

THE ROLE OF PSYCHOLOGICAL SUPPORT FOR PAIN IN PALLIATIVE CARE

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Abstract

This review examines the contention that palliative care offers a restricted level of service to the community if it does not formally incorporate the psychological support of dying patients and their families in routine terminal care. The attributional model of responsibility for problems and solutions proposed by Brickman and colleagues (1982) is used to encapsulate the difference between a traditional medical role for patients compared with a more satisfactory psychological orientation, whereby the dynamic participation of patients and families in the treatment of the final days of life is strengthened. Use of alternative therapies is suggested as one method by which this could be achieved. This review suggests that at the present time, in Tasmania and possibly further afield, the contribution to palliative care which psychologists are capable of making is insufficiently utilised. They are able to provide a much needed resource at a time when treatment of terminal illness is moving beyond physical care towards a more holistic approach to patient care in order to maximise the quality of the last stages of life.

Diseases are expressed in different ways in different people (Holmes, 1992). The outcome of any treatment of disease depends on more than just the curative power of the treatment; it depends on a range of physical and psychological variables pertaining to the patient (Cassell, 1991). This being the case, a multidisciplinary approach to disease, routinely involving a range of health care professionals, is likely to lead to the best overall outcomes (White, 1996), because each discipline will make its own unique contribution to the patient's ailment. That contribution refers to more than the specialist knowledge that, for example, psychology or physiotherapy can offer. It refers to the professional orientation of the practitioner and his or her fundamental treatment goals. Delineating the contributions of each of these professions is beyond the scope of this paper, therefore the particular potential of psychological intervention in palliative care will provide an example of the benefits of holistic care.

Psychology is uniquely suited to palliative care because, unlike acute medical care, the primary goals of psychological intervention emphasise quality of life rather than prolongation, and promote patient efficacy rather than acting for the patient (see for example, Bannerman, 1992). These goals are complementary to the aims of palliative care, specifically those aims directed at improving quality, autonomy and achieving a peaceful acceptance of death (Ipswich & West Moreton Division of General Practice (I&WMDGP), 1994).

Psychological shifts in palliative care

On the one hand, palliative care, as a discipline separate from mainstream

acute hospital care, is a comparatively recent phenomenon (White, 1996), with hospice programs, home care and specialist units developing in Australia mainly from the early 1980s. In Tasmania, it has largely been focussed on units based in acute care hospitals (Hodder & Turley, 1991). On the other hand, it can be argued that it is one of the oldest medical disciplines, given that palliation was often the only way to deal with many serious illnesses in the days before the complex, technologically sophisticated treatments now available for diseases such as cancer (Woodruff, 1993). These treatments emphasise the greater potential for a cure or remission, and perhaps result in greater attention to medical care for physical illness, somewhat to the detriment of psychological and/or palliative care (Cassell, 1991).

In the simplest terms, palliative care refers to intervention at the stage of terminal illness in which the disease has progressed to the point where curative treatment is no longer likely to bring about positive results (World Health Organisation (WHO), 1990). The focus shifts, instead, to making a patient as comfortable as possible by treating the symptoms rather than the cause of the illness (Dudgeon, et al., 1995). Actively attending to psychosocial problems is equally important, with the prevailing goal being the maximum quality of life for patients and their families (WHO, 1990). A patient must learn to relinquish hope of recovery and adjust to imminent mortality (Sarafino, 1990). In the best circumstances a patient is encouraged “to live until he (sic) dies, at his own maximum potential...with control and independence wherever possible” (Saunders, 1984, p.233). The family must also make this adjustment, in addition to preparing for further changes after a patient’s death (Parkes, 1984).

Unfortunately, a traditional medical approach takes a reductionist perspective by placing greater weight on the biological aspects of a patient than on the psychological (Birch, 1993; Horne, 1992). In fact, the actual physical disease is only a component of the whole experience of an illness (Zalcberg, 1992). Patients and carers often receive haphazard guidance in adjusting to terminal illness and death, depending upon the degree to which their distress is recognised and/or interferes with medical treatment. Specialist palliative care facilities and practitioners in the community have considerable experience in working with people who are facing death. A patient with a terminal illness must make the psychological shifts from 'well person' to 'sick person' to 'dying person' and come to terms with all the disappointments inherent in this progression (Parkes, 1984). However, in Tasmania, there is no emphasis on and no formal structure to support these shifts, apart from information about the progression of the illness. This means that many patients lack help in making these very difficult transitions. In order to help patients best, physicians and carers must also make these shifts in terms of the way they interact with patients and the goals they are working towards.

The ability to accommodate a given treatment regime is determined by the specified goal. If the goal is to eradicate the disease, patients will be more willing to tolerate undesirable side effects for a finite period of time and less likely to interpret symptoms as painful (Turk, 1996). If a cure is not feasible, then palliative care takes over from mainstream medical care and the goal of treatment must alter to focus on quality of life issues, for example, symptom control and family affairs. Side effects from both the disease and the treatment become less tolerable and attain greater

significance (Lowenthal, 1990). This emphasis on quality of life, while relinquishing the prospect of a cure, represents a departure from the usual medical goals. The training offered during undergraduate medical degrees is focussed upon the eradication of injury or disease, although in recent years a more patient-centred orientation has been introduced (University of Melbourne, 1995).

Attribution of responsibility

In the case of terminal cancer, patients must contend with an uncertain and curtailed lifespan, a restricted range of activity, and, in many cases, with pain that has no positive meaning and may not be entirely preventable, all of which severely reduce their quality of life (Bonica, 1992). The achievement of control over pain is extremely important in easing physical and mental distress (Patt, 1992). Medication is the core of cancer pain control (Hodder & Turley, 1991) and is ideally supported by many other therapies, according to the needs and wishes of the patients and their families. Control of chronic benign pain requires a long term approach which cautions against overreliance on pharmacotherapy (Bonica, 1992; Kinney & Brin, 1992). With palliative care, however, the expectation is that drugs should be able to alleviate most pain, because the disease is progressive. Patients have significantly reduced life spans and are often too physically incapacitated to make the physical and mental adjustments that are possible, for example, for someone suffering from chronic lower back pain. This may explain the heavy reliance on pharmaceutical intervention, which requires minimal effort from patients.

The difference between the traditional role of a patient and the role supported by this present review can be described using a fourfold model of attribution of responsibility defined by Brickman and colleagues (Brickman et al., 1982). The model proposes the following categories of attribution of responsibility based on both the problem and the solution: moral, compensatory, medical and enlightenment. This model can discriminate the form behaviour takes when people try to help others or help themselves (See Table 1).

The enlightenment model could be described as a correctional model, in which individuals must be punished and/or rehabilitated for their misdeeds. The traditional patient role obviously fits the medical model, in which people are seen as not responsible for either their illness or their cure and hence what they require is treatment from physicians. This model, if it is accurate, dictates that the role of physicians

Table 1

Attribution of responsibility for the development of a problem and solution.

<u>Model/Attribution</u>		<u>Responsibility</u>		<u>Requirement</u>
Enlightenment	➡	Problems only	➡	Discipline
Medical	➡	Neither	➡	Treatment
Compensatory	➡	Solutions only	➡	Power
Moral	➡	Problems AND solutions	➡	Motivation

(Brickman, Rabinowitz, Karuza, Coates, Cohn & Kidder, 1982)

and other health professionals is a paternal one and patients are expected to follow instructions and do not require explanations or choices, except as a courtesy. The preferences and opinions of patients are nominally involved, if at all, and it is difficult for patients to assert them (Brickman et al., 1982).

It is argued here that the therapeutic effects of psychological intervention on the delivery of mainstream medical care extend beyond direct patient work to having the potential to improve the range of options offered to terminally ill patients and relieve a portion of the extraordinary responsibility that physicians traditionally have in nominating appropriate treatment. This is because change in the attribution of responsibility for problems and solutions alters the focus of what help is offered to the patient and how it is done.

Psychologists are trained to work principally from a theoretical framework that fits either the compensatory or the moral model (Brickman et al., 1982), depending on the nature of the problem. In the former, people are not viewed as responsible for their problems, but are responsible for their solutions, and what they require is power to implement the expertise that professionals can offer and to utilise their own skills. This process of empowerment occurs by professionals working with patients to identify their goals and giving them the support and the information to realise them.

The moral model postulates that individuals are responsible for problems and solutions and only require motivation. They are capable of proactive action and of

generating solutions, again, provided they are supplied with the expertise and the support to act.

Palliative care patients could be described by both models, according to the identified problem. In the case of cancer patients, the moral model provides the best therapeutic fit. Patients are not responsible for causing the cancer, although their lifestyle may have contributed to it. They can make choices about treatment and about what they are prepared to endure and how far they will modify their own lives to deal with the cancer.

For the problem of maladaptive or distressing emotional or cognitive responses to cancer or to pain, the distress can be described as self-generated, because of the particular perspective adopted by patients when they become ill and the illness becomes terminal. Cancer is a feared and common illness, but patients are capable of altering the way they view their cancer or their pain and thus diminishing the distress that results (Bannerman, 1992). Psychologists can offer a range of techniques, including cognitive therapies, which emphasise the contributions that patients bring to the physician-patient relationship. The movement away from the role of victim-of-cancer provides a good environment for positive consequences for patients and for health professionals because responsibility for outcome is shared. This type of 'mutual participation' relationship between patient and professional, has been described as "the most effective physician-patient interchange that can occur" (DiMatteo, 1991, p. 194).

Chronic pain in terminal illness

In modern times, improvements in medical techniques, disease control, sanitation and nutrition have resulted in longer life spans, with death from injury or opportunistic infections (AIDS and hepatitis being exceptions) becoming less predominant compared with 'lifestyle' illnesses such as heart disease and cancer (Lerner, 1984). Cancer is the leading cause of death after heart disease, both generally and for premature death (Australian Bureau of Statistics, 1992) and because cancer can progress slowly (Parkes, 1984), people with cancer comprise the largest group of patients in palliative care.

The term 'cancer' refers to a category of diseases which vary significantly in their actions and aetiology (Hyde, 1988). All forms of cancer represent uncontrolled and disorganised cell growth, growing independently of surrounding tissue and having no value for the host. Environmental, personality and genetic factors have all been implicated in the aetiology of different categories of cancer and research into causation continues (Hyde, 1988; Thomas, 1993). Although the actual incidence of cancer is considerably higher than its mortality rate (depending on the type of cancer), its emotional impact is severe. Quite apart from the strong association people make between cancer and death (Lowenthal, 1990; Twycross & Lack, 1983), pain is considered to be the most feared side effect of cancer (Cain & Hammes, 1994; Hammes & Cain, 1994; Woodruff, 1993). This belief has intuitive appeal, although it has been argued that it is a misperception held by medical staff rather than patients (Charlton, 1994). This argument is a logical supposition, given that patients are more likely to express this particular fear to medical staff, who have the expertise to

control pain. Alternatively, it may be that the fear that is most salient for patients depends on their stage of illness. The most common fear has been suggested to be a fear of separation from the components of everyday life, such as friends, home and profession (Parkes, 1973, cited in Lichter, 1991) or concerns about family or becoming a burden (Dudgeon, et al., 1995). In fact, pain is likely to induce this type of separation, because it is a compelling distraction.

Pain is one of the most common symptoms of advanced cancer (Walsh & Saunders, 1984), with significant pain occurring in approximately two-thirds of patients at this stage (Twycross, 1984). However estimates vary widely. Bruera (1993) argues convincingly that this variation is a natural consequence of the lack of uniformity among the methods of assessing pain and the views of the patients themselves. This highlights a particular difficulty, namely that pain cannot be measured objectively with any real confidence.

Pain is a complex behaviour and not a simple sensation. The most frequently referred to (see for example, Hoffert, 1992; WHO, 1986) and succinct definition describes pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage” (Merskey & Bogduk, 1994). It is modified by the mind and is always subjective and unique to the individual (Merskey & Bogduk, 1994; Woodruff, 1993). There is both sensory and affective processing within the central nervous system when a person experiences pain (Chapman & Gavrin, 1993). Psychological data suggest that higher brain functions are able to modify the patterns of nerve impulses produced by an injury (Holzman & Turk, 1986); hence psychological variables play a direct role in the pain experience. How a person

reacts to pain sensations is as important a variable as the specific physiological mechanisms involved in transmitting and generating pain experiences.

In advanced cancer, pain is the most significant symptom (Patt, 1992). In the developed world, people are protected from pain to a large degree by the wide range of analgesia and anaesthesia available, so the unconscious expectation of the lay public is that all pain can be controlled. In situations in which this is not possible, as in severe chronic pain from arthritis or terminal cancer pain, the response of individuals is likely to be highly negative, unless they develop some sense of personal control and meaning in dealing with that pain: for example, if they operate from the perspective that their pain can act as a trigger for constructive action, such as altering medication, using relaxation, or active distraction, as opposed to being just unpleasant and unavoidable. Patients who perceive pain as a challenge have more positive reactions to it, such as less depression or reporting less pain, than those who view it as the enemy or a punishment (Barkwell, 1991).

Chronic pain, whether benign or malignant, serves no biologically useful purpose and interferes with constructive behaviour, often occupying patients' whole attention. It is very different in character and meaning from much of the pain encountered in everyday life, and has a powerful impact on the psychological state of cancer patients. They can attribute pain to the malignancy even when it is unrelated, thus enhancing their emotional concern about the progression of the disease (Zimmermann & Drings, 1984). There is evidence to suggest that chronic pain patients develop specific psychological and physiological problems because of their inability to escape from their pain (Turk, 1996). Cancer pain can promote fatigue,

sleep disturbance, emotional distress, poor concentration and restricted movement (Chapman & Gavrin, 1993). Anxiety, dysphoria, hypochondriasis, depression and withdrawal are caused by the long term 'wearing down' effects. Gradual physical deterioration is the result of the effect of pain on sleep, appetite, behaviour and, frequently, the combined effect of multiple medications (Bonica, 1984).

The reverse is also true, with psychological factors playing a major role in the way in which patients react to cancer pain (Lichter, 1991; Turk, 1996). This can form a vicious circle, exacerbating both conditions (Schreml, 1984; Zimmermann & Drings, 1984). In contrast, patients who are well informed about their treatment, and are confident in the skills and levels of concern in the professionals who work with them, are better able to tolerate pain which would be intolerable otherwise, particularly if emotional problems are not addressed (Shreml, 1984).

Morphine and pain control

The benchmark approach to pain control is the three step analgesic 'ladder' propounded by the World Health Organisation (1986) (e.g. Brooks, Gamble & Ahmedzai, 1995; McCaffery & Ferrell, 1995; Ripamonti & Bruera, 1996). In this model, mild analgesics such as aspirin or panadol form the first response to mild pain. Stronger pain requires mild narcotics such as codeine, with morphine being reserved for very strong pain. The effectiveness of these cardinal analgesics is heightened by combining them (e.g., morphine and panadol) and by the addition of other non-narcotic medications such as nonsteroidal anti inflammatories (NSAIDS), anticonvulsants, antidepressants and tranquilizers, all of which are capable of

diminishing pain via different mechanisms (Ripamonti & Bruera, 1996; Twycross & Lack, 1983). Further flexibility is offered by the variation in dosage available for each component medication. In addition, patients can be offered an analgesic to take at their own discretion if breakthrough pain occurs (Twycross, 1984). This system offers significant opportunity for individualised pain control with morphine being capable of suppressing the strongest pain. It is the 'top rung' on the analgesia ladder.

Worldwide, morphine is recognised as a powerful analgesic, well researched and widely available (Woodruff, 1993). It is the most frequently prescribed of all medications for strong pain (Brooks, Gamble & Ahmedzai, 1995; Lang, Beardon, Ladlow & Macrae, 1992; Lopez de Maturana, Morago, San Emeterio, Gorostiza, & Arrate, 1993). It is available in multiple forms, is well absorbed, provides long lasting relief and can be taken for long periods of time. Addiction rarely occurs, probably because of the slow rise in concentration of morphine in the blood when administered by sustained release preparations (Woodruff, 1993), and given the curtailed life span of terminally ill patients, the concerns about addiction have far less relevance than in the case of patients with chronic benign pain. Psychological dependence or 'pseudoaddiction' is more likely to be the result of previous poor pain control and/or incorrect prescription of opioids (Joranson, 1993; Zenz, 1993) and tolerance to morphine is usually mild (Woodruff, 1993).

