coping skills, such as relaxation or distraction, were more important than information about the procedures to be undergone.

Sofaer (1984a) demonstrated the effectiveness of a nurse training programme, for surgical pain assessment and management, in reducing post-operative pain and anxiety. She found that not only was pain relief for patients improved, but that training in pain assessment was received with enthusiasm by ward nurses at all levels. Doctors were also found to be receptive to the objective information so provided. A more recent study by

Seers (1987) confirmed earlier findings of the relationship between pain and anxiety, but she noted wide individual variations between patients, which did not appear predictable. She recommended that individual assessment, and the recording of pain with the patient, were essential as a basis for pain management.

Wilson-Barnett (1988) drew a distinction between information-giving, teaching and counselling in helping patients to cope with illness and suggested that it is important for nurses to be able to recognise which form of support is appropriate in a particular situation. Dunnell and Dobb (1982), in a survey of community nursing, identified that 12 per cent of district nurses' time was given to counselling and reassurance, while 50 per cent was spent on technical procedures and practical nursing care, and only 2 per cent on assessment.

1.3.2 Cancer pain

In the field of cancer pain, numerous studies have examined the impact of different regimes of drug administration upon patient comfort. Stjernsward and Ozorio (1985) identified narcotic analgesia to be the mainstay of cancer pain management and suggested that the technology is now available to provide all patients with freedom from cancer pain. The use of narcotics is entirely appropriate in the relief of pain caused by malignancy, since the issues of tolerance and addiction are of little relevance. The aim is to provide sufficient doses of drugs at intervals which ensure the complete avoidance of severe pain. A review of the literature by Anderson (1982) identified that a comprehensive assessment of cancer pain should include the severity and duration of the pain, the nature of the disease, probable life expectancy, psychological state and the patient's occupational, domestic and economic background. She suggested, however, that a consistent approach to assessment appeared to be lacking, and that further research into the pain-related needs of cancer patients is needed. She commented briefly that the nurse-patient relationship can be a positive intervention in helping the cancer patient adapt to chronic pain, although this aspect of care appeared to have attracted relatively little research.

Cancer is a stressful illness for patients and carers, and it is arguable that optimum pain control cannot be achieved unless the patient's anxieties and fears are attended to. Murgatroyd and Hitch (1984) investigated some of the problems faced by nurses in caring for cancer patients. The key issue identified was that of communication. Nurses often did not know what the patient had already been told about their diagnosis and prognosis, while patients frequently felt that information was being withheld. The nurses felt themselves to lack the necessary skills for effective counselling, or for the assessment of the patient's psychological state. They found that good pain control was difficult to achieve, partly because of patients' reluctance to take analgesics. Only one nurse respondent mentioned the use of alternative methods of pain reduction such as comfortable positioning. The researchers also identified communication difficulties and lack of appropriate support when patients were returned to the community.

1.3.3 Nurses' perceptions of pain

The need for adequate pain assessment was reinforced in a series of studies by Davitz and Davitz (1981) into nurses' inferences of patient's suffering. They found a tendency for nurses to underestimate patients' pain, and overestimate their distress. However these results afford a limited interpretation, since the vignettes used gave medical and demographic detail, but little personal background information of relevance. Davitz and Davitz also looked at the effects of patient and nurse variables on nurses' assessments of patients' physical pain, illness severity and psychological distress. They found both the nurses' and the patients' ethnic background to be an important determinant of nurses' assessments of physical pain and psychological distress. This may reflect genuine cultural differences in pain response since their results were similar to those of Zborowski (1969) in identifying Jewish and Hispanic peoples as reacting more dramatically to pain, and nurses of North European background to infer less suffering.

Davitz and Davitz found that nurses who had experienced greater pain themselves inferred greater pain in others. They concluded that belief systems about suffering in others are influenced by individual experience and socially learned attitudes.

The issue of communication between nurses and patients was investigated by Johnston (1982). She found that other patients were more accurate in their assessment of patients' worries than were nurses. Nurses overestimated the number of worries but were not sensitive in identifying individual worries. Johnston reported that there was little evidence that nurses' inaccuracies were related to under reporting by patients or to social desirability influences. Nurses seemed able to identify issues which were potentially of general concern to patients, but were less good at identifying who was doing the worrying. Teske et al (1983) examined the relationship between nurses' observations of patients' pain and the patients' own reports. They found correspondence to be modest, though significant, but discrepancies were greater in the chronic pain sample than for acute pain.

Taylor et al (1983) used an experimental vignette method to investigate nursing attitudes towards different types of pain. They found that priorities in the administration of medication were related to the presence of identifiable pathology. Negative personality and behavioural traits were attributed to patients with negative signs of pathology, indicative of an organic / psychogenic model of pain. The data also confirmed the assignment of negative stereotypes to chronic pain patients.

The problems of patient stereotyping or labelling was the subject of a classic study by Stockwell (1984). She found, perhaps not surprisingly, that patients whom nurses enjoyed caring for were those who could communicate readily, were able to joke and laugh, and cooperated in being helped to get well. The least popular patients were those who grumbled, demanded excessive attention, were hostile, or whom the nurses suspected of malingering, including those without a firm diagnosis. One particular unpopular patient (p.47) was identified as a woman who was very crippled with rheumatoid arthritis, and who became cross and sarcastic when kept waiting for assistance. As a consequence, nurses tended to leave her until last thus, presumably, perpetuating the problem.

Copp (1974) explored the pain experiences of 148 persons in hospital. She found that patients' own pain remedies were often discounted by nursing staff in hospital as unscientific. She also identified individual differences in pain responses and coping strategies which she has subsequently categorised into a typology of five pain postures (Copp 1987a). These were:

victim - where the sufferer is hopeless and coping is passive.
combatant - where the pain is seen as invading, coping is active and confronting.
responder - where meaning is sought and coping is analytical.
reactor - where pain is seen as cunning, coping requires vigilance therefore medication may be refused.
consumer - where pain is demanding, pain relief an expected service and coping a process of negotiation.

It is suggested that understanding these perceptions and coping strategies might provide an aid to the formulation of nursing goals for treatment and care. Copp (1987b) stressed that a nurse acts as pain therapist, evaluator, negotiator, advocate and care planner / provider, and that nursing assessment must include patients' expectations, perceptions and coping strategies.

1.3.4 Pain assessment in the home

The studies outlined above all concern patients in hospital under close nursing scrutiny. Few research studies have examined the nursing needs of patients who cope at home with pain. One such was by Raiman (1986) who examined the use of a home pain diary as an aid to pain assessment in a small sample of terminally ill patients being cared for in their own homes. The results showed the diary to be of significant benefit to nurses in improving pain assessment and communication. No study has yet examined the specific nursing needs of patients in the community who experience chronic benign pain (Walker 1987a, b).

1.4 The nursing management of pain

Assessment is the foundation, not only of pain management, but of the nursing process. This is a systematic approach to nursing care which is currently taught in all schools of nursing and which is supported by the General Nursing Council (GNC 1977). It is based upon a scientific problem-solving concept and consists of four stages: assessment, planning, implementation and evaluation. The nursing process provides nurses with a framework of nursing action, however it offers no guidance about the precise nature of those actions. For this reason a number of nursing models have been proposed which aim to identify patients' needs and how these needs might be fulfilled in nursing terms. These models have sprung out of a growing dissatisfaction with the medical model in favour of models which emphasise health rather than sickness, prevention rather than cure, and self-determination rather than dependence (Walker and Campbell 1989). They are all holistic models in which the patient is viewed as someone whose physical and psychosocial needs and problems are interlinked.

An holistic approach seems desirable in terms of pain management, yet in spite of these recent advances, there is evidence from the nursing literature to suggest that pain is neither given a sufficiently high priority within nursing, nor is it being adequately assessed. Analysis of the possible reasons for this (Walker and Campbell 1988) suggest that failure to consider pain as a basic need in popular models of nursing, and difficulties in the formulation of adequate care plans, contribute to present inadequacies. Care plans, based upon nursing models, generally provide a shopping list assessment of physiological factors, and psychological factors such as self-esteem and belongingness, but it may be difficult to integrate these as aspects of pain response without adequate knowledge of the nature of pain experience. Furthermore there seems to be little guidance as to how to act upon such information once it has been obtained. For example how is the nurse to intervene to improve pain patients' self-esteem? A more comprehensive analysis of these issues is given in Walker and Campbell (1989).

There are a number of very excellent general texts for nurses on pain management, including McCaffery (1979) and Sofaer (1984b), which highlight psychobiological and social aspects of pain, and contain recommendations for nursing practise. However recent studies (for example Carr 1989) continue to suggest that these are not being implemented.

1.5 Acute and chronic pain

It has already been suggested that one of the fundamental problems for the nursing management of pain in the community may be that the nurse's hospital training does not afford preparation for the ongoing problems of caring for older patients with persistent intractable pain. Furthermore there is actually very little information about the needs of such patients, since the majority of research into chronic pain has focused upon samples of pain clinic attenders. These are, as Crook et al (1989) observed, a select group of pain patients who have worked their way through the referral filter and show greater psychosocial problems. They also represent a relatively young age group. For example, in a study by Doan and Wadden (1989), based upon pain clinic attenders, the mean age of subjects was 39 years. Roy (1986) confirmed that the problems of chronic benign pain in the elderly have been largely ignored in the literature. It is not possible to assess pain adequately until research has identified which factors can be manipulated to maximise the effectiveness of interventions. Acute or chronic pain, benign or malignant pain, pain in hospital or at home, pain in the young and the elderly, may each require quite different nursing approaches.

Acute pain and chronic pain are generally afforded quite separate consideration in the pain literature since the differences, quite apart from that of duration, are apparently profound. Acute pain signals a warning of tissue damage caused by physical injury or disease, without which survival would be threatened (Melzack and Wall 1982). It produces physiological responses in the sympathetic nervous system, characteristic of the fight-or-flight pattern, and is associated with psychological symptoms of anxiety (Sternbach 1986).

Human beings are thus prompted to move away from dangerous situations, avoid, remove or reduce noxious stimuli, seek causes and treatments for underlying tissue damage and pathologies. Pain is, in fact, a basic human need state (Wall 1983).

Chronic pain is that which persists beyond the normal healing period and no longer serves a warning function. Continuous pain experienced over a prolonged period causes physiological disturbances consistent with autonomic habituation, such as appetite loss, constipation, insomnia, irritability and affective symptoms of depression (Sternbach 1986). Chronic pain may disrupt interpersonal relationships, lead to reduction of activity, loss of independence, financial problems and lowering of self-esteem. It may also lead to the development of maladaptive pain behaviours which interfere with successful treatment. Fordyce (1982) proposed that pain behaviours which communicate suffering are often reinforced and maintained by such social contingencies as the attention of doctors, or the taking over of responsibilities by a spouse. He made the point that once these behaviours are learned, they may be perpetuated even after the physical pain has subsided.

The distinction between acute and chronic pain cannot accurately be defined in terms of duration alone, since the acute phase of an injury or disease may vary considerably according to such factors as underlying pathology, severity or individual differences in healing. It does not seem particularly useful to define pain caused by a varicose ulcer as acute, if present for less than six months, and chronic if longer. Crue (1983) recognised this limitation and proposed an alternative taxonomy which distinguished recurrent from persistent pain, malignant from benign pain and adequate from inadequate coping. The main difficulty for research with elderly patients is that they often experience multiple pain problems, including chronic persistent conditions, fluctuating problems and acute episodes. Attempts to control for each or any of these factors will inevitably limit the selection of subjects, and result in a loss of meaningful information about pain experiences and responses. On the other hand the failure to take account of these distinctions may render the the final results impossible to interpret. These types of issue make a clear theoretical framework for research a necessity.

1.6 The gate control theory of pain and its implications

Traditional specificity theories of pain presumed a direct relationship between the pain experienced and the underlying organic pathological cause, such that the intensity of pain is proportional to the extent of tissue damage. According to these views, physical and mental pain are regarded as separate entities, whereby psychological causes for pain complaints are usually sought only once attempts to find a physiological explanation and treatment have been exhausted (Engel 1959). Many of these 'psychogenic' causes have been subjected to a psychoanalytic interpretation (Gibson 1982). Studies, such as that by Mersky and Boyd (1978) which sought to identify relationships between 'non-organic' pain, neurotic traits and disturbances in childhood, have featured frequently in the pain literature.

Melzack (1986) suggested that specificity theory was still being taught in most medical schools. However traditional theories about pain have recently undergone thorough revision in the light of the gate control theory of pain proposed by Melzack and Wall in the 1960s (Melzack and Wall 1982). The theory has had a profound effect upon current understanding of the nature of pain. It has been a major influence in most subsequent pain research, and in the development of new approaches to the treatment of pain.

It is not my intention here to consider the gate control theory of pain in depth, but to outline the theory insofar as it has potential implications for this research.

The theory describes the presence of large diameter myelinated (A-beta) fibres, which, together with small diameter myelinated (A-delta) and unmyelinated (C) fibres transmit signals from the peripheral site of injury to the dorsal horn in the spinal cord.

Here, in substantia gelatinosa, is located some kind of 'gating mechanism'. This is influenced to facilitate or inhibit the onward transmission of pain signals by the relative activity of the input fibres, and by the influence of descending control fibres from the brain via the spinothalamic tract (Melzack and Wall 1982). Descending inhibitory projections from the mid brain are subject to multiple influences, including somatic, visual and auditory projections to the reticular formation, and higher brain influences. It has long been postulated that psychological factors influence pain perception, however with the formulation of the gate control theory came the first indication of how this might occur at a physiological level. It opened up the possibility that pain signals could be *"facilitated or inhibited by sensory inputs, and by psychological factors so that pain is increased, decreased, or even abolished"* (Melzack and Wall 1982 p.227).

There is now a substantial body of research data to support the gate control theory. Frenk et al (1986) reviewed evidence in favour of multiple neural mechanisms which are capable of modulating pain perception, notably demonstrating the role of monoamine neurotransmitters in descending pain inhibition. For example, serotonin facilitates the release of encephalins. These are naturally occurring narcotic substances which act upon opiate receptors in the substantia gelatinosa to inhibit pain.

The chief propositions of the gate control theory, proposed by Melzack and Casey in 1968 (Melzack and Wall 1982), have remained essentially unchanged. They are:

1. The selection and modulation of the sensory input through the neospinal project system provides, in part at least, the neurological basis of the sensory-discriminative dimension of pain.

2. Activation of reticular and limbic structures underlies the powerful motivational drive and unpleasant affect that trigger the organism into action.

3. Neocortical or higher central nervous system processes, such as evaluation of the input in terms of past experience, exert control over activity in both the discriminative and motivational systems.

The theory has done much to illustrate the complex interactive nature of organic factors, perceptual information, arousal, cognitive processes and past experience, in the perception of pain. Pain is conceptualised as an experience which incorporates sensory, affective, discriminatory and motivational aspects (Melzack 1986). This concept affords a much broader approach to pain assessment and management.

Kim (1980) asserted that the general postulate, based upon the gate control theory, that psychological variables play an important part in pain perception, implies that nurses have a significant role to play in influencing patient's individual psychological processes, or in manipulating environmental variables that affect those processes. Yet she found this implication to be far from specific, and so failing to provide a pragmatic direction as what to do or how to do it. She suggested, at that time, that most research had concentrated on the identification of bivariate relationships between pain and, for example, anxiety, information, distraction and control. She recommended the implementation of multivariate studies in order to develop additional insights into the relationships between pain and other variables. She suggested that such studies would enhance the possibility of applying effective nursing interventions in pain management.

1.7 Coping with pain

One of the chief problems in assessing the importance of psychological factors in pain response is the issue of individual variation in the ability of different people to cope with pain. It is logical to assume that coping involves genetic factors, past learning experiences, information about the organic cause of the physical pain and the environmental circumstances in which the pain occurs. Patients' knowledge, skills, behaviour, and the situation surrounding the patient are all potentially open to nursing interventions. The identification of critical individual and environmental factors, which influence the ways in which people cope with pain, would directly enhance the possibility of providing effective nursing management for pain. In order to do this, it is first necessary to understand what is meant by the term 'coping' and to determine suitable methods by which it can be measured.

1.7.1 The coping concept

Fisher (1986) describes how the concept of coping mechanisms derives from a psychoanalytic view in which the individual's responses to situations are determined by his early experiences. Thus defence mechanisms such as projection, denial, repression and sublimation are functionally prewired as a result of adjustments to earlier tensions between the id, the ego and the superego.

In contrast to this view, the concept of coping as a rational conscious process was elaborated by Lazarus (1966) in relation to psychological stress. Lazarus described a stressful event in terms of a person or animal confronted by 'threat'. Lazarus (p.28) defined threat as *"the condition of a person when confronted with a stimulus that he appraises as endangering important values and goals"*. When a threat occurs, some behaviour, or psychological process, is activated for the purpose of mitigating or eliminating it, and it is this activity which is called coping. According to Lazarus, stress is indicated by four main classes of reaction: affective disturbances, motor-behavioural reactions, cognitive changes, and biochemical and autonomic physiological changes. He identified (p.208) that *"observable threat and stress reactions are reflections or consequences of coping processes aimed at reducing threat"*. It is hence logical to assume that the same four classes of reaction also provide measures, or indicators, of how people are coping with stress.

Lipowski (1970) provided a thorough analysis of coping, based upon the concept introduced by Lazarus. He defined coping (p.93) as *"all cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment"*. Lipowski distinguished between coping style - individual predisposition to deal with challenges; and coping strategies - techniques actually used to deal with illness. He suggested that coping may be evaluated as adaptive or maladaptive, depending upon its appropriateness to the patient's age, situation and effectiveness in achieving maximum possible functional recovery or compensation. A common maladaptive coping strategy is identified as that of regression, or passive withdrawal, whereas adaptive coping is generally identified with active strategies.

Lazarus and his colleagues have continued to expand the theory of coping. Folkman (1984), described the distinction between primary and secondary appraisal processes in response to situations of threat. Primary appraisal consists of the appraisal of harm / loss, threat or challenge. All are directed towards expectations concerning the future, however whereas harm, loss and threat are all associated with negative predictions, and hence with negative emotions, challenge is directed towards what might be gained, rather than lost. Secondary appraisal involves an evaluation of coping resources in which the individual decides what he can do about the situation. Coping resources include physical, social, psychological and material assets, which are judged in relation to the demands of the situation.

Lazarus and Folkman (1986) suggest that coping is a multivariate, multiprocess system in which no single variable, whether in the environment or within the person, whether causal antecedent, process or outcome can alone define stress. All the variables in the system contribute to the appraisal of stress and its emotional effects. They emphasise that stressful situations cannot be measured on any objective scale, since stress is defined by the way in which a situation is interpreted by an individual. Thus stress is a relative phenomenon which is cognitively mediated. It is also a process of constant recursive change in which the environment influences the individual which, in turn, influences the environment.

Folkman (1984) defined coping as *"cognitive and behavioural efforts to master, reduce or tolerate the internal and / or external demands that are* *created by the stressful transaction.*". Lazarus and Folkman (1984) expressed a preference for the term 'management', rather than mastery, as the aim of coping with stress. This was because they felt that certain stressful events, such as aging or terminal illness, were not amenable to mastery, but could be successfully managed. They distinguished between coping and adaptation and suggested that coping requires the mobilisation of effort, while adaptation includes routine or automatic modes of getting along.

In considering the determinants of coping, Lazarus and Folkman suggested that environmental ambiguity was often associated with uncertainty and hence with coping difficulties. They suggest that ambiguity is common in the social context in which most people operate, where information is not always clearly provided. However they also point out that there may be circumstances in which such ambiguity might enable an individual to construct a hopeful interpretation in a situation such as that of terminal illness.

Folkman (1984) described two distinct functions of coping. Firstly it serves to regulate emotions or distress (emotion-focused coping). Secondly coping involves the management of the problem which causes the distress (problem-focused coping). It is suggested that emotion-focused coping is aimed primarily at relieving emotional distress since it is argued that negative emotions may interfere with problem-focused forms of coping. Problem-focused coping involves problem-solving, decision-making and / or direct action. Neither Folkman nor Lazarus provide a clear explanation as to why emotions, rather than the cognitions which give rise to them, should impede problem-solving. Indeed Folkman suggests that emotion-focused coping can be used to alter the meaning of a situation, thus suggesting that cognition is really the key element in this type of coping. She presents evidence to suggest that the type of coping associated with positive outcome, as determined by the number of psychological symptoms, depends upon the match between the appraisal of controllability in a stressful encounter, and the extent to which the situation is actually controllable. A good match is a prerequisite for an adaptive outcome.

One way in which individuals cope with, or adapt to, situations of illness or pain is by changing their behaviour to reduce symptoms or elicit the help of others. Mechanic (1961) introduced the concept of illness behaviour to describe the ways in which symptoms are differentially perceived, evaluated and acted (or not acted) upon. He identified such behaviour as learned, and hence subject to individual, family and cultural variations. His analysis of the learning processes involved in the development of illness behaviour led him to propose (p.193) that individual decisions to seek medical aid will be influenced by:

1. The commonality of incidence of an illness in a given population
2. The relative familiarity of symptoms
3. The relative predictability of the outcome of the illness
4. The amount of threat and loss likely to result from the illness

Pilowsky (1984) applied the concept of illness behaviour to chronic pain. He described cognitive style and level of functioning, affective status and overt behaviour as important components of the assessment of pain behaviour. He suggested that cognitive aspects will be influenced by personality structure and developmental history (which together determine cognitive style), and the availability of information about all aspects of the painful condition. Affective status is described as dependent upon the meaning of the pain to the patient. The main affects encountered are depression, anxiety and anger. Behaviour may facilitate recovery or rehabilitation, or it may be maladaptive or abnormal in which, Pilowski suggests, there is disagreement between patient and doctor as to the nature of the sick role to which the patient is entitled. Abnormal pain behaviour is termed malingering when consciously motivated and is, he asserted, associated with psychotic or neurotic disorders. It is evident, from Pilowski's analysis, that pain behaviour is analogous to pain coping, and that the cognitive, affective and behavioural components of pain behaviour reflect pain coping processes.

Pilowski's research has been concentrated in the sphere of chronic benign pain, however Dalton and Feuerstein (1988) reviewed evidence to suggest that the same coping processes prevail in patients with cancer pain. They reported a dearth of research in this field into coping strategies, psychological characteristics and environmental factors.

1.7.2 Pain coping research

Research studies have been designed to identify the efficacy of coping strategies that people use in order to control their pain or decrease their level of pain. Rosenstiel and Keefe (1983) explored the efficacy of cognitive and behavioural strategies, based upon the development of the Coping Strategy Questionnaire (CSQ). They identified six possible cognitive coping strategies: diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, praying or hoping, and catastrophising. Two behavioural strategies were identified: increasing activity level and increasing pain behaviour. Each strategy was measured by a subscale of six items. Pain ratings and rating scales for depression and state anxiety were also administered. Pain history included disability status and pain duration. Subjects were 61 chronic low back pain patients with a mean age of 43 years. Principal component analysis of coping strategies revealed 3 factors: cognitive coping and suppression, helplessness (including decreased activity levels and decreased control over pain), and diverting attention and praying. Multiple regression analyses were used to identify the relationships between coping strategies and pain history (the independent variables), and measures of adjustment: pain, mood and functional capacity (dependent variables). They found that coping strategies accounted for a significant proportion of the variance for all measures of adjustment. Cognitive coping was found to be associated with functional impairment, helplessness with depression, and anxiety and diverting attention with higher pain levels and functional impairment. Some of the coping strategies, such as catastrophising, were identified as maladaptive, since they were associated with poor emotional adjustment. The authors suggest a counselling approach to these patients.

A subsequent study of patients with osteoarthritis of the knee (Keefe et al 1987) confirmed the above results. They identified the coping factor comprising catastrophising, inability to control pain or decrease pain, as most predictive of anxiety, depression, pain, immobility and lack of dexterity, in a sample of 87 patients whose mean age was 63 years. Brown and Nicassio (1987) sought to distinguish between the use of active and passive coping strategies in a sample of rheumatoid patients whose mean age was 53 years. They found that patients using active coping strategies (keeping busy, reading, distraction, exercise) tended to have higher internal health locus of control and self-efficacy, and lower depression, helplessness, pain and functional impairment. In contrast passive coping strategies (wishing, relying on others, suppressing feelings) were associated with the opposite pattern, and poorer adjustment.

The positive nature of the relationship between activity and pain coping is supported by behavioural research. Fordyce (1982) cited studies which demonstrate behavioural treatment approaches to be instrumental in increasing activity levels and reducing pain medications. A study by Skevington (1983a) showed activity level to be an important indicator of illness behaviour in chronic pain patients, and Roberts (1986) outlined a successful operant programme designed to increase exercise and activity levels, so reducing disability and need for analgesics. While Fordyce referred specifically to behavioural programmes for people with post-traumatic chronic pain, Keefe (1987) suggested that a behavioural approach might also be appropriate to help increase activity and reduce pain-related problems in patients with osteoarthritis of the knee.

Attempts to find a direct relationship between pain levels, pain behaviour and subjective pain experience have generally failed. Richards et al (1982) found that the relationship between observable manifestations of pain, using behavioural measurements, and self-reports of pain experience did not appear to be close.

This highlights the need to collect multidimensional data concerning the patient's pain and pain experiences from as many sources as is feasible.

Although coping is defined in terms of thoughts, feelings and actions, research into the effectiveness of coping strategies tend supports the view that coping is primarily an active cognitive and behavioural process in which poor or maladaptive coping is identifiable by negative mood states and passive attitudes.

1.7.3 Coping as control

Janis (1962) suggested perceived control, or sense of mastery, over events to be a major determinant of reactions to stressful life events. Janis proposed that the person threatened with loss of control over a situation would strive to regain control but, if unsuccessful, would develop feelings of helplessness and depression. Based upon this definition of stress, perceived control would appear to an important element in coping. In fact the definition of coping *"dealing successfully with an event or gaining control over it"* (Vogel 1985) makes it clear that coping and control are synonymous in the sense that to cope with an event is to gain and / or maintain control over it.

Frenk et al (1986) examined evidence of the relationship between psychological stress and pain. They suggested a direct link between psychological control and pain mechanisms with the assertion (p.37) that *"controllability or coping factors and not simply exposure to stress per se may dictate the impact of stressors on endogenous mechanisms of analgesia"*.

There is considerable evidence in favour of the relationship between stress, stress responses, predictability and controllability. Bowers (1966) identified that perceived lack of control increased reports of pain and anxiety due to electric shock, although he suggested that personality factors may interact with perceived control in the production of anxiety. Mandler (1972) identified anxiety as a general state of helplessness. He argued that arousal turns into anxiety when no situationally or cognitively appropriate behaviours are available. Mandler (1982) suggested that it is perceived lack of control in any situation, rather than lack of actual control, which gives rise to feelings of threat and anxiety. Thus the interpretation of an event can radically influence the stress reaction, and control is subjective, rather than objective. Mandler asserted that a sense of mastery reduces the deleterious effects of stress, and alleviates the subjective sense of emotional disturbance. Glass and Singer (1972) argued the importance of predictability and perceived control as determinants of responses to stress, and Garber et al (1980) confirmed that anxiety occurs in situations which involve uncertainty, unpredictability and uncontrollability.

Seligman's learned helplessness model of depression (Seligman 1975) has stimulated a wealth of clinical and experimental control research. Central to Seligman's theory, which was formulated in the animal laboratory, is the concept of uncontrollability, defined as learned non-contingency between actions and outcome. Maier and Seligman (1976) identified that uncontrollability was associated with behavioural, cognitive and affective deficits so that, in future situations, not only did the animal fail to respond, but it predicted a negative outcome and showed affective symptoms of depression. Seligman's model of learned helplessness was reformulated, by Abramson et al (1978), for application in human situations, using attribution theory. They proposed that, in uncontrollable situations, people attribute their helplessness to a cause which may be stable or unstable, global or specific, internal or external.

Internal and external attributions of control are central to the concept of locus of control outlined by Rotter (1966). Locus of control describes a person's generalised set of expectancies about the source of control in a particular situation. Thus a person might anticipate that an outcome is contingent upon either his own actions, those of others, or is due to chance. Phares (1976) examined research evidence regarding internal versus external control and concluded that internal locus of control is generally associated with lower anxiety in situations of threat than externality.

Internal locus of control is similar to the concept of self-efficacy (Bandura 1977) in which expectations of personal mastery affect both initiation and persistence of coping behaviour. Bandura suggested that the most potent source information about personal efficacy comes from performance accomplishments, since they have an authentic experiential base, while social persuasion is likely to be less influential. Bandura also proposed that aversive experiences create expectations of injurious effects which activate both fear and defensive behaviours. High emotional arousal is maintained until effective coping behaviours are achieved.

Miller (1980) explored aspects of experimental controllability which influenced stress responses and found that, although individuals generally choose to retain control over aversive stimulation, they do so only for as long as they believe their own response is the most stable factor for limiting danger. They relinquish control to another person when they believe that the other individual has a more stable controlling response. She found, in an experimental situation, that those with internal expectations of control generally showed higher anxiety levels than those willing to yield control to a stable external source. Miller states that the data are consistent with the view that stability (predictability) of the situation is an important element in determining emotional outcome, such that uncontrollability will be preferred under conditions where external factors are construed as more stable than internal factors. It is evident that Miller equates the relinquishment of control to an external source with uncontrollability, whereas Maier and Seligman (1976) identified uncontrollability in terms of non-contingency between response and no-response. This highlights the need for careful interpretation of experimental data regarding control.

An additional problem for control research was highlighted by Piper and Langer (1986), who drew attention to the fact that much past work on control has been somewhat limited by adopting the perspective of the observer or experimenter, rather than that of the actor or participant, and this may have led to theoretical flaws and false predictions about controllability in experimental situations.

Maier and Seligman (1976) distinguished active from passive control. Active control corresponds to personal (internal) control where the organism acts to obtain an outcome. Passive control is inactive, the organism waits until an external factor in the environment provides an outcome. Another important aspect of the active nature of personal control has been identified by Skinner (1986). She proposed that control beliefs, the degree of control perceived by an individual in a given situation, are determined by the frequency of confirming actions, relative to disconfirming actions. Those who engage in a greater number of actions are more likely to have opportunities to confirm their control beliefs from direct experiential evidence. Thus active engagement is an important prerequisite for control.

Bandura (1982) suggested that people are not social isolates, therefore coping with difficulties often involves collective effort. He suggested that social support systems reflect collective efficacy. He also identified that some social situations may undermine personal efficacy by limiting opportunities for competence.

A final important issue in the study of control is that anxiety and depression are both caused by stress, and are both associated with uncontrollability, yet they give rise to quite distinct sets of behaviours, cognitions and emotions. Garber et al (1980) acknowledged this apparent confusion. They identified that, although belief in uncontrollability is common to both anxiety and depression, anxiety is characterised by uncertainty, while depression is characterised by hopelessness. Tache and Selye (1986) identified anxiety as a short-term consequence of stress while, in the context of Selye's General Adaptation Syndrome (GAS) (Selye 1956), depression is a longer term generalised consequence of unresolved stress which may be due to either physiological or psychological factors. This is congruent with findings, noted above, that anxiety is associated with acute pain and depression with chronic pain. Time scale may therefore be an important element in determining responses to a stressful painful event.

1.7.4 Pain coping research and the controllability concept

Uncontrollability is a common feature of some chronic painful conditions. Wiener (1984) suggested that rheumatoid arthritis patients learn that their disease is not only incurable, but that its manifestations are unpredictable. They are haunted by uncertainties which increase as the disease progresses, yet they are often told to 'learn to live with it'. Skevington (1983a) investigated beliefs about control in depressed chronic pain patients, including rheumatoid arthritis sufferers, using pain locus of control measurements which included the three categories: internal attributions, chance happenings and powerful doctors. She identified that their helplessness was universal in the sense that, while they did not believe that they were personally to blame for failure to control events, they believed that nobody was able to help them. In other words, they believed that neither they nor anybody else could do anything about their pain. Skevington (1983b) identified perceived control, not only over pain, but also over situations in which chronic pain patients find themselves, as a central issue for chronic pain research. She recommended that involvement in decision-making processes about treatments may be an important psychological factor in recovery, in reducing disillusion and resentment towards doctors, and in alleviating depression. Likewise Raiman (1986) suggested that involvement in assessment gives the patient a feeling of increased control over his own pain. Skevington (1986) asserted that attitudes, beliefs and expectation about pain, illness and the control of pain have not been examined in any systematic way, even though research increasingly shows that perceptions of being in control (whether real or illusory) lead to better mental adjustment and ability to cope with chronic disease, than those of uncontrollability.

Crisson and Keefe (1988) investigated locus of control in relation to coping strategies and psychological distress in patients attending a pain management programme (mean age of the sample was 47 years).

Using the CSQ, they found that patients who regarded outcomes as controlled by external factors, such as chance, tended to rely upon deficient or maladaptive pain coping strategies, and exhibited greater levels of anxiety and depression. They suggested that treatment should include educational instruction in self pain management, and behaviour therapy techniques aimed at improving coping skills and hence increasing personal control.

Research into controllability shares many commonalities with coping research. Both highlight the importance of cognitive, affective and behavioural elements. Both identify aspects of coping style (generalised expectancies or personality), and strategies (cognitions and behaviours) which will influence the ways in which an individual facing a stressful or painful situation will respond. The chief difference is that of psychological perspective. Much coping research is derived from psychoanalytic psychology, whereas research into the concept of controllability derives directly from behavioural research. In order to make use of relevant research findings from the literature on each, it is necessary to appreciate that, though the terminology is often quite distinct, and the underlying philosophies may differ in perspective, they are both describing the same phenomenon and often appear to reach similar conclusions. Research into pain coping and control, from both sources, suggest that the following principles of management apply to all stressful situations, including those in which pain is the predominant feature:

1. personal control can enhance coping.
2. Personal control is influenced by past experiences of control, and the predictability, or certainty, of the current situation.
3. active strategies for coping are preferable to passive ones.
4. accurate and adequate information is a prerequisite for coping.
5. anxiety, depression and anger are affective responses to threat, coping difficulties or uncontrollability.
6.. cognitive and behavioural responses may be classified as adaptive or maladaptive, depending upon their appropriateness or outcome.

The nature and extent of stress responses may also depend upon time scale and the magnitude of the stressful event, nevertheless there is considerable theoretical and empirical evidence to suggest that the above principles are universally applicable in all types of stressful situation.

Given that personal active strategies have been identified as those most likely to maintain control, therapies which aim to increase activities should also increase overall control, as well as pain control. There has been a substantial body of research to demonstrate that operant programmes can be successful in increasing activity levels, and in reducing medication, depression or pain levels, depending upon the outcome criteria used (Linton 1986). Linton suggested that research was still required to identify treatments which are most economical and effective, and which are most likely to lead to improvements which are maintained.

Dalton and Feuerstein (1988) reviewed the current literature on biobehavioural factors in cancer pain and identified omissions in research into the role of perceived control as a modulator of pain and response to treatment, the influence of coping strategies and pain behaviours, and the role of social support. Tunks and Bellissimo (1988) recently called for clarification of the term 'coping'. They suggested that basic research is required to address the fundamental issues in coping and how to measure it.

1.8 Coping with old age

It has already been identified that the subjects of this study are not only coping with life in pain, but with other problems, or advantages, conferred by old age. A stereotyped view of 'old age' is unhelpful, particularly in this day and age when more and more people are surviving to enjoy active retirement. Nevertheless elderly people must cope not only with pain, if they have it, but with many other problems that have increased probability, or are accentuated, by the fact of being old. Past personal observations, many of which are confirmed by Twining (1988), suggest that these include moving house and / or changing locality (many move to retirement areas or to smaller properties), loss of close relatives and friends, increasing health problems, including diseases such as diabetes and respiratory disorders, increased disabilities, for example loss of mobility, urinary incontinence, impaired eyesight and hearing, and the possibility of intellectual and memory impairment.

Chaisson-Stewart (1985) investigated these problems of old age as potential causes of depression. She described the stressors faced by old people in terms of loss (e.g. role, mobility, income), attack (e.g. illness, pain), restraint (e.g. poor health) or threat (e.g. suffering, death). She maintained that even the well elderly must fight to maintain self-esteem in a society which fears old age and death. She also identified loss of worth, evaluated by loss of skills, abilities and occupation, as a cause of depression in the elderly.

Depression and loss of self-esteem are common phenomena in the elderly (Roy 1987) caused, at least in part, by increased vulnerability to the physical, environmental and social factors identified above. Williams (1986) investigated depression on two separate occasions in a sample of 133 middle-aged and elderly persons and found subjective health, pain, death anxiety and income to be the best predictors of depression at the time of initial measurement. At the second measurement they found that only a change in pain was predictive of changes in depression scores. Pain, therefore, appears to be a significant contributory factor in depression in the elderly.

Of direct relevance to the relationship between control and activity is the activity theory of aging outlined by Knapp (1977). Based on earlier work, the theory identifies a positive relationship between level of participation in social activity and life satisfaction in the elderly. Knapp provided support for the theory in a study which demonstrated that measures of current activity and social participation were good predictors of contentment and fulfilment. These factors included hours spent in contact with kin, in productive pursuits, social activity, with associations and organisations, and in employment. Brandtstadter (1984) suggested that emotional reactions to aging are closely related to action regulation and control, where control is an active process of information seeking and problem solving.

Evers (1981) suggested that activity theory formed the basis of DHSS directives for geriatric hospital care. These recommend the promotion of physical and psychological independence while in hospital, and the creation of conditions where purposeful activity may take place, in order to promote patients' self-esteem and quality of life. However Bond and Bond (1987) present arguments which suggest that although active engagement appears to improve personal well-being in institutions, including day centres, increased active engagement will not necessarily lead to improvements in well-being. They suggest that there is little to choose between enforced activity and enforced inactivity, and that the nature of the setting may have an important influence upon generating spontaneous activity.

A number of studies have explored controllability and loss of control in relation to old age. A study by Schulz (1976) showed how significant short term improvements in happiness, alertness and physical health were brought about, in a sample of institutionalised old people, by providing control over the frequency and duration of visits from volunteers. However the ethical implications of this study were exposed in a follow-up study by Schulz and Hanusa (1978) in which they discovered that, 2 years after the termination of the study, subjects who had benefited were slightly worse off, in terms of zest for life, than those who had received no treatment. Increasing control by raising levels of personal responsibility in a nursing home setting was found to increase activity levels and reduce feelings of unhappiness (Langer and Rodin 1976). In this case an eighteen month follow up revealed sustained beneficial effects (Rodin and Langer 1977). Rodin (1986) suggested that these results demonstrate that the direct manipulation of environmental factors, through the exercise of control, can impact on health-relevant outcomes in the elderly.

O'Brien (1984) reviewed the literature on locus of control in relation to aging and concluded that internal locus of control is associated with better adjustment and life satisfaction. While they found evidence that institutionalisation decreased perceptions of personal control, they found no support for a lowering of personal control in the elderly as a whole. Coleman (1984) explored self-esteem in the elderly and found it to be significantly lower among women aged over 75 and higher among those with an additional pension. The results identified those living independently in the community as having a much higher level of self-esteem than those in sheltered or institutional settings. Their sources of self-esteem were reported to include family contacts, independence, hobbies and interests, and work role.

Lazarus and DeLongis (1983) explored the dynamics of stress and coping in the process of aging. They observed that much of the research in this area concerned life satisfaction. Some old people manage poorly, while others manage well, even among those who are institutionalised. Lazarus and Delongis also examined commitments, and identified that when commitments are active they reflect an investment of energy and persistence of effort, whereas absence of commitments probably underlies a pervasive sense of meaningless. They suggested that a process perspective on coping was particularly important in the study of aging because of the imminence of widespread losses of roles and relationships.

Luggen (1986) investigated the pain experiences of ten selected elderly women in the belief that they might be different from those of younger age groups. She reported finding little information in the literature on which to base pain assessment and management decisions for the older age group. Her sample were all 'old elderly', widowed and on low incomes. She found that they had little social contact, experienced a number of medical problems, had pain of a high intensity for most of their waking hours, and were moderately depressed.

When she examined their coping strategies, she found that they used few medications, a variety of mobility aids, and cognitive strategies, such as praying, hoping, and self-statements about coping.

In addition to the physical and environmental problems which are likely to have impact on people as they grow older, there may also be differences in coping cognitions. Increasing age seems to bring with it, for many, an increasing need to justify past existence. As life recedes in front of them, many reflect upon past mastery. Marshall (1986) described this process as the 'legitimation of biography', and Erikson (1959) referred to the 'eighth identity crisis'. Coleman (1986) described a study of old people living alone in sheltered accommodation in London, in which he found a number to be very happy people who were coping well in spite of such difficulties as blindness, angina and arthritis. However he identified over one third of his sample as being significantly demoralised, admitting to feelings of depression and other mood disturbances. Some of these expressed considerable regrets about their past lives. As Coleman pointed out, inability to be content in one's own company can be hard to bear, particularly in view of the loneliness that so often accompanies old age.

Whitbourne (1985) described the construction of a life-span approach to coping with stress. Her analysis was designed to integrate the concepts of coping and adaptation using a dynamic developmental perspective which, she claims, is of particular value in gerontological research. She suggested that adaptation involves a continuous process of review of the past, present and future. Therefore the individual's appraisal of how his or her life has been shaped is an important element of development which will be reflected in cognitive and emotional frames of reference. She favoured a model which centres upon cognitive and emotional aspects of coping with stress, rather than a behavioural control model.

Kuhl (1986) presented a theoretical analysis of control in relation to aging. He suggested that perceived loss of control may accelerate the mental and physical concomitants of aging by reducing the individual's motivation to exercise control. He proposed that this may lead to a deterioration of cognitive and motor skills, an acceleration of psychological deficits by a reduction of physical exercise, by decreasing the level of neurotransmitters needed to maintain optimal mental and physical functioning, and by weakening the immune system. He stressed the importance of maintaining both mental and physical activity and suggested that an action-oriented and innovative attitude is associated with longevity.

Piper and Langer (1986) also highlighted the need to consider prediction and control as a mindful ongoing process. and suggested that care should be taken not to over-help the elderly. Karuza et al (1986) explored the relationship between helping and coping. Their analysis (p.377) identified two critical issues which determine people's helping behaviour in problem situations: firstly, establishing who is responsible for the cause (blame), secondly, establishing who is responsible for the solution (control). They examined a number of models of responsibility, in which individuals are seen as responsible either for causing or solving their problems. They suggested that whether an elderly recipient is blamed for their problem, or expected to take responsibility for its solution, is a product of prevailing beliefs and ideology of the helpers. Under the medical model, individuals are commonly stripped of any responsibility at all, however Karuza et al described a recent paradigm shift. Nowadays greater emphasis is placed upon community and family-based care for old people, rather than institutional care, and self-reliance and autonomy are encouraged among the elderly themselves. They suggested that this shift represents a move from helping to the encouragement of coping. This change is reflected in current nursing theory, as previously described, which has involved the rejection of the medical model and the introduction of models of nursing whose guiding philosophy is to help patients to help themselves. It is also embodied in current government philosophy, based upon the Griffiths Report (Griffiths 1988).

A major European study of people's needs for nursing care (Ashworth et al 1987) explored the nursing requirements of 707 elderly patients from 11 countries aged between 65 and 98, 167 of whom lived at home, the remainder being treated in hospital. They described, within their conceptual framework (p.34), the patient as an active participant in the nursing process - '*... someone who must cope with a multitude of events occurring simultaneously at all levels, physiological, psychological and social'*. They identified *a priori* factors which they presumed to influence the level of individual health. These included religious or belief system, family and community support, need and ability to be responsible for self and others.

The findings of the above study revealed that 40 per cent of their sample lived alone and 10 per cent had no close caring person. Between 20 and 30 per cent were totally independent for shopping and domestic care, and about half were totally independent with respect to personal care. Only half were engaged in social activities and 37.6 per cent did not participate in leisure activities, but those who did reported them to be of positive value to health. Religious or belief system was found to be important to a majority of participants. The most common medical problems were diseases of the cardiovascular and respiratory systems, and of the musculoskeletal systems. Half of the participants had experienced life events which, they felt, had significantly diminished their present health. These included death of someone close, an accident, or household move. 44 per cent of all elderly reported changes related to body movement and, for about half of these, this was associated with physical discomfort. One quarter of participants reported emotional change. The study showed that over 40 per cent of nursing objectives in the care of these elderly people were physical / physiological in nature, 27 per cent were psychomotor, 15 per cent concerned affective status and less than 5 per cent related to social / interactive factors. The largest category of planned nursing interventions for this elderly sample involved 'doing / acting for' the patient, although only about 8 per cent of the sample were totally incapacitated. 'Doing / acting with', and 'education and information-giving' were the other two main categories identified.

Atkinson and Sklaroff (1984) explored the care of disabled patients in acute hospital settings. They found that the communication of information was the most crucial factor associated with patient satisfaction, although a large proportion of patients seemed not to appreciate the nurse's potential role in this process. Robinson and Marcer (1979) investigated health beliefs among elderly patients and found that, while they were willing to maintain some responsibility for their own health in conjunction with the doctor, they tended to be either ill-informed or fatalistic about the possibility of preventing specific illness such as lung cancer or stroke.

In summary, the concept of control appears to provide a sound theoretical basis for understanding many of the problems and difficulties faced by the elderly, and for planning interventions. Active involvement, personal control, regrets about the past, negative life events, pain, information and religious beliefs all emerge as important factors in determining the well-being of the elderly. Although the present trend in health care is towards a model of self-care, recent evidence suggests that nurses still tend to act for patients, rather than help them to help themselves.

1.9 Carers and elderly people in pain

It has already been identified that many elderly people in the community either live with relatives, or rely upon relatives, or friends, for assistance or care. This study is primarily concerned with personal coping and nursing care, but neither can be isolated from a social context in which lay carers and helpers play a vital role. Years of personal experience of working in the community, have indicated that caring, like pain, is multidimensional and contains a mixture of perspectives. There are, by definition, at least two actors on the set, each with their own set of interpretations, expectations, behaviours and emotional responses. Patients may lie anywhere on a continuum from independence to total dependence. They may be sensitive to the needs of their carers or totally egocentric. Carers may be kind or insensitive, facilitative or domineering, calm or distraught.

The nurse's perspective adds a third dimension to, what may already be, a complex situation.

Many elderly people are married and live with their spouse, but a large proportion of very elderly are likely to widowed or single. Women are more likely to outlive their menfolk. The task of caring for aging relatives usually falls to women rather than men. In a study by Twining (1988), four out of five carers were women, one in five was a spouse and two out of five were daughters. The caring task is accentuated by the increasing numbers of elderly, and the expanding philosophy of community care, previously outlined. Belle (1982) described how women often carry job responsibilities as well as work in the home. Caring for an elderly relative may be an additional burden, for many of them. It is also inevitable, with the increasing age of many elderly, that many of these women will be approaching retirement themselves. Twining described how caring daughters often confront the conflicting demands of a growing family, husband and elderly parent.

Stueve (1986) investigated interactions between adult daughters and their elderly parents living separately, and found that contact was largely a function of proximity. Daughter's feelings tended to reflect their experiences of stress, rather the extent of involvement. Many of the daughters worked, and those with full-time jobs saw less of their parents than those with part-time jobs. Belle (1982) stated that the ability to provide social support is a precious human resource which can be destroyed by overload. Guilt is a common feeling among those who wish to care, but are faced with excess or conflicting demands on their time and resources.

Twining (1988) made the point that it is often very difficult for a frail older person to look at the demands of caring from the daughter's point of view. He also stressed that the quality, and the history, of the relationship are important. It can be very hard for either party to adopt a position of role reversal - former parent now cared for, and former child now carer.

The relationship may therefore contain many potential undercurrents of resentment on both sides.

Spouses commonly experience problems when their partner suffers a chronic painful condition. Roy (1986) pointed out that when one partner becomes incapacitated, a reorganisation of roles is required. He suggested evidence that the spouses of chronic pain sufferers are prone to the development of a variety of psychophysiological and psychiatric disorders through changes in interpersonal relationships, loss of emotional support and financial burdens, although this may be particularly true for younger patients. Roy suggested that a patient may use pain to avoid responsibilities, but equally the partner may treat the patient as an invalid and encourage a position of dependency. He proposed that a symptom, such as pain, creates a new homeostasis within the family which can often be observed from a clinical perspective. These observations are important to note, since the pattern of family interaction is likely to be reflected in the coping behaviour and emotional status of the pain patient and of any other family members involved.

Finally, an important theoretical aspect of caring concerns the nature of the social support conferred by the caring relationship. This aspect of social support is well reviewed by Gottlieb (1985). He identified that early research into social support compared its presence with its absence, rather than trying to identify its qualities. Furthermore much research had concentrated upon a psychological, rather than a transactional perspective. He identified that separation from significant others, passive or active rejection, interpersonal conflict, social isolation and the death of a loved one or friend were all events likely to trigger feelings of loneliness, and potentiate increased needs for support. Perhaps most interesting is his review of, what he described as, a vast literature on the importance of reciprocity in interpersonal relationships. This suggests that social support is contingent, not only upon support received, but on the symmetry or perceived equity of the exchange.

Gottlieb concluded by identifying major shortcomings in research into social processes and interdependence.

This brief insight into the caring situation is included in view of its importance to the nursing assessment of coping in the elderly. All of the factors described above, including the nature, as well as the presence or absence, of social networks and interpersonal relationships, are likely to influence the stress and emotional status of both patient and carer. They will, therefore, also influence the nursing management of pain, in the context of a family situation where the patient is not the sole consideration.

1.10 Summary

This introductory chapter is designed to explore issues which are of relevance to the nursing management of pain in a community setting, with particular reference to the existing literature. Chronic pain is identified as a common phenomenon, particularly among the elderly population in whom degenerative disorders have a high prevalence. It is observed that many patients appear to cope very well in spite of conditions which cause considerable pain, but that the nursing care of patients who have not learned to cope adequately is likely to be a problem. Nursing research has done much to focus upon issues in acute pain, pain in terminal illness and the importance of recognising sociocultural factors. It also suggests that nurses are not particularly good at assessing pain. The need for accurate pain assessment has been highlighted throughout the review of pain research in nursing, although the lack of a consistent approach has been identified, particularly at the level of application. The nursing process is now widely applied, however nursing interventions are dependent upon adequate assessment of the patient's nursing needs, and this is particularly important in the case of pain.

Differences between physiological and psychological responses to acute and chronic pain are outlined, which may indicate different requirements for management. The importance of psychological factors in pain management are emphasised, and provided with a firm physiological basis, by the gate control theory of pain. Coping is described as a central issue in understanding individual psychological responses to pain. Controllability is an important concept within current research into pain and stress, and appears to be synonymous with coping. Control is identified as an active process. Personal control is associated with positive mood, and hence good coping, whereas passive or external control is associated with depression. Coping with pain cannot be separated from coping with other stressors, and a number of studies have been outlined which show that elderly people are particularly vulnerable to stress, both at an individual level and within the context of their social situation. Elderly people in the community are not simply coping with pain, they are coping with life in pain. Therefore the nursing management of pain cannot be isolated from the context in which the pain occurs.

Coping, and hence control, has emerged from the literature review as a key focus for the nursing management of pain. If it is possible to compare coping across individuals who have pain, taking into account personal and environmental factors which contribute to the stress they are under, it should be possible to identify common factors which enhance, or mitigate against, pain coping. Such findings may then be utilised by nurses in their assessment of pain, and form the basis for nursing interventions in the management of pain in the community. In order to achieve this, it is first necessary to be able to measure coping and to identify the pain and general stress factors which might be expected to influence it. A reliable research design depends upon a strong theoretical model, particularly where a quantitative study is planned. The next section describes the development of such a framework.

CHAPTER 2 THEORETICAL MODEL

In order to study how patients cope with pain, it is necessary to have a clear definition of what is meant by coping, and to understand the relationship between pain, stress and coping. This chapter is concerned with the development of a theoretical model which will clarify these issues and provide a sound basis for the research design.

2.1 Theoretical Issues in pain research

The literature review highlighted the complexities of pain experience: the interaction of cognitions with physical stimulus in the perception of pain; the importance of controllability in relation to coping; the close association between pain, anxiety, depression and old age; yet each of these relationships requires clarification prior to the formulation of the research design. The most critical research issues arising from the review of the literature are identified below:

1. Is the distinction between acute and chronic pain really necessary and, if so, how should this be determined?
2. Is it possible to compare pain experiences across people with very different pain problems and diagnoses, including benign and malignant conditions, and, if not, according to what criteria should subject selection be made?
3. Is it possible to integrate the concepts of coping and controllability into a coherent framework, or alternatively which focus is most appropriate?
4. Elderly people are not only coping with pain, but with the problems of life in pain. Which other aspects of their lives is it necessary to consider and how can these be integrated with pain data?
5. Individual responses to similar types of pain seem to vary greatly. Much of the variation may be accounted for by differences in personality and past learning experiences, yet how can these influences on coping be measured or accounted for?
6. Is a quantitative or a qualitative research design most appropriate to meet the needs of this type of research?

7. If a quantitative approach is suitable, how might coping be measured and how can coping strategies be identified and quantified?

The literature review appeared to pose as many questions as it provided potential solutions, not least at the level of semantics. Terms such as coping, adaptation, mastery and control are used by different researchers, but may or may not have similar meanings. Stress and coping are variously described in behavioural, cognitive or emotional terms, or any combination of the three, though the interrelationships are not always specific. Tunks and Bellissimo reviewed the problems and stated:

> *"basic research in how to address the fundamental issues in 'coping' and how to measure it are still needed ... it is opportune to encourage research with novel strategies, and using comprehensive frameworks that attempt to address 'coping' within the simultaneous contexts of behaviour, physiology and cognition"*
> (Tunks and Bellisimo, 1988, p.174)

These observations support the decision to construct a theoretical model as a basis for this research. It is based upon the literature on stress, control, coping and pain. Little of the content is novel, rather it is a synthesis of theoretical approaches and research findings which were outlined in the introductory chapter. Much of it was formulated, from first principles, prior to the publication or availability of some of the articles previously mentioned, but they have since been found to support the analysis offered and add weight to its validity. Its development is detailed below.

2.2 Pain as stress

It has already been suggested that the short- and long-term physiological responses to pain appear to be identical to responses to other types of stressor. Furthermore, 'controllability' has been identified as a key concept in determining responses to both pain and stress. It is entirely logical to view pain as a stressor. Selye (1956) identified stress as a general response which results from either physiological or psychological disruption. Pain involves both damage to physical structural integrity, and psychological threat which arises from the perceived causes and inferred consequences of having pain.

Acute pain generates protective responses which are required to combat immediate physical threat, whereas chronic pain appears to require responses which not only meet the need to combat the pain but, where necessary, adapt to the continuing presence of pain. In the long term, the positive solution for the person in pain is either to find a direct way of controlling the pain, or to identify ways of coping with life despite the pain and associated disability . A range of possible responses to a painful event are illustrated in a descriptive model given in figure 2a. This is based upon Selye's General Adaptation Syndrome (GAS) (Selye 1956), the concept of threat proposed by Lazarus (1966), and responses to pain identified from a wide pain literature. It should be emphasised that these responses are not necessarily discrete and do not therefore represent mutually exclusive categories.

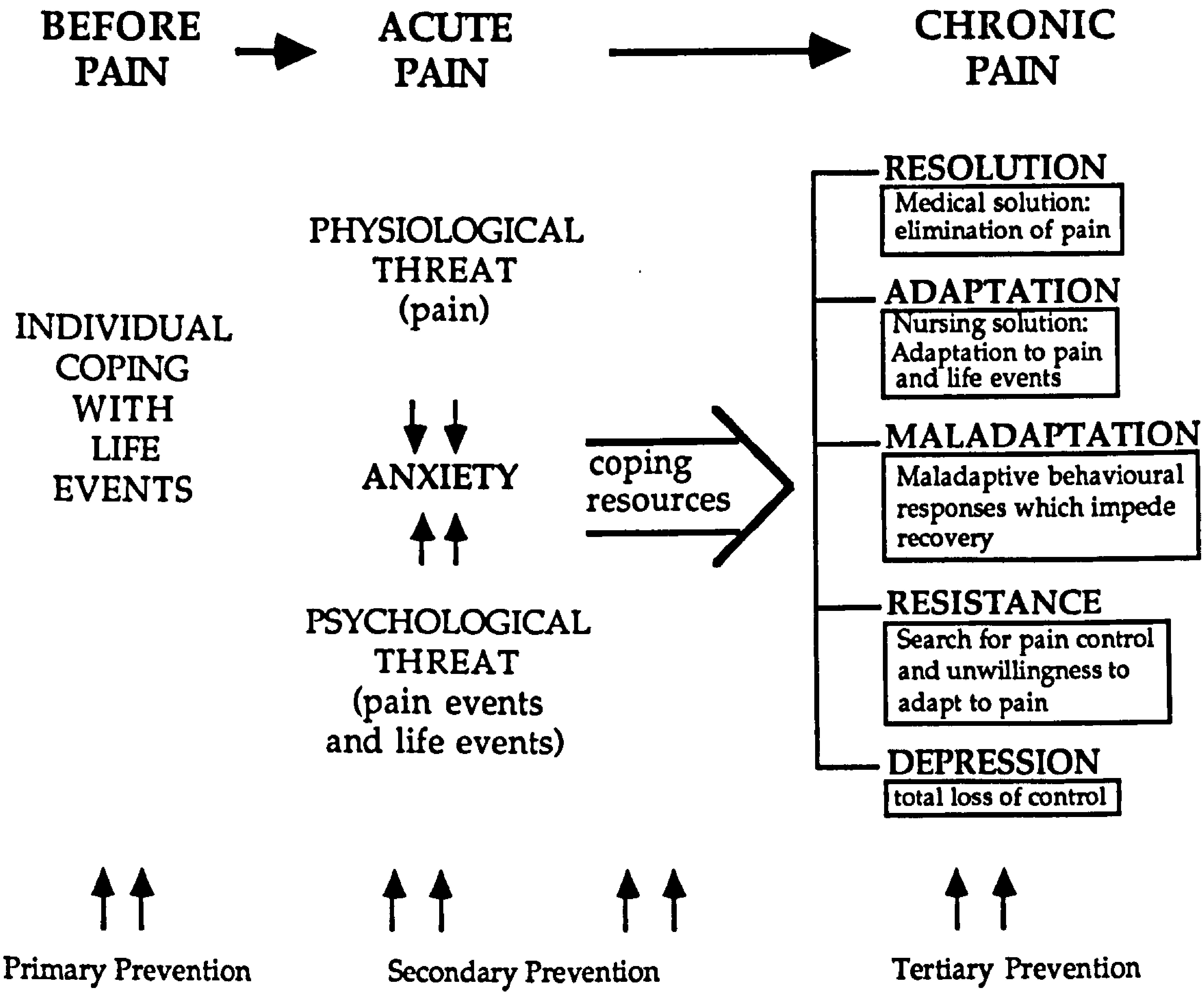


Figure 2a Descriptive model of pain experience

Figure 2a identifies an individual who is coping with life events prior to the onset of a painful event. Pain indicates a potential physiological threat to homeostasis, together with a psychological threat to the person's control over the situation in which the pain has occurred, and possibly future events. The degree of perceived threat, and hence anxiety, caused immediately by the painful event, depends upon the pain sensation, the information available about the nature, cause and potential consequences of the pain, and the individual's interpretation of all of this in relation to existing knowledge and past experience.

In the long term, there are a limited number of potential outcomes to a painful event which are determined by healing processes and available coping resources. These resources comprise personal, social and medical factors, including personality and attitude, available social and practical support, and the availability of effective medical or alternative pain treatments. The pain may be eliminated completely, either by natural healing or with medical assistance, in which case the pain never extends beyond the acute phase. The elimination of pain is identified as the medical aim of pain treatment, using the medical model. If treatments fail, and the pain becomes chronic, the patient may nevertheless learn to live it. This involves a process of psychological and physical adaptation, and is identified as a nursing aim in the management of patients with intractable pain, using an holistic model. In this context adaptation is defined in terms of the cognitive and behavioural adjustments which are required to facilitate the maintenance of control in the face of physical, environmental and social changes (including pain and disability).

Some patients, as has already been identified, exhibit maladaptive pain behaviours and responses. They are maladaptive because they mitigate against rehabilitation, give rise to emotional disturbance, or are identifiable as inappropriate or unstable. In other words they do not, in the long term, facilitate the maintenance of control. Maladaptive behaviours are, as Fordyce et al (1985) described, contingent upon external sources of reinforcement for their maintenance and are shaped by the responses of others, such as carers, nurses or doctors. These behavioural strategies may fulfil coping needs in the short term, but changes in circumstance, such as withdrawal of support, may well result in coping failure, unless effective adaptive coping strategies can be identified. It seems likely that those using maladaptive strategies will show emotional disturbances, such as anxiety, depression or hostility, if these methods of coping are not functioning adequately to maintain control. In the absence of any emotional disturbance, behavioural strategies are usually labelled as inappropriate, or maladaptive, from the perspective of others, such as doctors or caring professionals. This is often because the patient uses the sick role to make, what appear to be, unreasonable demands upon carers or statutory services.

The stage of resistance is so named because it is used to describe the responses of patients who desperately seek a medical cure for their pain, even though it may be inappropriate or unavailable. Meanwhile they resist the need to adapt to continuing pain and any accompanying disability. This often represents a transitional stage between acute and chronic pain, in accordance with the GAS, however there are a substantial number of patients who spend fruitless years in pursuit of physical relief, rather than accept the inevitability of their situation. These people live with unresolved threat and are therefore predicted to be highly anxious.

Repeated failure to adapt to pain, or to find a cure, will ultimately lead to feelings of loss of control and depression. Depression is identified within the GAS as a response to prolonged stress, and is recognised as a common physiological and emotional response to chronic pain (Sternbach 1986). Sternbach stressed that he referred specifically to continuous pain of several months' duration which gives rise to autonomic habituation and symptoms of depression. In terms of control, continuous chronic pain is inescapable and is therefore potentially uncontrollable. It is almost impossible to cope successfully with very severe continuous pain, as exemplified by post-herpetic neuralgia, and depression is common among sufferers.

Nevertheless feelings of depression are also associated with other types of chronic pain. Skevington (1986) identified that chronic pain patients, who suffer intermittent unpredictable pain, expressed feelings of helplessness and misery, even though they were not necessarily depressed in terms of the clinical definition. She suggested that these feelings may be influenced by other social, environmental and individual factors which mitigate against control, and hence interfere with coping.

2.3 Pain prevention and management

The pain model, outlined in figure 2a, identifies opportunities for primary, secondary and tertiary prevention. Primary prevention includes the provision of safety measures to prevent accidents, self-care behaviours to avoid injury and preventable painful disorders, and preparation for predictable painful events, such as surgery. Thus health education is seen as an important aspect of pain management. Secondary prevention includes treatment of the painful condition; pain reduction, based upon accurate pain assessment; giving information about the causes and consequences of the pain; and teaching strategies, such as relaxation and distraction, to help coping. If the pain persists, and cannot be completely cured or relieved, tertiary nursing measures are identified as those designed to enhance patients' control over their pain, minimise or reduce anxiety and depression, and help provide adaptive coping strategies. It is these secondary and tertiary aspects of pain management measures which this research is designed to identify.

2.4 Defining coping concepts

Coping has already been defined in terms of controllability. From the patient's point of view, to cope with pain is to gain and / or maintain control over it, even if it persists. It is hence a process of adaptation. The term control is defined by the researcher in terms of survival needs:

> 'control implies the emission of responses which are required to maintain physiological and ecological homeostasis'

This definition accords with observations by Antonovsky (1979) that (physiological) homeostasis is paralleled by learned mechanisms required to meet the needs of an ever changing environment.

In chapter 1, stress was associated with situations of threat, uncertainty, unpredictability and uncontrollability. The need for precise semantics has already been identified, and the terms, as they are to be used, are therefore defined below:

threat:	an event which is perceived to afford potential disruption to homeostasis, unless, or until, appropriate action can be taken to gain or maintain control over it.
uncertainty:	"I don't know what is happening"
unpredictability:	"I don't know what is going to happen"
uncontrollability:	"I don't know what to do about it"

Using the above definitions, it can be seen that uncertainty and unpredictability are both sufficient, but not necessary, causes of uncontrollability. If I do not know what is going on, or what is likely to happen, I am unlikely to know what to do about it. However possession of this knowledge is no guarantee that I will be able to act to control the situation.

A theoretical analysis which integrates these concepts is given in figure 2b. It is based upon contemporary theories of perception, learning, stress and the concept of control.

The model depicts a painful event which generates information. Here information is used in its broadest meaning to include every aspect of continuous input to all the senses which is both received and actively sought (Gibson 1966). It includes all that we see, hear, and feel by touch, proprioception and nociception. All of the information which is picked up is subsequently integrated and processed in relation to existing knowledge about the causes and consequences of similar events. This 'information processing' results in predictions about the likely outcome and hence the most appropriate response.

According to this model, physiological arousal occurs in response to any change in external or internal circumstances which threatens to disrupt physiological or ecological homeostasis. Disturbances of physiological homeostasis require internal compensatory responses. Ecological homeostasis is the term used here to describe the relationship between man and his physical and social environment, which is balanced to ensure survival. Disturbances to this require cognitive and behavioural responses. Evolutionary theory suggests that sympathetic arousal occurs in preparation for the responses of fight or flight in situations of threat. Simeons (1960) suggested that this response is redundant in modern man, however it is suggested, using this model, that it is necessary to prepare the person perceiving a potential stressor, such as pain, to investigate or appraise its causes and potential consequences in order to respond appropriately to the threat, restore control and thereby ensure survival.

There are a limited number of outcomes possible in any situation of threat. The individual may identify an appropriate course of action which resolves the situation (in this instance the painful situation), in which case control is restored. If that action is inappropriate, or has destabilising results for the individual in the long term, it is termed maladaptive control. Alternatively the individual may be unable to identify an appropriate course of action, either because the situation is perceived as uncertain or unpredictable, or because he lacks the knowledge or skills to be able to act to gain control. In this instance arousal is maintained and is experienced as anxiety. This state of chronic arousal is maintained until either a solution is found and control restored, or the individual may ultimately predict that there is no course of action which can be taken to resolve the situation, control is lost and depression results.

Feedback from any of these outcomes will result in learning, which will influence predictions and performance in future situations.

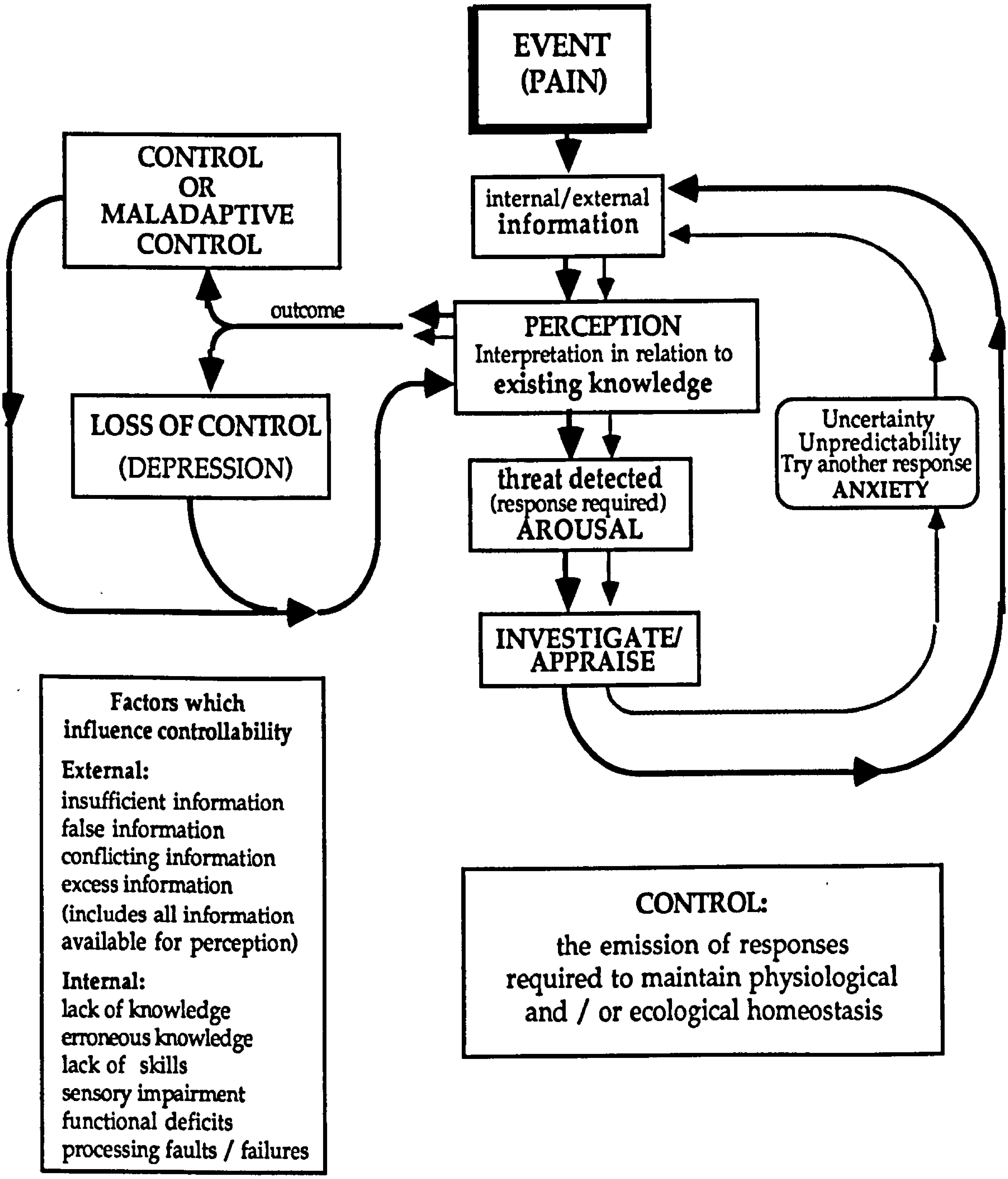


Figure 2b Theoretical model of learned control

The theory of anxiety contained within the analysis outlined above is entirely congruent with that of Mandler, who asserted:

> *"in a state of arousal, the organism who has no behaviour available to him, who continues to seek situationally, or cognitively appropriate behaviour is 'helpless' and so may consider himself, in terms of the common language as being in a state of anxiety"* (Mandler, 1972, p.369)

It is also supported by Bandura (1977) who stated that high emotional arousal is maintained until effective coping behaviours are achieved. Mandler went on to argue that helplessness is defined, not by the objective situation, but by the repertory of behaviour. This analysis, on the other hand, highlights the equal importance of external situational factors and internal cognitive and behavioural factors in ensuring controllability. Man lives in a social world in which a major source of information is provided by interactions with other people. The provision of conflicting, or false information, or the deliberate withholding of information by medical professionals will inevitably influence the ability of patients to make accurate decisions about how to maintain control. This is a situation which arises frequently in the care of the sick, often with the best of intentions on the part of health carers, in the belief that a patient will be unable to cope with the truth. Thus patients may be forced into situations of dependency or uncertainty through no direct fault of their own.

The resources available for controlling or coping with a situation of threat are determined, primarily, by the personal knowledge, practical and problem-solving skills, and the past experiences of the individual which enable him to evaluate the situation and determine the appropriate response. Lack of the knowledge and skills required to predict and implement controlling strategies will mitigate against control. Thus lack of knowledge about pain control (e.g. drugs or other treatments), erroneous or insufficient knowledge about the painful condition, lack of skills in pain control (e.g. relaxation techniques) or inability to learn or implement these skills through disability or impairment will all lead to coping difficulties. In the short term these will cause anxiety as the individual makes an attempt to find a solution. In the longer term, depression may ensue if a solution cannot not found.

Although this model has identified situational, as well as personal cognitive and behavioural factors which influence coping, it is the relationship between these which is likely to account for a large proportion of individual differences in pain response. Lazarus et al (1985) maintained that stress lies not in the environmental input but in the person's appraisal of the relationship between environmental input and its demands, the person's beliefs and their capabilities to meet, mitigate, or alter these demands in the interests of well-being.

Coping resources also depend upon the ability of the individual to obtain help from external sources. The social structure of human society ensures that we are all interdependent. The availability of such factors as family support, medical and social services and money to buy aids and services, are all important external coping resources. Nevertheless it often takes considerable personal investment in terms of knowledge and effort to obtain the outside help required to maintain a lifestyle which is satisfactory to the individual with a pain problem.

Equally important is the fact that the greater the number of demands that are made upon coping resources, at any particular time, the greater the strain on the individual striving to maintain overall control. Pain is not the only source of stress with which individuals, especially elderly people, must cope. Other sources of threat must be considered when attempting to assess the degree of control an individual has at any particular time.

The model of stress identified here has highlighted control as an active process of gathering information, interpreting that information in the light of existing knowledge and predicting suitable responses, based upon the utilisation of existing skills and external help. The next stage is to explore further the process and consequences of making predictions in situations of stress.

2.5 Contingency analysis of perceived pain control

It is pertinent to investigate how a person might arrive at a decision about the best course of action necessary to maintain control in a situation of threat, since the consequences of the decision may be critical to future well-being. In terms of pain, there are many possible actions which may or may not turn out to be effective or adaptive. Contemporary learning theory, based upon animal research (Dickinson 1980), suggests that we learn about the probability of an occurrence, and that responses are predicted by the probability of gaining reinforcement. In fact control over a painful stimulus is often used experimentally, in psychology, as a negative reinforcer. The concept of predicted outcome, based upon the perceived probability of gaining pain control, is encapsulated in a contingency analysis of pain experience given in figure 2c.

This contingency analysis is based upon the presumption that man lives in an environment which is primarily social. When a painful event occurs, it can be controlled either by own actions or by the actions of others, thus resources for control may be internal or external. Prior learning experiences will generate expectancies or predictions about the likelihood of maintaining control by utilising either personal resources (internal locus of control) or external help (external locus of control). Thus information detected about the painful event is processed in relation to these expectancies, and these determine the perceived probability of maintaining control, utilising internal or external resources. This constitutes the cognitive element of coping.