Unfortunately a number of common unpleasant side effects are associated with morphine use, such as vomiting, drowsiness, unsteadiness, mental confusion, constipation, sweating and depression. These side effects are well documented (Twycross & Lack, 1983) and with careful management, many such negative

consequences of using morphine can be avoided or at least diminished, provided the basic principles for administration are followed, thus alleviating the concerns of patients and their families.

Individual dose titration and ongoing monitoring of morphine are crucial (Patt, 1992), due to the number of factors which affect the required dose. Different people experience pain of differing intensities and their thresholds of pain tolerance depend on variables such as cultural background, current mood, expectations, and previous history of pain control (i.e., whether pain was controlled satisfactorily or not) as well as the duration of treatment and the impact and severity of other distressing symptoms. Patients' use of co-analgesics and non-drug measures will also influence their morphine requirements (Twycross & Lack, 1983). Overuse of morphine can lead to toxicity which generates a range of highly unpleasant symptoms for the patient including mental confusion, disorientation, motor incoordination, drowsiness, extreme constipation and nausea (Dunne, 1996). Inadequate prescription will lead to poorly controlled pain. Either condition is likely to increase patient distress and anxiety, which are further exacerbated if patient and physician have negative beliefs and expectations of morphine: for example, that it will cause dependency or addiction.

There is a variety of negative beliefs about the use of morphine amongst both professional staff (e.g., Twycross & Lack, 1983) and recipients. The latter may make associations between morphine and addiction, near death and euthanasia (Brasseur, Larue, Colleau, & Cleeland, 1993). For example, morphine has been regarded as a means of covertly achieving euthanasia (Lowenthal, 1990), or at least,

unconsciousness. The answers to this type of claim are better symptom control and better support offered to patients and their families, because a wish for euthanasia can be a reaction to the severe and unpleasant symptoms of an illness or its treatment, and to the belief that patients have nothing left to live for (Australian Psychological Society, 1996). One belief in particular relates to the longer term use of morphine for patients with inoperable cancer, where the opinion is that morphine should be saved for the final stages of patients' lives, regardless of the degree of pain they are experiencing before that time (Twycross & Lack, 1983). In fact, if it is used correctly, patients will not need rapid escalation of their dose for increased pain (Twycross & Lack, 1984). Some patients fear that morphine weakens the mind or the body and/or that it will make them die more quickly, but often the reverse is true, because good pain control allows patients to rest, sleep, and eat better which will, in turn, have positive repercussions on their overall quality and length of life.

Australia ranks amongst the top 10 countries for per capita consumption of morphine, with all 10 being developed countries (Joranson, 1993). However, the literature indicates that cancer pain is seriously undertreated worldwide (Patt, 1992; Weinstein, Hill, Laux, Thorpe, Thornby, Vallbona, & Merrill, 1992), for example, in Germany (Zenz 1993; Zenz, Zenz, Tryba, & Strumpf, 1995), France (Brasseur, et al., 1993) and the United States (McCaffrey & Ferrell, 1995). Prescription of morphine must be accompanied by intensive monitoring and paperwork in most countries. Such governmental control has the advantage of causing those who prescribe and those who ingest morphine to take it very seriously, but there is the corresponding danger that it will result in situations in which morphine could be used very

advantageously but is not, because of the difficulties associated with its use. Controls aimed at preventing illicit use have hindered or threatened to hinder appropriate opioid prescribing (Dahl & Joranson, 1992; Joranson, 1993; Shapiro, 1994). Countries with more liberal laws for regulation of opioid use report higher levels of consumption, with no indication of increased misuse (Zenz 1993), which suggests that the restrictions used by some governments are not achieving their intending purpose and may, in fact, be harming patients.

In short, it can be demonstrated that the use of morphine for pain control in cancer is hindered by an aggregate of related factors, which could be expected to have repercussions on each other. These factors include governmental restriction, the limitations of professional knowledge and professional and patient prejudice.

Alternative therapies for pain control

Brickman et al.'s (1982) attributional models, described earlier, emphasise the indirect and often unacknowledged benefits, beyond the overt effects on stress and pain, that alternative therapies, in particular cognitive therapies, can provide. The emphasis is on choice and individualised therapies and on empowering and motivating patients, rather than 'fixing' the illness by using treatments on (as opposed to with) them.

This is not to be confused with forcing patients to become experts in oncology or psychology, regardless of their level of debility or cognitive skills. Patients may actively choose to leave physical treatment choices in the hands of others. The point is that they choose to do this, rather than having that position

forced upon them by the unconscious ethos of the professional treating them. Furthermore, they are professionally supported in directing their energies to issues such as emotional, financial and familial concerns, rather than just being left to deal with these concerns in the best way they can.

Modification of life style, radiation therapy and nerve blocks are significant and frequently accessed non drug components of pain control for both benign and malignant chronic pain (Twycross, 1984; Twycross & Lack, 1984). It is logical to expect that simple physical interventions such as massage, hot or cold packs and positioning would be more regularly used to supplement medication, because they require minimal effort from the patient. By comparison, it is hypothesised that interventions which require cognitive effort from the patient, such as relaxation training, meditation and distraction, would infrequently be recommended by medical staff. Yet these are among the most portable and easily accessed methods of supplementing pain control, and, furthermore, they emphasise the choice and the active involvement of patients in their own palliative treatment. Given the crucial role of pain control in palliative care, and the less than perfect control available, augmentation of pharmacological therapy by techniques such as relaxation, imagery, massage and distraction is worthy of greater attention and implementation.

There is evidence to encourage the use of cognitive-behavioural techniques such as guided imagery (Kearney, 1992), relaxation (Sloman, Brown, Aldana, & Chee, 1994) and distraction (Ellis & Spanos, 1994) to control or decrease pain. Hypnosis can alter both intensity and unpleasantness of pain in susceptible subjects and the magnitude of that intervention is increased if the hypnosis is also applied to

any concurrent anxiety (Dahlgren, Kurtz, Strube, & Malone, 1995). Magill-Levreault (1993) summarises a range of research which supports the positive effects of music on mood, psychological and relaxation responses, and reports distraction from pain, reduction of nausea and vomiting, enhanced communication and a decreased need for postoperative pain medication. Melzack, Weisz, & Sprague (1963) demonstrated that people can learn to use auditory inputs (white noise and music) combined with suggestion, to decrease pain, in this case, having a hand immersed in ice water. The subjects in the study did not just passively listen, but attended to the music and noise, tracking the volume of one with the other, becoming actively rather than passively involved.

These types of intervention may assist in improving patients' feelings of control over their lives (Turk, Meichenbaum, & Genest, 1983) and increasing their positive expectation concerning future pain or discomfort, each of which is likely to improve their tolerance of pain or discomfort (Bandura, 1989; Melzack, Weisz, & Sprague, 1963). People who have lived with a diagnosis of terminal cancer have different expectations of a 'successful' outcome than those with non terminal cancer. It alters their perception of self efficacy to have a terminal illness because, by definition, treatment options are directed at alleviating discomfort rather than at a cure. This will negatively impact on the coping strategies of patients and thus on the pain they may be experiencing. They will tend to rehearse cognitively negative experiences and in consequence the latter become more likely. If people's beliefs in their own coping efficacy are strengthened, they approach situations more assuredly and will make better use of the skills they have (Bandura, 1989; Turk, 1996).

Where patients have a high internal control over the *course* of their illness, an area cognitive-behavioural interventions could significantly augment, this is associated with the tendency towards a 'fighting spirit' and towards more positive characteristics in early stages of the disease, such as higher self esteem, higher social support, less anxiety and few negative feelings. These characteristics are further enhanced if the health professionals who work with them operate according to the compensatory model of attribution of responsibility discussed earlier in this paper. By comparison, patients who have a high internal control over the *cause* of cancer, regardless of disease status, are more inclined to experience an anxious preoccupation about the disease and a loss of control (Watson, Greer, Pruyn, & van den Borne, 1990).

Many cognitive behavioural techniques are useful life skills, and provide general benefits from stress reduction, at a time in life when stress is likely to increase physical tension and interfere with both peace of mind and the immune system (Bernard & Krupat, 1994; Whitehouse et al., 1996). In addition, these techniques will positively impact on patients' subjective experiences of pain, with the stipulations that the patients are allowed to make an active choice of the alternatives, and that the chosen technique is clearly explained and individualised and delivered by an appropriately qualified individual. Basic psychological training states that techniques which are not delivered correctly may irritate or discourage the patient. A creative, interactive approach to supplement traditional pain control methods, based on good communication with patients and their families, should be encouraged. An

individualised treatment is the best response to the person-specific experience of pain.

A role for psychologists in palliative care

The use of morphine in conjunction with non drug treatments, which include psychological support of the patient and family, is a logical pairing, given the dual nature of the experience of pain, namely, that the reporting of sensations experienced is modified by patients' emotional reactions to it. Negative affect particularly influences the way individuals perceive their bodies and bodily sensations. Koller, Kussman, Lorenz, Jenkins, Voss, Arens, Richter and Rothmund (1996) make this assertion with the implication that the health assessments made by examining and external physicians are more accurate than the subjective assessments of patients. However, if pain itself is defined as a subjective event, then it follows that patients' judgements of intensity and severity are more accurate than any 'objective' assessment. It is a principal flaw in physician-patient communication that professionals tend to believe they can assess pain better than their patients.

The emotional reaction to pain is influenced by factors which include patients' feelings of self efficacy in coping with it, the general level of anxiety, anger and/or depression and expectations of pain (Twycross & Lack, 1983). In addition, Hodder and Turley (1991) include fatigue, relationship difficulties, communication difficulties, uncertainty, health system difficulties, side effects of treatment, non cancer pathology, loss of income and role and other unique patient aspects, such as previous experience of pain. Feelings of control, independence and self worth will

increase pain tolerance (Bandura, 1989; Chapman & Gavrin, 1993). These are areas that could be effectively targeted by psychological intervention.

With such breadth of considerations to take into account, it may often be difficult for patients to communicate the intensity of their subjective experience of pain. For a health professional to assess and treat pain with any accuracy, it is necessary to take all of these factors into account in acquiring a detailed pain history. To do this requires time, effort, experience and good counselling skills, which may explain why, in the domain of palliative care, this type of intensive assessment is often neglected (Cleeland, 1993).

Unfortunately, medical wards in Tasmania tend to have a restricted range of psychological services available to support the type of intensive information gathering required for a comprehensive pain assessment. Yet inadequate clinical and diagnostic pain assessment is the most obvious barrier to good pain control (Cleeland, 1993), followed by patients being reluctant to report symptoms (Janjan, et al., 1996). In palliative care, the serious nature of patients' illnesses emphasises attention on physical care. However, even if good quality physical care is available, the lack of skilled psychological intervention may contribute to patients' alienation, hopelessness and loneliness (Weisman, 1984).

Ideally, palliative care is a form of treatment which is directed according to information provided by the patient. Medical practitioners must rely on their communication skills and experience to discover what they can about patients' subjective perception of pain. Those who have had no specific experience of or training in palliative care may pursue the goal of disease eradication beyond logical

hope of recovery and without the explicit consent of their patients. They may select treatment based primarily on aetiology, reported severity of pain and the patient's medical history, and not attend to patients' preferences or resources. Cain and Hammes (1994) comment that respecting patients' wishes involves considerably more than merely listening to what they say. The traditional approach, in which the beliefs and opinions of the professional do not incorporate the perspective of the patients, may be time efficient, but is ultimately alienating and disempowering for the latter, particularly where pain cannot be completely controlled. A patient-centred approach and the enhancing of patients' feelings of control, independence and self worth are highly likely to have a positive impact on their experience of pain and on their medical treatment overall. Psychologists have a definite role here in engaging psychosocial resources and teaching coping skills (Chapman & Gavrin, 1993).

There is a wide degree of variability in what will constitute a high quality of life for each individual and for different stages in an individual's life. Physician-patient communication must be operating efficiently to provide the best outcome for patients, but patients may not be able adequately to articulate their priorities and physicians may not have the resources to elicit them (Cleeland, 1993). This is an ideal arena for psychological intervention. Unfortunately physicians and patients rarely consider using psychological services in this manner, partly because of a low level of community awareness of what psychologists have to offer, particularly within the medical domain. Professional associations such as the Australian Psychological Society have a role to play in the provision of this type of information. Treatment of pain is ideally a joint effort which includes the beliefs and opinions of

the health professionals, the patients and their families. Those involved must be able to ask the right questions and convey the necessary information effectively. Lichter (1987) comments that effective communication is “the cornerstone not only to the management of anxiety, depression and a number of emotional problems, but also to the relief of pain and other symptoms” (p.1), and notes that poor communication causes more suffering in terminal illness than anything except unrelieved pain. Perhaps the frequent claim that cancer pain is undertreated (e.g., Weinstein et al., 1992; WHO, 1990) is accounted for by the fact that many physicians and nurses are not fully familiar with a genuinely holistic approach to dealing with chronic terminal pain.

Future directions for research

Australia’s history of palliative care is shorter than that of countries such as England and the United States, where there are comparatively sophisticated resources available to dying patients and their families (eg. *Saunders*). However, palliative care is now gaining recognition, and this recognition is likely to increase in the light of the current euthanasia debate. There are considerable ethical problems in offering euthanasia as a solution to suffering which could be contained by other means, such as multimodal pain control and a treatment approach which considers the mind equally with the body.

The greatest contribution to patient well-being in terminal cancer care, for reasons outlined earlier, would be to augment existing pain control and this review suggests there are many domains which could be exploited to improve existing

techniques, many of which are in the realm of the behavioural sciences. The starting point for research in this area would logically be with the physicians, within whose domain pain control in cancer traditionally falls. By questioning the beliefs and opinions physicians have about the main concerns with and barriers to pain control in terminal cancer care and the degree to which they routinely consider simple alternatives to pharmacotherapy, it should then be possible to make informed decisions about where positive changes could realistically occur within the present system.

Conclusion

As the current generation of post war children ages and lives longer than their predecessors, the next century is likely to see unprecedented numbers of people requiring palliative care. Currently, people are not always able to access specialist palliative care services. With the introduction of case mix as the principal funding determinant of hospital care, it will become increasingly important to consider alternatives to hospital care and to facilitate the best use of community resources, in particular, general practitioners (GPs). Research in this field is particularly necessary in the case of smaller communities, in which resources are, and will continue to be, limited.

Indications are that the role of psychologists and psychological care in palliative care will need to expand as technology becomes more sophisticated and the human life expectancy increases. The impact of psychological intervention, essential because of the impact of cancer on mind as well as body, is far more subtle than the

more obvious results of practical medical techniques such as surgery or pharmacotherapy. Thus professional psychological care is in danger of being overlooked unless it can be clearly demonstrated that it is both advantageous, and ultimately more efficient in the long term, to provide patients and families with more than straight medical treatment. In addition, this could lessen the pressure on GPs and diminish the problem of professional burnout caused by patients having overly high expectations of them.

Ideally, all health care in the future will routinely integrate psychological with medical care, but in crisis situations this is particularly critical. The earlier psychological intervention is offered, the better the results are likely to be. Psychologists must actively promote the use of their particular expertise in advising, counselling, debriefing and providing cognitive-behavioural therapy. There is a very real limit to what can be achieved by one profession alone for a truly integrated system of cancer care, but this type of professional promotion serves as an acceptable preliminary. Psychology is an expanding discipline whose potential is only now beginning to be realised. In an affluent and sophisticated society in which humanity has the resources to provide people with genuinely holistic care which emphasises quality of life, psychological care is gaining in recognition.

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**ATTITUDES TO MORPHINE
FOR CONTROLLING CANCER PAIN
IN PALLIATIVE CARE**

**A report submitted as partial requirement for the degree of
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Abstract

This study questions the range of resources regularly accessed by Tasmanian general practitioners (GPs) in treating cancer pain and, in particular, their use of and attitudes to morphine, with a view to identifying new directions for cancer pain management. It is also concerned with which health professionals and services GPs access and the degree to which GPs suggest non-medical, non-pharmaceutical interventions. A mail survey of 236 GPs was carried out in Tasmania. The results indicated that GPs commonly use morphine to treat serious cancer pain in terminally ill patients, but are less united in their choice of medication for milder or non-terminal pain. Unexpectedly, GPs agreed that non-pharmacological interventions can assist pain management and had suggested such interventions to their patients. Interviews with 12 patients and 10 carers in a specialist palliative care ward reinforced the view that psychological factors caused them considerable concern, whereas pain control was good. This research supports the proposition that psychologists working directly with patients and consulting with GPs would provide a substantial resource and assist in enhancing quality of life for patients with terminal illnesses.

Palliative care has only come to widespread research and funding attention in recent years, as evidenced by the rapid increase in periodicals, publications and research funding (see, for example, New South Wales Palliative Outcomes Forum, 1996). 'Palliative care' refers to the care offered to a patient suffering from a chronic deteriorating organic illness, when a cure is no longer achievable and the goals of care have shifted from disease eradication, to symptom relief and quality of life (World Health Organisation, 1996). The underlying assumption is that palliative care patients have a prognosis of six months or less to live (Dudgeon, et al., 1995). This study was designed to investigate factors which affect the satisfaction of GPs with pain control in terminally ill cancer patients. Specific areas of interest were barriers to patient access of morphine, non-pharmacological adjuncts to pain control and attitudes of physicians, patients and carers to methods of pain control.

Morphine prescription was selected as a focal point of this investigation because it has been reported as the most effective and reliable medication for relief of strong pain and is widely available world-wide (Brooks, Gamble, & Ahmedzai, 1995; Woodruff, 1993). Access to morphine is the first essential step in controlling many types of cancer pain. Its effectiveness in controlling pain is augmented by the addition of milder forms of analgesia, such as paracetamol and codeine, and other types of medication, for example, anti-inflammatory agents (Hodder & Turley, 1989; Twycross & Lack, 1983). The major disadvantages of using morphine are the side effects and fears held by the public about dependence and disguised euthanasia (Brasseur, Larue, Colleau, & Cleeland, 1993; Eccleston, 1997). The latter term refers to the belief that morphine may hasten death, unintentionally or otherwise. It was hypothesized that although terminally ill patients and their carers will tend to

express concerns about using morphine for pain control initially, their fears might be alleviated by experience of the drug.

A number of researchers have explored attitudes and practices of GPs, nurses and/or patients towards the management of cancer pain and particularly the use of morphine both overseas, notably in the United Kingdom, and in Australia, but overall results are not clear. Morphine is the most frequently prescribed drug for severe pain, world-wide, but there is evidence that it is often not prescribed enough (Patt, 1992; World Health Organisation, 1996). Also, knowledge of pain management in palliative care is less than optimal and many patients do not have the best possible pain control (Elliott, et al., 1995; Fife, Irick, & Painter, 1993; Hill, et al., 1991; Lang, Beardon, Ladlow, & Macrae, 1992; Lopez de Maturana, Morago, San Emeterio, Gorostiza, & Arrate, 1993; McCaffery & Ferrell, 1995; Wakefield, Beilby, & Ashby, 1993; Wallace, Reed, Pasero, & Olsson, 1995; Zhukovsky, Gorowski, Hausdorff, Napolitano, & Lesser, 1995).

Health professionals also have misunderstandings about morphine including commonly identified issues of tolerance, use predicated on prognosis rather than need, and the magnitude of inadequate pain management, (Elliott, et al., 1995; Fife, et al., 1993; McCaffery & Ferrell, 1995; Twycross & Lack, 1983). There is less concern about long term use of morphine in terminally ill patients than in patients with chronic benign pain (Polatin, 1996). Because GPs prefer to use morphine as the ultimate response to pain in the final stages of patients' lives (Twycross & Lack, 1983), they might have more reservations about prescribing morphine to non-terminal cancer patients compared with terminal patients. However, correct use of morphine will prevent the rapid escalation of tolerance even in non-terminal patients

(Twycross & Lack, 1984). Cautious prescribing of morphine on the basis of prognosis might account for the expressed concern that cancer pain is undertreated (McCaffery & Ferrell, 1995; Weinstein, et al., 1992).

In contrast to the concerns about tolerance raised above, no evidence of overconcern about opioid tolerance was found in a sample of South Australian GPs (Wakefield, Beilby & Ashby, 1993). There is, however, evidence of a lack of knowledge about good pain management practice particularly in those professionals who trained some time ago, (Boughey, cited in Lester, 1996; Brunier, Carson, & Harrison, 1995; Elliott et al., 1995; Fife et al., 1993; McCaffery & Ferrell, 1995). Side effects are expected and therefore are a frequent focus for medical intervention (Twycross, 1995), thus it was predicted that GPs might be more concerned about these than about tolerance or dependence in prescribing morphine.

Cancer is the leading cause of death in Australia after heart disease, and the incidence of cancer is increasing (Australian Bureau of Statistics, 1992). Effective control of strong pain should significantly improve the quality of life of terminally ill cancer patients, because pain has significant impact on the psychological state of the patient (Turk, 1996; Zimmermann & Drings, 1984) and often triggers or enhances related symptoms such as sleeplessness, inability to concentrate and nausea (Chapman & Gavrin, 1993). The incidence of pain in cancer is difficult to determine accurately, given the subjective nature of pain; estimates indicate that from one third to over two thirds of palliative care patients with cancer experience pain (Bruera, 1994; Cleeland & Daut, 1982; Twycross & Lack, 1983; World Health Organisation, 1996). Thus, in the public mind, cancer is not unreasonably associated with death (Lowenthal, 1990) and pain (Saunders, 1984; Woodruff, 1993). It was hypothesized

that GPs would identify pain as instilling greater fear than death in cancer patients. The prospect of unrelieved pain can be frightening and patients might be more inclined to refer to physicians with concerns about pain, directing fears about death to family or pastoral carers.

Communication is likely to be difficult for GPs who treat patients with terminal cancer because of the high level of emotion involved, the imminence of death and the many issues of grief and loss entailed, and because of the responsibility physicians carry in treating unpleasant physical symptoms and influencing the course of disease. A survey of GPs conducted by Wakefield et al., (1993) found that despite GPs general confidence in treating palliative care patients, the psychosocial needs and emotional distress of patients and their relatives were regularly identified as difficult issues. These issues call upon psychological rather than medical proficiency. It is hypothesised that GPs will report difficulties in communicating with patients and families and will find greater difficulty dealing with terminally ill patients than other patients.

A basic component of good physicians-patient communication involves routine provision of information about specifics of treatment and treatment options. One of the aims of this study was to determine the extent to which GPs routinely provide information about morphine, suggest supplemental techniques for pain control to patients and carers, and refer to psychologists for implementation of such techniques. If GPs do not see communication and counselling as their particular domain, they might assess pain control only in terms of pharmacological considerations. It is, therefore, hypothesised that most GPs will consider they are able to offer satisfactory pain control.

Successful pain relief is a significant factor in decreasing the preoccupation of patients with their physical welfare, enabling them and their attendant health professionals to pay more attention to issues of psychological well-being (Saunders, 1984), although the two aspects of care ideally operate concurrently rather than sequentially. For this reason it is valuable to assess the degree to which morphine is used by GPs in caring for cancer patients, and the concerns and problems that GPs may face in prescribing morphine.

Patients in rural areas cannot always access palliative care units, either because they live too far away or because increasing demand on public health services means there is often a waiting list (Rothwell, 1996). Even in metropolitan areas, most patients continue to die at home, in general hospitals, or in nursing homes (Saunders, 1984). In Tasmania, a large proportion of the small population live in rural areas and are relatively isolated from mainland Australia. As a result, there is limited availability of specialist services, for example, there is only one specialist palliative care ward in the state. Given that cancer is relatively common and that significant pain occurs in many cancer patients, particularly in the later stages of the disease (Twycross, 1984), it is hypothesized that most Tasmanian GPs will encounter patients suffering from cancer pain. GPs often need to assist those who are unable or unwilling to use specialist services, and many GPs manage without help from these services (Lang, et al., 1992). Consequently, GPs are an essential component in palliative care (Wakefield, et al., 1993), and must provide an extensive range of services. However GPs have been identified as “a weak link” in the care of cancer (Lester, 1996), probably because so much is expected of them, from a specialist’s knowledge of cancer to being on call at all hours. It is, therefore, hypothesised that

most GPs will have limited experience or formal training in palliative care despite regular contact with cancer patients.

Because there is evidence that the public is inclined to regard morphine as a 'dangerous drug' (Zenz, 1993), and to counterbalance the professional views of the practitioners (GPs), the views of 'consumers', that is, the patients, were also investigated. Thus, in addition to canvassing the opinions of GPs, a limited sample of terminally ill cancer patients was approached in order to explore their personal experiences of pain control, and, more specifically, their experiences of the impact of morphine on their pain control. Identified carers were also interviewed to broaden the perspective of each individual's experience. Patients were recruited from a specialist ward, in which they would be expected to be receiving the best palliative care available in the state and therefore their experiences are set in the context of quality medical care.

This is a difficult population to access, given their physical frailty and the potential for emotional stress. The ethics of involving such people in research has been questioned (Bruera, 1994; de Raeye, 1994; Kristjanson, Hanson, & Balneaves, 1994; Mount, Cohen, MacDonald, Bruera, & Dudgeon, 1995). However, provided that the research is conducted gently, guided by the wishes and experiences of the patients, involving them is not unethical.

This exploratory study uses a broad approach to examine factors which have the potential to improve the terminally ill cancer patient's quality of life within the medical treatment framework, with a particular emphasis on the use of and beliefs about morphine.

Hypotheses

In summary, from the preceding review, the following predictions were made:

Hypotheses relating to GPs

- GPs will regularly encounter cancer patients suffering pain.
- GPs will have limited training in palliative care.
- GPs will have reservations about prescribing morphine to non-terminal cancer patients.
- Side-effects of morphine will be of greater concern to GPs than dependence or tolerance.
- GPs will prescribe morphine without routinely informing patients and their families about its properties and side effects.
- GPs will report difficulties in communicating with patients and families.
- GPs will report that more patients fear pain rather than death.
- GPs will support the use of pharmacological, medical procedures alone rather than incorporating non-pharmacological non-medical interventions to supplement pain control, and will refer to health professionals other than psychologists for assistance in pain control.
- GPs will report greater difficulty dealing with terminally ill patients than with other patients.
- GPs will express the need for further education in pain and symptom management rather than counselling or communication skills.
- Most GPs will report satisfaction with the pain control they can offer patients.

Patient/Carer Hypotheses

- In a palliative care ward, patients and carers will express concerns about using morphine for pain control, but their fears will be alleviated by experience.
- Patients and carers will express general satisfaction with medication and most will describe pain as being under control.
- Patients and carers will express psychological concerns relating to the terminal medical condition.
- Patients and carers will rely primarily on medical treatment for pain relief and will have little experience of, or belief in, cognitive-behavioural and other alternative therapies.

Method

Participants

Three groups of participants were recruited for this research. The first group consisted of 467 GPs, who were contacted by letter using the current mailing lists of the Tasmanian Divisions of General Practice. Of the GPs contacted by letter, 236 (50.5%) completed a questionnaire, 61 refused on the first contact and 22 refused in response to the reminder. In total, 319 (68%) of the target population made a response. Participants reported practising as GPs for between one and 54 years, with a median of 17 years. Sixty-eight percent had received their medical training in Australia, 23% in the United Kingdom and 9% percent elsewhere. Respondents were asked for a minimum amount of identifying information to encourage frankness and ensure confidentiality. Consequently, no details were acquired concerning gender, age or location of practice.

The second group comprised 12 palliative care patients (7 males and 5 females), out of a possible 36 patients admitted to the ward during the recruitment interval. The average age of patients on the ward, according to a file review conducted between June 1993 and March 1994, was 63.6 years (Lord, 1995). Given the ethical concerns noted earlier, great care was needed in selecting and approaching patients, many of whom were unconscious or extremely weak, consequently, the number of patients included in this research was restricted. For this reason, the patient/carers interviews are presented as a pilot study. Patients were interviewed during their stay on a 10-bed palliative care ward, over a five week period. All patients were in the terminal phase of cancer and undergoing palliative treatment only. They had been admitted for one of three reasons: respite care, refining of

medication, or hospital support in the final days of life. Research inclusion criteria required a formal diagnosis of cancer and current or previous use of morphine. Primary tumour sites comprised roof of mouth (1), shoulder (1), lung (3), pancreas (1), bowel (1), colon (2), rectum (1) and Transitional Cell Carcinoma of the bladder (2).

The third group was a sample of 10 identified carers (5 males and 5 females), each of whom was nominated by a patient as the person most involved with his or her daily life. This resulted in interviews with four spouses, four adult children, one sibling and one friend. A further two carers were uncontactable.

Patients and carers all fulfilled the study criteria of being over 18 years of age, mentally alert, able to speak and understand English and to provide written informed consent to participate in the study. Identifying information was kept to a minimum in both samples, in order to encourage participation and free disclosure of opinions. For this reason, no individual background information was collected, other than relevant medical information.

Ethics

This research received approval from the Royal Hobart Hospital Acute Care Program Research and Ethics Committees.

Materials

GP Questionnaires: The questionnaire (Appendix A) was designed to elicit perceptions from GPs about selected issues relating to pain management in palliative care. Ideas and items from a number of previous surveys conducted in other states and countries were incorporated (e.g., Lang et al., 1992; Lopez de Maturana et al., 1993; Wakefield et al., 1992), in addition to items created specifically for this research.

The GP questionnaire presented 54 items grouped into 40 questions. Question format was varied with the majority of questions providing either multiple choice or yes/no responses. Five point Likert-type scales were also used for some items. These scales were presented in alternating order to compensate for any order effect. Open ended questions were only incorporated when a yes/no or multiple choice response was impractical. To increase response efficiency, questions with embedded items were used, with subordinate items being conditional on the response to the first item.

The questionnaire opened with general items eliciting the respondents' relevant experience, training and frequency of contact with patients experiencing cancer pain. This was followed by questions relating to the control of cancer pain generally and then with morphine specifically, including typical consumer responses to its prescription and the identification of difficulties and advantages in using morphine for cancer pain in terminal and non terminal care. The focus of the questionnaire altered in the second part, from strictly medical to more holistic material, such as the frequency with which GPs accessed other health professionals in caring for cancer patients, use of non-pharmacological interventions, the degree of

difficulty GPs found in working with terminally ill patients, and what further training would benefit their practice.

Patient/Carer Interviews: The interview schedules (Appendices D and E) were created to correspond in part to the GPs' questionnaire, and included a set of core questions in common with it (Questions 4, 7, 12, 14, 18, 22, 23, 25). These core questions were described in the preceding sections.

The patient interview proforma consisted of 41 items grouped into 26 questions. Question format varied, comprising yes/no, open-ended, multiple choice and one Likert-type scale. Large font (Times Roman 20 point, Appendix F) prompt sheets were used to assist respondents make their choices in multiple choice questions in which the number of choices exceeded three. Given the strict time constraints, embedded questions using 'yes/no' screens enabled the interviewer to direct the interview more efficiently to the areas applicable to each respondent. The first section of the interview contained questions for the interviewer to complete, including a short check-list to confirm patient eligibility. The patient's primary diagnosis and current medication were also recorded.

The patient interview was designed to obtain details about the respondent's experience of morphine, to identify any prejudices and examine medication and pain control generally from the patient's perspective. The focus remained on the individual experience of the patient. The interview began with questions about the respondent's experience of pain and satisfaction with medication. The next part of the interview concerned initial and current reactions to the prescription of morphine, previous experiences with it and the information given to them about it. Questions relating to the respondents' opinions about their overall medication were followed by

core questions which were replicated from the GPs' survey (Questions 22 to 25). These relate to non-pharmacological interventions to control pain, and what the respondent regarded as the greatest difficulty encountered while being ill.

Carer interviews were designed primarily to provide confirmation and supplementation of patient responses, and did not differ in any significant respect from patient interviews. The principal difference was that carers were instructed to answer most items according to their perceptions of the patients' experiences. The structure of the interview was identical to that of the patient interview schedule, with two exceptions. Firstly, the section completed by the interviewer prior to speaking with carers did not include the patient's primary diagnosis and medication, but instead noted the carer/patient relationship. Secondly, the item referring to how medication for pain relief was administered was omitted since confirmation of this from carers was not necessary.