The emotional responses of anxiety and depression are identified, within the contingency space, as corresponding to the perceived probability of being able to gain, or maintain, control over situations, such as pain, which represent a potential threat to survival. This is congruent with the theory of emotion

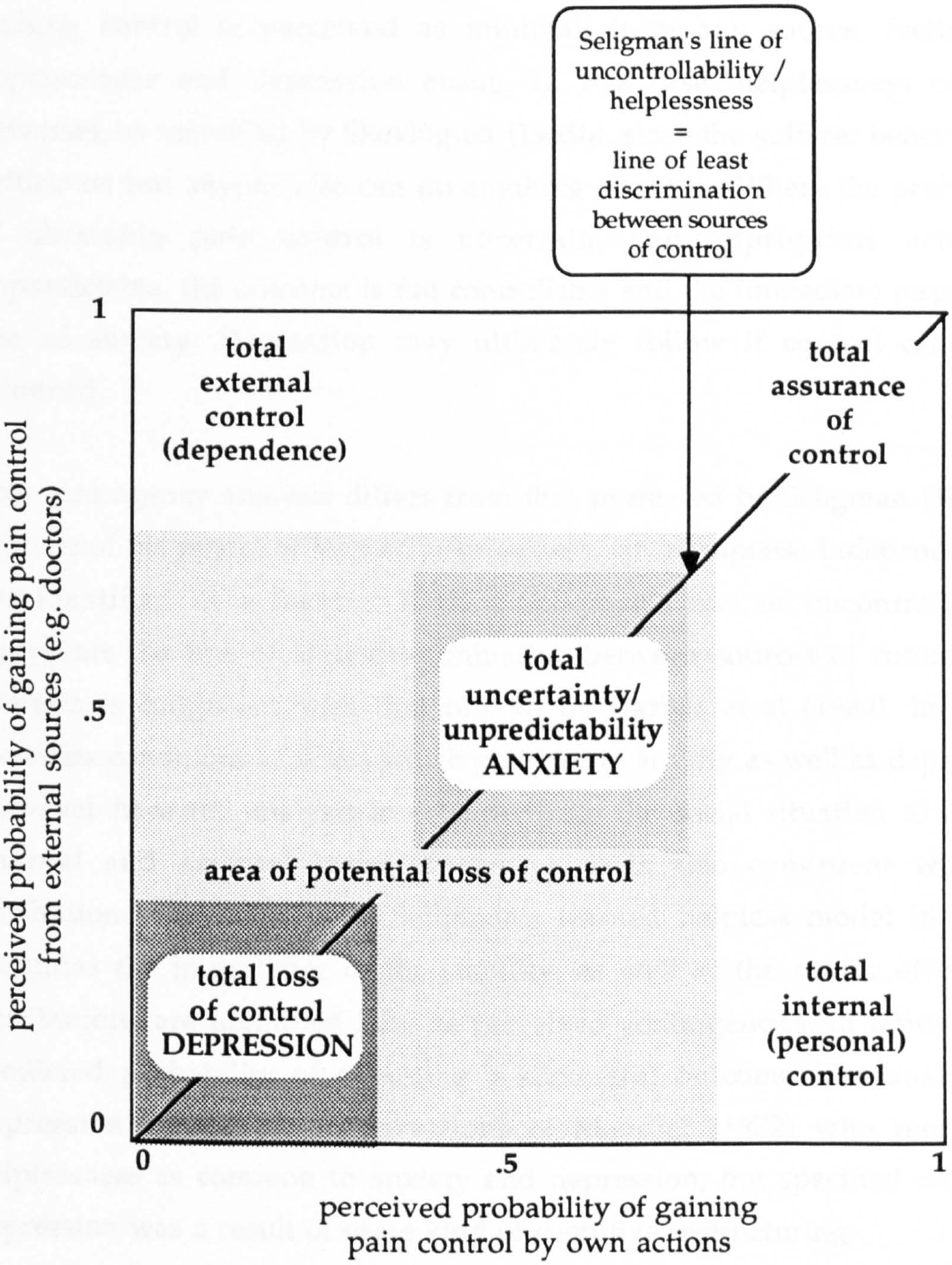


Figure 2c Contingency analysis of pain control

presented by Lazarus and Averill (1972 p.269) in which emotion is defined as *"a reaction shaped by judgments about an event of significance to the person's welfare"*. The source of control available to an individual faced with threat is not critical, provided it is stable, reliable and congruent with that person's predictions of need. Where control is assured, from whatever source, the person will feel confident and assured. Where the probability of gaining control is perceived as minimal, from any source, feelings of hopelessness and depression ensue. In this case, helplessness is truly universal, as identified by Skevington (1983b), since the sufferer believes that neither he nor anyone else can do anything about it. Where the probability of obtaining pain control is uncertain, and appropriate action is unpredictable, the outcome is not controllable and the immediate response is one of anxiety. Depression may ultimately follow if control cannot be achieved.

This contingency analysis differs from that presented by Seligman (1975) in support of his model of learned helplessness, since response independence is not identified as a feature. Rather, Seligman's line of uncontrollability represents the line of least discrimination between sources of control. The analysis is congruent with that offered by Garber et al (1980), in that it identifies conditions of stress which give rise to anxiety as well as depression. However here the analysis is extended into the social situation to include internal and external locus of control. It is also congruent with the attribution reformulation of Seligman's learned helpless model in that it identifies the importance of the stability, as well as the source of control. Attributions are identified here as perceived contingencies, in terms of the predicted probability of obtaining a successful outcome. The analysis of depression extends the observations of Mandler (1972) who recognised helplessness as common to anxiety and depression, but specified only that depression was a result of some kind of cognitive restructuring.

2.6 Personal and external control

Personal control implies that the individual perceives himself to be the best architect of the solution to a particular problem, whereas external control implies that he perceives the solution to lie in the hands of others. When confronted by situations which are potentially threatening, we minimise stress by our abilities, as problems solvers, to make accurate predictions, and implement appropriate actions. It is easier to make accurate predictions about the implementation and consequences of own actions, than about the actions of others. There is always a degree of uncertainty when others are left to act for us, therefore personal control is likely to be associated with less perceived threat and anxiety. However the strength of predictions about the level of personal control will depend upon past experiences of gaining control, in line with Bandura's concept of self-efficacy (Bandura (1977).

It could be argued that the line between personal and external control is frequently very thin. Individuals may have to work hard to achieve external support or control for their painful condition. Bandura (1982) referred to the use of proxy control to describe situations in which individual exert influence over others who wield power. Wallston and Wallston (1981) recognised this within the scoring system used for their health locus of control scales. They gave almost equal weighting on personal and external scales to those consulting a doctor. The reality of human experience dictates that control is rarely gained by failing to respond at all to a situation. Thus there is seen to be a difference between passively waiting for outside help and actively adopting behaviours which will mobilise helping interventions. Others may resent these so-called pain behaviours, which make demands on themselves or others, even when they work perfectly well in ensuring the well-being of the pain sufferer. Such pain behaviours are therefore often labelled 'maladaptive', not because they fail to provide control for the pain sufferer, but because of their effect on the persons doing the labelling.

Locus of control questionnaires generally take into account the fact that some individuals make chance attributions about events. Levenson (1974) distinguished between those who believe that the world is unordered (chance) from those who believe in an order imposed by powerful others, with the view that different beliefs might lead to different behaviours. It is suggested by the contingency analysis, presented above, that 'chance happenings' may represent an orthogonal attribution only if this represents the attribution of control to an external factor, for example a force of nature, or a god. If, on the other hand, chance attributions are caused by uncertainty about the causes or potential consequences of an event, then it cannot be regarded as an orthogonal scale. Levenson (1981) confirmed that chance scales are negatively correlated with sense of well-being. In fact undue reliance upon nebulous external forces, which are inherently uncertain and unpredictable, leads, eventually, to lack of control, anxiety and even depression.

2.7 Emotional state and trait

Using the theoretical analysis presented above, it is possible to define the terms 'state' and 'trait' so often distinguished in anxiety research (Spielberger 1975). Trait is identified here with the generalised expectancies and predictions which the individual brings to a particular situation, which are based upon past learning experiences and genetic influences in the acquiring, processing and organisation of knowledge and skills. State is identified with responses to the immediate situation, which will be influenced by information, expectancies (trait), and available knowledge and skills.

The contingency analysis presented in figure 2c proposes that the emotional responses of anxiety and depression are directly associated with predictions about outcome. If state anxiety depends, to some extent upon trait anxiety, then the analysis suggests the trait and state concept to be equally true for depression (endogenous and reactive depression) and for optimism.

2.8 Anger, hostility, frustration and fear

The contingency analysis identifies anxiety and depression as emotional states which are directly associated with the perceived probabilities of gaining or maintaining control in a social situation. However other emotions were also identified in chapter 1 as being associated with chronic pain, notably anger and hostility. Mandler, in his analysis of helplessness, stated:

> *"the next step is to examine anger in relation to helplessness and hopelessness"* (Mandler, 1972, p.372)

There is evidence to associate anger and hostility with perceived control. Feelings of anger may be generated against oneself or against others, nevertheless hostility and resentment are normally feelings which are directed against an external force. Anger, frustration and hostility seem to occur in situations where the desire to attain a particular goal is prevented, either by own inability, or by external forces. Anger is a common response to serious illness, notably cancer (Penson 1988). Penson identified that anger is often displaced towards external sources, such as God, close family or the doctor, and suggests that anger is fuelled by feelings of helplessness. It is therefore suggested that anger, resentment and hostility are emotional concomitants to situations in which loss of control is perceived to be caused the actions, or inactions, of others.

Whereas hostility and resentment are focused on external forces or actors who prevent, or are seen as preventing, fulfilment of desired actions, frustration is associated with the personal inability to perform those desired actions. Both situations may be accompanied by anger, when a desired outcome is identifiable, but achievement prevented. Anger, hostility, resentment and frustration are all, therefore, identified as being closely associated with lack of control, and with beliefs about personal or external control.

Fear is another emotion associated with pain, and is considered an important emotion in relation to the care of the terminally ill. Penson (1988) identified that cancer patients' fears were caused by the threat of death, suffering, dependence, disfigurement and isolation. Fear and anxiety both involve adrenergic arousal and both are associated with situations of threat. The chief difference appears to be that while anxiety is associated with uncertainty, unpredictability and inability to identify a suitable response in a novel situation, fear is primarily associated with a positive prediction of a negative outcome. Thus fear is an emotion associated with predicted future loss of control.

In terms of the theoretical analysis presented above, it seems evident that feelings related to anger, and those of fear, may all potentially occur in situations in which control is predicted to be threatened or lost. Hence they are closely associated with pain and painful events. These emotions are likely to occur in conjunction with anxiety and depression.

2.9 Research implications of the theoretical analysis

The theoretical analysis, presented above, has explored the experience of coping with pain, and other stressful events, and has sought to present a coherent theory of coping which utilises existing theories of perception, learning, stress and coping. It has attempted to provide a clear definition of coping in terms of control. Central to this theory is the tenet that emotions are directly related to the perceived probabilities of maintaining control over life events or situations, including those involving pain, which threaten homeostasis or survival. It has identified emotional states of anxiety, depression, hostility and fear as indicators of perceived coping difficulties. The importance of expectancies and predictions are highlighted, together with situational information, in determining actions and emotional response. Above all, coping is defined as an active process, in which personal control is associated with less stress than reliance upon external agents for control.

The potential implications of the above theory of control, for pain management, are considered in Walker et al (1989). The implications for the research design, incorporating some hypotheses, are outlined below.

1. Response to pain is determined by its perceived controllability. This in turn depends upon the relationship between the peripheral pain signal, information available about the prevailing situational contingencies (including causes and potential consequences of the pain), and the existing knowledge, expectancies and available skills of the person experiencing the pain.

2. Emotional response is related directly to subjective perceptions of the controllability of the painful situation, and is influenced by factors such as disability, life events, and the provision of information.

3. The emotions of anxiety, depression, hostility and fear are identified as responses which indicate the degree of perceived control a person is experiencing over a situation at any particular time.

4. The definition of control, in terms of survival needs, implies that it is not the control of pain *per se* which is of paramount importance, but control over the whole life situation, given the existence of pain or a painful condition.

5. Diagnosis is predicted to be of critical importance only insofar as it influences the degree of perceived threat, and the controlling abilities of the individual.

6. Pain duration is a possible factor in the development of loss of control and onset of depression, but this is likely to interact with the temporal pattern of the pain, the scale of threat perceived, the availability of internal and external resources for coping, predictions about controllability based upon past experiences and the extent to which coping resources are already in demand to cope with other problems.

7. The theoretical model supports the use of a quantitative approach to data collection and analysis, in which emotional state is the dependent variable (the indicator of coping). Independent variables include pain, information, expectancies, disability, and the additional life problems confronted by the elderly in the community.

These considerations confront the issues raised at the commencement of this chapter. The theoretical model provides a logical basis for encompassing both acute and chronic pain. Likewise it avoids the problems of controlling for diagnosis, or type of pain, and allows for the inclusion of stressors other than pain. It has defined coping in terms of controllability and has identified that it can be measured by assessing emotional state. It identifies that individual differences in locus of control are likely influence susceptibility to stress, and that personal control is likely to associated with a reduction of stress and anxiety. Maladaptive pain behaviour is unlikely to be measured using this approach, since it may or may not involve emotional disturbance. Therefore assessment from an alternative viewpoint, such as nurse or carer, may be sought. The theoretical model provides an ideal framework for a multivariate quantitative study.

The research objectives for the study are given below.

2.10 Research objectives

1. establish how, and to what extent, pain among patients in the community is at present being controlled.
2. identify factors which influence the abilities of patients in the community to cope with pain, using the theoretical model outlined above.
3. explore district nurses' perceptions of patients' experiences of pain.
4. use the findings of the study to formulate a protocol for the assessment of pain in the community, and to propose nursing interventions which will increase pain control and enhance coping for elderly patients in the community.

The study, described in chapter 4, is designed to fulfil the objectives identified above, and is based upon the theoretical model outlined in this chapter. It is dependent upon the selection of suitable methods of measurement for the dependent and independent variables. This important aspect of the research is considered in some depth in chapter 3.

CHAPTER 3 METHODOLOGICAL ISSUES

The theoretical model, developed in the previous chapter, provides a strong framework for a quantitative study of pain coping. Yet a quantitative study is dependent upon accurate and reliable methods of measurement. This chapter is included in order to investigate fundamental issues in the measurement and assessment of pain coping variables, for use in a community study with elderly subjects. These include the method of data collection, the nature and type of data to be collected, and, in particular, a review of the applicability of existing measurement tools for use in this particular study.

3.1 Data collection and research method

Face-to-face interview is the method of choice for data collection from subjects, most of whom are elderly, since this allows the greatest individual freedom to describe pain experiences. Past personal contact with elderly people indicates that most respond eagerly to a patient and sympathetic ear, and will wish to talk freely about their individual experiences. The imposition of rigid structural constraints, during interview, is likely to result in loss of rapport, and the loss of a wealth of potentially useful information about what the patients perceive as important issues. These are of special value in enhancing an understanding of the patient's perspective. It is therefore considered desirable that the interview should be semi-structured.

The formulation of the theoretical model, outlined in chapter 2, provided the basis for a quantitative study, in which mood state is the dependent variable. A variety of potential independent variables have been identified, in the literature review, which are likely to influence coping. However the existence of little previous research into the pain experiences of a population within the community, most of whom are elderly, suggests a need for the collection of descriptive data. Tripp-Reimer (1985) suggested that qualitative studies provide rich descriptive and documentary information about background features of a topic. It therefore appears that a combination of qualitative and quantitative methods of data collection may be most appropriate.

Nursing provides an area of research which draws upon knowledge from all disciplines within the social and life sciences, in which the application of both qualitative and quantitative research methods make a valid contribution. Patton (1980) recommended the use of methodological triangulation, in terms of measurement, design and analysis, for research involving naturalistic inquiry. Several authors have outlined the advantages of using both types of method, simultaneously, in nursing research programmes. Goodwin and Goodwin (1984) argued against a paradigmatic distinction between qualitative and quantitative research design, in favour of using both strategies in a single study. They suggested that such integration could achieve a comprehensiveness which neither approach, if used alone, could produce. They advocated the use of both types of measure in a single study as a means of cross-validating the findings. Akinsanya (1988) argued cogently in favour of linking the two approaches in nursing research studies, and suggested that content analysis provides a suitable method by which qualitative data can, where appropriate, be transformed into numerical data for quantitative analysis. Alternatively, as Patton (1980) pointed out, it is quite possible to superimpose quantitative scales and dimensions on qualitative data for the purpose of statistical analysis.

All of the above observations have relevance for this study, and it is suggested that methodological triangulation provides for a most appropriate design. However a quantitative method of data collection presumes that suitable methods of measurement can be identified. These are considered below.

3.2 Measurement and assessment

The literature review outlined a number of assessment tools which have been designed specifically for the purpose of measuring aspects of pain, stress and coping. These have the advantage of established checks on validity and reliability, and provide the basis for comparison with existing pain coping studies. However, many the subjects for this study are likely to be very elderly, in pain, and to have additional handicaps, illnesses and potential coping problems. The administration of inventories designed for self-completion are unlikely to be of use, unless they can be adapted for verbal administration. This is because the demand for adequate eyesight, concentration and motivation, is unlikely to be fulfilled in a sufficiently representative sample. Some of the tools, currently used in the measurement of pain, mood and coping are considered below, together with the difficulties of collecting reliable and valid data from such a sample.

3.2.1 Pain measurement

Simple pain rating scales

The cornerstone of pain assessment is the measurement of pain intensity, for which a suitable rating scale is essential. One which is frequently used in pain research and clinical practice is the visual analogue scale (VAS). This is generally a line, ten centimetres in length, which represents the limits of pain experience. Subjects are asked to mark a point on the line corresponding to the severity of their pain between 'no pain' and 'worst pain imaginable'. The VAS has been identified as the most sensitive method of pain measurement (Huskisson 1983). However Carlsson (1983) found evidence that some patients appeared to find difficulty in using it reliably, and Kremer et al (1981) found that failure to complete the VAS increased significantly with age. Thus it appears that, although the VAS may be the scale of choice for sensitive measurement of pain intensity, compliance may prove difficult. Alternative scales should therefore be considered for use with an elderly population.

An alternative categorical scaling method is the five or ten point numerical rating scale, where 0 represents no pain and either 5 or 10 represent the worst pain ever. This appears to be much less commonly used than word-based or visual analogue methods, although some nurses have incorporated it into innovative measurement tools. Hayward (1973) used a painometer, which consisted of an illustration of a thermometer, graduated from one to ten, with verbal pain intensity cues attached to the numbers for guidance. Gurrie (1984) devised a pain assessment speedometer, graduated from 0 to 130 with corresponding verbal cues. There is little evidence to confirm the reliability of these tools for research purposes, and it is difficult to judge whether the numbers, or the verbal cues, provide the greatest amount of information in guiding patients' decisions.

A number of purely verbal rating scales exist. The one used by Kremer et al (1981) included the terms mild (1), moderate (2), horrible (3) excruciating (4). One of the most widely used verbal scales is the present pain intensity scale of the McGill Pain Questionnaire (MPQ). This scale includes mild (1), discomforting (2), distressing (3), horrible (4), excruciating (5). Kremer et al identified that their verbal rating scale was no more influenced by mood variables than the visual analogue or numerical methods of measurement. However in spite of this, the terms distressing and horrible do not seem to be straightforward descriptions of intensity, but appear to contain some emotional or evaluative overlay. Raiman (1986) used a word-based rating scale in the formulation of the London Hospital pain observation chart. This employs the terms just noticeable, moderate, severe, very severe and excruciating, which appear to provide a good range of intensity descriptors.

Kremer et al (1981) compared the use of visual analogue, numerical and verbal rating scales and found a good level of inter correlation between all three. The compliance failure rate for the VAS was 11 per cent, for the numerical scale 2 per cent, and for the verbal scale nil. Patients showed a significant preference for verbal rating scales.

A common objection to the use of word-based rating scales is that the scoring system assumes interval spacing of the items included. Heft and Parker (1984) showed that ratings do not necessarily provide an ordinal index, although they demonstrated the words mild, moderate, strong, intense to show a reasonable homogeneity of spacing. The ultimate choice of scales is somewhat arbitrary, because of the range of intensity descriptors in use. Raiman's scale is selected for use in this study because of its proven usefulness with British subjects of all ages, many of whom were seriously ill.

The McGill Pain Questionnaire (MPQ)

Melzack (1983) described how the measurement of pain intensity, using one of the above scales, fails to provide a complete picture of pain experience. Simple pain rating scales, like specificity theory, fail to reflect the true complexity of pain perception and experience. The advent of gate control theory highlighted the fact that tissue damage gives rise to a sensation of pain which varies in its sensory quality. It is also modulated by central control mechanisms. Nociceptive signals lead to a pain reaction which is influenced by perception, evaluation, motivation and affect. The gate control theory led directly to the development of a new pain measurement scale which recognised all of these factors. This development was initiated by Melzack and Torgerson (1971), who devised a new approach to describing and measuring pain, by categorising and scaling verbal descriptors. 102 pain descriptors, taken from the pain literature and clinical descriptions, yielded three major classes of descriptor: sensory, affective and evaluative, comprising 16 subclasses. This formed the basis of the McGill Pain Questionnaire (MPQ) (Melzack 1975), which includes four additional miscellaneous subclasses of descriptors (see Appendix II). The MPQ thus provides a score on each of sensory, affective, evaluative and miscellaneous scales. It is designed for either verbal administration, taking approximately five minutes to complete, or for pencil and paper administration (Melzack (1983).

The MPQ has undergone many validity and reliability trials, and has been used widely as a tool for clinical and nursing research. Reading (1983) confirmed acceptable levels of reliability and face, construct, discriminant and concurrent validity. Burckhardt (1984) found it a useful tool in comparing the pain experiences of inpatient with outpatient arthritis patients. Gaston-Johansson et al (1985) used the MPQ to establish a simplified assessment tool for use in clinical nursing practice. It has been found suitable for the assessment of cancer pain in Britain (Lahuerta and Campbell 1986).

The scoring method recommended originally by Melzack (1975) was based upon rank scores. Prieto et al (1980) examined the factor structure of the MPQ, and concluded that their results supported the continued use of Melzack's original scoring system. However alternative methods have been tested. Charter and Nehemkis (1983) used a visual analogue adaptation. Melzack et al (1985) compared a weighted-rank method of scoring with the conventional method but found the sensitivity of the MPQ to be only relatively slightly increased. Overall the alternative methods of scoring available are more complex in application and appear to offer little advantage over the conventional scoring scheme which has been widely used. The MPQ appears to be a useful research tool, applicable to many different types of pain. It provides meaningful scores for use in quantitative analysis and allows comparison with many other pain studies. It was found by Marcer[1] (personal communication) to be quick and simple to administer to elderly patients in a clinical situation. He confirmed that they find it relevant because it directly addresses a description of their pain experience. Above all, it provides measurement of affective and evaluative aspects of pain, in addition to sensory qualities, which are predicted to be important elements of pain experience, according to the gate control theory of pain.

The MPQ has been incorporated into a Comprehensive Pain Questionnaire (Monks and Taenzer 1983), which includes assessment of pain modifiers, effects of pain, mood and attitude towards pain, in addition to pain and medical history. Issues explored include knowledge of causation, coping methods and religious beliefs. Pain description includes the temporal pattern of pain (continuous, intermittent or transient), and intensity of the pain at its worst and least. Each of these aspects form an important part of the assessment of pain experience, and are incorporated into the research design for this study.

3.2.2 Mood, affect and well-being

The affective scale of the MPQ represents an attempt to measure emotional pain response, but its utility is limited in terms of the theoretical model proposed here. This identified the assessment of anxiety, depression and hostility as critical elements in the measurement of pain coping, and hence as dependent variables in this study. One of the most popular measures of anxiety is the Spielberger State Trait Anxiety Inventory (STAI) (Spielberger et al 1983). This uses two 20 item scales to measure both tendency to anxious responses (trait anxiety), and current status regarding feelings of anxiety (state anxiety). One of the most popular measures of depression is the Beck Depression Inventory (BDI) (Beck et al 1961). The BDI employs twenty groups of feelings associated with depression, each containing a choice of 5 statements measuring the degree of negative thoughts. Both of these mood measures consider only the degree of negative affect, whereas it is desirable that a study designed to measure coping should consider positive as well as negative affect. Furthermore, it is a requirement of the theoretical model that mood assessment should include both anxiety and depression, and the use of two separate inventories is necessarily a more lengthy process.

The Mood Adjective Checklist (MACL) (Nowlis 1966) includes 49 adjectives, each rated on a seven point scale, which provide scores on 12 subscales, or types of mood. This provides a relatively simple procedure, however not all of the mood types, for example egoism and skepticism, are readily interpretable in terms of the theoretical model. A more recent mood assessment scale, which is more easily interpretable, is the Profile of Mood States - Bipolar (POMS - BI) (McNair et al 1982). This includes 6 scales of adjectives: composed / anxious; confident / unsure; agreeable / hostile; elated / depressed; energetic / tired; clear-headed / confused; and comprises a total of 72 items, each to be rated on a four-point scale. This is clearly too long for administration in its entirety in the planned study, although it would be possible to limit presentation to the first four scales only, for the purposes of this study. However detailed examination reveals that terms which define the positive pole of the elated / depressed scale (joyful, playful, elated) appear to have little validity in the assessment of an elderly population suffering from pain. If subjects do not find that the descriptors have relevance, they are unlikely to comply fully. This measurement tool was therefore rejected for use in this research.

Coleman (1984) selected a very simple bipolar method of measuring self-esteem in the elderly. His scale comprised eight bipolar items which included feelings of usefulness, enjoyment, helplessness, importance, alertness, hopefulness and confidence. This measure of self-esteem reflects aspects of mood state, indeed it was based upon existing depression and well-being scales. Coleman's measure has the advantage of being short, simple, easy to administer, and has been tried and tested on an elderly population. He found that self-esteem scores showed considerable stability over time and was able to demonstrate a high degree of internal reliability. However this measure of self-esteem excludes aspects of anxiety and hostility which were identified as important indicators of control.

With this last exception, all of the methods outlined are too lengthy, or are designed primarily for self-adminstration. No mood state inventories, which include measures of anxiety, depression and hostility, have been identified which exhibit the characteristics of both relevance and brevity. However Coleman's approach to the measurement of self-esteem confirms that it is possible to adopt a measurement scale which is simple and brief, yet retains both validity and reliability. It is therefore decided to adapt this approach, using a bipolar scale, for use in this study. It includes verbal indicators representing anxiety, depression and hostility at the negative pole, and indicators of control and well-being at the positive pole. Its construction is described in chapter 4.

3.2.3 Coping strategies

The ways in which elderly people cope with painful conditions is the primary focus of this study. The Coping Strategy Questionnaire (CSQ) has already been referred to in chapter 1 (1.6.2), and was developed for the purpose of measuring different types of coping. The questionnaire comprises a total of ten cognitive, behavioural and effectiveness subscales, each containing 6 items rated on a 7 point scale (Rosenstiel and Keefe 1983). The information generated by this questionnaire was found to be extremely useful in predicting emotional adjustment to chronic pain, in a sample of back patients in the middle age range. Rosenstiel and Keefe suggested that the result of their CSQ study tends to agree with previous experimental studies in which subjects' use of coping strategies were assessed by an independent observer. This suggests that self-report is a valid method of data collection in the identification of coping strategies.

The CSQ was validated on a sample of younger patients and may not be appropriate for use with older patients. No studies of pain coping strategies used specifically by elderly people have been identified. Yet it is quite possible that, as people get older, they modify or amend their strategies in the light of experience. As they approach the end of their lives, they may respond quite differently, to pain and disability, than do younger people facing similar problems.

In view of these potential differences, it appears more appropriate to employ a qualitative approach to the identification of coping strategies in this study. Content analysis, guided by categories in the CSQ, may provide data for inclusion in subsequent quantitative analysis, in order to assess the success, or otherwise, of different types of strategy in promoting coping.

3.2.4 Locus of control

Locus of control was identified, in the theoretical model, as a potentially important predictor of coping. There have been many attempts to formalise the evaluation of locus of control. Rotter (1966) is often accredited with the development of the concept of internal and external locus of control, although he attributed the first measurement scale for internal and external expectancies to Phares in 1959. Levenson (1974) used Rotter's scale to derive an alternative form of measurement which included three dimensions:

internal, powerful others and chance (I,P,C). The scales included a total of 24 items presented in Likert format and were validated on an adult population. However it is evident from the results of the factor analysis that the three dimensions accounted for a total of only 33 percent of the variance, which is far from optimal.

Wallston et al (1978) developed a locus of control scale specifically concerned with health issues using the three I,P,C dimensions. They suggested that the scales provided good test-retest reliability, but that they were not reliable for those undergoing surgery. This is taken to suggest that locus of control is not necessarily stable in situations of acute stress.

No pain locus of control questionnaire was identified which was entirely suitable for administration in an interview situation where many other issues compete for in-depth attention. Furthermore it has already been identified in the previous chapter that the chance and powerful other external scales are not necessarily orthogonal. Nevertheless locus of control has been identified as a potentially important factor in determining pain experience and coping strategies. It is therefore proposed that patient's expectancies about the source of pain control should be explored within the context of the interview. Comments should be categorised, using qualitative analysis, and these categories will, subject to an independent check on reliability, be included in subsequent quantitative analyses.

3.2.5 Disability

Pain and disability are often closely linked, and disability may be expected to influence the ways in which people cope with their pain. The most popular measures of disability in the clinical sphere are indices of activities of daily living (ADL), however the choice of index is somewhat overwhelming in view of the number available (Selman and Barnitt 1983). The reason for this is that ADL indices are usually tailor-made to suit particular needs. They comprise a list of self-care and mobility variables, each of which is measured on a scale of limitation. Donaldson et al (1973) estimated evaluation using an

ADL index to take up to 60 minutes, but this was done for clinical purposes. Sheikh et al (1979) assessed the reliability and validity of 17 items of ADL rated on a three-point scale. They found good inter-observer and within-patient reliability in a group of patients suffering from stroke, arthritis, multiple sclerosis and post-surgery. However they identified that it was possible to reduce the activities measured to five: walking, making tea, bathing, dressing and transfer from floor to chair. Feinstein et al (1986) pointed out that an index must satisfy the intended purpose and setting. They suggested that a new specific, simple index aimed at a well-defined purpose is often easier to develop and use when well-established indices do not do a satisfactory job.

ADL indices are generally designed as objective measures of performance or performance deficits, however Nichols (1976) pointed out the need to assess both disability and handicap. He defined handicap as the disadvantage accruing from disability and impairment. Disability is only a disadvantage if it is perceived to be so, for example, inability to get into the bath is only a problem if you actually wish to have a bath. Mental adjustment will not therefore relate directly to the level of disability, but to the consequent handicap afforded by perceived disadvantage. In spite of these observations, it is useful to have some measure of disability which can be used for purposes of comparison. It is proposed that a short list of activities, most appropriate to elderly pain patients in the community, should be assessed, using self-report, during interview.

3.2.6 Pain and illness behaviour

The concept of pain and illness behaviour was outlined in chapter 1. These are terms used to describe cognitive and behavioural reactions to chronic pain, sickness and invalidity. The illness behaviour questionnaire (IBQ), formulated by Pilowsky and Spence (1975), was designed to explore these aspects. It consists of 52 yes - no items which concern the patient's attitudes and feelings about his illness, perceptions of the reactions of significant others (including the doctor) and the patient's own view of his psychosocial situation. Factor analysis yielded 12 rotated factors, accounting for 85.5 percent of the variance. Factors included a general feeling of interpersonal alienation, disease conviction, psychological conviction, affective inhibition and affective disturbance. The questionnaire was validated using a sample of 100 unselected pain clinic patients with a mean age of 49 years (s.d. 15 years). A self-completion method was used. Behaviour, referred to in the title of the questionnaire, is used in its widest sense to describe all aspects of pain response. Many of the interpretations offered by Pilowsky and Spence are, on their own admission, psychoanalytic in origin. The data generated may therefore be difficult to interpret in terms of control theory, which is the basis for this study, because of its psychoanalytic structure. There is no evidence, in the literature, that the IBQ has been validated on a population of elderly people. Indeed, as the authors suggest, there may be differences in pain responding among elderly people. Therefore this tool is unlikely to be of use for application in this study.

Richards et al (1982) constructed the UAB (University of Alabama in Birmingham) Pain Behaviour Scale to measure behavioural change during programmes of behaviour modification. They distinguished between objective, observable manifestations of pain, and subjective feelings. They included vocal and non-verbal complaints, lying down time, mobility, use of supportive aids and the taking of medications. The whole consisted of 10 target behaviours, each rated as occurring either never, occasionally or frequently. It is designed for use in a variety of disciplines including psychology, nursing and social work, requires minimal training and was shown to demonstrate good inter rater reliability.

The authors of the UAB scale describe it as quick, reliable, simple but valid. However it was designed primarily for use with hospital in-patients and combines direct observations of interactions as well as patient questioning. It was also designed for repeated administration in order to detect change. For these reasons it is not suitable for use in a one-off interview in the patient's home.

Nevertheless, self-report aspects of the approach are usefully incorporated into the patient interview to identify mobility, use of supportive equipment and medication.

3.2.7 Life events

Life events are considered important in relation to the theoretical model because patients must cope with these, in addition to any pain and disabilty which they experience. The endeavour to measure the stressfulness of life events in order to assess the impact of stress on psychological and physical illness has been long and largely unsatisfactory. Holmes and Rahe (1967) designed their social readjustment rating scale in order to assess the relative impact of important life events. These ranged through the death of a spouse (score 100), marriage (50), to minor violations of the law (11). The scale was designed to measure change, rather than unpleasantness, and stress was measured by the summation of these weighted scores. This scale was designed for the general population and does not appear to be appropriate for the needs of an elderly population who, it has already been suggested, are especially vulnerable to particular types of stress.

There have since been many attempts to improve life events measures. Dohrenwend and Dohrenwend (1978) identified the importance of considering individual and environmental factors which mediate the impact of life events. Perkins (1982) suggested that most investigators were, at that time, in agreement that simple objective measures of life stress are destined to be replaced by multifactorial models and a renewed interest in qualitative aspects of life stress. Dohrenwend et al (1984) subsequently attempted to produce a life events scale that was much more relevant to the types of stressor experienced during the course of everyday life. These included household meals (e.g. preparing meals), inner concern hassles (e.g. being lonely), and health hassles (e.g. physical illness).

Lazarus et al (1985) pointed out that the appraisal process cannot be removed from the measurement of psychological stress, and that the measurement of environmental independent variables cannot remain uncontaminated from their perception or appraisal. Whitbourne (1985) also asserted that current life-event rating scales are unsuitable within a model of adaptation since they fail to provide a sense of how past events are perceived nor how they influence future expectations. She suggested that even those designed to take account of individual perceptions carry an assumption of the universality in the occurrence of particular events.

The Dohrenwend scale is unsuitable for this research because the tool is designed primarily for a working population. Nevertheless it identifies hassles, such as 'being lonely' and 'side effects of medication' which provide a useful basis for the identification of common problems which are predicted to add potentially to the stress to which elderly people in pain are exposed. These items are therefore utilised within the interview schedule.

3.2.8 Discussion of measurement tools

A number of research tools have been reviewed which are commonly used to measure aspects of pain coping and stress. These have generally been developed for samples derived from a much younger average age group, and most are designed for self-completion. With the exception of the MPQ, the majority are not appropriate for verbal administration. Most are lengthy, particularly when considered for use in conjunction with other measures. There are doubts about the relevance of some aspects to the sample in question.

There is yet another important reason why many of the above research tools are not suitable for use in this type of research. The aim of the study is to identify factors which nurses can subsequently assess and use as the basis for intervention. Psychological inventories tend to produce results that are not necessarily readily interpretable for this specific purpose. For example a score on a scale which includes 10 individual items may be very reliable, but it may be difficult to simplify down to a single item for nursing assessment. For this reason it is suggested that the questions asked of patients during the course of the research interview should, wherever possible, resemble the types of questions which district nurses can address during the course of their routine visits.

In accordance with these observations, pain rating scales and the McGill Pain Questionnaire are selected for inclusion in the patient interview. None of the mood measures was found to be entirely appropriate to the study population or the theoretical model, but a simple bipolar scale, to include indicators of anxiety, depression and hostility, is identified to be most suitable. The remainder of the measurement tools are rejected for use as they stand, for reasons already given, although aspects from them will be adapted for verbal administration during the course of the patient interview.

3.3 Data analysis and sample size

The theoretical model, outlined in chapter 2, identified a multifactorial model of coping, in which mood state is an outcome measure. A variety of coping factors have been identified, some of which may influence mood indirectly, and some of which may interact. Therefore multivariate procedures represent the most appropriate approach to statistical analysis, in which mood state is the independent variable, and coping factors are included as independent variables.

The sample size, using multivariate statistical methods, is influenced by the number of variables for analysis. A large number of potentially influential coping variables have been identified from the literature, therefore it is envisaged that a large sample will be required for interview. This clearly has implications for the collection of additional qualitative data. These are generally based upon recordings made at the time of interview, and subsequent analysis of the transcriptions. This is clearly not feasible for a large sample, in view of the time required. Therefore qualitative data, in this study, must be limited to items which can be recorded in writing at the time of interview.

3.4 Perspectives on pain experience

A major problem in the collection of data about pain experience, by interview, is that subjects may be influenced by the interviewer to give answers which are biased. For example subjects may not wish to admit that they are not coping well, or that they are unsatisfied with their care or their treatments. They may be reluctant to admit to problems with personal relationships, or to financial difficulties. There may also be areas of knowledge to which not all patients have access, for example their precise diagnosis and cause of their pain.

For these reasons, it is appropriate to collect data from the nurses who visit each subject interviewed, and who know the subject well. Since it is likely that more than one nurse may be in regular contact with each subject, it is envisaged that data should be collected from each nurse who visits regularly, in order to provide a cross-check on nursing perspectives. These data will be collected in questionnaire format, and will provide a valuable supplement to the interview data collected by the researcher, in addition to providing opportunities for comparison.

3.5 Planning the methodological approach

Issues of measurement and assessment have been considered in some depth, in this chapter, in order to illustrate the difficulties involved in selecting analytical methods and measurement tools which are suitable for use with an elderly sample of pain patients who have not previously been the focus of such detailed study. This review has highlighted the usefulness of methodological triangulation, using multivariate quantitative analyses in accordance with the theoretical model. Qualitative analysis will provide supporting contextual information, using content analysis where appropriate.

It is inevitable that the research design will, of necessity, involve a compromise between the need to produce results which are valid and reliable, and a pragmatic judgment of the nature and volume of information which it is possible to obtain, given the elderly and probably frail nature of the majority of the patient population. Most of the existing tools identified here have been rejected because they are unsuitable for administration, at interview, by the researcher to the particular population under study. Nevertheless, while these may not be appropriate for use in their entirety, there are many aspects which are adapted for inclusion into the research design, using simplified scaled questions.

It is envisaged, on the basis of all the above considerations, that the interview should be based upon a semi-structured schedule to include questions scaled to facilitate quantitative analysis, in accordance with the theoretical model. Additional open-ended questions will be included to provide descriptive contextual information, together with data for content analysis, where applicable. This approach will maximise opportunities for obtaining meaningful data about pain experiences, both at an individual level and for the sample as a whole. Quantitative data analysis will be used to identify independent variables which significantly influence coping, using bivariate and multivariate procedures. Patients' comments will be used to support the validity or otherwise of the resulting statistical model. Additional data from nurses with respect to each subject will be used to complement the interview data.

The method used is described in detail in chapter 4, together with an analysis of the pilot study.

Footnote: [1] D. Marcer, Senior Lecturer in Psychology, University of Southampton

CHAPTER 4 METHOD

4.1 Ethical considerations

The study was centred upon district nurses and their patients within one health authority. Permission to conduct the research study was obtained from the research and ethics subcommittee of the local medical committee, and from all nurse managers concerned. Wherever possible the study was introduced, by the researcher, to community nurses at staff meetings prior to commencement, in order to allow the opportunity for familiarisation, questions, and comments, including confirmation of confidentiality. All general practitioners in the practices concerned were contacted in writing, given an outline of the study and asked for their signed agreement before any patient of theirs was approached to participate. All communications with patients and nurses contained undertakings that any information received would be treated in the strictest confidence. Schedules and questionnaires were individually pre-coded and treated anonymously for the purposes of analysis.

All patients were asked for their permission before information about them was obtained from any other source. The researcher had no knowledge of any patient's condition or situation prior to interview.

4.2 Design

A four-stage procedure was used as a basis for the study. The first stage involved the selection of a sample of patients in the community who were being visited by a district nurse, and who had some degree of persistent pain. The second stage was the patient interview. The third stage was the collection of questionnaire data about each patient interviewed, from the nurses who visited. The final stage involved the collection of questionnaire data from each of the nurses who participated in the study, about their nursing background and attitudes to pain management. This design is illustrated in figure 4a.

Copies of all letters, schedules and questionnaires used in the main study are given in Appendices I to IV. These differ from those used in the pilot study in layout, and contain a some minor alterations and extensions which are identified within the text. The chief difference between the pilot study, and the main study was that patients under retirement age were not, initially, excluded.

STAGE	PATIENTS	NURSES
1	Subject Selection Questionnaire	
2	Subject Interview	
3		Patient Assessment Questionnaire
4		General Questionnaire

Figure 4a Four-stage research design

4.2.1 Sample selection

It is necessary that the sample of pain patients selected for the study should be representative of the population of patients visited by district nurses. However it was impractical to take a random sample of patients from across the district in view of the large numbers of practices and nurses involved. The solution adopted was to select a random sample of group practices and then to centre the study upon the district nursing teams attached to these (district nurses are group-attached in this particular health authority). This afforded a good mixture of semi-rural and urban practices, large and small, with a reasonable cross-section of social strata.

4.2.2 Stage 1: Selection of subjects

Once written permission was obtained from the general practitioners concerned, the district nurses in each selected practice were asked to supply the name and address of each patient visited, excluding those who were considered too ill to interview (severe pain alone was not a sufficient reason for exclusion), or who were profoundly deaf, confused or demented. An introductory letter and questionnaire (shown in Appendix I) was designed for personal delivery, by one of the nurses, to each patient in the district nurses' caseload. This asked if the patient had continuous or intermittent pain, or was being treated for pain which had lasted for more than three weeks. Patients were also asked to indicate the sites of their pain and if they were willing to be interviewed.

The purposes of this letter were to:

1. allow self-selection of pain patients for interview, since selection by nurses might exclude some who were coping well and thought not to suffer pain.
2. include all types and duration of pain except for minor transient episodes which were not likely to be of interest in terms of coping.
3. identify the proportion of patients visited by district nurses who experience persistent pain.

The letter encouraged patients to have a relative or friend present at the time of interview, if they wished, in order to reassure those who were nervous of receiving visitors alone, and to lead to some input from significant others.

Appointments were made for the interview as soon as a positive response was received, in order to maximise the probability of cooperation, and before patients' circumstances were likely to change.

4.2.3 Stage 2: Patient interview

The patient interview was designed to explore all factors identified, from the literature review and preliminary inquires, as relevant to pain coping experience or likely to influence mood state.

Construction of bipolar mood scale

A bipolar mood profile scale was constructed specifically for the purpose of this research study, and is given on page 7 of the interview schedule in Appendix II. It was designed to be brief, simple to administer, of relevance to an elderly population with pain, and to reflect the theoretical model. A semantic differential format was chosen, using a 7 point measurement scale (Moser and Kalton 1979).

Twelve scale items were initially selected as representative of feelings associated with anxiety, depression and hostility. These were also identified as relevant to patients with pain (the items 'frightened' and 'frustrated' were not included at this stage). A pretest on 10 college lecturers indicated the need for minor amendments to ensure that the positive and negative pole items selected were totally mutually exclusive. A test - retest reliability check was then carried out on a miscellaneous group of 18 people, aged between 45 and 72 years, who reported no substantial changes in circumstances during an interval of one week. Test - retest scores revealed a correlation of $r= .83$ $(p<.001)$. In addition, the mood profile was administered, by the researcher, to two very elderly people, one with painful malignant disease, the other with osteoarthritis. A conversational approach was used to pinpoint their position on each item . It took no more than 5 minutes to complete and no difficulties were identified. The use of a seven point scale might appear, at first glance, to be too wide to achieve any degree of accuracy during interview presentation. However it is accomplished in two stages. First: subjects are asked if they identify with either the positive or negative pole, or neither. Second: if positive or negative, the choice of words used to guide patients towards selection of the most appropriate point on the scale is illustrated in figure 4b.

The 7 point scale and the selected items were found to be appropriate, and were retained unchanged in the format shown in the interview schedule (see Appendix II).

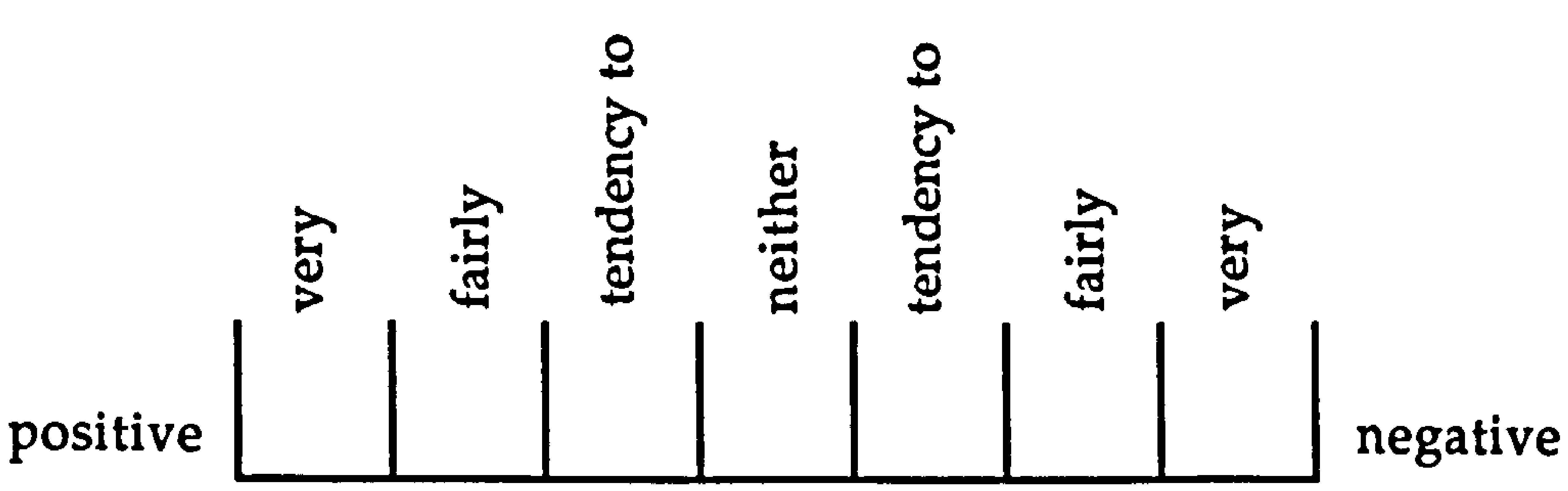


Figure 4b Semantic differential presentation format

Pain assessment

The MPQ was selected as a suitable research tool for inclusion in the interview after a pretest with two elderly people with painful conditions. Administration was simple and took about 5 minutes. Both found it easy to comprehend, and seemed to find it interesting and relevant. The MPQ is given in page 3 of the interview schedule in Appendix II. Additional pain measures included a verbal discrimination 5 point pain rating scale (Raiman 1986), given on page 2 of the interview schedule, to be completed for levels of pain 'when it is least troublesome', pain 'when it is worst' and pain that you have 'right now'. 10 centimetre visual analogue scales (no pain - worst pain imaginable) were included in the pilot study as an additional measure of these three aspects of pain.

The interview schedule

The initial questions in the interview schedule covered demographic factors, including age, gender, marital status and living arrangements. These were followed by questions concerned to identify the cause and sites of the pain, and the knowledge and certainty of the patient about the diagnosis. A body outline chart was used in the pilot study for patients to identify their pain sites, although this was not subsequently used and is not shown in the appendix.

The duration of the pain, pain ratings scales and the temporal pattern of the pain were included on page 2, followed by the administration of the MPQ.

Pages 4 to 6 of the interview schedule were concerned with the effects of pain. Disability was measured using an activities of daily living scale based on items predicted to be of major relevance to patients in the home, including general mobility, washing, dressing, cooking, cleaning, shopping and gardening. Patients were asked what life was like generally, what effect pain had had on their lives, what their interests and hobbies were and if they felt occupied or lonely. These were followed by questions about the level of social contact inside and outside the home, and the provision of social service aids and support. Patients were then asked (p.6) about health, personal or financial problems in addition to pain and how troublesome these were in relation to their pain problem.

Page 7 of the interview schedule was devoted to the mood profile. Patients were asked to describe how they felt these days, since they had the pain. They were also asked if they would expect to feel any different if they were no longer in pain, and if so how. They were encouraged to elaborate on why they thought they felt as they did, and what, if anything, had caused their feelings to change.

Page 8 developed the theme of mood by asking patients if they felt anxious or depressed - this was to ascertain how well these descriptors matched with scores identified from the mood scale. Patients were asked if they felt their pain to be under control and , if so or if not, to give reasons.

Page 9 was designed to explore pain treatments received, including medications, and their perceived success. Coping factors were identified on page 10, together with religious faith - it was stressed during interview that it was spiritual faith which was of interest, not church attendance or affiliation.

Patients were then asked it they thought that their pain would get better, and whether or not they felt that they had been fully informed about their condition and treatments. Patients were also asked a hypothetical question about whether or not they would wish to be fully informed, should they have something seriously wrong with them, even if the outcome was not good. This was used to establish patients' desire for this type of information.

The final section of the interview (pages 11 and 12) was devoted to questions about nursing care. Questions 33 to 35 were designed to establish the level of patient contact with the nurse, and their perceptions of the reasons for nursing visits. Subsequent questions concerned the patients' perceptions of the nurses' role in helping with their pain problem. Finally all subjects were asked if they would be willing for the researcher to obtain further information from the nurses who visited them.

A blank page was appended to the schedule for the recording of comments from the subjects, significant others, and the researcher, either during or immediately after the interview.

Administration of the patient interview

The whole interview schedule was designed for administration in an interested conversational manner. Where scales of measurement were used, the choices were presented to the patient verbally, and the response was checked by making use of non-verbal signals and intonation in addition to the patient's verbal reports. The result perceived by the researcher was then fed back to the patient, where necessary, for confirmation or negotiation prior to recording, in order to maximise accuracy. Where discrepancies were picked up between answers to direct questions and comments already received, these were followed up and agreement reached before the answer was finally recorded.

Pretest of the patient interview

This comprehensive interview was pretested on an elderly gentleman aged 80 who experienced severe pain from what he knew to be a chronic malignant condition, multiple myeloma. It took one and a half hours to complete, but this included ample time for the patient to record his own views about his situation present and past.

It did not appear to tire him unduly and he responded throughout in an enthusiastic manner. He was aware that his critical opinion would be welcomed, but his report was positive, and he seemed genuinely to have enjoyed the opportunity to discuss even the negative aspects of his life in a frank open manner. The district nurse who visited him later also received positive feedback. Following this successful interview the pilot study was commenced.

4.2.4 Stage 3: Nurses' assessments of the patients

Each of the nurses and auxiliaries in the selected practice was invited to complete a self-administered questionnaire about the patients interviewed with whom they had regular contact. Assurances were given that the patient's permission had been obtained and that confidentiality would be maintained. The questionnaire, together with the explanatory letter, is given in Appendix III, and includes a request for the patient's medical diagnosis, brief assessment of general mood and behaviour, the presence and type of any additional medical or social problems, and the level of pain thought to be experienced. It included the extent and source of pain control, effects and impact of pain, perceived exaggeration of pain complaints, whether or not improvement was anticipated and the efficacy of their nursing contact. Finally it asked if a standard form of pain assessment had been used, when last contact with the patient had been made and if the patient's condition had recently changed. It was necessary to avoid bias by an assumption of the presence of pain. Therefore nurses were advised, in the accompanying letter of instruction, that not every patient, for whom a questionnaire was sent, would necessarily have pain.

Questions were designed to allow some comparisons of pain levels and mood state with the researcher's recordings. Questionnaires about each subject were given to more than one nurse to complete, usually the DN and the EN or auxiliary. This was done to maximise the amount of information available about each patient from different perspectives. It was also to try to identify systematic discrepancies between the recordings of nurses and those of the researcher, and to identify, if possible, systematic differences between the recordings made by different grades of nurse in relation to the researcher's recordings. Additional comments were invited throughout the questionnaire to supplement the quality of the data provided.

4.2.5 Stage 4: Nurses' general questionnaire

This was a final self-administered questionnaire (see Appendix IV) presented to each nurse and auxiliary who participated, and was designed to provide information about the training and experience of each, including the amount of tuition received with respect to pain control. Participants were also asked to identify any particular problems they faced in relation to pain control, and whether or not they thought adequate attention was paid to pain issues during nurse training. Additional comments were invited throughout.

4.3 Planned data analysis

Data from patients and nurses were prepared to facilitate the creation of a data file for use with the Statistical Package for the Social Services version 10 (SPSSX).

Factor analysis was planned, in order to analyse the mood profile data, to assess whether or not there was any differentiation between emotional states, and to check if all items made a significant contribution to the mood scale. Preliminary analysis of the rest of the quantitative data involved the use of frequencies and correlations. From these correlations, independent variables were selected for inclusion in multiple regression analyses, using factor scores from the mood profile as dependent variables.

An incongruity was recognised between the use of non-parametric statistics for the preliminary correlations, and the use of multiple regression which is based upon an assumption of interval data. It was recognised that the verbal rating scales used were not necessarily interval or ratio.

Expert statistical advice was sought, and assurance received, about the validity of adopting regression for this type of data (Meddis [1], personal communication).

Pain locus of control was not assessed quantitatively during the interview, therefore relevant answers and comments from subjects concerning pain control and behavioural strategies was subjected to content analysis. The data were quantified as internal or external locus of control using a five point scale. Subject to satisfactory inter-rater reliability checks, these scores were included in subsequent quantitative analyses.

Content analysis was also used to categorise and group qualitative data obtained in response to open questions throughout the interview. These results are used to lend support to the quantitative findings.

Non-parametric procedures were used to assess the degree of similarity between the nurses' quantified observations of patients' pain and mood, and observations recorded during interview.

4.4 Pilot Study

4.4.1 Pilot Study: Subjects

The nurses who took part in the pilot study comprised the district nursing team attached to one group practice, and was composed of one district nurse (DN), one enrolled nurse (EN) and one auxiliary. Subjects were 22 patients who formed the regular case load of these nurses and who were self-selected in accordance with the requirements of stage 1 of the study. A lower age limit of 18 was imposed, but no other age restrictions were included at this stage of the research. However only two subjects were below retirement age.

4.4.2 Pilot Study: Procedure

Obtaining the general practitioner's permission

A letter was sent to the general practitioners of the practice concerned, outlining the nature and purpose of the study and requesting their written permission, using the return slip and prepaid envelope provided, for the researcher to approach their patients to take part (see Appendix I).

Implementation of stage 1 of the study

Once permission has been obtained, the names and addresses of all eligible patients were obtained from the district nurse and personalised letters / questionnaires were prepared for distribution during routine visits. The questionnaires were accompanied by a letter to each nurse involved giving instructions for distribution. This is also given in Appendix I. A prepaid envelope was provided with each questionnaire so that these could be returned directly to the researcher.

Stage 2: The patient interview

As soon as a positive response was received, telephone or written contact was made with the subject to arrange an appointment for interview within the following few days, to suit the subject's convenience. No more than two interviews per day were scheduled in order to allow each to be as relaxed as possible, and to allow time after each interview for checks on recorded information and additional written comments by the researcher, based upon recent memory. The appearance of the researcher was smart and formal. As an introduction, the researcher described her nursing background and gave an outline of the purpose of the study to the patient.

The sequence of questions contained in the research schedule was designed to follow a logical format and was adhered to as far as possible, but a flexible approach was adopted, where necessary, in order to maintain the flow of information from the subject.

Stages 3 and 4: The nurses' questionnaires

After about four weeks, once all of the patient interviews for that practice had taken place and the flow of replies had ceased, a list of respondents was sent to the district nurse to encourage the return of the remaining questionnaires.

Following this, questionnaires concerning each subject were prepared and given to each of the nurses who visited them. Questionnaires contained a patient code number and a nurse code number so that they could be returned in anonymity, and each nurse was also sent a letter of instruction outlining the requirements (see Appendix III). A prepaid envelope was provided to each nurse for direct return of the questionnaires.

Once these questionnaires had been returned, the final general questionnaire was sent out with a prepaid return envelope and a letter of instruction as shown in Appendix IV. Finally, all nurses were thanked individually for their cooperation.

4.5 Results of Pilot Study

Out of a total regular caseload of 60 patients, 14 (23 per cent) were excluded because of terminal illness or dementia, temporary in-patient treatment or unforeseen problems, such as the illness of a spouse.

46 questionnaires were distributed, of which 40 were returned, giving a response rate of 87 percent. Of these 40, 3 were not adequately completed, 7 patients were not in pain, and 6 declined to be interviewed. Of the 24 who agreed to interview, 1 was admitted to hospital prior to interview, and 1 reply was received too late for inclusion.

The results indicated that 81 percent of the district nurse's caseload, who responded to the questionnaire, had pain over at least a three week period.

A total of 22 patients was interviewed. This represented 61 percent of those eligible, and 45 percent of the total caseload excluding, in both cases, those who claimed not to have any pain. The district nurse was unable to identify any systematic differences between the type of patient who volunteered to be interviewed and those who did not.

The average time of the interview was 1 1/2 hours, ranging from 40 minutes to 4 hours. All patients interviewed were able to supply some useful information.

Problems were encountered in the administration of the visual analogue scale to the older patients. Out of 18 patients aged over 70, only 4 were able to complete the VAS, although all could, without any difficulty, use the verbal scale to describe their pain. Several patients were reluctant to complete the body outline, or had difficulties in distinguishing right from left during completion (including the researcher). Problems in the completion of the mood profile and the MPQ were encountered in two instances. One patient was too deaf to distinguish the words, and one lacked sufficient energy and concentration because of physical illness. None of the other patients had any difficulties with either of these tools, and no other aspects of the interview appeared to cause any problems. Most subjects expressed pleasure at being able to talk freely about their pain experiences.

4.5.1 Pilot study: Quantitative analysis of patient interview data

Demographic data

The mean age of patients was 75.7 years (range 43 to 92 years).

19 subjects were female and 3 were male.

6 subjects lived alone, 7 lived with their spouse, 2 lived in rest homes, and 7 lived with a close relative or relatives (including one female subject, aged 80, who cared for her mentally handicapped middle-aged son).

Pain diagnoses

Diagnoses were confirmed from the district nurse's data, and details are given in table 4.1. Some patients experienced pain from more than one source of origin.

The care of terminally ill patients in this locality is generally undertaken by the specialist MacMillan service and this accounts for the lack of such patients in this sample.

osteoarthritis	8	
rheumatoid arthritis	3	
post-herpetic neuralgia	3	
stroke	2	
cancer	2	(one of whom had not been told)
varicose ulcer	1	
diabetic ulcer	1	
back pain	1	
post-traumatic pain	1	
post-operative pain	1	

Table 4.1 Diagnoses (pilot study)

Pain data

Mean duration of pain was 8.5 years (range 3 months to 30 years).

13 patients experienced continuous pain, 8 had intermittent pain.

7 patients (30 percent) expressed uncertainty about the cause of their pain.

Mood state

9 patients reported themselves to very or fairly anxious and 4 admitted to being generally anxious.

5 patients said they were fairly depressed and 2 very depressed. One of these had suffered a stroke and did not appear to be cooperating with rehabilitation exercises. One was separated from her husband who had recently been admitted to a nursing home after a stroke. One post-stroke patient appeared extremely depressed and could only cry whenever she was asked how she felt.

Some patients indicated that 'frightened' and 'frustrated' should be included in the assessment of their current feelings (these terms had been omitted in the pilot study).

Only 9 subjects thought that they would be trouble-free if it were not for their pain.

Factor analysis of mood profile

Factor analysis revealed that the communality of all variables was high, the lowest being for calm / irritable and optimistic / hopeless at .53. Varimax rotation revealed 3 factors which together accounted for 73 percent of the variance. Each had an Eigen value in excess of 1 and the model provided a good fit to the data (χ^2 = .36, df 33, p 0.32). Factor 1 accounted for 38 percent of the variance, included angry, resentful, worried, upset, sad, tense and irritable and was labelled 'anxiety, hostility'. Factor 2 accounted for 24 percent of the variance. It comprised unsure, threatened, worried and tense and seemed to indicate 'uncertainty'. Factor 3 accounted for 10 percent of the variance, included powerless, guilty, hopeless and was labelled 'depression'. Factor scores were used in subsequent correlational analyses.

Correlations

Nonparametric Spearman correlations are reported throughout.

Scores on factor 1 of the mood profile (FS1, hostility) were found to be associated with the patients' self-report of depression (r_s=.67,n=19, p.001).

Scores on factor 2 (FS2, uncertainty) were found to be associated with the patients' self-report of anxiety (r_s=.59, n=19, p.001), with the presence of other life or situational problems (r_s=.51, n=19, p<.05), and with 'mood if not in pain' (r_s=.61, n=19, p<.01).

Scores on factor 3 (FS3, depression) were found to be associated negatively with level of occupation (r_s=.65, n=19, p.001), and with the evaluative factor on the MPQ (r_s=.5, n=19, p<.05).

Ratings of 'least pain' were those most closely associated with FS2 and FS3, (r_s=.44 and .4 respectively, $p \leq .05$).

Rating of 'worst pain' was associated with the affective factor on the MPQ (r_s=.69, n=21, $p<.001$), with ability to pursue hobbies (r_s=-.66, n=20, p.001) and with appetite decrease (r_s=.52, n=20, $p<.01$).

Further quantitative analyses were not undertaken because of the small sample size.

4.5.2 Pilot study: Qualitative analysis of patient interview data

Q 13: What is life like these days, since you have had pain?
11 subjects focused upon restriction of activities, while 9 highlighted effects on mood. 6 subjects acknowledged acceptance, and a further 4 identified the need to control or fight the pain.

Q 15: What is the worst aspect, for you. of being in pain?
7 subjects identified the restriction of activities of daily living as the worst aspect. 6 focused on pain intensity or frequency. 4 subjects focused upon worrying or frightening aspects of pain (mostly uncertainty about being able to cope in the future).

Q 38: What do you think that nurses can do to help people in pain?
5 subjects identified practical treatments, while 16 focused upon supportive factors such as understanding and encouragement. 4 subjects mentioned the need for regular contact with the nurse. 3 were doubtful if nurses could help and one did not know.

Younger patients in the pilot study
2 patients in the sample were under retirement age. One was Mrs X, aged 48, who had bronchiectasis, had suffered pain all her life, and had recently undergone a painful operation.

She had become a member of a minority religious sect and spent much time during the interview quoting the bible. When questioned about her feelings and how she coped, Mrs. X expressed considerable concern that negative thoughts indicated a lack of faith on her part. The interview was lengthy (in excess of 4 hours), but much of that time was spent on counselling to help redress some of the guilt feelings the interview seemed to have exposed.

The other younger patient was Mr Y, aged 43, who had a long history of ankylosing spondilitis. He had had a back operation and had attended pain treatment clinics, including Liverpool, but all attempts at pain relief had failed and he was currently self-injecting Temgesic (buprenorphine) on a regular basis. Mr. Y was married with two teenage children, was anxious, depressed, and expressed considerable bitterness about his situation. His relationship with the district nurse had broken down, and he appeared to typify the most intransigent of pain behaviour management problems.

Older patients in the pilot study

The interviews served generally to confirm the fortitude with which many older patients cope with quite high pain scores associated with arthritic conditions. The main concerns of these patients seemed to be the maintenance of independence in activities of daily living. The most anxious patient was one who was subsequently found to have a malignant condition, but claimed at interview to have been told her pain was due to shingles. She clearly suspected this diagnosis and questioned the researcher throughout about the likely cause of the pain. Several patients appeared considerably depressed. All of these patients had other health or personal problems in addition to pain. Expectations of relief from physical pain appeared to be low among the older age group, and there appeared to be a general reluctance on their part to take prescribed analgesics on a regular basis.

4.5.3 Pilot study: Nurses' data

The response rate for both questionnaires to all three members of the nursing team was 100 percent.

The district nurse (DN)

The DN had considerable experience in hospital, including as a geriatric ward sister, and 8 years' community experience. She subsequently obtained her Diploma in Nursing. She had received tuition in acute pain management and cancer pain treatment, pain theories, psychological factors in pain, but not in the assessment of pain, nor chronic pain management. She completed questionnaires for all 22 patients interviewed in the pilot study. These were patients that she knew very well and it took her between 3 and 4 hours in all to complete.

There was found to be no significant correlation between the DN's ratings of the patients' pain or mood state and the recordings provided during interview. On inspection there appeared to be a trend for her to over-estimate the level of 'least pain' and under-estimate the level of 'worst pain'. The DN's comments revealed a high degree of sensitivity to the patients' pain experiences and concurrent life problems. She felt that few patients exaggerated their pain.

The enrolled nurse (EN)

The EN had 11 years' community nursing experience and claimed to have received tuition in the treatment of all types of pain. She complete questionnaires for 3 subjects, none of whom she assessed as having any pain at all. One of these patients was recovering at the time of interview, therefore this assessment may have been fair. Both of the others suffered considerable pain, one from osteoarthritis and the other from rheumatoid arthritis, although they appeared to cope well.

The auxiliary

The auxiliary had 9 years' community experience, but no formal training of any kind. She completed 7 questionnaires - too few to analyse quantitatively. She expressed awareness that most of these patients suffered from pain, though there appeared to be a consistent underestimate of the level of pain, compared to the levels recorded during interview. It also appeared from inspection that her perception of pain exaggeration was related to the level of pain complaint. She thought that the main reason for the exaggeration of pain complaints was loneliness, and that regular visits by the nurse of great help. She also identified that patients with depression presented the most difficult management problems.

4.6 Discussion of Pilot Study

Structure and selection process

The four-stage procedure adopted for the pilot study was demonstrated to be feasible, and was thought to be applicable to a larger scale study. No recommendations for change were found to be necessary.

The self-selection system adopted for obtaining the sample of patients with pain appeared to work well, although the high response rate was probably aided by the high motivation for cooperation of the district nurse concerned and may be lower in a larger study. There was no evidence of bias in this sampling method, but the failure of the EN to recognise pain in three subjects supported the view that selection of the sample of pain patients by nurses may have proved unrepresentative.

Validation of research tools

One of the chief purposes of the pilot study was to check the validity and reliability the data collection tools used. The mood profile presented no problems in administration and was well-received by the patients who seemed to find it interesting and relevant. The seven point scale used required limited negotiation and the few who could not complete it would doubtless not have complied with even a simplified form. The words 'frightened' and 'frustrated' were identified as missing items. Factor analysis appeared to confirm that all items contributed significantly to the model, and the structure provided for relevant interpretation in terms of the theoretical framework.

The VAS was found to be totally unsatisfactory for use with the older age group. This confirms the findings of Kremer et al (1981). However the verbal pain rating scale used was easy to administer and no patient appeared to have any difficulty in classifying their pain using the words provided. They appeared to have little difficulty in identifying levels of pain when least troublesome, and worst. The results revealed a number of statistically significant correlations between pain ratings and other data, while several more approached significance. These results would appear to confirm the appropriateness of using this pain rating scale. The MPQ proved to be a very satisfactory instrument for use with elderly patients.

The body outline was a problem, contributed to by failing eyesight and a lack of familiarity with such tools on the part of the patient, particularly as the chart was presented towards the beginning of the interview. It was found to be unnecessarily time-consuming to complete and added little to the information obtained for the purposes of this research. This is not to suggest that it might not be usefully applied in nursing practice.

The remainder of the questions which demanded quantification presented few difficulties during the course of administration. The verbal rating scales used to quantify variables within the interview schedule were generally found to be easy to administer and interpret, and patients displayed considerable willingness to negotiate a level of precision in their answers which is essential if the data is expected to yield results of statistical significance.

The adequacy of interview topics

Patients reported the interview to be comprehensive from their point of view and did not raise, at that stage, any other issues that were not already covered in some form within the interview schedule.

Although the concept of controllability was used as the basis of the theoretical framework, the interview schedule used in the pilot study made little reference to the degree of control the subjects felt themselves to have. Some patients were questioned informally about the extent of their control over pain and appeared to be able to identify well with the concept. It was found necessary to rectify this omission in the main study.

Length of the patient interview

The time taken for the interviews varied considerably. Some patients were keen to answer the questions fairly directly, while others wished to describe their experiences in great depth. Some, naturally, tended to digress somewhat. The pilot study revealed that three hours was the maximum time allowable for a fruitful interview. Beyond this the discussion was invariably repetitive or non-relevant. On the other hand, to restrict some subjects to less than this duration would have meant loss of useful information. For some it was necessary to allow time to relax and unburden themselves of years of experience, about which they normally had little opportunity to talk in depth. Many were happy to answer direct questions only once they felt satisfied that they had been attended to and their problems understood. For this reason the allocation of a maximum of two three hour interviews per day seemed most satisfactory.

Sequence of the interview

Initial attempts to impose constraints on the sequence of questions proved not only impossible, but counterproductive. Nevertheless some potential sequence effects were identified. For example, at least three subjects alluded to feelings of loneliness until asked directly, when they replied 'no'. It was observed that these contradictory responses were received when the question "do you often feel lonely?" followed discussion of social support. It is possible that an affirmative answer implied criticism of family. The inclusion of the question about loneliness after the discussion of hobbies, interests and occupation led to responses which appeared more harmonious with the general tenor of their overall comments.

In the light of the above observations, small adjustments were made to the sequence of questions in the interview schedule, and it is the final version which is given in Appendix II. There was obviously a need for caution in allowing too much flexibility in the pattern of the interview, and the need for awareness on the part of the interviewer that these effects might occur in any deviation from the prepared schedule.

Interview technique

The interview is highly dependent upon the interview technique and the skills of the interviewer. It was found necessary to be very alert to verbal and non-verbal cues during the interview, and if direct answers failed to correspond to the manner in which they were delivered, or with previous comments, it was necessary to stop and clarify what was really meant. A failure to do this would inevitably result in a high level of error which would jeopardise the results. Although the same researcher would be conducting the interviews throughout, it is nevertheless essential to apply the same approach as rigorously as possible throughout.

Out of the 22 patients interviewed, half were alone throughout. 6 patients had their spouses present throughout the interview and the remainder had another close relative at hand, but these were usually not present throughout. The contact with the spouse or significant other provided useful information about the patient's attitude and behaviour from another perspective, however the task of interviewing in the presence of another person calls into question the reliability of the data obtained. The intermittent presence in the room of young Mr Y's teenage daughter imposed a significant constraint upon the intimacy of questioning, which he may well have planned himself in view of time of interview requested. This did not appear to be the case with older patients, however. It was very noticeable, from the outset, that when a significant other put forward ideas, the subject generally emitted very clear verbal or non-verbal signals of agreement or disagreement.

The majority of subjects seemed to feel that this was going to be their interview, and nothing and no one was going to get in the way.

It was necessary to develop a clear strategy to deal with these potential difficulties. Where the subject was accompanied, it was found necessary to stress that it was the subject's own feelings which were of special interest, however if the other person had any observations these would be recorded afterwards. Where interjections occurred, it was necessary to impose restraints which were generally accepted on both sides, however it was not usually felt appropriate to ask the other person to leave the room - older people often only possess one warm sitting room and many of the interviews took place in cold weather. It was often the case that the other person would leave the room for at least a short period to make tea, and this could be used as a time for clarification and for testing reliability of previous comments. On two occasions the subject himself specifically asked the other person to leave the room, and on one occasion the subject ensured privacy by being interviewed in the kitchen. Comments from others present were often received at the front door after the interview, beyond earshot of the subject.

It was felt that the opportunity to observe interactions between subjects and others could provide much useful information about the status of their relationship, but that interference by others in the interview would not be tolerated. This was generally accepted because the researcher was not asking about independent facts which were open to dispute, but about feelings which were personal. Verbal and non-verbal cues, and discrepancies, were noted and opportunities sought to investigate these in the absence of the other person. In this way it was sought to maximise the reliability of the data collected within the social context.

The significance of age differences in pain experience

The pilot study confirmed that the overwhelming majority of patients visited by district nurses are elderly. Two subjects were aged under 60, and these confirmed earlier suspicions that the pain problems of younger patients were too dissimilar to those of older patients for meaningful comparison. From this there emerged a clear necessity to separate those over retirement age from those of working age. Since there was likely to be a lack of sufficient data to interpret the pain experiences of younger patients, it was found necessary to include only those aged over 65, or retired, in the main study.

Nurses' data

The patient questionnaires proved somewhat time consuming to complete because of the numbers involved. The number of items concerning mood state and pain factors were reduced as a consequence. These minor changes were thought unlikely to have a detrimental effect upon the overall assessment. A limit was imposed of twenty patient questionnaires for any one nurse to complete.

In the pilot patient assessment questionnaire, pain ratings were requested at the outset and, if the nurse judged the patient not to have pain, there was no need to continue. It was thought possible that the EN may have rated her patients' pain as 0 in order to avoid answering further questions. Therefore the sequence of questions was altered to include medical diagnosis, mood state and concurrent problems before pain ratings and pain-related problems. Further probing into the motives of the EN who failed to complete the questionnaire accurately was not conducted because it was thought to be a potentially sensitive issue.

4.7 Implications of pilot study for main study

1. The four-stage protocol to be retained unchanged
2. The questionnaire used to for the self-selection of subjects to remain unchanged.
3. Patient Interview:
   The VAS as a measure of pain, and the body outline pain chart to be omitted.
   The mood profile scale extended to 14 items to include 'frightened' and 'frustrated'.

Questions about the extent of perceived pain control and the source of control to be included.
All remaining questions to be retained.
The layout to be altered to allow more space for the recording of comments throughout.

4. The main study to focus upon the management of pain in the elderly in the community.

5. Nurses' questionnaires to be shortened, though the same topic areas to be retained.

4.8 Method: Main Study

4.8.1 Design

The design of the main study was in accordance with that described in section 4.2. Based upon the results of the pilot study, 12 group practices were randomly selected for inclusion in the main study. It was predicted that this would provide a total of about 200 patients for interview. This number was feasible in terms of interviewing time, and statistical advice indicated that this would generate a sufficient sample of subjects for the use of the multivariate statistics planned.