Procedure

General Practitioners: Questions were presented in a four page, double sided, A5 booklet, and were primarily forced choice responses, but with some space for voluntary comments. The emphasis on forced choice was aimed at enhancing response speed in order to optimise the return rate from a frequently surveyed population and to facilitate coding. The questionnaire was designed to take approximately 10 to 15 minutes to complete.

Respondents who identified themselves as never working with patients who had cancer and its resulting pain were instructed to discontinue the questionnaire as soon as that information had been established (Questions 4 & 5).

Those who never prescribed any type of narcotic analgesic (Question 9) were directed to resume the questionnaire where it returned to items not specifically related to morphine prescription (Question 28).

The GP questionnaire was piloted on a sample of health professionals comprising four psychologists and four GPs. One-to-one discussions with members of the pilot group were conducted and reviews of specific comments received. As a result of feedback from the pilot study, amendments were made before the main mailout.

Participants received an explanatory letter (Appendix B), a questionnaire, and a self addressed post paid envelope, followed by a reminder letter one week later (Appendix C). To maintain the confidentiality of the respondent, no record was kept of the names of those who did or did not complete questionnaires, therefore reminder letters were sent out to everyone unless GPs elected to identify themselves when returning the completed questionnaire or the refusal form.

Patients/Carers: The scope of the patient interviews was restricted in comparison to the GPs' questionnaire, because of the constraints imposed by the infirmity of the sample. The patient contact time was designed to take between 10 to 20 minutes. This time included explanations, obtaining consent, interviewing and debriefing.

Prior to the commencement of data collection on the hospital ward, nurses were given an information session by the researcher, who had previously spent time on the ward in order to become familiar with the staff and routines. The nature of the research, its requirements and the type of patient sought were discussed and an

opportunity was given for questions. An information summary sheet (Appendix J) reiterating key points was distributed during the session.

To select appropriate participants in the inpatient sample, the researcher reviewed the daily list of patients on the ward and consulted with nursing staff in order to select patients who fulfilled the research criteria and to obtain information relating to their physical conditions and mental status.

The procedure was devised to satisfy the most important ethical concerns raised by Kristjanson et al (1994) when interviewing a sample of terminally ill patients. Patients were given an explanation of the research and an information sheet (Appendix G). The researcher made an informal assessment of the patient's mental status during this time, supported by file information and nurses' judgements. If the patient was regarded as suitable and agreed to participate, she or he completed two copies of a consent form (Appendix H) to enable both the researcher and the patient to retain a copy. Interviews were terminated immediately if there was any sign of discomfort or stress, or an indication of the wish to discontinue. To ensure consistent presentation the researcher conducted all interviews. When a multiple choice question was asked, the interviewer would ask the question and pause to allow the recording of any spontaneous answers. The response sheet was then presented, to provide suggestions or reminders. After completion of each interview the patient was offered the opportunity to comment or question. She or he was then asked to identify a carer and give permission for the researcher to send or leave a letter (Appendix I) with the patient, inviting the carer to complete a companion interview. Debriefing was provided if any issues raised in the interview warranted it.

Carers were interviewed as soon as possible after the corresponding patient interview, either on the ward or at home according to their preference. They were approached only by letter, and were asked to contact the interviewer or the ward to arrange an appointment or refuse. The interview procedure then continued in the same manner as for patients.

SPSS (Statistical Package for the Social Sciences) for Windows 6.1 (SPSS Inc., 1994) was used to analyse the data. A variety of inferential statistics was used to analyse the data from the GP sample. It is acknowledged that the multiple statistical tests performed on the same data have implications for a Type I error when considering the statistical significance of results. Totals varied throughout the GPs' data because not all respondents answered every question. The patient-carer sample was presented as a pilot study. Descriptive statistics were used for the patient-carer sample, due to the low sample size. The sample was further reduced to 10 patient-carer pairs when numerically reporting patient/carers responses, to maintain consistency of data presentation. Interviews were content rich and consumers' personal experiences provided valuable insights, therefore, individual comments made by interviewees have been selected to illustrate different perspectives.

Results

General Practitioners

The greater percentage (62.4%) of Tasmanian GPs encounter patients with cancer on at least a weekly basis (Figure 1).

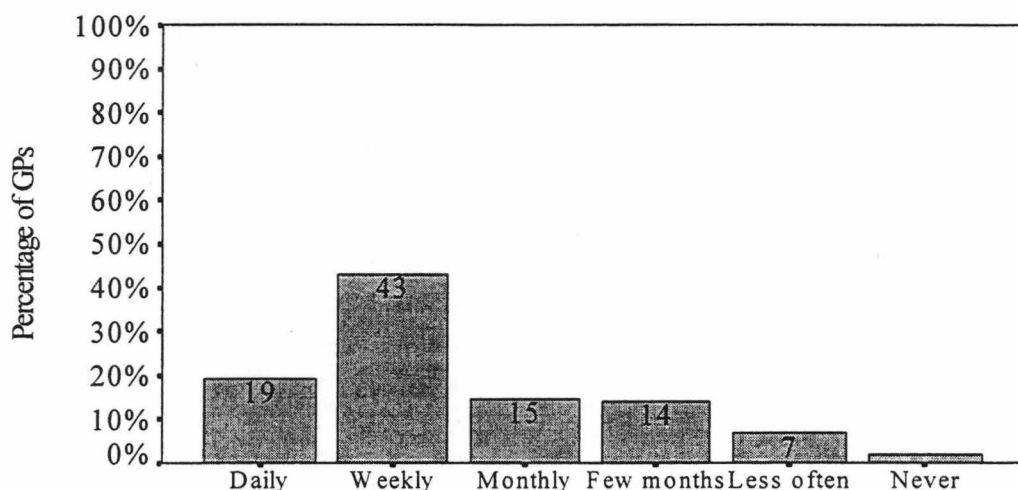


Figure 1: Frequency of GP encounters with cancer patients (Question 4).

Over 86.3% of GPs report some or more frequent contact with patients who have pain caused by cancer (Figure 2).

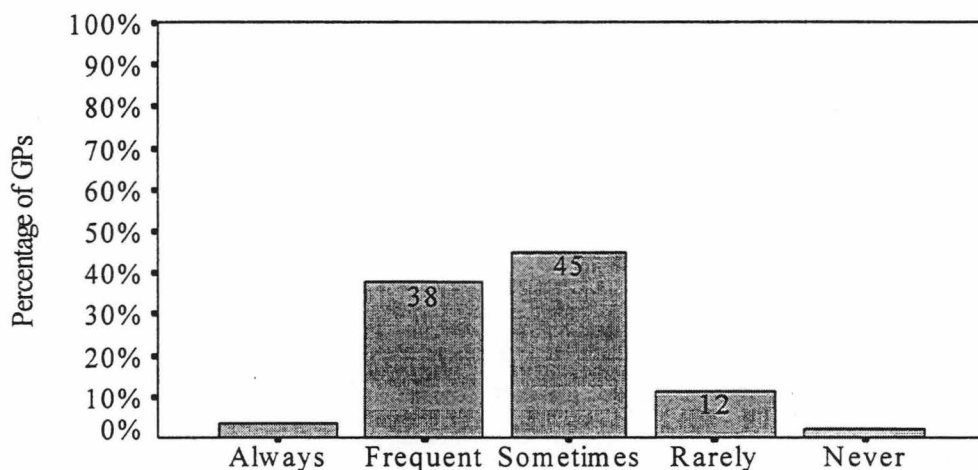


Figure 2: Frequency of patients with cancer pain seen by GPs (Question 5).

Of the GPs who responded, 12.4% reported specialist training in palliative care which included attending lectures, correspondence courses, workshops or

seminars and postgraduate courses, and 34.2% had worked in a palliative care setting at some stage.

Different medications are recommended according to the proposed aetiology of the cancer pain experienced (I.&W.M.D.G.P., 1995), therefore pancreatic cancer was specified when asking GPs about first choice analgesic agents. Morphine was chosen as the analgesic of choice for severe pain in pancreatic cancer by 74.1% of GPs. Choices for treatment of moderate pain in pancreatic cancer were more varied, ranging from aspirin to morphine, with paracetamol and/or codeine being chosen by 55.3% of GPs. For 67.5% of GPs, paracetamol or aspirin were the first choice analgesic agents for mild pain in a case of pancreatic cancer.

When comparing the degree to which GPs prescribe morphine for cancer, there was a significant difference between the mean reported frequency with which morphine is prescribed between cancer patients generally and non-terminal patients specifically, according to the paired samples t-test ($t(216) = 20.42, p < 0.01$). GPs prescribed morphine more often for cancer patients generally (mean = 2.33, S.D. = .65) than for non-terminal cancer patients (mean = 3.39, S.D. = .73). Response categories were 'all' = 1, 'most' = 2, 'some' = 3, 'few' = 4, 'none' = 5. Non-terminal cancer patients were considerably less likely to be prescribed morphine, with 66.7% of GPs stating that they prescribed it for all or most cancer patients, compared with only 8.2% prescribing it for all or most non terminal cancer patients (see Figure 3). This result is statistically significant according to the McNemar's test (Siegel & Castellan, 1988) ($\chi^2 (1, N = 219) = 123.19, p < .001$). More than a third of GPs (38.2%) agreed they had reservations prescribing morphine to non-terminal patients.

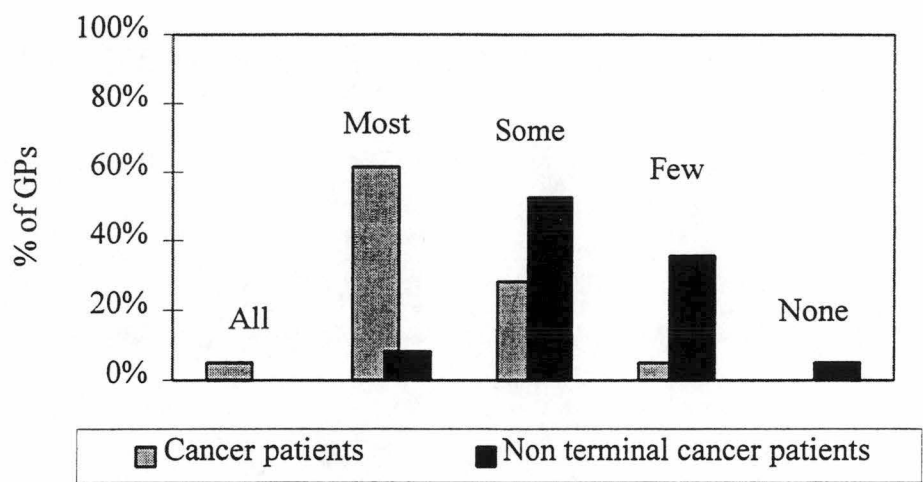


Figure 3: Comparison of cancer patients and non-terminal cancer patients prescribed morphine by GPs (Questions 11 & 12).

From Table 1 it can be seen that the control of side effects was the most frequently cited factor that interfered with optimum pain control, accounting for approximately a third of the responses. A further third of GPs noted that communication problems or misinformation to patients interfered with good pain

Table 1
Factors interfering with optimum pain control (Question 16).

	N	%
Control of side effects	64	30.0
Communication problems	36	16.9
Misinformed patients	28	13.1
Patient denial	27	12.7
Patient confusion	26	12.2
Other/all/none	22	10.4
Lack of resources	10	4.7
Total	213	100.0

control. The term ‘patient denial’ in Table 1 refers to the patient denying the existence or progress of their illness, or its effects.

It can be seen from Table 2 that a third of GPs perceived patient resistance, either to the initial prescription of morphine or its resultant side effects, as the greatest obstacle in using morphine for cancer patients. However, a small percentage (10.5%) encountered no major problem in using this analgesic.

Table 2

GPs' greatest difficulty using morphine with cancer patients (Question 18).

Problem	N	%
Patient resistance to prescription or side-effects	72	32.7
Knowledge and development of side-effects	43	19.5
Administrative difficulties in prescription	40	18.2
None	23	10.5
Prescribing dosage	21	9.5
Knowledge of longer term use	10	4.5
Other	11	5.1
Total	220	100.0

Table 3 lists the most common difficulties noted by GPs in treating cancer patients. Concerning the greatest difficulty in treating cancer patients, 38.1% of GPs indicated 'treatment of other physical symptoms', compared with 15.6% who chose 'treatment of pain'. Family problems accounted for over a quarter of responses on the list of difficulties.

Table 3

Greatest difficulty GPs encounter when treating cancer patients (Question 17).

Problem	N	%
Treatment of other physical symptoms	83	38.1
Family problems	62	28.4
Treatment of pain	34	15.6
Other/all/none	34	15.6
Giving information to patient	5	2.3
Total	218	100.0

Table 4 shows aspects of treating pain with morphine which GPs have indicated are of concern to them. A higher percentage of GPs were more concerned about impairment of cognitive function and other side effects than about tolerance, and only a few were worried about dependence.

Table 4
Aspects of concern in treating pain in terminal cancer patients with morphine (Question 22).

Area of concern	N	%
Impairment of cognitive function	125	53.0
Other side effects	98	41.5
Tolerance	56	23.7
Dependence	8	3.4

Half of the GPs surveyed estimated that patients and families never or rarely objected to the prescription of morphine and 61.0% reported rarely experiencing difficulty with compliance when morphine was prescribed. However, a third of GPs (36.1%) noted that they sometimes had difficulty with compliance. The most common objection to the prescription of morphine was the fear that there would be nothing stronger to control pain if it should continue or worsen (23.8%). Concern about side effects was the next in importance (15.2%). GPs believed that, in comparison, families were more concerned about the possibility of patient addiction (27.5%). Cohen's kappa indicated similarity between what GPs believed patients objected to, and what their families objected to when morphine was prescribed (kappa = .41, $p < 0.01$). Most GPs (95.6%) agreed they routinely give basic information about morphine to their patients, with 74.7% also indicating that they give information to the patients' families. This information is usually given verbally (92.9%) as opposed to written material or a combination.

In Figure 4 it can be seen that approximately two-thirds of GPs (67.6%), report that their patients fear pain more than they fear death. There were no differences in the mean levels of GPs' satisfaction with the pain control they can offer terminally ill patients (an ordinal/dimensional variable) across categories of patients' perceived fear (a nominal/categorical variable) as determined by a one way analysis of variance (ANOVA) ($F(3,218) = 1.28$, n.s.). There was no difference between whether nonpharmaceutical interventions were suggested or not for each category of GPs' satisfaction with pain control ($t(212) = -.75$, n.s.). Similarly, there was no difference between whether nonpharmaceutical interventions were suggested or not across the categories of the frequency with which GPs' patient base experienced cancer pain ($t(209) = -.55$, n.s.).

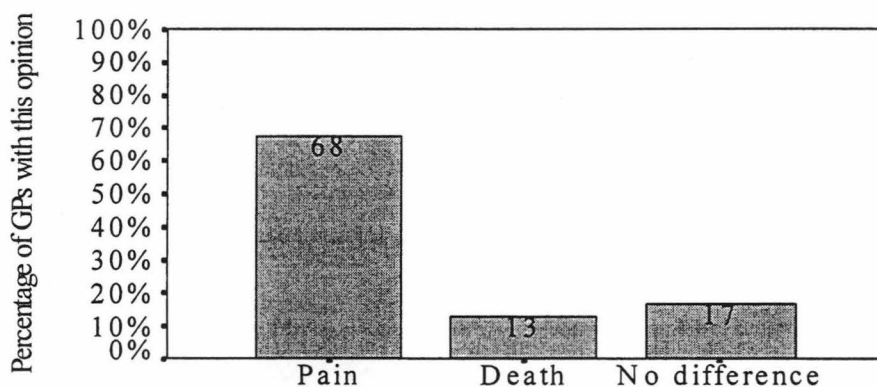


Figure 4: GPs' beliefs about patients' fears of death and pain (Question 28).

Overall, GPs reported being mostly or very satisfied (81.0%; 183 out of 226) with the pain control they were able to offer terminally ill cancer patients, with only 1.8% noting they were slightly satisfied or not satisfied. When asked about their resources for pain control, 79.6% agreed they were satisfied with them.