4.8.2 Subjects

Subjects in the main study were 170 male and female patients who were being visited by members of the district nursing teams attached to the 12 group practices selected from within one district health authority. With the exception of two retired subjects aged between 60 and 65 years, all were aged over 65 years. All identified themselves as having continuous or intermittent pain, or as being treated for pain, over a period of at least three weeks.

4.8.3 Procedure

Practice selection

A list of group practices within the health authority was obtained and each practice was given a number. Selection was then made using random number tables.

Practices where staff or patients were already engaged in research projects, or where there were acute staff shortages, were eliminated from the study, and random substitutions made.

All general practitioners working in the selected practices were contacted in writing and their written permission obtained before proceeding. Permission was received in all instances.

Timing and sequence of study

The district nurses were contacted and provided with an outline of the study. They were asked about the suitability of timing in relation to staff holidays or long term sickness.

The study was conducted so that two practices in proximate locations commenced concurrently. Once interviews were in hand, nurses in the next two practices were approached so that their patients would be ready for interview as previous set was completed. Interviews were conducted throughout the 10 month period from October 1987 until July 1988.

Selection of subjects

Where possible, district nurses were asked to supply a list of names and addresses of all the patients eligible to participate in the study, as indicated in the research design. Personalised letters and identification questionnaires, as given in Appendix I, were subsequently provided for the nurses to distribute during the course of their normal visits. Nurses were asked to provide assistance with the completion of these forms wherever necessary. In some instances, where computerised records were not held, the nurses were provided with blank questionnaires and asked to distribute these, ensuring that the patient's name and address were included on the return form. In all instances, arrangements were made to meet with members of the district nursing teams to explain the requirements of the study at first hand. These verbal instructions were supported by the explanatory letter given in Appendix I.

Patients were requested to return the form, whether or not they wished to be interviewed and a prepaid envelope was included for each patient to return the questionnaire direct to the researcher.

Appointments were made to interview the patients as soon as a positive response was received and interviews usually took place within a week of return.

Patient interview

Patient interviews followed the format described in the research design and were conducted as described in the pilot study. The interview schedule used was that given in Appendix II, and up to three hours were allowed per person. Although the logical order of the interview schedule was satisfactory for the majority of patients, flexibility was allowed in those cases where the patient initiated topics out of sequence. In a small minority of cases where the patient was obviously unwell, though wished the interview to proceed, only those aspects of the interview which he or she wished to cover were included, and a qualitative approach alone was adopted.

Nurses' patient assessment questionnaires

As soon as the interviews were completed for each practice, nurses were provided with a list of respondents, in order for them to encourage the return of the remainder. A further meeting with the nursing team was arranged at which it was decided who should complete the questionnaires for which patients. Questionnaires were coded and allocated, together with an explanatory letter, as given in Appendix III.

Nurses were allowed a maximum of two weeks for the completion of these questionnaires, since an extended interval between the collection of interview data and the nurses' data increased the possibility of error, especially for those patients whose condition was not stable. Prepaid envelopes were supplied to each member of the nursing team for the return of their questionnaires.

District nurses were also asked if they could identify any apparent differences, in terms of pain problems, between patients who had returned their forms and those who had not, and those who had agreed to be interviewed and those who had not, using the form given in Appendix V.

Nurses' general questionnaire

Once the patient questionnaires had been returned, the final questionnaires, given in Appendix IV, were distributed to the nurses by post, along with a letter of thanks for their effort in participating in the study. Return was again requested within two weeks.

4.8.4 The inclusion of additional variables during the study

The researcher was alert, throughout the study, to the need to identify additional variables of relevance to pain and coping. The only factor of major importance which emerged during the course of the main study was the report of feelings of regret. This was subsequently included as an addendum to the patient interview schedule (see Appendix II), in which subjects were asked to caste their minds back over their lives, consider if they any regrets and if so, the extent of those regrets.

4.8.5 Data analysis

The analyses planned for the main study are as described in section 4.3.

The results of the study are given in Chapters 6 to 9.

Footnote: [1] R. Meddis, Senior Lecturer, Department of Human Sciences, Loughborough University

CHAPTER 5 RESULTS: THE PATIENT SAMPLE

This chapter is devoted to an analysis of the process by which subjects were selected for interview, and of the extent to which the resulting sample may be considered to be representative of the population of elderly patients visited by district nurses. This aspect of the study is considered to be critical, since the interpretation and generalisation of the results is dependent upon a sound research design and adequate sampling methods.

5.1 Responses to the patient selection questionnaire

In this section, response rates are examined in order to evaluate the representativeness of the sample of subjects interviewed, in relation to the population of elderly patients visited by district nurses as a whole.

5.1.1 Response rates for return of preliminary pain questionnaires

Over the 12 randomly selected practices, which were included in the main study, a total of 604 questionnaires were circulated among nurses for distribution to patients. 289 of these were returned, indicating an overall response rate of 48 per cent. Response rates for the different practices were variable. These are given in table 5.1, and range between 34 per cent for practice 7, to 60 per cent for practice 6. In practices 5,7,8 and 9, patient questionnaires were pre-addressed, based upon patient lists. In the remainder of practices, unnamed questionnaires were provided for the nurses to distribute because of the absence of a readily available patient list.

5.1.2 Analysis of reasons for exclusion and non-response

The number of questionnaires distributed was calculated, in the case of practices for whom patient lists were not available, by the number of questionnaires given out, minus the number returned unused. The numbers of questionnaires provided for distribution within each practice was influenced, at the outset, by both practice size and patient population characteristics. Practice 3 comprised 3 young doctors, and the nurses reported that a higher proportion than average, for the locality, of their patients were

Practice	Questionnaires Distributed	Questionnaires Returned	Response rate %
1	65	35	54
2	40	14	35
3	38	15	39
4	45	21	47
5*	73	36	49
6	50	30	60
7*	53	19	34
8*	52	29	56
9*	63	33	52
10	45	19	42
11	30	14	46
12	50	24	48
OVERALL TOTAL	604	289	48%

* Practices where questionnaires were pre-addressed

Table 5.1 Preliminary questionnaire response rates

below the age of retirement. Large long-established practices situated in popular retirement areas, such as practice 5, were more likely to contain a high number of elderly patients. Factors which might have influenced the number of patients contacted, were assessed from responses, given by district nurses, to the questionnaire given in Appendix V. Responses from 6 practices indicated that an average of 10 per cent of patients in these district nurses' caseloads were below the age of retirement, 8 per cent were considered too ill to participate in the study, and 14 per cent were confused, deaf or had major communication difficulties. Therefore only 68 per cent of all patients were eligible for inclusion in the study.

Four weeks after the initial distribution of questionnaires, nurses were provided with a list of patients who had responded, so that they could encourage the remainder to return theirs. On the whole, however, questionnaires which were not returned within the first four weeks of contact were not returned at all.

The mean response rate for practices where questionnaires were addressed to individual patients was 48 per cent, whereas the mean response rate for practices who were given unnamed questionnaires for distribution was 47 per cent. This indicates that the method of distribution did not appear to influence the response rate, although the actual number of questionnaires distributed in the first instance might have been greater in the case of preaddressed questionnaires.

The design of the study allowed district nurses to delegate the distribution of questionnaires to the nurses and auxiliaries who were scheduled to visit patients included, or eligible for inclusion, in the study. Although attempts were made to contact all nurses personally, this was not always possible. There may, therefore, have been varying levels of commitment to the study among individual nurses and auxiliaries in each practice. This is likely to have influenced the response rate through the degree of encouragement and help offered to patients. Many elderly subjects had problems with vision and fine manipulation, as well as mobility, and therefore required assistance with the completion and posting of the questionnaire. The practice with the highest response rate of 60 per cent was one where a colleague commented upon the time devoted by the district nurse to ensuring that her patients were individually informed and encouraged to participate. The impression was gained, from subjects interviewed, that there were variations in the degree of active encouragement given to them to participate. Some said that they were only taking part to please their nurse, who had completed the form for them. Others reported that they were given the form, told that it was up to them whether or not they wished to participate, and were left to wait for a visitor or home help to help complete it. The fact that a subject in practice 5 reported receiving her questionnaire by post illustrates that instructions regarding distribution were not always adhered to. Staff holidays, pressure of work, and the use of relief staff were all given as reasons why routine visits might have been deferred, forms not delivered, or instructions overlooked. The return of spare questionnaires was requested, so that an accurate response rate could be calculated. However few were received back, and there was no way of confirming, because of the numbers of nurses involved, if all of the remainder had, in fact, been given to patients. Some may have been lost or forgotten, in which case the response rate was probably higher than the 48 per cent calculated.

Care was taken, at the outset, to ensure that nurses participating in this study were not taking part, concurrently, in other studies. However, soon after the study commenced, a district computerised system of recording was introduced, which occupied a considerable amount of the nurses' time and caused them additional stress. This may well have influenced the time and effort devoted to this study. Comments from some patients indicated that they were aware that their nurses were currently under some pressure.

The major reason put forward by nurses for the low response rate, was that many patients did not like filling in forms, and had no wish to have forms filled in about them. Suspicion about forms is certainly not uncommon among the elderly, of whom these patients were among the most vulnerable. The district nurse in practice 8 telephoned to apologise for the poor response among her patients, explaining that they were very elderly and, on the whole, very insular and suspicious of interference from outsiders. The response rate from practice 7, in the same locality, was particularly low. Reluctance to provide information may have been increased by fear of the possible consequences of exposing their difficulties to an outside agent. In fact, many subjects interviewed expressed fear of losing their homes and their independence. These characteristics may have been accentuated among the population of this particular retirement location, many of whom were relative newcomers.

Comments from other nurses suggested that quite a few patients could not see the point of filling in a form, either because they had little or no pain, or because they would not derive any personal benefit. The response rate appeared to be particularly low in the period immediately prior to Christmas, which could have caused by both nurse and patient factors.

5.1.2 Summary of response to patient questionnaires

Overall there is evidence, from the variable response rates among practices and from subjects' own reports, to suggest that low response rates may have been contributed to by factors related to the nursing distribution of questionnaires. The average response rate of 48 per cent, reported above, is probably conservative, because there was no guarantee that all of the questionnaires retained by nurses actually reached the patients.

Reasons suggested by nurses to explain the low response rate among patients included a general suspicion about forms, which was unrelated to the topic in question. Others failed to see any point in returning the form. It is difficult to identify any major source of systematic sample bias, although such may exist and should be sought within the data. In general, a low response rate is not unsurprising among a population of whom most are, by their very need for nursing care, frail and vulnerable.

5.2 Analysis of initial respondents

Of the 289 subjects who returned their preliminary questionnaires, 57 (20 per cent) reported that they did not have any pain. A further 51 (18 per cent) did not wish to be interviewed. Some of these patients took the trouble to give reasons, which included *"the nurse will give details"*; *"the pain is not troublesome"* and *"I am already receiving treatment"*. These responses suggest that the purpose of the interview was not fully understood.

181 subjects agreed to be interviewed, of whom 7 had died, or been admitted to hospital or nursing home, before the interview could take place. 2 subsequently declined an appointment, and 2 were not interviewed because of difficulties in making contact with them. A total of 170 subjects were interviewed as part of the main study.

District nurses involved in the study were provided with the names of those who had responded and those willing to be interviewed, and were asked to identify any possible differences between interviewees and those who actively declined to be interviewed. Replies varied and included:

> *"Most extraordinary really. Those who refused seemed to suffer as much pain and have similar problems"*
>
> *"Those who did not take part did not want to be bothered or did not find pain a problem"*

One nurse commented that some patients could just about cope with their problems without having to think about anything else, and therefore did not wish to be interviewed. Another stated that those who refused to be interviewed had little pain and could not see the point of the interview.

Overall, there was no evidence of any systematic differences between those who agreed to be interviewed and those who refused. Nurses reports indicated that patients with the most and the least problems seemed to be as likely to decline to be interviewed, the former because they could not cope with it, and the latter because they could not see the relevance.

5.3 Analysis of sampling adequacy

There was clearly a considerable difference between the high response rate obtained in the pilot study (see chapter 4), and that obtained in the main study. In the pilot study, the protocol for administration of the questionnaires was carefully worked out in conjunction with the district nurse concerned. This district nurse was completing an advanced nursing course at the time of the study, and had actively volunteered to help with this research. In the main study, while every effort was made to ensure that nurses were adequately briefed, at group meetings, and by personal contact wherever possible, random selection of practices ensured that the nurses involved were not necessarily those with particular enthusiasm for, or commitment to, research. Furthermore patient characteristics in different practices and practice areas may have influenced both response and interview rates.

The response and interview rates reported in the main study are far from those optimally sought. It is not possible to claim, on the basis of the response rates achieved, that the sample of elderly pain subjects included in the study are necessarily representative of those contained in the regular caseload of district nurses. Nevertheless it has not proved possible to identify any substantial differences between subjects interviewed and those who declined to participate.

The response rate in the pilot study was very much higher (87 per cent), yet the percentage of respondents reporting pain in the pilot study (81 per cent) is similar to that in the main study (80 per cent). In the main study, 170 subjects were interviewed, out of the 289 who returned their initial questionnaires (58 per cent). In the pilot study 22 subjects were interviewed out of 40 questionnaires returned (also 58 per cent).

Figures from computerised returns for district nurses, obtained from the district health authority, indicate that those aged over retirement age account for 83 per cent of patient contacts. This includes figures for district nurse / midwives, none of whom participated in this study. Therefore the figure, given in section 5.1.2, of 10 per cent aged under retirement age appears to be reasonably accurate. Figures obtained from this source suggest the average age of retired patients to be 81 years, compared to 79.7 years in the subject sample (see section 6.1). Bearing in mind that the old elderly are more likely to suffer from confusion or dementia, this indicates that the age distribution of the sample was probably representative of the patient population. The coding system for types of visit, obtained from the district computer, did not, as had been hoped, allow direct comparison with details obtained during interview, as further validation of the sample.

5.4 Conclusions

There seems no evidence overall to reject the validity of the sample selected for study. Although the response rate was not high in the main study, the ratio of those in pain, to those not in pain, was similar in both the pilot and the main study. Collective computerised data for district nursing confirmed that the age distribution of the study sample was representative of the patient population. The method of distribution is a likely cause of poor response in some practices. Careful scrutiny of the range of interview data should establish whether or not the range of responses appears adequate for analysis. However some caution must be applied in the interpretation of results, since those who do not like providing information, filling in forms, or being interviewed, may exhibit coping characteristics which are not necessarily shared by those who do so willingly.

The results of the study are given in the following four chapters.

CHAPTER 6 RESULTS: THE STUDY POPULATION AND PAIN COPING CHARACTERISTICS

In this chapter, the demographic and pain coping characteristics of the sample interviewed are described, based upon both quantitative and qualitative data analysis. Results are based upon interview data for 190 subjects, gained during the pilot study and the main study, unless otherwise stated.

It is not possible to assume that data based upon verbal rating scales are interval because the ratios between the scale positions are likely to vary. Therefore nonparametric statistics, based upon the rank position of scores, are reported, wherever possible, for this type of data.

A large number of correlations are reported during the course of the results as a whole. Correlations which have a probability of greater than, or equal to 0.05 are reported throughout as significant. However a cautious interpretation is encouraged of results which show only modest correlation coefficients or marginal significance, since some of these may be due to type one errors. Such results must be viewed carefully in the light of theoretical predictions, and supportive evidence from alternative sources.

Because pain is a subjective experience, the data in this, and the following three chapters, are supported by patients' comments, and by brief case reports, which provide contextual information. It is not possible to present these types of data without commenting upon the reasons for focusing upon particular aspects. Some elements of discussion are therefore included throughout the results sections, each of which is referred to again in the conventional comprehensive discussion provided in chapters 10 and 11.

6.1 Demographic and domestic data

145 subjects (76.3 per cent) were female and 45 were male. Their mean age was 79.7 years (s.d. 7 years, range 61 to 98 years).

The living arrangements of subjects are given in table 6.1. Those with cohabiting relationships of long-standing, though few in number, were included in the same category as those who were married, since the quality of the relationship was judged to be similar. Category 5 comprised those who had lodgers, or others living in the same house, but were not reliant upon them for any substantial aspect of care.

Living arrangements (N=190)	Number	Percent
1. Married or living with close partner	76	40
2. Cared for by relatives or significant others	30	16
3. Living in a rest home or council home	5	2
4. Living alone in warden service unit	11	6
5. Others living in same house but independent	8	4
6. Living alone	60	32

Table 6.1 Living arrangements

91 subjects (48 per cent) were widowed and 22 (11.5 per cent) were single. Of those widowed, the mean duration of widowhood was 15.7 years (s.d. 14.4 years, range 9 months to 65 years).

6.2 Mood state

Mood state is a critical variable in this research, since it is used as the measure of coping, and hence the dependent variable, throughout. For this reason mood state characteristics are reported first.

6.2.1 Analysis of the semantic differential mood profile

14 items from the semantic differential mood profile were included in a

correlation matrix which is given in Appendix VI. Correlation coefficients were in the range 0.32 to 0.75.

All items from the mood profile were included in a principal component analysis. The item 'frustrated - fulfilled' was found to have low communality (0.29), whereas the remaining items displayed communalities in the range 0.50 to 0.71. 'Frustrated' was eliminated from further analysis at this stage.

The remaining mood items were subjected to factor analysis, selecting the maximum likelihood method of extraction and Varimax rotation. Sampling adequacy was found to be excellent at 93.6 per cent, using the KMO measure. Factor 1 had an eigenvalue of 7.67, and this was the only factor to have an eigenvalue greater than 1, the second and third factors having eigenvalues of 0.94 and 0.85. The scree test also identified a single factor which accounted for 57 per cent of the variance. However Chi-square tests of significance suggested that neither the single factor solution, nor the two factor solution provided a good fit to the data (χ^2=202, df 65 p<.001; χ^2=128, df 53, p<.001 respectively). The three factor solution provided a more satisfactory solution in terms of fit to the data (χ^2=61, df 42 p.03), and in terms of interpretation. The rotated factor matrix for this solution is given in table 6.2, and the full results of the factor analysis are given in Appendix VII.

The three factors are identified as 'depression' (powerless, hopeless, guilty, sad); 'anxiety' (tense, frightened, worried, unsure, upset, threatened); and 'hostility' (angry, resentful, irritable). The proportion of the total variance explained by this solution was 65 per cent. However the shared variance between the factors was such that while the first factor accounted for 56.3 per cent of the total variance, factors 2 and 3 accounted only for 4.5 and 4.1 per cent each.

Mood descriptors	1	Factors 2	3
powerless	.83		
hopeless	.72	.31	
guiltly	.61		
sad	.57	.42	.44
tense		.75	.31
frightened		.69	
worried	.34	.58	
unsure	.53	.54	
upset	.46	.50	.41
threatened	.45	.47	
angry			.77
resentful	.46		.67
irritable		.39	.61

Values of less than 0.3 are not given

Table 6.2 Rotated factor matrix (mood scale)

Had there been a clear distinction between the factors, each factor would have been treated as a distinct aspect of coping, and factor scores would have been used as dependent variables in future analyses. However there was extensive overlap between all aspects of mood, and each remaining item in the mood profile contributed substantially to the overall analysis. Therefore the total mood score, excluding the item 'frustrated - fulfilled', was used as the measure of coping for the purpose of further analysis. The range of mood scores was -33 to +39 with a mean of 14.0 (s.d. 17.3), indicating considerable variability and a positive skewness within the data. This is best illustrated by the histogram given in Table 6.3.

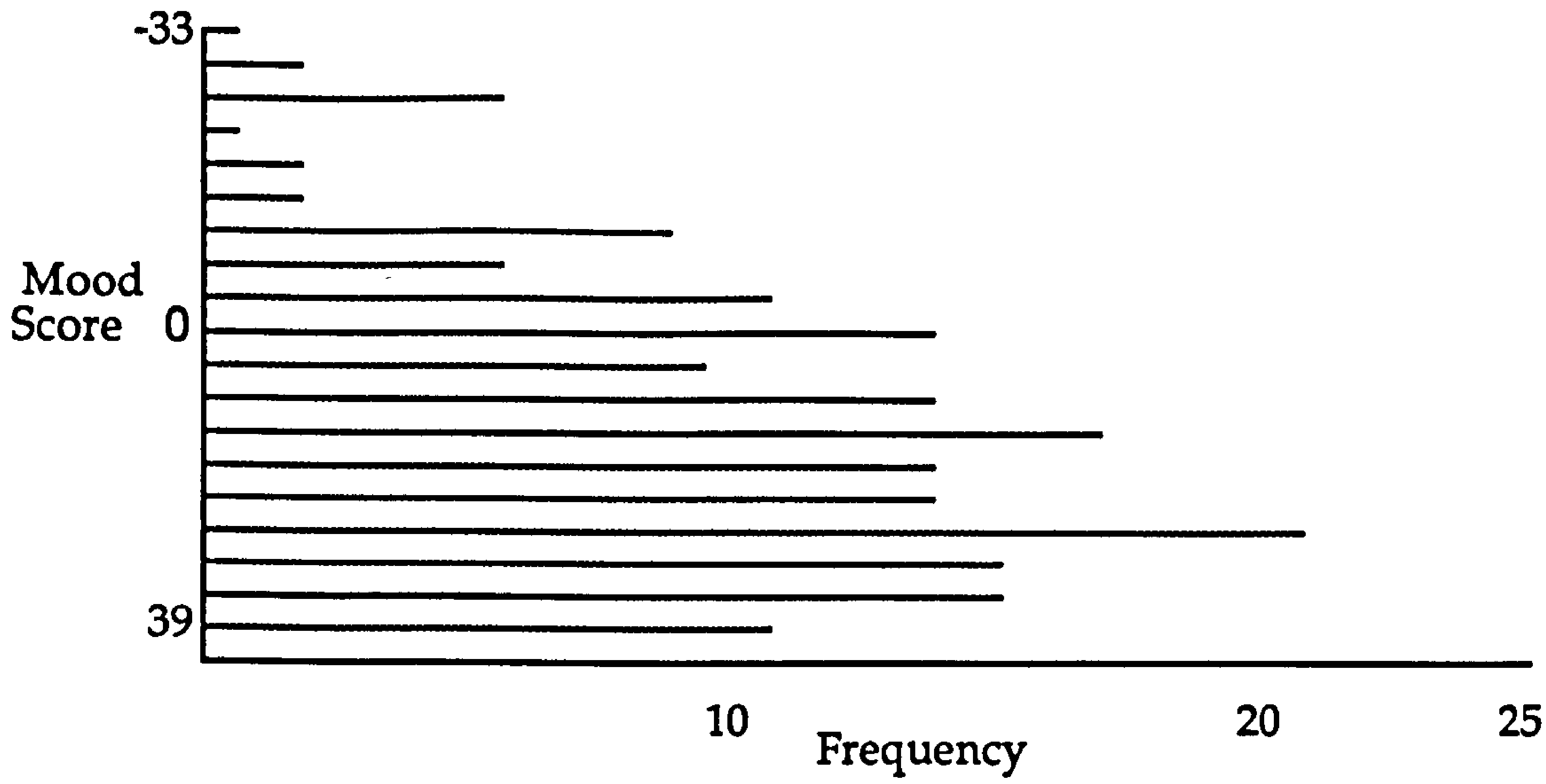


Table 6.3 Histogram showing distribution of mood scores

6.2.2 Self-report of anxiety and depression

In addition to completing the mood profile, subjects were asked if they would describe themselves as anxious at the present time (state anxiety), and if they were generally an anxious type of person (trait anxiety). The results are given in table 6.4.

	Anxious at present (N=175)		Generally anxious (N=174)	
	n	%	n	%
No	109	62	131	75
A little	30	17	20	11
Quite a lot	25	14	21	12
Very much	11	6	2	1

Table 6.4 Self-report of anxiety

Patients who reported anxiety, frequently related this to causes and potential consequences of the pain itself. These are examined in greater depth during the following sections. Other reported causes of anxiety mainly concerned future uncertainty. Subject 12 expressed general concern about what would happen in the future. Subject 87 was worried about the possibility of losing the use of her hands with increasing arthritis. Subject 96 was concerned that her disabilities would ruin her husband's future retirement. Some subjects expressed anxiety about dying. These included subject 48 who was concerned he might have to pay for some past misdeed, and subject 75 who lived with a constant fear of dying of cancer, like her father and sister.

Some subjects admitted that they had a tendency to be anxious, although several elderly women reported that they worried less since they had got older. These included subjects 41 and 86, who no longer felt they needed to worry about the family, and subject 84 who said that she had given up worrying after her heart attack.

Self-report of state anxiety was found to correlate positively with the sum of the scores on items denoting anxiety (tense, frightened, worried, unsure, upset, threatened) included in the mood profile (r_s=.64, n=170, p<.001). These results indicate that self-report of anxiety offers a fairly accurate reflection of state anxiety. Self-report of trait anxiety was found, as expected, to correlate less strongly with the same items (r_s=.37, n=170, p<.001). The correlation between state and trait self-report of anxiety was r_s= .61 (n=173, p<.001), indicating a strong tendency for those perceive themselves to be generally anxious, to report feeling anxious at the time of interview.

Subjects were also asked if they were depressed and, if so, how severely and how often. Results are given in table 6.5. The Spearman correlation between the frequency and severity of depression indicated little differentiation between the two aspects of depression (r_s= .95, n=181, p<.001). Self-reports of the frequency and severity were found to correlate strongly with the sum of the scores of depression items (powerless, hopeless, guilty, sad), taken from the mood profile (r_s= .71, n=175, p<.001; and r_s= .73, n=175, p<.001

respectively). These results indicate that self-report of depression probably affords a fairly accurate representation of feelings of depression. No attempt was made, during the course of this study, to identify or diagnose clinical depression, although a few subjects who reported prolonged, severe depression were probably clinically depressed.

Depressed (N=181)					
Frequency			Severity		
	n	%		n	%
Never	80	44	Not at all	80	44
Sometimes	60	33	Mildly	37	20
Often	29	16	Moderately	48	27
Usually	12	7	Severely	16	9

Table 6.5 Self-report of depression

One of the most severely depressed subjects was subject 63, aged 80. She had arthritis and bedsores, and experienced intermittent severe pain. Her mood score was -26. She had given up her home to live with her son who described her (in front of her) as depressed and dementing. She admitted to being a little forgetful, but showed little evidence of confusion throughout the interview. She was not allowed to participate in household activities, and spent the day reading library books and watching television.

Six subjects mentioned suicidal thoughts, each of whom had negative mood scores. Subject 108, aged 77, had osteoarthritis, abdominal pain, breathing difficulties and right hemiplegia following a stroke. Her pain ranged between moderate and very severe, her mood score was -30, and she was taking antidepressant medication. She had experienced many illnesses and traumas in the past. Her husband had taken over completely since her stroke and described, in detail and in front of her, all the things that she could not do. She described herself as *"useless"* and said she felt like taking an overdose.

Subject 49, aged 86, was blind, lived alone, and was never free of less than moderate pain from arthritis and leg ulcers. Her mood score was -15. She said, quite calmly, that she had asked her doctor for tablets that she could take to finish her life, because she did not wish to surrender her independence. She went on to inquire if the tablets she had were suitable for this purpose. Subject 122, aged 73, said he thought life was *"bloody awful ... would be better to finish it all ... not worth living"*. His mood score was -18. He had suffered a stroke and experienced continuous pain, in addition to marital problems of long standing.

At the positive end of the mood scale was subject 149, aged 82, who was confined to a wheelchair with osteoarthritis in all her joints, including her hands. Her pain ranged daily between just noticeable and very severe, and she described it as a *"bloody nuisance"*. She lived alone, and required assistance with getting up, going to bed, all household chores and meals. She kept herself well occupied bird-watching, watching television, trying to write letters to family, all of whom lived abroad, and thinking a lot about the past. She had bought an electric wheelchair in which she went into the town centre for coffee occasionally, but rejected attending the day centre because she *"can't be bothered with a lot of old folk"*. Her mood score was +32.

If low mood scores were not an inevitable consequence of continuous pain, neither were they of stroke. Subject 119 was aged 66, and suffered from arterial disease, diabetic ulcers and glaucoma, in addition to left hemiplegia. She suffered just noticeable to severe continuous pain. Her husband, on the advice of the district nurse, encouraged her to participate in household chores, even though it hurt him to see her painstaking attempts. Her mood score was +10, slightly below the average.

6.2.3 Frustration

The term 'frustration' was included in the mood profile scale, following the pilot study, in response to patient's own reports of how they felt. In total, 116 subjects out of 178 reported feeling some degree of frustration because they could not do what they wanted to do. Frustration showed a weak association with self-report of anxiety (r=.17, n=170, p<.05), and a closer association with depression (r=.4, n=174, p<.001). Reasons given for frustration are discussed more fully below.

6.3 Pain data

6.3.1 Pain sites

The majority of patients had pain in more than a single site. The number of sites reported is given in table 6.6.

Sites	Frequency (N=190)	Percent
1	17	9
2	19	10
3	38	20
4	22	12
5	24	13
6	21	11
7	17	9
8	12	6
9	6	3
10+	14	7

Table 6.6 Number of pain sites

The most common location of pain was in the lower limbs. Where joints were affected, each individual joint, with the exception of fingers and toes, was counted separately.

6.3.2 Pain diagnoses

The range of pain diagnoses is given in table 6.7. These diagnoses were obtained from the patients and verified by data supplied by the nurses. Arthritis, notably osteoarthritis, was, as predicted, the most common pain problem. Other common pain problems in this age group were leg and foot ulcers, angina, peripheral vascular disease, stroke, and gastrointestinal disorders, at least 11 of which appeared to be iatrogenic effects of aspirin and anti-inflammatory drugs. Many patients experienced pain of different aetiologies. Table 6.7 gives diagnoses according to total incidence, and shows which conditions were identified by subjects as the cause of their worst pain. At least three patients, identified by a nurse as having a malignant disease, appeared to be unaware of their true diagnosis. In addition, two subjects were suspected by the researcher to have a malignancy, although this was unconfirmed and they are not included as such in the results.

These results have been seen by large numbers of community nurses locally. They have confirmed that, with the possible under-reporting of foot problems, the results appear to be representative of elderly patients in their caseloads who would have been eligible for interview. It seems likely that the majority of such foot problems are subsumed under the heading of 'arthritis' because of other joint involvement.

6.3.3 Pain duration and temporal pattern

The mean duration of pain was 11.7 years (s.d. 13.3 years, range 6 weeks to 66 years). As can be seen from the range of diagnoses, the majority of conditions causing pain were chronic, and this is supported by the mean duration of pain. The chief exceptions were venous ulcers, which varied substantially in both severity and duration, and many patients had experienced previous outbreaks. This makes them difficult to categorise as either acute or chronic.

86 subjects (46 per cent) described their pain as continuous, 87 (47 per cent) as intermittent, and 14 (7 per cent) as transient.

One of the worst afflicted subjects was a widow, subject 137 aged 86, who said that she had suffered from trigeminal neuralgia since 1938 (50 years), and had remained in continuous pain despite a variety of treatments and surgery. She had additional pain problems, including osteoarthritis, but stated that the neuralgia pain was worst because *"it is there all the time"*. Her pain ratings ranged between moderate and excruciating. She had experienced

Diagnosis	Incidence	Worst pain problem
arthritis (unspecified)	56	38
osteoarthritis	54	38
leg / foot ulcers (venous and diabetic)	39	16
angina	27	4
stroke	25	12
gastro-intestinal disorders [1]	25	7
peripheral vascular disease	22	6
rheumatoid arthritis	21	12
old fractures	18	7
back pain[2]	17	9
chronic respiratory disease	11	4
malignant disease	9	4
neuralgias (inc. trigeminal and post-herpetic)	9	4
pressure sores	9	1
foot problems (inc. bunions, corns, ingrowing toenails)	5	0
not known	5	3
Other [3]	38	19

[1] Includes hiatus hernia, gastric ulcer, diverticulitis, colostomy, haemorrhoids, gallstones, indigestion

[2] Includes Paget's disease, osteoporosis,. kyphosis, Guillan Barre syndrome

[3] Includes gout (4) headaches (2) multiple sclerosis (2) glaucoma (2) thrush (2) sciatica (2) phantom limb pain (2) stump pain, polymyalgia, brittle bone disease, myelitis, vasculitis, temporal arteritis, prostate, prolapse, RTA (2), "social problems" (nurse), "old age" (nurse and patient aged 94) and "debility" (nurse)

Table 6.7 Pain diagnoses

many additional personal problems, including the deaths of her husband and only daughter. Her son-in-law had recently remarried and she said she felt *"like a dog that has been abandoned"*.. She felt very bitter, and her mood score was -32.

Another married lady, aged 68, subject 168, suffered severe to excruciating pain from arthritis and damage to the spinal cord, following an accident in 1973. She said that she was *"glad to get to bed, but don't know how to stay there". "I don't know what to do with myself"*. This lady was doubly incontinent. In addition, her daughter had been diagnosed as having leukaemia. Her mood score was +1. She said that the doctor thought she was depressed, but she did not agree. She was taking anti-inflammatory drugs, with no discernible effect, Distalgesic (dextropropoxyphene hydrochloride with paracetamol) two or three times a day and Fortral (pentazocine) twice during the night. Both of these analgesics gave fairly good, if brief, relief.

6.4 Pain measurement

6.4.1 Pain rating scales

A 10 point numerical rating scale was included in the patient interview schedule to assess pain levels. However this, like the VAS, was found to be unsuitable for use with very elderly patients, because many found difficulty in conceptualising their pain in numerical terms. Nevertheless all of the patients were able, with ease, to use Raiman's 6 point verbal rating scale to describe their pain. Distribution of pain ratings is given in table 6.8. These are for the level of pain when it was judged to be least troublesome (least pain), and pain level when it was at its worst (worst pain) .

Figures for pain ratings show that 89 (47 per cent) of respondents were pain free for at least some of the time, however 30 (15 per cent) reported that they never experienced less than moderate pain and, of these, 7 were in severe continuous pain. 110 subjects (58 per cent) experienced very severe or excruciating pain at times.

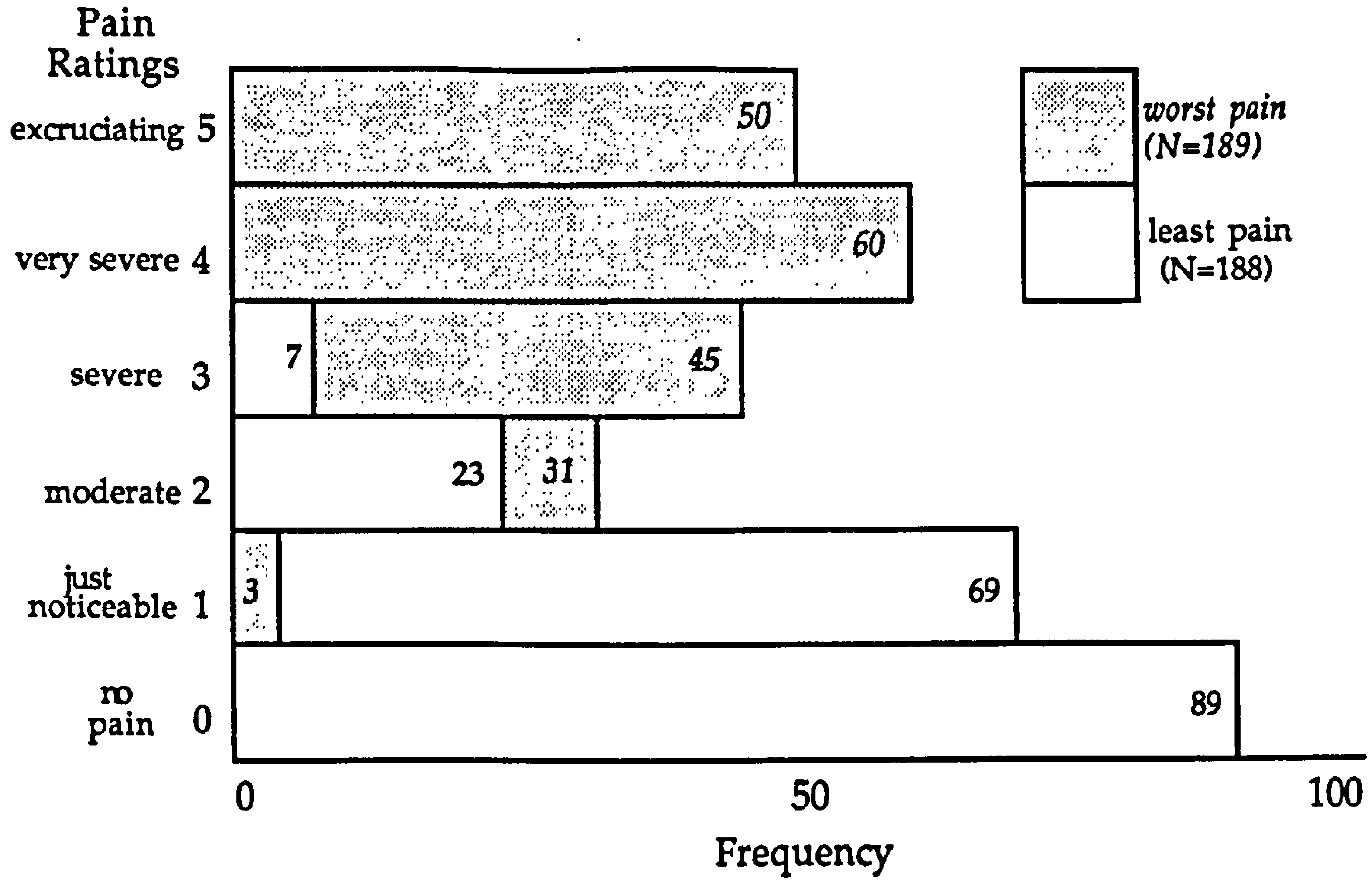


Table 6.8 Histogram of pain ratings

The number of pain sites was associated with the level of least pain (r_s=.18, n=188, p<.01), and with the level of worst pain (r_s=.15, n=189, p<.05).

The measurement of worst pain was a little misleading, since some subjects reported isolated incidents, while others reported regular occurrences. Of the 167 subjects who identified frequency of occurrence, 112 subjects (67 per cent) reported a daily occurrence of their worst level of reported pain (sometimes several times a day). Another 21 subjects reported an occurrence of between once and four times a week. 20 per cent experienced less frequent exacerbations, or no longer experienced such severe pain.

6.4.2 The McGill Pain Questionnaire (MPQ)

179 subjects, out of the sample of 190, completed the MPQ. Of the 11 who did not complete the MPQ, one refused to answer most questions, two spoke little English, and the remainder were either too poorly, tired or distracted at the time of interview.

It is worth stating that although the oldest subject, aged 98, was too tired to complete the MPQ, another aged 97 completed the entire interview without difficulty, as did many others who were in their 90s.

Analysis of the pain rating indices (PRIs) is given in table 6.9. Scores from the MPQ were not differentially evaluated according to diagnosis because of the multiplicity of painful conditions experienced by the majority of subjects. However in view of the predominance of arthritic conditions, these scores appear congruent with those given by Melzack (1975 p.289) for a small sample of arthritis patients whose mean age was considerably younger (55 years). These results, together with the high compliance rate for the MPQ, mitigate doubts about the reliability of verbal report data collected from a very elderly sample and support the validity of the MPQ as a suitable tool for use with the elderly.

(N=179)	Mean score	S.D.	Min.	Max.
PRIS (sensory)	11.2	5.5	1	25
PRIA (affective)	2.6	2.5	0	11
PRIE (evaluative)	2.8	1.5	0	5
PRIM (miscellaneous)	3.4	2.7	0	12
PRIT (total)	19.9	9.4	1	43

Table 6.9 Data from McGill Pain Questionnaire

The sensory scale (PRIS) was associated with levels of least and worst pain (r_S=.34 and .38, n=179, p<.001). An association between the sensory scale and pain intensity scales was predicted, since it was designed to incorporate a scale of intensity. Given this prediction, the r_S values appear modest.

The impression was gained, during the interviews, that arthritis appeared to produce a greater number of descriptors than some other types of pain, although the reported levels of intensity were often not noticeably different. For example, subject 168 (see above, 6.3.3) with spinal cord damage, chose just one descriptor 'searing' (PRIS score 4), to describe her pain, while subject 149 (see above, 6.2.2), with arthritis, chose five descriptors: 'shooting, stabbing, lacerating, wrenching and heavy' (PRIS score 18).

In some instances, an appropriate descriptor was absent, noticeably the word 'gripping', which was mentioned at least three times by subjects to describe angina and claudication pain. Those with leg ulcers tended to select descriptors such as 'pricking, smarting, stinging, sore and tender'. Their own descriptions were often more colourful. Subject 58 likened hers to a *"red hot knife"*. Subject 62 described hers as severe pain, like *"stinging nettles"* or *"sunburn"* all the time.

The PRIS showed no association with self-report of anxiety (r_s=.1,n=170,ns) and little association with self-report of depression (r_s=.16, n=175, p<.05). The level of correlation between the PRIS and subjects' mood score was r_s=-.12 (n=174, ns). These results suggest that there is little relationship between emotional response and the use of sensory descriptors.

The affective scale on the MPQ (PRIA) was found to be negatively associated with mood score (r_s=-.37, n=174, p<.001). Those with high affective scores were, as expected, more likely to exhibit negative mood and hence poor coping. However the mood score took into consideration all other problems with which the subject was coping, while the affective scale was essentially a measure of affect with respect to pain. It was therefore thought likely that this association might increase if non pain-related problems were taken into account. A partial correlation, controlling for other life problems showed that this was not the case (r=-.36, df=167, p<.001).

126 subjects (70 per cent) selected either 'tiring' or 'exhausting' (scale 11) as a relevant descriptor. Since this population of subjects consisted predominantly of those who were very elderly, with a variety of health problems (including anaemia) and disabilities, it seems doubtful if the use of these descriptors really represents an affective response to pain. Indeed subject 94, aged 97, commented that his tiredness was probably due to old age. The terms sickening and suffocating (scale 12) were selected exclusively by subjects with gastric disorders and respiratory disorders, respectively. It is therefore difficult to see how these items can be interpreted, for this sample, solely in terms of affect, rather than sensation. Likewise the terms wretched and blinding (scale 15), though rarely selected, were used almost exclusively to describe headache. Only the items in scales 13 and 14, representing fear and punishment, appeared to contain true predictive value in the assessment of affect.

Subjects frequently commented upon the descriptors 'frightful', 'fearful' or 'terrifying'. Many stated that the pain was not frightening, or was no longer frightening, because they knew what it was. Subject 107 selected 'fearful' because *"it is frightening because I wonder what will happen"*. Subject 30 described her pain as 'terrifying', and said that it was frightening because the pain was getting worse. Subject 87 selected 'terrifying' because she did not want to lose the use of her hands. Subject 67 described the pain as 'frightful' because *"I don't know what it is"*. Likewise, subject 135 said of her 'frightful' back pain *"I wonder what it is?"*.

The punishment scale was associated with mood score (r_s=-.26, n=167, p<.001), and with hostility, as measured by the sum of scores for resentment, anger and irritability (r_s=-.26, n=167, p<.001). Overall, the fear and punishment descriptors appeared, together, to provide a useful indicator of affect in relation to pain.

The PRIM (miscellaneous scale) produced significant correlations with pain levels, and all other scales on the MPQ, as shown in Appendix VI.

However this also includes items which, for this sample, appeared to represent sensation. Items from scale 19 (cool, cold, freezing) were used only by subjects, with peripheral vascular disorders, whose extremities were both cold and painful. Many subjects had difficulty in identifying a suitable descriptor from scale 17 (spreading, radiating, penetrating or piercing) since few appeared to comprehend the first two terms. Subjects who chose the term 'nauseating' from scale 20 were generally those with gastric problems.

Some subjects identified descriptors which were not present in the MPQ. Most of these appeared to be either affective or miscellaneous. At least two subjects said the pain was 'aggravating'. Other words used included 'beastly, awful and fierce'. This led to some difficulties in classification, although subjects were usually persuaded to opt for a close alternative. Thus aggravating became annoying, awful became agonising, and fierce became vicious. Beastly appeared to indicate an affective influence, but there was no suitable existing alternative.

The evaluative scale of the MPQ consists of a single scale (16) and appeared, at a purely intuitive level, to provide a good appraisal of the impact of pain on the lives of these elderly subjects. Most subjects gladly identified with one of the descriptors in this scale. Scores were significantly associated with mood state ($r_s=-.33$, $n=173$ $p<.001$), with levels of least pain ($r_s=.3$, $n=178$, $p<.001$) and with worst pain ($r_s=.58$, $n=178$, $p<.001$). They were not associated with self-report of generalised anxiety ($r_s=.02$), but it showed a weak association with self report of current anxiety ($r_s=.14$, $n=169$, $p<.05$) and a significant association with self-report of depression ($r_s=.32$, $n=174$, $p<.001$).

In summary, the MPQ was simple and quick to administer to the whole age range, however there appeared to be some anomalies in the sensory scale and, more particularly, in the affective and miscellaneous scales. These may have been due to the age of the sample, and to the range of chronic benign conditions experienced.

These observations throw into question the usefulness of these scales, as they stand, for this age group. The evaluative scale appeared to emerge, from the indications so far, to be a useful broad indicator of pain experience, as did the fear and punishment scales of the affective subscale..

6.5 Knowledge of the painful condition

The majority of patients (74 per cent) were either very or fairly certain about the cause of their pain. 22 subjects (12 per cent) were uncertain and 27 (14 per cent) did not know the cause of their pain. In four instances, the nurse was unable to identify a medical cause for the pain, and medical investigations had failed to reveal a cause for one subject.

In many instances, uncertainties were associated with anxiety. Subject 5 stated *"I think I have cancer. The doctors have never really told me what the results of the tests were"*. This lady, aged 80, was experiencing abdominal discomfort associated with vaginal bleeding, so her suspicions were not without foundation. The district nurse subsequently reported that the doctor was reluctant to initiate further investigations, although she, too, was concerned about this lady's symptoms.

Feeling fully informed (N=180)	n	%
3 Yes	108	60
2 Most likely	42	23
1 Probably not	10	6
0 Definitely not	20	11

Table 6.10 Feeling informed about the painful condition

Subjects were asked if they felt that they had been fully informed about their painful condition.

Responses are given in table 6.10. Comments by subject 68, aged 88, represent the type of dissatisfaction expressed: *"the doctor fobs me off. I have told the doctors about my backache ... but the GP passes it off. The hospital X-rayed it but I heard no more"*.

More serious were comments by Subject 114. He reported that he had an operation at the Royal Marsden Hospital 6 years ago for *"a perforated valve from the bladder to the bowel"*. He said they had operated with a view to a colostomy, but he was then told there was nothing wrong and was sent home. He later haemorrhaged and they operated again. He now gets nausea, and pain at the site of the operation. He says that he does not know what they did and *"the GP does not give me the results of anything he does. I worry because I don't know what to do"*. The nurses' reports about his diagnosis and pain failed completely to mention this problem, focusing only upon the severe varicose ulcer which they were currently treating. Such accounts were rare, although not isolated, and it was apparent that lack of information was capable of causing great distress for a minority of subjects.

It was often difficult, as a researcher entering the situation without the benefit of any prior information, to determine if some patients' reports were due to misinformation or misunderstanding. One lady (subject 136) stated, quite calmly, that a social worker had told her that her diabetes was *"terminal"*. Perhaps the term used by the social worker was incurable, but fact remained that the patient had prepared herself for an imminent demise. There was no evidence at all, from interview data, nor from information subsequently supplied by the nurses, to support her belief.

In view of the importance that many subjects appeared to place upon being given information, a question posed to a subsample of 114 subjects was:

> *"if you had something seriously wrong with you, would you want to be told all about it, even if the outlook was not good?"*

92 (81 per cent) of those asked stated that they would wish to be told. Most were emphatic about it. The probability of imagining the worst was the most common theme. Other common reasons for wishing to know was so that they would know what to do or how to cope, and a general dislike of having information withheld from them. Subject 81 commented *"when you are over a certain age they do not bother"*. Examples of comments about the desirability of being told included:

> *"I would rather be told than be fobbed off"* (subject 86)
>
> *"I would want to know if I had cancer. At one time doctors treated people like morons"* (subject 134)
>
> *"so I could get my house in order"; "(I) would imagine the worst"* (subject 161)
>
> *"so I would know what to do"* (subject 149)
>
> *"(I) could put up with it if I knew what it was"* (subject 67)
>
> *"I think it is better for you to know and you can plan your life out"* (subject 165)

Only 9 subjects (8 per cent) stated that they would not wish to be told and gave such reasons as:

> *"ignorance is bliss"* (subject 127)
>
> *"I don't want to die"* (subject 149)
>
> *"It is no use living in despair"* (subject 106)
>
> *"Leave me in a fool's paradise"* (subject 138)

5 patients were unsure about the issue, while 8 thought it immaterial whether or not they were told.

Over half of all subjects had no expectations that their pain would get better, 20 per cent were uncertain, and 20 per cent thought that they would get better. This question was posed towards the end of the interview and these expectations appeared, on the whole, to be realistic.

Subject 120, a 73 year old widow, described how she had had Hodgkin's disease for 8 years and did not expect to get any better. She knew it was cancer, and said that they had explained her condition to her, although she had since forgotten. She would have liked more information, but did not like to ask questions.

One subject who was not realistic in her expectations was subject 75, aged 70. She suffered continuous moderate to severe back pain, together with abdominal pain and bowel problems, and was in a very sorry physical and psychological state. She was convinced that she had cancer, although this was almost certainly not the case. Her father and sister had died painful deaths from cancer, and no amount of information to the contrary would, she said, convince her otherwise. She was taking antidepressants, anxiolytics, sleeping tablets, and four hourly Co-proxamol (dextropropoxyphene with paracetamol) for pain, which no longer worked. She lay on the sofa all day watching television, while her family took care of all the household management. She described her life as 'hell'.

6.6 Pain treatments

The majority of patients were taking analgesia for their pain. The frequency with which different types of analgesics were taken is given in table 6.11. 33 subjects took no drugs for pain at all, and another 23 took only non-steroidal anti-inflammatory drugs (NSAIDs). 3 subjects were taking carbemazepine for trigeminal neuralgia.

Of the 8 patients using narcotic analgesia, 5 subjects took either Diconal (dipipanone hydrochloride) or oral morphine for back pain. One of these was, to the knowledge of the researcher but apparently not the patient, caused by secondary metastasis. Two of the other back patients had been seen at the pain clinic. One lady with spinal damage, subject 140, aged 90, complained that she no longer received any benefit from Diconal, although the pain clinic advised against increasing the dosage. The remaining diagnoses included osteoporosis and multiple sclerosis.

Two subjects appeared to in the terminal stages of illnesses which were not caused by malignancy.

	Type of analgesia			
frequency	Counter analgesics for mild to moderate pain[1]	Prescription - only analgesics for mild to moderate pain[2]	Narcotic analgesics for severe pain[3]	Non-steroidal anti-inflammatory drugs
occasionally when really necessary	30	16	0	0
regularly prn	44	15	1	3
regularly at prescribed intervals	6	12	7	49
unstated	4	4	0	0

[1] Includes paracetamol, Anadine, Co-Codamol

[2] Includes dihydrocodeine, Co-Dydramol, Co-Proxamol

[3] Includes MST, Diconal, Temgesic

NB many patients were taking more than one type of analgesia

Table 6.11 Consumption of analgesia

50 subjects admitted taking sleeping tablets, but it appeared evident that some doctors discouraged their use. 8 subjects were taking antidepressants, 5 of which were prescribed primarily for pain to patients who had attended the rheumatology clinic. 2 subjects had been taking Ativan (lorezepam), and 2 Librium (chlordiazepoxide), over many years for reasons which were not entirely apparent, either to the subjects or to the researcher.

Subjects were asked how effective they found their analgesic medication, but many subjects found it difficult to provide a reliable answer. The degree of relief was often qualified by the duration of relief conferred. Other confounding factors included the variety of different analgesics prescribed, frequency of consumption, and the severity of pain experienced. This study was not designed to study the efficacy of different types of pain treatment. Such studies require very careful control and this was quite beyond the scope of this research. Nevertheless a number of pertinent observations are reported here for consideration.

27 subjects stated that they did not like taking tablets or drugs for pain. One could not swallow them and two complained that they caused drowsiness. Many subjects expressed fears of tolerance, for example *"they don't work if you keep taking them"* (subject 132). Some of these comments were based upon personal experience - subject 141 said that *"you get used to them so you don't know if you still need them"*. She had stopped the regular use of painkillers for continuous arthritis pain in hips, knees and arms, and now took Co-Dydramol (dihydrocodeine with paracetamol) at night, when necessary, with good effect. Some subjects had no faith in pills, while others were afraid of side effects, often based upon past experiences. Subject 122 kept an up-to-date, and well used, copy of the British National Formulary to hand in order to know, precisely, the effects of his prescribed medications. 26 subjects had developed side effects from drugs used to treat pain. 6 had had severe constipation from using codeine compound drugs or paracetamol. Most of these had stopped taking them. Subject 88 said *"Painkillers gave me constipation. I prefer to put up with the pain"*. 16 subjects had developed gastric disorders while taking NSAIDs, of whom one had suffered a gastric haemorrhage and two were currently being treated for gastric ulceration. 9 subjects reported having been treated with Opren. All claimed that it had been very effective in controlling their arthritis and only two reported noticeable side effects, yet the experience had made them more cautious about taking any drugs.

The side effects described above are well documented, and subjects were generally right to be concerned over the continued use of some drug treatments for pain. It must be stressed that many subjects obtained considerable relief from prescribed analgesics and anti-inflammatory drugs, and they play a major role in pain control. However some were obtaining little benefit, and the effects did not appear to be well monitored. Of the 52 subjects taking NSAIDs, 8 reported that they were very effective, 6 fairly good, 1 a little benefit and 7 no good at all. Another 8 subjects stated that they were unable to tell if they still helped, while the remainder did not comment. Some of these subjects had taken these drugs over a long period, and it is of concern that patients are taking potentially harmful drugs when they do not appear to be perceiving any beneficial effects.

Many subjects had sampled a variety of additional pain treatments. Figures for these are not entirely reliable since, unlike tablets which were generally lined up for inspection, elderly subjects often confused or forgot the names of therapies or treatments, and could not remember how long ago they had tried them. 32 subjects were currently receiving treatment from a rheumatology clinic, and the impression was gained that these patients, in contrast to those attending general departments, were well informed and had received a wide range of effective pain relieving treatments including physiotherapy, hydrotherapy, TENS and antidepressants. Only 6 subjects had visited the local pain clinic. Few other subjects appeared to have heard that a pain clinic existed, although the local clinic has been in operation for over 20 years and offers a wide range of pain treatments including acupuncture.

32 patients were currently receiving, or had recently undergone hospital treatment. Departments visited included orthopaedics, geriatrics, dermatology, chest and general surgical. Not all patients were satisfied with their treatment in general hospital departments, lack of information being a major source of discontent. Subject 81 commented that she had a long wait for an X ray but was given no results. Likewise subject 104 reported that she *"went to hospital, but they didn't say much"*. The husband of subject 163 felt that the hospital had washed their hands of his wife, aged 82. She had had 2 hip replacements but now suffered pain in her knee and groin for which they had received no useful advice. Subject 162, aged 75, had been waiting for a second knee operation for six months.

She was, in the meantime, totally immobile and stoically endured immense pain. 3 months previously, she was informed that she was top of the waiting list and all subsequent inquiries, made by herself and the GP, confirmed that she had remained there. She and her husband said that they could cope *"if only we had some idea when it would be"*.

Three subjects were currently receiving physiotherapy, two of whom paid for a private service. One subject had been waiting three months for an NHS appointment. 31 had attended physiotherapy within the NHS in the past, of whom only four reported obtaining long term benefit, and two of these had continued to do exercises on their own. Another 6 subjects did regular exercises which they found very beneficial. 5 subjects described having used TENS, of whom 3 reported good relief. One of these had remained pain free for eighteen months following a course of TENS for long standing arthritis pain in the knee. Other therapies or treatments tried included osteopathy or chiropractic (8) acupuncture (3), herbal remedies (4), special diet (3), reflexology (1), homeopathy (1), and faith healing (3). Patients' reports suggested that these forms of therapy were generally of little long term benefit, although a few had obtained short term relief.

Most popular forms of self-treatment were the application of heat, and a combination of massage and one of many topical pain-relieving creams and sprays including 'Firey Jack' and 'Devil's Claw'. It had been anticipated that subjects might describe a variety of old-fashioned home remedies, but this was not the case. In contrast a lot of subjects clearly liked to keep up to date with current treatments via the media and many described following current dietary advice. It was evident that many subjects liked to feel informed about recent innovations in treatment.

6.7 Pain control

6.7.1 Perceived pain control

Patients were asked if they felt their pain to be under control. Results, given in table 6.12, show that over 30 per cent of those who responded did not perceive their pain to be under adequate control, while 25 per cent felt that it was mostly or totally under control. This question was not included in the pilot study, hence the number of respondents is reduced.

Q. 23a: Do you feel that your pain is under control?

N=166	n	%
Totally	7	12.0
Mostly	46	13.3
Partly	71	42.8
Not really	22	27.7
Not at all	20	4.2

Table 6.12 Perceived pain control

The degree of perceived pain control was associated with the level of least pain (r_S=-.35, n=166, p<.001), with the level of worst pain (r_S=-.32, n=166, p<.001) and, less strongly, with the number of pain sites (r_S=-.19, n=166, p<.01). Pain control was associated with the evaluative scale of the MPQ (r_S= -.54, n=162, p<.001), and with the affective scale (r_S=-.38, n=163, p<.001). The punishment scale of the PRIA was also associated with perceived pain control (r_S=-.36, n=163, p<.001).

The means by which subjects controlled, or tried to control, their pain are explored below.

6.7.2 Pain controlling strategies

Patients described a variety of strategies which they used to relieve or control their pain. These included taking prescribed medicines, including analgesics, obtaining and using aids to comfort (chairs, beds, special clothing), supportive bandages, sitting down, putting the feet up or down, keeping moving and doing exercises, getting up slowly, hot water bottles, heat lamps, application of topical sprays and ointments, massage by self or spouse, keeping busy or occupied, special diet, and consulting the doctor, nurse, alternative therapist or faith healer. These strategies are not enumerated, because they are meaningful only in relation to the nature of the pain experienced.

It was evident that some people had far more strategies for alleviating, controlling, or countering the effects of their pain than others. Subject 80 (male aged 75) had suffered from rheumatoid arthritis for 30 years, which affected all of his joints. He had an array of household aids provided by the local social services department, in addition to which he described a variety of tips for maintaining comfort and independence. He kept a German style purse attached to his braces so that he could get at his money. He wore a special pair of expensive French boots which improved his mobility, and a padded body warmer in bed to maintain warmth. He had received a variety of treatments through the rheumatology clinic, including wax treatments, but had found the hydrotherapy pool most beneficial. His medication consisted only of Indocid (indomethacin) suppositories taken at night. He rejected taking additional pain killers as *"you could go on for ever"*. He said that it had been harder to manage before he retired because the pain made it so hard to concentrate at work. Now he alternated activity with rest and claimed that life was *"all right"*. His chief hobby was calligraphy, which he executed most delicately in spite of his grossly distorted hands.

Figures for the number of strategies which people used to control pain are given in table 6.13. Taking medication is counted as a single strategy. 29 subjects relied wholly on tablets (or suppositories), while 155 described alternative strategies, which were either initiated by themselves (e.g. exercise, heat, topical ointments) or administered by others (e.g. dressings, massage). These observations do not take into account the degree of pain experienced.

For some conditions, medical treatment was sufficient to control pain. For example in the case of leg ulcers, regular dressings and the use of analgesics, when necessary, were often adequate. For other conditions, notably osteo and rheumatoid arthritis, medical treatments seemed to achieve little in the way of effective pain control in the absence of additional pain coping strategies. It was hypothesised that, for those subjects for whom arthritis was the chief pain problem, there would be a positive association between the degree of perceived pain control and the number of strategies used to control pain. This was found to be the case (r_s= .25, n=81, p<.05).

Number of pain-controlling strategies used	n (N=184)	%
0	1	0.5
1	47	25
2	71	39
3	40	22
4	16	9
5	6	3
6	3	1.5

Table 6.13 Number of pain coping strategies used

29 subjects were totally reliant upon tablets to control pain. Subjects reporting the use of active personal strategies, such as exercise or rubbing in topical applications, appeared to report a greater degree of perceived pain control than those who adopted passive strategies, such as resting or reliance upon others for help. Subjects were therefore classified according to whether or not they had at least one active strategy for controlling pain. The use of analgesics was included as a pain-control strategy: taking tablets at own initiative was classified as an active strategy, whereas taking tablets in strict accordance with

prescribed doses and times was classified as a passive strategy. The results are given in table 6.14.

Type of strategy (N=184)	n	%
None	1	
Active	111	60
Passive	45	15
Indeterminate	27	25

Table 6.14 The use of active / passive pain control strategies

It was anticipated that passive strategies might be adaptive for some types of pain and maladaptive for others. Most osteoarthritis sufferers were free of pain while in bed, or when sitting in a comfortable chair, yet excessive rest was a maladaptive strategy in view of the pain experienced upon subsequent movement. On the other hand, leg ulcer sufferers were often pain-free when sitting with their foot down, but in severe pain when in bed, or exercising. For them, sitting appeared to be, on the whole, an adaptive strategy in the short term, provided passive leg exercises were practised. It was adaptive for subjects with angina or claudication to rest for a short time when in pain. Therefore reports of rest as a strategy for coping with pain could be judged as adaptive or maladaptive only in relation to the type of painful condition and its likely duration. Subject 113 reported a conflict. She needed to sit with her foot down to ease her leg ulcer pain, but move about for her arthritis. She had decided *"I can't tackle the arthritis until the ulcer is better"*.

It was hypothesised that, for those subjects for whom osteo or rheumatoid arthritis was the main pain problem, the use of active strategies would be associated with better perceived pain control than the use of passive strategies.

The Mann-Whitney test was used to compare perceived pain control for 53 subjects using active strategies, with 19 subjects using only passive strategies. The result showed a trend in the predicted direction (mean ranks were 53 and 19 respectively) however it did not attain statistical significance (U=366, p=.06). 16 arthritis sufferers used only tablets to control their pain, compared to 83 who used at least one alternative strategy. Although these numbers are small for meaningful comparison, the Mann-Whitney test showed that those relying on tablets alone were less likely to report adequate pain control (U=390, p<.01).

These results indicate that if medical pain treatments are inadequate to control chronic pain, and this appears to be the case for many arthritis sufferers, then those who employ a greater number of pain-controlling strategies are more likely to report better pain control. This is particularly so when the pain is continuous. There is also some indication that active strategies may be more effective than passive strategies, especially when the passive strategy consists only of taking prescribed medicines.

6.7.3 Pain locus of control

Questions 23b and 23c asked subjects about the source of their pain control with a view to establishing pain locus of control. In addition, subjects made many other comments throughout the interview which provided a rich source of data about pain locus of control. These data were compiled and categorised using a 5 point scale from 1 (total personal or internal control) to 5 (total reliance upon other people or external sources for pain control). The midpoint represented uncertain or chance predictions about sources of pain control, those with a balance of internal and external sources of control, and also included patients who perceived a total absence of any source of pain control, in accordance with figure 2c in chapter 2. The form used in compilation, together with agreed instructions for categorisation are given in Appendix IIA. The results for two independent raters are given in Table 6.15.

N=178	Rater 1		Rater 2	
Score	n	%	n	%
1 (internal)	23	12.9	18	10.1
2	42	23.6	41	23.0
3	50	28.1	59	33.1
4	37	20.8	40	22.5
5(external)	26	14.6	20	11.2

Table 6.15 Pain locus of control

Scores were based upon the type of data given below:

Subject 56 reported *"self-reliance"* to be his chief way of coping. *"I control the pain myself. I don't like taking tablets"* (total internal control) - this subject also stated that he had set his own limits and would kill himself if his health deteriorated.

Subject 26 reported that coping was aided by *"reassurance from the nurses and doctor that it will eventually go. When the pain is worst, I just wait until it moves"* (total external control)

Subject 97 stated that it was best to *"get all the medical help - then you have to endure it cheerfully"* She has private physiotherapy and thinks that the pain will probably get better *"if I keep trying"* (mixture of sources of control)

The Spearman correlation coefficient between the LOC scores of the two raters was r_s=.88 (n=178, p<.001). This compares very favourably with inter-rater reliability correlations of .73 and .72 accepted by Mussens (1985) in his study of life satisfaction at age 70. Mean scores from the two sets of data were derived to provide individual locus of control scores for use in subsequent analyses.

Locus of control was found to be associated with perceived pain control (r_s=-.35, n=165, p<.001), and with mood state (r_s=-.31, n=176, p<.001), such that internal locus of control was more likely to be associated with adequate pain control, and with positive mood state.

Locus of control was based entirely upon patients' own perspectives, yet it was apparent that an outside observer might have made very different judgments about the extent of their personal control. Subject 105 attributed her pain control to her own attitudes and, from her comments, she was classified as internal locus of control. In actual fact she did nothing practical to help herself at all. Her actions were directed entirely towards organising relatives, friends and supportive agencies. During the interview, a young neighbour called to take her shopping list, and, when the home help organiser telephoned, she remonstrated with her about the erratic service, demanding better attention. She was totally dependent upon external sources for control, yet she was in control of them all. Her mood score was +26. A major cause of her inactivity seemed to be her gross obesity, and if this lady not been suffering from a malignant disease, as well as arthritis, angina and hiatus hernia, her behaviour would have been classified as maladaptive. Most helpers do not tolerate this level of control for very long without good reason.

6.8 Subjects' verbal reports of pain experience

In the preceding and following sections, a quantitative approach to data analysis is used predominantly to identify variables of statistical importance in determining pain coping. However the variables selected for the structured part of the interview schedule were based upon predictions and presumptions about what would be the key elements of pain coping experience. Questions 13 and 15 in the interview schedule, on the other hand, were open questions designed to elicit subjects' views about the effects of pain upon their lives, and the worst aspects, for them, of having pain. The following descriptive analyses provide some indication as to whether or not the structured questions were sufficiently comprehensive and wide-ranging, and provide support, or otherwise, for the final results, which are based upon quantitative data analysis.

Question 13 was posed before any particular aspects of pain experience, other than a description, were explored, and asked generally what life was like these days. It is natural, in view of the explicit nature of the study, that most subjects should focus upon aspects of pain in their answer. In reality, the answers to question 15 were either a reiteration or an elaboration of the answers to question 13, and data for these questions are therefore integrated. A few subjects gave answers which encompassed more than one category of response, therefore the figures below add up to more than the total number of subjects.

21 subjects spoke about their lives in positive terms. Subject 82, aged 88, who had osteoarthritis in most joints and could not walk, said life was *"lovely - I have nothing to worry about - my daughter helps me, and my son-in-law"*. Subject 57, aged 95, who attributed her joint pain to old age, said that she was quite happy - she had felt all right until she was 80. Subject 97, aged 83, who had had a slight stroke and some arthritis of the knees said that life was *"quite good. I'm lucky - there are many worse off"*. Subject 98, aged 88, had been married for 64 years. She said that she had *"got a lot to be thankful for"*. She was happily married and had no regrets. She had not retired until the age of 74, and she and her husband now spent much of their time playing dominoes and table skittles together. Subject 61, aged 71, with multiple sclerosis, said *"I can cope because I have accepted it. I'm thankful for what I can still do"*.. 8 of these 21 subjects identified that pain had little effect on their lives. Subject 33 commented that pain had not affected her life much because she was so well looked after (in a Christadelphian Rest Home). Subject 43, aged 71, had venous ulcers, and had had an operation for lung cancer, after which, he said, he was warned that he would get pain. He said that pain had not had any effect on his life, in fact he was still working. The worst aspect of the pain was that, when it was bad, he could not get rid of it, and did not like taking tablets.

Subject 46 reported no restrictions due to pain. He said that he was able to get about quite well because his wife drives. The main problem was the intensity of the pain, caused by back problems. Subject 55, aged 83, had arthritis in her hands and feet, but said that life was *"all right - it's all right as long as I keep* *my hands moving"*. Subject 70 said that the pain was *"not too bad. I do get out and people in the road are friendly"*. Subject 90, aged 90, said that the pain disturbed her at night, but *"I'm happy - I've got grandchildren and great-grandchildren and I knit for them"*. Subject 111 said *"I just get mad with myself because I can't walk quickly, but I enjoy life"*. Subject 119, aged 66, said that life was quiet. *"We belong to a couple of clubs. I will join the stroke club. We belong to the Evergreens. I've got used to it (the pain)"*. Subject 123 described herself as *"worth a thousand dead'ns"*, though the worst thing was not being able to get out into the garden. Subject 109, aged 82 commented that life was *"not too bad - I've revived my lace-making skills"*.

Subject 138, aged 80, with osteoarthritis in most joints and angina, said that life was *"not too bad. I've had a very full life. Pain becomes part of your life - you get used to it but it is wearying and you must guard against letting it get you down - I keep occupied"*.

2 subjects focused specifically upon the fact that they could still 'do things'. For example subject 29 said that pain had not really affected her life because *"it doesn't stop me from doing things"*. Her main interests were reading, watching television, walking and chatting to neighbours. She had not given up any interests because of pain. Subject 129, aged 84 said *"as long as I can keep active then I don't mind"*. 2 subjects stated they could cope with the pain, and one that he could control his pain. Subject 87 focused positively upon the support conferred by her religious faith: *"Life is good because I am a Witness"*, although the pain had made her housebound.

122 subjects (64 per cent of all subjects) reported restriction of activities to be the chief influence of pain in their lives. Of these, 49 mentioned not being able to 'do things'. Subject 107 said *"I can't do things. If I could not take aspirin, I would be very depressed and I'm not that sort of person"*. On the other hand, she said, life was not too bad because she could still cook and sew. Subject 112 described her pain as *"annoying - I can't do the garden as I want"*. Subject 120 said that she was *"fed up"* because she *"can't do things"*.

Subject 96, aged 61, with osteoarthritis, angina and a leg ulcer, described her life as *"limited - I can't do half the things I used to"*. Subject 22, aged 89, said *"I can't do anything in the house - not even make a cup of tea because of the weight of the kettle"*. Subject 67, aged 73, said the pain *"draws you down in time - you can't do what you could ... You've got to keep going and fight against it"*. Subject 117, aged 82, with arthritis and angina said that she had lost interest since she could no longer do so many things - *"I sit and stare into space"*. Subject 86, aged 75, said that the pain *"hampers me doing things"*. Subject 85, aged 85, said *"I want to do things and I can't, so I get mad"*. Subject 10 described not being able to do things as *"thwarting"*, while subject 45 used the term *"frustrating"*.

13 subjects focused on not being able to do 'what they wanted to do'. Subject 105, aged 75, with angina, osteoarthritis in most joints, hiatus hernia and cancer of the bowel, said that the worst thing about her continuous pain was *"I can't do what I want to do"*. This included threading a needle and knitting. Subject 60, aged 81, said that the worst aspect of pain was *"not being able to do things I want when I want to"*. She said that, as a result, she had lost all interest. Subject 47, aged 94, said *"can't do things you want to do ... (I) can't settle to anything"*. Subject 104, aged 83, said that the pain *"annoys me because I can't do what I'd like to"*. Subject 84, aged 73, described pain as *"a perishing inconvenience - you want to do more and you can't"*.

24 subjects mentioned that they could no longer walk, or were no longer mobile, and 33 focused on not being able to go out. Subject 93, aged 91, complained that she *"can't get out and about. I like to window shop"*. Subject 81, aged 76, said *"it annoys me that I can't go out"*. Subject 68, aged 88 said it *"stops me from walking"*. Subject 66, aged 85, said that the pain *"prevents you from getting about. You have to put up with a quiet life"*. Subject 23, aged 80, complained that she could not go out and, in particular *"can't go to church"*. Subject 20, aged 67 said that she could no longer drive after her stroke, and had given up all activities outside the house.

Subject 13, aged 78, said that the pain stopped her from getting about, walking and getting on a bus.

5 subjects complained of loss of independence. Subject 49, aged 86, said she *"can't get about and do things. I like to be independent and now I have to rely on others"*.

In addition to these 122 subjects, 11 used the words like 'just sitting' 'boring', 'monotonous'. Subject 106, aged 76 said *"I make the most of it but I'm stuck here. You could sit beside it (the pain) and have the miseries, but that doesn't get you anywhere - you must get up and do something"*. She was riding a bicycle until the age of 72 and missed going out. Subject 32, aged 69, with metastatic cancer of the pancreas (she said it was non-malignant) said *"I haven't got no life as such at the moment. I can't do anything"*. Subject 130, aged 85 said that life was *"dreadful - I sit here all day, It's so awful not to be able to do anything"*.

20 subjects focused directly upon the pain itself as the chief problem. Of these 9 complained that it was continuous or 'always there'. Subject 72, aged 77, with multiple pain problems, said of the pain *"it never goes away"*. Subject 79 said of her shingles pain *"it's there all the time"*. 9 focused upon the intensity of the pain, or the discomfort, and one on the unpredictability of the pain. Subject 59 had an ulcer on her left foot which had started 10 weeks previously. She said that she *"nearly went mad with the pain"*. She said *"I didn't understand why it was so painful"* and *"didn't know what to do with myself"*. Subject 44, aged 81, described his back pain as unpredictable. He said *"it cripples me and is agonising"*.

37 subjects described their lives in terms of negative affect. 21 focused upon feeling miserable or depressed, of whom 7 subjects subsequently identified inability to 'do things' as the cause, while only 2 subjects directly blamed the pain. 6 subjects reported that worry about the painful condition was the worst problem.