A large percentage of GPs (92.5%) stated that they had suggested non-pharmacological interventions to supplement pain control medication, apart from radiation or chemotherapy. Of the entire sample, most GPs (74.7%) believed that some of this range of non-pharmacological interventions significantly assisted patients' ability to cope with pain, compared with 21.7% who did not. In addition, there was a positive correlation between those who had suggested these interventions and GPs who believed these interventions significantly assisted with a patient's ability to cope with pain (Pearson product-moment correlation = .28, $p < .001$).

Table 5 summarises the frequencies and percentages of GPs who have suggested specific non-pharmacological interventions. Relaxation was the most

Table 5

Non-pharmacological interventions suggested by GPs to terminally ill cancer patients (Question 34).

Intervention	N	(%)	Intervention	N	(%)
Psychological Techniques					
Relaxation	168	71.2	Distraction	52	22.0
Imagery	46	19.5	Active coping	45	19.1
Thought stopping	23	9.7			
Practical Physical Interventions					
Massage	123	52.1	Positioning	72	30.5
Hot and cold packs	71	30.1	Movement	56	23.7
Breathing techniques	36	15.0			
Alternatives					
TENS	175	74.2	Acupuncture	124	52.5
Hypnosis	53	22.5	Naturopathy	18	7.5
Laser therapy	14	5.9	Homeopathy	13	5.5
Other					
Music	90	38.1	Art	7	2.9

frequently suggested technique (71.2%), followed by acupuncture (52.5%) and massage (52.1%). In general, 20% of GPs had suggested some form of

psychological therapy in the past, apart from relaxation, with other techniques being more variably accessed.

In total, 62.3% of GPs reported that they referred to other health professionals at least sometimes to provide non-pharmacological intervention to augment pain control. It can be seen from Figure 5 that physiotherapists (53.0%; $n = 125$), psychologists (42.8%; $n = 101$) and nurses (43.2%; $n = 102$) were the most commonly consulted. When GPs were asked to identify the services they regularly involved in their management of cancer pain, only one cited psychologists. There

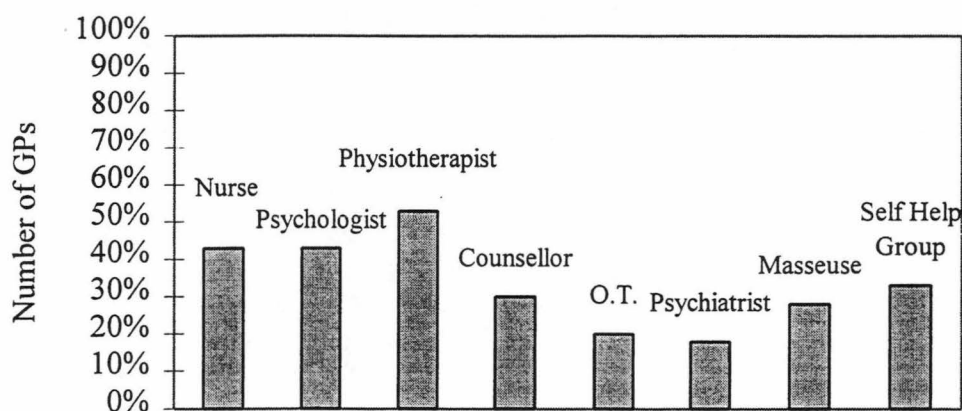


Figure 5: Health professionals used by GPs to assist pain control (Question 36b).

was a statistically significant, but low, negative correlation between how often GPs involved services other than palliative care in managing cancer pain and the frequency with which they referred to health professionals other than oncologists, radiotherapists and palliative care specialists for the provision of nonpharmacological interventions to supplement pain control medication (Pearson correlation = $-.25$, $p < .001$).

Overall, 97.4% of GPs reported palliative care services were available to patients in their area, with 88.6% indicating that they regularly referred to them.

Table 6 describes the frequencies with which GPs use services other than palliative care in managing cancer pain, and shows that almost a quarter of GPs surveyed involve them always or frequently and a third sometimes use such services.

Table 6

Frequency of GPs' use of services other than palliative care in managing cancer pain (Question 38).

Frequency	N reporting using other Services	Percentage (%)
Never	16	7.2
Rarely	71	32.1
Sometimes	83	37.6
Frequently	48	21.7
Always	3	1.4
Total	221	100.0

Most used services were identified as district and community nurses (37.1%), specialist doctors (11.3%), clergy (6.2%), and a pain clinic (4.1%), with other services each accounting for less than 3% of the responses.

In Figure 6, it can be seen that on the subject of doctor-patient interactions, 42.7% of GPs expressed the belief that it was more difficult dealing with terminally ill patients compared with other patients, because of the high levels of time and

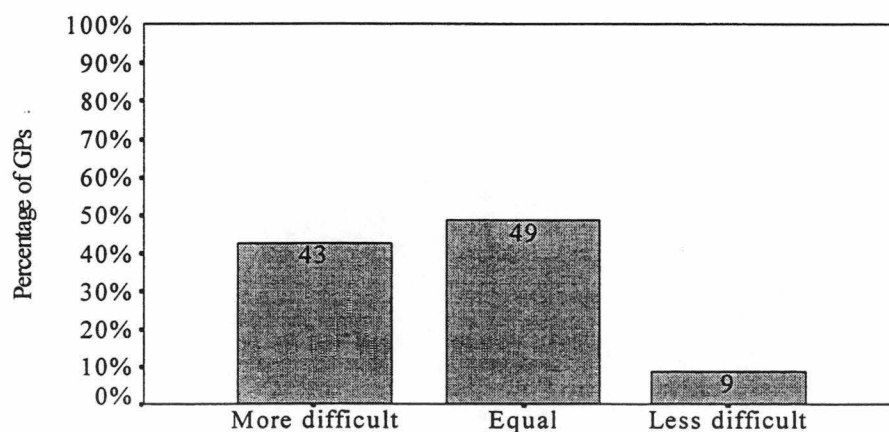


Figure 6: GPs' responses when asked whether terminal patients were more difficult to deal with compared with other patients (Question 39a).

energy required (23.2%) and 16.8% noted the difficulty of dealing with the emotion involved. However, 48.6% reported that dealing with terminal and non terminal patients was equally difficult.

When questioned about professional development, at least half of all GPs surveyed indicated further training in some aspect of palliative care would benefit their practice. Table 7 demonstrates that control of pain and other symptoms are the most popular topics, but over a third of all respondents expressed interest in each of the topics presented. Only about 10% of GPs indicated that none would be useful.

Table 7

Professional development topics GPs consider would benefit their practice. (Question 40).

Professional development topic	Topic beneficial (N = GPs)	Percentage (%)
Non-pharmacological methods of supplementing pain control	125	53.0
Control of other symptoms	122	51.7
Cancer pain management	114	48.3
Bereavement counselling	107	45.3
Communicating with dying patients	97	41.1
Access to advice from practitioners experienced in palliative care	97	41.1
None of these	23	9.7

Table 8 displays the results of independent samples t tests comparing GPs' expressed beliefs about whether professional development topics would benefit their work or not, according to their number of years in practise. The GPs who believed that 'cancer pain management' was a beneficial topic had a longer mean length of service (21.37 years) than those who did not (18.68 years), but the difference narrowly failed to reach statistical significance ($t(224) = 1.93, p = .055$). GPs who identified 'control

of other symptoms' as a topic beneficial to their practise had a shorter mean number of years in practise (18.44 years) than those who did not (21.54 years) ($t(211) = 2.23$, $p < .05$). A separate variance t-test was employed for this topic because Levene's test (Levene, 1960) indicated that the group variance was significantly different from each other

($p < .01$), violating the assumption of the standard t-test (Ferguson & Takane, 1989).

Table 8

Independent samples t-tests comparing perceived benefit of professional development topics (yes/no) on GPs' number of years in practise. (Questions 1 and 40).

Professional development topic	Benefit GPs practise	Years in practise			t-value	2-tailed significance
		Mean	S.D.	N		
Cancer Pain Management	Yes	21.37	10.59	108	1.93	.055
	No	18.68	10.39	118		
Control of Other Symptoms	Yes	18.44	9.30	115	-2.23	*
	No	21.54	11.54	111		
Communicating with Dying patients	Yes	20.77	10.67	91	.94	n.s.
	No	19.42	10.48	135		
Bereavement Counselling	Yes	19.28	9.95	101	-.88	n.s.
	No	20.52	11.02	125		
Non-Pharmacological Methods of Supplement-ing Pain Control	Yes	18.81	10.16	118	-1.72	.086
	No	21.22	10.87	108		
Access to Advice from Practitioners Experienced in Palliative Care	Yes	20.41	10.42	91	.52	n.s.
	No	19.67	10.67	135		
None of these	Yes	22.05	11.90	22	.97	n.s.
	No	19.74	10.40	204		

* $p < .05$

Finally, there was no significant difference in mean length of service of GPs who believed that 'non-pharmacological interventions of supplementing pain control' was a beneficial topic and those who did not ($t(224) = 1.72$, $p = .086$).

There was no significant association, as assessed using the chi-square test, between GPs who had specialist training in palliative care (yes/no) (Question 3b) and their choice of professional development topics (beneficial/not beneficial) (Question 40), or in those who believed that none of the topics would benefit their practise. (See Table 11 in Appendix K).

The above results are concerned with individual pairwise correlations between a range of variables and the degree of satisfaction which GPs have with the pain control they are to offer terminally ill cancer patients. In order to examine the relationships between several of the above range of variables taken together and the degree of satisfaction which GPs have with the pain control they are able to offer terminally ill cancer patients, a multiple regression/correlation analysis (Cohen & Cohen, 1983) was performed as an extension of the individual correlations.

This analysis employed the backward elimination approach (Miller, 1990). Initially all the variables selected by the researcher were entered. At each step the variable with the lowest F statistic was removed from the model, if the F statistic was not significant at the .10 level (the SPSS for Windows default) to allow for variables that may not be statistically significant by themselves but may be more effective predictors when combined with others.

Pearson correlations were firstly calculated between the individual variables, "ENCOUNTER" (how frequently GPs encounter patients with cancer; Question 4), "CANCERPAIN" (how frequently GPs saw patients with cancer pain; Question 5), "PROPORTION" (the proportion of cancer patients GPs prescribed morphine to; Question 11), "NONTERMINAL" (the proportion of non-terminal patients GPs prescribed morphine to; Question 12), "RESERVATIONS" (the reservations GPs

had in prescribing morphine to non-terminal patients; Question 13), “INFORMATION” (whether GPs routinely gave patients basic information about morphine; Question 29), “NONPHARM1” (whether GPs ever suggested non-pharmaceutical interventions to supplement pain control medication Question 34), “NONPHARM2” (whether GPs considered non-pharmaceutical interventions significantly assisted patients in coping with pain Question 35), “PALLIATIVE” (whether there were palliative care services available to patients in the area; Question 37), “HOWOFTEN” (how often GPs involved services other than palliative care in managing cancer pain; Question 38), “TOPIC1”, “TOPIC2”, “TOPIC3”, “TOPIC4”, “TOPIC5”, “TOPIC6”, “NOTOPIC” (whether any of the following topics would benefit GPs’ practises - cancer pain management, control of other symptoms,

Table 9

Pearson correlations between potential predictor variables for the degree of satisfaction GPs express regarding the pain control they are able to offer terminally ill patients (“SATISFY”).

Variable name	Correlation with satisfaction (r)	Significance (p)
ENCOUNTER	.17	*
CANCERPAIN	.08	n.s.
PROPORTION	.20	**
NONTERMINAL	.17	*
RESERVATIONS	-.11	n.s.
INFORMATION	.11	n.s.
NONPHARM1	.05	n.s.
NONPHARM2	-.01	n.s.
PALLIATIVE	.03	n.s.
HOWOFTEN	.10	n.s.
TOPIC 1	-.13	*
TOPIC 2	-.12	n.s.
TOPIC 3	-.08	n.s.
TOPIC 4	.03	n.s.
TOPIC 5	-.04	n.s.
TOPIC 6	-.19	**
TOPIC 7	.16	*

* p < .05 ** p < .01

communicating with dying patients, bereavement counselling, non-pharmaceutical methods of supplementing pain control, access to advice from practitioners experienced in palliative care or none; Question 40), and “SATISFY” (the degree of satisfaction GPs express regarding the pain control they are able to offer terminally ill patients; Question 32). Correlations are given in Table 9.

The multiple regression selected six variables, shown in Table 10. The final model accounted for 13.85% of the variance ($r^2 = .1385$, $F(6,186) = 4.98$). The strongest predictor of satisfaction with pain control was the item which stated that none of the topics suggested for professional development would benefit the practise. The proportion of cancer patients GPs prescribed morphine to was also a predictor of satisfaction. It is not necessarily intended that the above variables be employed to predict satisfaction. The six variables taken together do however account for greater variance in satisfaction than the best of the individual variables (PROPORTION) ($r^2 = .1385$ vs $r^2 = .04$ respectively).

Table 10

Variables selected by backward elimination multiple regression as contributing to the variance of how satisfied GPs are with the pain control they are able to offer terminally ill patients.

Variable name	Beta	t-value	2-tailed significance
PROPORTION	.1604	2.03	*
NONTERMINAL	.1148	1.66	n.s.
NONPHARM1	.3576	1.91	*
TOPIC4	.1651	1.69	n.s.
TOPIC6	-.2128	-2.16	*
NOTOPIC	.4547	2.56	*

* $p < .05$

Patients/Carers

Caution needs to be exercised when interpreting the following data because of the small sample size. For this reason, verbatim quotes were utilised in addition to simple statistical comparisons. The data represent a pilot study only and only attempt to explore patient and carer responses to morphine, pain control and nonpharmacological interventions within this narrow context.

All patients were taking multiple medications (range = 8 - 14) at the time of the interview. All were on morphine, with the length of use ranging from 1 day to 13 months. Nearly every patient (n = 11) was prescribed laxatives and/or stool softeners and most (n = 8) were also prescribed simple analgesics such as paracetamol. Other medications included anti-inflammatories, anticonvulsants, diuretics, sedatives, hypnotics, antidepressants, anti-anxiety agents, and agents to enhance gastric motility or inhibit secretions. Anti-inflammatories, antidepressants and anticonvulsants assist in the control of certain types of pain, in addition to their more common function (I.&W.M.D.G.P., 1995; Kinney & Brin, 1992).

Reactions to the initial prescription of morphine were mixed, and there was evidence from both patients and carers of prejudices against its use. Overall, three times as many carers as patients expressed positive reactions to the initial prescription of morphine, with two patients making positive comments and the rest being evenly divided between neutral and negative comments. There was no agreement between patients and carers when asked whether they or the patient/their families had ever worried about the patient taking morphine.

Some patients and carers stated that relieving the pain was their primary concern. *"Very pleased to give it (morphine) to him. I knew it would stop any pain"*

(Carer). *I was worried more about the cancer than the morphine*” (Carer). *“It’s a case of anything that would help would be better”* (Patient). Others spoke of relinquishing control to their doctors: *“I just agreed to whatever the doctor suggested”* (Patient). *“I leave it to them (doctors). They know what they’re doing.”* Negative comments included the following: *“I fought against it (using morphine). I thought I’d become addicted”* (Patient). *“...apprehensive. I thought his pain must be greater than it appeared to me”* (Carer). Several people indicated they believed the prescription of morphine held implications for the prognosis: *“Perhaps this is the beginning of the end”* (Patient). *“Things must be pretty bad if she had to take such a strong drug for pain relief”* (Carer).

When asked “How do you feel about morphine now?”, all patient and carer comments were either neutral or positive. When asked specifically what were the concerns about being prescribed morphine, interviewees had much less to say. Most of the patient and carer sample indicated they had received information about morphine (carers: 60%, patients: 70%). The information was most often given by a doctor (carers: 50%, patients: 70%), and questions were generally answered to their satisfaction (carers: 60%, patients: 80%). Over a third of carers (carers: 40%, patients: 20%), stated they had not had any questions to ask about morphine.

Seven out of nine patient-carer pairs indicated that they were satisfied with the medication the patients were taking. Two patients were not, but their carers were, (carers: 90%, patients: 80%) and two out of ten patient-carer pairs agreed they would not change anything about the medication if they could (carers: 60%, patients: 50%) and one pair agreed that they would. Three patient-carer pairs agreed that the patients needed the amount of medication they were currently receiving, compared

with one patient-carer pair who did not (carers: 60%, patients: 60%). On the question of pain control, eight patient-carer pairs agreed that the patients' pain was under control, and none agreed that it was not (carers: 70%, patients: 100%). Where pain was not thought to be controlled, patients and carers indicated they would prefer no medication at all, or that it was not working well. Half the sample of patients and carers (carers: 60%, patients: 50%), stated they believed the medication caused side effects. Of these, three patient-carer pairs agreed there were side-effects and two agreed there were none. Constipation was viewed as the most problematic side effect by 50% of patients, whereas 55.6 % of carers (5 out of 9 non missing) commented that none of the side effects caused problems; six pairs agreed it was a problem while one pair agreed it was not.

Patients and carers were asked to identify the greatest difficulty encountered while being ill. The responses included treatment of pain (carers: 20%, patients: 30%), family problems (carers: 30%, patients: 10%), treatment of other physical symptoms (patients: 20%), loss of independence (patients: 20%) and no particular problems (carers: 20%).

Inspection of the data indicates that cognitive strategies and other methods of augmenting pain control were not suggested by medical staff (carers: 80%, patients: 80%), and that patients and their carers made use of only a few techniques. Temperature (i.e., hot or cold packs) were the most frequently identified (carers: 50%, patients: 40%), and others included massage (carers: 40%, patients: 20%), acupuncture (carers: 30%, patients: 20%), relaxation (carers: 10%, patients: 10%), distraction (carers: 20%), breathing (carers: 10%, patients: 20%), music (carers: 20%, patients: 10%), naturopathy (carers: 20%, patients: 10%), and movement (carers:

20%, patients: 10%). When asked what other techniques had been tried, use of alcohol (carers: 10%, patients: 20%) and ignoring the pain (carers: 10%) were acknowledged.

In Figure 7, it can be seen that opinions about the effectiveness of non-pharmacological techniques, (relaxation, thought stopping, imagery, deep breathing,

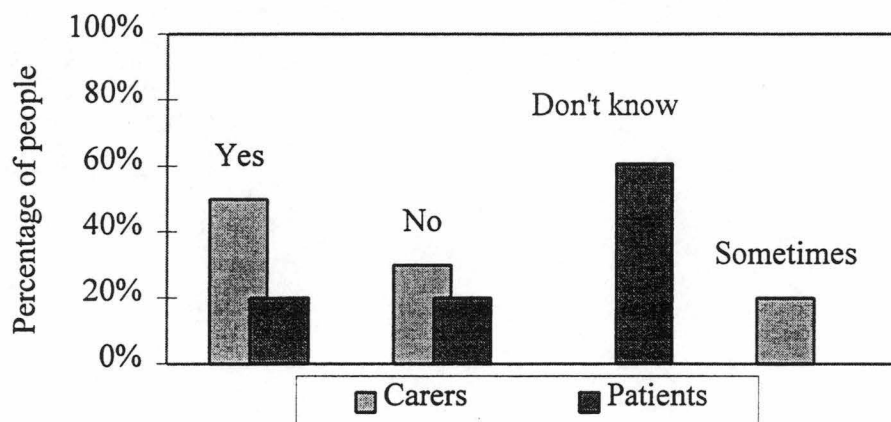


Figure 7: Belief of patients and carers that cognitive techniques would help them to control pain (Question 24).

massage, distraction, active coping, temperature, hypnosis, TENS, positioning, movement, music, naturopathy, art therapy, laser therapy, homoeopathy and acupuncture), were evenly distributed overall. Generally speaking, more carers (70%) expressed greater confidence in cognitive coping strategies than patients (20%), over half of whom were undecided (60%). Two patient-carer pairs agreed the strategies helped to control pain and three agreed they did not.

Discussion

The results of this study generally support Wakefield et al.'s (1993) contention that GPs are an essential component in palliative care, because they regularly encounter patients with cancer, many of whom experience pain, although results need to be treated with caution. The following hypotheses were supported by the study: Few GPs reported specialist training or placements in palliative care, although most indicated palliative care facilities were available and that they regularly referred to them. Morphine was regularly prescribed for severe cancer pain with a much greater range of choice evident for moderate cancer pain. This overall trend is in accord with the World Health Organisation (W.H.O.) analgesic ladder (W.H.O., 1996). GPs did report reservations about prescribing morphine to non-terminal cancer patients and prescribed morphine to a smaller proportion of non-terminal compared with cancer patients as a whole. Tolerance and/or dependence were considerably less frequently identified as aspects of concern for GPs, which is consistent with previous research in Australia (Wakefield et al., 1993) and with expert opinion that tolerance will not occur if morphine is properly prescribed (Twycross & Lack, 1984).

Looking at the results as a whole, the data support the proposition that GPs regard morphine as a satisfactory response to pain in terminal cancer patients but many perceive that consequent side effects and patient responses such as resistance, denial, misinformation and communication problems complicate appropriate delivery of morphine. In spite of this, GPs were 'mostly satisfied' with the pain control they were able to offer terminally ill cancer patients and with their resources for pain control generally. Morphine was less acceptable for non-terminal patients despite the

fact that severity of pain rather than prognosis is considered to be the most satisfactory determinant of morphine use (Hodder & Turley, 1989; W.H.O., 1996) and that this belief in use predicated on prognosis may contribute to undertreatment of cancer pain (McCaffery & Ferrell, 1995; Weinstein et al., 1992). Most GPs did report they believed patients feared pain more than death. Consequently, according to the perspective of many GPs, addressing factors other than patient access to morphine could improve quality of life in terminally ill cancer patients. It would be interesting to pursue this question in a large patient sample and determine whether patients themselves confirmed this belief.

The hypothesis that GPs prescribe morphine without routinely informing patients and their families of its properties and side effects was not supported in this research, although the quality of the information given was not assessed and in most cases it was delivered only verbally and was therefore more easily forgotten. Contrary to the hypothesis, most GPs recorded that they did suggest non-pharmacological interventions to supplement pain control medication and most also agreed that they believed some of these interventions significantly assisted patients' ability to cope with their pain, however there was only a low correlation between these two items. This suggests either that those who believed in the utility of supplementary interventions did not tend to recommend them, or that they suggested these techniques for other reasons. In addition, GPs indicated that they did sometimes use psychologists for the provision of non-pharmacological interventions and only physiotherapists were more frequently identified. It is worth noting however, that when asked who they regularly involved in their management of cancer pain, only one doctor identified psychologists.

The hypothesis that GPs would identify terminally ill patients as more difficult to deal with than other patients was not supported, although a substantial number did agree with the statement. Finally, although topics related to direct medical care were the most frequently selected professional development topic, many GPs indicated that bereavement counselling and communication would benefit their practises. Overall, GPs appeared to be willing, in theory, to incorporate psychosocial dimensions into their care of terminally ill cancer patients and to involve psychologists and psychological interventions.

Patient and carer hypotheses were generally supported. The interviews supported the hypotheses that patients and carers had concerns about the prescription of morphine, and that many of those concerns dissipated with actual experience of the drug. The quantity of medication patients were consuming rendered their judgements about morphine alone of limited value objectively, given that side effects and pain control could be attributable to interactions with other medication, and the course of the illness. However, these judgements are useful in so far as they are likely to pertain to the subjective, psychological impact of the drug and the overall effects attributed to it and results from the GPs' questionnaires suggest patient prejudices or misconceptions about morphine are a concern.

From the consumer's perspective, medication and pain control was largely judged satisfactory, which would be expected from patients on a specialist ward. Carers expressed more positive attitudes to morphine than patients, but patients' opinions of morphine either improved or remained neutral after experience of it. Multiple psychological concerns were elicited from patients and carers, which support the claim that for some palliative care patients and their carers psychological

concerns supersede the more obvious physical ones. Non-pharmacological interventions were not frequently suggested by medical staff nor used to supplement pain control and carers expressed higher levels of belief in the efficacy of such interventions than patients. Agreement between patient and carer expressed beliefs was generally poor. This insinuates that communication between patients and carers may be flawed, given that both interviews were primarily focussed upon the patients' experiences.

GPs are likely to be the first professional contact for patients diagnosed with cancer. For patients who prefer to remain at home through the course of their illness, knowledge about pain management and the communication skills of practitioners play a large part in the quality of life they experience after the disease is diagnosed (I.&W.M.D.G.P., 1995; Twycross 1995). Yet the current results have also indicated that many of the GPs in Tasmania have limited training in palliative care and are interested in further education on both medical and more multidisciplinary topics. Given the vulnerability of terminally ill patients and their carers, greater expertise on behalf of practitioners, particularly in considering psychological support for and empowerment of patients and carers, can only benefit them when there is evidence to suggest that cancer pain is undertreated and medical staff susceptible to inaccurate information (Patt, 1992; Elliott et al., 1995; Fife et al., 1993; Lang et al., 1992; Wakefield et al., 1993).

Morphine is commonly prescribed, although the data from all quarters indicated that there are concerns about its prescription. Side effects are a particular concern, however the deleterious effects of negative patient factors were also referred to. This result emphasises the value of good doctor-patient communication, which is

further borne out by the fact that problems concerning the family were identified by almost a third of the sample of GPs as the greatest difficulty in treating cancer patients. This category of problems is particularly likely to benefit from clear and effective communication between doctors and patients/carers. Faith in the provision of medical services and opinions will diminish the anxiety and misunderstanding, in addition to doctor-patient communication contributing to satisfaction with pain control (Zhukovsky et al., 1995). The data provide some support for the proposition that the quality of life of cancer patients would be likely to be improved with greater training in, and support for, communication skills for GPs, together with input by other professionals. However, medical topics were more frequently selected, rather than counselling or communication skills, as potentially beneficial by the GPs themselves. This may mean that although these issues of communication can represent difficulties for GPs, either they are not perceived to be critical problems, or GPs do not regard these skills as being within their professional responsibility. Further research would be useful in clarifying this issue.

Most GPs reported providing information about morphine to patients, yet a large number of GPs cited patient resistance to either morphine or fear of its side effects as the most significant problems in prescribing morphine, implying the message is unsuccessful. Also, patients and carers were usually unable to report details of the information, if any, that they had been given by doctors about morphine. Future research could explore the relationship between information provided by GPs and patient attitudes to morphine.

In spite of the many difficulties identified by the GPs, most reported being satisfied with the pain control they were able to offer their patients and the resources

they were able to access. The data indicated that GPs reporting that none of the suggested palliative care topics would benefit their practise, was predictive of their overall satisfaction with pain control in terminal cancer patients. Similarly, the variables relating to the proportion of patients GPs prescribed morphine to and whether GPs suggested alternatives to medical pain control also contributed to the variance of GPs' satisfaction with pain control. GPs did not frequently endorse alternative therapies as adjuncts to pharmacotherapy. However, it was not within the scope of this study to assess how often these alternatives were used or how professionally they were applied. The term 'relaxation', for example, can define a range of events from listening to a recording of relaxing music to an individualised session of muscle relaxation guided by an experienced professional. It was encouraging to note that many GPs believed that non-medical procedures significantly assisted patients' ability to cope with pain, because these techniques offer choice and can enhance feelings of self-efficacy in patients.

The patients interviewed for this research had access to highly specialised care. Admission to the palliative care ward was an indication that pain or other side effects were causing problems, or that they were close to death, which characterises this patient sample as particularly vulnerable. As might be expected, in this environment, the overall level of satisfaction with medication was high and most patients and carers reported that pain was under control. Side effects were identified as problems, but were rarely selected as the greatest difficulty encountered while being ill. There was clear evidence of initial patient concerns about the prescription of morphine in this restricted sample, but with experience of the drug and the

continuing feedback from doctors that many had received, these concerns appeared to be largely neutralised.

Although the quality of care was high in the ward sampled in this study, as evidenced by patient : staff ratios and patient and carer feedback, patients were offered few alternatives to medication for pain control. The alternatives offered included relaxation tapes, distraction, spas, heat and cold packs, physiotherapy, pastoral care visits and positioning. Given the seriousness of the patients' disease, the advanced age of most and the short duration of the average stay, many non-pharmacological alternatives are less helpful in this environment than they would be at an earlier stage in the illness. Nonetheless, modified forms of intervention could be adapted to fit the special conditions of very debilitated patients in order to enhance medical control of pain and/or other unpleasant symptoms, such as smell, itching or constipation, to relieve boredom or stress and to improve the experience of being in hospital. These alternatives include customised relaxation, thought stopping, imagery, goal setting, cognitive reframing and counselling to deal with issues that could be affecting pain perception, such as grief and loss of independence. Many of these techniques are equally appropriate for carers, given both patients and carers expressed concerns about how families were coping with the illness. Despite high levels of unpleasant physical symptoms and terminal prognoses, some patients and carers indicated they were more troubled by psychological concerns, which supports Lichter's (1991) beliefs.

One of the major difficulties inherent in using patients from a hospital setting as part of a research sample is that patients may feel dependent on the ward and consequently unwilling to criticise any aspect of their care, including their

medication and further, patients may feel they have to participate in research because of their need for care. Kristjanson et al (1994) commented that this poses an ethical problem when including a patient sample in palliative care research. It is nonetheless ethical and practical to continue to return to the patient population for consultation when hypothesising about what constitutes good palliative care, particularly if research is designed with these limitations in mind.

A future study might undertake to interview terminally ill and non-terminal cancer patients in the community who are being treated by GPs, to look at the differences in their attitudes and experiences of pain control. A matched sample of patients and their doctors could provide interesting comparisons of patients' care from the two perspectives. It would be particularly valuable to look at the population of patients in an area outside the jurisdiction of a palliative care ward, who have poor access to specialist services, because such a ward often acts as a resource centre for GPs in the surrounding area, in addition to disseminating information to the community and areas distant from these services may not receive this benefit.

Other areas for future research include obtaining more specific information about how doctors assess severity of pain, in particular, examining the criteria for judging pain as 'severe'. In addition, in the present study GPs indicated they were generally satisfied with their resources for pain control, however the question could be extended to determine whether GPs are equally satisfied with their resources for pain in non-terminal patients and/or for non-cancer pain. Devising a study which compares doctors' opinions about different forms of pain control in palliative care with their actual prescribing and referral practices could provide some useful insight into 'best' versus 'realistic' practice.

In theory, it is well recognised that patients in palliative care and their families require a time- and resource-intensive approach to give them the type of care which supports them adequately through a period of life which is often physically and emotionally complex and painful. Unfortunately, at the present time, it seems as if the structures are not in place to provide more than haphazard 'holistic' care and psychologists must be encouraged to campaign actively for greater inclusion of their particular expertise in this field.

Pain is equally a sensation and an emotional reaction to that sensation (Merskey & Bogduk, 1994). Morphine only addresses the first, which it does very effectively, albeit with undesirable side effects. The results of this study suggest that concern for the unmet analgesic needs of cancer patients should not be limited to improving access to morphine and similar pharmacology. This leads to the prediction that in the medical environments of general practise or palliative care wards, greater attention to and provision for patient self efficacy and emotional support will affect pain directly and indirectly. It could be productive to investigate patient reaction to morphine specifically and pain control generally with and without techniques aimed at enhancing these variables. Self efficacy can be bolstered by the addition of an increased range of non-pharmacological options to supplement pain control, based on patient preference and available expertise and extending beyond the options used in this study. Examples could include simple practical techniques, psychological techniques, psychodynamic therapy and alternative therapies, with the emphasis on choice and family involvement. When these types of interventions are routinely added to mainstream medical treatment, patients may ultimately achieve better pain control and higher quality of life.

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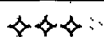
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APPENDIX A



Attitudes to Pain Management



Attitudes to Pain Management



The following questions relate to **opinions** and **preferences** regarding the management of pain. Please answer them according to your current opinion. Do not spend too much time on any one question.