The remainder did not identify specific reasons for their feelings. Subject 121, aged 84, said *"you get hopeless - is it going to be like this all the time?. It is not worth living - you can't do anything"*. Subject 58, aged 70 said *"you begin to wonder whether it will ever end. You get depressed"*. Subject 48, aged 84, described life as *"miserable - I can't walk"*. Subject 38, aged 84 said the pain *"makes you miserable - especially when you can't get around"*. Subject 34, aged 72, said *"can't do anything ... feel miserable"*. Subject 30, aged 75 said the pain *"makes me miserable and depressed - not being able to get out and do activities"*. Subject 28, aged 78, said the pain *"makes me feel bloody minded. I can't understand why I get it and why something can't be done about it"*. Subject 5, aged 80 said the pain *"gets me very nasty. I feel life is not worth living. I can't do things and then get worried, especially about my husband"*. Subject 103, aged 74 said that life was *"pretty miserable"* and the worst aspect of pain was *"not being able to get away from it"*. Subject 62, aged 83, who had suffered a stroke in addition to varicose ulcers and an old fractured hip, said *"I've got to put up with it 'til my time comes, day by day. It wears you out"*.

7 subjects described their lives as 'awful' or 'hell'. Subject 51, aged 92, said that life was *"awful - I sit and cry"*. Subject 63, aged 80, with arthritis of the knees and feet, an old fractured hip, and bedsores, described life as *"awful...nothing to look forward to... I worry about what will happen if anything happens to my son ...afraid of falling...worries me because I can't do anything...afraid of getting worse"*. 2 subjects described life as 'dull'. Subject 56, aged 77, said that life was *"pretty dull"*, since he had suffered a fractured leg, although he still managed to get out on his motor bike. Subject 133, aged 85 also described life as *"pretty dull - I have a wheelchair but no one to take me out"*. 2 subjects said life was 'difficult'. Subject 134, aged 77, said *"I don't like getting old - everything is difficult"*.

Of the remaining answers, 4 subjects said that they found it difficult to concentrate. Subject 78, aged 87, said that life was not worthwhile. He said he gets forgetful and the pain makes things worse.

2 subjects said that they had difficulty coping with the pain. 3 others complained primarily of being lonely. Subject 53, aged 70 and a widow of 3 years, had a leg ulcer, and arthritis in her shoulder. She said *"I love life but I'm very lonely. I do things to make up for this"*. She missed walking, dancing and socialising, and said that the pain *"makes you weary"*. 2 subjects reported that pain disturbed their sleep, and one focused upon difficulties in personal relationships.

These results appear to indicate that a large proportion of these elderly subjects placed great emphasis on the loss of ability to do things. Even where people focused primarily upon feelings of misery and depression, this was often because they were unable to do the things they enjoyed doing. Doing things appeared to give life some purpose, and make life worthwhile.

6.9 Summary

This chapter has described a very elderly population with a wide range of different types of pain problems, the majority of them chronic. Data from the mood profile revealed little differentiation of mood factors. Mood showed considerable variability, although the mean showed a tendency towards the positive pole. Those with negative mood did not appear, necessarily, to be those with the worst pain. Self-reports of anxiety and depression showed good correlations with anxiety and depression descriptors taken from the mood profile.

Pain measurement data revealed a wide spread of pain intensity. About half of subjects were rarely pain-free. Almost half reported intermittent pain, of whom the majority experienced regular frequent exacerbation. Although the majority of patients felt adequately informed, lack of information was, for a few, identified as a major source of discontent. Problems were identified with pain treatments received. In particular, drugs were often ineffective, poorly monitored and caused a number of side effects. Nevertheless drugs were the dominant form of treatment for pain, often with good effect. Preliminary analyses suggest the personal use of additional active pain controlling strategies to be beneficial in maintaining pain control. Inability to engage in desired activities, or get out of the house, was overwhelmingly identified as the predominant effect of pain by these subjects.

The extent of disabilities, and activities currently engaged, in are described and analysed, in greater depth, in the next chapter, together with other aspects of subjects' lives which are predicted to influence coping abilities.

CHAPTER 7 RESULTS: PAIN EFFECTS AND COPING INFLUENCES

In chapter 6, subjects' mood state and pain experiences were described and subjected to some preliminary analysis. The literature review and theoretical analysis (chapters 1 and 2) highlighted a number of other factors associated with pain coping, either as causes or effects. Questions reflecting these variables were included in the interview schedule, and are the subject of analysis in this chapter.

7.1 Sleep and Appetite

Tables showing measures of sleep and appetite are given in table 7.1.

	Sleep (N=189)		Appetite (N=183)	
	Number	Percent	Number	Percent
Poor	14	7.4	13	7.1
Not very good	53	28.0	24	13.1
Fairly good	84	44.4	23	12.6
Very good	38	20.1	123	67.2

Table 7.1 Reports of sleep and appetite

Few patients complained about the quality of either sleep or appetite. Pain appeared to be identified as a major causal factor in loss of sleep in only a minority of cases. Many people who did not sleep well said that they did not expect to at their age. A common cause of sleep disruption appeared to be the need to get up in the night to use the toilet or commode. Many appeared to be afraid of wetting the bed and did not sleep well as a result.

For others, getting out in the night was a painful procedure, after which it was difficult to return to sleep.

Appetite did not seem to be a significant problem, according to subjects' own reports. Subjects reporting poor appetite were mainly those who were poorly or who suffered from gastric or respiratory disorders which made eating a less enjoyable activity.

7.2 Activities of living

7.2.1 Mobility

Only 14 subjects (7 per cent) reported good mobility, which was defined as being able to get about inside and outside the house without any difficulty. 41 subjects (12 per cent) experienced difficulties in walking outside the house and were unable to use public transport. 114 subjects (60 per cent) used some kind of walking aid, and 21 (11 per cent) required assistance from other people to move about, or were wheelchair bound.

One of the chief problems with this objective type of definition is that these categories do not necessarily reflect the extent to which the subject is actually handicapped by his or her lack of mobility. For example a patient confined to a wheelchair is placed within the most immobile category even though, if the chair is electrically powered for self-use, he may have as much freedom to get about as the person who experiences few difficulties in walking. Subject 149 (see section 6.2.2) was one of the most severely disabled yet, with all her aids to independence, she was not too seriously handicapped. In terms of the theoretical model of controllability, it can be seen that objective measures, such as these, provide little information about the degree of control the person actually has, or perceives himself to have.

7.2.2 Washing and dressing

Measures of ability to wash and dress are given in table 7.2. Those who lived with a relative or spouse often received assistance with these activities, whereas they may have been able to manage alone, albeit with difficulty, if

	Dressing (N=187)		Washing (N=186)	
	n	%	n	%
No problem	59	31.6	42	22.6
Manage alone with difficulty	68	36.4	27	14.5
Receives assistance	45	23.7	97	52.2
Totally dependent	15	7.9	20	10.8

Table 7.2 Ability to wash and dress

they lived alone. This represents a measurement difficulty which cannot be easily resolved, in a one-off interview, where it is not possible to judge what people were capable of doing, only of recording what they reported they were actually doing. The mismatch between what was done for people, and what they could really manage for themselves was exemplified by subject 85, aged 85, who lived alone. She described how she had a private helper to put her to bed, after which she would get up to watch the late film on the television, which was in the kitchen. She found the nightly visit greatly reassuring and was prepared to pay for the privilege, so she maintained the pretence of need. (She showed no enthusiasm for the idea of obtaining a television for the bedroom).

7.2.3 Cleaning and cooking

Engagement in cooking and cleaning activities are given in Table 7.3. Once again, people were classified according to what they said they did. Only a few of the men interviewed participated in, or wished to participate in, cooking or cleaning activities, whereas many of the women were prepared to tolerate considerable difficulties in order to continue doing these things for themselves. Those who were cared for by others often did not carry out these activities even though they may have been able to do so had they tried, or been given the opportunity. Some carers reported that they considered the subject too slow or unsafe to be allowed in the kitchen. Subject 130, a charming 85 year old amputee, with phantom limb pain and post-herpetic neuralgia, lived with a niece. The niece, who listened to her aunt's responses during the interview, described a conflict between knowing that her aunt should participate, and the lack of time to allow her do so. This subject selected the pain descriptor 'miserable' because *"- just sit in the chair all these years"*. She longed, more than anything else, to be able to make scones.

	Cooking (N=182)		Cleaning (N=183)	
	n	%	n	%
No problems	43	23.6	15	8.2
Manages alone with difficulty	37	20.3	22	11.6
Receives assistance	33	18.1	65	34.2
Does not engage in this activity	69	37.9	81	44.3

Table 7.3 Participation in cooking and cleaning

7.2.4 Shopping

Only 11 subjects did their own shopping without any difficulty. A further 9 managed alone with difficulty, while 21 (11 per cent) managed with some assistance. 141 subjects (77 per cent) did not undertake any shopping activities at all. These people relied upon relatives, neighbours, home helps, or upon local stores which offered a delivery service. However the inability to go shopping is not necessarily a handicap for those who have regular essentials delivered, and use mail order for the remainder, provided they are content to do so, which many appeared to be.

7.2.5 Gardening

A question about gardening was included in the questionnaire because past contacts with elderly people indicated that many of them worry about the state of their garden when they are no longer able to take care of it for themselves. In fact so few people were able to undertake any kind of gardening activity that the question appeared to have little relevance at a quantitative level. On the other hand, gardening was often identified, by subjects, as a desired hobby or interest in which they could no longer engage. Since those who lived in flats, or with carers, lacked the opportunity to garden, gardening appeared to be a poor predictor of actual disability, and was therefore excluded as such.

7.2.6 Help in the home

The impression was gained, during the interviews, that, on the whole, local services catered effectively for those who were disabled. 85 subjects received home help from the Social Services, and a further 10 identified private help. 3 subjects received help from a local charitable organisation. Others had relatives who helped with housework, in addition to those who relied upon resident relatives, friends or services. Only 17 subjects reported receiving meals on wheels, but many had meals cooked by their home helps, and one milk round had recently commenced delivery of precooked meals to dubious acclaim. 32 subjects attended a day centre or luncheon club once or twice a week.

63 subjects reported having received a visit by an occupational therapist from a social services department. Aids acquired from this source included geriatric chairs, trolleys, toilet seats and rails, bath aids, helping hands, and a stair lift. Other aids included walking frames, wheelchairs and commodes. There were complaints about the statutory services, but these were very few, and at least 10 subjects had been offered services which they had declined.

17 subjects reported having bought their aids from the independent sector. 5 subjects had bought themselves self-propelled electric wheelchairs for

outside use. These included a gentleman aged 97 (subject 94), who wished to get out to the shops, and two ladies who were subsequently too nervous to go out alone in theirs. Other privately obtained aids included a stair lift, automatic bath seat, and many small useful items.

7.2.7 Measure of disability

It was necessary, for the purpose of further analysis, to reduce the number of variables used to measure activities of daily living to a single measure of disability. A simple summation was unsuitable, since the variables may have varied in their importance as measures of disability, and factor analysis was therefore performed. The variables included were general mobility, and the ability to wash, dress, cook, clean and shop.

The results of the factor analysis are given in Appendix VIII. Sampling adequacy was satisfactory (83 per cent), and factor analysis revealed a single factor which accounted for 63 per cent of the variance. Factor scores were used in future analyses as a measure of disability.

Disability scores showed a weak association with the number of pain sites (r_s=.16, n=182, p.016). While it was predicted that those with a greater number of pain sites would be more disabled, it was evident, during the interviews, that the location of pain sites was as important as the number. Those with pain in the hands, hips and knees were generally those who experienced the greatest difficulties in maintaining activities of daily living.

7.3 Occupation

7.3.1 Being occupied

The majority of subjects felt themselves to be well occupied. A histogram showing occupation scores is given in table 7.4 and reveals a bimodal distribution skewed in favour of feeling 'well occupied'.

Subjects described a variety of ways in which they kept themselves occupied and these are summarised in table 7.5, together with mean scores for 'being occupied' recorded for subjects reporting each activity. The results confirmed an impression, gained during the interviews, that higher scores on being occupied were obtained for occupations which required practical or social activity, such as knitting, writing letters, gardening and involvement in clubs (though it was evident that some had not included their weekly trip to the day centre as a way of keeping occupied). Watching television, and other passive pastimes tended to attract low scores.

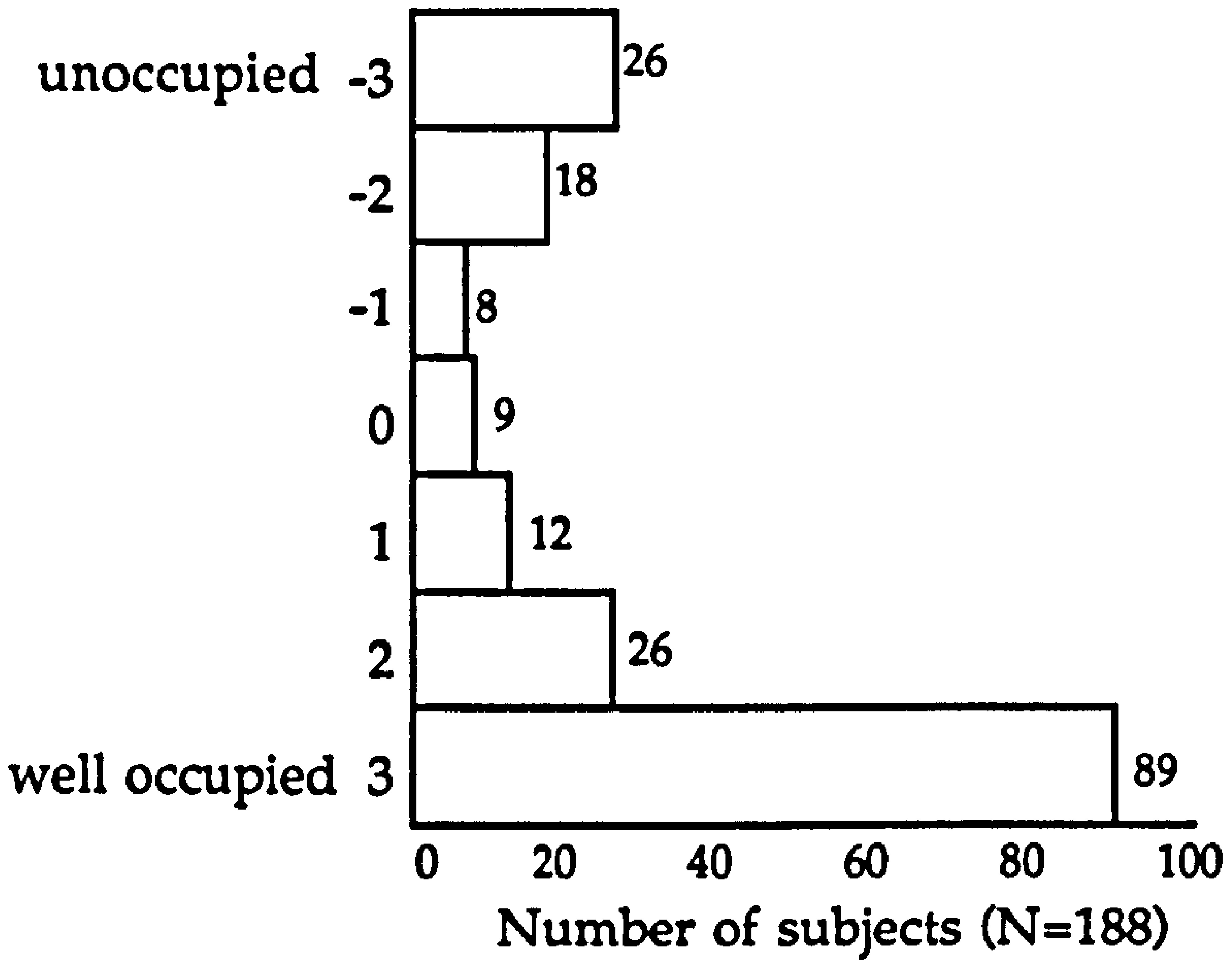


Table 7.4 Histogram of 'feeling occupied'

There are two possible explanations for these observations. The first is that those who reported more types of occupation had less disability, and therefore had more opportunity to be active and occupied. The second was that it was active involvement, as opposed to having passive pastimes which was critical, regardless of the level of physical effort. Table 7.6 gives the number of occupations reported.

The numbers of occupational strategies reported were indeed found to be associated with feeling occupied, and with mood state (r_s=.39, n=184, p<.001, and r_s=.2, n=175, p<.005 respectively).

occupation	n	mean 'occupied' score (range +3 to -3)
Reading *	68	1.8
(read the paper only) *	6	-1.7
Watch TV *	75	0.8
(watch TV only) *	17	-0.9
Listen to radio/ talking book/music *	18	1.6
Arts/crafts/hobbies (knit, sew, paint etc)	62	2.3
Games (patience etc.)	10	2.5
Household chores (cook, clean etc)	45	1.5
Gardening/plants	13	2.8
Clubs	14	2.4
Church	9	2.3
Intellectual studies/ creative writing	6	2.7
Writing letters	13	2.2
going out	17	1.5
Visitors/company	12	2.3
working (P/T)	3	2.7
Pets	3	2.7
Living in the past *	2	2.5
Plenty to do	1	3.0
Telephoned by family *	1	-3
Looking out of the window *	4	-0.5
Nothing *	10	-2.9

* denotes passive interests
with the exception of the last category, many subjects reported participating in more than one activity

Table 7.5 Reported ways of keeping occupied

n of occupations	n (N=185)	%
0	10	5
1	45	24
2	49	26
3	44	23
4	25	13
5	11	5
6	1	<1

Table 7.6 Number of reported occupations

One of the least occupied subjects visited was subject 31, a diabetic aged 71 who had recently lost his sight. He had severe intermittent claudication, an ulcer on his right foot, and was unable to walk outside the house. He had only occasional moderate pain, but described it as punishing and miserable. He had been a manual worker all his life and, since retirement to this locality, his hobbies had been gardening and decorating. He now had nothing at all to do and no friends. His wife refused to allow him to make even a cup of tea, since he had once switched off the refrigerator by mistake. His mood score was +3, but he was quite tearful and very worried about the future.

One of the best occupied was a widow of 74 (subject 183) who had rheumatoid arthritis and was recovering from a very disabling and painful illness, vasculitis, which had kept her in hospital for almost a year. She was never free of less than moderate pain, but had recently visited friends in Sweden, in her wheelchair, and was now learning Swedish in preparation for another visit. Her mood score was +20.

7.3.2 Active vs. passive occupations

Subjects were divided into those who had only passive occupations, and those with at least one active occupation, as indicated in table 7.5.

Active occupations were defined as those requiring active observable participation, with a productive, or socially productive, outcome. Results are given in table 7.7.

Type of occupation	n (N=185)	%
None	10	5
Only passive	56	30
At least one active	119	64

Table 7.7 Involvement in active and passive occupations

The Mann-Whitney test confirmed that those with at least one active interest were more likely to feel occupied than those only passive occupations (U=1706, n=66,118, p<.001)). When those with no interests at all were excluded from the analysis, the difference remained (U=1667, n=56,118, p<.001). Those with active interests were also more likely to demonstrate positive mood state than those with passive occupations (U=2092, n=53,114, p.005).

Both the number of strategies, and whether these were active or passive, appeared to influence feeling occupied and mood state. However those who were mobile were thought more likely to have a greater number of occupational strategies at their disposal, and it might be the case that it was physical activity that was influencing both feeling occupied and mood state. Subjects with active interests were therefore divided into those who were independently mobile, and those who could only move about with aids or assistance. 78 patients were actively involved but immobile, while 41 patients were both active and mobile. No difference was found between these groups in terms of feeling occupied (u=1504, n=119, ns), or mood state (u=1435, n=118, ns), thus supporting the hypothesis that it is active involvement which is critical in terms of coping, rather than the any aerobic effects of physical exercise. Finally, when active versus passive types of activity were controlled for, there was found to be no statistical relationship between the number of occupations and feeling occupied (r=.1, n=172, ns) and no relationship between the number of occupations and mood state (r=.05, n=172, ns).

The analyses reported above necessarily involved generalisations in order to allow quantification into active or passive occupations. Reading may be a passive pastime for some, but for others it demonstrated considerable scope for involvement. Subject 138 paid a regular subscription to Mills and Boon. She reported enthusiastically that these books took her *"all over the world"*, and were her chief source of occupation. Likewise one or two television watchers reported total involvement in soap operas which appeared to provide a surrogate social life and formed the basis for conversation with relatives or neighbours.

Only two people reported living in the past, and both reported being well occupied. Evidence from Coleman (1986) suggests that it may be incorrect to classify reminiscence as a passive interest, rather it is probably an active process even though it involves no observable or productive behaviour. Subject 110, aged 91, enthusiastically related how she had kept race horses in Kenya and had been a newspaper correspondent on the subject, producing cuttings to prove it. She said *"I've had a brilliant life... but I've had it now"*. She was now completely disabled, following a stroke, and was never pain free, due to arthritis, but her mood score was +36 and she reported *"no complaints"*.

In spite of difficulties in the categorisation of active and passive occupations, these results tend to support the view that active personal involvement is the critical factor in determining feeling occupied, and hence an important influence upon mood state.

An example of missed occupational opportunities was highlighted by subject 114, who had been apprenticed as a cabinet maker and had examples of exquisite wood carvings that he had made in the past. However he had given most of his tools to a nephew when he retired to this area, three years ago. He now regretted that he had not pursued his woodwork interests, but had no facilities at all in his present home. He was rather depressed, mood score -8.

Of those who reported occupation scores of -2 or -3 (little or nothing to do), it was found that 24 were married, 9 lived with a relative or significant other, and only 5 lived alone, of whom one was in warden service accommodation. This indicates that proportionately less of those living alone were unoccupied, than those who lived with either a husband or significant other. Likewise of those who were unoccupied, and who appeared depressed, with mood scores of less than -10, 7 were married, 1 lived with a relative, and 2 lived alone. This appears to support the view that having things to do about the house is therapeutic.

In summary, the majority of subjects reported feeling well occupied, and the majority of these reported active participation in either household activities, self care, or some type of hobby. There was statistical evidence that those who engaged in such activities were more likely to report feeling occupied than those with passive pastimes, such as watching television or reading the newspaper, regardless of the number of occupational strategies available. Evidence suggests that involvement in active processes, rather than physical activities, are critical in determining how well occupied people feel, and in influencing their mood state. Those who lived with another person were more likely to report being unoccupied than those living alone.

7.4 Loneliness and social contact

7.4.1 Loneliness

The majority of subjects stated that they did not feel lonely. A histogram showing distribution of loneliness scores is shown in table 7.8.

Those who lived entirely alone were far more likely to report feeling lonely than those who were married (Mann-Whitney U=1165, p.<.001). However data from 59 subjects who lived alone (from table 6.1) indicates that loneliness is by no means an inevitable consequence of living alone. More than half of patients who lived entirely alone reported that they did not feel particularly lonely. Subject 149 (see section 6.2.2) was one of these, and several others reported that they actually enjoyed solitude.

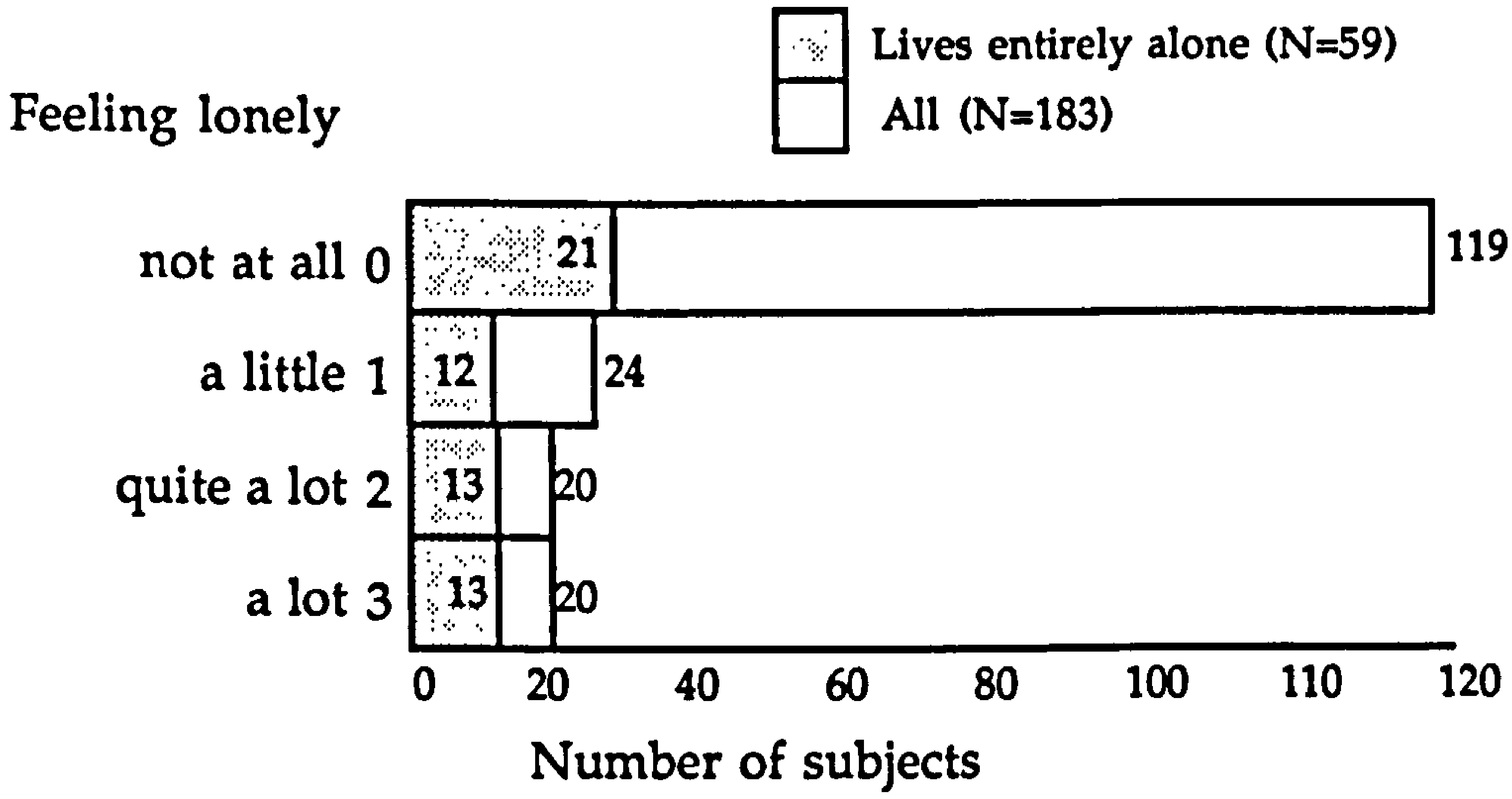


Table 7.8 Histogram of 'feeling lonely'

7.4.2 Social contacts

Subjects were asked (q 17b) how often they went out of the house. 81 subjects (43 per cent) left their home for some kind of outing less than once a week. 24 subjects (13 per cent) went out about once a week, 43 subjects (23 per cent) went out two or three times a week, and 36 subjects (19 per cent) went out most days. No attempt was made to categorise the type of outing according to the nature of social contact afforded. Outings included shopping trips, attendance at a day centre and visits to friends or family.

Subjects were also asked about the number of social visitors to their home (q 17c). More than half of all subjects were living with a spouse or caring relative and therefore had daily contact with other people. Including these, 133 subjects had social contact within their home on most days.

23 had visitors two or three times a week, 9 subjects reported receiving a social visit only once a week and 11 reported less frequent social visits.

Frequency of social contact inside the home was a fairly good predictor of loneliness for all subjects (r_s=-.37, n=178, p.<001). Among those who lived alone, frequency of social visitors to the home was a predictor of loneliness (r_s=-.32, n=55, p<.01), whereas frequency of outings from the home was not related to loneliness (r_s=-.05, n=58, ns).

Subjects were left to define for themselves who they would consider a social visitor, and it was evident from the data that many of them failed to recognise visits by wardens or home helps as 'social' visits. These results appear to indicate that it is the quality of social relationships which is a good predictor of loneliness, not the incidence of social contact *per se.*

It was evident from subjects' responses that not all of those who were married or lived with carers found companionship within the home. One elderly lady (subject 60) gave pain scores that were not unduly high, yet she was very depressed and stated that she sometimes wished she were dead. She had a lovely home, what appeared to be a supportive husband, and gave no hint of any problems, other than pain, until her husband left the room to make tea. At this point she leant forward and said that on her wedding day (over 50 years ago) her father had said to her *"are you sure you are doing the right thing?"*. She said that she had started to cry and had been crying ever since. Subject 179, a delightful 83 year old lady, with a large close family and many interests, said she wished that her husband would die. He had done nothing since his retirement and she felt trapped.

These were extreme examples of marital disharmony, however a number of other elderly married people expressed either irritation or resigned tolerance towards their spouses, in contrast to many who displayed shared affection, humour and companionship.

For these reasons, a quantifiable objective measure of social support, based upon social contact, is difficult, if not impossible, to obtain.

It is interesting to note that, of those with mood scores of less than -10, and who appeared very depressed, 12 were married and living with their spouse, 1 with a significant other, and 4 lived alone. Of the four who lived alone, three reported feeling lonely. Subject 187 was, in fact, married, but her husband was currently in a nursing home following a severe stroke which had left him unable to speak and severely depressed. She felt very guilty that she was unable to help him because of her own disability.

Many of those living alone were widowed. It was hypothesised that loneliness would be more prevalent among those recently bereaved than those who had had longer to adjust to living alone or forge new relationships. The negative association between loneliness and duration of widowhood was confirmed ($r_s=-.36$, $n=46$, $p<.01$). Subject 65, aged 81, described loneliness as her worst problem - her husband had died the previous year. There were, as always, exceptions. Subject 105, aged 75, said that she had stayed with her husband for the sake of the children. She described the feeling of relief, when he died at home 4 years ago, and said *"I could not get him out (of the house) quick enough"*.

In summary, it appears that, while those who lived alone were more likely to report feeling lonely, this was likely to be associated with the recent loss of a spouse. Those who were married were much less likely to feel lonely, although companionship could not be assumed, even after 50 years of marriage. For those alone, the number of social visitors into the home was the best negative predictor of loneliness, although social outings from the home were generally associated with improved mood state.

7.5 The presence of other life problems

Many of the elderly subjects interviewed were having to contend with a variety of problems which were not necessarily associated with pain or the painful condition. Subjects were asked to report if they thought they would be trouble-free if it were not for their pain. The results are given in table 7.9 and show that, while many of the problems faced by the subjects in this study appeared to be pain-related, an equal number were not.

Other life problems (N=178)		n	%
None	0	46	26
Some	1	40	23
Considerable	2	45	25
Major	3	47	26

Table 7.9 Presence of life problems apart from pain

The types of non pain-related problems reported by subjects were categorised as health, personal or financial and each of these was measured on a four-point verbal scale of intensity. The results are given in table 7.10. The types of additional health problems identified included blindness, deafness and incontinence, in addition to a variety of disorders commonly found among district nurses' caseloads, including Parkinson's disease and diabetes. Blindness was frequently encountered, in this sample, in association with diabetes, because district nurses call on these patients on a daily basis to draw up insulin for them. For many elderly people, the combination of physical pain, from leg ulcers or arthritis, with loss of vision had a devastating effect. Many more were fearful of losing the sight they had.

However not all subjects had succumbed to such adversity. Subject 92, aged 82, a widow of 11 years, had arthritis of the spine, claudication and angina, and experienced moderate to very severe pain, unless she was flat on her back. She had been diabetic for 24 years, was registered blind, and had recently been diagnosed as having breast cancer which was being treated with drugs. In spite of all this she was a most cheerful person, with a mood score of +38.

She said that she had always enjoyed a full life, still did daily exercises (and could still touch her toes), did her own cooking, listened to tapes for the blind, and educational and documentary programmes on radio and television.

Problem	Health (N=187)		Personal (N=183)		Financial (N=178)	
Extent	n	%	n	%	n	%
None	56	30	84	46	150	84
Some	23	12	13	7	7	4
Considerable	42	23	58	32	16	9
Major	66	35	28	15	5	3

Table 7.10 Incidence of health, personal and financial problems

The most common distressing personal problems identified were the death or illness of a close relative or friend. Many had not recovered from the loss of their spouse even after several years had passed. Subject 172, aged 71, reported how she still missed her husband terribly. He died just prior to retirement six years previously. She had since moved to a warden service flat, where she made two good friends, both of whom had subsequently died. She expressed a reluctance to get involved with any new friends. In addition to these losses, her sister had recently had a stroke, and she was unable to get to see her.

The very ages of this sample inevitably meant that many had experienced losses within the close family, and among their friends. The extent of the loss was, as previously discussed, related to the strength of the relationship. It was possible to foresee many potential problems among couples who were visited, and who were completely reliant upon each other emotionally, as well as practically.

Subject 86 made frequent reference to the fact that life was not too bad because *"I've got my husband"* and *"we've got each other"*, although he had already had several heart attacks.

Many subjects were reluctant to discuss details of their finances and few reported having any such problems. The majority who openly admitted to having financial problems were those, particularly women, who owned their own homes and were finding difficulties with maintenance. One elderly widow (subject 152) reported considerable concern about the need to maintain the family home which she had inherited upon her parents' death. It was badly in need of outside decoration and she had no savings at all. She could not bear to give it up and felt very guilty at allowing it to deteriorate.

Many elderly people could ill afford to employ outside agencies to implement repairs, and even those who could commonly experienced difficulties in engaging reliable workmen. Three elderly women described how they had been victims of fraud in this respect.

An additional problem regarding finances concerned those recently widowed women whose husbands had handled all the domestic finances in the past. Several widows described how they had never written out a cheque prior to their husband's death and some had no idea how much income they had, nor how to manage the household bills.

7.6 Religious beliefs

Subjects were asked if they had an inner spiritual belief that gave them comfort and, if so, how strong was that belief. It was stressed that the question did not concern church attendance, baptism or confirmation, although some respondents clearly had difficulty in making the distinction. The results are given in table 7.11. This scaling differs from the criteria, given on page 82, in that those classified as having very strong religious beliefs were those who identified their faith as a coping factor without prompting, and spontaneously elaborated upon it as a source of spiritual comfort.

This distinguished them from those whose claim to very strong faith, on the basis of adherence to a strict religious code, appeared somewhat superficial in spiritual terms.

Strength of religious or spiritual belief		
(N=176)	n	%
None	51	29
Some	43	24
Fairly strong	45	26
Very strong	37	21

Table 7.11 Religious beliefs

Some subjects gave indications of great suspicion when asked about their religious beliefs. Subject 157 was reluctant to reveal his complete lack of belief in God until he had elicited a declaration of personal disinterest from the researcher. Others expressed very strong commitment. Subject 61, aged 71 with multiple sclerosis, completely accepted her disability because of her strong Christian belief. She was confidently awaiting the second coming. The sister who cared for her, did not share her beliefs, and expressed considerable resentment about her role as carer. Many others were sustained by their spiritual beliefs. Subject 140 said that she prayed to God to help her through each day *"and He does"*. Subject 164 was greatly comforted by the words of a priest *"you never get more than you can bear"*. Some received great practical, as well as spiritual support from their church. Subject 33 lived in a Christadelphian rest home where, she said, she was much more contented than alone at home. Subject 113 had a faith that meant very much to her *"more so than ever before"*. She said she was Catholic and, since she could no longer go to church, they regular came to give her communion at home. Subject 121 expressed a strong religious faith and said *"I should never have got over the shock of my husband (dying) without the vicar"*.

However some had their beliefs severely tested by their problems. Subject 172 questioned why some of us must suffer, though she thought it must be for a reason. Subject 108 said *"I have suffered enough. I say my prayers, but I don't seem to get any answers"*. While beliefs generally encouraged the sufferer to persevere, subject 196, aged 75, was awaiting healing and making no attempt at all to rehabilitate himself after a stroke. He felt deeply resentful that none of his past Spiritualist friends had offered to help him. Subject 62, aged 83 suffered continuous pain from an old hip fracture, varicose ulceration on both legs and a stroke. She reported having a fairly strong religious faith, though she commented at one stage *"Father, don't punish me any more"*.

Overall, it was apparent that many were sustained, both spiritually and practically, by their beliefs and church associations. Religious beliefs were, for the majority of those who held them, a great source of consolation, hope and support.

7.7 Regrets

It became evident, during the course of the interviews, that a number of people who appeared to be depressed were expressing regrets or bitterness about events in the past. This aspect was highlighted in the life stories told by two elderly sisters. The younger sister, aged 78, (subject 71) had a congenital foot defect (club foot), for which she had had several operations, and now had osteoarthritis in both hips. She had been disabled throughout her life and had been cared for by her older sister. The sister, aged 79 (subject 70), described how both of them had been subjected to what would nowadays be described as abuse as children. She said that she and her sister were the black sheep of the family. She had been forced to look after her brothers and sisters, and had subsequently cared for her mother and father until their death. Now she cared for the disabled sister without any help from the other siblings who were still alive. They had no financial security. They lived in a flat which was not of their choice and which they disliked intensely. The depression which they both exhibited appeared to relate not to the pain, which they both experienced, but to the bitterness and resentment surrounding their past, and to regrets, on the part of the older caring sister, that it was now too late to find any fulfilment in life.

All subjects subsequently interviewed were asked if, looking back over their lives, they had any regrets. The results are given in Table 7.12.

Presence of regrets (N=116)	n	%
None	69	59
A few	24	21
Quite a lot	14	12
Many	9	8

Table 7.12 Regrets

The majority of subjects stated that they had no regrets, and many went on to express considerable satisfaction with past achievements and lifestyle. Sources of satisfaction related to jobs well done, the successful rearing of offspring, pride in grandchildren and happy marriages. Such attitudes appeared to mitigate against feelings of resentment. Subject 40 said that, although she did not accept the pain, she did not feel angry because *"I have wonderful memories"*. Regrets were often associated with pain. Many who expressed these feelings described their chief source of regret as having looked forward to retirement as a time for fulfilling leisure ambitions, only to be thwarted by the onset of the painful condition.

Other sources of regret were various. Subject 54 bitterly regretted that she had not been able to afford to train as a nurse. Subject 164, who had cancer of the bowel, regretted the loss of three of her children, two of whom had died simultaneously from gastro-enteritis. Subject 115 regretted having married young to the wrong man and, although she had subsequently made a very happy remarriage, she still felt guilty about the divorce.

Subject 48 was seriously ill and expressed fear of dying because he wondered if we must pay for our past misdeeds. He obviously experienced considerable distress about some past event, but declined to discuss it further. The most tragic example of past regrets was subject 103, aged 74, who had been confined to a wheelchair since 1964. His wife had died, one year previously, from a heart attack. This followed soon after an incident where she had lost control of his wheelchair and fallen. He felt totally ridden with guilt and remorse.

Overall, the impression was gained that regrets played a considerable role in determining subjects' current state of mind. The majority of those with positive memories of the past appeared to relish discussing them, while those with regrets often displayed a negativity which permeated their whole current outlook. This impression is explored further at a quantitative level, in the following chapter.

7.8 Summary

This chapter has identified a number of factors, in addition to pain, which appear to play an important part in determining how elderly subjects cope with their lives. Sleep disturbance was a problem, although seldom perceived to be a direct result of pain. Appetite did not seem to be a particular problem. Mobility was reduced in the majority of subjects, and most subjects required some help with daily living, although there was some evidence of mismatch between ability and performance. In spite of difficulties, the majority kept themselves well occupied. Occupations requiring active involvement appeared to be most therapeutic. Those who reported only passive pastimes were more likely to report having little to do, and depression. Most of those who were very depressed were being cared for by others. Relatively few subjects reported feeling very lonely and, of those who lived alone, loneliness was most common among the recently bereaved. Subjects reported many health, personal and financial problems, in addition to pain, which appeared to cause considerable distress. Many identified strong religious beliefs which, they felt, helped them to cope.

Some reported the presence of regrets about past events or relationships which caused bitterness, resentment or guilt.

These last two chapters have attempted to set the scene with respect to the pain and coping experiences of the elderly sample interviewed. Brief case reports have been included to illustrate the types of problems encountered, and the ways in which people either cope, or fail to cope. Above all, these results demonstrate that no single factor inevitably accounts for poor coping. Thus for every subject who has succumbed to difficulties in coping with any particular aspect of pain or other life event, there is an example of how another person, with a similar objective experience, will have overcome it. It really seems possible for some people in this age group to come to terms with just about any difficulty in life.

All of the variables identified so far are potentially involved in the coping process. In the next chapter, these will be examined statistically, in conjunction with the pain variables, using mood score as the dependent variable, in order to assess their relative impact upon coping.

CHAPTER 8 RESULTS: QUANTITATIVE MODEL OF COPING

The nature of the sample, together with details of their pain and coping characteristics have been described in chapters 6 and 7. These included analysis of a variety of factors which are predicted to be associated with coping in a population of elderly people suffering from painful conditions. In this chapter, these independent variables are included in a multivariate analysis, using mood score as the dependent variable. This analysis forms the basis of a model of coping which will be used to determine appropriate nursing interventions in the management of pain in the elderly in the community.

8.1 Correlational data analysis

Preliminary correlations are used to identify, at a bivariate level, which of the independent variables are associated with mood state, as measured by the sum of scores on the mood profile scale, and to measure the strength of the association. These results do not include data from the MPQ.

8.1.1 Non-significant results

The association between the independent variables and total mood score is given in table 8.1. The following results did not show a significant association with mood state. The reasons for this are discussed, and they are omitted from further analysis.

No effects on mood score were found for pain duration, the number of pain sites, pain rating at the time of interview, sleep, or the rating of pain at the time of interview.

The absence of effect for duration of pain may explained by the nature of the sample under study. The majority of the pain was chronic, the mean duration of pain being almost 12 years. It is therefore likely that adjustments to painful conditions would, for most subjects, be fairly stable, in which case duration would be unlikely to exert a significant effect on coping in this sample.

Correlations between mood score and independent variables

	Correlation coefficient	N	1-tailed significance
Age *	.241	179	.001
Duration of pain*	.013	176	insig
Number of pain sites*	-.100	179	insig
Rating of pain 'now'	-.112	179	insig
Rating of 'least' pain	-.288	179	<.001
Rating of 'worst' pain	-.178	179	<.01
Feeling informed about painful condition	.230	171	.001
Perceived level of pain control	.411	164	<.001
Locus of control	-.309	176	<.001
Sleep	.135	179	.036
Appetite	-.317	175	<.001
Disabilityscore	-.226	176	.001
Feeling occupied	.507	179	<.001
Loneliness	-.331	177	<.001
Presence of other life problems	-.362	175	<.001
Religious beliefs	.225	170	.002
Regrets	-.499	116	<.001

*denotes use of Pearson correlation, otherwise Spearman used

Table 8.1 Association of independent variables to mood state

Results, given in chapter 6, indicated an association between the number of pain sites, and the levels of least pain and perceived pain control. However there is no evidence of any relationship between the number of pain sites and mood state. Even if there were, this effect would most likely be an indirect one, dependent upon its influence on the amount of pain perceived and the degree of disability.

The lack of effect for pain, as rated at the time of interview, was anticipated, since subjects' current perceptions about their pain were certain to be influenced by the fact that they were in the company of the researcher, and also by time of day, or by a variety of other unavoidable transient influences. While these influences would possibly colour responses to all other questions posed during the interview, such effects were thought unlikely to be as strong as for the level of current pain.

Sleep showed only a weak association with mood score. The relationship between sleep and mood is difficult to assess, probably very complex, and beyond the scope of this thesis. The interviews indicated that only 4 people attributed sleep disturbance directly to pain. Insomnia is recognised to be associated with depression, however clinical depression was not measured as part of this research and was thought to be present in only a few subjects. Furthermore any effects of sleep on mood were almost certain to be confounded by variations in general practitioners' prescribing habits with respect to sleeping tablets, and the use, in a few instances, of antidepressant and anxiolytic drugs.

8.1.2 Factors associated with mood

All of the remaining independent variables, which were predicted to influence coping, were found to be associated with mood score, as shown in table 8.1 (above). Variables showing the strongest correlations with mood score were 'being occupied' (r_s=.51, n=179, p<.001), 'having regrets' (r_s=-.50, n=116, p<.001), pain 'under control' (r_s=.41,n=164, p<.001) and the presence of 'other life problems' (r_s=-.36,n=175, p<.001), most particularly the presence of personal problems (r_s=-.45, n=175, p<.001).

In order to assess the relative effects of the independent variables on mood state, and to identify a coherent structure for intervention to enhance coping, all significant variables, identified above, were entered into multiple regression analysis, with mood score as the dependent variable.

8.2 Regression analysis

Regression analysis is used to identify the best model possible from the point of view of data analysis, theory and interpretation. It therefore involves many stages of model fitting. Appetite was excluded as an entry variable at an early stage for theoretical reasons. It was considered more likely to be a consequence of coping difficulties, rather than a causal factor, while the purpose was to construct a causal model in relation to mood. Its exclusion had no discernible influence upon the resulting model. Age was subsequently eliminated from the regression analysis, since its effect, while independent of all other variables, made no significant contribution to the regression model, and it is not a variable which is amenable to change. 'Other life problems' was initially included to encompass health, personal and financial problems, so as to reduce the number of variables for inclusion.

Bivariate Spearman correlations indicated that the highest level of correlation between variables included in the regression analysis was 0.43. This gave no indication of multicollinearity which might distort the analysis. Graphical analyses showed no evidence of non-linear relationships within the data.

The remaining variables were included in the regression equation, and preliminary work demonstrated that 'having regrets', 'being occupied', and pain 'under control' were consistently selected. Together they explained about 50 per cent of variance, regardless of which other variables were included into the regression equation, or the order of inclusion.

Variables included in the penultimate analysis were the ratings of 'least' and 'worst' pain, perceived pain control, locus of control, presence of other life problems, strength of religious belief, feeling informed about the painful condition, disability factor scores, being occupied, loneliness and having regrets. The results of stepwise regression identified 'having regrets', 'being occupied', pain perceived to be 'under control', 'other life problems' and 'feeling informed' to be the best predictors of mood state.

This analysis was repeated using backwards and forwards selection procedures with no effect upon the outcome, neither did changing the order of entry affect it. Hence the possibility of multicollinearity was excluded. The model accounted for 56.7 per cent of the variance, and only 6 outliers were identified, as might be expected by chance. Nevertheless the contribution of 'loneliness' and 'locus of control' were only just outside the range of significance, suggesting some doubt about the stability and reliability of the model.

Reinspection of of the data showed that, of the life problems reported by subjects, health problems were closely associated with disability, and hence with feeling occupied, whereas it was the presence of personal problems which appeared to have the greatest independent effect on coping. The regression analysis was therefore repeated, substituting incidence of 'personal problems' for 'other life problems'. The full results of the final stepwise regression analysis are given in Appendix IX and the equation given in Table 8.2. The model admits 'regrets', 'being occupied', 'control over pain', 'personal problems' and 'feeling informed' as contributory independent factors which are all significant at the 0.01 level. The constant term was not significantly different from zero. No other factors approach significance, and this appears to indicate a robust model. The five variables selected account for 57.7 per cent of the variance. This level of explanatory power is considered to be good for social science data generally, and is particularly pleasing in view of the simplicity of the variables used. The final model identified only four outliers, none of which was found to be due to coding error. The exclusion of extreme outliers did not influence the regression model in any way.

Dependent variable = mood score

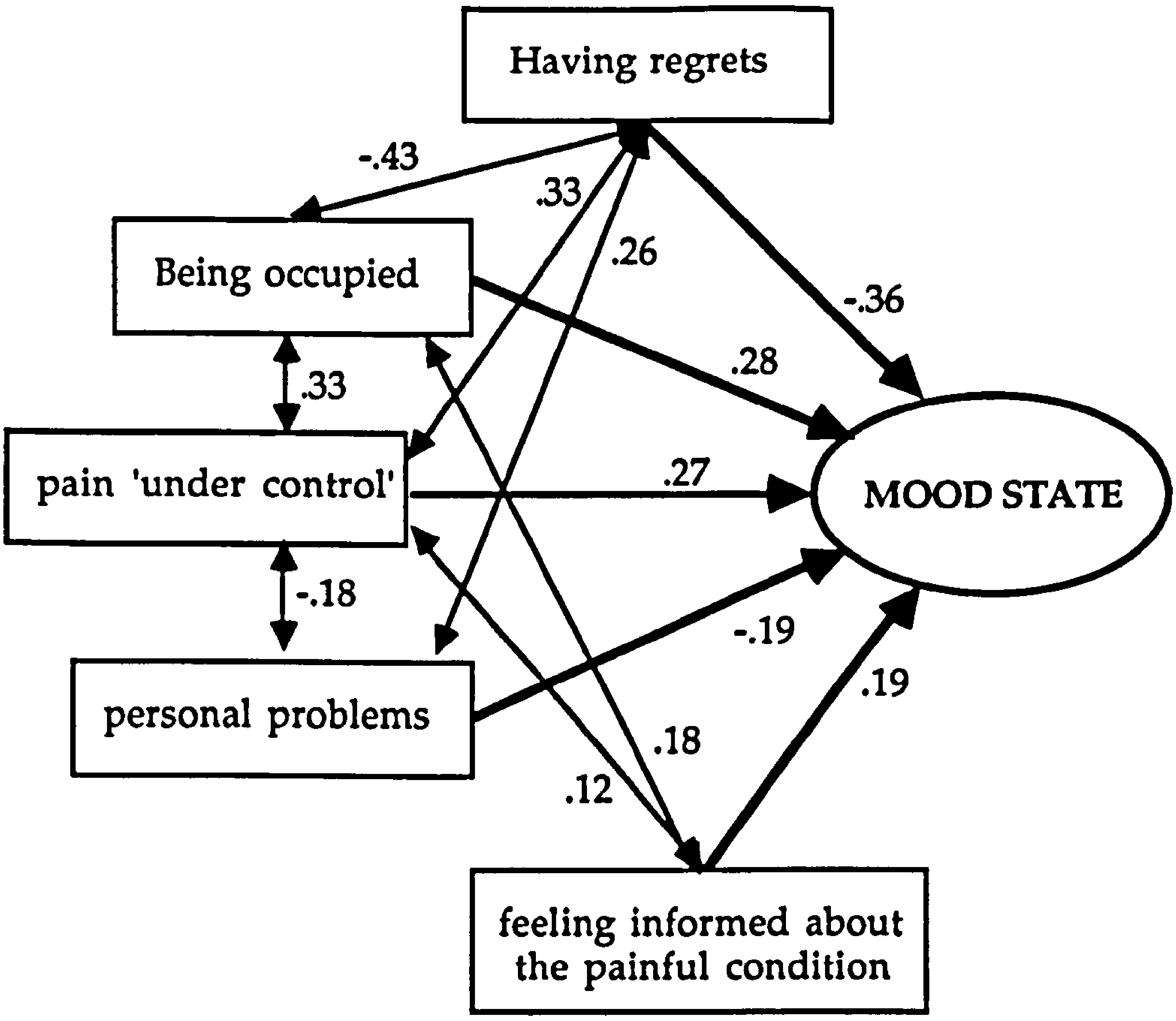
	B (slope)	Beta (standardised coefficient)	T	Sig T
Having regrets	-6.65	-.36	-4.9	<.001
Being occupied	2.41	.28	4.0	<.001
Pain under control	5.03	.28	4.1	<.001
Personal problems	-2.94	-.19	-2.8	<.01
Feeling informed	3.50	.19	2.8	<.01
Constant	3.08		.75	.45

Multiple R = .77 $R^2 = .60$ Adjusted $R^2 = .58$
F=26.92 Sig F = .0000

Table 8.2 Regression equation

The regression model appears to be robust. However the use of non-interval data suggests that the standardised beta coefficients, which normally indicate the relative importance of variables within the model, are unlikely to be precise. These should therefore be treated with some caution. Nevertheless the variables selected into the model were those with high nonparametric correlation coefficients at a bivariate level. It is regrettable that the sample size was not sufficiently large to perform an adequate split-half test of reliability. This was because the question of 'regrets' was included for a subsample only, thus limiting the numbers included in the regression analysis.

The model chosen represents the most acceptable fit in terms of statistical significance and theoretical interpretation. It is illustrated in figure 8a, and considered below.



figures given are Spearman correlation, or beta coefficients for associations significant at, or below the 0.05 level

Figure 8a Regression model

8.3 Interpretation of the regression analysis

8.3.1 Overall interpretation of the model

Figure 8a illustrates graphically the relationships within and between the independent variables included in the model, and mood score, based upon the correlation coefficients (or beta slope). It thus highlights the interactive effects, as well as the independent effects of the variables included in the model, although the causal nature of these relationships remains speculative.

It is evident that those with regrets are less likely to report being well occupied, less likely to report good pain control and more likely to report having personal problems which are not pain-related. The onset of a painful condition, or personal problem, such loss or illness of a loved one, may, in many instances, be the cause of the regret, while lack of occupation may indicate that the individual has more time to think about past regretful events. An alternative interpretation is that regrets may reflect a negative assessment of past events which has generalised to current events. This may determine a feeling of loss of control over pain and over other problems which arise. Possibly both causal explanations are correct, depending upon the nature and extent of the regrets.

Those who are less well occupied are more likely to report poor pain control, possible because they have more time to dwell upon the pain, or because the painful condition makes it more difficult to keep occupied. Alternatively, lack of occupation may indicate a loss of active control which has generalised to all aspects of life, as evidenced by depression. Lack of occupation is associated with feeling ill-informed, possibly because lack of occupation provides more time to think about the causes and potential consequences of the painful condition, or because sufferers are preoccupied by their pain.

Those with personal problems are more likely to report poor pain control. The theoretical model predicted that this might be the case, since the greater the number of problems the individual has to deal with, the greater the demands upon coping resources, thus increasing the difficulty in maintaining control.

The relationships within the regression model are clearly open to different interpretations, but, above all, the interactions, identified above, emphasise the complexity of pain coping. Perceptions of pain control are associated with every other variable in the model. Thus there is a reduced likelihood that patients' pain will feel adequately controlled while they harbour bitter regrets about the past, have considerable personal problems to contend with, have little to do with their time, and / or feel ill-informed about their condition.

This statistical model outlined above is entirely in accordance with the theoretical model given in figure 2b in Chapter 2. This identified perceived control over pain, and over other problems, as determinants of mood state. It identified that information and past experiences would exert strong influences upon controllability, and hence upon mood state, and it proposed control to be a process which requires active responding. All of these elements have been identified as critical determinants of how elderly subjects cope with their lives, given the presence of a painful condition.

It is clear from examination of the regression analysis that the variables which were not included in the final model were wholly or mostly explained by the selected variables. It is anticipated that relationship between variables excluded, and those included in the final model, might help to determine appropriate nursing interventions. Therefore each selected variable is interpreted separately, below, in relation to the overall model, and in relation to the other variables with which they are associated.

8.3.2 Regrets

Having regrets was identified as a critical variable in predicting mood state in this sample of elderly people with painful conditions. In chapter 2, it was identified that knowledge, based upon past experiences, forms the basis by which individuals interpret current events and make predictions about actions which are appropriate to gain or maintain control over them. This in turn determines mood state. It seems likely that having regrets reflects a negative view of past events, outcomes or actions. In fact the regrets described all focused upon events or situations which the individual could not, or had failed to, control. These are likely to lead to negative predictions about the likelihood of gaining or maintaining control over the current situation, together with negative predictions about the future. In this sense, the presence of regrets is, perhaps, a negative measure of available personal coping resources. The majority of subjects interviewed were approaching the end of their lives. Some commented that they had 'no future'. For such a group, success or failure, control or loss of control, lie primarily in their assessments of the past. If the past is viewed negatively, then this will inevitably be reflected in current mood state.

Variables, other than those included in the main model, which are significantly associated with having regrets are illustrated in figure 8b, together with Spearman correlation coefficients.

Religious beliefs appear to act as a buffer against regrets. Interviews indicated that those with strong beliefs were, on the whole, more able to justify negative events in their lives. At a theoretical level, faith in God may be viewed as a source of external control, although the relationship between religious belief and locus of control did not quite attain significance (r_s=.12,n=170,p=.055). The overall impression, gained from the interviews, was that the ideal situation occurred when God was regarded as an additional source of support for those with internal locus of control, according to the maxim 'God helps those who help themselves'. Thus people are able to take credit for their own successes and share responsibility for negative events.

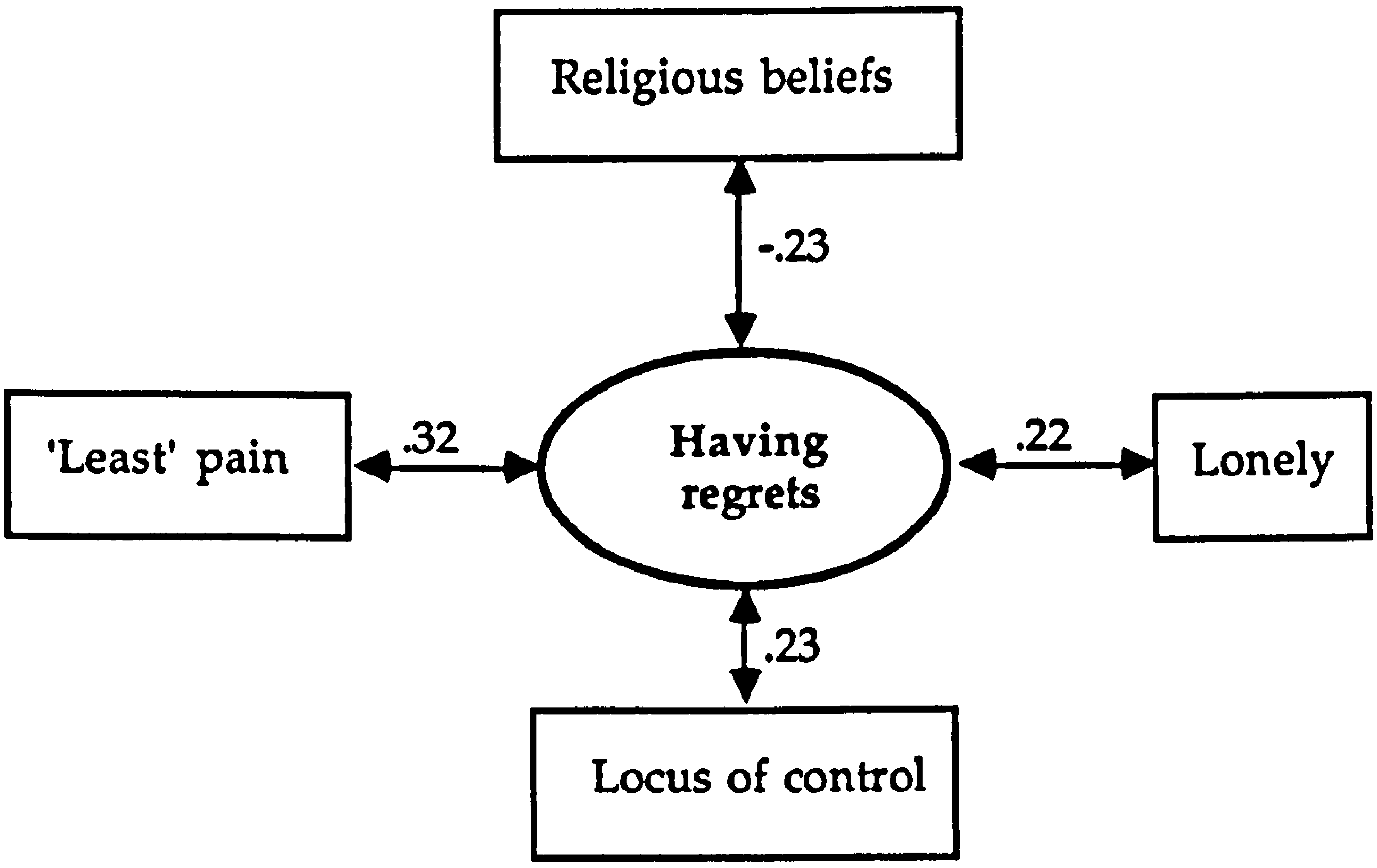


Figure 8b Additional factors associated with having regrets.

The presence of continuous pain, evidenced by the level of least pain, was found to be directly associated with having regrets. Possibly the relationship between pain and regret reflects a vicious circle in which regrets increase negative perceptions of pain control, which in turn increase the level of regret.

Loneliness was the other important variable associated with having regrets. 32 per cent of subjects lived alone, however it has been identified in chapter 6 that loneliness was not an inevitable consequence of being alone. Coleman identified this in his research with elderly people and commented :

> *"Loss of contact can be hard to bear, but far worse is an inability to be content in one's own company"* Coleman (1986 p.79)

People with regrets about the past are far less likely to tolerate their own company than those with happy memories to look back on. Another factor, which became evident during the interviews, was that not all couples were happily married, and reports of regret were sometimes related to the quality of the marital relationship. In these cases, it was not their own company with which subjects were discontent, but the company of their spouse. Similar observations appeared to apply to the relationship between subjects and other carers. Some elderly people deeply regretted having given up their own home to live with a son or daughter.

8.3.3 Being occupied

The theoretical model identified control as an active process. It also identified personal control to be a more adaptive strategy than reliance upon external sources of control. This theoretical model was supported by findings, outlined in chapter 7, which identified the importance of active personal involvement in determining reports of being occupied, and in influencing coping.

Variables associated with being occupied are illustrated in figure 8c. Increased disability was associated with a decrease in reports of being occupied.

Subjects who were physically disabled had a reduced range of interests available to them and were more likely to have to fill time with sedentary activities. In particular, elderly housebound women, who had spent much of their lives cooking and cleaning, found themselves deprived of valuable time-filling and satisfying behaviour when they no longer had the ability or opportunity to do these things for themselves.

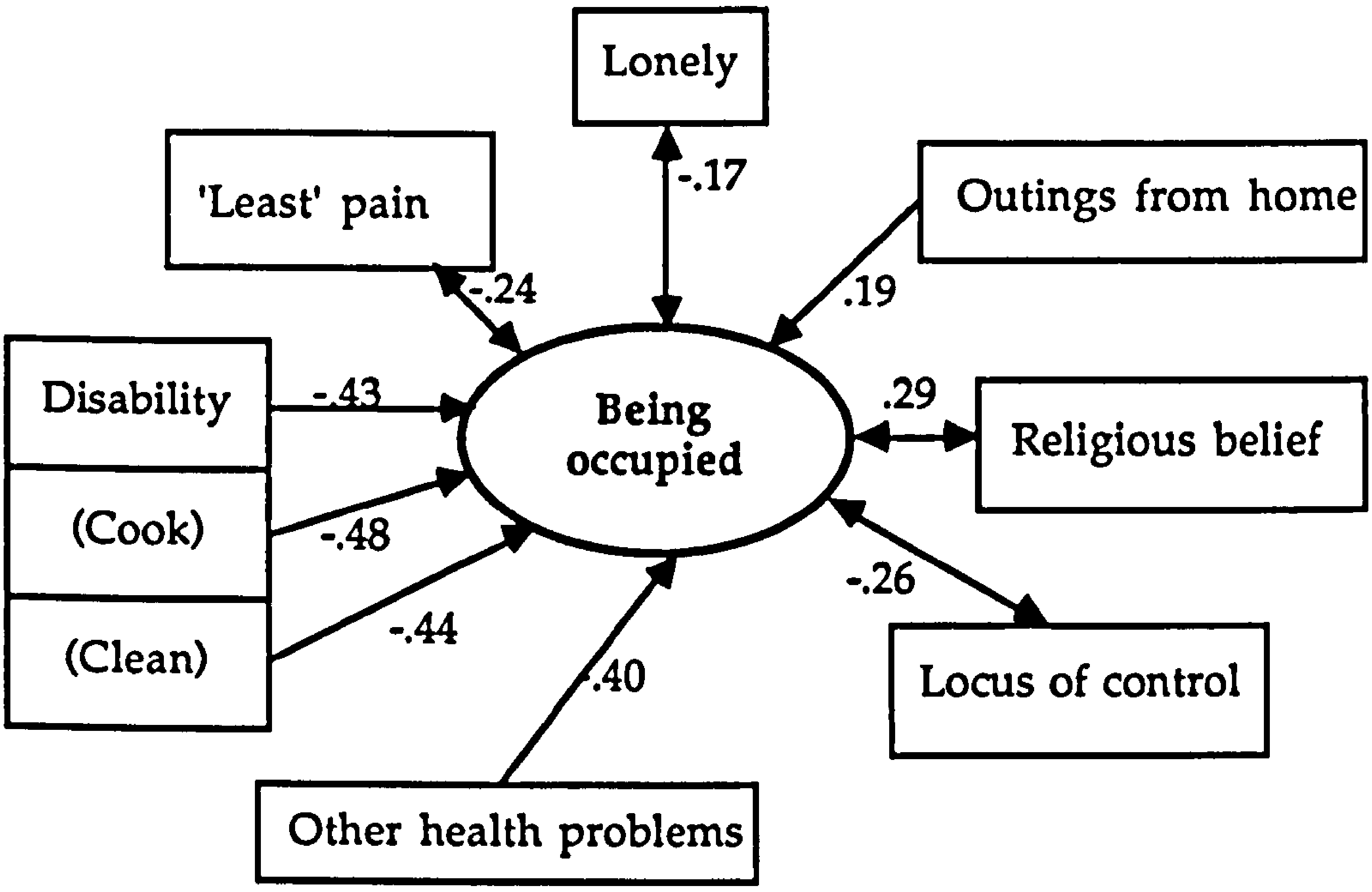


Figure 8c Variables associated with being occupied

Higher levels of least pain were associated with increased disability, and with lack of occupation. It is anticipated that those with continuous pain are less likely to be physically or mentally able to do the things that they would have previously done to keep occupied. They are certainly less likely to be able to go out unaided or undertake household chores, as discussed above. The less occupied people are, the less distraction they have, and the more time they have to focus upon the pain. It seems likely that this relationship is another vicious circle in which increased pain and disability reduce opportunities for occupation, which in turn reduce distraction and pain tolerance. Those with other health problems were likely to report less occupation. It was shown in the last chapter that blindness and other disabling conditions, such as

Parkinson's disease, commonly imposed additional restrictions upon available activities.

Religious beliefs were found to be associated with being occupied. Although subjects were asked specifically about their spiritual beliefs, rather than church attendance, this result probably reflects involvement in church activities, together with the social and practical support received from other church members. Interviews also suggested that some subjects were involved with religious books and prayer in a very active way which provided a substantial source of occupation.

Those who reported being well occupied were less likely to feel lonely. It is interesting to note that subjects who reported that they liked to be on their own were, without exception, those who reported being well occupied. These results indicate that loneliness should be interpreted not simply as a lack of company or social support, but as a more complex and multifactorial construct in which the presence, or absence, of time-filling and involving activities plays a significant role.

The relationship between being occupied and locus of control is entirely in accordance with the theoretical model which identifies control as an active process, and emphasises the importance of internal control. External locus of control implies passivity, while internal control implies that cognitive and behavioural responses are being directed towards pain control, control over other aspects of life, and hence survival. This is supported by findings reported in the last chapter which identify active involvement, rather than passive pastimes, to be associated with being occupied. The most common activities described, knitting and crochet, necessarily require a degree of personal control, although in many instances external motivations or purposes, such as knitting for grandchildren or charity, were also involved. Those who were least occupied were very often those who were dependent upon other people for care. In some instances, they were deprived, by their carers, of things to do.

8.3.4 Pain perceived to be 'under control'

The identification that perceived pain control is an important predictor of coping reflects the importance of pain as a potential stressor in the lives of these elderly subjects. Pain control reflects a judgment which encompasses not only pain levels, but other factors which influence perceptions of pain. The literature review identified pain to be a complex experience, and this analysis has produced a useful structure from which to identify factors, other than the physical presence of pain, which influence perceptions of pain control. These findings are entirely in accordance with the gate control theory of pain.

The model itself has identified the importance of past regrets, current personal problems, current level of active involvement and information as significant influences on perceptions of pain control. Other variables associated with the perception of pain as 'under control' are illustrated in figure 8d. This demonstrates the multifactorial nature of pain control.

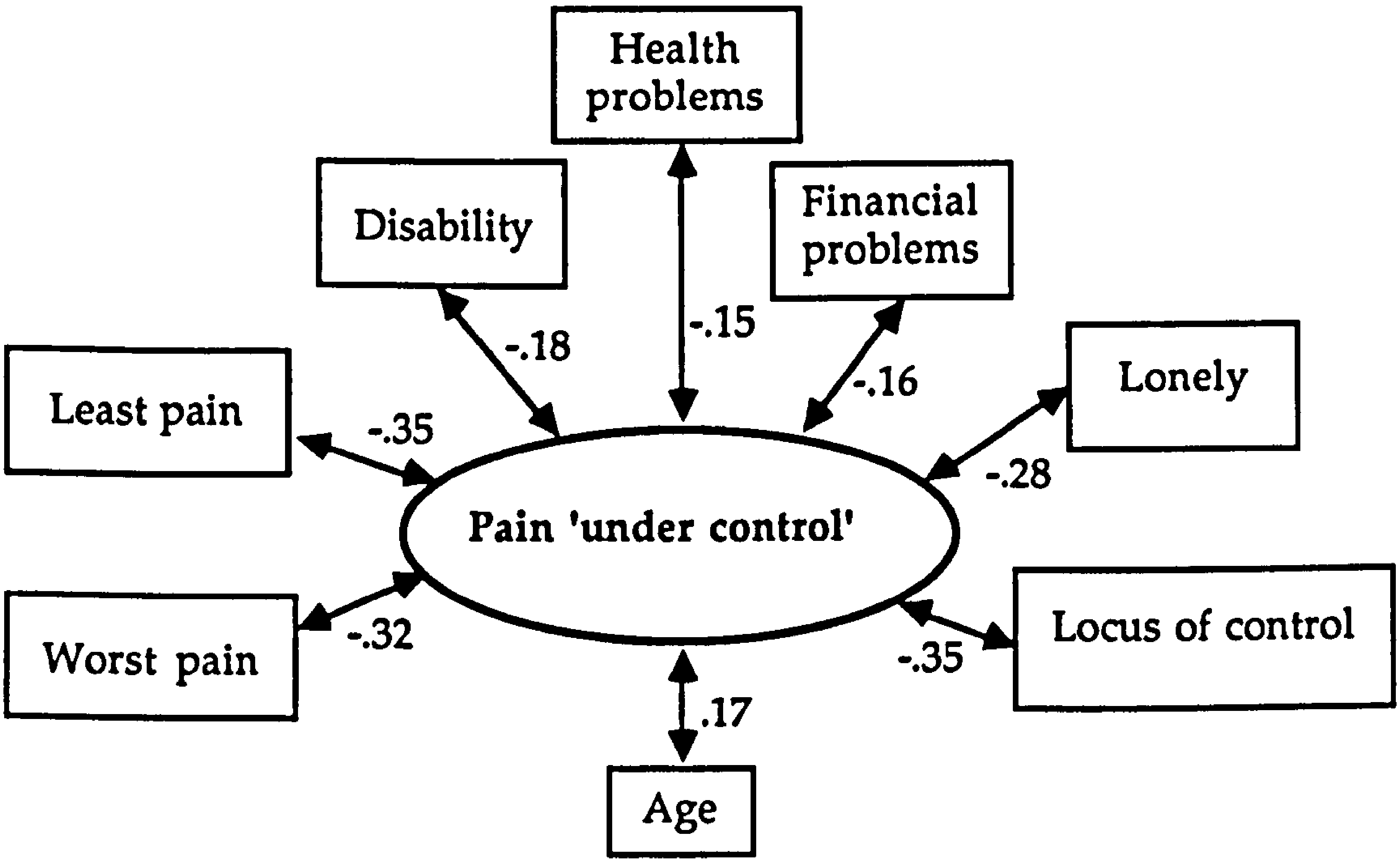


Figure 8d Factors influencing perceived pain control

Ratings of pain when it was least and worst troublesome were, as previously described, and as anticipated, among the most significant factors associated with perceived pain control.

Locus of control was found to exert a significant influence over perceptions of pain control. This is congruent with findings, outlined in chapter 6, which indicated that patients perceive greater control over chronic pain if they employ personal active pain control strategies. The results support the view that patients should be encouraged to become involved in determining, implementing and evaluating their own pain treatments.

Disability was associated with perceptions of pain control, indicating that those who were most disabled were less likely to feel that their pain was under control. Disability is, to some extent, an additional measure of the severity of the painful condition. As the pain increases, so does the disability and vice versa.

Non pain-related health and financial problems were associated with pain control, although personal problems were not. It was actually very difficult to isolate pain-related from non-pain related health problems. Clearly, even without the pain, many subjects would still have had health deficits, yet most of these were inevitably intricately involved with the pain experience. For example diabetes is not directly a painful condition, but it gives rise to a variety of painful disorders. Many of the financial problems described were a direct consequence having to pay others to do things that the subject could no longer undertake because of the painful condition. On the other hand, the loss or illness of a relative or friend was never (or rarely) a cause, nor a consequence of the subject's painful condition.

Loneliness was associated with poor pain control. It is impossible to determine if this is a cause or an effect, and loneliness is considered separately below.

Age was weakly associated with pain control - older subjects, in this study, had a tendency to cope better. The interviews suggested that older subjects showed greater acceptance of both pain and the painful condition, especially if they were satisfied with their past lives. Newly retired people appeared more likely to express greater resentment towards the presence of pain. There was no evidence of any interaction between age and the duration of pain.

In addition to the independent variables considered above, the evaluative and affective scales of the MPQ also showed association with perceived control over pain ($r_s=-.54$, $n=162$, $p>.001$, and $r_s=-.38$, $n=163$, $p<.001$) while the sensory scales showed a less significant association ($r_s=.19$, $n=163$, $p<.01$). This appears to indicate that the evaluative and affective scales may provide useful additional measures of perceived pain control.

8.3.5 Personal problems

The personal problems which appeared to distress subjects most were the recent loss or illness of a spouse, and illness or death of a close relative or friend. These types of loss, particularly the loss of a spouse, are recognised to place extreme demands upon coping resources. They are rated most highly in the Social Readjustment Scale (Holmes and Rahe 1967), and in the Peri Life Events Scale (Dohrenwend et al 1978). Figure 8e shows that personal problems were likely to be associated with financial problems and with loneliness. Both of these appear to be associated with the types of loss described above. Clearly the loss of a spouse imposes maximum change in lifestyle and places the greatest demand of all upon coping resources. The additional presence of a painful and disabling condition is, in these circumstances, very likely to exacerbate coping difficulties.