Date: / / 1995

- (1) How many years have you been practising? year(s)
- (2) Was your medical training obtained in Australia? Yes ☐ No ☐ [Tick one]
 (If No), which country?
- (3) a) Have you treated patients with cancer? Yes ☐ No ☐ [Tick one]
 b) Have you had any specialist training in palliative care? Yes ☐ No ☐ [Tick one]
 (If Yes) What was that training?
- c) Have you ever worked in a palliative care setting? Yes ☐ No ☐ [Tick one]
- (4) How often do you encounter patients with cancer in your practice?
- Daily ☐
 Weekly ☐
 Monthly ☐
 Every few months ☐
 Less often ☐
 Never ☐ [Tick one]
- (5) In your practice, how often do your patients have pain caused by cancer? [Tick one]
- Always ☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never ☐

IF YOU ANSWERED "NEVER" TO BOTH QUESTIONS 4 & 5: THANK YOU FOR YOUR CO-OPERATION.

OTHERWISE, PLEASE CONTINUE ↻ ↻



(6) In a case of pancreatic cancer, what is your **first choice** analgesic agent for treatment of:

a) Mild pain?

b) Moderate pain?

c) Severe pain?

(7) Of the following, which factor do you rate as the **most important** when choosing an analgesic for cancer pain?

Intensity of pain

☐

Specific aetiology of pain

☐

Previous experience of analgesic

☐

Duration of action

☐

Stage of illness

☐

Client preference

☐

Cost

☐

[Tick one]

(8) Overall, do you have reservations in prescribing **narcotic** analgesics?

Yes ☐

No ☐

[Tick one]

(9) Have you ever used any type of narcotic analgesic, including morphine, in the treatment of a cancer patient?

Yes ☐

No ☐

[Tick one]



(IF NO) PLEASE GO TO QUESTION 27

(IF YES) PLEASE CONTINUE ➤➤

(10) When treating cancer patients, which narcotic analgesic do you prescribe **most frequently**?

(11) In what proportion of cancer patients have you prescribed morphine?

All ☐

Most ☐

Some ☐

Few ☐

None ☐

[Tick one]



Attitudes to Pain Management



Attitudes to Pain Management



(12) In what proportion of **non-terminal** cancer patients have you prescribed morphine?

All ☐ Most ☐ Some ☐ Few ☐ None ☐ [Tick one]

(13) Overall, do you have reservations in prescribing morphine to non-terminal patients?

Yes ☐ No ☐ [Tick one] Comments:

(14) **Generally speaking**, what are your criteria for prescribing morphine?

(15) Does your awareness of the thriving black market in opiates ever influence your decision to prescribe morphine?

Yes ☐ No ☐ [Tick one]

Comment:

(16) What factor **most** interferes with optimum pain control for your patients? [Tick one]

<i>Communication problems</i>	<input type="checkbox"/>
<i>Misinformed patients</i>	<input type="checkbox"/>
<i>Patient confusion</i>	<input type="checkbox"/>
<i>Patient denial</i>	<input type="checkbox"/>
<i>Control of side effects</i>	<input type="checkbox"/>
<i>Lack of resources</i>	<input type="checkbox"/>
<i>Other (specify):</i>	<input type="checkbox"/>

(17) What is the **greatest** difficulty which you have encountered when treating cancer patients? [Tick one]

<i>Family problems</i>	<input type="checkbox"/>
<i>Treatment of pain</i>	<input type="checkbox"/>
<i>Treatment of other physical symptoms</i>	<input type="checkbox"/>
<i>Giving information to client</i>	<input type="checkbox"/>
<i>Other (specify):</i>	<input type="checkbox"/>

☆☆ Attitudes to Pain Management	☆☆☆ Attitudes to Pain Management ☆☆☆
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(18) What is the **greatest** difficulty which you have encountered in the use of morphine in cancer patients? [Tick one]

- | | |
|--|--------------------------|
| <i>Administrative difficulties in prescription</i> | <input type="checkbox"/> |
| <i>Prescribing dosage</i> | <input type="checkbox"/> |
| <i>Knowledge and development of side effects</i> | <input type="checkbox"/> |
| <i>Knowledge of longer term use</i> | <input type="checkbox"/> |
| <i>Patient resistance to prescription/side effects</i> | <input type="checkbox"/> |
| <i>Other (specify):</i> | <input type="checkbox"/> |

(19) Which method of administration do you prescribe **most often** for morphine? [Tick one]

- | | |
|-----------------------|-------------------------------------|
| <i>Injection</i> | <input type="checkbox"/> |
| <i>Syringe driver</i> | <input type="checkbox"/> |
| <i>Tablet</i> | <input type="checkbox"/> |
| <i>Solution</i> | <input type="checkbox"/> |
| <i>Suppository</i> | <input type="checkbox"/> |
| <i>Other</i> | <input type="checkbox"/> (specify): |

(20) For terminal cancer patients, do you **usually** provide pain control at fixed time intervals or on demand? [Tick one]

- | | |
|------------------------|--------------------------|
| <i>Fixed intervals</i> | <input type="checkbox"/> |
| <i>On demand</i> | <input type="checkbox"/> |
| <i>Both equally</i> | <input type="checkbox"/> |

(21) Which of the following side effects do your patients **regularly** encounter with morphine use? [Tick all relevant]

- | | | | |
|-------------------------------|--------------------------|-------------------------------|--------------------------|
| <i>Constipation</i> | <input type="checkbox"/> | <i>Sedation</i> | <input type="checkbox"/> |
| <i>Nausea</i> | <input type="checkbox"/> | <i>Vomiting</i> | <input type="checkbox"/> |
| <i>Confusion</i> | <input type="checkbox"/> | <i>Hallucinations</i> | <input type="checkbox"/> |
| <i>Nightmares</i> | <input type="checkbox"/> | <i>Urinary Retention</i> | <input type="checkbox"/> |
| <i>Dizziness/Unsteadiness</i> | <input type="checkbox"/> | <i>Respiratory Depression</i> | <input type="checkbox"/> |
| <i>Addiction</i> | <input type="checkbox"/> | <i>Other</i> | <input type="checkbox"/> |
| | | <i>(please specify):</i> | |



Attitudes to Pain Management



Attitudes to Pain Management



- (22) Which of the following aspects of treating pain with morphine in terminal cancer patients are you concerned about? *[Tick all relevant]*

Tolerance ☐
Dependence ☐
Impairment of Cognitive Function ☐
Other Side Effects ☐

- (23) In your opinion, what is the greatest **advantage** of using morphine?

- (24) In your opinion, what is the greatest **disadvantage** of using morphine?

- (25) Do patients or families usually object to the prescription of morphine for pain control?
[Tick one]

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

- (26) What is the **most common** objection to morphine raised by patients? by their relatives?
[Tick one in each column]

	Patients	Relatives
<i>Fear of addiction</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Pain not severe enough</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Fear there will be nothing stronger if pain continues/increases</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Familial disapproval</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Fear of dying</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Method of administration</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Concern with side effects</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Cost</i>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Other (please specify):</i>	<input type="checkbox"/>	<input type="checkbox"/>

- (27) Have you experienced difficulty with patient compliance when morphine has been prescribed?

Always ☐ *Frequently* ☐ *Sometimes* ☐ *Rarely* ☐ *Never* ☐ *[Tick one]*

◆◆ Attitudes to Pain Management ◆◆◆ Attitudes to Pain Management ◆◆

(28) Which do you believe your patients fear **more**, pain or death?

Pain ☐ *Death* ☐ *No Difference* ☐ [Tick one]

(29) a) Do you **routinely** give patients basic information about morphine, when you prescribe it?

Yes ☐ *No* ☐ [Tick one]

b) Do you **routinely** give information about morphine to a patient's relatives or significant others, when you prescribe it?

Yes ☐ *No* ☐ [Tick one]

(30) In what form do you **most often** give patients and relatives information about morphine?
[Tick one]

Verbally ☐
Book ☐
Pamphlet ☐
Referral ☐
Other ☐ (specify):

(31) a) Do you have experiences of the use of morphine outside your professional life?

Yes ☐ *No* ☐ [Tick one]

(If Yes) b) Were those experiences predominantly

Positive ☐ *Neutral* ☐ *Negative* ☐ ? [Tick one]

(32) How satisfied are you with the pain control you are able to offer your terminally ill cancer patients? [Tick one]

Very satisfied ☐
Mostly satisfied ☐
Moderately satisfied ☐
Slightly satisfied ☐
Unsatisfied ☐

◆◆ Attitudes to Pain Management ◆◆◆ Attitudes to Pain Management ◆◆

(33) a) Are you satisfied with your resources for pain control **generally**?

Yes ☐ No ☐ [Tick one]

(34) Apart from radiation or chemotherapy, do you ever suggest non-pharmaceutical interventions to **supplement** pain control medication?

Yes ☐ No ☐ [Tick one]

(If Yes) What are they? [Tick all relevant]

<i>Relaxation</i>	<input type="checkbox"/>	<i>Active Coping</i>	<input type="checkbox"/>
<i>Thought Stopping</i>	<input type="checkbox"/>	<i>Heat & Cold</i>	<input type="checkbox"/>
<i>Imagery</i>	<input type="checkbox"/>	<i>TENS Machine</i>	<input type="checkbox"/>
<i>Deep Breathing</i>	<input type="checkbox"/>	<i>Positioning</i>	<input type="checkbox"/>
<i>Massage</i>	<input type="checkbox"/>	<i>Movement</i>	<input type="checkbox"/>
<i>Distraction</i>	<input type="checkbox"/>	<i>Hypnosis</i>	<input type="checkbox"/>
<i>Acupuncture</i>	<input type="checkbox"/>	<i>Naturopathy</i>	<input type="checkbox"/>
<i>Laser Therapy</i>	<input type="checkbox"/>	<i>Homeopathy</i>	<input type="checkbox"/>
<i>Music</i>	<input type="checkbox"/>	<i>Art Therapy</i>	<input type="checkbox"/>
<i>Other</i>	<input type="checkbox"/> [specify]:		

(35) In your experience, do any of the non-pharmaceutical interventions listed above **significantly** assist a patient's ability to cope with pain?

Yes ☐ No ☐ [Tick one]

(36) a) Do you refer to health professionals **other** than oncologists, radiotherapists and palliative care specialists for the provision of non-pharmaceutical interventions to supplement pain control medication? [Tick one]

Always ☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never ☐

b) Which other health professionals do you refer your patients with pain to?
(Tick all relevant)

<i>Nurse</i>	<input type="checkbox"/>	<i>Art Therapist</i>	<input type="checkbox"/>
<i>Psychologist</i>	<input type="checkbox"/>	<i>Physiotherapist</i>	<input type="checkbox"/>
<i>Counsellor</i>	<input type="checkbox"/>	<i>Occupational Therapist</i>	<input type="checkbox"/>
<i>Psychiatrist</i>	<input type="checkbox"/>	<i>Masseuse</i>	<input type="checkbox"/>
<i>Music Therapist</i>	<input type="checkbox"/>	<i>Self Help Group</i>	<input type="checkbox"/>
<i>Other</i>	<input type="checkbox"/> (specify):		



Attitudes to Pain Management



Attitudes to Pain Management



(37) a) Are palliative care services available to patients in your area?

Yes ☐ No ☐ [Tick one]

(If Yes) b) Do you regularly refer to them?

Yes ☐ No ☐ [Tick one]

(38) a) How often do you involve services **other** than palliative care in your management of cancer pain? [Tick one]

Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Always ☐

b) Which other services do you **regularly** involve in your management of cancer pain?

(39) a) Do you regard dealing with terminally ill patients as more difficult than dealing with other patients? [Tick one]

More difficult ☐ Equal ☐ Less difficult ☐

(If Yes) b) What specifically do you find difficult?

(40) Which of the following professional development topics do you consider would particularly benefit your practise? [Tick all relevant]

- | | |
|---|--------------------------|
| <i>Cancer pain management</i> | <input type="checkbox"/> |
| <i>Control of other symptoms</i> | <input type="checkbox"/> |
| <i>Communicating with dying patients</i> | <input type="checkbox"/> |
| <i>Bereavement counselling</i> | <input type="checkbox"/> |
| <i>Non-pharmaceutical methods of supplementing pain control</i> | <input type="checkbox"/> |
| <i>Access to advice from practitioners experienced in terminal care</i> | <input type="checkbox"/> |
| <i>None of these</i> | <input type="checkbox"/> |

❧ THANK YOU FOR YOUR CO-OPERATION ❧

APPENDIX B

«Title» «FirstName» «LastName»
«Address1»
«City» «State» «PostalCode»

November 29th, 1995

Dear «Title» «LastName»,

We are conducting a short survey concerning practices in pain management and current attitudes in the medical community in Tasmania. I would like to take this opportunity to ask you to participate in this survey, which is being conducted under the auspices of the Hobart Repatriation General Hospital and The University of Tasmania. Completing this questionnaire should only take approximately ten minutes of your time. Your name and address details have not been requested, so please be assured that any information you provide is **confidential** and will be used only for the purpose of gathering information about pain management in general practice.

If you have any questions or comments to make, please note them here, together with a contact name and address and I will be happy to answer them. Alternatively call me on (002) 250 863, which has an answering machine.

If you are willing to participate, please complete and return the questionnaire in the reply paid envelope provided, as soon as possible. Otherwise, please decline below and return these papers in the same envelope.

Thank you for your time.

Caroline Long
Master of Psychology (Clinical) Student

I DO ☐ DO NOT ☐ wish to participate in this survey. (Tick one)

Please Note: Information about the results of this survey will be sent to all Tasmanian Divisions of General Practice. If you would like further information, please contact the researcher at the above number.

APPENDIX C

December 5th, 1995

Dear Doctor,

A week ago you received a letter asking you to complete an accompanying ten minute questionnaire concerning the use of and attitudes towards pain management in the medical community in Tasmania.

- If you have replied to this request, thank you for your trouble. Please disregard this letter.
- If you have not yet completed EITHER the questionnaire OR the refusal, please do so, **as soon as possible**. I am sure you appreciate that good research requires a respectable response rate.

Your name and address details have not been requested, so please be assured that any information you provide is **confidential** and will be used only for the purpose of gathering information about pain management in general practice. This survey is being conducted under the auspices of the Hobart Repatriation General Hospital and The University of Tasmania.

If you do not wish to participate, please indicate this below and return the papers in the self addressed envelope provided. If you require a replacement copy of the questionnaire, please call me on (002) 25-0863 or write as soon as possible, providing your name and a contact address.

Yours sincerely,

Caroline Long
Master of Psychology (Clinical) Student

I DO <input type="checkbox"/> DO NOT <input type="checkbox"/> wish to participate in this survey. (Tick one)
--

APPENDIX D

◆◆ Pain Management ◆◆ Pain Management ◆◆ Pain Management ◆◆

PATIENT:

Screening questions: Is patient taking morphine? Yes ☐ No ☐
 (If No) Has (s)he ever taken morphine? Yes ☐ No ☐
 (If Yes) Was it for the present diagnosis? Yes ☐ No ☐

Completed Interview Yes ☐ No ☐

Subject Number: _____ A ☐ B ☐

Date: / /95

First Name: _____

Primary Diagnosis: _____

Medication presently used: _____

(1) Are you feeling any pain right now? Yes ☐ No ☐

(If Yes) a) On a scale of one to five, with five being the strongest pain you would imagine and one being a mild twinge, how would you rate your current pain? _____

b) How long have you been feeling this pain? _____ mths ☐ days ☐ hrs ☐ mins ☐

(If No) Have you had any pain with this illness? Yes ☐ No ☐

(2) How long ago did you first learn of your illness? _____

(3) Are you satisfied with the medication you are taking? Yes ☐ No ☐

(If No) What don't you like about it? _____

(4) Do you think your medication gives you any side effects? Yes ☐ No ☐

(If Yes) What side-effects have you noticed? Constipation ☐ Sedation ☐ Nausea ☐

Vomiting ☐ Confusion ☐ Hallucinations ☐ Nightmares ☐ Urinary retention ☐

Dizziness ☐ Addiction ☐ Unsteadiness ☐ Dependence ☐ Other: _____

(5) What side-effects cause the greatest problems for you? _____

(6) Are you taking morphine/MS Contin/(morphine brand names)? Yes ☐ No ☐

(If Yes) How long have you been taking it? _____ days ☐ wks ☐ mths ☐ yrs ☐

(If No) Has your doctor ever suggested you take morphine? Yes ☐ No ☐

(If Yes - GO TO Qn 8 ☞☞)

(If No - Go to Qn 17 ☞☞)



Attitudes to Pain Management



Attitudes to Pain Management



(7) How do you usually take morphine? *Injection* ☐ *Syringe driver* ☐ *Tablet* ☐
Solution ☐ *Suppository* ☐ *Other* ☐: _____

(8) What was your reaction, when it was first suggested that you take morphine?