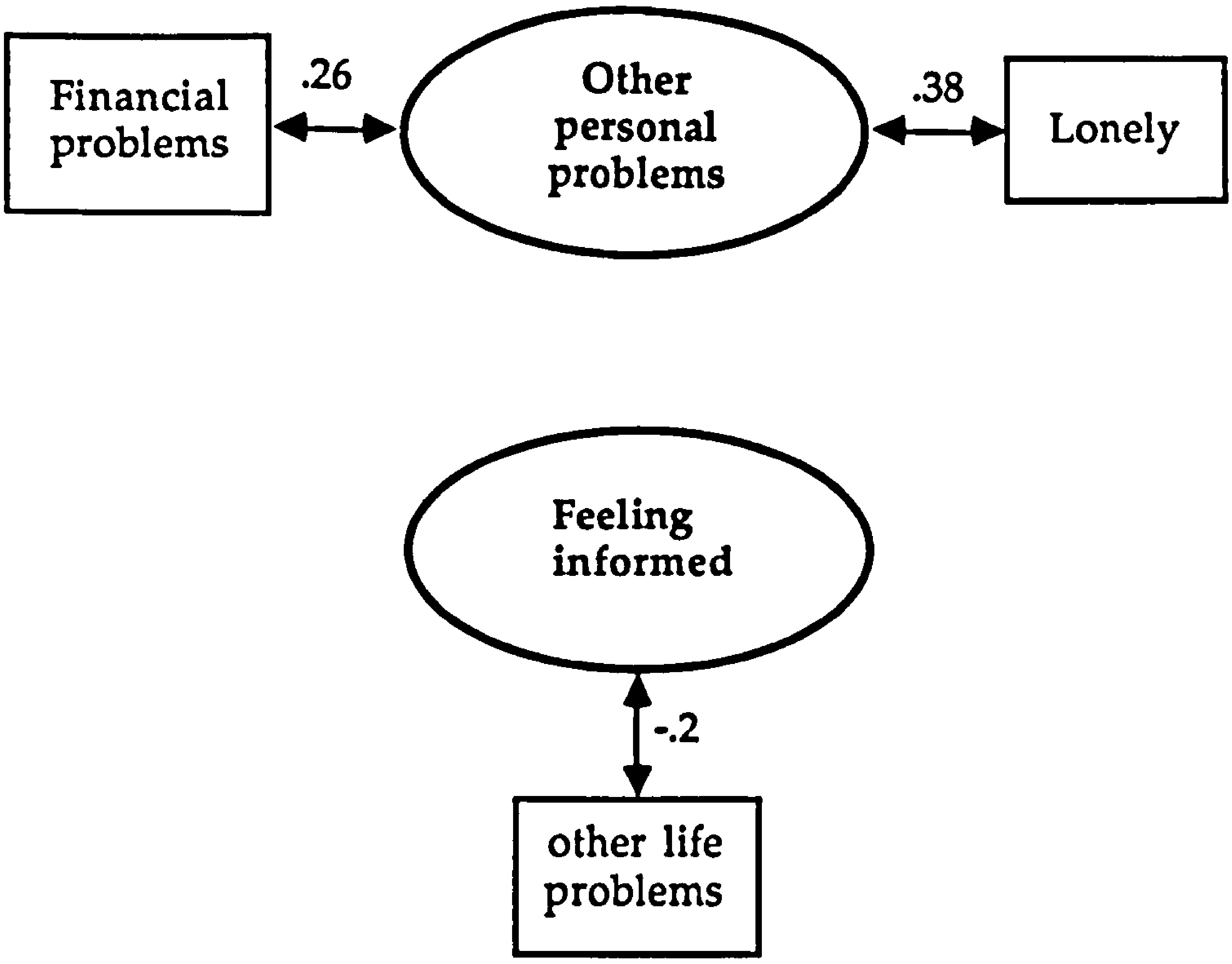


Figure 8e Factors associated with personal problems and feeling informed

8.3.6 Feeling informed about the painful condition

It is interesting that feeling informed should emerge as a significant contributory variable in its own right. It is well established that information can reduce anxiety and enhance control in acute painful procedures (Hayward 1973). The control model outlined in figure 2b (chapter 2) identified information, in its broadest sense, as a prerequisite for the maintenance of control. When painful conditions are being treated by doctors, it is information about the painful condition and pain treatments which enables patients to be able to cope with their situation. The distribution of data from the question about feeling informed was very skewed, with a large majority feeling adequately informed. However those who did not feel informed expressed very strong opinions about this deficit. It was not only doctors who denied information. Several subjects described information-giving deficiencies within the hospital administrative bureaucracy (see chapter 6).

The relationship between feeling informed and the presence of non pain-related problems (figure 8e) may be spurious. Alternatively worry about the painful condition may be heightened by worry about other problems, while other problems may increase self-concern.

8.4 Discussion of variables excluded from the regression model

8.4.1 Levels of 'least' and 'worst' pain

The pain ratings used reflected subjects' perceptions and, as such, were not objective measures of physical pain. Nevertheless the relationship between the rating of 'least' pain, 'worst' pain and the other variables reflects associations which would have been predicted, at a theoretical level, had they been objective measures of pain. The theoretical model predicts that levels of physical pain influence perceptions of pain control which in turn determine mood state. Verbal ratings cannot be 'pure' or objective measures of physical pain. Nevertheless the results of this study give no indication that pain is other than what the patient says it is, and suggest that verbal reports are quite adequate for routine assessment purposes.

During the stages of the regression analysis, most of the variance from the rating of pain when 'least' troublesome, as a contributory determinant of coping, was explained by 'being occupied' and 'having regrets' as well as 'pain under control'. Continuous pain appeared to pervade all aspects of life for these subjects. It is inescapable and therefore makes continuous coping demands. Just as other problems impinge on pain control, so it is likely that the presence of continuous pain makes it more difficult to cope with other problems and difficulties as they arise. Results, given in chapter 6, indicate that a range of personal active pain controlling strategies may help chronic pain sufferers to cope with continuous pain, especially for conditions where medication is largely ineffective.

Most of the variance from pain 'at its worst' was explained by 'pain under control'. Many subjects identified themselves as having severe pain for at least part of the day, and the identification of trigger factors appears to be an appropriate way of avoiding situations which induce episodes of severe pain.

8.4.2 Religious Beliefs

Almost all of the variance from 'religious beliefs' was explained by 'being occupied' and 'having regrets'. This indicates that religious associations make both a practical and a psychological contribution to coping, but that these effects are indirect. Religious activity was of positive benefit through providing occupational opportunities, and spiritual beliefs through their cognitive buffering effect against negative expectancies. There was no evidence of any independent effect of religious belief on coping.

8.4.3 Disability

Most of the variance from the disability score was accounted for in terms of feeling occupied. The validity of this finding is supported by comments from the majority of subjects that the worst aspect of pain and the painful condition was that it stopped them from 'doing things' or from 'doing what they wanted to do'. It is also entirely in harmony with the theoretical model which indicates that control is an active process. Disability reduces resources for activity and active control, while increasing demands upon coping resources in order to ensure survival. It also increases the likelihood of external control through enforced dependency.

8.4.4 Loneliness

Loneliness is the variable which has, during the presentation of these results to nurses, been most consistently selected by them as the major influence upon mood and coping among their elderly patients. However almost all of the variance from 'loneliness' was explained by 'being occupied', 'having regrets' and by the presence of 'personal problems'. It made no independent contribution to the regression model, indeed there was no clear theoretical reason why it should.

Loneliness is very closely associated with problems of bereavement, most notably the loss of a spouse. Bereaved patients lack not only the social company of the lost partner, they have lost the motive, and the motivation, to engage in time-filling activities. They often express bitter regrets that the partner has died unless, or until, overall control is regained and acceptance is attained. Results given in chapter 7 showed that social visitors to the home were more likely to reduce loneliness than outings from the home. This supports the view that bereaved patients who express loneliness require personal support in coming to terms with such a loss and while they restructure their lives to gain control over their new situation, rather than encouragement to go out. Social visitors into the home imply a closer supportive relationship than outside encounters. Nevertheless this study has identified that regrets and occupation are additional important components of the loneliness construct. This suggests that interventions which focus solely upon social support may not always represent the most appropriate approach to solving the problem.

These findings, concerning loneliness, suggest that it is an emotional state which, while not independent of anxiety and depression, appears to represent a social component of coping. As such, it might form an important element of nursing assessment, provided it is recognised that the provision of social contact is not the sole solution to the problem.

8.4.5 Locus of control

Locus of control was associated with several variables selected into the model, but offered no significant explanatory variance in its own right. This finding is entirely in harmony with the theoretical model which predicted that locus of control beliefs shape perceptions and predictions which in turn determine emotional state. For this reason, the fact that some residual unexplained variance existed, albeit at an insignificant level, may in fact indicate the presence of an absent variable. Internal or personal locus of control was consistently associated with better adjustment on all variables, as was predicted theoretically.

8.5 Differential aspects of mood state

Factor analysis of the mood profile failed to differentiate clearly between anxiety, depression and hostility. This lack of distinction between anxiety and depression was in accordance with the theoretical analysis presented in figure 2c (chapter 2), in which it was identified that anxiety and depression are not orthogonal emotional states. Rather they are distinguished in terms of degree of control and duration of the uncontrolled event. Despite the fact that the overwhelming majority of subjects had chronic painful conditions, they were nevertheless coping with other life events which were often acute stressors. Inability to control one event (or condition) may generalise to difficulties in controlling other events. Hence it was theoretically predictable that depression and anxiety would coexist for many subjects.

Hostility is, from a theoretical viewpoint, a distinct aspect of mood. Furthermore, the importance of regrets in determining mood state was identified primarily because those reporting resentment attributed this to bitterness and resentment about past events. If hostility was directed towards the inability to control events, then it was predictable that hostility would increase as loss of control increased and there would be little differentiation between mood state. In order to test this, some further analysis was conducted in order to determine if the different mood factors, identified during factor analysis, were each associated with a discrete set of independent variables. If this were so, it would make appropriate nursing interventions easier to predict, given an assessment of mood state.

Factor scores, obtained from factor analysis of the mood profile, were the *a priori* choice of dependent variable for further regression analyses because of their continuous nature. However in view of the overlap between factors, it was unlikely that these would provide distinctive solutions. This indeed proved to be the case, and the same variables were selected, to a greater or lesser extent, into each analysis. As an alternative, the sum of the scores for the variables which contributed most to each of the factors identified by the three-factor solution in table 6.2 were used as dependent variables in regression analyses. The analyses are not reported here because the dependent variables were not strictly continuous and the results were, as a result, not statistically sound. Nevertheless the variables 'occupied', 'having regrets' and 'perceived pain control' were selected into the solution for each of the three mood states. The chief difference of interest is that hostility was, as predicted in chapter 2, related more closely to external locus of control. This supports the proposition that, while depression and anxiety are both caused by loss, or threatened loss of control, they are likely to be accompanied by hostility when control is perceived as being denied by the actions of external agents. In other words hostility is most likely to be felt, or exhibited, when an individual blames others for his or her lack of control over events, present or past.

These considerations tend to confirm that the determinants of all moods are multifactorial. It also suggests that it is negative affect *per se* which is the most important consideration in establishing effective coping, rather than any particular aspect of mood.

8.6 A model of coping for elderly patients with painful conditions

This chapter has used regression analysis to identify a statistical model of coping, based upon data from elderly subjects who were experiencing pain, and upon the theoretical model outlined in chapter 2. Each aspect of the model has been discussed. It appears to be sound theoretically, and at the level of common sense. It is supported, in many respects, by the subjects' own observations.

A model of coping experience is suggested on the strength of the analyses presented above and is given in figure 8f. This model forms the basis of recommendations for nursing interventions which will be proposed in chapter 11.

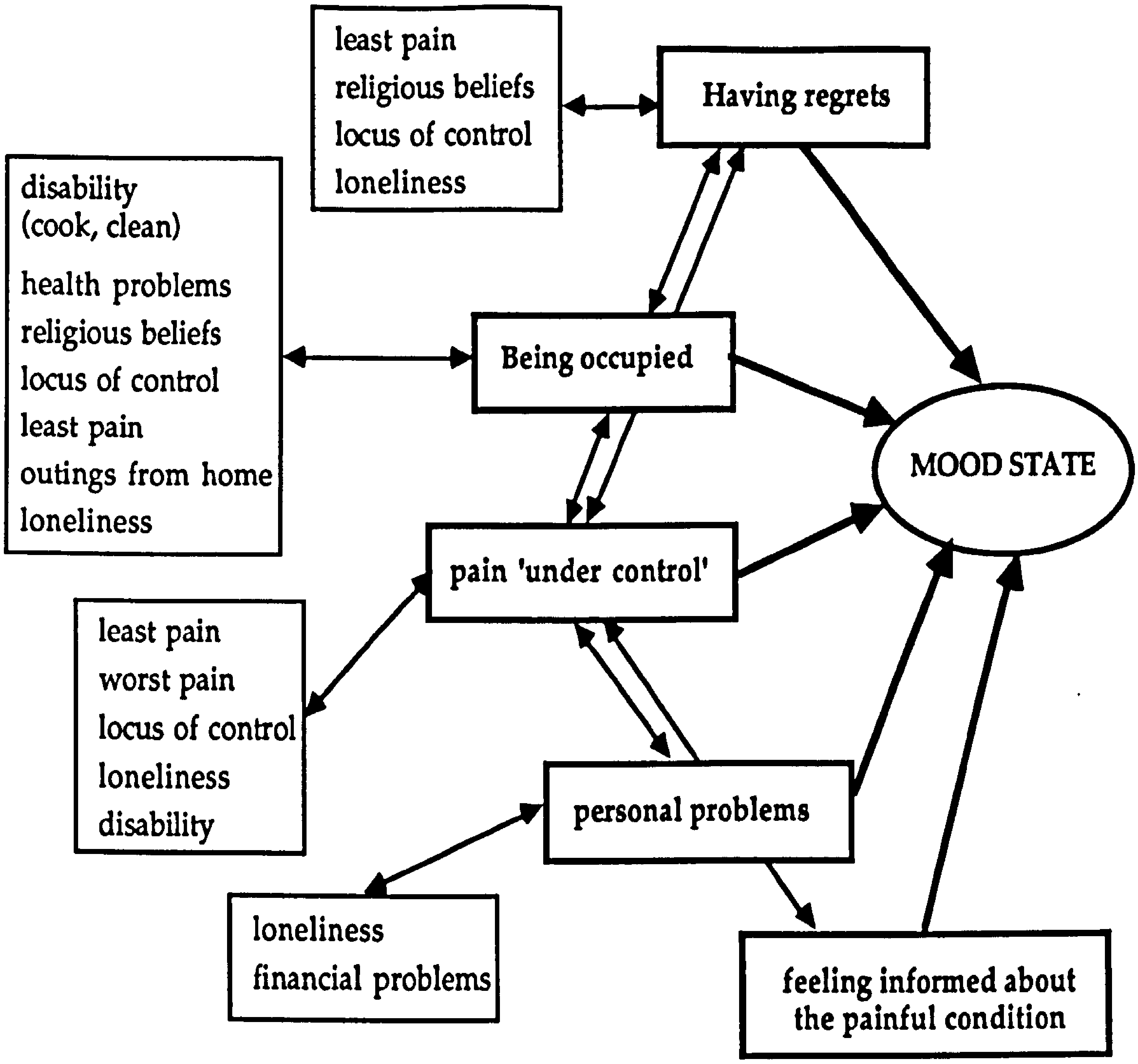


Figure 8f Model of coping for elderly patients with pain in the community

8.7 Summary

This chapter has presented a statistical analysis of the quantitative data produced by this study, and this has been used to construct a model of coping for elderly patients suffering from pain. In it the key variables are identified as having regrets about the past, being occupied, perceiving the pain to be under control, having additional personal problems (most commonly related to bereavement), and feeling informed about the painful condition. Each of these, in turn, influence, and are influenced by, many other important variables which require consideration when formulating suitable interventions. These results have highlighted the multifactorial nature of pain control, the necessity for a broad-based approach to pain assessment and the need for a patient-centred, as opposed to a treatment oriented, approach to pain management.

Before proceeding to elaborate upon recommendations for the nursing management of elderly patients with pain who live in the community, it is first necessary to examine the current relationship between patients and the nurses who offer care. The next chapter examines data from patients about their expectations and experiences of nursing care, and from the nurses about their assessments of patients' needs. This is designed to identify the extent to which management is already congruent with the model identified during this research, and to identify potential training needs.

CHAPTER 9 RESULTS: THE RELATIONSHIP OF SUBJECTS TO NURSES AND CARERS

In this chapter, the comments made by subjects about their nursing care, with respect to pain, are outlined, together with an analysis of the data supplied by the nurses about subjects who were their patients, and about pain management issues in general. Comments given in quotes are those which were recorded verbatim (in writing) at the time of interview or, in the case of the nurses, recorded on the questionnaires. A section is included at the end of this chapter which examines some case examples of relationships between subjects and their carers.

9.1 Question 36a and 36b of the patient interview: *"Do you feel that the district nurse has helped you with your pain?"*

Many patients appeared, quite understandably, to find it difficult to answer question 36a in quantitative terms and, in retrospect, it was probably not a suitable question to have included. This was because, while many subjects appeared to derive support from the nurse, they still had the pain. As subject 48 commented *"it is agony really"*. Therefore they could not honestly answer yes, but did not wish to answer no.

Answers to question 36b, which allowed them to elaborate on their relationship with the nurse, if they wished, were more revealing. Categories of response are outlined in table 9.1. These are based upon comments received from 93 subjects. The remainder were not pressed to comment.

The majority of comments was favourable. Although it is arguable that subjects would not wish to pass adverse comments through fear of lack of confidentiality and reprisal, or simply of causing offence, these questions were posed towards the end of a long and often intimate interview, by which time subjects were generally perceived to be quite free with their comments.

Results, given in table 9.1, highlight the importance of communication and caring, in the eyes of the patients, in addition to practical assistance and skills.

Ways in which the nurse helped (or not) with pain N=93	n of times mentioned
Practical procedures	18
Listens, understands	18
Application of nursing skills (being gentle, careful)	10
Is kind, nice, helpful	10
Is cheerful, chats	10
Informs the doctor	5
Explains, discusses pain	5
Provided, offered aids	3
Gave useful advice	3
Total number with positive comments	80
Too little time spent	10
Complaints re nursing care	8
Total number with negative comments*	18
Nothing, not discussed	6

* some subjects gave positive comments about one nurse, and negative ones about another

Table 9.1 Comments on the help received from nurses with respect to pain

Many subjects emphasised the attitudes and caring qualities of the nurse, as being of help with pain. Comments which illustrate this are plentiful, but those selected below are fairly representative:

> *"Sister listens and tries to understand"* (subject 5)
>
> *"I like to talk to her - it's a relief and comforting"* (subject 41)

> *"You can talk to her and she understands - takes your mind off problems - it helps to share them"* (subject 185)
>
> *"I pray that she (the sister) will come each time - she is so interested"* (subject 114)
>
> *"I regard her (the sister) as a friend"* (subject 161)
>
> *"They always talk to me and are pleasant - they don't make it a burden"* (subject 147)

Only one subject, 46, mentioned the use of formal pain assessment. He said of the sister *"she is wonderful ... uses charting. She is interested"*.

Subjects who commented upon aspects of practical help included those for whom dressings were instrumental in the healing process, and hence in pain relief, for example those with varicose ulcers. Subject 51, aged 92, was delighted because the sister had cured her ulcer. Other comments included:

> *"I like Sister X, she is gentle"* (subject 93)
>
> *"I look forward to them coming for the pain relief after the dressing"* (subject 113)

Subject 53 enjoyed the chats as well as the treatment, and commented jokingly *"I don't want my leg to get better"*. In view of the excruciating pain she was still frequently experiencing, and her comment that *"it makes you weary"*, it is difficult to believe that she really meant this.

Subjects who mentioned practical help included many who depended upon nurses (usually auxiliaries) for bathing. Positive comments included:

> *"She's really nice and considerate. She holds me so I'm not in pain"* (subject 162)
>
> *"The nurse always makes the bed when she washes me"* (subject 153)

Practical skills are so often taken for granted until something goes wrong. This is probably why comments about such skills were sometimes negative. These included:

> *"The nurse pulled my leg once and it hurt - you lose control with the unexpected"* (subject 109)
>
> *"We lost our best bath nurse - she was friendly, but didn't over help. I don't have any confidence in (the present one)"* (subject 122)
>
> *"One nurse swiped off the dressing and made the ulcer bleed"* (subject 139)

These, and other adverse comments, generally related to a single event, or a specific nurse. They illustrate how one incident of lack of care, or skill, linger long in the memory of the patient. When a specific nurse was singled out, it was usually, though not always, the opinion of a single individual.

Adverse comments about attitude, as with those about skill, also usually reflected a single incident. Subject 172 recalled the time a relief nurse had called to attend to her colostomy, which was blocked and caused her excruciating pain:

> *"One nurse upset me noend. She was late coming and was cross because I had phoned the surgery (to find out what had happened to her). She said "I leave this until last because this a dirty job". I sobbed my heart out"*

This subject praised the regular nurses saying *"they are interested in my welfare. They don't just do what they've got to do"*. Nevertheless pain assessment revealed that the twice weekly washouts she received guaranteed that she experienced excruciating pain for one whole day every week.

3 other complaints were influenced by a policy change in bathing practice, affecting one practice in this study. This was effected for the safety of both nurses and patients, but it had deprived some subjects of the opportunity to get into the bath, and caused great discontent. Subject 122 had written to the nurse manager to complain, while subject 125 thought it unkind not to give

her a bath as she had no one else to help her. This reinforces the importance that many elderly subjects place upon their bath. Subject, 87, aged 87, complained that the nurses had not volunteered to give her a bath, although she had arthritis, was incontinent and had a painful vulval thrush infection. Subject 72 commented that the nurse *"just did my foot - did not offer to bath me"*. It should be pointed out that these comments were made prior to changes which now make it the responsibility of many home helps (home care assistants) to assist clients with bathing.

Some subjects regarded the nurse as a source of information. Subject 25, with secondary metastasis, commented *"I pick their brains"*. Subject 11, with a leg ulcer, thought the nurse had helped her by *"explaining it to me so I understand it"*. Some mentioned that the nurse had obtained aids. Subject 118 commented that they had got her a bath board. Others thought the nurse provided a useful link with the GP. Subject 165 said that the nurses reported to the doctor, and she got more attention. Subject 81 said the the nurse *"discusses the pain, and asked the doctor to call"*. Subject 120 said that the nurse (auxiliary) would not liaise with the doctor about her pain, she was told to contact the surgery direct. She commented *"They surely don't come just to bath you"*. However in spite of this last complaint, which appeared to have concerned a single incident, this lady commented:

> *"Since I've had cancer, the doctors and the nurses are much nicer to me and more attentive. In the past, doctors have been rude and unkind. I had a lot of ill-health in the past."* (subject 120)

A general complaint, from 10 subjects (11 per cent of comments received), concerned the limited amount of time devoted to them. Some comments, typical of those received, are given below. None of these subjects was referring to the same nurse.

> *"She's not here five minutes"* (subject 68)
>
> *"(they) only give injections, they don't hang about"* (subject 100)
>
> *"She is in and gone like a shot. She is not the sort of person you could sit and talk to"* (subject 117)

> *"She is in and out like a dose of salts and doesn't take the trouble to find out"* (subject 169)

This last subject said that she did not think that nurses can help people with pain because they are so busy. She said that she would like to talk, and said that she had seen the health visitor to talk to, which was helpful.

Other subjects acknowledged that the nurse must be short of time, and felt even more grateful that time was given in spite of this. Comments made by subject 148, who was recovering from an episode of acute back pain, exemplified this. She identified that visits from one district nursing sister had been especially helpful because:

> *"I always felt that she was not rushed. She gave me the assurance that she had the time, even though she did not really"* (subject 148)

Another general comment concerned not seeing the same nurse. Subject 104, an 83 year old lady with arthritis, commented that she preferred to know who was coming and when they were coming. Subject 85 said that she did not know the present nurses as she sees different ones to dress her leg ulcers (the practice concerned was known to have staffing difficulties). In fact most of those who complained about seeing different nurses were the ones who depended upon them for regular dressings. Some of these had been counting. Subject 173, with a leg ulcer, reported that she had no regular nurse and had seen 7 different ones. Subject 121, who had had leg ulcers for 5 years, during which time she had moved house once, complained that, in all, she had seen 27 different nurses. She commented*"how can they tell if it has progressed?"* Another reason for disquiet at seeing different nurses was because, as subject 37 commented, they tended to have different ideas about what type of dressing to use.

In summary, nurses who were particularly valued as being of help with pain were those who devoted time, or gave the impression of devoting time, to listening, talking, explaining, and advising patients, in a manner which was reassuring, caring and cheerful.

Thoughtfulness, carefulness and consideration were greatly appreciated, while isolated incidents of lack of care were long remembered. Information, aids and liaison with the doctor were all mentioned as ways of helping. Patients who were dependent upon nurses for regular dressings tended to be most concerned about continuity of care.

9.2 Question 38: *"What do you think that nurses can do to help people in pain?"*

The categories of response to this question are summarised in table 9.2. The most popular response to this general question was to identify aspects of caring. Words most commonly mentioned were sympathy, understanding, comfort, security, reassurance and confidence. Comments which characterise this are given below:

How patients think nurses can help with pain	N=180 *
Give understanding, sympathy, comfort, security, reassurance, confidence	59
Nothing, not much, don't know	38
Give advice re drugs, treatments	23
Social, chat, cheer up	18
Practical procedures (dressings, baths)	15
Someone to talk to, listen, re pain and pain problems	15
Other	12
Maintain contact with doctor	5
Give information	4

* 8 subjects gave replies in more than one category

Table 9.2 How subjects think that nurses can help patients who have pain

"Be someone you can rely on - gives you a feeling of security" (subject 10)

"Be understanding - not just write them off as complaining" (subject 11)

"Give them confidence and be truthful" (subject 26)

"Someone to trust and give confidence will help" (subject 36)

"A sympathetic ear - though not soft as people must cope" (subject 96)

"Be sympathetic - some nurses are not" (subject 149)

"Look in on them - it makes a world of difference to know she cares enough" (subject 161, whose district nurse provided social visits)

"You can talk to a nurse, but doctors talk to you" (subject 160, male, aged 81)

"The worst thing is uncaring and unkindness" (subject 174)

Subject 115 commented:

"When there is no medicament they can give you, then a sense of confidence that you can bear it. She (the nurse) can sustain that strength by her attitude"

Subject 114 suggested:

"The comfort that the nurse gives to you in a cheerful manner and the time she gives"

These comments support and supplement comments made to the previous question about help received from individual nurses. They confirm the therapeutic value, to patients, of a caring attitude in nursing pain management.

Of the 38 (21 per cent) who felt that there was nothing much that the nurse could do, most did not comment further. Some had received only short-term care, and had little idea of what nurses could offer. A few were very independent and expressed no need for outside help. Some, for example subject 171, an 81 year-old paraplegic, felt that it was up to the doctor, since doctors prescribe treatments, and nurses cannot find a cure.

Finally, subjects were asked (question 39) if they felt that regular visits by the nurse were important in helping them to cope. Of the 130 subjects who responded, 101 felt that regular visits were helpful, while 30 felt that them to

be of little or no benefit. Those who did not respond were mostly those who were receiving only short term care.

Subject 87 did not receive regular visits from the nurses, who delivered incontinence pads to her, although she thought that it would be better if they did call regularly. Other subjects commented upon the timing of visits. Subject 137 thought that the nurse would be more help *"if you could rely on them to come at the time specified, so they don't worry you"*. Subject 1 said *"I get anxious if they don't arrive on time"*. Subject 114 said that he particularly liked the sister who comes early at a given time.

9.3 Summary of subjects' perceptions of nursing care

It appears, from the qualitative data, that many subjects identified nursing support to be of considerable importance in helping them to cope with their painful condition. The majority of these identified caring and supportive aspects of nursing to be of prime importance. Most of those with chronic pain did not expect the nurse to be able to cure, or even reduce their pain. Rather they valued the interest the nurse took in them, and the confidence she (they were all female) engendered. Few were outright in their criticisms of nurses, and adverse comments usually concerned an isolated incident of nursing contact. However this serves to illustrate just how strong is the patient's memory for a thoughtless word or deed. Time was identified as a problem by several patients. Visits which were seen to be rushed were not therapeutic in supportive terms. Those patients who relied upon the nurse for dressings were among those who most appreciated continuity of nursing care. Comments about timing of visits were confined to the few who reported that the uncertainty made them anxious.

Subjects appeared, on the whole, to be realistic in their perceptions of their nursing needs. Although some valued the nursing visit purely for its social element, many valued the support offered in more concrete terms, notably to provide encouragement and confidence. Those who received purely social visits from their nurse generally appreciated their therapeutic value. Practical skills were valued where practical procedures were required, however the majority of subjects emphasised the importance of the interpersonal skills of all grades of nurse, in relation to their pain management.

9.4 Nurses' perceptions of patients' pain experiences

37 nurses and auxiliaries completed a total of 205 data sheets concerning 132, out of the total of 170 subjects. Subjects from the pilot study are excluded from these results because of amendments to the nurse's questionnaire. 8 subjects died before the nurse's questionnaire could be completed, 6 had been admitted to hospital or nursing home, 7 questionnaires were miscoded. In 73 instances, 2 nurses completed questionnaires about the same patient and, because of this, the numbers of nurses' reports exceeds the number of subjects interviewed throughout these results. The overall response rate was 78%. All questionnaires were completed within between two and six weeks of interview.

The mean length of acquaintance between nurse and subject was 2.26 years (s.d. 2.143, range 1 month to 10 years). In fact, 4 subjects had been known to a nurse for at least 10 years. Nurses who responded completed between 1 and 13 patient questionnaires each (mean = 5.5).

Frequencies for nurses' data are given in Appendix X. In this section 'nurses' are taken, for the sake of simplicity, to include all grades of nurse and nursing auxiliary, unless otherwise stated.

These data were used to answer the following research questions:

1. How close is the association between information about pain, mood and pain factors, obtained from subjects at interview, and similar data obtained from the nurses who visit them?

2. To what do nurses attribute subjects' level of pain control?

3. What are the relationships, if any, between nurses' perceptions of subjects' pain experiences and patients' coping status, as determined at interview?

4. Is there any evidence for effects of nursing grade, length of service, or length or acquaintance with the patient, on nursing assessments of aspects of patients' pain experience?

9.4.1 Pain measurement by nurses and auxiliaries

The association between nurses' assessment of subjects' pain, and that reported by subjects at interview, for levels of 'least' and 'worst' pain was r_s=.27 (n=196, p<.001) and r_s=.31 (n=196, p<.001) respectively. The sign test was used to establish whether or not these results concealed any consistent under- or overestimation of subjects' pain levels. For the levels of least pain this revealed 76 ties, 46 underestimates and 74 overestimates (z=2.5, p.01). For the levels of worst pain, the sign test revealed 47 ties, 19 overestimates, and 130 underestimates (z=9.0, p<.001).

It has already been pointed out that some measurements of worst pain did not refer to regular occurrences. Therefore another analysis was conducted including only those who reported occurrences of worst pain of at least once a week. The correlation between subjects' own reports and nurses' reports improved only slightly (r_s=.36, n=117, p<.001), and the under-reporting by nurses was only marginally reduced (z=5.7, p<.001).

While the level of correlation between patients' reports of pain and nurses' assessments of patients' pain is, as expected, highly significant, the correlation statistics are modest in terms of the variance explained (the r^2 values). Furthermore, the relationship concealed discrepancies in absolute terms, since nurses tended to overestimate levels of least pain and underestimate levels of worst pain.

It was thought possible that some subjects' conditions or circumstances might have changed between interview and the nurses' assessments, or that the nurse might have placed undue reliance upon memory if she had not had recent contact with the subject. Unfortunately, the questions regarding recency of contact and changes in the subject's condition were omitted from the initial batches of questionnaires. However reanalysis was performed for 59 subjects known to have been seen within the previous month, and whose condition was recently unchanged. Using these data, the correlation between nurses' assessments and subjects' reports of least and worst pain improved substantially (r_s=.53 and .44 respectively), although, the sign test showed that nurses still consistently overestimated the level of least pain (z=3.1, n=59, p<.005) and underestimated the level of worst pain (z=4.9, n=59, p<.001).

It was hypothesised that nurses who had known the subject for longer would provide assessments of subjects' pain levels which were more closely associated with subjects' own reports. Sign tests confirmed that the tendency to overestimate the level of least pain disappeared when analysis included only nurses who had known subjects for at least a year (z=1.9, n=123, ns), however the tendency to underestimate levels of worst pain remained (z=6.7, n=123,p<.001).

The level of association between nurses' assessments of patients' levels of least and worst pain, for nurses reporting on same patient was r_s = .39 and .46 respectively (n=68, p<.001).

Difference scores between the patient's own pain ratings, at interview, and ratings provided by the nurses, were used to test the prediction that registered nurses, with district nurse training, might be better at judging pain levels than untrained staff. The Mann-Whitney test revealed no differences whatsoever between district nurses' and auxiliaries' assessments, for levels of least pain (mean ranks: 68.66, n=93 (DNs); 66.55, n=42 (auxiliaries), U=1892, ns) or for levels of worst pain (mean ranks: 67.44, n=93 (DNs); 69.25, n=42 (auxiliaries), U=1900, ns). There were insufficient data from district trained and untrained ENs to include in similar analyses.

In only 18 instances, out of 146 valid responses, did the nurse report having used a formal pain assessment protocol. This was an inadequate number to use as the basis for any type of comparison. Only one district nurse stated she regularly used formal pain assessment, while two others used it occasionally.

There were 15 instances, in the main study, where a nurse judged a patient to have no pain at all. Nine of these assessments were made by 6 district nurses, one by an auxiliary and, of the remainder, four of these assessments were made by the same EN. One district nurse judged three patients to be suffering no pain, in spite of reporting that they had arthritis. Her enrolled nurse colleague, in keeping with the interview findings, judged the minimum pain levels of these subjects to be just noticeable or moderate, and the worst pain levels to be moderate or severe. The district nurse might have had less regular recent contact with each of these subjects (this information was not provided), however she had known each subject for at least two years, which was longer than the EN.

One particular patient, who was judged to have no pain by an enrolled nurse, was subject 76. He was aged 78 and was married to a much younger Spanish lady who spoke limited English and had few social contacts. He was interviewed in bed, and appeared to be very frail and seriously ill. He reported having had extensive surgery for stomach cancer 20 years ago, and had recently been an in-patient at the local chest hospital where he was treated for a *"collapsed left lung"*. He felt too weak to leave the bed for more than a short period. He described having pain *"everywhere"* which, he said, the doctor attributed to arthritis. He said he always had some pain, usually moderate, sometimes very severe, for which he took paracetamol with little effect. He was very depressed and said that he had *"no future"*.

He was very critical of local medical services because of previous experiences of misinformation from doctors, and insensitive nursing, in local hospitals. He and his wife found little support from the district nurse who called to deliver incontinence pads (he had uncontrollable diarrhoea at times). However they described the enrolled nurse as lovely because *"she sits and talks"*. The two district nurses in this practice, one of whom was part time, declined to supply information, because of pressure of work. However they passed questionnaires on to the enrolled nurse. This enrolled nurse was universally liked by subjects interviewed, and conscientiously supplied rich data in spite of a very heavy workload caused by the temporary absence of an auxiliary. She described this subject as having 'respiratory disease' and recognised that he was very anxious, resentful and frightened, yet she stated *"Not all of his problems are psychosomatic, but most of them are"*. This particular patient appeared to epitomise, what Stockwell (1984) termed, the 'unpopular patient'. He was undoubtedly difficult, critical, and even hostile, yet his nursing needs, not to mention those of his wife, seemed almost overwhelming. His pain was totally uncontrolled, and his wife was in great distress.

The case study, outlined above, was an extreme example, yet it was not entirely isolated, and it illustrates problems which can occur when nursing 'care', as opposed to treatment, breaks down for whatever reason.

9.4.2 Summary of nurses' assessments of patients' pain levels

Overall, the nursing assessments of pain levels seemed fairly congruent with subjects' reports at interview, when judged statistically, although modest in absolute terms. However nurses tended to judge the pain as less extreme, especially where contact had not been recent. In particular, levels of worst pain were consistently underestimated. It is possible that some subjects tended to over-report these levels of pain in discussion with an interested third party during interview. Certainly some subjects tended to recall vividly, past isolated or specific painful incidents. However patients' and nurses' reports differed even when these were eliminated from the calculation. Some subjects stated that they did not discuss their pain with the nurses, either because visits were too rushed, because other topics were the focus of discussion, or because they did not like to complain. If the pain was not discussed, let alone assessed, it is hardly surprising that discrepancies should have arisen in nursing reports of patients' pain.

There were a few erroneous reports about subjects' pain which are sufficient to give rise to some concern about individual differences in the adequacy of pain assessment and nursing management. The finding that nurses' assessments improved with recency of contact suggests that these nurses' assessments were based primarily upon memory, rather than upon recorded observations. This is particularly likely in view of the fact that formal assessment was rarely used. The recency effect might even suggest that some nurses had updated their knowledge in the light of this study. There was no evidence to suggest that training had any impact at all upon the sensitivity of the nurse to their patients' pain.

9.4.3 Nurses' assessments of pain control

There was a fairly good overall correlation between the nurses' perceptions of the extent to which subjects' pain was under control, and the subjects' own perceptions (r_s=.5,n=137,p<.001). This level of correlation was not improved by limiting the analysis to those visited in the previous month. The sign test again revealed a significant tendency to overestimate the extent to which pain was controlled, compared with the subjects' perceptions (z=2.5, n=94, p.01), however this tendency was completely eliminated when only the 55 subjects known to have been seen in the previous week were included in the analysis.

The nurses were asked to identify which factors, from the list provided, contributed to control, or lack of it, over pain. Results are summarised in table 9.3. Overall, these attributions suggest that the greatest emphasis is placed upon medical treatments and the patient's attitude, whether it be in positive or negative terms.

Less emphasis appears to be placed upon supportive factors. However these categories were predetermined by the researcher and might not accurately reflect the true feelings of the nurses. Nurses were invited to give additional reasons, but few were put forward to account for pain control. One district nurse commented that the pain seemed much less when the patient had other distractions.

Pain control substantially due to:	Reponses*	Lack of pain control substantially due to:	Reponses*
subject's attitude	66	subject's attitude	20
medical treatments	79	failure of medical treatments	25
nursing care	37	lack of social support	8
family support	42	overdependence	20
little pain felt	28	presence of other problems	21
		worry about the condition	27

* responses were allowed in more than one category

Table 9.3 Nurses' attributions of chief sources of subjects' pain control (or lack of it)

In 30 instances, out of 148 completed responses (20 per cent), the nurse reported feeling substantially able to help the subject, directly or indirectly, with the pain. In 61 instances (41 per cent) the nurses felt they had helped a little, while 57 reports (39 per cent) indicated that the nurse felt no help at all. In only 32 responses, out of 149, did the nurse think it likely that the patient's pain would improve. This highlights the chronic, intractable nature of the majority of the pain in this sample.

Nurses were asked if they felt that subjects exaggerated or understated their level of pain. More responses indicated that subjects understated their pain (65) than exaggerated it to any degree (23), while 49 responses indicated that pain reports accurately reflected the level of pain. Nurses were also asked if patients complained. The level of complaint was found to be strongly related to the degree of pain exaggeration perceived (r_s=.54,n=134,p<.001).

The assessment of complaints, and of pain exaggeration, were associated with the coping status of subjects, as measured by their total mood score at interview (r_s=-.21,n=86 and r_s=-.22,n=133, p<.005 respectively). This negative correlation suggests that subjects with coping difficulties, as measured by negative mood, were more likely to complain and thereby be perceived as exaggerating their pain. Indeed no association was found between perceived exaggeration of pain by the nurse, and subject's mood score, given the level of complaint, using a partial correlation procedure (r=-.04, ns). In actual fact the relationship between complaints and mood score was clearly not entirely linear, since the few who were most severely depressed did not complain. The results suggest that those who do not complain will include those who are very depressed and are therefore not coping at all, however those who complain are likely to be those with coping difficulties.

It is interesting to note that the extent to which subjects were reported as complaining, by their nurses, showed a negative association with the extent to which they felt occupied (r_s=-.2,n=195,p<.005) and a positive association with their reports of having regrets (r_s=.18,n=121,p<.05)

9.4.4 Nurses' assessments of patients' mood and pain coping factors

Correlations between nurses' assessments of mood and other factors are given in table 9.4.

Sign tests showed that nurses' assessments of subjects' anxiety were significantly higher than subjects' own reports (z=5.5, n=113, p<.001). This difference held for those seen only recently (z=3.8, n=51, p<.001), although the correlation between patients' reports and nurses' assessments of patients' anxiety remained substantially unchanged (r_s=.25).

The sign test showed that nurses' assessments of depression were not significantly different from the patients' own reports.

Association between nurses' reports and subjects' reports			
	r_s	n	p
Anxious	.22	179	.001
Depressed	.26	188	<.001
Resentful	.32	185	<.001
Frightened	.18	183	<.01
Occupied	.32	192	<.001
Lonely	.33	192	<.001

Table 9.4 Association between nurses' assessment of mood and occupation with patients' reports

Significant correlations were found, overall, between patients' reports and nurses' assessments of additional health, personal and financial problems (r_s=.26, n=178, r_s=.22, n=190, r_s=.22, n=183, respectively, $p \leq .001$). However it is noticeable that the numbers of responses regarding each issue was variable throughout. This may indicate that nurses, as requested, omitted to answer those questions about which they were uncertain. The majority of omissions were made by auxiliaries, two of whom commented that they did not feel that it was their role to make such assessments.

Substantial effects of pain on subjects, based upon responses from 148 nurses, were reported in the spheres of independence (74), social life (72), hobbies (59), sleep (41), mood (40), relationships with others (32) and appetite (16).

9.4.5 Nurses' views on the effects of pain

When asked to identify the main effects of pain for individual patients, a total of 108 responses were received from 25 nurses concerning 93 patients. These are summarised in table 9.5. Not all nurses chose to complete this question, including most auxiliaries.

Main effects of pain upon elderly individuals (N=93), identified by their nurses (N=25) *	n
Physical and mobility problems	43
Inability to go out	10
Having to give up desired activities	10
Loss of social contact / isolation / loneliness	25
Emotional effects of which:	40
Depression	18
Anxiety / worry / fear	6
Frustration	5
Irritability / impatience	3
Bitterness	2
Aggression	1
Over-dependence	7
Complains a lot	3
Copes well / little or no effect / acceptance	9
Other (embarrassment (2) debility (1) sleep disturbance (2) blames others (1) lack of motivation (1) withdrawal (2) poor concentration (1) self-pity (1) loss of confidence (1) inability to cope (2) loss of independence (2))	16

* Responses from individual nurses were recorded in more than one category

Table 9.5 Nurses' assessments of the effects of pain upon individual patients

Many nurses gave stock responses, such as 'physical' or 'social', which could have had a number of possible implications, although most had already elaborated upon the precise nature of the patient's problems. These results show that nurses place more emphasis upon the emotional effects of pain, and on loneliness than did the patients themselves, most of whom emphasised the physical and practical effects.

9.4.6 Nurses' perceptions of helping subjects with their pain

Nurses were asked how they felt that they had been able to help each patient with his or her pain. Results are given in table 9.6, which is based upon the responses of 25 nurses and concerned a total of 93 subjects.

Nurses overwhelmingly identified 'support' as their chief role in helping patients. These perceptions of help are congruent with the perceptions of subjects about the help that nurses can give, in that priority is given to the quality of the interpersonal relationship, rather than to practical actions. Nurses very commonly used the word 'support', rather loosely, to describe aspects of care which were predominantly social or psychological, rather than practical. Assessment was accorded low priority by nurses.

9.4.7 Summary of nurses' assessments of subjects' pain control and coping

Nurses' assessments of their patients' pain control and mood state were, on the whole, fairly congruent with patients' reports at interview, provided contact had been recent. Even so, levels of worst pain were consistently underestimated. Assessments of pain control were more accurate than nurses' assessments of actual pain levels, particularly where contact was recent. However nurses tended to use patients' level of complaint as a indicator of pain exaggeration, while subjects who complained were, in general, those with the greatest coping difficulties. Nurses tended to overestimate patients' anxiety, although nurses' assessments of feelings of hostility and depression were more accurate. Nurses' assessments of additional problems faced by their patients were, for those who completed answers, similar to those identified at interview. The results suggest, overall, that nurses in the community tend to place greater emphasis, than do the patients themselves, upon the emotional effects of pain. Nurses commonly identified 'support' as the type of help provided to subjects in pain, although they generally did not identify what this entailed. Assessment, either of pain or medication, was little mentioned at an individual level.

Types of help given by nurses to individual subjects with respect to pain	n *
Communication	
listening	14
talking / discussion	11
counselling	4
encourage communication	1
answer questions	1
Support	
support	28
reassurance	4
boost confidence / morale	4
visit regularly	3
try to understand	3
take an interest	1
provide social contact	1
Advice	
Give advice	15
Advise re medication	11
Education re specific topics	2
Encourage compliance with medication	2
Assessment / Evaluation	
General assessment	3
Assess medication	2
Assess need for aids	3
Nursing care / Treatments	
Wound care / dressings	19
Self-care / personal hygiene	5
Specific treatments	3
General nursing care	1
Massage / embrocation	1
Encourage exercise / movement	8
Referral to / liaison with GP	9
Referral to / liaison with pain clinic	1

* Individual responsesoften included more than one category

Table 9.6 Help with pain, given by nurses to individual subjects

9.5 Nurses' education and attitudes to pain management

9.5.1 Sources of information

26 nurses and auxiliaries, completed questionnaires giving general background information (see Appendix IV). This represents a response rate of 55 per cent overall, and 70 per cent for those who returned patient questionnaires. 13 were district nurses, 3 were district enrolled nurses, 5 were enrolled nurses and 5 were auxiliaries. They had between 8 months and 20 years' experience of working in the community (mean = 7.8 years, s.d. 5.4 years). In addition, they had up to 17 years of previous hospital or alternative nursing experience (mean = 5.7 years, s.d. = 4.7 years), although some auxiliaries had no experience other than in the community. 5 nurses had attended an ENB course on care of the elderly, and 2 had attended an ENB course on care of the dying patient. 3 others had attended seminars or study days on pain control in terminal illness.

Of the 21 trained nurses who responded, 19 claimed to have gained information about pain management from experience, 12 from colleagues, and only nine from formal instruction. 9 had gained information from journal articles. Most respondents identified more than one source of information. Only 2 nurses claimed to have received tuition in pain assessment during their general training. Furthermore only 2 out of 17 nurses had received tuition in pain assessment during their district training, although another 12 stated that it had been discussed. 7 had gained knowledge of pain assessment from other courses, including the above-mentioned ENB courses. 9 trained nurses (43 per cent) claimed to have received no tuition in the management of acute pain, 11 (52 per cent) no tuition in chronic pain, although 16 (76 per cent) had received tuition in the care of the patient with cancer pain. 10 (48 per cent) had not learned about pain theories, 12 (57 per cent) had not learned about pain assessment, and 9 identified that they had not received tuition about psychological factors in pain.

In spite of this apparent lack of formal tuition, 16 (76 per cent) of the trained nurses thought that their knowledge of the use of drugs in pain control was fairly good, and another 2 very good. 11 nurses (52 per cent) thought that their knowledge of pain assessment was fairly good, while 2 thought it very good. Interestingly, the two auxiliaries who completed this section also rated their knowledge of pain assessment as very good or fairly good. One trained nurse thought that her knowledge of psychological factors in pain was poor, while 10 (48 per cent) thought that it was not too good. On the other hand 14 (67 per cent) thought that their knowledge of the use of psychological methods of pain control was fairly good, and 7 (33 per cent) very good. 8 trained nurses (38 per cent) thought that their knowledge of the psychological effects of pain was not too good. These included three of the enrolled nurses who had not received district training.

Only 2 nurses were not sure if objective pain assessment would be useful. 10 thought it would be useful, and 9 thought it possibly of use. Only one nurse (a district nurse) thought that sufficient attention was paid, during nurse training, or preparation, to the problems of people with chronic or persistent pain. The remaining 19 (95 per cent) thought not (one did not respond). One enrolled nurse (53) stated *"more attention could be paid to the psychological effect of pain on patients as a whole, not individual medical problems"*.

9.5.2 Attitudes of nurses towards pain patients

In section 9.4.6, it was identified that nurses tended to select 'support' as being of most help to individual patients with pain. However patients who complain a lot, and are thus perceived to exaggerate their pain, may not appear so amenable to support as those who are stoical. Therefore it was considered that a general question inviting observations on reasons for pain exaggeration might reveal underlying attitudes of nurses in the community towards the most difficult of pain patients.

Of the 25 nurses and auxiliaries who responded, only 1 thought that no patients exaggerate their pain, while 10 thought that few do.

14 felt that there are some patients who exaggerate pain, though none thought that many do. The most common spontaneous reason given for exaggeration was to gain or maintain attention. This was mentioned 15 times. Loneliness was mentioned 10 times. Other reasons given included fear and anxiety (5), depression (4), low pain threshold (4), lack of diversion or distraction (2), bereavement, self-obsession, lack of fulfilment, and being worn down by pain (each mentioned once). One enrolled nurse (53) considered reasons for exaggeration were *"unwilling to take advice, lack of confidence in medical staff, stubbornness".* Categorisation of the reasons given for exaggeration appears to conceal qualitative differences in response. For example there appears to be a subtle difference between the responses of nurses 12, 13, 62 and 103, who suggested *"attention-seeking"*, and that of nurse 94 who suggested *"needs attention"*. Nurse 91 stated *"Lonely or unhappy patient wanting a little more time and sympathy.* Nurse 42 suggested that exaggeration was *"effective to keep the nurse visiting i.e. if pain is relieved will the nurse continue to visit?"* Her colleague, nurse 41, stated *"ensures 'ongoing' attention"*. The implications of these comments are considered in more depth below.

9.5.3 General help with pain

The nurses were asked, in the general questionnaire, to identify how they thought that nurses were able to help patients with chronic pain. Answers were similar to those given in the individual questionnaires, and are given in figure 9.7. These are based upon responses from 21 nurses.

Table 9.7 confirms that support is the most popular approach to helping patients with chronic pain, although few trained nurses were explicit about what they meant by this. One auxiliary observed *"help them to feel that someone cares"*. Another auxiliary commented *"being able to listen and understand the person themselves as an individual"*. One enrolled nurse suggested *"give a little time and a willing ear"*, while another said*"talk through hopes and fears with the family"*. District nurse 11 suggested teaching patients to identify methods of controlling their own pain, and advocated the use of relaxation and distraction. However she felt that lack of time was a problem and commented:

> *"Very difficult. We don't have time to spend hours with patients - they need to be taught or motivated, if possible, to control their pain as best as possible. ... It is easier to be empathetic with someone in terminal pain than listening day after day for years to someone's complaint of, for example severe and disabling arthritis pain, as the nurse gets stressed, unable to offer curing solutions"*

Other nurses also injected hints of pessimism. An enrolled nurse said that she felt *"quite helpless unless the GP can assist"*.

Helping activities identified	n*
Support	10
Refer to / liaise with GP	8
Listen	6
Explain / advise	5
Pain assessment	4
Encourage social activities	4
Obtain aids / equipment	4
Encourage self-control methods	3
Provide general nursing care (to enhance patient comfort)	3
Refer to pain clinic	3
Encourage exercise	2
Psychological distraction	1
Treat depression	1
Refer for physiotherapy	1

* Responses may include more than one category

Table 9.7 Ways nurses identified of helping patients with chronic pain

Nurses recognised the value of supportive types of intervention in pain management, particularly at an individual level. However they were generally much less specific than subjects in identifying particular aspects of supportive care. At a more general level, they were inclined to place greater emphasis upon liaison with the general practitioner even though, in reality, he was often unable to help. General comments from nurses were few, however they appear to indicate a lack of current focus in pain management and a desire to be able to do more at the level of assessment and intervention. These results suggest that, while nurses in the community appear, on the whole, to demonstrate a fairly broad understanding their patients' pain and problems, there is, nevertheless, much room for improvement in the nursing management of pain from the perspective of both patients and nurses.

9.5.4 Summary of general nursing issues in pain management

The numbers of nurses who completed the general questionnaire was small, and no claim is made that these responses are representative of community nurses as a whole. Nevertheless it is interesting to note that educational sources of information about pain management appeared, on the whole, to be confined to specialised courses which related specifically to the care of the terminally ill or elderly patient. Personal experience was the major source of information for the majority, while information from colleagues was another important source. The paucity of formal education in pain management, identified in this small sample of nurses, is particularly worrying in view of the confidence that these nurses appear to have in their abilities to assess pain. In addition, some nurses' rated their knowledge of psychological methods of pain control, and the psychological effects of pain, as good, in spite of having little general knowledge of psychological factors in pain, or of pain theories. The attitudes of nurses towards patients who appear to exaggerate their pain is of concern in view of the tendency to identify exaggeration with attention-seeking behaviour. The overwhelming negative view of the attention paid to chronic pain, during nurse training, appears to highlight a very real perceived deficit.

Nurses recognised the psychological or emotional needs of their elderly pain patients, since they identified supportive types of intervention most frequently, to be of importance. Yet the term support was not clearly defined, and nurses were generally less specific about supportive aspects of care, than were their patients. At a general level they were inclined to place greater emphasis upon liaison with the general practitioner even though, in reality, he was often unable to help. Pain assessment was mentioned at a general level, even though it was rarely mentioned at an individual level, and few nurses used any kind of formal assessment. Assessment of medication was rarely mentioned, and this was identified, from the patient data, to be deficient. The general results suggest the lack of a clear focus in pain management among this client group.

Little mention was made of the role of the carer in any of the nurses' responses, although nurses in the community are ideally placed to assess, and provide support and advice for carers. This may have been because none of the questions specifically invited the nurse to consider this aspect. This is a deficit which cannot go without remark. The importance, to nursing care, of the relationship between subjects and carers is considered below. It is based upon observations made, by the researcher, during patient interviews.

9.6 The relationship between subjects and their carers

It was not possible, during this research, to include interviews with carers as part of the research design. This is because the patient interviews were, on the whole, very lengthy, and an additional component would have entailed a return visit. Furthermore any attempt to integrate interviews with patients and carers would have detracted from the full individual account of pain experience obtained from the patients. This prediction was supported by the irritation that many subjects demonstrated when their spouse attempted to interrupt during interview. Subject 50, aged 83, was totally disabled by a combination of long standing arthritis and a recent severe stroke. She became very cross with her husband when he attempted to intervene over one of her answers. She told him very firmly that she was *"not stupid"* in spite of her present condition.

The impression was gained that attention given to carers would have lessened the patient's confidence in the interviewer.

Although carers were not interviewed, the patient interviews gave many opportunities to observe patient / carer relationships at a subjective level. Because of the importance of these relationships in the coping process, as was illustrated by the high prevalence of depression among patients who were being cared for, it is felt pertinent to record some of these observations. Some brief case observations are provided below, together with a theoretical interpretation, based upon control theory. They are intended to highlight important issues, and to provide impetus for further research.

The majority of caring relationships appeared to be harmonious. The majority were husband - wife relationships of long standing. A typical example of many was subject 135, aged 81, and her husband of the same age. She had severe arthritis of the back, hips and knees; he had had a heart attack a few years ago. Neither could go out of the house. They did what little they could in the house together, and had a daily home help. He sat quietly while she was interviewed, going out to make the tea towards the end. When the interview was completed, she invited him to recount his out of body experience at the time of his heart attack. They had had an interesting and full life together, which, she said, they now sit back and think about. This was so typical of many elderly married people who had grown old together, and evidenced a relationship of mutual help and respect. In theoretical terms this represented a relationship of reciprocal control. This lady's mood score was +10, reflecting sorrow at the recent death of their daughter, aged 52, following a stroke, and their son's recent major accident.

Reciprocal control was also evident in the case of many mother-daughter caring relationships. Subject 51, aged 92, lived with her daughter and family in apparent harmony. She had a leg ulcer which was now almost healed and caused only mild continuous pain. Her mood score was +31 - she worried about the future of her grandchildren.

She had limited mobility and did little in the house, but she was able to deal with her own self-care needs, and she was clearly afforded a position of respect within the family. She had been widowed young, but had set up her own successful business which both she and her daughter shared pride in talking about.

Situations where carers have assumed complete control have already been outlined in 6.2.2 and 7.3.1, and will not be repeated. Evidence of this control was provided, in the most extreme cases, by the tendency of the carer to talk over the head of the subject about the subject's deficiencies, thus reinforcing the subjects' feelings of helplessness. The patient, in this situation, was in a position of complete dependency, enforced either deliberately or unwittingly by the carer. This meant that the subject was totally deprived of any controlling activities or occupations and was, as a consequence, very depressed. Subject 108, section 6.2.2, was not allowed any active role by her husband, who had assumed complete control over her. He resisted any suggestions to increase his wife's participation in household activities. Subject 130 (section 7.2.3) illustrated loss of control caused by lack of time and attention to the provision of suitable aids. The carer, in this case the niece, identified the problem herself and described steps which could be taken to rectify it. The former case may be somewhat resistant to intervention, while the latter is highly amenable to change.

Dependency is not always enforced by the carer, but is assumed by the patient. Subject 158, aged 82, was an unmarried lady who had shared her life with the friend with whom she had lived for many years, and who now cared for her. She had osteoarthritis of both knees, causing very severe pain upon movement, and had lost the use of her left arm following a stroke three years ago. The main problem was that she was grossly obese, and could hardly move. She did nothing except read, watch television and said that she was all right if there was someone to talk to. In fact she was totally dependent upon the friend whom, she stated many times, would not leave her or let her down. The friend, who appeared always to have been the more independent of the two, expressed some desperation, once out of earshot. They had enjoyed a long and happy life together and she felt some obligation to care. Yet she resented the fact that the subject would not even try to walk, and she was fast running out of energy and patience. In this case the patient exhibited strong external locus of control, while the carer, who was in complete control of her own life, had no wish to assume a position of control vis-a-vis the patient.

Some caring relationships are more complex than those previously described. Subject 95 was aged 71 and was married at the outset of the war. Her husband joined the RAF, and they described how they had taken their present house, by the airfield, so that they need not be separated. She would watch him take off, then sit chain smoking until his return. He worried about her worrying, especially if he was late returning, and was eventually invalided out because of 'nerves'. He remained on invalidity benefit after that, and had taken Librium for the past 20 years. She enjoyed work until retirement, 2 years ago, through ill health. She was now in continuous moderate pain from osteoporosis, and was using continuous oxygen for emphysema. She did nothing but watch television, and was bored - *"same old thing, day after day"*. The husband was now well in control. He did all the house work and, although he complained about this, had refused to accept any home help. She referred to him to answer all her questions, or verify her answers. He described her major problem as 'nerves'. Her mood score was -22. She showed no hostility at all, only complete submission.

This last case study was fairly unique. It is included to exemplify the fact that any attempt to improve pain control, or any other form of control, for the wife, was simply not possible without reference to the husband. The husband, after all these years, was at last in control. This control was afforded by the caring role he now had, and it appeared that the wife's level of control could only be improved at the expense of the husband's.

A final case is outlined because it highlights the presence of hidden agendas in caring relationships. Subject 6, was aged 84. She suffered from Parkinson's disease in addition to arthritis of the back and knees. Her son wrote requesting that she be interviewed. She had been widowed for 20 years and had lived with the son and his wife since the deaths of her daughter and grandson, both from cancer, 10 years previously. Her mood score was +10. She was interviewed in bed, where she said she spent most of the day. She expressed concern about the family, who had promised to look after her in spite of having bad backs. She said that she used to complain to the nurses about the pain, which still troubled her periodically, but she now kept it to herself. During the interview she alluded to family difficulties and *"a personal tragedy"* but did not elaborate. Upon my departure, I was accosted by an aggressive daughter-in-law who complained that her mother-in-law exaggerated her pain and her disability, and that the nurses would support this. Her complexion was ruddy, and her breath smelt strongly of alcohol, therefore no attempt was made to prolong the discussion. Nurses called to give a weekly bath, and two nurses provided questionnaire comments. Each recognised that the patient had pain, though estimated its worst level to be moderate, rather than severe, as reported by the subject. The enrolled nurse, who had known the subject for 2 years, felt that she exaggerated her pain and could be very irritable at times. The district nurses stated *"by nature she likes to be waited upon"*. Both identified good social support and attributed lack of pain control to the patients' attitude, reluctance to exercise, and overdependence. Overall, this presents a very incomplete picture of, what appears to be, a complex situation in which both carer and patient have undisclosed coping difficulties and probably conflicting coping needs.

These case observations of caring relationships are included to emphasise the potential complexities involved in improving the coping status of patients in the community who are cared for by others. Each case illustrates a quite different set of constraints, some of which are amenable to immediate change, others probably not. Any study of the management of pain in the community would be incomplete without at least passing recognition of the importance of these factors. It is suggested that the theoretical model, detailed in chapter 2, may provide an appropriate basis for future research into transactional aspects of caring, with particular reference to an analysis of the reciprocity of coping between patient and carer.

9.7 Summary

Results given in this chapter suggest that patients in the community generally place great value upon the nursing care and support offered by nurses, given good interpersonal skills. Nurses working in the community are fairly good at judging their patients' pain control, problems, and emotional state, although they tend to underestimate the worst level of pain experienced and overestimate patients' anxieties. They also tend to use the patients' level of complaint as an indicator of exaggeration, and place undue reliance upon memory in their assessment of pain. Nurses recognise the value of support, although this is generally stated in terms which are not specific, and they place greater emphasis upon medical treatments than do the patients themselves. Overall, nurses recognise the interaction of pain, emotions and other problems, although pain assessment tends to be emotion-focused, while pain management is variable and appears to lack focus. The relationship between subjects and their carers was not a focus of this study, nevertheless some case illustrations are included to emphasise the complexity of many of the caring relationships, and their potential influence upon coping.

The next chapters are devoted to a general discussion of the implications this study, in the context of other recent research, together with recommendations for assessment and nursing interventions which offer opportunities for improvements in patient care.

Chapter 10 DISCUSSION OF MAIN FINDINGS

10.1 Summary of main findings

Data from the patient interviews revealed that the best predictors of coping, as measured by mood state, were having regrets, being occupied, perceived pain control, non pain-related personal problems (notably bereavement loss), and feeling informed about the painful condition. These, together, accounted for 58 percent of the variance using multiple regression. Being occupied was found to imply active involvement, rather than passive pastimes. For those with intractable pain problems, such as arthritis, there was an indication that the implementation of personal active pain-reducing strategies, rather than sole reliance upon pain relieving drugs, may be associated with enhanced pain control. The effectiveness of pain medications, which have potentially harmful side-effects, was not being adequately monitored. Factors which exerted indirect effects upon coping included least and worst levels of pain intensity, disability, health and financial problems, all of which were negatively associated with mood state; religious beliefs and internal locus of control, which were indirectly associated with positive mood. Loneliness was identified as a multifactorial affect, associated with regrets, lack of occupation and bereavement loss. Patients' verbal reports of pain experiences supported the statistical findings in identifying restriction on 'doing things' as a major effect of pain.

Patients identified supportive aspects of nursing, such as giving encouragement and maintaining confidence, to be most beneficial in terms of pain management. A significant minority identified lack of time as the factor most likely to have a detrimental effect upon their nursing care. Nurses in the community tended to underestimate patients' most severe pain levels, regardless of length of acquaintance with the patient, or recency of contact. They tended to overestimate levels of least pain and underestimate the extent to which pain was under control, unless contact was recent. Nurses emphasised the emotional effects of pain. They were good at judging depression, but overestimated anxiety.

Nurses tended to associate pain complaints with exaggeration, even though those who complained were often patients with coping difficulties. There were individual differences in nursing assessments, but there was no evidence that district nurse training, or even nurse training, had any influence upon the ability to assess pain. Few nurses used any formal method of pain assessment, some had received no education in pain management, and many relied upon experience, and colleagues, for knowledge of pain. A brief analysis of some patient - carer interactions suggests that these impact upon patient coping and require consideration as part of pain management.

10.2 Discussion of main findings

10.2.1 Mood measurement

The findings of this study depend, primarily, upon the assessment of mood state, since this is used as the indicator of how people are coping at any given time. A bipolar mood profile was constructed, which incorporated aspects of anxiety, depression and hostility, since these, it is argued in chapter 2, are emotions which reflect threat to, or loss of, control.

The literature review showed that no existing measure of mood was suitable for use in this study. This was most regrettable, since existing scales have the advantage of established checks on validity and reliability, and they allow direct comparisons with other studies which have used the same or similar measures. Most were too lengthy or were not suitable for verbal administration. Others contained items which were inappropriate for use with a frail elderly sample, and which would have nullified their validity in this study. Those which were particularly suitable on both of these counts were not sufficiently comprehensive, in terms of mood content, to suit the theoretical objectives. It is argued that, under these circumstances, there was no alternative but to construct a new mood measurement scale.

The validity and reliability of the mood measure is open to challenge. In terms of validity, the terms included were based, essentially, upon existing measures, and its construct validity, in terms of the mutual exclusiveness of the positive and negative terms, was checked prior to use. The elderly subjects themselves appeared to have little difficulty in determining their position vis-a-vis each pole. The measure sought to maximise the amount of mood data which could be collected at the least cost, to subjects, in terms of concentration and effort. It provided data which showed an adequate distribution for use as the dependent variable in subsequent regression analyses.

Factor analysis appeared to confirm the construct validity of the mood scale by selecting one major factor on grounds of percentage of variance explained, and three discrete factors, clearly identifiable as anxiety, depression and hostility, as the model of best fit. The identification of a single factor was not entirely surprising, given the theoretical position. However a greater degree of differentiation might have been anticipated in view of the fact that existing scales are designed on the premise that anxiety, depression and hostility are distinct affective states. Possible reasons for the failure to distinguish these aspects more positively, include the age of the sample. With their range of chronic disabilities, varied past histories of coping, and the day-to-day uncertainties which failing independence brings, they may be more prone to a combination of depression, anxiety and hostility. Alternatively it might have been attributable to the small number of items included in the scale: 13 each of positive and negative items, of which only three of each appeared, from factor analysis, to be distinctly related to depression and hostility. This aspect of validity would require careful reconsideration if the mood scale was to be used in future research. However factor analysis confirmed that none of the terms included was redundant, in terms of contribution to the single factor. For the purpose of this research, it is argued that the range of scores, from positive to negative, appeared to provide an adequate indicator of coping, in accordance with the requirements of the research design.

The test-retest reliability of this mood measure was not assessed, as initially intended, on an elderly sample, although it was designed, primarily, with the elderly in mind. The reason for this was that, although the mood measure was quick to administer, most elderly people do not provide direct answers about their feelings without giving justifications which are often lengthy. The result would have been a time-consuming enterprise which, in addition to the time demands of the pilot study and main study interviews, was not feasible. The fact that almost all subjects appeared to find it relevant, interesting and simple, and were prepared to give careful consideration to their answers, can only support its likely validity and reliability. However, if the scale was to be used in future research on the elderly, suitable tests of reliability would be an essential prerequisite.

One advantage of the mood profile scale is that the descriptors, contained within it, can be incorporated into a quick method of mood assessment for everyday use by nurses during the course of their routine visits. This should enhance their ability to identify patients who have the greatest coping difficulties. It is not always entirely apparent to nurses which patients have the greatest need for nursing interventions. Quiet uncomplaining patients may comprise those who are coping very well, in addition to those who cannot cope and are depressed. Loud complaining patients may comprise some whose method of coping is to exert control over their helpers, as well as those with profound coping difficulties. If, as is suggested by the theoretical model proposed here, mood state differentiates good copers from poor copers, then mood assessment is a critical element in pain assessment, and hence in identifying those who might benefit from nursing interventions. It is not envisaged that nurses need use a complete measuring scale for mood assessment. However the inclusion of positive and negative descriptors may help to clarify the extent of anxiety, depression and resentment, and avoid problems of under or overestimation of mood reaction.

The distribution of mood scores was skewed in a positive direction. This appeared to indicate that subjects were, on the whole, coping well.

However it does not indicate that the sample was necessarily biased in favour of copers, since a skewed positive distribution was an anticipated artifact of the assessment tool. The reason for this is that the positive poles were carefully selected to reflect good coping in an elderly population with pain, but being in control does not imply a state of elation. Many of those who, for example, reported feeling contented, would not have felt particularly playful or jolly. Thus descriptors which reflect more extreme positive mood states were omitted because they were not relevant. Had they been included, a normal distribution of mood scores would probably have been achieved.

The chief purpose of the mood profile was to provide scores which could be used as the dependent variable in subsequent bivariate and multivariate analyses. In this, the measure appears to have been successful. In particular, multiple regression identified five distinct variables which together accounted for 58 percent of the variance. This level of explanatory power tends to support a reasonable level of reliability in the measurements used.

In summary, mood was measured using a novel tool devised specifically for the population under study. Evidence has been presented in favour of the validity of the measure used, however it is recommended that further reliability checks on an elderly population should take place if it were considered for use in any further research. Nevertheless, the distribution of mood scores, and results based upon them, tend to lend support to the overall reliability and validity of the mood measure in the context of this particular study.

10.2.2 Pain control

Pain control is the first independent variable to be considered in relation to coping because pain was the primary focus of this research project, and because it was found to be related to all of the other variables associated with coping. The relationship of these other factors to pain control cannot be assumed to be causal.

The presence of uncontrolled pain might enhance regrets, reduce occupation, make it more difficult to cope with other problems, and increase the need for information. Equally the presence of regrets and other problems, lack of occupation and the need for information might all reduce the likelihood of achieving and maintaining pain control. Those who are lonely are likely to dwell more upon their pain in their isolation, while pain probably intrudes to heighten feelings of loneliness in someone who might, otherwise, be reasonably content to be alone. The assumption is that therapeutic interventions in any domain, which improve overall control, will also enhance pain control.

The extent to which subjects reported their pain to be under control was found to be one of several critical factors in determining their overall mood. The complexity of pain perception was confirmed, in that this variable was found to be directly related to almost every other variable included in the analysis. Most important of these were the intensity levels of least and worst pain. However although the relationships were highly significant, the correlation coefficients of .32. to .35 were modest, and, assuming that such low values are not entirely due to error, appear to signify the influence of additional factors.

The relationship of pain control with locus of control was almost as strong as with pain levels themselves, while internal locus of control was also closely associated with positive mood. Rudy et al (1988) demonstrated that the relationship between pain levels and depression was an indirect one. The intervening variables that they identified, using the West Haven-Yale Multidimensional Pain Inventory (WHYMPI), were self-control and interference, where self-control appears to represent internal locus of control, and interference is a measure of the effect of pain upon work, family and recreational activities. In fact the results of Rudy's study offer substantial evidence in favour of the validity of the findings presented here.

Other studies, such as that by Partridge and Johnston (1989), have consistently shown that internal locus of control is more adaptive in situations of stress, and predicts better health outcomes in people with disability. Subjects in this study displayed an equal tendency to external, as to internal, locus of control, with respect to pain. It is not at all clear if this distribution also applied to locus of control with respect to other aspects of life, although classification took into account some more general comments about care. External expectancies, regarding the control of pain, are encouraged by current medical practises in which the patient attends the doctor to have his pain treated. Patients are encouraged to comply with instructions for medication, rather than use their own initiative and adopt their own strategies. External attitudes are also fostered by a paternal attitude on the part of some GPs, and a reluctance to give information and feedback. It may be difficult to overcome such attitudes on the part of either medical professionals, or patients, and this is why further research is necessary to provide evidence in support of a change of approach to pain management.

The results concerning pain reducing strategies are tentative, yet they lead to a questioning of traditional pain management strategies for chronic arthritic conditions, in general practice. These rely almost exclusively upon the use of anti-inflammatory and analgesic drugs, intended to be taken at prescribed intervals. Most of these drugs are capable of producing painful iatrogenic effects, yet there was evidence that lack of monitoring had led to some unnecessary use. There is some indication, in these results, that patients with arthritis should be encouraged to exercise personal discretion over the use of painkilling drugs, as well as being given every encouragement to develop their own active strategies to control their pain. This is contrary to recommendations given for the management of terminal pain, due to malignancy, where analgesics must be given sufficiently frequently, and in adequate doses, to ensure the elimination of pain. Many patients were, in fact, using considerable discretion by refusing to take medication, or taking it only sparingly and when really necessary. This is in keeping with research observations that more pain can be endured if some means of personal control is available (Bowers 1966). In this study, the use of discretion in drug-taking weighed in favour of internal locus of control during classification. It is not at all clear if encouraging patients to exert discretion would actually lead to an increase in internal locus of control, and this issue also requires further research.

Overall, the results concerning pain control suggest a new line of research into the administration of analgesics to the elderly, not least because, in many instances, potentially dangerous drugs are having little or no discernible effect upon the pain. The elderly are particularly vulnerable to side effects from the long term use of anti-inflammatory and analgesic drugs and display a natural reluctance to take regular dosages. Those who used their own discretion and initiative were those who were more likely to report their pain to be 'under control'. Further research is required to verify these results, and to support the use of alternative strategies for pain management, so that drugs may be retained for use when the patient feels that he really needs them, rather than administered routinely. Patients should be encouraged to monitor the effects of their own medication, and district nurses should participate in monitoring the effectiveness of all drugs used to treat pain in the elderly, to ensure that no such drugs are being taken unnecessarily.

In this study, many patients were able to bear continuous, and often severe pain, by employing simple expedients, such as rubbing in topical pain-relieving creams, applying heat, or doing simple exercises. Past nursing experiences suggest that medical professionals are inclined to dismiss lay methods of self-control, whereas these results suggest that nurses should actively encourage patients to use alternative strategies which they can apply themselves. The results presented here, indicate that pain is more likely to be controlled if the patients has available a greater number of these pain controlling strategies.

It appears, from this study, that self-control treatments, such as TENS (transcutaneous electrical nerve stimulation), are being underutilised, although this potentially useful tool is particularly appropriate for patients with a strong desire to maintain control for themselves. Likewise biofeedback is another instrument which promotes self-control, and which has been specifically recommended for use with elderly post-stroke patients (Abdellah 1981). Such strategies all have the added compensation of being time-consuming activities. There appears to be little reason, other than financial, why district nurses, given appropriate training, should not be able to supply and advise patients in the use of TENS. At present few patients have access to the equipment. While not all patients would benefit, none will experience harmful effects from this type of treatment.

Another useful strategy in the control of pain is the use of antidepressant drugs. Clomipramine has been shown to exert a specific effect upon symptomatology in chronic pain, without necessarily involving an effect upon preexisting depression (von Knorring 1988). In fact cases were highlighted in the results section, where subjects with continuous pain showed some degree of depressed mood, and might have benefited from the use of antidepressant therapy on both counts. Antidepressants must be used with caution in the elderly, as they can cause confusion (BNF 1985), however some patients, who had received prescriptions from the pain or rheumatology clinics, reported considerable benefit. This, and the other strategies mentioned, are of particular importance for patients who are never, or rarely, free of pain.

The ability to identify trigger factors to episodes of severe pain may be helpful in planning avoidance strategies. This can be achieved simply by assessing the levels of worst pain, using a verbal rating scale, such as that of Raiman (1986), and recording the incidence of such episodes. However a solution is not always simple. For example, arthritis sufferers commonly experience an exacerbation of pain when they get up in the morning, and would therefore benefit from the prior use of analgesics.

Pain medication is difficult to swallow unless taken in an upright position, with a drink. The need to use the toilet usually takes precedence over the latter, hence the pain may be unavoidable. Many subjects had devised their own methods of doing things so as to avoid the worst consequences of pain, although some could not avoid pain, particularly if it was associated with weight bearing movement. A few patients had identifiable trigger factors which they did not always seek to avoid. Assessment, with the nurse, should elicit such factors and allow nurse and patient, together, to work out suitable avoidance strategies for the patient to use as he sees fit.

In summary, these findings confirm the complexity of pain control and identify that many different factors contribute to the maintenance of control. Personal control over pain, using a variety of active controlling strategies should be encouraged. Pain controlling drugs need much more careful monitoring, and further research is required into prescribing practices for chronic painful conditions in the elderly. The measurement of least and worst pain levels provides a good basis for the identification of drug or treatment efficacy and the planning of suitable nursing interventions. The role of the nurse appears, potentially, to be as important as that of the doctor in helping patients with chronic painful conditions to gain and maintain pain control.

Additional nursing interventions which are likely to enhance pain control are considered below in relation to each of the other variables which were included in the regression model. It is suggested that whenever patients are identified who are not coping well, and who cannot achieve pain control, alternative reasons for coping difficulties should be sought from among these factors.

10.2.3 Regrets

The advantages of using a flexible semi-structured approach to interview is highlighted by the fact that it led to the identification that having regrets was an important factor in determining mood.

This had not been identified at the stage of questionnaire design. Regrets about specific incidents were often reported to be slight, however major regrets generally concerned past events which were perceived to have changed the course of the individual's life (and hence the individual's control over his life), such as the onset of a painful condition, or the break up of a marriage. In this sense regrets appeared to influence to the degree of control the individual perceived himself to have over his present life. This is supported by the negative association between regrets and internal locus of control. Regrets may be interpreted, in terms of the theoretical model, as a negative assessment of past actions, or events, which give rise to specific or generalised negative predictions about control over current and future events.

The findings of this study, with respect to regrets, are well summed up by the observation given below:

> *"It is easy to see how one's inner thoughts and feelings can assume greater importance as one is cut off from the outer world through factors common to old age, such as loss of occupation, physical disability, sensory deprivation / attentional difficulties, bereavement, isolation ..."*
> (Coleman and McCulloch 1985 p.252)

Coleman (1986) identified that regrets may be amenable to a counselling approach. He described how, over a period of time, three of his elderly subjects moved subtly towards a greater degree of acceptance of their past lives, and a less negative attitude. Reminiscence may, for some elderly people, provide an opportunity for cognitive restructuring. The individual may, with some encouragement, reconsider the past and make a more positive interpretation, or a better justification, of events. With hindsight, it may become apparent, to the regretful individual, there was little alternative action which could have been taken, under the circumstances. Being able to talk these things through with a sympathetic caring nurse could make an important contribution to readjustment.

Counselling is an approach which may not work for those whose negative attitude is based upon a very profound and generalised sense of failure or guilt (internal attribution), or of resentment (external attribution). Nevertheless the very understanding that regrets are a significant contributory factor to poor pain control, or even to outright hostility in some patients, should enable the nurse to take a more sympathetic and helpful view of the patient's current coping difficulties. For such patients, the control of pain, by medical means alone, may be destined for failure, although blaming the patient only makes matters worse in terms of the nurse / patient relationship. The fact that the nurse is able to identify regrets as a causal factor in poor coping and poor pain control, may, even if it is not amenable to change, help her to come to terms with her own sense of helplessness and failure, and remain sympathetic towards the patient. Coleman (1986 p.156) suggests that those with deep feelings of regret should not be left alone to brood upon their negative thoughts. He suggests that creative use of them, such as writing autobiographical accounts, may be cathartic. Alternatively, increasing social and recreational occupational opportunities may reduce preoccupation with the past, and enhance perceptions of current worth and control.

In summary, regrets about the past emerged as an important negative factor in current coping status, loneliness and pain control. Recognition of this should lead to a more sympathetic and positive approach to dissatisfaction and discontent among elderly patients, and interventions which are based upon individual counselling, and encouragement to engage in new interests.

10.2.4 Occupation

Probably the most important variable, in terms of potential intervention, was that of being occupied. Classic pain research studies have identified that increasing activity levels lessens demands for analgesics, reduces depression, and appears to result in reductions in levels of pain (Linton 1986). The results of this study raise questions about the types of activity which are required to improve mood and pain control.

Certainly, in this elderly sample, it appeared that being occupied implied an active process of involvement, in other words 'doing things'. Most popular hobbies among women were knitting and sewing. Passive entertainments, while being arguably distracting, did not appear to have much therapeutic value.

There is no lack of supporting evidence in favour of the value of activities for the elderly. An investigation, by Boyle and Counts (1988), into what, for elderly Americans, constituted health, revealed what the researchers classified as 'physical activity' to be a major factor. In fact many of the physical activities described by their subjects were similar to 'doing things' described by subjects in this study. They involved routine tasks such as *"working at what you can", "doing this and that", "puttering"*. Even more recently, Doan and Wadden (1989) found patients' reports of loss of ability for social and recreational activities to be a contributory factor in discriminating between mild and moderate / severe depression, using the Beck Depression Inventory.

Hunt (1978) found that indoor hobbies and pastimes (apart from reading) were most popular among those who were housebound, men and women aged over 75, and those who were single. For these categories, indoor hobbies were reported to be more important than the company of family and friends, although these findings probably reflected enforced circumstances. Hobbies and interests were similar to the present study, and included reading, watching television and listening to the radio, indoor games, music, arts and crafts and church activities, although the majority only identified television following a prompt. Women identified knitting, needlework and cooking as hobbies, while men were more likely to report involvement in gardening, outdoor sport, woodwork and painting and decorating. Failing eyesight and other health problems were identified as the major causes of difficulty in pursuing hobbies in the very old.

Watching television was not, on the whole, identified as a fulfilling occupation by those who mentioned it in this study. This observation is supported by Lodziak who observed that television viewing is higher than average among the poor, the unemployed and the retired. Being housebound and poor limits the range of leisure activities, however *"viewers are more than ready to exercise their choice not to view television when given the opportunity to participate in 'more enjoyable' activities"* (Lodziak 1986 p.133). His suggestion that gratification from television is of little importance where viewing is routine and selection not purposeful, is fully supported by the findings of this study. However Macheath (1984) found that staff working with the elderly in institutions believed television watching to be an ideal activity for the elderly.

The results of the study, reported in this thesis, support the view that activities requiring active involvement, as opposed to those providing passive entertainment, are critical factors in determining control and mood state. These results are probably the most crucial of the whole study, in terms of possible interventions with elderly people in a variety of settings. It is evident, from subsequent discussions with district nurses, and with those working in hospital settings, that little attention is paid to how elderly people fill their time during the course of each day. Indeed Godlove et al (1982) identified that elderly patients in hospital wards spent 72 percent of their time doing nothing and talking to no one, while even in day centres this accounted for 23 percent of the time. Increased physical disability limits the opportunity to participate in any kind of daily activity, even within the patient's own home, and can leave the days empty of purpose and meaning. In terms of the theoretical model used, control is seen essentially as an active process. This implies that loss of ability to produce controlling actions, of any kind, may lead to loss of control and, once control is lost, a degree of depression is inevitable. It is argued here that clinical depression may be defined in terms of the extent of negative predictions about the possibility of gaining control through any kind of action.

Thus, in clinical depression, there is a vicious circle of events in which loss of control leads to a reduction of any type of activity which, in turn, reinforces loss of control. If this occurs, any attempt at inducing change through persuasion is likely to be greeted with predictions of negative outcome. However the majority of subjects in this study, who showed depressed mood, were not totally negative in their outlook, and were probably not clinically depressed, as defined above. This indicates that their mood, and hence their coping status, may be amenable to improvement through a change in circumstances which may be brought about by increasing opportunities for occupational activity.

Interventions to increase occupation depend upon the circumstances in which the elderly person lives. For those who live in their own homes, self-care and household activities are very important controlling and occupying activities. Self care is recognised as a desirable aim in the context of nursing care (Orem 1985). The results of this study suggest that self care is desirable as a time-filling, productive, and self-controlling activity. For these reasons it should be encouraged, and the provision of suitable aids to independence are fundamental in maximising self-care opportunities. However some of those who appeared most depressed, in this study, were those who were being cared for by other people, particularly when they were actively discouraged from helping or participating in the home. A recent study by Thompson et al (1989) identified overprotection as the most significant cause of depression in post-stroke patients, but confirmed that depression was not an inevitable consequence of stroke. Some carers, in this study, had taken complete control over the patient to the extent that they were not only completely dependent for self-care, but had nothing to do at all and, as a consequence, were very depressed. It may be relatively easy to rectify situations where dependence and inactivity on the part of the patient are due to well-intentioned overprotection by the people who care for them. It is likely to be more difficult where dependence is forced upon a patient by a carer whose own sense of control is dependent upon this relationship. In situations where the patient exhibits external locus of control and hence undue dependence, a behavioural approach to increasing activities may be most appropriate. Whatever the circumstances, improving conditions for the patient cannot be envisaged in isolation from consideration of the needs and cooperation of the carer.

In addition to aspects of self-care, identifying means of enhancing active occupation is dependent upon the knowledge, skills, and physical and environmental resources of the individual. These results support incentives to engage in craft activities, games and correspondence. It is possible, indeed it is already practised in some, for day centres to teach craft-type skills to the elderly housebound, and provide outlets for the sale of items made at home. It is arguable that all elderly people, no matter how disabled, are able to participate in some type of involving activity, given the wherewithal and the incentive. The facilities should be available from either day centres or from peripatetic occupational therapists. The incentive may require a little imagination and, as Bond and Bond (1987) observed, no one should be forced into activities against their will. Many subjects identified their own intrinsically rewarding activities, such as playing one handed scrabble. Others were extrinsically motivated, for example knitting for grandchildren or sewing for charity. It is necessary to assess individuals to identify their skills, the types of activity which they have enjoyed or would enjoy, and then provide sufficient extrinsic motivation to persevere. This might be achieved by social efforts at day centres to encourage work at home, or by individual voluntary visits to those at home to provide incentives to home activity of some kind. Many elderly people have skills which they could teach to others. Thus subject 114, who had forsaken his wood carving, could, if provided with the tools, not only keep himself occupied and generate income for charity, but teach others of all ages some of his rare skills.

Men whose hobbies centre upon physical activities, such as decorating and gardening, face real occupational problems when afflicted by pain or disability, whereas elderly women are often content to sit and knit. In the not too distant future, a generation of working women will retire without the sewing and knitting skills displayed by the sample in this study. Preparation for retirement is important, but education must surely continue in retirement if the rising population of aged people are to find means of keeping themselves occupied. New activities may replace old ones. Perhaps, in the future, some will keep occupied playing computer games. Whatever the future holds, there appears to be as waste of skills, resources and opportunities at present. This holds prospects for further research and imaginative interventions within nursing, social services and voluntary organisations.

The results of this study, with respect to the importance of occupation, provide an opportunity to reflect upon the results of previous studies which have investigated control in the elderly. Munson (1989) has recently criticised the interpretation of the study by Langer and Rodin (1976), outlined in Chapter 1, which purported to demonstrate that it was increased responsibility for everyday events, rather than any other factor, which produced an increase in happiness, activity and well-being. The results of the study, reported here, indicate that an increase in active involvement, by any means, is likely to be associated with improvements in well-being. It may, therefore, have been the increase in occupation, produced by the research intervention, rather than responsibility which caused the improvement. The intervention included attending meetings and caring for a plant, which are both time-filling and involving activities likely to afford an increase in control through increased action.

The finding that occupation was a critical factor in determining mood in this elderly sample of patients with pain requires verification. An intervention study is required to examine the effects of appropriate occupational therapies upon mood and pain control. These findings cannot necessarily be generalised to other groups within the population, however further research may be justified to study the effects of lack of occupation, and increased occupational opportunities, on many other groups of people, particularly those in long stay institutions, the disabled, the mentally ill and mentally handicapped.

10.2.5 The presence of other personal problems

It was predicted that the presence of additional problems would influence pain coping in the community. The patient in hospital is, to a degree, sheltered from the demands of life outside. The staff encourage him to forget about other issues, and the family often conspires to conceal problems from him until he is better. His illness and his pain become the predominant issue, and the relief of pain a priority. In the community, the patient has no respite from additional stressful life events and hassles, particularly if the pain continues for months or years. The results of the statistical analysis confirm that additional life problems, particularly those which involve the loss of close family or friends, were not only a significant factor in overall coping status, but also influenced the degree of pain control experienced.

The elderly are particularly vulnerable to bereavement loss, especially the loss a spouse, which leaves them alone to cope with the everyday problems of life, and with pain and disability. A recent study by Smallegan (1989) showed that 60 percent of their sample, aged between 65 and 99, reported the death of a friend or relative, and that bereavement represented the most significant life event. Nevertheless they found that depression scores, as in this study, were, on average, quite low. They found that disability, and not living with a spouse, were most closely related to depression, but that age and gender were unrelated to depression. Smallegan suggests that, overall, the relationship between life events and depression is not straightforward.

In this study, the identification of the magnitude and type of personal problem recorded was left to the discretion of the individual subject. It was therefore a subjective, rather than an objective measure. As observations from the interviews showed, not all subjects were distressed by the loss of their spouse, just as not all found support from the presence of a spouse.

This makes it very difficult to construct a reliable objective measure of life events.

Help with coping with any of the personal problems that subjects identified is likely to improve coping prospects, although bereavement is the most traumatic event. Self-help organisations, such as Cruse, are recommended as providers of support following the loss of a spouse (Clegg 1988). However these results indicate that loneliness, associated with widowhood, may be most effectively alleviated by close social contact within the home. It is evident that district nursing organisation does not always provide for continuity of nursing care, nor is sufficient time always available for social visiting. However it is suggested that it is particularly important for those who have experienced a recent loss, and feel lonely and isolated, to have the benefit of a consistent relationship with a nurse, or even a voluntary helper, whom they can trust, and who will give them confidence to deal with present and future problems. Furthermore, an investment in time, during a period when the patient is regaining control, is likely to be an investment in the future mental health of the patient. Many subjects, in this study, identified how much they valued their relationship with the nurse, if it was a good one. It may, therefore, be most appropriate for the nurse herself to provide bereavement support, if she has already established a relationship of trust with the patient prior to the loss, rather than referring to another statutory or voluntary body. It was clearly the policy of nurses in some practices to undertake social visiting, and there may be a good case for extending this practice, and for extending counselling skills.

10.2.6 Feeling informed about the painful condition

It had been anticipated, from the theoretical model, that information which specifically concerned the painful condition, would influence pain control, and hence coping. However the results showed that feeling informed exerted an effect on mood which was independent of pain control. It was evident, from the results, that the majority of subjects felt quite satisfied with the information they had been given.

However those who felt uninformed displayed a strength of feeling which often went beyond simple dissatisfaction. In terms of the theoretical model, they had been deprived of the opportunity for self-control because they did not know what it was that they could, or could not, control.

These results accord with other recent investigations of the importance of information in coping with pain. Marcer et al (1989) investigated various aspects of pain experience in 137 patients attending a pain clinic with chronic non-cancer pain, based upon personal interviews. These aspects included requirements for information about the cause and likely progress of their pain, and the extent to which the patient was worried about the possibility of some undiagnosed or undisclosed malignancy. The findings revealed that the majority admitted to worry about the cause of their pain, and rated their needs for coping skills and information higher than their need for pain relief. Marcer et al were able to demonstrate that the provision of information and realistic coping advice was able to restore quality of life without necessarily lessening the level of pain. Some subjects in this study were identified by the researcher, and subsequently confirmed by information from the nurse, as having a malignant condition, purely because of their high levels of anxiety. Given the fact that they were already very anxious, it is difficult to see how the provision of the truth could make things any worse for them. Patients are often aware that doctors withhold bad news and develop their own suspicions. This can lead to a charade in which each of the actors avoids the truth of the situation. Patients are often reluctant to ask for details, but lack of inquiry must not be taken, necessarily, to indicate a desire not to know.

Beisecker (1988) investigated requirements for information among rehabilitation patients and found that older patients were less likely than younger ones to wish to be involved in decision-making processes regarding their treatment, although they shared the same overwhelming desire for information. However few, in any age group, asked questions of the doctor during consultation. Such evidence contradicts the view, expressed by some doctors, that the patient will ask if he wishes to know. The results of this study indicate that the provision of information about a painful condition may be critical, at least for some patients, in determining their ability to cope successfully. Furthermore the other studies, mentioned above, suggest that the elderly are no different to any other group when it comes to requirements for information.

Community nurses are ideally situated to identify those who require information, however they will only find out if they are prepared to ask and to listen. The patient's chief worries may not necessarily concern the focus of the nursing visit, particularly where there are multiple pain problems. If visits are rushed, they will allow no opportunity for the patient to express his needs. Qualified nurses may be able to provide information themselves. However if the patient does not seem reassured with this, the nurse should liaise about this with the general practitioner. Patients often do not appear to comprehend medical information which has been provided. Such information should always be specific, given in a form that patients can understand, and explanations may need to be repeated to ensure that the patient has comprehended its full implications (Ley 1988). The district nurse is ideally placed to discuss patient's hopes, fears and understanding about his condition, because of good understanding of the medical reports, and because of close and frequent contact with the patient. The results of this, and of the other studies cited, suggest that the nurse should make full use of these opportunities for communication.

Subjects in this study indicated that the majority desired information, even if it contained bad news. It is clearly desirable to identify some way of distinguishing those who wish to know the worst from those who do not. In this respect it was surprising that there was no relationship between the desire for information and locus of control, since theory should have predicted that those with internal locus of control would express a greater desire for information in order to ensure the maintenance of self-control. Information may reflect a universal need, regardless of locus of control.

However there may be some doubt about the reliability of answers to hypothetical questions concerning whether or not people would wish to know the worst, should the situation arise. These findings certainly suggest a need for further research into this important issue for nurses and doctors.

Finally, there is an additional aspect of information which is of fundamental importance to patients who require treatments, such as regular dressings. Some patients with varicose ulcers did not understand how their progress could be adequately monitored by a succession of different nurses. Surely the solution is to use a simple method of charting which is accessible to, and negotiated with, the patient. In this way the patient is provided with feedback and information about his progress, and should be involved in any decision concerning changes in treatment. The patient should be encouraged to become, what he probably already is, the expert on his own condition. He should be better able to accept the temporary discomforts, inevitably caused by some treatments, if he has participated in treatment decisions, and knows that he can influence the termination of a treatment, should it become too uncomfortable. The patient is best placed to identify any allergic or iatrogenic responses, provided he given, in advance, suitable information about what is normal and what is not.

10.2.7 Additional coping factors

The regression model identified independent factors which exerted the greatest influence upon mood state. However other important variables were identified to be indirect coping factors. These included physical disability and other health problems, loneliness and social contact, religious beliefs, and locus of control, each of which is discussed below.

Physical disability and health problems

Physical disability was common among the sample in this study, in fact some degree of disability was the norm. Disability was found, in this study, to be associated with the level of perceived pain control, but it exerted an even stronger influence over the ability to keep occupied.

In addition to disability caused primarily by immobility, many subjects had health problems which reduced activity and occupation. These included degenerative diseases, such as Parkinson's disease, and blindness.

MacCarthy and Brown (1989) showed that disability was related to depression in patients with Parkinson's disease, but that coping behaviour was an important intervening variable. In this study, disability was also found to exert an indirect effect on depression via being occupied. Support for this finding comes from the fact that the term 'useless' was used by many subjects to describe themselves. This was commonly because they could not 'do anything'. The relationship between occupation, coping behaviours, disability and depression appears to deserve further research in the future. Heinemann et al (1988) explored leisure activities in elderly subjects (mean age 75) with low vision and found a decline in activities such as knitting, sewing, gardening and cooking, with an increase in watching television and listening to the radio. They found that the effects of visual impairment were, in many cases, compounded by chronic health conditions such as diabetes, cardiac conditions, arthritis, stroke and hearing impairment. The study did not, unfortunately, attempt to measure the incidence of depression. The combination of physical disability with visual and auditory loss inevitably places severe limits upon the ability of people to maintain any type of occupation, and depression is likely to be a common consequence. These severely disabled patients require more imaginative interventions, probably with the help of an occupational therapist or self-help organisation, to provide information and devise ways of providing rewarding time-filling activities. The provision of a talking book service to blind patients may benefit some, but these results suggest that training in braille, normally denied to the elderly, may confer greater advantages, for those who are able, in terms of active occupation.

Loneliness and social support

During the presentation of these findings to groups of district nurses, the nurses have consistently identified loneliness as the variable most likely to predict negative mood. However the results have shown that a relatively small proportion (20 percent) of subjects actually reported feeling particularly lonely. This may indicate under-reporting. Certainly a potential bias was detected in the pilot study, and the sequence of questioning altered to reduce this effect. Although loneliness was found to be significantly related to negative mood state, this relationship is not a direct one. Loneliness is found to be related, not only to the loss of close relationships, but to past regrets and the ability to keep occupied.

Loneliness and social support are the subject of much ongoing research, although loneliness is generally defined purely in terms of social relationships. Knussen and Cunningham (1988) described how social support has received much attention as an important coping resource, although it is often vaguely defined. They suggested that independence and control are major issues related to the use and function of social support variables. The results reported in this thesis certainly appear to show that social support may, in some instances, reduce independence and remove control, thereby serving as a negative coping resource.

Stewart defined loneliness as

> *"a subjective, unpleasant, emotional experience ... resulting from a perceived or actual deficit in social relationships or relational provisions which would provide a sense of social integration and / or emotional intimacy".*
> (Stewart 1989 p.1280))

If the findings of this study are at all accurate, then they suggest that this definition, and such causal models of loneliness as that recently proposed by de Jong-Gierveld (1989), are not sufficiently comprehensive. De Jong-Gierveld made no reference to time-filling activities in her causal model of loneliness, although she acknowledged the complexity of the loneliness construct. Neither did she identify the importance of positive or negative memories of past events as a potential factor in reports of loneliness.

Further research is required to verify the relationship between occupation and loneliness, since it is possible that this particular relationship may have been an artifact of the order of questioning. Loneliness was explored after issues concerning loss of occupation. Nevertheless the association is a logical one deserving of further attention.

Additional issues in loneliness centre upon the fact that outings from home were found to be associated with positive mood, but not loneliness, while social visitors to the home reduced loneliness, and were of particular importance after loss of spouse. The study by Schulz and Hanusa (1978) discussed in Chapter 1, in which the benefit elderly subjects derived from voluntary visits was negated upon the termination of the study, has important implications for the nursing management of pain. The withdrawal of a nurse, with whom the patient has a close relationship may represent a severe loss. At least one bereaved patient in this study stated that she would be sad to lose the nursing contact, afforded by her condition. There is a common belief among community nurses, which may well be apocryphal, that elderly leg ulcer patients sometimes interfere with dressings in order to prolong treatment. Nurses are generally aware that withdrawal of nursing support may result in increased loneliness and depression, particularly where the patient has little other close social support. The promise of continued social visits, with contingency plans for subsequent gradual withdrawal of support, and possible replacement by some other agency or activity, may be of important therapeutic value in some instances.

This study showed that many nurses described their role in the management of pain as one of 'support'. It is a term which covers a multitude of potential activities from unfocussed conversation with elderly patients, to specific encouragement in measures of self-control, and practical help with personal and financial problems. This research did not identify what the nurses themselves thought they meant by support, however past personal experiences suggest that an awareness of needs, such those highlighted by presence of loneliness, may generate an increase in social visits which, if lacking focus, leave the nurse, or helper, with a feeling of helplessness and inadequacy. Some nurses actually expressed these feelings about their patients with chronic pain. If this is the case, then these findings may help to provide the basis for a clearer problem-solving approach to loneliness, as well as a basis for further research.

Religious faith

The regression analysis demonstrated that religious beliefs had an indirect effect on mood which appeared to comprise two distinct components. The first was closely related to being occupied, and appeared to be associated with organised church activity. In fact it was evident, during the interviews, that some people identified religion with church attendance, rather than spiritual belief. The other aspect of religious belief was the negative association with having regrets. It appeared that it was spiritual beliefs which were acting as a buffer against having regrets about the past. These assumptions are supported in a study by Koenig et al (1988). They found intrinsic religious belief to be closely associated with morale and subjective coping among elderly Americans. This effect was independent of health, social support and financial status. They suggested that religious beliefs may provide a durable source of support and comfort which facilitate adaptation to life changes. They also identified that organisational religious activity contributed to morale among the elderly and observed that the Christian religions are highly social in orientation, particularly for women. Their findings showed that organisational religious activity was more closely related to morale than intrinsic religiosity, but that women were significantly more likely than men to engage in any type of religious activity. These findings are congruent with the indirect effect of religious beliefs on mood, through regrets and occupation, identified in this study.

It is evident that engagement in church activities is a valuable occupational resource for the elderly, as well as a spiritual comfort. Nevertheless almost 30 percent of all subjects held no religious conviction, and it was evident, from the interviews, that many agnostics viewed the whole question of religion with deep suspicion. Some degree of faith or commitment is clearly a prerequisite for initiating or reestablishing church contact, however the church remains a very useful resource for social and spiritual support. In addition to this aspect of religious belief, it appeared that, although their beliefs were a significant buffer against bitterness and regrets for some, there were others whose religious commitment had been severely challenged by their suffering. A crisis of faith, caused by suffering, can be very distressing, particularly if the patient has little else to turn to. Nurses, who feel able to, may find that the patient is greatly helped by counselling in order to find a positive, or at least less negative, meaning for their pain and suffering in spiritual terms.

Locus of control

The locus of control measure, used in this study, was based entirely upon a qualitative analysis of patients' comments about their pain control, pain treatments and life in pain. Since it was centred essentially upon comments about pain experience, it was primarily a pain locus of control measure. However it was certainly not a pure pain locus of control measure, since it included comments about reliance upon others for aspects of care which were not necessarily pain related. Classification of locus of control was dependent upon the amount of information collected during interview. Some interviewees volunteered more useful information than others, and this may have placed limitations upon accurate coding, and reduced the reliability of the variable so created. Nevertheless, the indirect influences of locus of control upon mood state identified were theoretically sound. It was predicted in Chapter 2 that locus of control represents generalised predictions about sources of control which, in turn, determine perceptions of control and hence mood state.

The relationships between regrets, occupation, pain control and locus of control deserve further research, using validated measuring scales. In particular, it would be interesting to investigate now amenable is pain locus of control to change, given encouragement to use personal pain controlling strategies.

The McGill Pain Questionnaire and pain rating scales

The McGill Pain Questionnaire was used as a research tool in order to determine its utility as an assessment tool for nursing, in the context of the study population. Certainly patients had no difficulty completing it, and most of the verbal descriptors proved to be of relevance. However the evaluative scale, and the fear / punishment parts of the affective scale appeared to present the greatest value in terms of nursing assessment because of their direct relevance to perceived pain control.

Davis (1989) presented an evaluation of the MPQ for the clinical assessment of chronic pain, within nursing. She identified that the affective subscale discriminated between acute and chronic pain, although the results were only of marginal significance. It is suggested that her finding may have been partly a function of the patient samples upon which the study was based. It is true that acute pain is associated with anxiety, and is therefore likely to be associated with increased affective pain score. However chronic conditions are not necessarily stable or familiar conditions. Subjects in this study reported that the pain was fearful or frightful, either when the causes or consequences were not fully known, as is often the case in acute pain, or when they were not fully understood, as might equally apply in the case in chronic pain. These descriptors were also used when the pain or disability was getting worse, or when the condition fluctuated, as is often the case in chronic pain in the elderly. These results suggest that the critical value of the affective subscale should be to alert the assessor to the threat that the pain presents to the patient, no matter how long the pain has been present. The fear and punishment scales, together with the evaluative scale of the MPQ, were identified as having particular relevance to pain assessment in elderly subjects in this study and may provide a useful contribution to the nursing assessment of pain control.

The verbal pain intensity scale (Raiman 1986) appeared to provide a very useful assessment tool for least and worst levels of pain. Patients, without exception, were able to describe their pain intensity using it. Therefore what it lacks in sensitivity to change, it probably gains in validity and reliability. It is also very quick to administer. The information it yielded appeared sound, in terms of interpretation and relationships with other variables, and it appears to provide an excellent tool for the assessment of pain in the elderly in the community. This is of particular value in identifying trigger factors in exacerbations of worst pain. It is suggested that this assessment could be achieved during nursing visits, rather than necessarily using a chart or diary, since patients' memory for the circumstances and extent of worst episodes appeared to be fairly vivid.

10.2.8 Missing variables

It is necessary to consider if any variables were omitted which, if included, would have enhanced the amount of variance explained and added to the explanatory power of the model. The strongest contender is the consumption of mood altering substances, including drugs and alcohol, which have direct, though possibly opposing, effects upon mood state. Only a few subjects were known to be taking antidepressants, which might have enhanced their mood state. Even fewer were taking anxiolytics which might, in the short term, reduce anxiety, although in the longer term cause depression. Many subjects took some kind of sleeping tablet which may have influenced their mood. Alcohol is a depressant, although only one subject was identified by the researcher, and confirmed by the nurse, to be an alcoholic, and she failed to provide any useful information for analysis. One other male subject displayed symptoms of heavy drinking, while a few others reported occasional drinking. There were no reports from the nurses, other than the one mentioned, of any drink problems. In spite of this, it is possible that concealed drinking was taking place, and might have had an influence upon the results. One home help reported that it was not uncommon to find a bottle of sherry on the shopping list of elderly clients (though not the subject being interviewed at the time).

An additional issue which might have had an impact upon the mood of this elderly sample concerned their predictions for the future, most particularly their attitude towards death. The topic of death was deliberately not raised during interview because, although the researcher had no prior knowledge of the condition of any subject, it was thought that some might have suspected such a question to imply prior knowledge. Although some subjects expressed acceptance or fear of death, there were too few comments from which to draw any general inferences.

Many people, when using the terms 'fearful, frightful or terrifying' to describe their pain, commented upon fears about the consequences, as well as the causes, of the painful condition. This was particularly important in terms of predicted loss of independence. Having analysed the results of this study, if were possible to go back and ask just one additional question, it would be *"How do you feel about the future?"*. It seems likely that negative answers would reflect a mixture of fears about loss of independence, fear of unbearable pain, fear of the loss of a loved one and fear of death. It is anticipated that such a variable might contribute significantly to the overall model.

One factor, which was actually found to have an independent positive, though insignificant, association with mood state, given the overall model, was age. It seems likely that those who survive to great age are, both physically and psychologically, the most hardy.

Further additional factors which may influence pain coping include the time of year the subject was visited, diurnal effects and possibly the weather (Laborde et al 1986), although it was predicted that such effects would be relatively small, and no attempt was made to control for them. The theoretical model predicts that mental processing difficulties will disrupt control, although those with confusion or dementia were deliberately excluded from this study.

Finally, it is necessary to be alert to the possibility that missing variables, such as those suggested above, may exert particular influence upon people such as those who declined to be interviewed, or even return the initial questionnaire, in this study.

10.3 A critical analysis of the patient study

The above discussion is based upon assumptions that the results are sound, and that generalisation is possible. However this assumption is dependent upon the accuracy of the theoretical framework, the research design, the adequacy of the sampling procedures used, the use of a competent interviewing technique, and appropriate and accurate analysis of the data. These issues all require some critical analysis.

10.3.1 The theoretical model

The theoretical model, upon which this study was based, was a fundamental part of the research project. The literature review identified a wide range of existing approaches to the study of pain, many of which had examined the influence of a single variable or small group of variables. Most had used pain ratings as the measure of pain and sought to identify the influence of independent factors upon pain. In terms of coping, it was clear that coping was dependent upon a wide range of different factors, but that active coping was most adaptive. The theoretical framework was devised in order to establish how this process might operate, and how coping might be measured. It was clear that many measures of coping were in fact measures of process rather than of outcome. By establishing that mood state was a good outcome measure of coping, based upon the concept of control, it was possible to produce a research design which would identify independent factors which was predictive of that outcome. This entailed measuring not only the effects of pain, but the effects of additional stressors in the lives of elderly people. Thus pain was actually an indirect focus of the study.

The approach used appears to have been successful in producing interview data which has yielded a statistical model of best fit to the data, which is also congruent with the theoretical model. This has provided the basis for a comprehensive and integrated interpretation of the results. The similarity between the theoretical and the statistical model is best illustrated in figure 10a. Comparison is invited between this outcome model and the theoretical model which was proposed in chapter 2 (see figure 2b). It is apparent that the key elements predicted are included.

The model appears to provide fertile ground for further research, in pain and stress, at an environmental, psychological and physiological level. Fry (1989) recently observed a lack of clarity in the control construct, together with an absence of a coherent theory of the biological, genetic, social and environmental factors involved in stress production. The control construct, outlined in this thesis, is presented as a model for research. It is testable in the laboratory, using physiological measures of anxiety, as well as psychological measures of anxiety, hostility and depression. It is only by testing and retesting that it can ultimately verified, improved, or disproved. Marteau and Johnston (1987) reaffirmed the importance of psychological models, as opposed to the medical model, and this is of particular importance in the nursing management of pain. This model is primarily psychological, and has identified a nursing role which is of equal value to, and in many cases more important than, that of the doctor, in the care of elderly people with chronic intractable conditions.

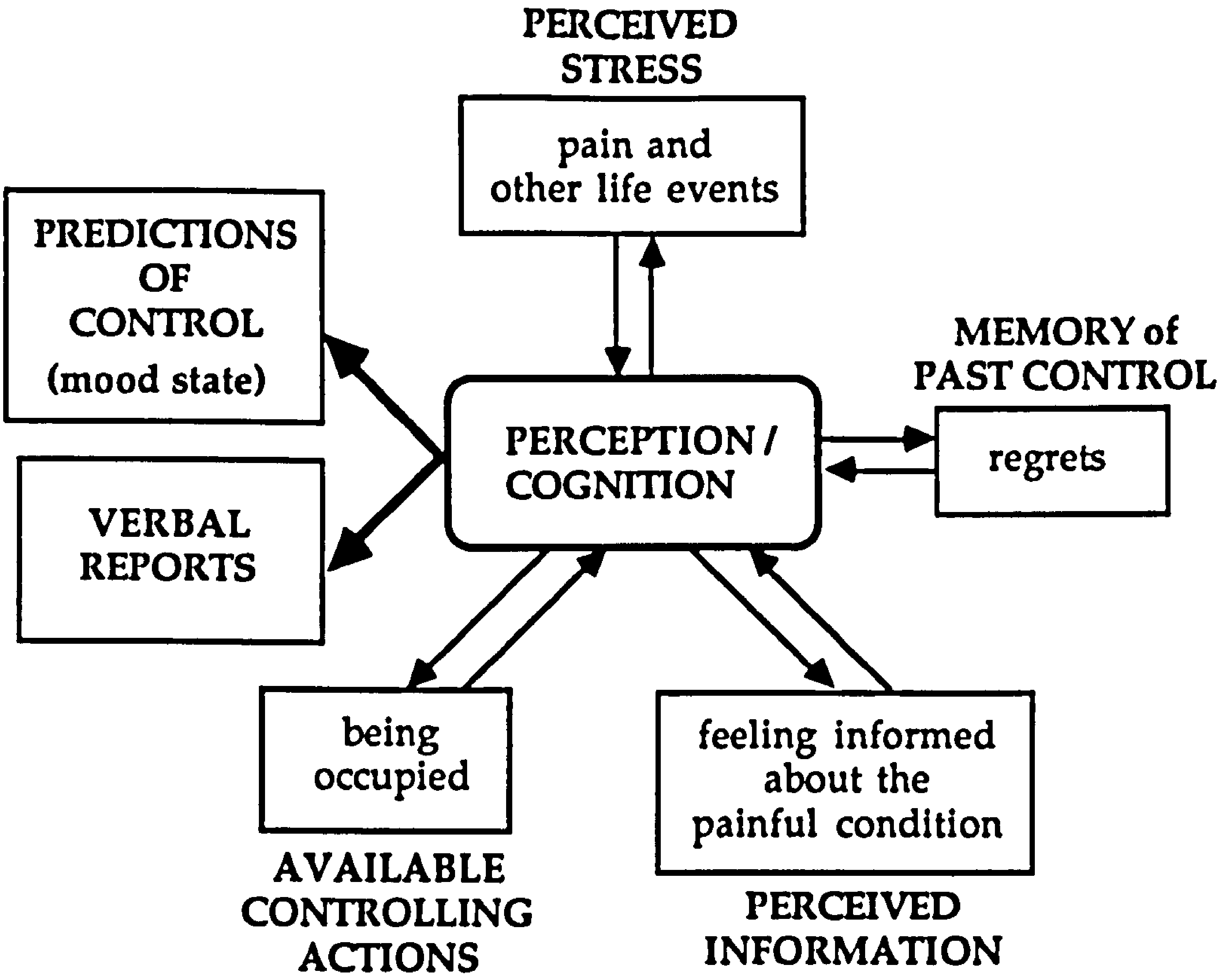


Figure 10a Outcome model of control

10.3.2 Sampling procedures

Analysis of the sampling procedures used in this study revealed a low response rate to the preliminary questionnaire sent out to patients. Identifiable factors indicate that this was probably due partly to the nursing distribution process adopted, and partly to reluctance and physical difficulties, on the part of some elderly people, in completing and returning the forms. It is difficult to determine how, in retrospect, these difficulties might have been overcome. It was necessary to include an element of randomisation into the research design and this was only practicable at the level of the practice team. Forms were not sent to the patients direct because not all practices had readily available patient lists. In addition, it was thought that patients would be more receptive to, and less threatened by, questionnaires delivered by their nurses, and that the nurses would provide assistance and encouragement in completing and returning the questionnaires. Although the response rate of less than 50 percent was not high, local evidence has been provided to suggest that this process of self-selection produced a sample which was adequately representative of the population of patients visited by district nurses. The results find much support among recent studies of the elderly. Overall, there is no reason to suppose that these results should not generalise to the population of elderly people with painful conditions.

The nurses' response rate, in completing patient questionnaires, was good, and respondents included all grades of nurses working in different types of practice and locality. The random sampling procedure used appears to have been successful in producing a representative sample of nurses from within the district. Responses to the nurses' personal questionnaires was lower. This could have been because too much was ultimately demanded of nurses participating in the study, because the nurses had no wish to provide personal information about their training background, or because of competing local bureaucratic demands. The results of this part of the study provide a fairly subjective insight, from the point of some nurses, into their attitudes on pain management, and should not necessarily be taken as representative of district nurses, as a whole.

10.3.3 The research design

The main difference between this, and previous pain studies, is that pain, and pain-related variables, are included alongside cognitive and objective stress measures, as predictor variables, with emotional response as the outcome measure. In this way, the influence of pain is examined in relation to other factors, as well as in relation to coping.

The second difference between this, and most other studies of coping, is that the measures used, with the exception of mood state, are based upon very simple self-report measures. This inevitably leads to questions about reliability. Nevertheless, the strength and nature of the associations between these variables, identified in the results, suggest that such self-report measures are appropriate for the collection of this type of data.

Physiological and perceptual feelings may be subjective, but perceptual information about internal events is more immediate than information concerning external events. Only the patient knows how he feels. If pain is what the patient says it is, then so too are other perceptions. Measurement scales based upon verbal reports lack precision, but it is argued that reporting accuracy is increased by the provision of distinct and decisive categories. Even those who were mildly confused about the day of the week, or even their age, were able, with minimal effort and little hesitation, to identify a verbal category to describe how they felt. It is argued that such results would not have been achievable, had standardised psychological inventories been used. Furthermore this approach has provided results which instantly accessible and meaningful to the nurses for whom they are primarily intended.

The interview schedule itself was administered in a more intimate manner than is normally the case in quantitative research. It is recommended that *"the job of the interviewer is to serve as a neutral medium of communication"* (Polit and Hungler 1983 p.318), in order to avoid the introduction of interviewer bias. This approach has recently been challenged, in the context of nursing research, by (Wilde 1989). She argued that the data she collected from nurses, about their attitudes to nurse training, was much more rich and informative once she allowed herself to engage in a greater rapport. In the study reported here, the subjects frequently asked the researcher for comments about aspects of their condition or situation. Although such comments were kept as non-committal and uninformative as possible until the interview schedule was complete, a failure to enter into dialogue with subjects about their experiences would have resulted in very poor sparse data. In fact the interview often resembled a counselling session, in which the researcher, like the counsellor, leads the subject, or client, to explore particular areas of experience, but makes no attempt to impose his or her own interpretations upon the answers received. Some of the brief case reports illustrate just how much information subjects were willing to volunteer upon a single encounter.

This was only possible given positive encouragement, interest, and some degree of self-disclosure, on the part of the researcher. Any interviewer effects were minimised by the fact that only one researcher was involved, although changes in the mood, and differences in the attitudes of different subjects towards the researcher may have introduced variability into the results. Some systematic bias might have occurred, which would affect the reproducibility of the study. For these reasons, a replication study may be considered desirable to verify the findings in a similar population.

The analysis of the results showed that much of the data was skewed. The mean mood score was skewed in a positive direction, and most of the predictor variables showed skewed distributions. Furthermore, the predictor variables were based upon ordinal verbal rating scales, rather than interval scales. This facts is of little importance when using non-parametric statistics, however the inclusion of these variables in multiple regression analyses is a more problematic issue. Statistical advice confirmed the utility of multiple regression as a modelling procedure for this type of data, provided the other assumptions of regression were fulfilled. These were carefully checked throughout. There was no evidence of multicollinearity from bivariate correlations, and the use of backwards, forwards and stepwise procedures confirmed this. The model finally selected as the best fit to both theory and data was, in fact, remarkably stable and robust. No variables among those included or excluded showed any degree of marginal significance, while the elimination of outliers had no effect upon the resulting model.

The most compelling argument in support of the resulting statistical model, is that all of the variables selected into the model were those which would have been selected as critical factors related to mood, using bivariate non-parametric procedures. The primary purpose of the regression analysis was to select out those which had a direct independent effect upon mood. Since the variables selected were readily explicable in terms of the theoretical model, while those which were not selected could be explained in terms of indirect effects, the use of regression appears to have been successful.

Overall the utility of multiple regression, in this particular study, lies in its use as an aid to interpretation. The results themselves do not stand or fall by the use of this somewhat controversial procedure, rather the pattern of interpretation is facilitated by its use.

The strongest reservation about the regression model concerns the resulting standardised weightings, which normally indicate the relative importance of each variable. It is suggested, in view of the distributions and characteristics of the independent variables, that these relative weightings are not likely to be of particular significance and should be treated with caution.

10.4 Conclusions to chapter 10

The results of this study, it is argued, appear to be statistically and theoretically sound. They are supported by much recent research from alternative sources. They also appear satisfactory at the level of common sense. In fact, in many ways, these results are so unstartling as to appear rather obvious. Perhaps this apparent weakness conceals the essence of a good nursing study. So much nursing care is accomplished by art, rather than by science. It is therefore gratifying when scientific findings confirm applications which appear intuitively reasonable and practicable. However the fact that something may appear obvious when it is pointed out, does not necessarily imply that it was evident all the time. There is ample reason, from the results of the previous chapter, to suppose that nurses are not currently aware of many of these aspects of pain, and that failure to manage pain adequately can cause much helplessness and frustration.

The only finding which, although tentative, contradicted current practice, was that, for patients with chronic intractable benign pain, pain-relieving drugs taken in accordance with the patient's own discretion, when most needed, appeared to be associated with a greater degree of well-being than drugs taken at prescribed intervals. Further research is clearly required before nurses start to encourage patients to alter their drug use, however there may be a case for nurses to stop encouraging the routine use of analgesic among patients, who have chronic pain, and who express a natural reluctance to do so.

Perhaps the most important finding was the confirmation of the theoretical model in terms of identifying the importance of the role for the nurse in the psychological management of persistent intractable pain. The nursing role is so often identified as secondary to that of the doctor in the treatment of the patient with pain. However when medical treatments are inadequate or unavailable, then the role of the nurse assumes paramount importance in improving and maintaining the patient's quality of life. These aspects of the findings are discussed in the final chapter, together with the results of the nurses' general questionnaire, concerning knowledge of pain management. The implications for nurse training are considered, and recommendations for the nursing management of elderly patients with pain, in the community, are given.

CHAPTER 11 IMPLICATIONS OF THE FINDINGS FOR NURSING, AND RECOMMENDATIONS

11.1 Consideration of the findings with respect to nurses' data

The discussion thus far has been concerned to explore and support the validity of the key research findings regarding patient coping, and the model on which much of the methodology was based. The remainder of the discussion is centred upon the nurses for whom these findings are ultimately intended.

11.1.1 Nurses' assessments of pain and coping

Comparison of the nurses' data with data obtained from subjects at interview shows that nurses systematically underestimated patients' worst levels of pain, regardless of duration of acquaintance and recency of contact. They were rather better at judging levels of least pain and the level of pain control, given recent contact. The nurses in this study placed emphasis upon the emotional effects of pain, rather than the physical and practical effects which were highlighted by patients themselves. In fact nurses overestimated patients' levels of anxiety, although they were fairly good at recognising depression and resentment. These findings support those of previous research by Davitz and Davitz (1981) and Johnston (1982), which demonstrated that nurses consistently underestimate pain and overestimate anxiety. These results suggest that nurses in the community are, for all their opportunities for intimate long term patient contact, little or no better than their hospital counterparts at judging patients' pain experiences. Furthermore, it is of particular concern that nurses who had received both general and district nurse training were no better at assessing their patients' pain than were untrained nursing auxiliaries.

The correlation between nurses' and patients' assessments of the extent of pain control was rather higher than that for levels of pain intensity. However the underestimation of pain control, which was found in the absence of recent contact, suggests that the nurses tended to rely upon impressions, based upon memory, rather than recorded assessments. This is supported by reports from 21 trained nurses which showed that only one regularly used any form of pain assessment protocol. Those who claimed to be proficient in methods of pain assessment and control were mostly those who had undertaken specialised courses in the management of terminally ill or elderly patients.

Nurses recorded that their main source of information about pain was more likely to be derived from experience, and from colleagues, than from training or journal articles. Most reported little tuition in psychological aspects of pain, although more, apparently, felt competent in the use of psychological methods of control. Nurses placed emphasis upon the importance of medical treatments in controlling pain. They stressed the importance of 'support' in the management of elderly patients with pain, although they generally failed to specify what, precisely, they meant by this. On the other hand, patients were more specific in recognising the value of nursing visits in providing encouragement, and in increasing and maintaining their confidence. Individual nurses, including auxiliaries, spontaneously recognised the importance of many of the individual factors identified in the research findings presented here, such as occupation and lack of fulfilment. However overall there appeared to be a lack of focus in pain assessment and management, which is precisely what this study set out to identify and, if possible, to rectify. 20 out of 21 nurses felt that they had received insufficient input in the management of chronic pain during their training. This deficit is reflected in the fact that in over 40 per cent of contacts, nurses felt that they had not been able to help subjects with their pain.

It is against this background that the finding of a strong relationship between nurses' reports of patients' pain complaints and perceived exaggeration of pain is of great concern. This result is, in fact, not surprising in view of previous research findings which have identified the cultural value which is placed, in this society, upon stoicism (Zborowski 1969). However it is clear that in this study, those who complained most were among those with the greatest coping difficulties. Hence they had the greatest nursing needs. The attitudes of nurses towards patients who are thought to exaggerate pain, identified in the general questionnaire, are very revealing. In particular, the subtle differences in nurses' responses to this issue appear meaningful. The nurse who regards a patient as needing attention may try to give her time willingly to help that patient. On the other hand, the nurse who regards exaggeration as an 'attention-seeking' device may be inclined to regard such patients less sympathetically, while the nurse who defines such patients as 'stubborn' shows a distinct undercurrent of resentment towards the 'difficult' patient.

The findings presented above confirm those of Kratz (1978). She demonstrated that nurses in the community feel helpless when unable to help alleviate long term suffering. Comments from individual nurses in this study support this view. Kratz suggested that hospital training did little to prepare community nurses for the management of chronic conditions. Davis (1984) suggested that nurses in hospital conform to a role model which may mitigate against the development of an understanding relationship with the patient. Whether or not this is as likely to occur in the community is open to debate. District nurses were all hospital nurses at one time in their lives. However it is possible that they have chosen to work in the community in order to escape from the very situation which Davis describes. Certainly nursing the patient in his own home encourages the development of a close relationship, as well as allowing a greater level of autonomy on the part of the nurse. This autonomy places great responsibility upon the shoulders of the community nurse. Labelling patients' complaints as exaggeration in order to gain attention merely dismisses the patients' coping problems and blames the victim for the misfortune of being in pain.

Before considering, in greater depth, the reasons for these findings, and their implications for nurse education, the other major findings of this study, with respect to the nursing management of pain, are discussed below.

11.1.2 The nursing role in pain control

While the majority of patients acknowledged the importance of supportive aspects of nursing in helping them to cope with pain, the results showed that many who relied upon regular nursing treatments for painful conditions recognised the importance of practical skills and continuity of care. There were, however, instances, identified during this research, where the organisation of nursing care was directly responsible for causing the patient pain. It is surely an anathema to provide twice weekly treatments when the fact that there are an odd number of days in the week ensures that the patient is left in excruciating pain for at least one day in seven. It must be possible to identify a more suitable routine, in conjunction with the patient, to avoid such distress. Indeed a simple assessment of pain intensity would instantly reveal this type of problem.

Another disturbing finding of this study was that some patients were taking potentially harmful drugs with little or no observable benefit, while their effectiveness was not being monitored by nurses. In fact in only two instances, out of reports on 93 subjects, was the assessment of medication mentioned by nurses. While deficiencies in other aspects of management may be excusable, there is no reason for an almost total absence of medication monitoring in this age group, particularly when the drugs involved are known to have common painful, and occasionally lethal, side effects.

Perhaps the most controversial indication from this study, and one which requires further research, is that concerning drug administration. Analgesics for continuous pain are often prescribed, by doctors, for regular use, for example three times a day, or four hourly. Several nurses in this study stated that they encouraged patients to make more regular use of analgesics. Indeed McGhie (1986) states that, for chronic pain patients, analgesics are given on a regular basis, rather than only when the pain is present, in order to make them less reinforcing. Many subjects who were coping well with their pain were, however, taking analgesics only when they felt them to be really necessary, and this generally meant once a day or less. Clearly not all elderly people are able, or willing, to make such decisions, but many are not being given the opportunity. They take tablets three times a day because they are told, on good authority, that it is good for them to do so. The patient, in this situation, is not in a position to judge whether or not this is the correct advice. Nurses, on the other hand, are in a position to question the validity of this approach to treatment.

There has been much research into the administration of pain-relieving drugs for the terminally ill, but none, so far as I am aware, into the regime of administration of analgesics to those with chronic benign conditions, such as arthritis. Pain is a relative phenomenon. It becomes impossible to detect the pain relieving properties of drugs, including NSAIDs, which are taken routinely over a long period of time. The patient can only really judge this by stopping them. Many patients feared taking regular analgesia because they thought they would cease to work effectively, or because they would not know if they were still effective. One subject regularly stopped taking her anti-inflammatory agent for a short period, in order to reassess its effectiveness. Such patients may well be right in their beliefs. However there is a real danger that the patient who chooses to exercise such discretion may be labelled as non-compliant. This behaviour may be seen as uncooperative, rather than adaptive. Advice by Walsh (1987) on how to deal with the uncooperative geriatric patient assumes that the doctor is always correct in his judgment. These results indicate that there may be instances when the patient is the best judge of what is good for him, particularly when it comes to his pain. The time is right for a reappraisal of drug administration for benign conditions involving chronic diagnosed pathologies, and there is no reason why suitably qualified nurses should not undertake such research, in conjunction with their medical colleagues.

11.2 The influence of nurse education on pain management

The remainder of the discussion investigates issues in the nursing management of pain, with particular reference to nurse training and education, and contains suggestions for improvements.

11.2.1 Psychology and the nursing management of pain

It has been argued, from the outset, that effective pain management must be based upon adequate assessment. However assessment is of little use, if it is not linked to appropriate strategies for intervention. It is of little value for the nurse to assess pain intensity levels, if this serves only to highlight the patient's predicament, rather than provide a basis for intervention. It is futile to recognise that the patient is anxious, or has low self-esteem, if the nurse has no clear idea of how to enhance coping. Reassurance is counter-productive if the patient requires information. It is of little value to recognise the importance of psychological factors in pain, if the nurse is unable to identify which psychological factors are amenable to therapeutic intervention, and how. Drugs to reduce pain are unlikely to be effective if the patient is consumed with bitterness about the past. Loneliness and depression are not likely to be cured by referral for a weekly visit to the day centre, if the patient has nothing to do with the rest of his time. No incident was identified, in this study, in which severe depression was found to be caused by pain alone. In other words there was no direct relationship between pain intensity and emotional response. Therefore management of pain, based primarily upon the level of pain intensity experienced, is unlikely to be successful. Inappropriate interventions, which are ineffective, may damage the nurse-patient relationship, while advice about treatment is unlikely to be heeded if the patient has no faith in the reliability of the nurse.

In these circumstances, psychology has, potentially, much to offer the nurse in the management of pain. Yet it is evident from texts on psychology, which have been produced especially for nurses, that little guidance in the nursing management of pain, particularly chronic pain, is offered. Some standard texts are reviewed, briefly, below, with reference to pain.

One of the most widely read texts on psychology for nurses is that of Altschul and Sinclair. In the third Edition (Altschul 1969), which is still on the nursing shelf of at least one major medical library, pain is not indexed. Neither is it indexed in the 5th Edition (Altschul and Sinclair (1981), of which several well-used copies were found on the shelf. In the 6th Edition (Altschul and Sinclair 1986), which is kept on the reference shelf, pain is allocated half a page. This is included in the chapter entitled 'Psychological disorders', and under the subheading of 'Psychosomatic disorders'. Gate control theory confirms that pain is truly psychosomatic in the real sense of the word. It not only involves both mind and body, but a complex interaction between the two. Nevertheless, it is perhaps unfortunate that Altschul and Sinclair should have chosen to include it under such as heading, since the term 'psychosomatic' is open to frequent misuse and misunderstanding within nursing. This was exemplified in the case example included in section 9.4.1, in which the EN dismissed a patient's problems as psychosomatic. In another standard text on psychology for nurses, now in its eighth edition, McGhie states of the term psychosomatic:

> *"at times this diagnostic category has been applied so loosely to such a wide variety of disorders that it has functioned as a temporary waste-bin for conditions whose physical aetiology is at the time unclear".*
> (McGhie 1986 p.161)

The two-page section on chronic pain by McGhie highlights vividly the scenario in which chronic pain patients persist in seeking relief from the medical profession for their predicament, while doctors and nurses eventually label such patients as attention - seeking pests. The findings of this study tend to confirm that this view applies also to elderly patients. When the majority of patients in the community cope well, in spite of pain, it is hardly surprising that those who cannot cope are eventually blamed for their own inability. This is particularly likely to be the case if there is little understanding of past or present factors which mitigate in favour of, and against, coping. McGhie's text on psychology for nurses, like that of Altschul and Sinclair, makes reference to gate control theory. It is suggested that pain is under the influence of higher brain centres, and that emotional and psychological components of pain are of considerable importance. However what, precisely, does this mean to the nurse who is faced, day after day, by the patient who complains of uncontrollable pain? I suggest not a lot. McGhie suggests referral to a pain clinic, where behavioural treatments are available. He suggests that such treatment can help to reestablish the patient's ability to control his pain experiences, rather than being a helpless recipient of them. In this he is undoubtedly quite right, but he fails to identify a role for the nurse in this process. This tends to confirm her helplessness, particularly when medical referrals have been exhausted. Furthermore it is doubtful, in view of the limited resources available, if he ever intended this suggestion to apply to elderly people.

The psychology text for nurses by Hall (1982) includes a whole chapter on pain by Ray. However even this is written very much from the point of view of the psychologist, rather than the nurse. It includes sections on personality and culture, rewards and expectations, theory and research, somatic and psychological therapies and psychological preparation for painful procedures. This latter section is one which has been developed within nursing itself, and reference is made to nursing studies on the subject. However the other sections are presented very much from the point of view of psychological research and theory. For example the section on psychological therapies includes behaviour therapy and hypnosis, neither of which fall within the competency of most district nurses. This also serves to place emphasis upon psychological procedures, rather than applied psychology in relation to care. It is not until the last section that Ray provides final comments which are pertinent to community nursing:

> *"the total care of the pain patient should be concerned not only with the relief of pain but also with the psychological stress to which this suffering can give rise ... it is important to adopt a balanced approach in the care and management of the person in pain, helping him to help himself while at the same time providing the sympathy and reassurance to reduce anxiety and prevent despair".* (Ray 1982, p.343-4)

These sentiments are entirely in harmony with the research findings of this study. Yet they are general, if not vague, and, even against the background of the chapter as a whole, they surely leave the nurse wondering how she can achieve such a delicate balance of management with the knowledge and skills available to her.

Of the texts on pain produced by nurses, the management of acute pain is covered comprehensively by Sofaer (1984b). The text which is most wide ranging in its discussion of all aspects of pain management, and which is most widely quoted by others, is that of McCaffery (1979). This is written, for nurses, by an experienced nurse who provides thoughtful consideration of many of the aspects of pain covered in this thesis. However it based largely upon logical, but intuitive assumptions, rather than upon research. Reasons why this is of importance to nursing, in the 1990s, is considered in more depth below, in relation to the changes which are currently taking place within nurse education.

Nurses, in this study, identified training deficits in all aspects of pain management, during general and district training. Since this research has identified psychological aspects of management to be most critical, in terms of nursing care, the teaching of psychology to nurses must be of critical importance. If standard psychology texts for nurses are inadequate to meet the needs of nursing pain management, then it is realistic to believe that the teaching of psychology may, in some instances at least, present similar deficiencies. Wattley and Muller (1987) confirmed that poor teaching of psychology to nurses is a problem. They suggest that academic psychologists tend to stress theory, rather than application, while clinical psychologists tend to stress abnormal aspects of psychology. Both of these comments are pertinent in the context of pain, as highlighted by the literature reviewed above. Wattley and Muller stress the need to teach applied psychology which is prescriptive, and which encourages nurses to try out ideas and knowledge in practice.

From the point of view of nursing practice, pain management demands that the nurse should be able to assess the patient from a physical, psychological and social perspective, and integrate this information in the formulation of a plan for intervention. Myles (1987) observed that if student nurses are required to assess their client's biopsychosocial needs and formulate an individualised plan of care, it is logical to propose that they will need an adequate foundation in the biopsychosocial sciences from which they can base and rationalise their care plans. Myles reviewed the contribution of psychology to nurse education and identified that although psychology was making an expanding contribution within the curriculum, studies in the early 1980s revealed that nurses still felt inadequate to meet patients' emotional needs. One of the reasons, identified for this, was that the medical model of care had militated against an emphasis on psychology.

Since that time, the syllabus for psychology in nursing has been extended to include a wide range of relevant topics, including individual differences, emotion, adaptation, effects of ill-health on behaviour, interpersonal skills, life-span development and family systems. All of these areas are relevant to the management of pain in the community. Yet it is one thing to have knowledge of these individual aspects of psychology, and quite another to be able to apply them, effectively, in a complex situation, such as helping an elderly person to cope with chronic pain. It is often much simpler for the nurse to rely upon the familiar, ubiquitous, medical model of care.

11.2.2 Nursing and the medical model

The prevalence of the medical model in nurses' attitudes to pain management was highlighted by a recent personal experience of reporting these research findings to a group of nurses undertaking an ENB course in the care of the elderly. The title of the talk was 'The nursing management of elderly patients with pain'. I later received a letter from the tutor which suggested that the title had misled the students to anticipate methods of pain relief. She therefore suggested that the title should be changed for future reference. It appears that nurses, even nurse tutors, make little distinction between the medical and nursing management of pain.

Nurses work closely with doctors whose medical training, in many cases, fails to equip them with an holistic view of pain and suffering. Marcer and Deighton (1988) revealed a large gap in the knowledge of general practitioners about pain, and identified the very limited role accorded to the behavioural sciences in the undergraduate curriculum. Even Melzack (1986) expressed the fear that doctors were still being taught specificity theory in schools of medicine. The negative implications of this were considered in chapter 1. The findings of this study showed that nurses were quite likely to attribute successful pain control to medical treatments, and to seek medical treatments for uncontrollable pain. Patients, themselves, were much less likely to attribute pain control to medical treatments than to their own efforts and attitudes. If nurses continue to rely upon doctors to control patients' pain, while medical education remains so woefully inadequate in this field, then patients with the greatest needs are likely to receive inadequate care.

11.2.3 Nursing models

The introduction of holistic models of nursing has been a relatively recent event. These were largely born out of dissatisfaction with the medical model, yet there is no definitive nursing model. The number of models available appears to reflect uncertainty about the precise nature of nursing, and about patient needs. I have argued (Walker and Campbell 1989) that even the models in common use do not satisfactorily address all of the issues involved in pain management, either at a theoretical level, or at the level of application. Yet is certainly right, from the point of view of pain management, that holistic models, based upon psychology and social psychology, as well as physiology, should take the place of the medical model.

The research presented here is used to produce guidelines for the nursing management of pain. However the theoretical model, upon which it was based, was not a model of pain, but a model of stress in which pain was identified as but one potential stressor.

In this respect, the model shares much in common with popular models of nursing, such as those of Roy (1980) and Neuman (1980), both of which focus upon stress and use a biopsychosocial approach.

Nursing models tend to be complex, and most are not entirely clear or easy to understand. For this reason they were rejected as theoretical models for this research in favour of one which was built upon fundamental principles, and which identified clearly which variables were dependent, and which were independent, for the purposes of analysis. Nevertheless nursing models require research which is designed to test and improve them. The theoretical model used in this research may help in this process, since it is not only testable, but there are many areas of overlap and similarity with existing models. For example the concepts of self-care, adaptation, activities of living, stress and well-being, which are to be found in popular nursing models, are all incorporated into this research. Furthermore, since nursing models already form an important part of the nursing curriculum, they provide a useful basis from which to relate psychology to nursing practice. Such an approach would, I suggest, be particularly useful in helping nurses to understand the complexities of pain experience from an early stage of their education, and help to relate nursing and psychology theory to nursing practice in pain management.

11.2.4 Project 2000

This research has taken place at a time when nursing is anxious to establish itself as a professional autonomous body, and when dramatic changes in nurse education are about to be implemented, based upon the report Project 2000 (1986) . This report states states:

> *"The practitioner of the future should be both a 'doer' and a 'knowledgeable doer'. S/he should be able to marshal the the relevant information to make an assessment of need, to devise a plan of care consequent upon that assessment, to implement, monitor and evaluate it".* (Project 2000, 1986 p.40)

The above quote encapsulates much of the philosophy of Project 2000. In this, the nurse of the 1990s, and beyond, is envisaged as a practitioner whose role is determined and evaluated by the use of scientific research, and in which the art practised by the individual nurse is based upon sound scientific reasoning. The quote also encapsulates the principles of pain management espoused by this research. Thus it is of concern that these results should identify no effects of training upon nurses' assessments of their patients pain. Although there was much evidence of excellent nursing care in the community, it appeared to be as likely to be practised by auxiliaries as by qualified district nurses. It is desirable that the art of nursing should be maintained, but that it should be supplemented by a systematic approach to care which has a firm scientific basis. It is no longer enough to do things, simply because they have always been done that way. Neither is it sufficient to do things because the doctor says that is what should be done. Nurses have, for years, accepted a role which is subordinate to that of the doctor, and this is precisely the image which the profession is endeavouring to rid itself of at present. Nurse education for the future demands research of the highest quality to support a range of nursing options in the care of patients. It also requires innovative models and methods which challenge traditional medical perspectives. This research project was initiated as part of this process.

The implementation, in the near future, of project 2000 provides an opportunity for a renaissance within nursing. Nurse education will, for the first time, give priority to college-based, rather than practice-based learning. This will encourage the acquisition and application of a body of research-based nursing knowledge, free from early pressures to conform to a task-oriented medically-dominated role. Nursing is an attractive profession for those who wish to work with people. It provides a unique opportunity for helping and caring while, at the same time, encouraging patients to maximise their own health potential. The theoretical model for this research has clearly identified the role of the nurse, in relation to pain management, in assisting patients to regain, and maintain, self-control.

This is entirely congruent with models of nursing which advocate self-care or adaptation. It is therefore envisaged that the research findings, and recommendations resulting from this study, are entirely in accordance with current nursing ethos, and make a useful addition to the body of nursing knowledge which will form the basis of the future profession. In particular, the findings of this study relate directly to the requirement for nursing competence, identified within Project 2000, that the nurse should *"recognise common factors which contribute to and those which adversely affect physical, mental and social wellbeing of patients or clients and take appropriate action".*

11.2.5 Summary of the implications of this study for nursing

The research described in this thesis was based upon the premise that psychology has an important contribution to make to the nursing management of the patient with pain. The results have supported the theoretical view that a psychological approach provides the nurse with a unique and fundamental role in pain management for the elderly. This research is based, wholly, upon biopsychosocial theory and research. The biological element is based upon gate control mechanisms and those of stress. The psychological element includes coping, adaptation and controllability. The social element is predominently that of the caring perspective. The research was designed to provide results which are accessible to nurses at all levels. In this way, it is hoped that nurses will be encouraged to implement them in practice. At the same time, it is hoped that findings, such as these, provide a basis for a better understanding of the relevance of psychological theory to nursing practice. The nurse who not only knows what, but understands why, will have the confidence to know how to respond to the needs of individual patients. Such a nurse will be encouraged to seek alternative causes for patient's coping difficulties, to implement innovative solutions, and is freed from total dependence upon medical solutions to the problems of pain.

11.3 Recommendations

11.3.1 The management of elderly patients with pain, in the community

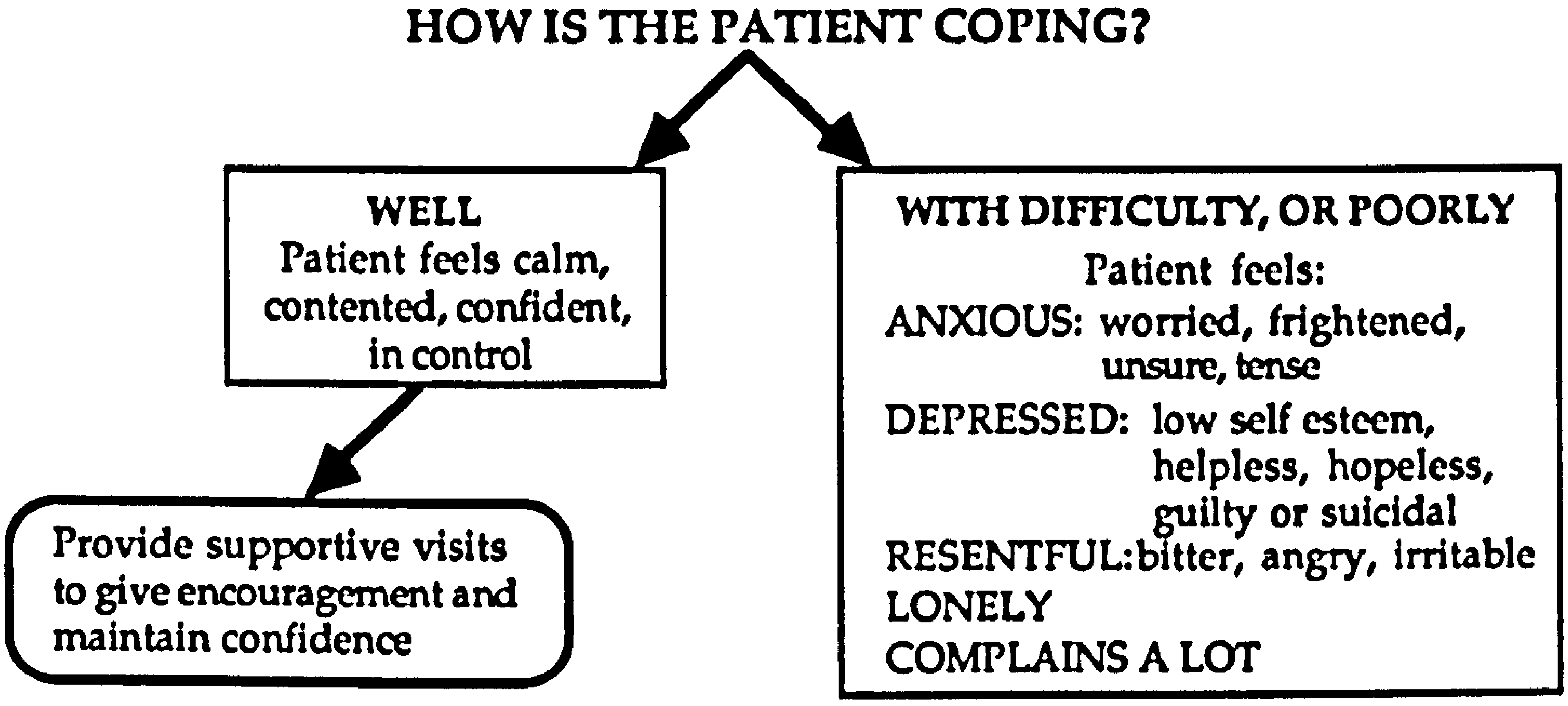
The role of the nurse in pain management depends firstly upon recognising all of the important factors which are likely to indicate, and influence, pain control and coping. Secondly, it depends upon the assessment and recording of all of these factors. Thirdly it depends upon the identification and implementation of suitable methods of nursing intervention, in which decisions must be made about priorities for each individual patient. Finally, it depends upon regular evaluation, so that the effectiveness of interventions may be judged, and strategies changed where necessary.

It is important to note that all of the coping factors, identified in this research, were based upon patients' reports of how they felt, rather than upon any objective observation. A patient might appear to have things to do but, if he does not feel involved, he may not feel occupied. Pain may be of moderate intensity, yet feel out of control. It is this type of incongruence which so often lies at the heart of patient / nurse misunderstandings. Patients are not always accurate in their reporting of events. They may, on occasions, be dishonest about their behaviour. Yet we must accept that only the patient knows how he feels. The essence of good nursing assessment lies in eliciting and recording those feelings accurately.

A plan for assessment, together with suitable interventions is outlined below. It is anticipated that it should be used in conjunction with a verbal pain rating scale, such as that of Raiman (1986). It is intended to help nurses of all grades, however it is based upon an anticipation that nurses should undertake only those interventions for which they are suitably qualified and competent. Referrals to counsellors, occupational therapists and self-help groups should be utilised wherever appropriate.

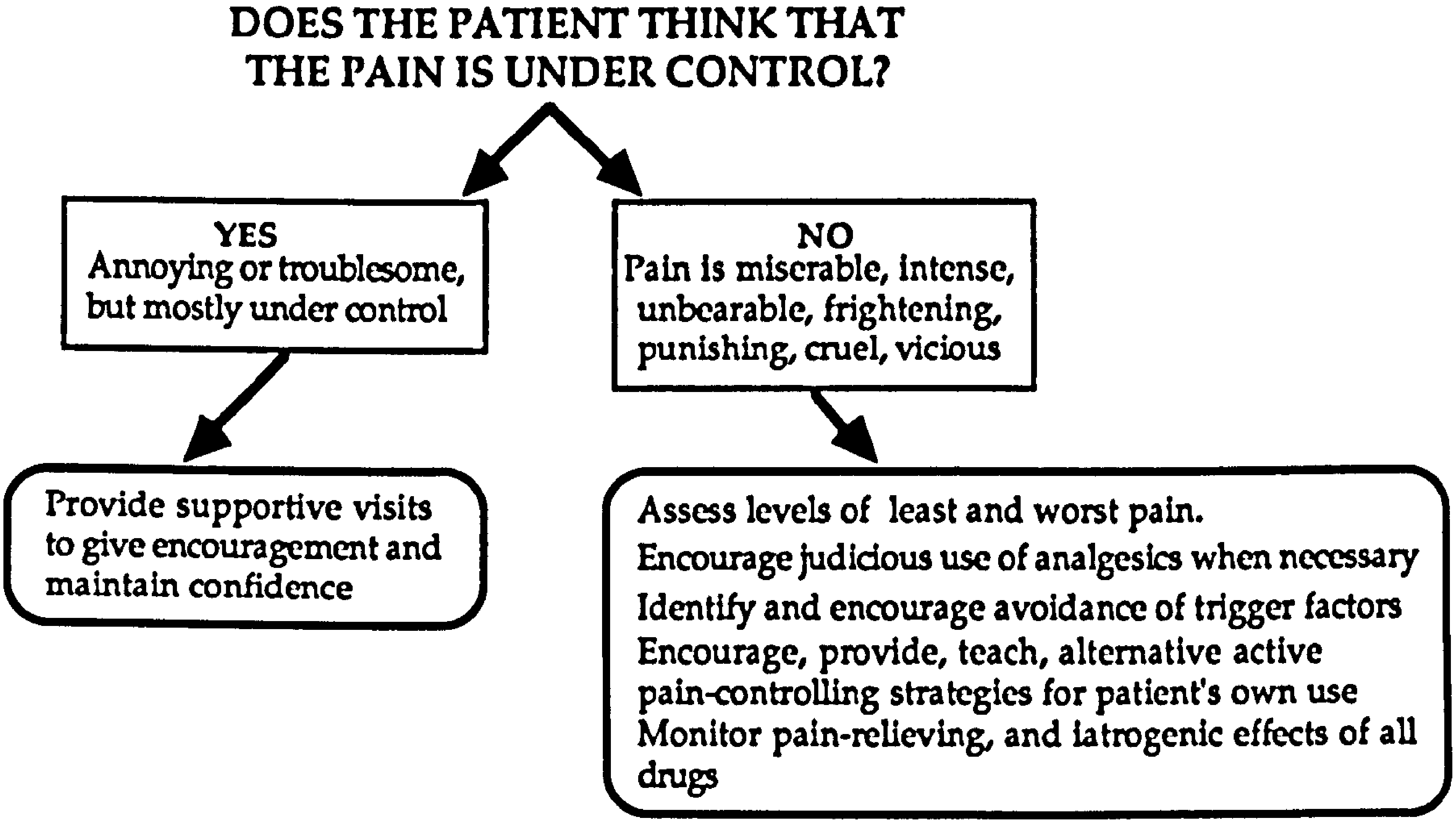
It is envisaged that interventions should be formulated on the basis of the total assessment. Thus the plan does not represent a stage-by-stage approach, nor does it indicate an order of priority for intervention - that is for the nurse to judge in relation to the needs of the individual patient. It is envisaged that assessment and plans should take place, as far as possible, with the patient, rather than about the patient. This is in order to enhance opportunities for self-control. The nurse should always anticipate future changes in circumstance which represent potential stressful events. In addition, the perspective of carers should be included in all assessments and planned interventions.

The first stage of the process is to assess the patient's current coping status.



If the patient demonstrates feelings of contentment, confidence and feels in control most of the time, then he or she is coping well, but may continue to benefit from supportive visits. If s/he demonstrates anxiety by feeling worried, frightened, unsure and tense; if s/he is depressed and feels useless, hopeless, guilty and has low self-esteem generally; if s/he expresses resentment, is bitter, angry or irritable; if s/he complains a lot or feels lonely, then s/he is not coping, or has coping difficulties which may benefit from nursing intervention. This assessment will be based upon observations made during nursing visits, and by direct questioning. All information should be recorded.

The next step is to assess if the patient is in pain and, if so, if the pain is felt to be under control; if the patient feels well-informed about the painful condition; if the patient feels occupied; if the patient feels dissatisfied and has substantial regrets; if s/he has other problems to cope with; or if there are any other potentially relevant reasons why the patient may not be coping well at the present time. Nursing interventions which are appropriate for each aspect of this assessment are suggested below. However the nurse must judge for herself which intervention is most appropriate, and which should take precedence, since the order described here does not necessarily reflect an order of priority for intervention. For example it may entirely inappropriate to encourage increased occupation until the patient has come to terms with a bereavement. Likewise, it may be inappropriate to encourage pain-control strategies while the patient remains ill-informed about the nature of his condition, or harbours deep regrets which influence his or her whole attitude to life. Thus the scientific method identifies critical factors, but the art of nursing may, at least for the present, lie in ascertaining priorities for nursing interventions. These may well vary across individuals, and depend upon prevailing circumstances and constraints.



DOES THE PATIENT THINK THAT THE PAIN IS UNDER CONTROL?

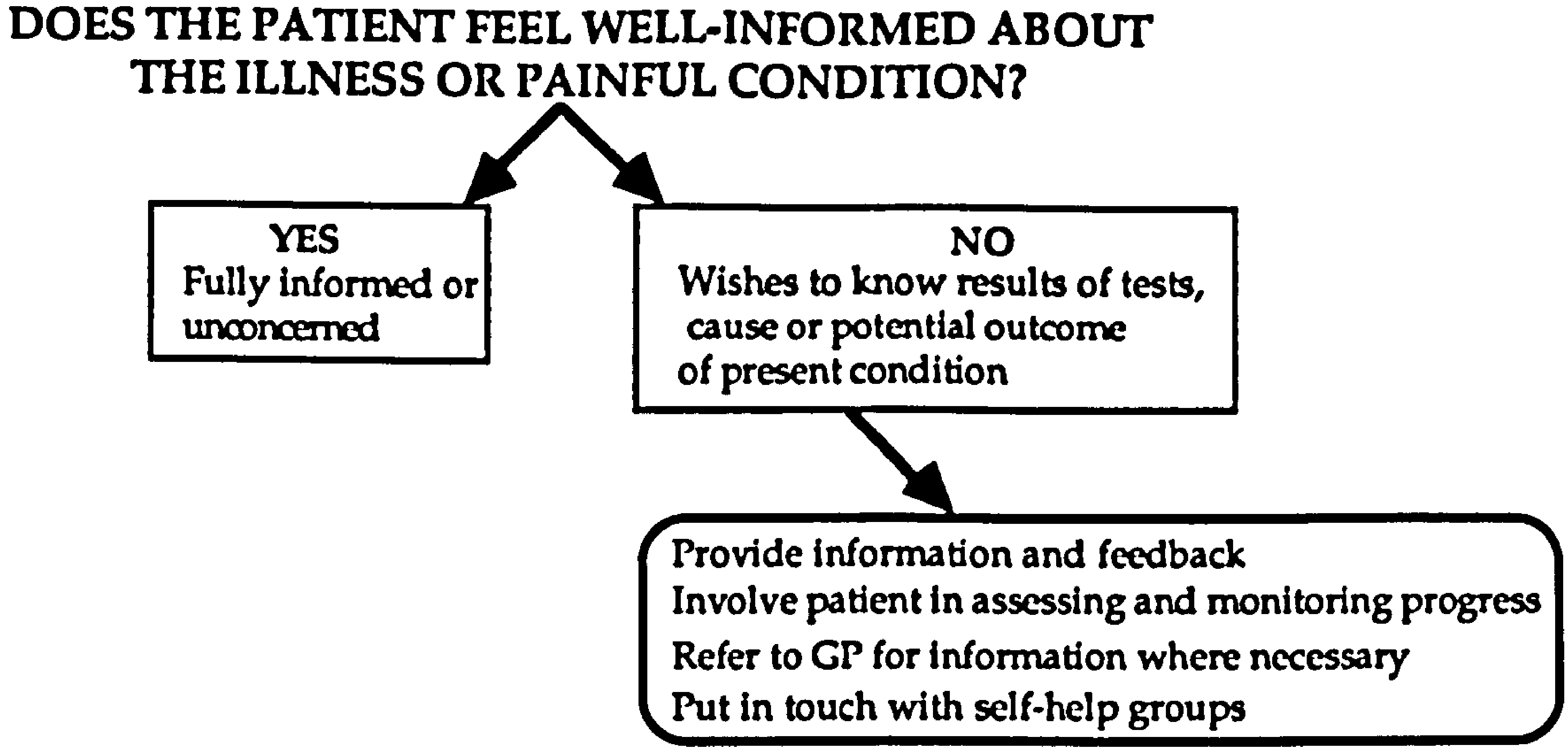
YES
Annoying or troublesome, but mostly under control

NO
Pain is miserable, intense, unbearable, frightening, punishing, cruel, vicious

Provide supportive visits to give encouragement and maintain confidence

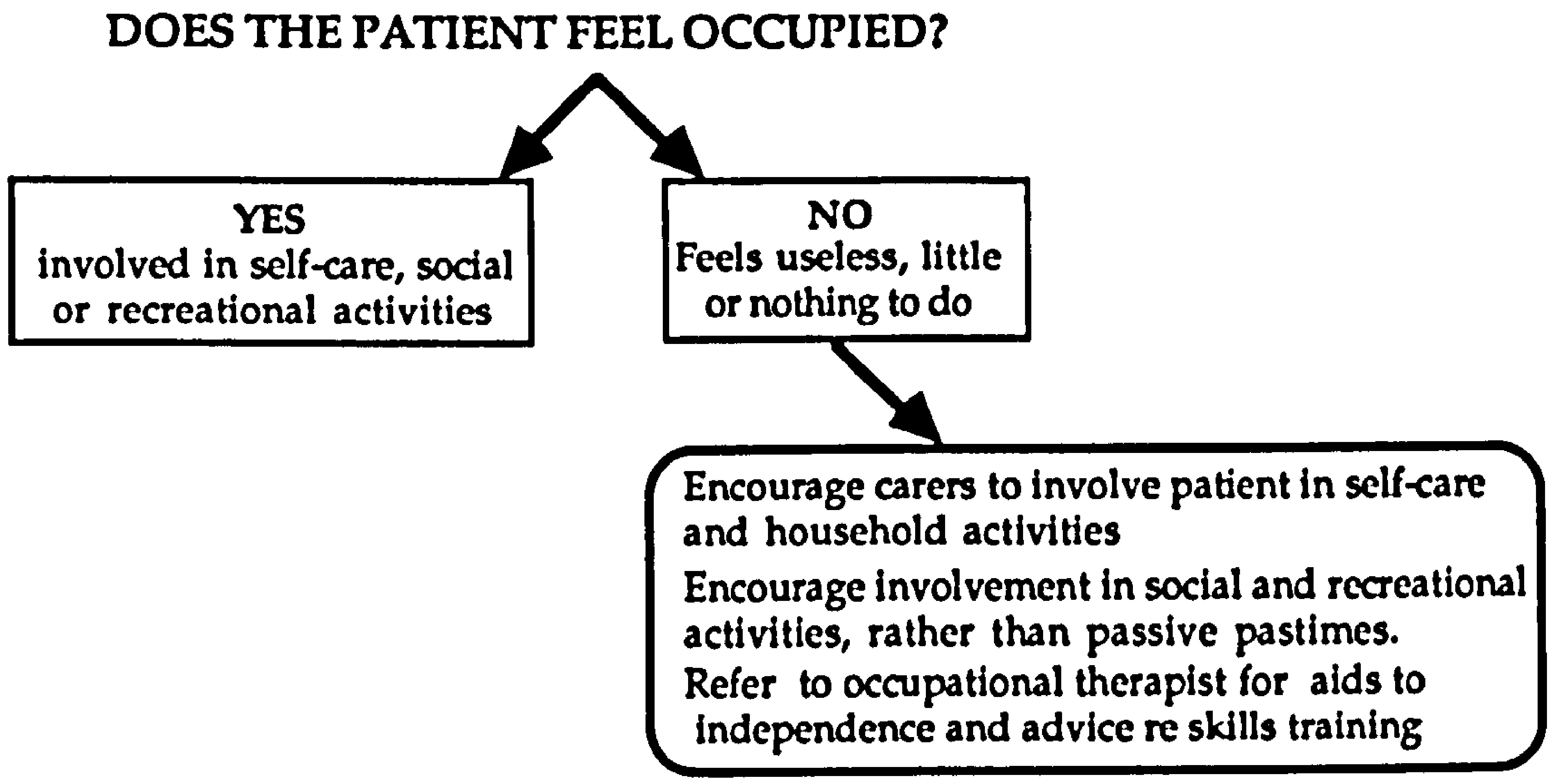
Assess levels of least and worst pain.
Encourage judicious use of analgesics when necessary
Identify and encourage avoidance of trigger factors
Encourage, provide, teach, alternative active pain-controlling strategies for patient's own use
Monitor pain-relieving, and iatrogenic effects of all drugs

Pain descriptors from the evaluative, fear and punishment scales of the MPQ are utilised in helping to establish the level of pain control, since they were identified in the study to be good predictors of pain control. Thus if the patient has pain which is described as annoying or troublesome, but mostly under control, then the nurse should record these findings and offer continuing supportive visits for the purpose of providing encouragement and maintaining the confidence of the patient in his or her ability to cope. It is also useful to record levels of pain intensity for future reference. If the pain is described as miserable, intense, unbearable, frightening, punishing, cruel or vicious, and is not felt to be under control, then levels of worst and least pain should be recorded, in conjunction with the times and circumstances when these levels occur. This assessment should enable the nurse to identify trigger factors which exacerbate the pain, and situations in which the pain is temporarily alleviated. All pain-relieving drugs should be carefully monitored for their effects with a view to changing or discontinuing them if they appear to have no noticeable effect. For those patients with chronic intractable pain, such as arthritis, patients should be encouraged in their use of discretion, to take analgesics when they judge their need to be greatest. Patients should also be encouraged to use their own alternative pain reducing strategies wherever possible, and taught to use additional self-control strategies, including TENS, heat, massage, topical sprays, and creams, wherever appropriate. If the patient contemplates using a strategy of doubtful utility, he or she should be encouraged, provided it can do no harm, to record the results for their own benefit, as well as that of the nurse and other patients. This should provide additional opportunities for the patient to gain control, even if the treatment proves ultimately to be a failure. Nurses should also apply their own initiative to ways of promoting self-control over the pain.



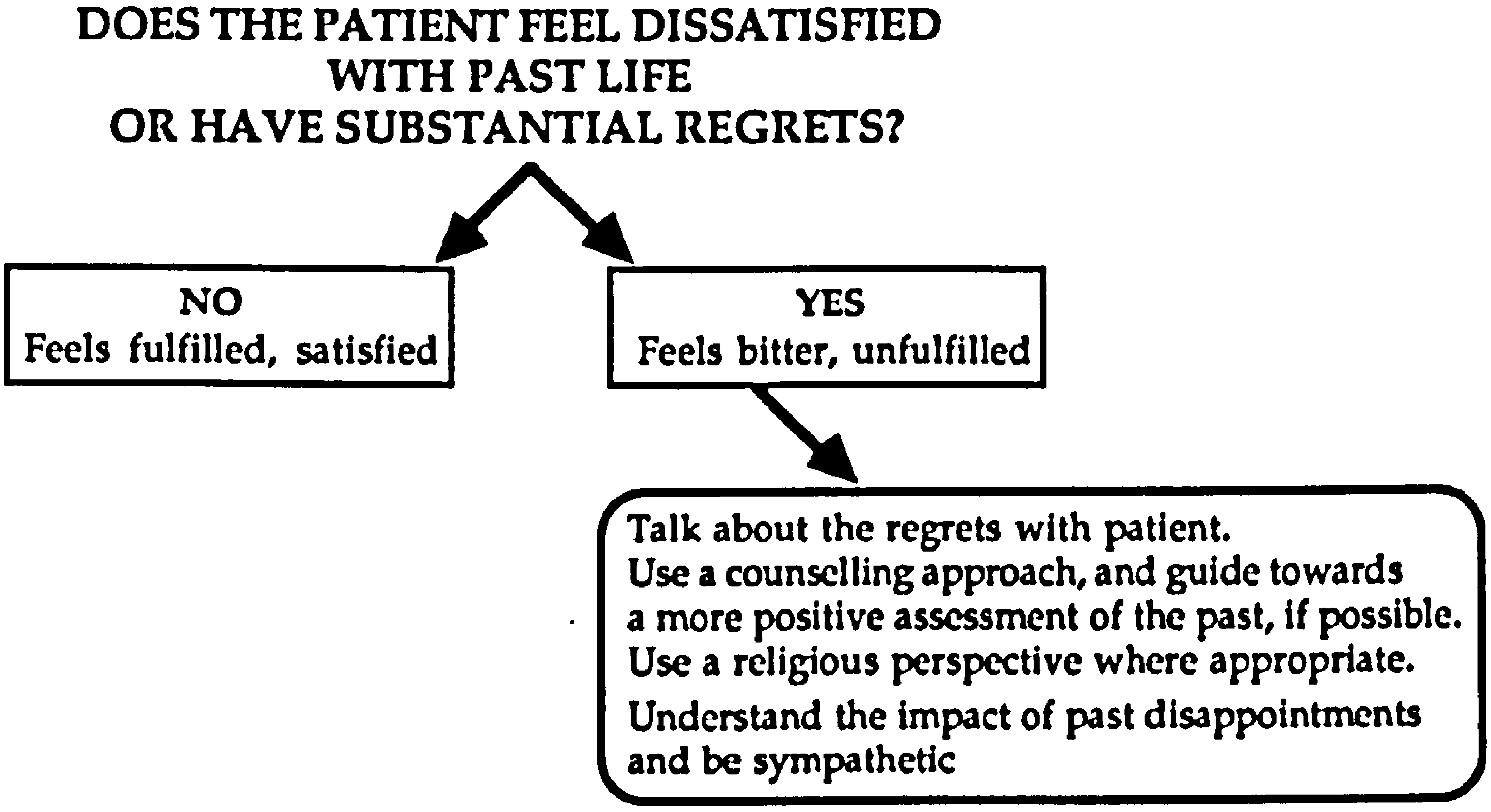
The nurse should assess whether or not the patient feels well-informed about the illness of painful condition and should record this. If the patient expresses the wish to know the results of tests, the cause or the potential consequences of their present condition, then the nurse should take steps to find out and either inform the patient directly, or ensure that the doctor informs the patient. If the patient is inclined not to believe the nurse, then the doctor should do so. Self-help groups are excellent sources of information about specific conditions and their treatments, and patients should be put in touch with them wherever possible. If the nurse is doubtful about whether or not the provision of complete information is appropriate, especially where the patient has a serious condition, every attempt should be made to elicit the patient's views. If the patient is already highly anxious, then information is unlikely to make matters worse, provided ongoing support, and opportunities for discussion are provided. The information referred to here is the verbal kind, however it should be remembered that information is also available to patients from the non-verbal behaviour of nurses and carers. Non-verbal cues often lead the patient to anticipate the worst, even when no explicit indication has been given.

The nurse should inform the patient about all changes in treatment, together with potential side effects, and invite the patient to record possible adverse effects. Steps should be taken to ensure continuity of care when regular dressings are required, by inviting the patient to hold or maintain a record of progress. This ensures that the patient has some degree of control over a protracted treatment, and allergic and adverse reactions can be picked up early.



The nurse should assess if the patient is well occupied, and if s/he is engaged in self-care, social or recreational activities. This should be recorded. If s/he feels useless, and has little or nothing to do, then plans should be made to help rectify this. If the patient lives alone, then the nurse should ensure that s/he has adequate aids to independence to be able to participate in self-care activities. The nurse should encourage participation in social activities by making referral to a day centre, church or secular group where appropriate, and endeavouring to encourage interim activities in the home. For patients with multiple disabilities, for example deafness, blindness or loss of motor control, then referral may be made to the occupational therapist for advice. If the patient is cared for by another, then the nurse should encourage the carer to maximise opportunities for self-care and participation in household management. The nurse should, wherever possible, motivate the patient to actively fill his or her time. The precise nature of occupation will depend entirely upon the patient's available skills and preferences. Patients should always participate willingly, or not at all. The art lies in motivation.

Where television is the only available resource foroccupation, the patient should be encouraged to report upon programmes s/he has watched, since involvement in discussion may provide impetus to active, as opposed to passive, engagement in television viewing.

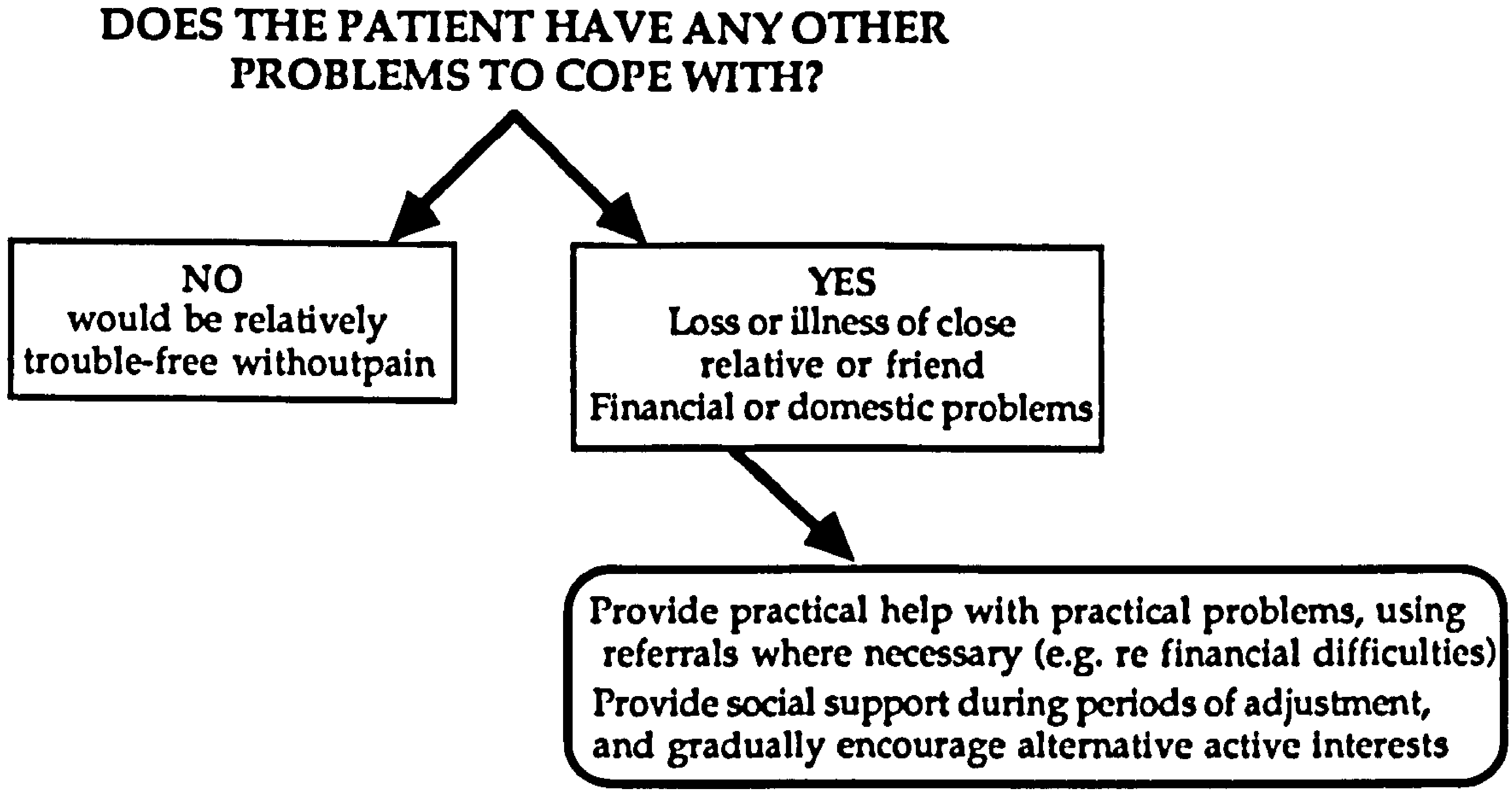

DOES THE PATIENT FEEL DISSATISFIED WITH PAST LIFE OR HAVE SUBSTANTIAL REGRETS?

NO
Feels fulfilled, satisfied

YES
Feels bitter, unfulfilled

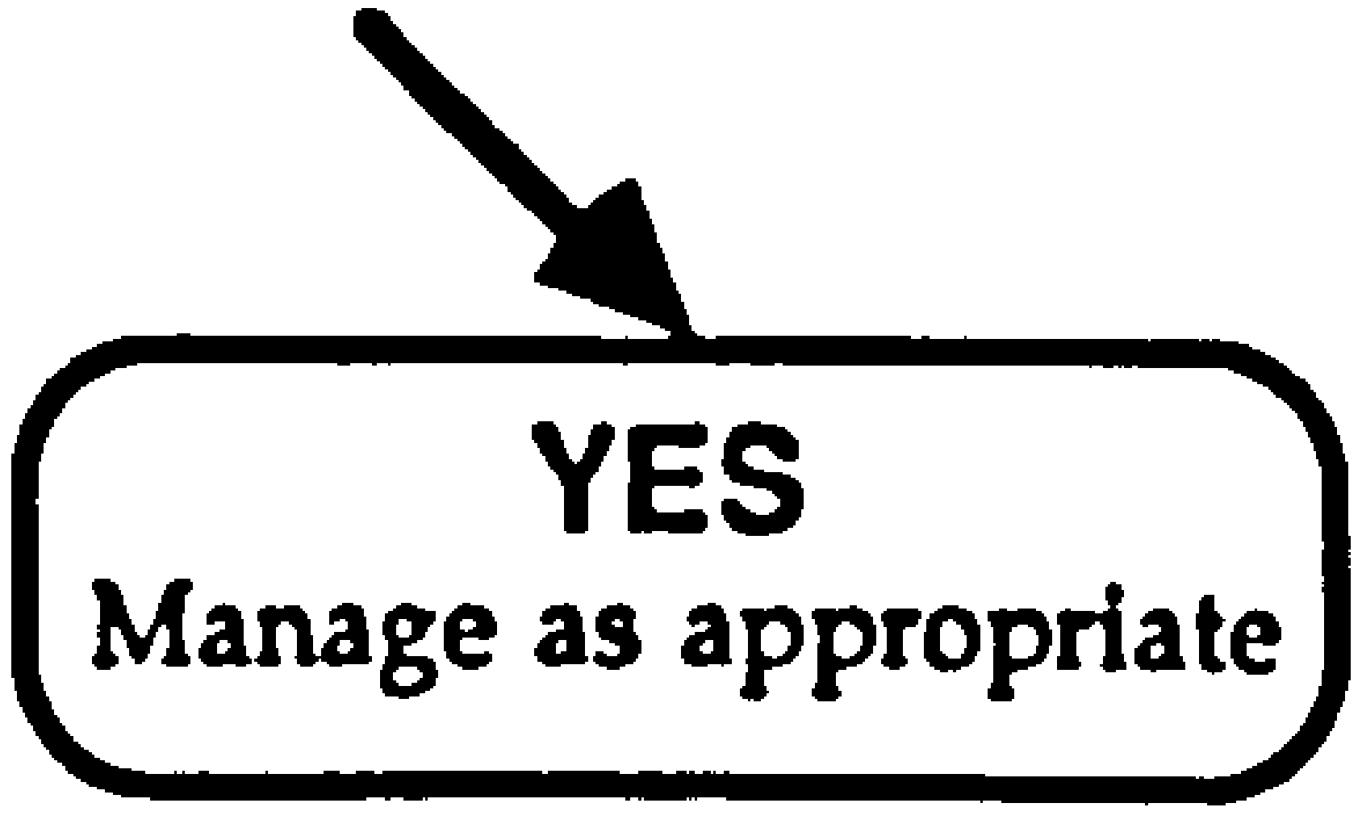
Talk about the regrets with patient.
Use a counselling approach, and guide towards a more positive assessment of the past, if possible.
Use a religious perspective where appropriate.
Understand the impact of past disappointments and be sympathetic

The nurse should record if the patient has any substantial regrets in life, and if s/he feels bitter, dissatisfied and unfilled. If s/he expresses such feelings, then the nurse should encourage the patient to talk about them. If they concern a specific incident, or set of incidents, then it may be possible, over time, to guide him or her towards a more realistic and positive assessment of the past. A religious perspective may be helpful, particularly if the patient feels that God has abandoned him or her to a life of suffering. If the regrets are overwhelming, it may still help the patient to realise that a caring person understands and sympathises. It may also help the nurse to understand why the pain complaints remain unresolved; that the patient's lack of pain control is not due to nursing failure, but to events of the past which have pervaded every aspect of the patients' life and mitigate against all attempts at help. These patients are often the most difficult people to like and to help. Yet they, possibly more than others, deserve care, and should, under no circumstances, be abandoned or rejected.



The nurse should assess if the patient has any other current problems to cope with, and should record this. If the patient has suffered the loss or illness of someone close, or has financial or domestic problems, then the nurse should ensure that s/he is provided immediately with any necessary practical help. This may involve referrals, especially where financial difficulties are concerned. Above all, the nurse should listen to patients' problems and provide empathy while the patient comes to terms with the loss or change in circumstance. The patient may then be gradually encouraged to develop new interests, occupations and skills which will act as a buffer against future loss of control. It may help to put the patient in touch with others who have experienced similar difficulties, and have taken steps to overcome them. As with regrets, it may help the patient to share the problem and know that there is at least one person in whom he or she can confide. S/he may not expect that the nurse should necessarily take any action on his or her behalf, and such action should, in any case, not be undertaken without the patient's informed consent.

ARE THERE ANY OTHER POSSIBLE REASONS FOR NEGATIVE FEELINGS, e.g. DEATH ANXIETY, CONCERN ABOUT THE FUTURE, DRUGS, ALCOHOL, DEMENTIA?



Finally, the nurse should consider any other reasons why the patient may have coping difficulties. If a reason has not yet been identified, or the reason appears out of proportion to the degree of negative mood identified, then there must be a reason. Possible suggestions include drink problems, fear of death or future loss of independence, iatrogenic effects of drugs, undiagnosed physical health problems, the onset of dementia, or the failure to disclose the true situation during the course of the previous assessment. Likewise, the nurse may care to be wary of undue euphoria in the face of current stress. This may, in some instances, be due to unrealistic predictions of control, and precede loss of control. Such patients require careful monitoring. This highlights the importance of the interpersonal, observational and analytic skills of the community nurse. It is one thing to predict the probable causes and consequences of stress at a statistical level, and quite another to make accurate predictions at an individual level. There will always be some individuals who appear to confound these predictions.

The necessity to record each assessed item is stressed throughout, because it is upon this that interventions are planned, and upon which evaluation must be based. If an intervention fails to succeed, it is only by reference to the original assessment that the nurse, or her successor, can judge the possible reasons for this, and plan an alternative approach. It also allows for the detection of changes over time which may require preventive measures. For example, a gradual reduction in occupation may be an important indicator of deteriorating eyesight. It is envisaged that, wherever appropriate, the patient should participate in his own assessment, and be invited to provide his own comments. The patient is then best placed to increase self-control in the light of information and feedback about his own condition, pain and responses.

These recommendations for management are designed purely for use with the elderly. They are based upon research findings which have yet to be tried and tested in practise. Nurses who choose to adopt this approach can do no harm provided they do not attempt to impose solutions upon patients, and provided they attempt interventions which are within their capabilities. It is hoped that those who implement these recommendations will, in turn, report upon their findings and experiences for the benefit of other nurses, since it is recognised that the area of chronic pain is worthy of very much more research. It is hoped that this particular research will be utilised by nurse educators, during training programmes for all nurses, and by nurses currently working in the community. It is envisaged that the findings of this study, and the theoretical model developed within it, should provide a background for much further research into the nursing management of pain, and the nursing assessment of patient's needs.

11.3.2 Recommendations for further research

The areas of nursing research envisaged for the future, include a reevaluation of drug regimes for patients with chronic benign pain, in order to test the hypothesis that self-control, and hence actual pain control, is enhanced by the use of discretion in the taking of analgesia. Such research is essential before nurses intervene to change patients' existing drug-taking habits, although there appears to be good reason not to recommend routine use of pain-relieving drugs to those who are already reluctant to take them. Meanwhile immediate steps should be taken by nurses in the community to ensure that the effectiveness, and iatrogenic effects of all pain-relieving and pain-reducing drugs are carefully monitored.

Future research may include studies to validate the findings of this study. Perhaps more important is the need for intervention studies to test the relative utility of methods of enhancing well-being. In particular, research is required to test the effects, on mood and pain control, of increased occupational activity, and the effects of counselling, for people with regrets, upon pain control. Research is needed into the role of information for patients with chronic, as opposed to acute, pain. Another useful area of research would be to examine the effect, on patient satisfaction and well-being, of involvement in self-monitoring, particularly for patients with leg ulcers.

The findings described here, apply only to an elderly population with chronic painful conditions, and there is no reason to suppose that they will, as they stand, generalise to other patient groups. Nevertheless, there is no reason why the research approach adopted here should not be applied to other age groups in order to identify coping factors in both pain and other aspects of stress, such as chronic illness. The theoretical model may also provide a framework for a transactional approach to the analysis of patient-carer relationships. As nursing seeks to become a research-based profession, pain and stress provide many, as yet unexplored, areas for nursing research, in which psychology provides the natural focus.

Finally, it is suggested that the theoretical model, proposed here, may provide a useful basis for further research into the nursing management of patient stress, particularly in relation to chronic illness and long-term hospital care. The care of the elderly in long-stay wards and institutions is an obvious choice here. The model may be usefully linked to existing models of nursing if it can be found to provide a suitable framework for research which tests those theories.

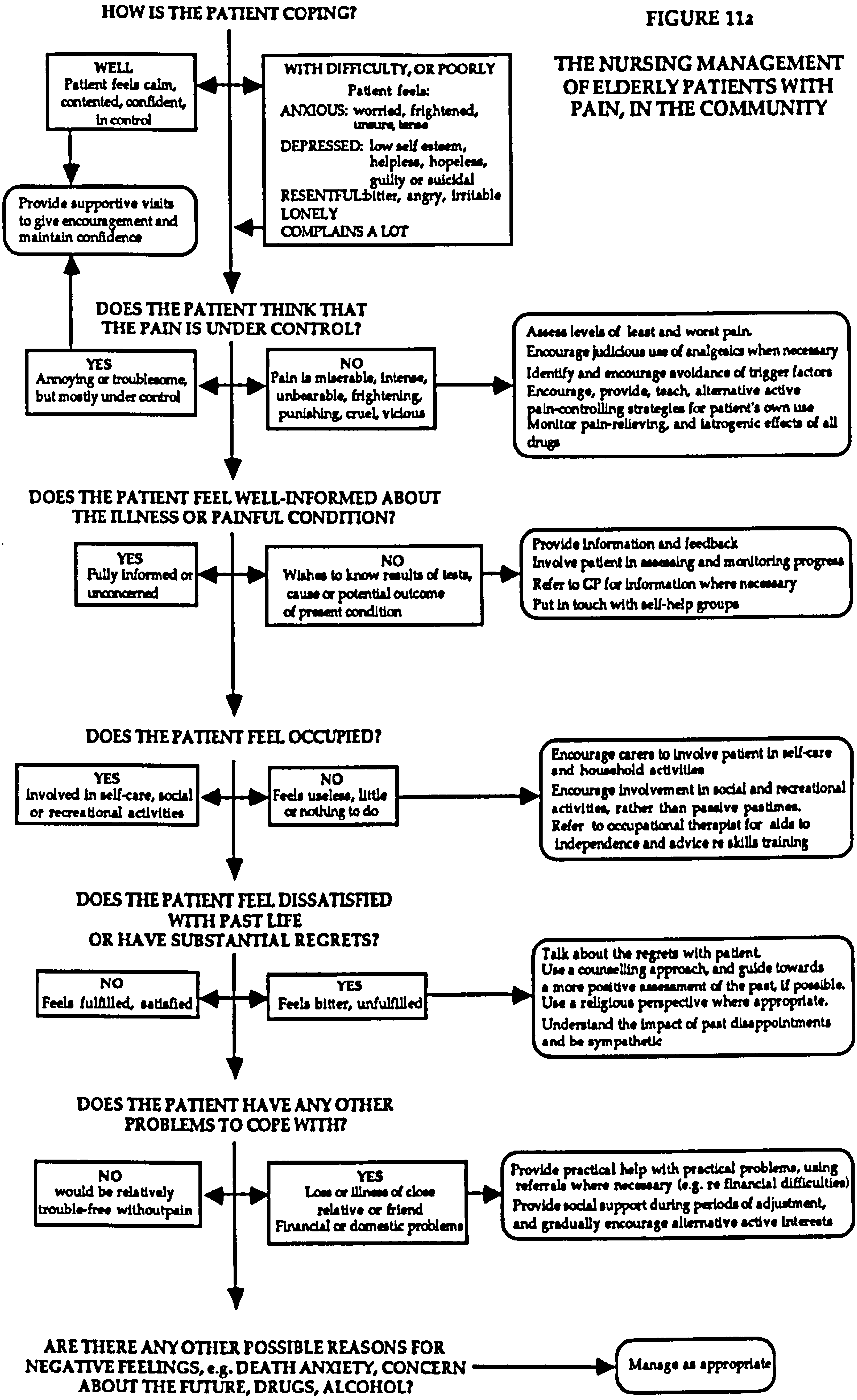
11.4 Concluding comments

The aim of this study was to identify factors which influence coping among elderly patients with pain in the community, in order to make recommendations for the nursing management pain. The research involved the formulation of a theoretical model which was used as a framework for the research design. The results identified a clear model of pain coping in the elderly. It also identified a need for a systematic approach to nursing assessment and intervention in this field. The results are used as the basis for recommendations for pain management in the elderly, in the community. These are summarised in the flow chart contained in figure 11a. This incorporates all of the main findings of this research, and is intended for dissemination and use among nurse educators, and nurses working in the community. It is hoped that the results of this research will make a contribution to the growing body of nursing knowledge in the management of pain, with particular reference to community care of the elderly. It is also hoped that it will stimulate future research into the nursing management of pain and stress.

This research indicates that there is a real need among nurses to identify concrete ways in which they can fulfil their patients' emotional needs with respect to pain. However nurses may still find the concept of a nursing contribution to pain management, based upon the application of psychology, somewhat peripheral to the real issue of the reduction of physical pain. I hope that anyone reading this thesis will, by now, recognise that the nurse has a very unique role to play in the management of elderly patients with chronic pain, which is as important, if not more important, for many elderly patients, than that of the doctor.

FIGURE 11a

THE NURSING MANAGEMENT OF ELDERLY PATIENTS WITH PAIN, IN THE COMMUNITY



HOW IS THE PATIENT COPING?

WELL
Patient feels calm, contented, confident, in control

Provide supportive visits to give encouragement and maintain confidence

WITH DIFFICULTY, OR POORLY
Patient feels:
ANXIOUS: worried, frightened, unsure, tense
DEPRESSED: low self esteem, helpless, hopeless, guilty or suicidal
RESENTFUL: bitter, angry, irritable
LONELY
COMPLAINS A LOT

DOES THE PATIENT THINK THAT THE PAIN IS UNDER CONTROL?

YES
Annoying or troublesome, but mostly under control

NO
Pain is miserable, intense, unbearable, frightening, punishing, cruel, vicious

Assess levels of least and worst pain.
Encourage judicious use of analgesics when necessary
Identify and encourage avoidance of trigger factors
Encourage, provide, teach, alternative active pain-controlling strategies for patient's own use
Monitor pain-relieving, and iatrogenic effects of all drugs

DOES THE PATIENT FEEL WELL-INFORMED ABOUT THE ILLNESS OR PAINFUL CONDITION?

YES
Fully informed or unconcerned

NO
Wishes to know results of tests, cause or potential outcome of present condition

Provide information and feedback
Involve patient in assessing and monitoring progress
Refer to GP for information where necessary
Put in touch with self-help groups

DOES THE PATIENT FEEL OCCUPIED?

YES
Involved in self-care, social or recreational activities

NO
Feels useless, little or nothing to do

Encourage carers to involve patient in self-care and household activities
Encourage involvement in social and recreational activities, rather than passive pastimes.
Refer to occupational therapist for aids to independence and advice re skills training

DOES THE PATIENT FEEL DISSATISFIED WITH PAST LIFE OR HAVE SUBSTANTIAL REGRETS?

NO
Feels fulfilled, satisfied

YES
Feels bitter, unfulfilled

Talk about the regrets with patient.
Use a counselling approach, and guide towards a more positive assessment of the past, if possible.
Use a religious perspective where appropriate.
Understand the impact of past disappointments and be sympathetic

DOES THE PATIENT HAVE ANY OTHER PROBLEMS TO COPE WITH?

NO
would be relatively trouble-free without pain

YES
Loss or illness of close relative or friend
Financial or domestic problems

Provide practical help with practical problems, using referrals where necessary (e.g. re financial difficulties)
Provide social support during periods of adjustment, and gradually encourage alternative active interests

ARE THERE ANY OTHER POSSIBLE REASONS FOR NEGATIVE FEELINGS, e.g. DEATH ANXIETY, CONCERN ABOUT THE FUTURE, DRUGS, ALCOHOL?

Manage as appropriate

GLOSSARY

ADL	Activities of Daily Living
BDI	Beck Depression Inventory (Beck et al 1961)
BNF	British National Formulary
CSQ	Coping Strategies Questionnaire (Rosenstiel and Keefe 1983)
DEN	District Enrolled Nurse (holding District Nursing qualification)
DN	District Nurse (holding District Nursing qualification)
EN	Enrolled Nurse (SEN)
ENB	English National Board for Nursing, Midwifery and Health Visiting
GAS	General Adaptation Syndrome (Selye 1956)
GNC	General Nursing Council for England and Wales
IBQ	Illness Behaviour Questionnaire (Pilowsky and Spence 1975)
LOC	Locus of Control
MPQ	McGill Pain Questionnaire (Melzack 1975)
OPCS	Office of Population Census and Surveys
PRI	Pain Rating Index (from MPQ)
SRN	State Registered Nurse (now RGN, Registered General Nurse)
STAI	State Trait Anxiety Inventory (Spielberger et al 1983)
TENS	Transcutaneous Electrical Nerve Stimulation
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting (formerly GNC)
VAS	Visual Analogue Scale

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APPENDIX I

Preliminary letters and questionnaires

14th September 1987

Dr. ... and Partners

Dear Dr. ... ,

Research Study:
The District Nursing Management of Elderly Patients with Chronic Pain

I am a health visitor with eight years' experience in this locality. I currently work as a research assistant at the Dorset Institute, where I am engaged upon the above project. This is designed to explore the nursing needs of elderly patients in the community who suffer from chronic pain. As you probably know, the Institute runs training courses for district nurses and the principal aim of this research is to provide findings which can be used to improve the education and preparation of nurses in this aspect of care.

The project is being supervised by Dr. Justus Akinsanya BSc,PhD,FRSH, Reader, Dept of Nursing and Social Service, Dorset Institute; Dr. Bryn Davis BSc,PhD, Principal Lecturer in Nursing Studies, Brighton Polytechnic; and Dr. Donald Marcer BSc,PhD,FRSM, Senior Lecturer in Psychology, University of Southampton. I hope to use this study as a basis for a PhD thesis and the research proposal has been accepted by the CNAA for MPhil/PhD registration.

This research study has been accepted by the medical ethics subcommittee of ... Health Authority and has the approval of senior nurse managers. I have already conducted a successful pilot study with the kind cooperation of Dr. ... , his partners, district nursing staff and a sample of 22 patients. I would now like your permission to include patients registered with your practice as part of the main study.

Cont..

I personally will interview patients aged 65 and over who currently receive visits from a district nurse and who are experiencing continuous or recurrent pain, given their prior consent. In each case the initial contact will be made via the district nurse using the enclosed letter and questionnaire. The interview is designed to record pain experiences and coping abilities, and does not include any physical examination. No treatments of any kind are offered. Terminally ill patients and those suffering from dementia will be excluded. The study will include questionnaires for the district nursing staff about current pain management strategies and difficulties.

I should like to commence the main study, which will include at least 12 GP practices in this area, including your own, as soon as I receive your consent. I enclose a copy of the preliminary patient questionnaire for your information.

Perhaps you would be kind enough to indicate your consent and that of your partners on the tear-off portion at the bottom of this letter and return to me in the enclosed pre-paid envelope. I should be most appreciative of your cooperation, please contact me if you would like any further information.

Yours sincerely,

Janet M. Walker (Mrs)
SRN,SCM,RHV,BSc(Hons)Psychology
Research Assistant

- -

I/We will be willing for Mrs. Janet Walker to contact patients of this practice at the discretion of the district nurse, and for her to interview patients provided they have given their permission.

Signed ____

Drs. ....

25th February 1988

Sister ...

Dear Sister ...,

Research Study:
The District Nursing Management of Elderly Patients with Chronic Pain

I am writing to ask for your assistance in conducting the above study which aims to explore in some depth the nursing needs of elderly patients in the community who suffer from painful conditions from a mainly psychological viewpoint. I have worked as a health visitor in East Dorset for over 10 years, and am temporarily engaged on this project at the Institute.

The project is being supervised by Dr. Justus Akinsanya BSc,PhD,FRSH, Reader, Dept of Nursing and Social Service, Dorset Institute; Dr. Bryn Davis BSc,PhD, Principal Lecturer in Nursing Studies, Brighton Polytechnic; and Dr. Donald Marcer BSc,PhD,FRSM, Senior Lecturer in Psychology, University of Southampton and forms the basis of my PhD thesis.

This research study has been accepted by the Medical Ethics Subcommittee of ... Health Authority and I have your nurse manager's approval to approach you to participate. It will involve some additional work for you for which I apologise in advance. This is explained below:

I have designed a brief questionnaire that I would like you to give to all your patients over the age of 65 (with the exception of those who are in the terminal stages of illness and those who suffer dementia or profound deafness).This will identify the proportion of those who have pain, and asks patients who do have pain for permission to interview them. The distribution of these questionnaires should be done during your normal routine visits, over the space of about 4 weeks. Patients may need some encouragement and help to complete and return the form.

I will then interview all of those who are willing. The interview is structured, but tends to take the form of a long chat about their experiences and situation. I do not examine patients nor offer any treatments, although some find it therapeutic to talk. Once the interviews have taken place, I will send you a short questionnaire about each of these patients (no more than 20) to ask how you think they are coping (having first obtained the patients' permission to do this). Finally there is checklist-type questionnaire for you to complete giving an outline of your background and experience. All this data is coded and is therefore returned to me anonymously.

Cont..

I have already completed studies, using six practices in this area, and have received excellent cooperation. I have written to Dr. ... and his partners for their permission.

I would like to commence some time after Easter if this is convenient to you. If there are any reasons why you think it inappropriate to commence at that time - for example staff holidays, I would be grateful if you would let me know. I will contact you again nearer the time for a list of patients and their addresses.

I look forward to meeting you. Please let me know if you would like any further information.

Yours sincerely,

Janet M. Walker (Mrs)
BSc, SRN, SCM, RHV
Research Assistant

Dear

'The Management of Elderly Patients with Chronic Pain in the Community' Study:
Patient Questionnaires

Thank you very much for taking part in this study. It is designed to explore the impact of pain upon the lives of elderly patients who experience it, and to identify factors which help patients to cope better with pain. I hope that this will provide information of value in the future nursing management of patients suffering from various types of chronic pain. Permission to conduct this study has been obtained from the ... Medical Ethics Committee, and from nurse managers.

As the first step in this study, I should be most grateful if you would kindly distribute one of these short questionnaires to EACH OF YOUR PATIENTS OVER THE AGE OF 65 when, during the course of the next six weeks, you visit them, regardless of whether or not they appear to have any pain. The only EXCEPTIONS should be those who are in the terminal stages of illness and those who are too confused or profoundly deaf to cope with answering personal questions, although I would like to know how many are omitted for each of these reasons.

Many patients seem to have difficulty in completing even a simple questionnaire and I would be grateful if you would offer to do this for them wherever possible. The decision as to whether or not he has pain, and if he wishes to participate in the study should, however, be entirely the patient's own. If you do assist, please could you record only the patient's own answers, even if you don't necessarily think they are accurate. I shall make an appointment to visit only once I have received a positive response.

Could you please ensure that the patient's correct name and address appears on the form, and encourage their return even if the patient does not have pain or does not wish to be interviewed.Complete confidentiality is, of course, assured. Return envelopes are provided.

I shall contact you for more information soon. I do hope that this does not give you too much additional work. Please let me know if you have any suggestions, criticisms or queries.

Many thanks for your help.

Janet M. Walker (Mrs) SRN,SCM,RHV,BSc
Research Assistant

Dear

My name is Mrs. Janet Walker. I am a nurse and a health visitor and I work in the Department of Nursing and Social Service at the Dorset Institute of Higher Education, where I am studying pain.

Very little is known at present about how many people suffer from different types of chronic pain, what effects it has had on their lives, how they cope with it, and what has helped most to control it. These are aspects of pain which I shall be looking at. I have permission from your doctor and district nurse to contact you, and I would greatly appreciate it if you would assist me by answering some questions.

I enclose a questionnaire in two parts. The first is to identify the proportion of people who have pain. I should be very grateful if you would complete this and return it to me in the envelope provided, whether or not you have any pain.

The second part is for those who do have pain. If you would be willing for me to come and interview you at home I will make an appointment at a time convenient to you. The interview will take up to about an hour and I will be happy if you would like to have a relative or friend present when I call.

I do not offer any treatments, nor can I promise personal help. I would like to visit those whose pain is well under control as well as those for whom pain is a problem. It is hoped that this study will increase our understanding of the experience of pain, and that the results will be of benefit to pain sufferers in the future and to the nurses who visit them.

Thank you very much for your help.

Yours sincerely

Janet M. Walker (Mrs) SRN,SCM,RHV,BSc

Part 1

(please tick yes or no)

1. Do you have any kind of pain or discomfort at the present time which has lasted for more than about three weeks?

Yes __ No __

2. Do you often experience pain or discomfort?

Yes __ No __

3. Are you currently receiving, or taking, any sort of treatment for pain? (e.g. tablets, drugs, physiotherapy, heat, osteopathy, homeopathy, etc.)

Yes __ No __

If you have answered 'yes' to any of the above questions:

4. Where do you get pain or discomfort? (please tick all the places which seem more or less right)

head ___ neck/shoulders ___ back ___ hips ___

knees ____ legs ____ feet ___

arms ____ hands ___

chest ___ abdomen (including stomach) ___

elsewhere ____

If you have answered 'YES' to ANY of these questions,

PLEASE TURN OVER

If you have answered 'NO' please return this form anyway -
thank you for your help

Part 2

If you would prefer me NOT to visit you please tick here ___ and return the form - thank you for completing my questions so far.

If you would be willing for me to call and see you, please would you ensure that your correct name and address is given below.

NAME ______________________

ADDRESS ______________________

____

TELEPHONE NUMBER ______________________

Would you also like to indicate below when it would **NOT** be convenient, and the days or times when you would **PREFER** me to visit:

(I will normally call between 10am and 6pm, Monday to Friday unless you prefer otherwise)

NOT (dates/days/ times) ______________________

____

PREFER (days/ times) ______________________

____

I look forward to contacting you again in the next few weeks with an appointment. If you have any queries, do ask your district nurse. You may, of course, change your mind at any time.

Thank you very much for your cooperation.

APPENDIX II

Interview schedule

PATIENT INTERVIEW

Practice ______________________________

Patient's Name ______________________________

Address ______________________________

____

____

Telephone Number ______________________________

Date/Time of Interview ______________________________

PATIENT INTERVIEW

[1] No _____

[2] Age ______ [3] 1 Male 2 Female

[4] 1.Married(together) 2.Lives with family 3.Residential home 4.Warden service
5. Multi occupancy 6. Alone

[4a] If widowed, when __________ (years)

[5] Please describe where you get pain

[5a] Number of pain sites

[5b] Number of different causes

[6a] If you have more than one pain which is the worst?

[6b] Why is it worse than the others?

[7a] What is causing your (main) pain ?

[7b] How do you know what the cause of the pain is? (who told you?)

[8] How long have you had the pain? ____________________ (years)

[9a] Rating scale for pain intensity (words)

Present level of pain

Worst level of pain

Least level of pain

0 no pain
1 just noticeable
2 moderate
3 severe
4 very severe
5 excruciating

[9b] Rating scale for pain intensity (1-10)

Present level of pain

Worst level of pain

Least level of pain

[10] How does your pain change with time?

1 Continuous, Steady, Constant
2 Rhythmic, Periodic, Intermittent
3 Brief, Momentary, Transient

[11a] How would you describe what your pain feels like? (own words)

[11b] McGill Pain Questionnaire PRIS

The following words are commonly used to describe pain. I will present you with blocks of up to six words. If any of them seem right to describe your (main) pain, please pick the ONE that seems best.

PRIA

PRIE

If none of them applies just say so. PRIM

1

Flickering
Quivering
Pulsing
Throbbing
Beating
Pounding

2

Jumping
Flashing
Shooting

3

Pricking
Boring
Drilling
Stabbing
Lancinating

4

Sharp
Cutting
Lacerating

5

Pinching
Pressing
Gnawing
Cramping
Crushing

6

Tugging
Pulling
Wrenching

7

Hot
Burning
Scolding
Searing

8

Tingling
Itchy
Smarting
Stinging

9

Dull
Sore
Hurting
Aching
Heavy

10

Tender
Taut
Rasping
Splitting

11

Tiring
Exhausting

12

Sickening
Suffocating

13

Fearful
Frightful
Terrifying

14

Punishing
Gruelling
Cruel
Vicious
Killing

15

Wretched
Blinding

16

Annoying
Troublesome
Miserable
Intense
Unbearable

17

Spreading
Radiating
Penetrating
Piercing

18

Tight
Numb
Drawing
Squeezing
Tearing

19

Cool
Cold
Freezing

20

Nagging
Nauseating
Agonising
Dreadful
Torturing

[12a] When was your pain last at its worst? days ago

[12b] How often is it at its worst? /month

[12c] What do you do when it is worst?

[13] What is life like for you, these days?

[14c] Do have problems (these days) with:

		a lot	quite a lot	a little	none
[a]	sleep				
[b]	appetite				
[c]	mobility				
	self-care				
[d]	dressing/undressing				
[e]	washing/bathing				
	work/housework				
[f]	cooking				
[g]	shopping				
[h]	cleaning/maintenance				
[i]	gardening				
[j]	social life				
[k]	other				

To what extent does pain contribute to each of these difficulties? (indicate above using P)

[15] Overall, what is the worst aspect, for you, of being in pain?

[16a] What are your main interests and occupations now?

[16b] Do you consider yourself to be

+3 well occupied I___I___I___I___I___I___I___I have nothing to do -3

[16c] What (if any) interests have you had to give up because of your present condition?

[16d] How much do you miss these interests

0 not at all 1 a little 2 quite a lot 3 a lot

[17a] Do you find life at all lonely these days?

3 very much 2 quite a lot 1 a little 0 no

[17b] How often do you go out of the house these days?

3 most days 2 two or three times a week 1 once a week 0 less

[17c] How often does someone come in to see you socially (apart from the nurse)?

3 most days 2 two or three times a week 1 once a week 0 less

[18] **What practical help do you receive?**

		received	**comments**
[a]	home help		
[b]	meals on wheels		
[c]	luncheon club/day centre		
regular help from:			
[d]	relatives		
[e]	neighbours		
[f]	church		
[g]	allowances (DHSS)		
[h]	Social Services aids		
[i]	Other		

Comments: (inc. have you refused any of the above services?)

[19a] If you did not have pain would you be

0	completely trouble free
1	fairly trouble free
2	still have considerable problems
3	still have major problems

[19b] What problems or worries do you have in your life at present apart from physical pain?

[a] health [d] personal [e] financial [f] other

3 major 2 some 1 minor 0 none

Mood profile

[20a] Please describe how you feel these days, since you have been in pain:

-3	worried	I___I___I___I___I___I___I___I	untroubled
+3	confident	I___I___I___I___I___I___I___I	unsure
-3	angry	I___I___I___I___I___I___I___I	accepting
+3	in control	I___I___I___I___I___I___I___I	powerless
-3	guilty	I___I___I___I___I___I___I___I	good
+3	contented	I___I___I___I___I___I___I___I	resentful
-3	hopeless	I___I___I___I___I___I___I___I	optimistic
+3	at ease	I___I___I___I___I___I___I___I	upset
-3	threatened	I___I___I___I___I___I___I___I	secure
+3	happy	I___I___I___I___I___I___I___I	sad
-3	tense	I___I___I___I___I___I___I___I	relaxed
+3	calm	I___I___I___I___I___I___I___I	irritable
-3	frightened	I___I___I___I___I___I___I___I	undaunted
+3	fulfilled	I___I___I___I___I___I___I___I	frustrated

[20c What are the most worrying aspects of your pain?

[20d If frightened, what about?

[20e] If guilty, why do you think that you feel guilty?

[21a] Would you describe yourself nowadays as anxious?

0 no 1 a little 2 quite a bit 3 very

[21b] If 1,2 or 3: What makes you feel anxious?

[21c] Are you generally an anxious person?

0 no 1 a little 2 quite a bit 3 very

[22a] Do you ever feel at all depressed these days?

[a1] 0 no 1 sometimes 2 often 3 all the time

[a2] If so 1 mildly 2 moderately 3 severely

[22b] If yes, why do think that you feel depressed?

[22c] Have you had episodes of depression in the past when you weren't in pain?

0 never 1 once 2 more than once

[22d] If so, why do you think that this happened?

[23a] Do you feel that your pain is under control?

4 totally 3 mostly 2 partly 1 not really 0 not at all

[23b] If 2-4, what helps to keep it under control?

[23c] If 0-2, what do you think might help to bring it under (greater) control?

Pain Control

[24] Have you ever attended a pain clinic?

1. general 2.rheumatology 3. private 4.no

[25a] What treatments help, or have helped, your pain?

0 = not at all 1 = a little 2 = quite a lot 3 = very much

analgesia:

[a]

[b]

[c]

[d]Sleeping tabs

[e]Antidepressants

[f]Physiotherapy

[g]Other (inc surgery, acupuncture etc)

[25b] Have you had any treatments which have been unhelpful?

[25c] Have you found any problems, or side effects, with taking or receiving any medical treatments?

[26] Have you identified any particular factors which you think make your pain worse at times?

[27] What helps you to cope with being in pain?

[28] Do you have a religious faith which helps you to cope?

0=no 1=some 2=fairly strong 3=very strong

a before pain b since pain

[29a] Do you anticipate that your pain will get better?

3 yes definitely	2 yes probably	1 yes possibly	8 hope so
-3 definitely not	-2 probably not	-1 possibly not	7 don't know

[29b] If hope so, how much hope do you hold out?

3 a lot 2 a little 1 not a lot

[30] Do you feel that you have been fully informed about:

a. the nature of your painful condition

3 definitely 2 most likely 1 possibly not 0 no

b. treatments for your pain or painful condition

3 definitely 2 most likely 1 possibly not 0 no

[31] Would you like more information about:

a.	**your condition**	yes	no	don't know
b.	**your treatment**	yes	no	don't know

[32] If you had something seriously wrong with you, would you wish to be informed about it, even if the outlook was not good?

3 definitely   2 most likely   1 probably not   0 no

NURSING

[33] Which nurses visit you at home?

[34] What are the main reasons for their visits?

1 pain	2 related medical condition	3 other medical condition
4 self-care needs	5 social	6 other

[35] How often do they visit you? ______________________

[36a] Do you feel that the district nurse has helped you with your pain?

0 no 1 a little 2 quite a lot 3 very much

[36b] If so, in what ways?

[37a] Have the district nurses helped with other problems?

0 no 1 a little 2 quite a lot 3 very much

[37b] If so, in what ways?

[38] What do you think that nurses can best do to help people in pain?

[39] Do you think that REGULAR visits by a nurse are important in helping you to cope?

0 no 1 a little 2 quite a lot 3 very much

[40] Will you be willing for me to contact your district nurse(s) for further information about your nursing care, their knowledge of your pain and your condition, including your medical diagnosis, and do you consent to the district nurse providing me with this information. Nurses will not provide any information without this consent.

[41] Do you have any real regrets in life?

0=none **1**=a few **2**=quite a lot **3**=major

APPENDIX IIA

Locus of control: coding instructions

Instructions for scoring locus of control

Comments from each subject about aspects of their pain control have been extracted from the interview schedule and compiled as shown on the attached sheet. These include:

Subjects' perceived sources of pain control, attitudes to treatments, coping factors, pain factors, certainty about the pain and any additional comments about pain and how they cope.

Please use all of these observations in order to rate their locus of control, with respect to pain, as on the score sheet attached. This uses a five point scale from 1 (strong internal locus of control) to 5 (strong external locus of control).

The rating will be 1 if the subject's comments relate only to self-control strategies initiated and executed by himself, as in the example provided.

A rating of 2 will indicate a predominance of self-control strategies.

The rating will be 5 if the subject's comments relate only to reliance upon others (including family, friends, professional services, doctors or God) for control and comfort.

A rating of 4 will indicate a predominance of reliance upon others.

The centre box 'mixture' (score 3) will apply to those who appear to place equal reliance upon internal and external factors in maintaining pain control. It will also apply to those who record no means of control, or who do not express a belief in any potential source of pain control. A copy of the contingency analysis, used in the theoretical framework, is enclosed to illustrate this, and to help guide you in making these decisions. (see page 54 of thesis)

Many of the statements may appear neutral. Statements such as "you've just got to put up with it" are regarded as neutral, since this gives no indication as to how this might be achieved.

Going to bed / resting is best regarded as a neutral avoidance strategy, unless there is context to indicate there is context to indicate otherwise - e.g. that this elicits help from others.

Re tablet-taking:
Reliance on analgesia taken in strict accordance with doctors' prescribed instructions is regarded as an indication of external control Painkillers taken at own initiative, or to suit individual needs or requirements are regarded as under internal control If no reference is made to either of these methods of consumption, it is best regarded as a neutral strategy. Most analgesics are obtained on prescription. Where relevant, if in doubt, consult the BNF.

It it impossible to make a judgment, then score as indeterminate.

QUALITATIVE ANALYSIS: LOCUS OF CONTROL (EXAMPLE)

CASE: 028

EXTENT TO WHICH PAIN CONTROLLED: mostly

SOURCE OF PAIN CONTROL:

"I accept it because I have to".
"If you know the enemy you can deal with it"

ATTITUDE TO TREATMENTS:

Takes panadol with good effect - works for about 2 hours

COPING FACTORS:

"It is not getting any worse; there are many worse off;
it is not there all the time."
"When the pain is worst (at night), I sit on the edge of the bed and it goes in 10 minutes". It returns after half-an-hour if not asleep.

PAIN FACTORS:

Lying on hip in bed

BELIEFS RE PAIN AND COPING:

Does not really know the cause of the pain - ? old age - says
it is not serious enough to bother doctor and no specialist can cure pain.

ADDITIONAL COMMENTS:

Says nurses can do nothing

Case _________

wholly internal	mostly internal	mixture / neither	mostly external	wholly external

Indeterminate __________ (8)

Case _________

wholly internal	mostly internal	mixture / neither	mostly external	wholly external

Indeterminate __________ (8)

Case _________

wholly internal	mostly internal	mixture / neither	mostly external	wholly external

Indeterminate __________ (8)

APPENDIX III

Nurses' patient questionnaire and covering letter

Dear

'THE MANAGEMENT OF PAIN IN THE COMMUNITY' STUDY
PATIENT PAIN QUESTIONNAIRES

I would like you to complete one of these questionnaires for each of the patients whose name is attached to the front of the form. All of these patients have given their verbal consent for me to contact you for this information, but please check with them first if you have any doubt.

Please do not assume that all of these patients are necessarily experiencing pain since some may not. If, in your opinion, the patient is not in pain, please omit those questions which do not apply.

I hope that the completion of these questionnaires will not take up too much of your time. I would prefer that you answer all the questions from your existing impressions and records. By all means refresh your memory next time you visit the patient but PLEASE DO NOT COMPLETE THE FORMS IN COLLABORATION WITH THE PATIENTS. It is *your opinion* in which I am interested, and this is not intended to be a personal test of any kind.

The information you provide is entirely confidential. Please ensure that each questionnaire applies to the patient named, you may then detach the name tags prior to returning them. Only anonymous data will be used in the analysis.

I enclose a prepaid envelope for the completed questionnaires. I would be most grateful if you could return them to me as soon as possible, but by
at the latest.

I am most grateful for your assistance and hope that I have not overburdened you with this request. If you have any questions (or complaints) please contact me straight away, or write comments on the completed questionnaires.

Many thanks for your help,

Janet M. Walker (Mrs)
Research Assistant

PATIENT ASSESSMENT QUESTIONNAIRE FOR NURSES

Nurse's Name: ______________________________

Practice Name: ______________________________

Patient's Name: ______________________________

Please feel free to add comments
if any of the questions do not give sufficient scope
for your answers.

There is room on the back page for any additional helpful information

Please ensure that your number is inserted in question 1(a)

You may then remove this front sheet prior to returning the questionnaire in order to preserve confidentiality

Many thanks for your help - Jan Walker

[1] [a] Nurse's number ______ [b] Patient 's number _______

[2] How long have you known this patient?

[3a] Please give this patient's medical diagnoses if they are known to you:

[3b] What are your main reasons for visiting this patient?

[4] How does this patient seem to you these days? (please tick as appropriate)

	very much	fairly	slightly	not at all
a Anxious				
b Depressed				
c Resentful				
d Frightened				
e Inactive				
f Occupied				
g Lonely				
h Complaining				
i Dependent on others				

[5] Do you think that this patient has any problems or concerns (IN ADDITION TO, OR APART FROM, PAIN) with respect to:
(please tick)

	Major	Considerable	Some	None
a Health				
b Maintaining independence				
c Family/Personal relationships (inc bereavement)				
d Finances				
e Social contact				
f Housing				

[5b] please elaborate briefly on these or any other particular problems

[1] [a] Nurse's number ______ [b] Patient 's number ______

[2] How long have you known this patient?

[3a] Please give this patient's medical diagnoses if they are known to you:

[3b] What are your main reasons for visiting this patient?

[4] How does this patient seem to you these days? (please tick as appropriate)

	very much	**fairly**	**slightly**	**not at all**
a Anxious				
b Depressed				
c Resentful				
d Frightened				
e Inactive				
f Occupied				
g Lonely				
h Complaining				
i Dependent on others				

[5] Do you think that this patient has any problems or concerns (IN ADDITION TO, OR APART FROM, PAIN) with respect to:
(please tick)

	Major	**Considerable**	**Some**	**None**
a Health				
b Maintaining independence				
c Family/Personal relationships (inc bereavement)				
d Finances				
e Social contact				
f Housing				

[5b] please elaborate briefly on these or any other particular problems

[6] Please use the rating scale to describe this patient's pain in a, b and c:
Please give the most appropriate number

No pain	0	[a] What level of pain does this patient USUALLY have ?	____
Just noticeable	1		
Moderate	2	[b] What is the pain like when it is at its WORST ?	____
Severe	3		
Very severe	4	[c] How the pain is when it is LEAST troublesome ?	____
Excruciating	5		

[If you have answered 0 to 6 a,b AND c, there is no need to continue - thank you]

[7] Where does this patient get pain (please include all sites and the causes if known)

[8a] Do you think that this patient's pain is under control?

0 Not at all __ 1 Not really __ 2 Partly __ 3 Mostly __ 4 Totally __

[8b] If 2-4 in 8a, is this degree of control due to:
(please tick each as appropriate)

	Mostly	**Quite a lot**	**A little**	**Not at all**
a The patient's own attitudes and/or actions				
b Medical help (prescribed drugs, treatments)				
c Nursing care / support				
d Social / family support				
e The low level of pain felt				

Any other reasons or comments?

[8c] If 0-2 in 8a, is lack of control due to: (please tick each as appropriate)

	Mostly	**Quite a lot**	**A little**	**Not at all**
a The patient's attitude/personality				
b Lack of social support/contact				
c Too much dependence on others				
d The patient has other problems to cope with				
e Failure of medical treatments				
f Worry about his/her condition				

Other reasons (please specify)

[9] What do you think have been the MAIN EFFECTS of PAIN on this patient? (include physical, social and/or emotional effects)

[10] Do you think that this patient's complaints of pain are: (please I_√_I)

exaggerated I___I___I___I___I___I___I___I **understated**

[11] To your knowledge, has PAIN adversely affected the following aspects of this patient's life ? (please tick as appropriate)

	very much	quite a lot	a little	not at all
[a] independence				
[b] relationships with others				
[c] social life				
[d] hobbies				
[f] appetite				
[g] sleep				
[h] mood				
[i] activities of daily living if so, please specify which below				

[12a] Do you feel that you have been able to help this patient , directly or indirectly, with his/her pain ?

a lot __ quite a lot __ a little__ not at all __

[12b] If so, how do you think that you have helped?

[13a] Do you expect this patient's pain to improve?

most likely __ fairly likely __ not very likely __ most unlikely__

[13b] If so, is this likely to be due to: (tick any possibilities)

surgery __ medical treatments__ natural healing processes__

other (please specify)

[14] Have you used any standard pain assessment procedure to assess this patient?

Yes __ No __

[15] Has this patient's condition or circumstances changed significantly during the past few weeks?
(Please tick and give brief reasons where appropriate)

No _____

A little _____

A lot _____

[16] When did you last see this patient? (Please tick)

during the last week _____

between 1 and 2 weeks ago _____

between 2 and 4 weeks ago _____

more than one month ago _____

APPENDIX IV

Nurses' general questionnaire, with covering letter

PAIN STUDY QUESTIONNAIRE (NURSES)

This is the final questionnaire which I would like you to complete.

This is a general questionnaire. It is quite confidential and to help ensure this your name appears only on this letter portion, therefore please remove this page before returning the remainder. For most of the questions included here, there are no right or wrong answers - it is your opinion which is required.

I would like to take this opportunity of thanking you very much for helping me with this study. Without your assistance it would not have been possible. I hope very much that the results will be of interest to all community nurses and contribute to our general knowledge of how patients cope with pain. Once the results have been analysed and interpreted, I hope to have the opportunity to discuss the findings with you all via group meetings.

Please return this to me in the prepaid envelope provided as soon as possible, but by
at the latest.

Many thanks,

Janet M. Walker (Mrs)
Research Assistant

[1] No. ______ [2] Practice No. ________

[3] Female / Male (please delete as appropriate)

[4] Present Post: (please tick)

District Nurse (Sister) __ DEN __ RGN __ EN__ Auxiliary __

Full Time__ Part Time __

[5] Please tick your qualifications, give year of completion, training centre / hospital (including town), and if pain was covered AS A DISTINCT TOPIC AREA:

	(√)	Year	Location of Training	Pain covered (√)
SRN / RGN				
EN/SEN				
NDNCert / DN Cert / QN				
SCM/RM				

Other(s) (Please state e.g. RMN, RSCN, RMHN, HV, and give date):

Diploma in Nursing?

ENB / JBCNS Courses (please give title and number where possible):

Other relevant courses (e.g. degrees, OU credits, refresher courses, induction courses etc):

[6] How long have you practiced (3 months minimum) as:

(duration)

staff nurse (or enrolled nurse), surgical wards: ____________

staff nurse (or EN), medical wards: ____________

staff nurse (or EN), other hospital depts.(please specify, e.g. theatres):

____ ____________

ward sister (surgical): ____________

ward sister (medical): ____________

sister (other departments) - please specify:

____ ____________

other posts (e.g. occupational health, nursing home) - please specify:

____ ____________

____ ____________

Community Nursing Experience (Total):

District Nurse (qualified) ____________

DEN ____________

RGN ____________

EN ____________

AUXILIARY ____________

Please put N/A against any questions that do Not Apply to you

[7] Have you at any time received tuition or instruction on: (please tick)

treatment of acute pain __ treatment of chronic pain __ treatment of cancer pain __

pain theories __ assessment of pain __ psychological factors in pain __

[8] Do you consider that your knowledge of the following is: (please tick as appropriate)

	good	adequate	inadequate	poor
a the use of drugs in pain control				
b pain assessment				
c psychological factors in pain				
d psychological methods of pain control				
e physiological and psychological effects of chronic pain				

[9a] Was objective pain assessment taught during General Training?

Yes __ No __ N/A __

[9b] Was pain assessment included during District Nurse Certificate Course?:

assessment taught __ assessment forms shown __ discussed __

not mentioned __ N/A __

[9c] Has pain assessment been included in any other courses attended?

Yes __ No __

If Yes, please specify which courses:

[10] Would you feel confident to advise on relaxation or imagery techniques in the control of pain?

Very __ Fairly __ Not really __

[11a] Do you FEEL that there are patients who exaggerate their pain? :

many __ some __ few __ none __

[11b] If so, what do you think are the possible reasons for this?

[12c] In what ways do you feel that you can be most help to elderly patients with chronic or persistent pain?

[13] Are there any particular types of pain which you find most difficult to help with?
(e.g. by diagnosis or location) - please include brief reasons

[14] What particular problems (if any) do you find in nursing elderly patients with chronic pain?

[15] Do you use a pain assessment record form ?

routinely __ often __ occasionally __ never __

for certain patients - (please specify whom)

[16] If you ever use any form of objective pain assessment, does this include:

pain intensity rating scale (or pain thermometer) __ body outline (for site of pain) __

frequency of occurrence___ pain quality description __

other factors or recordings (please specify)

[17] Do you think that objective pain assessment would be useful?

Yes __ Possibly __ Probably not __ No __ Not sure __

[18] Do you consider that sufficient attention is paid during nurse training (or preparation) to the problems of people with chronic or persistent pain?

APPENDIX V

Response analysis questionnaire

Dear

The response rates seem to quite variable and I would like to identify possible reasons for this in order to make assumptions about the representativeness of my study in the context of district nursing.

Please could you assist me by supplying the following information. The answers need to be reasonably accurate but not necessarily precise.

1. How many patients do you have in your total caseload? ______

2. Of these, how many patients require visits extending over a period of about 3 or more weeks? ______

3. How many pain questionnaires were delivered to patients in your practice? (This will be minus the number you have left over) ______

4. Approximately how many patients were excluded because they were:

a. too young ______

b. too ill ______

c. too confused or deaf ______

d. other reasons? ______ (please outline these reasons if possible)

5. Can you identify any likely reasons why patients did not participate in the study?

6a. Did you offer to assist patients to complete their questionnaires?

all __ some __ none__

6b. Do you think that there were patients who would have participated if you had completed the questionnaires for them (please tick)

Yes, quite a few __ Yes, but not many __ Probably not __

7. Can you identify any obvious differences between those who participated and those who did not? (e.g. were patients who did not participate receiving more specialist care? Were they more depressed? Were they suffering from different types of pain problem or no pain at all? Did they generally find pain more or less of a problem than the study group? or any other possibilities?).

Please return any unused questionnaires to me when you return this - many thanks, Jan

APPENDIX VI

Spearman correlation matrix, all variables

Code for computerised variables

MCH	Total mood score
ANXNOW	Self-report of state anxiety
ANXGEN	Self-report of trait anxiety
DEPSEV	Self-report of depression (severity)
DEPTIM	Self-report of depression (frequency)
SITES	Number of pain sites
PNOW	Pain intensity at time of interview
PLES	Pain when 'least' troublesome
PWORS	Pain at its 'worst'
APP	Appetite
IFS1	Disability score
OCC	Being occupied
SOCIN	frequency of social visitors to the home
SOCOUT	frequency of outings from the home
LIFE	presence of other life problems
PERS	Personal problems
HEALTH	Health problems
FINAN	Financial problems
CONT	Pain perceived to be 'under control'
LOC	Pain locus of control
INFO	Feeling informed about the painful condition
RELIG	Strength of religious belief

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14 AUG 89   CORRELATIONS
10:43:14    D.I.H.E Computer Services Unit DGMV7300Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - -


ANXNOW         -.5467
               N( 170)
               SIG .000

ANXGEN         -.3237      .5733
               N( 170)    N( 174)
               SIG .000   SIG .000

DEPSEV         -.7753      .3834      .2729
               N( 175)    N( 174)    N( 174)
               SIG .000   SIG .000   SIG .000

DEPTIM         -.7563      .4034      .2532      .9517
               N( 175)    N( 174)    N( 174)    N( 181)
               SIG .000   SIG .000   SIG .000   SIG .000

AGE             .2364     -.1034     -.0063     -.1734     -.1828
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)
               SIG .000   SIG .037   SIG .469   SIG .010   SIG .007

DUR             .0923     -.0433      .0666     -.0593     -.0630      .0746
               N( 176)    N( 174)    N( 173)    N( 179)    N( 179)    N( 186)
               SIG .113   SIG .285   SIG .192   SIG .215   SIG .201   SIG .156

SITES          -.1023      .1336      .1420      .0715      .0549     -.0492      .4277
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)    N( 190)    N( 186)
               SIG .085   SIG .034   SIG .031   SIG .169   SIG .232   SIG .250   SIG .000

PNOW           -.1117      .1161      .0243      .0444      .0329     -.1664      .0744      .2249
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)    N( 189)    N( 186)    N( 189)
               SIG .068   SIG .066   SIG .377   SIG .276   SIG .330   SIG .011   SIG .157   SIG .001

                  MCH      ANXNOW     ANXGEN     DEPSEV     DEPTIM       AGE         DUR       SITES
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS
10:43:19    D.I.H.E Computer Services Unit DGMV7300Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - -


PLES           -.2379      .1247      .0605      .1991      .1826     -.1872      .0961      .1794      .7465
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)    N( 188)    N( 185)    N( 188)    N( 188)
               SIG .000   SIG .050   SIG .214   SIG .004   SIG .007   SIG .005   SIG .097   SIG .007   SIG .000

PWORS          -.1771      .1212     -.0115      .1372      .1076     -.1769      .1541      .1528      .3746      .3351
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)    N( 189)    N( 186)    N( 189)    N( 189)    N( 188)
               SIG .009   SIG .055   SIG .440   SIG .033   SIG .075   SIG .007   SIG .018   SIG .018   SIG .000   SIG .000

PRIS           -.1194      .0958     -.0385      .1641      .1463     -.0533      .1684      .3093      .3733      .3364
               N( 174)    N( 170)    N( 170)    N( 175)    N( 175)    N( 179)    N( 177)    N( 179)    N( 179)    N( 179)
               SIG .058   SIG .107   SIG .309   SIG .015   SIG .027   SIG .239   SIG .013   SIG .000   SIG .000   SIG .000

PRIA           -.3563      .2661      .1727      .2812      .2932     -.2817      .1674      .2034      .2705      .2898
               N( 174)    N( 170)    N( 170)    N( 175)    N( 175)    N( 179)    N( 177)    N( 179)    N( 179)    N( 179)
               SIG .000   SIG .000   SIG .012   SIG .000   SIG .000   SIG .000   SIG .013   SIG .003   SIG .000   SIG .000

PRIE           -.3299      .1411      .0211      .3259      .3126     -.2533      .0831      .1473      .3404      .3069
               N( 173)    N( 169)    N( 169)    N( 174)    N( 174)    N( 178)    N( 176)    N( 178)    N( 178)    N( 178)
               SIG .000   SIG .034   SIG .393   SIG .000   SIG .000   SIG .000   SIG .136   SIG .025   SIG .000   SIG .000

PRIM           -.2239      .1918      .0679      .1977      .2059     -.2654     -.0026      .1866      .3757      .3251
               N( 174)    N( 170)    N( 170)    N( 175)    N( 175)    N( 179)    N( 177)    N( 179)    N( 179)    N( 179)
               SIG .001   SIG .006   SIG .189   SIG .004   SIG .003   SIG .000   SIG .486   SIG .006   SIG .000   SIG .000

PRIT           -.2773      .1974      .0517      .2761      .2659     -.2383      .1420      .3090      .4455      .4039
               N( 174)    N( 170)    N( 170)    N( 175)    N( 175)    N( 179)    N( 177)    N( 179)    N( 179)    N( 179)
               SIG .000   SIG .005   SIG .252   SIG .000   SIG .000   SIG .001   SIG .030   SIG .000   SIG .000   SIG .000

SLEEP           .1343     -.1476     -.0910     -.0906     -.1121      .0071     -.1499     -.2328     -.1419     -.1576
               N( 179)    N( 175)    N( 174)    N( 181)    N( 181)    N( 189)    N( 186)    N( 189)    N( 189)    N( 188)
               SIG .036   SIG .026   SIG .116   SIG .113   SIG .066   SIG .462   SIG .021   SIG .001   SIG .026   SIG .016

                  MCH      ANXNOW     ANXGEN     DEPSEV     DEPTIM      AGE!        DUR       SITES      PNOW       PLES
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS
10:43:26    D.I.H.E Computer Services Unit DGMV7800Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


APP            -.3165       .1415       .1154       .2816       .2331      -.1627       .0696       .2146       .2218       .3051
             N( 175)     N( 171)     N( 170)     N( 176)     N( 176)     N( 183)     N( 180)     N( 183)     N( 183)     N( 182)
             SIG .000    SIG .032    SIG .067    SIG .000    SIG .001    SIG .014    SIG .177    SIG .002    SIG .001    SIG .000

IFS1           -.2253       .0693       .0593       .1436       .1251       .1050       .1545       .1558       .1389       .2960
             N( 176)     N( 170)     N( 169)     N( 175)     N( 175)     N( 182)     N( 179)     N( 182)     N( 182)     N( 182)
             SIG .001    SIG .155    SIG .123    SIG .025    SIG .050    SIG .079    SIG .019    SIG .016    SIG .031    SIG .000

MOB            -.1329       .0330       .1009       .1128       .1053       .0122       .1788       .2008       .2001       .3152
             N( 179)     N( 175)     N( 174)     N( 180)     N( 180)     N( 183)     N( 185)     N( 183)     N( 188)     N( 187)
             SIG .007    SIG .146    SIG .093    SIG .066    SIG .079    SIG .434    SIG .007    SIG .003    SIG .003    SIG .000

DRESS          -.1380       .0555       .0632       .1190       .1118       .0945       .2147       .1698       .1815       .3091
             N( 179)     N( 175)     N( 174)     N( 180)     N( 180)     N( 187)     N( 184)     N( 187)     N( 187)     N( 187)
             SIG .033    SIG .233    SIG .204    SIG .056    SIG .068    SIG .099    SIG .002    SIG .010    SIG .007    SIG .000

WASH           -.1986       .1078       .0972       .1432       .1392       .0642       .2097       .2156       .1465       .2651
             N( 179)     N( 174)     N( 173)     N( 179)     N( 179)     N( 186)     N( 183)     N( 186)     N( 186)     N( 186)
             SIG .004    SIG .075    SIG .102    SIG .028    SIG .032    SIG .192    SIG .002    SIG .002    SIG .023    SIG .000

COOK           -.2401       .0770       .0734       .1553       .1354       .1910       .0425       .0494       .0370       .1852
             N( 176)     N( 170)     N( 169)     N( 175)     N( 175)     N( 182)     N( 179)     N( 182)     N( 182)     N( 182)
             SIG .001    SIG .133    SIG .171    SIG .020    SIG .037    SIG .005    SIG .286    SIG .254    SIG .310    SIG .006

CLEAN          -.2123       .0406       .0690       .1096       .0691       .1575       .0501       .0494       .0427       .1575
             N( 176)     N( 171)     N( 170)     N( 176)     N( 176)     N( 183)     N( 180)     N( 183)     N( 183)     N( 183)
             SIG .002    SIG .299    SIG .186    SIG .074    SIG .181    SIG .017    SIG .252    SIG .253    SIG .283    SIG .017

SHOP           -.0790      -.0609      -.0150       .0286      -.0009       .1795       .0322       .1155       .1306       .2603
             N( 176)     N( 170)     N( 169)     N( 175)     N( 175)     N( 182)     N( 179)     N( 182)     N( 182)     N( 182)
             SIG .143    SIG .215    SIG .423    SIG .354    SIG .495    SIG .008    SIG .334    SIG .060    SIG .039    SIG .000

                  MCH      ANXNOW      ANXGEN      DEPSEV      DEPTIM         AGE         DUR       SITES        PNOA        PLES
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS
10:43:33    D.I.H.E Computer Services Unit DGMV7800Phoenix  ACS/VS 7.6.2

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OCC             .5122      -.1641      -.1402      -.4142      -.4020       .0842       .1404       .0495      -.1370      -.2501
             N( 179)     N( 174)     N( 174)     N( 181)     N( 181)     N( 183)     N( 185)     N( 183)     N( 188)     N( 187)
             SIG .000    SIG .015    SIG .033    SIG .000    SIG .000    SIG .125    SIG .029    SIG .250    SIG .030    SIG .000

LONELY         -.3316       .2075      -.0099       .2493       .2297      -.0739      -.0225      -.0481       .0510       .0626
             N( 177)     N( 171)     N( 171)     N( 177)     N( 177)     N( 183)     N( 180)     N( 183)     N( 183)     N( 183)
             SIG .000    SIG .003    SIG .449    SIG .000    SIG .001    SIG .160    SIG .382    SIG .259    SIG .247    SIG .200

SOCIN           .0310      -.0554       .0340       .0196       .0511      -.0213      -.0652      -.0915      -.1473      -.0690
             N( 174)     N( 169)     N( 168)     N( 174)     N( 174)     N( 181)     N( 178)     N( 181)     N( 181)     N( 181)
             SIG .343    SIG .237    SIG .139    SIG .399    SIG .251    SIG .388    SIG .183    SIG .110    SIG .024    SIG .178

SOCOUT          .1483      -.0856       .0213      -.0434      -.0386      -.1363      -.0301      -.1887      -.1616      -.2314
             N( 177)     N( 172)     N( 171)     N( 177)     N( 177)     N( 184)     N( 181)     N( 184)     N( 184)     N( 184)
             SIG .024    SIG .132    SIG .391    SIG .283    SIG .305    SIG .033    SIG .344    SIG .005    SIG .014    SIG .001

LIFE           -.3623       .1502       .1477       .2839       .2357      -.1846      -.1546      -.0738       .0190       .0510
             N( 175)     N( 169)     N( 168)     N( 175)     N( 175)     N( 182)     N( 179)     N( 182)     N( 182)     N( 182)
             SIG .000    SIG .024    SIG .028    SIG .000    SIG .000    SIG .006    SIG .007    SIG .161    SIG .400    SIG .247

HEALTH         -.2553      -.0035      -.0261       .2542       .2259      -.0990      -.0921       .0165      -.0079       .0534
             N( 179)     N( 174)     N( 173)     N( 180)     N( 180)     N( 187)     N( 184)     N( 187)     N( 187)     N( 187)
             SIG .000    SIG .432    SIG .367    SIG .000    SIG .001    SIG .089    SIG .107    SIG .422    SIG .457    SIG .234

PERS           -.4451       .3190       .1909       .3981       .3391      -.0747      -.0267      -.0291      -.0405       .0672
             N( 175)     N( 170)     N( 169)     N( 176)     N( 176)     N( 183)     N( 180)     N( 183)     N( 183)     N( 183)
             SIG .000    SIG .000    SIG .006    SIG .000    SIG .000    SIG .157    SIG .361    SIG .348    SIG .293    SIG .263

FINAN          -.2326       .1363       .1435       .1757       .2231      -.0816       .0553       .1026       .0467       .0332
             N( 170)     N( 165)     N( 155)     N( 171)     N( 171)     N( 173)     N( 175)     N( 174)     N( 178)     N( 173)
             SIG .000    SIG .039    SIG .023    SIG .011    SIG .002    SIG .139    SIG .232    SIG .087    SIG .267    SIG .330

                  MCH      ANXNOW      ANXGEN      DEPSEV      DEPTIM         AGE         DUR       SITES        PNOA        PLES
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS
10:43:39    D.I.H.E Computer Services Unit D3MV7300Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - - -


CONT             .4111      -.2637      -.0999      -.3072      -.3173       .1633      -.0304      -.1831      -.3562      -.3516
              N(  164)    N(  162)    N(  162)    N(  164)    N(  164)    N(  166)    N(  154)    N(  165)    N(  166)    N(  166)
              SIG .000    SIG .000    SIG .103    SIG .000    SIG .000    SIG .015    SIG .349    SIG .008    SIG .000    SIG .000

LOC             -.3387       .1735       .1041       .2631       .2307      -.1851      -.0668       .1066       .2020       .2041
              N(  176)    N(  171)    N(  171)    N(  175)    N(  176)    N(  175)    N(  176)    N(  175)    N(  178)    N(  173)
              SIG .000    SIG .010    SIG .085    SIG .000    SIG .001    SIG .007    SIG .189    SIG .078    SIG .003    SIG .003

INFO             .2297      -.1016      -.0459      -.1130      -.1456       .0513       .2477       .0221      -.0315       .0230
              N(  174)    N(  171)    N(  170)    N(  177)    N(  177)    N(  180)    N(  178)    N(  180)    N(  180)    N(  180)
              SIG .001    SIG .093    SIG .263    SIG .072    SIG .027    SIG .247    SIG .000    SIG .384    SIG .492    SIG .354

RELIG            .2253      -.2130      -.1362      -.1877      -.2304      -.0449       .0655       .0501      -.0047      -.0408
              N(  170)    N(  167)    N(  166)    N(  172)    N(  172)    N(  176)    N(  174)    N(  176)    N(  176)    N(  176)
              SIG .002    SIG .003    SIG .040    SIG .007    SIG .001    SIG .277    SIG .195    SIG .255    SIG .475    SIG .295

REGRETS         -.4983       .3635       .3385       .3734       .3984      -.0956       .1336       .1502       .1963       .3168
              N(  116)    N(  109)    N(  109)    N(  113)    N(  113)    N(  116)    N(  114)    N(  116)    N(  116)    N(  116)
              SIG .000    SIG .000    SIG .000    SIG .000    SIG .000    SIG .154    SIG .079    SIG .026    SIG .017    SIG .000

                   MCH      ANKNOW      ANXGEN      DEPSEV      DEPTIM         AGE         DUR       SITES        PNOW        PLES


PRIS             .3763
              N(  179)
              SIG .000

PRIA             .5003       .3635
              N(  179)    N(  177)
              SIG .000    SIG .000

PRIE             .5336       .3523       .5029
              N(  178)    N(  173)    N(  178)
              SIG .000    SIG .000    SIG .000

                 PWORS        PRIS        PRIA
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS
10:48:43    D.I.H.E Computer Services Unit D3MV7300Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - - -


PRIM             .4373       .4622       .5329       .5521
              N(  179)    N(  179)    N(  179)    N(  178)
              SIG .000    SIG .000    SIG .000    SIG .000

PRIT             .5609       .5434       .6974       .6536       .7799
              N(  179)    N(  179)    N(  179)    N(  179)    N(  179)
              SIG .000    SIG .000    SIG .000    SIG .000    SIG .000

SLEEP           -.2331      -.2130      -.2229      -.1930      -.1777      -.2747
              N(  139)    N(  179)    N(  179)    N(  178)    N(  179)    N(  179)
              SIG .001    SIG .002    SIG .001    SIG .006    SIG .009    SIG .000

APP              .3556       .2430       .3462       .3130       .2567       .3440      -.1479
              N(  133)    N(  175)    N(  175)    N(  174)    N(  175)    N(  175)    N(  133)
              SIG .000    SIG .001    SIG .000    SIG .000    SIG .000    SIG .000    SIG .023

IFS1             .0351      -.0233       .1032       .1179      -.0020       .0275      -.0326       .1657
              N(  132)    N(  174)    N(  174)    N(  173)    N(  174)    N(  174)    N(  182)    N(  177)
              SIG .319    SIG .330    SIG .085    SIG .061    SIG .490    SIG .359    SIG .331    SIG .013

MOB              .0633       .0773       .1590       .1404       .1056       .1359      -.1436       .1369       .8035
              N(  138)    N(  179)    N(  179)    N(  178)    N(  179)    N(  179)    N(  138)    N(  183)    N(  182)
              SIG .192    SIG .152    SIG .017    SIG .031    SIG .080    SIG .035    SIG .025    SIG .032    SIG .000

DRESS            .0552       .0291       .1183       .0827       .0113       .0612      -.0435       .1756       .8691       .6657
              N(  137)    N(  179)    N(  179)    N(  178)    N(  179)    N(  179)    N(  137)    N(  182)    N(  182)    N(  137)
              SIG .226    SIG .349    SIG .057    SIG .136    SIG .441    SIG .208    SIG .276    SIG .009    SIG .000    SIG .000

WASH            -.0113      -.0327       .1062       .0895      -.0420       .0004      -.0615       .1470       .8375       .7095
              N(  136)    N(  178)    N(  178)    N(  177)    N(  178)    N(  178)    N(  136)    N(  181)    N(  182)    N(  136)
              SIG .433    SIG .332    SIG .079    SIG .118    SIG .289    SIG .498    SIG .201    SIG .024    SIG .000    SIG .000

                 PWORS        PRIS        PRIA        PRIE        PRIM        PRIT       SLEEP         APP        IFS1         MOB
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89    CORRELATIONS
10:43:49     D.I.H.E Computer Services Unit DGPV7800Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


COOK            -.0233      -.0834       .0394       .0438      -.0949      -.0679       .0661       .0759       .8379       .5750
              N( 132)     N( 174)     N( 174)     N( 173)     N( 174)     N( 174)     N( 132)     N( 177)     N( 132)     N( 182)
              SIG .377    SIG .123    SIG .303    SIG .234    SIG .106    SIG .137    SIG .183    SIG .148    SIG .000    SIG .000

CLEAN           -.0305      -.0891       .0234       .0551      -.0671      -.0603      -.0047       .0639       .8588       .5927
              N( 133)     N( 175)     N( 175)     N( 174)     N( 175)     N( 173)     N( 133)     N( 178)     N( 132)     N( 183)
              SIG .497    SIG .120    SIG .379    SIG .223    SIG .189    SIG .214    SIG .475    SIG .130    SIG .000    SIG .000

SHOP             .0685       .0435       .0213       .0090       .0147       .0221      -.0595       .0982       .5934       .5762
              N( 132)     N( 174)     N( 174)     N( 173)     N( 174)     N( 174)     N( 132)     N( 177)     N( 132)     N( 182)
              SIG .179    SIG .263    SIG .383    SIG .453    SIG .424    SIG .336    SIG .115    SIG .097    SIG .000    SIG .000

OCC             -.0654       .0333      -.1009      -.2771      -.1282      -.0867       .0694      -.2602      -.4325      -.3070
              N( 138)     N( 177)     N( 179)     N( 178)     N( 179)     N( 179)     N( 138)     N( 182)     N( 131)     N( 187)
              SIG .186    SIG .329    SIG .089    SIG .000    SIG .044    SIG .124    SIG .172    SIG .000    SIG .000    SIG .000

LONELY           .1703       .0535       .1293       .2047       .0613       .1063      -.1254       .1149      -.0543      -.0009
              N( 133)     N( 175)     N( 176)     N( 175)     N( 176)     N( 176)     N( 133)     N( 178)     N( 179)     N( 183)
              SIG .011    SIG .240    SIG .043    SIG .003    SIG .209    SIG .030    SIG .045    SIG .063    SIG .233    SIG .495

SOCIN           -.0399      -.1391      -.0613      -.0819      -.0985      -.1371       .0386      -.0161      -.0053      -.0843
              N( 131)     N( 173)     N( 173)     N( 172)     N( 173)     N( 173)     N( 131)     N( 176)     N( 177)     N( 181)
              SIG .297    SIG .034    SIG .209    SIG .143    SIG .098    SIG .036    SIG .303    SIG .416    SIG .472    SIG .119

SOCOUT          -.1374      -.1434      -.1387      -.1060      -.0913      -.1546       .1300      -.1640      -.4522      -.5377
              N( 134)     N( 175)     N( 176)     N( 175)     N( 176)     N( 176)     N( 134)     N( 179)     N( 131)     N( 184)
              SIG .073    SIG .027    SIG .033    SIG .081    SIG .113    SIG .020    SIG .039    SIG .014    SIG .000    SIG .000

LIFE            -.0332      -.0579       .0351       .1118       .0277       .0198       .0342       .0826       .2375       .1198
              N( 132)     N( 173)     N( 173)     N( 172)     N( 173)     N( 173)     N( 132)     N( 175)     N( 178)     N( 181)
              SIG .132    SIG .221    SIG .124    SIG .072    SIG .359    SIG .398    SIG .323    SIG .138    SIG .001    SIG .054

                 PWORS       PRIS        PRIA        PRIE        PRIM        PRIT        SLEEP        APP        IFS1         MOB
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89    CORRELATIONS
10:43:56     D.I.H.E Computer Services Unit DGPV7300Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


HEALTH          -.0399       .0077      -.0054       .0850       .0272       .0335      -.0747       .0913       .3761       .2434
              N( 137)     N( 173)     N( 178)     N( 177)     N( 178)     N( 173)     N( 137)     N( 161)     N( 132)     N( 186)
              SIG .111    SIG .460    SIG .472    SIG .130    SIG .359    SIG .305    SIG .155    SIG .111    SIG .000    SIG .000

PERS             .1033       .0756       .1965       .1939       .1139       .1530      -.0712       .1227      -.1409      -.1490
              N( 133)     N( 174)     N( 174)     N( 173)     N( 174)     N( 174)     N( 133)     N( 177)     N( 178)     N( 182)
              SIG .032    SIG .161    SIG .005    SIG .004    SIG .067    SIG .022    SIG .169    SIG .052    SIG .030    SIG .022

FINAN            .0703       .0049       .1319       .0946       .0502       .0662       .0520       .1652       .0119       .0222
              N( 178)     N( 169)     N( 169)     N( 163)     N( 169)     N( 169)     N( 178)     N( 172)     N( 173)     N( 177)
              SIG .174    SIG .475    SIG .009    SIG .111    SIG .258    SIG .196    SIG .245    SIG .015    SIG .439    SIG .384

CONT            -.3241      -.1967      -.3323      -.3361      -.3600      -.3950       .2035      -.3525      -.1846      -.1568
              N( 166)     N( 163)     N( 163)     N( 162)     N( 163)     N( 163)     N( 166)     N( 162)     N( 162)     N( 166)
              SIG .000    SIG .006    SIG .000    SIG .000    SIG .000    SIG .000    SIG .004    SIG .000    SIG .009    SIG .022

LOC              .2333       .0673       .1339       .2520       .1193       .1718      -.1081       .2503       .1111       .1210
              N( 178)     N( 174)     N( 174)     N( 173)     N( 174)     N( 174)     N( 178)     N( 174)     N( 174)     N( 173)
              SIG .001    SIG .189    SIG .003    SIG .000    SIG .058    SIG .012    SIG .075    SIG .000    SIG .072    SIG .054

INFO             .0213       .0757      -.0683      -.0663      -.0622      -.0011      -.0038      -.0741      -.0062       .0012
              N( 130)     N( 173)     N( 173)     N( 172)     N( 173)     N( 173)     N( 130)     N( 175)     N( 175)     N( 179)
              SIG .336    SIG .161    SIG .186    SIG .194    SIG .209    SIG .494    SIG .480    SIG .165    SIG .478    SIG .494

RELIG            .0021       .0308       .0619       .0017      -.0611       .0090       .1553      -.0039      -.0062       .0227
              N( 176)     N( 170)     N( 170)     N( 169)     N( 170)     N( 170)     N( 176)     N( 172)     N( 172)     N( 176)
              SIG .489    SIG .345    SIG .211    SIG .491    SIG .297    SIG .454    SIG .020    SIG .430    SIG .468    SIG .333

REGRETS          .2124       .2114       .2315       .2479       .0946       .2336      -.1441       .2941       .0353       .1910
              N( 116)     N( 112)     N( 112)     N( 111)     N( 112)     N( 112)     N( 116)     N( 114)     N( 113)     N( 115)
              SIG .011    SIG .013    SIG .001    SIG .004    SIG .161    SIG .007    SIG .061    SIG .001    SIG .135    SIG .020

                 PWORS       PRIS        PRIA        PRIE        PRIM        PRIT        SLEEP        APP        IFS1         MOB
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS                                                                                     PA
10:49:02    D.I.H.E Computer Services Unit DGMV7800Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


WASH          .3204
            N( 136)
            SIG .000

COOK          .6353      .6350
            N( 132)    N( 182)
            SIG .000   SIG .000

CLEAN         .6103      .6550      .8236
            N( 133)    N( 183)    N( 132)
            SIG .000   SIG .000   SIG .000

SHOP          .4174      .4897      .4322      .5958
            N( 182)    N( 182)    N( 182)    N( 182)
            SIG .000   SIG .000   SIG .000   SIG .000

OCC          -.3034     -.3135     -.4350     -.4364     -.1947
            N( 136)    N( 185)    N( 131)    N( 182)    N( 131)
            SIG .000   SIG .000   SIG .000   SIG .000   SIG .004

LONELY       -.0642      .0098     -.1172     -.1039      .0131     -.1754
            N( 133)    N( 183)    N( 179)    N( 180)    N( 179)    N( 183)
            SIG .194   SIG .448   SIG .059   SIG .083   SIG .431   SIG .009

SOCIN        -.0402     -.0432      .0711      .0113     -.0751     -.0721     -.3742
            N( 131)    N( 181)    N( 177)    N( 179)    N( 177)    N( 180)    N( 178)
            SIG .295   SIG .282   SIG .174   SIG .440   SIG .160   SIG .168   SIG .000

SOCOUT       -.3944     -.3635     -.3549     -.3456     -.5274      .1548     -.0247      .0060
            N( 134)    N( 184)    N( 131)    N( 182)    N( 131)    N( 183)    N( 131)    N( 183)
            SIG .000   SIG .000   SIG .000   SIG .000   SIG .000   SIG .018   SIG .370   SIG .468

              DRESS       WASH       COOK      CLEAN       SHOP        OCC     LONELY      SOCIN
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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14 AUG 89   CORRELATIONS                                                                                     PA
10:49:06    D.I.H.E Computer Services Unit DGMV7800Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


LIFE          .1363      .2434      .1349      .2233     -.0239     -.3128      .2493     -.0935      .0514
            N( 131)    N( 181)    N( 178)    N( 173)    N( 178)    N( 181)    N( 178)    N( 176)    N( 179)
            SIG .065   SIG .000   SIG .037   SIG .001   SIG .376   SIG .000   SIG .000   SIG .108   SIG .247

HEALTH        .2762      .3190      .3195      .3859      .2133     -.3948      .0475     -.0002     -.1166      .5855
            N( 136)    N( 185)    N( 132)    N( 183)    N( 182)    N( 186)    N( 183)    N( 181)    N( 134)    N( 182)
            SIG .000   SIG .000   SIG .000   SIG .000   SIG .002   SIG .000   SIG .262   SIG .499   SIG .057   SIG .000

PERS         -.1175     -.0748     -.1122     -.1276     -.2319     -.1160      .3335     -.1104      .1012      .3944
            N( 132)    N( 182)    N( 178)    N( 179)    N( 178)    N( 182)    N( 179)    N( 177)    N( 180)    N( 173)
            SIG .089   SIG .158   SIG .068   SIG .044   SIG .001   SIG .060   SIG .000   SIG .072   SIG .088   SIG .000

FINAN         .0371      .0612     -.0224     -.0033     -.1395     -.0844      .1829      .0386      .0041      .1950
            N( 177)    N( 177)    N( 173)    N( 174)    N( 173)    N( 177)    N( 174)    N( 176)    N( 175)    N( 173)
            SIG .312   SIG .209   SIG .385   SIG .483   SIG .034   SIG .132   SIG .008   SIG .307   SIG .478   SIG .005

CONT         -.1247     -.1910     -.1313     -.1308     -.1575      .3306     -.2793      .0768      .1390     -.1430
            N( 166)    N( 165)    N( 162)    N( 163)    N( 162)    N( 165)    N( 164)    N( 164)    N( 164)    N( 161)
            SIG .055   SIG .007   SIG .048   SIG .048   SIG .023   SIG .000   SIG .000   SIG .164   SIG .038   SIG .035

LOC           .0313      .0606      .1639      .1193      .1000     -.2712      .0627     -.0132     -.1487      .1837
            N( 178)    N( 173)    N( 174)    N( 173)    N( 174)    N( 173)    N( 176)    N( 173)    N( 176)    N( 173)
            SIG .339   SIG .211   SIG .015   SIG .058   SIG .095   SIG .000   SIG .204   SIG .432   SIG .024   SIG .008

INFO          .0522     -.0521     -.0145     -.0434      .0607      .1818     -.1202     -.0508      .0409     -.2054
            N( 179)    N( 179)    N( 175)    N( 176)    N( 175)    N( 179)    N( 176)    N( 174)    N( 177)    N( 175)
            SIG .244   SIG .244   SIG .424   SIG .284   SIG .212   SIG .007   SIG .056   SIG .253   SIG .294   SIG .003

RELIG         .0683     -.0139     -.0964     -.0107      .1091      .2876     -.1083     -.0874     -.0335     -.0195
            N( 176)    N( 175)    N( 172)    N( 173)    N( 172)    N( 175)    N( 173)    N( 171)    N( 174)    N( 171)
            SIG .152   SIG .428   SIG .104   SIG .445   SIG .077   SIG .000   SIG .078   SIG .128   SIG .330   SIG .400

              DRESS       WASH       COOK      CLEAN       SHOP        OCC     LONELY      SOCIN     SOCOUT       LIFE
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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- - - - - - - - - - - - -  S P E A R M A N   C O R R E L A T I O N   C O E F F I C I E N T S  - - - - - - - - - - - - -


REGRETS          .0744      .1027      .1047     -.0039      .0152     -.2443      .2139      .0011     -.2005      .1503
               N( 116)    N( 115)    N( 113)    N( 113)    N( 113)    N( 116)    N( 116)    N( 114)    N( 115)    N( 115)
               SIG .214   SIG .136   SIG .135   SIG .433   SIG .436   SIG .004   SIG .009   SIG .495   SIG .316   SIG .044

                 DRESS       WASH       COOK      CLEAN       SHOP        OCC     LONELY      SOCIN     SOCOUT       LIFE



PERS             .0093
               N( 133)
               SIG .450

FINAN           -.0112      .2628
               N( 173)    N( 173)
               SIG .441   SIG .000

CONT            -.1502     -.1734     -.1590
               N( 166)    N( 162)    N( 160)
               SIG .027   SIG .012   SIG .023

LOC              .0321      .1478      .1313     -.3696
               N( 178)    N( 174)    N( 169)    N( 165)
               SIG .133   SIG .026   SIG .044   SIG .000

INFO            -.1083     -.1126     -.1793      .1200     -.0156
               N( 130)    N( 175)    N( 171)    N( 165)    N( 176)
               SIG .073   SIG .068   SIG .009   SIG .062   SIG .403

RELIG           -.1410     -.1289     -.0269      .1230      .1229      .1571
               N( 176)    N( 172)    N( 157)    N( 153)    N( 170)    N( 171)
               SIG .031   SIG .046   SIG .365   SIG .062   SIG .055   SIG .020

REGRETS          .0592      .2536      .2177     -.2838      .2334     -.1213     -.2303
               N( 116)    N( 114)    N( 111)    N( 109)    N( 114)    N( 113)    N( 109)
               SIG .264   SIG .003   SIG .011   SIG .001   SIG .006   SIG .100   SIG .008

                HEALTH       PERS      FINAN       CONT        LOC       INFO      RELIG
" . " IS PRINTED IF A COEFFICIENT CANNOT BE COMPUTED.
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APPENDIX VII

Factor analysis, mood profile

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- - - - - - - - - - - - - - - - - - - - - - -   F A C T O R   A N A L Y S I S   - - - - - - - - - - - - - - - - - - - - -


ANALYSIS NUMBER  1  LISTWISE DELETION OF CASES WITH MISSING VALUES

                 MEAN     STD DEV   LABEL

WOR            .42169     1.97325
UNS           1.02410     1.86479
ANG           1.21637     1.69168
POW           1.41566     1.81962
GUI           1.16867     1.65379
RES           1.23313     1.63719
HOP           1.07229     1.70436
UPS            .76506     1.84200
THR           1.64458     1.35743
SAD           1.00602     1.74251
TENS           .72892     1.90820
IRR           1.00000     1.80937
FRI           1.42169     1.76237

NUMBER OF CASES  =      166


CORRELATION MATRIX:  .


               WOR       UNS       ANG       POW       GUI       RES       HOP       UPS       THR       SAD       TENS      IRR

WOR         1.00000
UNS          .60161   1.00000
ANG          .51892    .50547   1.00000
POW          .49608    .64710    .43835   1.00000
GUI          .47393    .55031    .45550    .66131   1.00000
RES          .47363    .59278    .72367    .62473    .55136   1.00000
HOP          .51356    .60538    .49910    .75057-   .61286    .61469   1.00000
UPS          .62263    .61737    .53049    .60613    .54827    .60657    .62331   1.00000
THR          .50832    .57317    .45859    .55526    .45342    .57346    .51423    .51905   1.00000
SAD          .57739    .66337    .55731    .67535    .52963    .70650    .70402    .67831    .59023   1.00000
TENS         .60515    .65410    .50043    .50742    .51583    .54355    .54098    .62837    .57092    .60017   1.00000
IRR          .43502    .47219    .64352    .47635    .42338    .62547    .43952    .55654    .41956    .61523    .61449   1.00000
FRI          .53760    .52241    .33180    .33914    .31855    .46712    .41156    .50491    .52917    .46653    .64153    .39919

               FRI

FRI         1.00000

KAISER-MEYER-OLKIN MEASURE OF SAMPLING ADEQUACY =  .93652
```

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- - - - - - - - - - - - - - - - - - - - - - -   F A C T O R   A N A L Y S I S   - - - - - - - - - - - - - - - - - - - - -

BARTLETT TEST OF SPHERICITY = 1470.2349, SIGNIFICANCE =     .00000

1-TAILED SIG. OF CORRELATION MATRIX:

' . ' IS PRINTED FOR DIAGONAL ELEMENTS.

                WOR         UNS         ANG         POW         GUI         RES         HOP         UPS         THR
WOR
               .
UNS            .00000
               .           .
ANG            .00000      .00000
POW            .00000      .00000      .00000
GUI            .00000      .00000      .00000      .
RES            .00000      .00000      .00000      .00000      .
HOP            .00000      .00000      .00000      .00000      .00000      .
UPS            .00000      .00000      .00000      .00000      .00000      .00000      .
THR            .00000      .00000      .00000      .00000      .00000      .00000      .00000      .
SAD            .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000      .
TENS           .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000
IRR            .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000
FRI            .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000      .00000
               .00000      .00000      .00000      .00000      .00001      .00000      .00000      .00000      .00000

                SAD         TENS        IRR         FRI

SAD
               .
TENS           .00000
IRR            .00000      .
FRI            .00000      .00000      .
               .00000      .00000      .00000      .


EXTRACTION  1  FOR ANALYSIS  1, MAXIMUM LIKELIHOOD (ML)


INITIAL STATISTICS:

VARIABLE      COMMUNALITY  *  FACTOR   EIGENVALUE   PCT OF VAR   CUM PCT
                           *
WOR              .54396    *    1       7.67106        59.0        59.0
UNS              .62150    *    2        .94523         7.3        66.3
ANG              .61950    *    3        .84789         6.5        72.8
POW              .69042    *    4        .57392         4.4        77.2
GUI              .53165    *    5        .48331         3.8        81.0
RES              .69971    *    6        .46735         3.6        84.6
```

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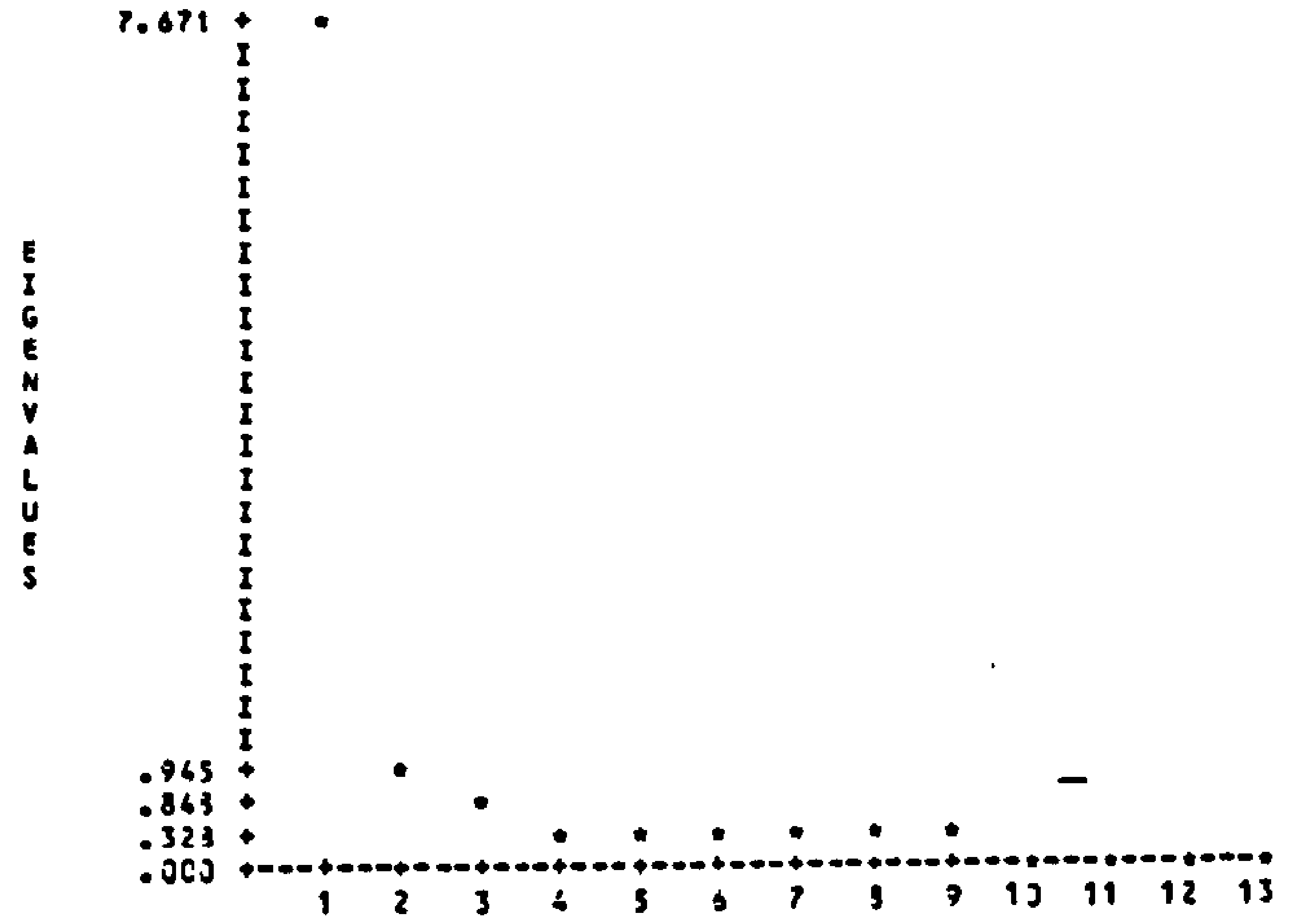
14 AUG 89   MOOD PROFILE FACTORS
11:05:46    O.I.H.E Computer Services Unit DGMV7800Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - - - - - - - - - - - -  F A C T O R   A N A L Y S I S  - - - - - - - - - - - - - - - - - - - - - - -

VARIABLE      COMMUNALITY  *  FACTOR   EIGENVALUE   PCT OF VAR   CUM PCT

HOP               .65773  *     7       .39650         3.1        87.6
UPS               .61563  *     8       .36007         2.8        90.4
THR               .51296  *     9       .32775         2.5        92.9
SAD               .70197  *    10       .27569         2.1        95.0
TENS              .65553  *    11       .25462         2.0        97.0
IRR               .57809  *    12       .20471         1.6        98.6
FRI               .49676  *    13       .18675         1.4       100.0
```



```
   ML EXTRACTED   3 FACTORS.    9 ITERATIONS REQUIRED.

CHI-SQUARE STATISTIC:    61.2036, D.F.:   42, SIGNIFICANCE:      .0230
```

```
14 AUG 89   MOOD PROFILE FACTORS
11:05:48    O.I.H.E Computer Services Unit DGMV7800Phoenix  AOS/VS 7.6.2

- - - - - - - - - - - - - - - - - - - - - - -  F A C T O R   A N A L Y S I S  - - - - - - - - - - - - - - - - - - - - - - -


FACTOR MATRIX:


               FACTOR  1     FACTOR  2     FACTOR  3

SAD              .83403
RES              .81201
POW              .80915      -.39962
HOP              .77291
UPS              .78832
UNS              .73830
TENS             .76434
ANG              .72621                    -.38797
IRR              .70169
THR              .69892
GUI              .69890
WOR              .69632
FRI              .61248                     .31604


FINAL STATISTICS:

VARIABLE      COMMUNALITY  *  FACTOR   EIGENVALUE   PCT OF VAR   CUM PCT
                           *
WOR               .54357  *     1      7.32257        56.3        56.3
UNS               .63259  *     2       .59372         4.5        60.9
ANG               .73814  *     3       .53691         4.1        65.0
POW               .81457  *
GUI               .53309  *
RES               .74624  *
HOP               .70273  *
UPS               .62875  *
THR               .50574  *
SAD               .69753  *
TENS              .74436  *
IRR               .53657  *
FRI               .55552  *
```

```
- - - - - - - - - - - - - - - - - - - - - - -  F A C T O R   A N A L Y S I S  - - - - - - - - - - - - - - - - - - - - - - -


VARIMAX   ROTATION  1  FOR EXTRACTION  1  IN ANALYSIS  1 - KAISER NORMALIZATION.

  VARIMAX CONVERGED IN    5 ITERATIONS.

ROTATED FACTOR MATRIX:

              FACTOR  1     FACTOR  2     FACTOR  3

POW            .82865
HOP            .72123        .30529
GUI            .61377
SAD            .56842        .42149        .44371

TENS                         .75083        .30637
FRI                          .68937
WOR            .34355        .53335
UNS            .52853        .54278
UPS            .46493        .49711        .40678
THR            .44819        .47723

ANG                                        .77335
RES            .46359                      .67049
IRR                          .38528        .60889

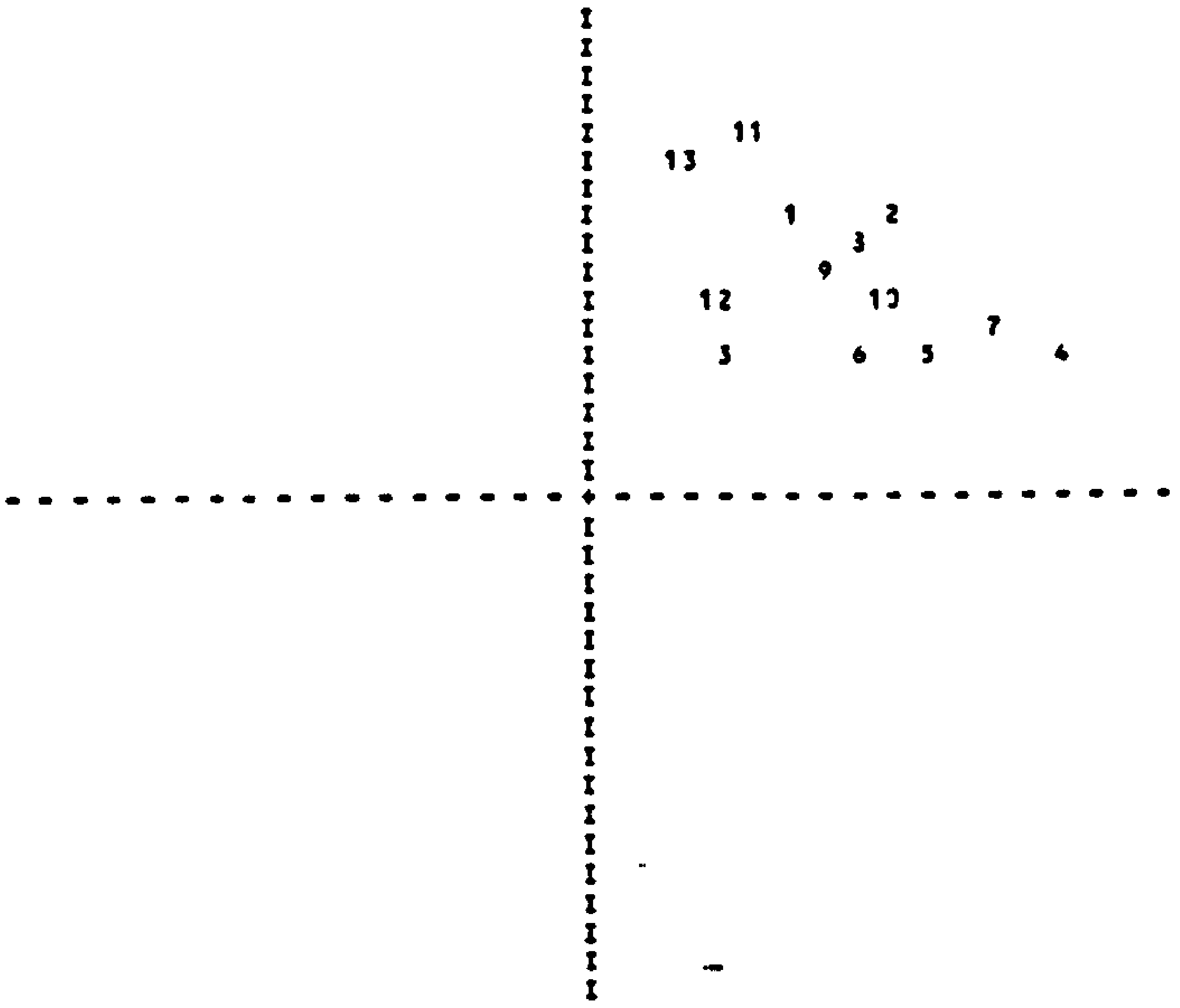

FACTOR TRANSFORMATION MATRIX:

              FACTOR  1     FACTOR  2     FACTOR  3

FACTOR  1      .54797        .54766        .32957
FACTOR  2     -.76355        .50257        .41107
FACTOR  3      .34111        .56912       -.74201
```

```
- - - - - - - - - - - - - - - - - - - - - - -  F A C T O R   A N A L Y S I S  - - - - - - - - - - - - - - - - - - - - - - -

                                  HORIZONTAL FACTOR  1   VERTICAL FACTOR  2
```



```
SYMBOL VARIABLE     COORDINATES      SYMBOL VARIABLE     COORDINATES      SYMBOL VARIABLE     COORDINATES

   1    WOR     ( .34385,  .53385)    2    UNS     ( .52353,  .54298)    3    ANG     ( .26795,  .25130)
   4    POW     ( .32365,  .24551)    5    GUI     ( .61377,  .28595)    6    RES     ( .46359,  .23596)
   7    HOP     ( .72123,  .30529)    8    UPS     ( .46493,  .49711)    9    THR     ( .44319,  .47723)
  10    SAD     ( .56342,  .42149)   11    TENS    ( .29487,  .75083)   12    IRR     ( .25977,  .33524)
  13    FRI     ( .19407,  .63937)
```

```
- - - - - - - - - - - - - - - - - - - - - -   F A C T O R   A N A L Y S I S   - - - - - - - - - - - - - - - - - - - - - -


FACTOR SCORE COEFFICIENT MATRIX:

              FACTOR  1     FACTOR  2     FACTOR  3

WOR            -.03334        .18816       -.03535
UNS             .07734        .15890       -.09424
ANG            -.17479       -.14999        .53316
POW             .63631       -.23327       -.20031
GUI             .14934       -.03127       -.03440
RES             .00442       -.16246        .40976
HOP             .29233       -.07645       -.07253
UPS             .01712        .10763        .03196
THR             .03501        .10037       -.03732
SAD             .10233        .02245        .05467
TENS           -.16732        .51545       -.09695
IRR            -.10542        .02431        .23449
FRI            -.10630        .30610       -.07930


COVARIANCE MATRIX FOR ESTIMATED REGRESSION FACTOR SCORES:

              FACTOR  1    FACTOR  2    FACTOR  3

FACTOR  1       .79874
FACTOR  2       .09669       .74437
FACTOR  3       .09625       .10366       .73417

  3 REGRESSION FACTOR SCORES WILL BE SAVED WITH ROOTNAME: MFS
FOLLOWING FACTOR SCORES WILL BE ADDED TO THE ACTIVE FILE:

  NAME        LABEL

MFS1          REGR FACTOR SCORE   1 FOR ANALYSIS    1
MFS2          REGR FACTOR SCORE   2 FOR ANALYSIS    1
MFS3          REGR FACTOR SCORE   3 FOR ANALYSIS    1
```

APPENDIX VIII

Factor analysis, activities of daily living

```
14 AUG 89    PRELIMINARY FACTORS                                                                                  PAGE
10:53:41     D.I.M.E Computer Services Unit DSMV73C0Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - - - - - - - - - - - -   F A C T O R   A N A L Y S I S   - - - - - - - - - - - - - - - - - - - - - -


 E    4.121 +    *
 I          I
 G          I
 E          I
 N          I
 V          I
 A          I
 L          I
 U          I
 E          I
 S     .694 +         *
       .547 +             *
       .000 +---+---+---+---------+
                1   2   3   4   5   6

   ML EXTRACTED   1 FACTORS.    5 ITERATIONS REQUIRED.

CHI-SQUARE STATISTIC:   113.0076, D.F.:    9, SIGNIFICANCE:      .0000


FACTOR MATRIX:


              FACTOR  1

WASH           .87513
CLEAN          .81735
DRESS          .81650
COOK           .79438
MOB            .73758
SHOP           .63730



FINAL STATISTICS:

VARIABLE     COMMUNALITY  *  FACTOR   EIGENVALUE   PCT OF VAR   CUM PCT
                          *
MOB              .62075   *     1       3.75941       62.7        62.7
DRESS            .66665   *
COOK             .63103   *
SHOP             .40615   *
CLEAN            .66805   *
WASH             .76594   *
```

```
14 AUG 89    PRELIMINARY FACTORS                                                                                  PAGE
10:53:40     D.I.M.E Computer Services Unit DSMV73C0Phoenix  ACS/VS 7.6.2

- - - - - - - - - - - - - - - - - - - - - - -   F A C T O R   A N A L Y S I S   - - - - - - - - - - - - - - - - - - - - - -



ANALYSIS NUMBER  1  LISTWISE DELETION OF CASES WITH MISSING VALUES


CORRELATION MATRIX:


               MOB       DRESS       COOK        SHOP       CLEAN       WASH

MOB          1.00000
DRESS         .63960    1.00000
COOK          .57090     .63038    1.00000
SHOP          .60618     .33806     .47948    1.00000
CLEAN         .60915     .59023     .79363     .64227    1.00000
WASH          .70390     .80536     .65162     .52232     .66726    1.00000

KAISER-MEYER-OLKIN MEASURE OF SAMPLING ADEQUACY =  .83225

BARTLETT TEST OF SPHERICITY = 762.56972, SIGNIFICANCE =     .00000


EXTRACTION  1  FOR ANALYSIS  1, MAXIMUM LIKELIHOOD (ML)


INITIAL STATISTICS:


VARIABLE     COMMUNALITY  *  FACTOR   EIGENVALUE   PCT OF VAR   CUM PCT
                          *
MOB              .60660   *     1       4.12125       68.7        68.7
DRESS            .69132   *     2        .69372       11.6        80.2
COOK             .67437   *     3        .54655        9.1        89.4
SHOP             .51462   *     4        .28655        4.8        94.1
CLEAN            .73091   *     5        .18317        3.1        97.2
WASH             .73330   *     6        .16375        2.8       100.0
```

APPENDIX IX

Multiple regression analysis

```
                                 * * * *   M U L T I P L E   R E G R E S S I O N   * * * *

Listwise Deletion of Missing Data

Equation Number 1    Dependent Variable..   MCH

Beginning Block Number  1.  Method:  Stepwise

Variable(s) Entered on Step Number  1..    REGRETS

Multiple R           .56835         Analysis of Variance
R Square             .32302                            DF        Sum of Squares       Mean Square
Adjusted R Square    .31589         Regression          1            9111.18773        9111.18773
Standard Error     14.17747         Residual           95           19095.05970         201.00063

                                    F =      45.32915       Signif F =  .0000

------------------ Variables in the Equation ------------------      ------------- Variables not in the Equation -------------

Variable              B          SE B         Beta          T  Sig T      Variable        Beta In  Partial  Min Toler          T  Sig T

REGRETS      -10.494390      1.558795    -.568349     -6.733  .0000      PLES          -.117596 -.137575    .926553     -1.347  .1813
(Constant)    25.743393      1.797621                 14.321  .0000      LOC           -.225495 -.265612    .939260     -2.671  .0089
                                                                         RELIG          .066269  .077482    .925463       .753  .4530
                                                                         PWORS         -.107230 -.124127    .907141     -1.213  .2282
                                                                         INFO           .283936  .344980    .999365      3.563  .0006
                                                                         IFS1          -.127915 -.154607    .938982     -1.517  .1326
                                                                         OCC            .341571  .393734    .879534      4.153  .0001
                                                                         LONELY        -.262512 -.314235    .969599     -3.210  .0018
                                                                         CONT           .358215  .422745    .942355      4.523  .0000
                                                                         PERS          -.199273 -.233705    .931099     -2.330  .0219
```

```
                                 * * * *   M U L T I P L E   R E G R E S S I O N   * * * *

Equation Number 1    Dependent Variable..   MCH

Variable(s) Entered on Step Number  2..    CONT

Multiple R           .66634         Analysis of Variance
R Square             .44401                            DF        Sum of Squares       Mean Square
Adjusted R Square    .43213         Regression          2           12523.72316        6261.86158
Standard Error     12.91645         Residual           94           15682.52426         166.83536

                                    F =      37.53319       Signif F =  .0000

------------------ Variables in the Equation ------------------      ------------- Variables not in the Equation -------------

Variable              B          SE B         Beta          T  Sig T      Variable        Beta In  Partial  Min Toler          T  Sig T

REGRETS       -8.913652      1.462553    -.482717     -6.095  .0000      PLES          -.055653 -.070715    .893535      -.686  .4959
CONT           6.350273      1.404101     .358215      4.523  .0000      LOC           -.109665 -.132817    .815493     -1.292  .1995
(Constant)    11.231006      3.602683                  3.117  .0024      RELIG          .071023  .091623    .874886       .887  .3772
                                                                         PWORS          .033206  .039371    .731630       .380  .7049
                                                                         INFO           .238375  .316138    .922912      3.216  .0018
                                                                         IFS1          -.097737 -.129841    .935475     -1.263  .2099
                                                                         OCC            .308813  .390934    .863722      4.096  .0001
                                                                         LONELY        -.148201 -.180493    .801740     -1.770  .0801
                                                                         PERS          -.173903 -.224446    .885490     -2.221  .0288

                                  * * * * * * * * * * * * * * * * * * * * * * * * * * * * *

Variable(s) Entered on Step Number  3..    OCC

Multiple R           .72731         Analysis of Variance
R Square             .52898                            DF        Sum of Squares       Mean Square
Adjusted R Square    .51379         Regression          3           14923.47320        4974.49107
Standard Error     11.95231         Residual           93           13285.77423         142.85779

                                    F =      34.82128       Signif F =  .0000
```

```
                              * * * *   M U L T I P L E   R E G R E S S I O N   * * * *

Equation Number 1    Dependent Variable..   MCH

------------------ Variables in the Equation ------------------        ------------- Variables not in the Equation -------------

Variable              B         SE B        Beta         T  Sig T      Variable        Beta In  Partial  Min Toler          T  Sig T

REGRETS       -7.235739     1.414019   -.391850     -5.117  .0000      PLES           -.023109 -.031722   .832056       -.304  .7615
CONT           5.830016     1.305484    .323867      4.466  .0000      LOC            -.115551 -.152016   .810877      -1.475  .1436
OCC            2.541720      .620533    .303813      4.096  .0001      RELIG           .010059  .013806   .826404        .132  .8949
(Constant)     7.005235     3.489743                 2.007  .0476      PWORS           .007077  .009088   .776705        .087  .9307
                                                                       INFO            .192795  .273573   .853473       2.725  .0076
                                                                       IFS1            .010275  .013921   .773960        .133  .8945
                                                                       LONELY         -.094862 -.123579   .797360      -1.194  .2354
                                                                       PERS           -.195420 -.273357   .810185      -2.726  .0077


                              * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *


Variable(s) Entered on Step Number  4..    INFO

Multiple R           .75115          Analysis of Variance
R Square             .56423                               DF      Sum of Squares      Mean Square
Adjusted R Square    .54528          Regression            4         15914.80707       3978.70177
Standard Error     11.55866          Residual             92         12291.44036        133.60261

                                     F =       29.78012       Signif F =  .0000

------------------ Variables in the Equation ------------------        ------------- Variables not in the Equation -------------

Variable              B         SE B        Beta         T  Sig T      Variable        Beta In  Partial  Min Toler          T  Sig T

REGRETS       -7.644540     1.375634   -.413939     -5.557  .0000      PLES           -.047216 -.066917   .826001       -.640  .5239
CONT           5.377593     1.273328    .303352      4.223  .0001      LOC            -.120515 -.164790   .797205      -1.594  .1145
OCC            2.251430      .609461    .273543      3.694  .0004      RELIG           .009449  .013436   .816907        .129  .8979
INFO           3.478553     1.275123    .192795      2.728  .0076      PWORS           .010903  .014554   .776455        .139  .8899
(Constant)      .471320     4.133375                  .114  .9096      IFS1           -.036055 -.049956   .727753       -.477  .6342
                                                                       LONELY         -.070008 -.094093   .737182       -.902  .3697
                                                                       PERS           -.196574 -.285904   .801404      -2.846  .0055
```

```
                              * * * *   M U L T I P L E   R E G R E S S I O N   * * * *

Equation Number 1    Dependent Variable..   MCH

Variable(s) Entered on Step Number  5..    PERS

Multiple R           .77450          Analysis of Variance
R Square             .59985                               DF      Sum of Squares      Mean Square
Adjusted R Square    .57786          Regression            5         16919.52381       3383.90476
Standard Error     11.13687          Residual             91         11286.72361        124.02993

                                     F =       27.28297       Signif F =  .0000

------------------ Variables in the Equation ------------------        ------------- Variables not in the Equation -------------

Variable              B         SE B        Beta         T  Sig T      Variable        Beta In  Partial  Min Toler          T  Sig T

REGRETS       -6.642767     1.367817   -.361915     -4.856  .0000      PLES           -.057456 -.084910   .773665       -.808  .4210
CONT           5.099399     1.230756    .287653      4.143  .0001      LOC            -.083775 -.117360   .785295      -1.121  .2652
OCC            2.361960      .588504    .256972      4.013  .0001      RELIG           .019312  .029463   .765041        .280  .7804
INFO           3.499175     1.228615    .193932      2.848  .0054      PWORS           .013413  .018690   .756993        .177  .8596
PERS          -2.952954     1.037535   -.196574     -2.846  .0055      IFS1           -.068690 -.096707   .727752       -.922  .3591
(Constant)     3.037717     4.021982                  .755  .4525      LONELY         -.017651 -.024004   .737497       -.228  .8203

End Block Number   1   PIN =     .050 Limits reached.
```

```
                              * * * *   M U L T I P L E   R E G R E S S I O N   * * * *

Equation Number 1    Dependent Variable..   MCM


Residuals Statistics:

                     Min           Max      Mean  Std Dev     N

*PRED         -32.9050       35.9693  18.2993  14.2512   107
*RESID        -37.2777       20.8254   -.4862  10.9906   107
*ZPRED         -3.3718        1.3153   -.0147   1.0735   107
*ZRESID        -3.3472        1.8730   -.0437    .9869   107

Total Cases =      190

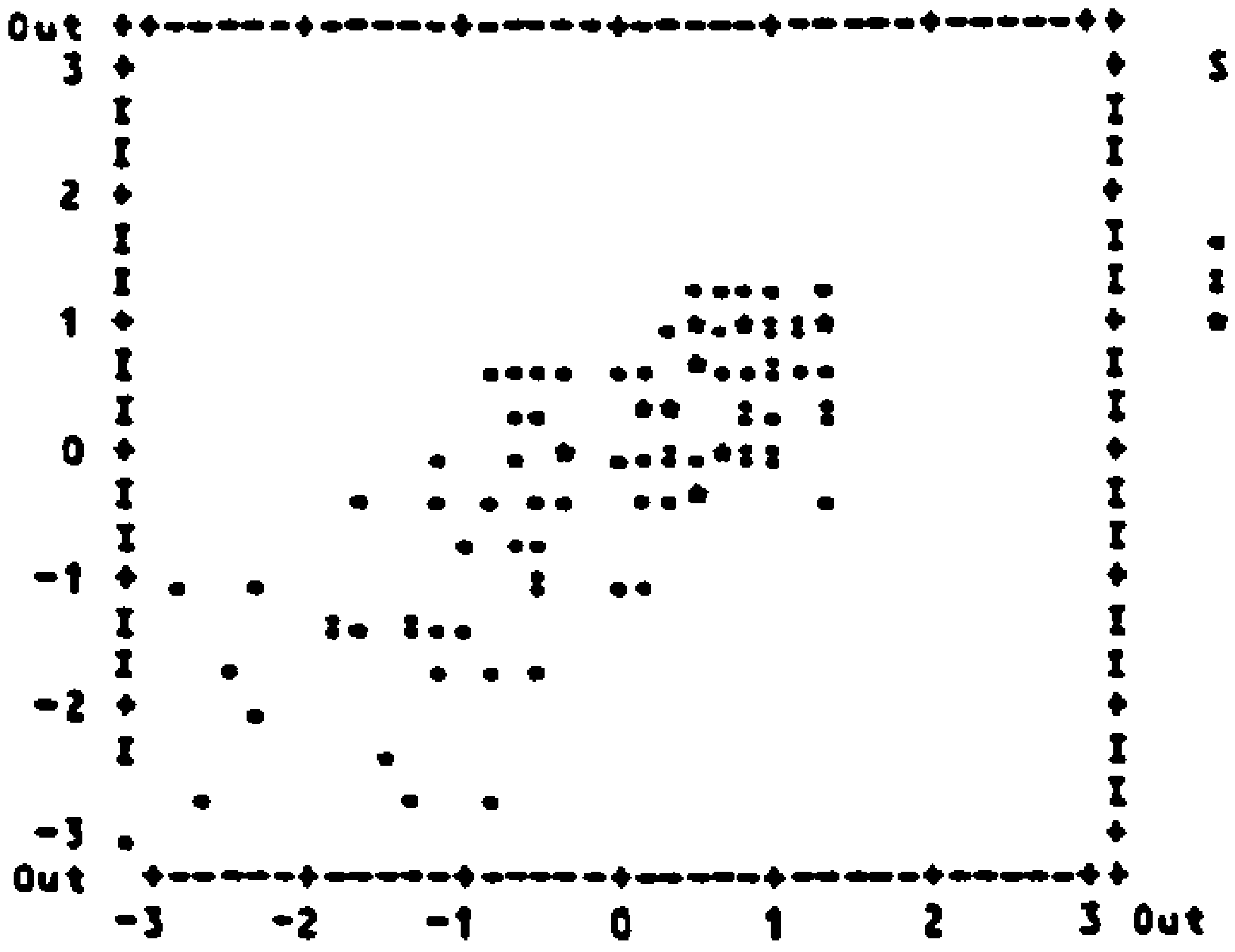
                              * * * * * * * * * * * * * * * * * * * * * * * * * * * * * *


Outliers - Standardized Residual

  Case #        *ZRESID

    103        -3.34724
     28        -2.55032
    114        -2.33133
    156        -2.03258
    151        -1.98578
     25         1.87034
     98        -1.85411
     58        -1.83471
    135         1.78646
     57         1.74695
```

Standardized Scatterplot
Across - *PRED   Down - MCM



```
Symbols:

   Max N

 .     1.0
 :     2.0
 *     5.0
```

APPENDIX X

Frequencies, nurses' data

Code for computerised variables:

Nurses' ratings of patient's pain and coping

ANXN	Nurses' ratings of patient's anxiety
DEPRN	Depression
RESN	Resentment
FIRN	Fear
INACTN	Inactivity
OCCN	Occupation
LONEN	Loneliness
COMPN	Complaints
PWORSN	patients' worst pain levels
PLESN	patients' least pain levels
EXAGN	perceived pain exaggeration
CONTN	level of pain control

```
- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

ANAN

                                                        VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         43     21.0     22.1     22.1
                                1         73     35.6     37.4     59.5
                                2         39     19.0     20.0     79.5
                                3         40     19.5     20.5    100.0
                                9         10      4.9  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES      195      MISSING CASES    10

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

DEPRN

                                                        VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         79     38.5     40.1     40.1
                                1         54     26.3     27.4     67.5
                                2         36     17.6     18.3     85.8
                                3         28     13.7     14.2    100.0
                                9          8      3.9  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES      197      MISSING CASES     8
```

```
RESN

                                                        VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0        122     59.5     62.9     62.9
                                1         38     18.5     19.6     82.5
                                2         23     11.2     11.9     94.3
                                3         11      5.4      5.7    100.0
                                9         11      5.4  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES      194      MISSING CASES    11

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

PIRN

                                                        VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0        121     59.0     62.7     62.7
                                1         43     21.0     22.3     85.0
                                2         16      7.8      8.3     93.3
                                3         13      6.3      6.7    100.0
                                9         12      5.9  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES      193      MISSING CASES    12

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

INACTN

                                                        VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         36     17.6     18.4     18.4
                                1         60     29.3     30.6     49.0
                                2         53     25.9     27.0     76.0
                                3         47     22.9     24.0    100.0
                                9          9      4.4  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES      196      MISSING CASES     9
```

```
DCON

                                                            VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         37     18.0     19.3     19.3
                                1         51     24.9     26.6     45.8
                                2         76     37.1     39.6     85.4
                                3         28     13.7     14.6    100.0
                                9         13      6.3  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES     192      MISSING CASES    13

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

LOVEN

                                                            VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         79     38.5     40.7     40.7
                                1         71     34.6     36.6     77.3
                                2         22     10.7     11.3     88.7
                                3         22     10.7     11.3    100.0
                                9         11      5.4  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES     194      MISSING CASES    11

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

COMPN

                                                            VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         92     44.9     47.2     47.2
                                1         41     20.0     21.0     68.2
                                2         36     17.6     18.5     86.7
                                3         26     12.7     13.3    100.0
                                9         10      4.9  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES     195      MISSING CASES    10
```

```
PWORSN

                                                            VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         16      7.8      8.2      8.2
                                1         11      5.4      5.6     13.8
                                2         74     36.1     37.8     51.5
                                3         62     30.2     31.6     83.2
                                4         24     11.7     12.2     95.4
                                5          9      4.4      4.6    100.0
                                9          9      4.4  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES     196      MISSING CASES     9

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

PLESN

                                                            VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                0         78     38.0     39.8     39.8
                                1         77     37.6     39.3     79.1
                                2         32     15.6     16.3     95.4
                                3          5      2.4      2.6     98.0
                                4          4      2.0      2.0    100.0
                                9          9      4.4  MISSING
                                     -------  -------  -------
                            TOTAL        205    100.0    100.0

VALID CASES     196      MISSING CASES     9
```

```
05 JUN 89   NURSES DATA                                                                          PAGE
10:54:29    D.I.H.E Computer Services Unit DGMV7300Phoenix  AOS/VS 7.6.2

EXAGV

                                                        VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                -3         21     10.2     15.3     15.3
                                -2         22     10.7     16.1     31.4
                                -1         22     10.7     16.1     47.4
                                 0         49     23.9     35.8     83.2
                                 1         12      5.9      8.8     92.0
                                 2          7      3.4      5.1     97.1
                                 3          4      2.0      2.9    100.0
                                 9         68     33.2  MISSING
                                      -------  -------  -------
                             TOTAL        205    100.0    100.0

VALID CASES     137      MISSING CASES    68
```

```
05 JUN 89   NURSES DATA
10:33:34    D.I.H.E Computer Services Unit DGMV7800Phoenix  AOS/VS 7.6.2

CONTN

                                                        VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 0          9      4.4      6.0      6.0
                                 1         24     11.7     16.1     22.1
                                 2         44     21.5     29.5     51.7
                                 3         72     35.1     48.3    100.0
                                 9         56     27.3  MISSING
                                      -------  -------  -------
                             TOTAL        205    100.0    100.0

VALID CASES     149      MISSING CASES    56
```

Code for computerised variables, nurses' data (qualified nurses only)

GRADEN	Nurse grade
ACRX	Tuition received in acute pain management
CHRX	Tuition received in chronic pain management
CARX	Tuition received in cancer pain management
PTH	Tuition received in pain theories
PASS	Tuition received in pain assessment
PSY	Tuition received in psychological pain factors
Q8A	Knowledge of use of drugs in pain control
Q8B	Knowledge of pain assessment
Q8C	Knowledge of psychological factors in pain
Q8D	Knowledge of psychological methods of pain control
Q8E	Knowledge of psychological effects of chronic pain
Q9A	Pain assessment taught in general training
Q9BASST	Pain assessment taught during district training
Q9BASSP	Pain assessment forms shown
Q9BDISC	Pain assessment discussed
Q9BNM	Pain assessment not mentioned
Q9C	Pain assessment included in other courses
Q11A	Do patients exaggerate their pain?
Q15	Use of pain assessment record form
Q17	Usefulness of objective pain assessment

```
GRADEN


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

ON                               1         13      61.9     61.9     61.9
OEN                              2          3      14.3     14.3     76.2
EN                               4          5      23.8     23.8    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

ACRX


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

NO                               0          9      42.9     42.9     42.9
YES                              1         12      57.1     57.1    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

CHRX


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

NO                               0         11      52.4     52.4     52.4
YES                              1         10      47.6     47.6    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0
```

```
CARX


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

NO                               0          5      23.8     23.8     23.8
YES                              1         16      76.2     76.2    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

PTH


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

NO                               0          9      42.9     42.9     42.9
YES                              1         12      57.1     57.1    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

PASS


                                                          VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY   PERCENT  PERCENT  PERCENT

NO                               0         12      57.1     57.1     57.1
YES                              1          9      42.9     42.9    100.0
                                      -------   -------  -------
                             TOTAL         21     100.0    100.0

VALID CASES      21      MISSING CASES     0
```

```
PST

                                                         VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                               0          9     42.9     42.9     42.9
YES                              1         12     57.1     57.1    100.0
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      21      MISSING CASES      0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q8A

                                                         VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 2          3     14.3     14.3     14.3
                                 3         16     76.2     76.2     90.5
GOOD                             4          2      9.5      9.5    100.0
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      21      MISSING CASES      0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q8B

                                                         VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 2          6     28.6     30.0     30.0
                                 3         11     52.4     55.0     85.0
GOOD                             4          3     14.3     15.0    100.0
                                 9          1      4.8  MISSING
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      20      MISSING CASES      1
```

```
Q8C

                                                         VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 2          8     38.1     40.0     40.0
                                 3         11     52.4     55.0     95.0
GOOD                             4          1      4.8      5.0    100.0
                                 9          1      4.8  MISSING
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      20      MISSING CASES      1

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q8D

  VALUE LABEL                                            VALID     CUM
                             VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 2         13     61.9     65.0     65.0
                                 3          7     33.3     35.0    100.0
                                 9          1      4.8  MISSING
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      20      MISSING CASES      1

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q8E

                                                         VALID     CUM
  VALUE LABEL                VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                                 2          7     33.3     35.0     35.0
                                 3         11     52.4     55.0     90.0
GOOD                             4          2      9.5     10.0    100.0
                                 9          1      4.8  MISSING
                                      -------  -------  -------
                             TOTAL         21    100.0    100.0

VALID CASES      20      MISSING CASES      1
```

```
Q9A

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0         20     95.2     95.2     95.2
YES                             1          1      4.8      4.8    100.0
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       21      MISSING CASES      0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q9BASST

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0         15     71.4     88.2     88.2
YES                             1          2      9.5     11.8    100.0
                                9          4     19.0  MISSING
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       17      MISSING CASES      4

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q9BASSF

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0         15     71.4     88.2     88.2
YES                             1          2      9.5     11.8    100.0
                                9          4     19.0  MISSING
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       17      MISSING CASES      4
```

```
Q9BDISC

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0          5     23.8     29.4     29.4
YES                             1         12     57.1     70.6    100.0
                                9          4     19.0  MISSING
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       17      MISSING CASES      4

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q9BNM

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0         14     66.7     82.4     82.4
YES                             1          3     14.3     17.6    100.0
                                9          4     19.0  MISSING
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       17      MISSING CASES      4

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q9C

                                                      VALID     CUM
  VALUE LABEL               VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                              0         12     57.1     57.1     57.1
YES                             1          8     38.1     38.1     95.2
                                2          1      4.8      4.8    100.0
                                     -------  -------  -------
                            TOTAL         21    100.0    100.0

VALID CASES       21      MISSING CASES      0
```

```
Q11A

                                                       VALID     CUM
  VALUE LABEL              VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

                               0          1      4.8      4.8      4.8
                               1          9     42.9     42.9     47.6
                               2         11     52.4     52.4    100.0
                                    -------  -------  -------
                           TOTAL         21    100.0    100.0

VALID CASES      21      MISSING CASES     0

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q15

                                                       VALID     CUM
  VALUE LABEL              VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NO                             0         17     81.0     85.0     85.0
OCC                            1          2      9.5     10.0     95.0
OFTEN                          2          1      4.8      5.0    100.0
                               9          1      4.8  MISSING
                                    -------  -------  -------
                           TOTAL         21    100.0    100.0

VALID CASES      20      MISSING CASES     1

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Q17

                                                       VALID     CUM
  VALUE LABEL              VALUE  FREQUENCY  PERCENT  PERCENT  PERCENT

NOT SURE                       0          2      9.5      9.5      9.5
POSSIBLY                       1          9     42.9     42.9     52.4
YES                            2         10     47.6     47.6    100.0
                                    -------  -------  -------
                           TOTAL         21    100.0    100.0

VALID CASES      21      MISSING CASES     0
```