(9) Have you or your family ever been worried about you taking morphine? *Yes* ☐ *No* ☐

(If Yes) What were you worried about? _____

(10) Have you ever been worried about becoming addicted to morphine? *Yes* ☐ *No* ☐

(11) How do you feel about morphine now? _____

(12) Have you had any previous experiences with morphine? *Yes* ☐ *No* ☐

(If Yes) Were those experiences mainly *good* ☐, *bad* ☐ OR *neutral* ☐?

(13) Has anyone you know ever used morphine? *Yes* ☐ *No* ☐

(If Yes), did it work well? *Yes* ☐ *No* ☐

(14) Did the medical staff give you any information about morphine? *Yes* ☐ *No* ☐

(If Yes) What information were you given about morphine? _____

(If Yes) Who gave it to you? _____

(15) Was the information volunteered, or did you ask? *volunteered* ☐ *asked* ☐

(16) Were all your questions about morphine answered to your satisfaction? *Yes* ☐ *No* ☐

(17) Would you consider your pain is under control? *Yes* ☐ *No* ☐

(18) Do you get pain relief when you ask for it, or at specific times of the day?

when I ask ☐ *regular intervals* ☐ *both* ☐

(19) Have you been taking your medication regularly? *Yes* ☐ *No* ☐

◆◆ Attitudes to Pain Management ◆◆◆ Attitudes to Pain Management ◆◆

(20) Do you think you need more or less medication than you are currently receiving?

More ☐ Less ☐ Same ☐

(21) Is there anything about your medication you would change, if you could, either now, or in the past? Yes ☐ No ☐

(If Yes) What would you change? _____

(22) What is the **greatest difficulty** which you have encountered while being ill?: (**prompt card**)

Family problems ☐ Treatment of pain ☐ Treatment of other physical symptoms ☐

Getting information from medical staff ☐ Other [specify]: ☐

(23) Have any of the medical staff ever suggested non-drug ways of helping you to control pain?

Yes ☐ No ☐

(**prompt card**)

(If Yes) What were they? Relaxation ☐ Thought stopping ☐ Imagery ☐

Deep breathing ☐ Massage ☐ Distraction ☐ Active coping ☐

Heat & Cold ☐ Hypnosis ☐ TENS machine ☐ Positioning ☐

Movement ☐ Music ☐ Naturopathy ☐ Laser Therapy ☐

Art Therapy ☐ Homeopathy ☐ Acupuncture ☐ Other (specify): ☐

(24) Have you ever tried other ways of dealing with pain? Yes ☐ No ☐

(If Yes) What were they?

(25) Do you think techniques such as relaxation, music, deep breathing, hypnosis, would help you to control your pain better? Yes ☐ No ☐

(26) Do you have any questions you want to ask me? _____

Would you like me to leave my card with you, in case you have questions later on?

Yes ☐ No ☐

THANK YOU FOR YOUR TIME.

APPENDIX E

CARER:

Screening questions: Is patient taking morphine? Yes ☐ No ☐

 If No) Has (s)he ever taken morphine? Yes ☐ No ☐

 (If Yes) Was it for the present diagnosis? Yes ☐ No ☐

Completed Interview: Yes ☐ No ☐

Subject Number: _____ A ☐ B ☐

Date: / /95

Patient's First Name: _____

Carer's Relationship to Patient: _____

(1) Is (*patient's name*) feeling any pain right now? Yes ☐ No ☐ Don't Know ☐

(If Yes) a) On a scale of one to five, with five being the strongest pain you would imagine and one being a mild twinge, how would you rate (*patient's name*) current pain? _____

b) How long has (s)he been feeling this pain? _____ mths ☐ days ☐ hrs ☐ mins ☐

(If No) Has (*patient's name*) had any pain with this illness? Yes ☐ No ☐

(2) How long ago did you first learn of (*patient's name*)'s illness? _____

(3) Are you satisfied with the medication (*patient's name*) is taking? Yes ☐ No ☐

(If No) What don't you like about it? _____

(4) Do you think the medication gives (*patient's name*) any side effects? Yes ☐ No ☐

(If Yes) What side-effects have you noticed? Constipation ☐ Sedation ☐ Nausea ☐

Vomiting ☐ Confusion ☐ Hallucinations ☐ Nightmares ☐ Urinary retention ☐

Dizziness ☐ Addiction ☐ Unsteadiness ☐ Dependence ☐ Other: _____

(5) In your opinion, what side-effects cause the greatest problems for (*patient's name*)? _____

(6) Is (*patient's name*) taking morphine/MS Contin/(morphine brand names)? Yes ☐ No ☐

(If Yes) How long has (s)he been taking it? _____ days ☐ wks ☐ mths ☐ yrs ☐

(If No) Has (*patient's name*)'s doctor ever suggested (s)he take morphine?

Yes ☐ (If Yes - GO TO Qn 8 ↻ ↻)

No ☐ (If No - GO TO Qn 17 ↻ ↻)

Don't Know ☐

◆◆ Attitudes to Pain Management ◆◆◆ Attitudes to Pain Management ◆◆

(7) How does (s)he usually take it?

Injection ☐ Syringe driver ☐ Tablet ☐ Solution ☐ Suppository ☐

Other ☐: _____

(8) What was your reaction, when it was first suggested that (*patient's name*) takes morphine?

(9) Have you or (*patient's name*) ever been worried about him/her taking morphine?

Yes ☐ No ☐

(If Yes) What were you worried about? _____

(10) Have you ever been worried about (*patient's name*) becoming addicted to morphine?

Yes ☐ No ☐

(11) How do you feel about morphine now? _____

(12) Have you had any previous experiences with morphine?

Yes ☐ No ☐

(If Yes) Were those experiences mainly good ☐ bad ☐ OR neutral ☐ ?

(13) Apart from (*patient's name*), has anyone you know ever used morphine? Yes ☐ No ☐

(If Yes), Did it work well? Yes ☐ No ☐

(14) Did the medical staff give you any information about morphine? Yes ☐ No ☐

(If Yes) What information were you given about morphine? _____

(If Yes) Who gave it to you? _____

(15) Was the information volunteered, or did you ask? volunteered ☐ asked ☐

(16) Were all your questions about morphine answered to your satisfaction? Yes ☐ No ☐

(17) Would you consider (*patient's name*)'s pain is under control? Yes ☐ No ☐

(18) Has (*patient's name*) been taking his/her medication regularly? Yes ☐ No ☐ Don't Know ☐

◆◆ Attitudes to Pain Management ◆◆◆ Attitudes to Pain Management ◆◆

(19) Do you think (*patient's name*) needs more or less medication than (s)he is currently receiving?

More ☐ Less ☐ Same ☐

(20) Is there anything about (*patient's name*)'s medication you would change, if you could, either now, or in the past?

Yes ☐ No ☐

(If Yes) What would you change? _____

(21) What is the **greatest difficulty** which you have encountered with (*patient's name*) being ill?:
(prompt card)

Family problems ☐ Treatment of pain ☐ Treatment of other physical symptoms ☐

Getting information from medical staff ☐ Other [specify]: ☐

(22) Have any of the medical staff ever suggested non-drug ways of helping (*patient's name*) to control pain? Yes ☐ No ☐ Don't Know ☐ (prompt card)

(If Yes) What were they? Relaxation ☐ Thought stopping ☐ Imagery ☐

Deep breathing ☐ Massage ☐ Distraction ☐ Active coping ☐

Heat & Cold ☐ Hypnosis ☐ TENS machine ☐ Positioning ☐

Movement ☐ Music ☐ Naturopathy ☐ Art Therapy ☐

Laser Therapy ☐ Homeopathy ☐ Acupuncture ☐ Other (specify): ☐

(23) Has (*patient's name*) ever tried other ways of dealing with pain? Yes ☐ No ☐

(If Yes) What were they? _____

(24) Do you think techniques such as relaxation, music, deep breathing and hypnosis would help (*patient's name*) to control his/her pain better? Yes ☐ No ☐

(25) Do you have any questions you want to ask me? _____

Would you like me to leave my card with you, in case you have questions later on?

Yes ☐ No ☐

THANK YOU FOR YOUR TIME.

APPENDIX F

- 1) Family problems***
- 2) Treatment of pain***
- 3) Treatment of other physical symptoms***
- 4) Getting information from medical staff***
- 5) Other***

- 1) Relaxation***
- 2) Thought stopping***
- 3) Imagery***
- 4) Deep breathing***
- 5) Massage***
- 6) Distraction***
- 7) Active coping***
- 8) Heat & Cold***
- 9) TENS machine***
- 10) Positioning***

11) Movement

12) Hypnosis

13) Acupuncture

14) Naturopathy

15) Homeopathy

16) Laser Therapy

17) Music

18) Art Therapy

19) Other

APPENDIX G

Attitudes to pain management with morphine in palliative care.

Chief Investigator: Dr Alison Garton

We would like to take the opportunity to invite you to participate in research about people's opinions on pain control, in particular, morphine. This study is being conducted by Caroline Long as part of a Master's thesis. It is being done to provide better information about the general effectiveness and value of morphine and to help improve knowledge about the best way to use it. **We are interested in interviewing patients with cancer who have been prescribed morphine at some stage in their illness, and their nominated significant others.** You do not need to be taking morphine at this time to be included. We are asking you to complete an interview with the researcher, answering questions relating to your personal experience of pain control. This should only take about fifteen minutes. We will then ask you to choose someone close to you, to answer similar questions. We will not be asking for anything further.

All the information you give is **confidential**. Every effort will be made to maintain confidentiality of research data and only researchers will have access to any identifying data. The only personal information required from you, is your first name.

This interview is not compulsory and **you can stop at any time**. If you decide not to answer any questions, this will have no effect on your treatment in hospital or at home, either now or in the future. If you are not feeling well enough, this interview can occur later. It is possible that talking about medication and pain control could make you feel uncomfortable or distressed. If you are not sure about the interview, you can answer just one or two questions and decide whether you wish to continue.

If you have any questions or concerns about this interview, you can contact the researcher, Caroline Long (ph: 25-0863) for more information. If you have concerns of an ethical nature or complaints about the manner in which this research is conducted, you may contact the following people:

Chair of the Ethics Committee	- Dr Paul McCann	ph: 38-8255
Acting Chair (from 1/10/95)	- Dr Rosalie Parton	ph: 38-8255
Secretary of the Ethics Committee	- Ms Chris Hooper	ph: 38-8160 or 20-2763

This research has received ethical approval from the Acute Care Program Ethics Committee and complies with the laws of the State. You will be given copies of this information sheet and the consent form for your own records.

If you are willing to be interviewed, please call Caroline Long on 25-0863 between the hours of 9-5 to make an appointment. This number has an answering machine for times when the telephone is unattended. Alternatively, please tell your Palliative Care Team member if you are willing to be involved and Caroline will call you to make an appointment.

Involvement in this research only requires one interview from you and one from the person you nominate. The interviews will be conducted in your home, at your convenience.

APPENDIX H

Consent Form:
Attitudes to pain management with morphine in palliative care.

I have read and understood the 'Information Sheet' for this study. I understand that the purpose of this interview is to gather information about opinions on pain control. The nature and possible effects of the study have been explained to me. I understand that I am only being asked to answer questions relating to my */patient's* personal experience of illness.

I have been told that all the information I may offer will be kept confidential and the only personal information required is my first name. I have been informed that the results of the study may not be of any direct benefit to my medical management. I also understand that this interview is not compulsory and I can stop at any time. If I decide not to answer any questions, this will have no effect on my treatment in hospital, either now or in the future.

I have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this investigation and understand that I may withdraw at any time without penalty.

Name:

Address:

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.

Name of **subject**

Signature of **subject**

Date

Name of **witness**

Signature of **witness**

Date

I have explained this study and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of **researcher** Caroline Long

Signature of **researcher**

Date

APPENDIX I

Dear

During his stay on Whittle Ward, your _____ agreed to be interviewed for his opinions about his pain management, which is part of some research we are conducting on the ward. As part of that interview, we asked him to choose the person closest to him, to answer some similar questions in a short interview and he chose you. He has an information sheet describing what the interview is about. It will give you a clearer idea of what we are doing.

We would like to get in contact with you to do this short interview, if you are willing. As with _____'s interview, this is not compulsory and you may stop the interview at any time. If you decide not to answer any questions, this will have no effect on his stay in hospital or future treatment. All the information you give is confidential.

If you are willing to be involved, please call Caroline Long on 25-0863 (bh) to arrange a time to come to Whittle Ward for this short interview. This telephone number has an answering machine for times when the telephone is unattended. Alternatively, you can leave your name and a contact number with the Whittle Ward receptionist, Ann, and Caroline will call you. Interviews can be arranged to fit in with what is convenient for you and can occur on weekends or weekdays. If you choose not to be interviewed, could you leave a message on the above number, or with Ann, to say so, so that we do not contact you.

Yours sincerely,

Caroline Long

APPENDIX J

RESEARCH ON WHITTLE WARD

For a short time in **December** and again in **January**, patients and families are going to be interviewed on Whittle Ward.

- My name is Caroline Long and I am completing a Master's degree in Psychology.
- I am exploring people's reactions to and beliefs about morphine in palliative care.

<ul style="list-style-type: none"> • I am interested in interviewing cancer patients who are using or have used morphine.

- I will be asking each patient I interview to identify someone close to them for me to interview.
- Each interview should only take approximately 15 minutes, plus a short time to explain the interviews and obtain informed consent. If a patient wants or needs to stop the interview, they can stop **at any time**. The interviews will take a back seat to any hospital care.
- The interviews ask about the patient's experience of pain, medication. They contain nothing overtly distressing or personal. All information given is **confidential**.
- All interviews will be completed by me. I am a qualified psychologist with clinical experience.
- I will ask each person I interview to sign a consent form beforehand. If they are not capable of giving informed consent then I can not interview them.

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| <ul style="list-style-type: none"> • Each day when I come in to interview patients I will ask the nursing staff to identify which patients are well enough for me to approach. • I will also be asking nursing staff to inform me if a patient has any comments or queries about the interviews, or if they appear to be in any way uncomfortable as a result of the interview. |
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- Any feedback nursing staff have about these interviews, any of the procedures, or any perceived effects they have on the patients, would be welcome.
- Interviews will be sought during the daytime on Tuesdays, Thursdays, and on the weekends. I will also be available after 5pm any other day of the week. Given it will be difficult to catch family members, I will be leaving each patient I interview with a letter asking their nominated family member to contact me for an interview, which they can refuse if they prefer.
- Dr Alison Garton from the Department of Psychology (University of Tasmania) is the Chief Investigator for this research, which has been approved by the Acute Care Program Research and Ethics Committees and the University of Tasmania. Dr Paul Dunne has been consulted throughout. Dr Christine Clifford is also acting as a supervisor.
- When this research is completed, the results will be summarised and made available to the hospital, particularly Whittle Ward.

APPENDIX K

Table 11

Associations between GPs who reported they had specialist training in palliative care (yes/no) and their choice of professional development topics (beneficial/not beneficial) (N = 232).

Professional development topic	Specialist Training	Beneficial to practise		Not beneficial to practise		χ^2	2-tailed significance
		N	%	N	%		
Cancer Pain Management	Yes	12	5.2	17	7.3	.55	n.s.
	No	99	42.7	104	44.8		
Control of Other Symptoms	Yes	19	8.2	10	4.3	2.5	n.s.
	No	101	43.5	102	44.0		
Communicating with Dying patients	Yes	11	4.7	18	7.8	.12	n.s.
	No	84	36.2	119	51.3		
Bereavement Counselling	Yes	13	5.6	16	6.9	.00	n.s.
	No	92	39.7	111	47.8		
Non-Pharmacological Methods of Supplementing Pain Control	Yes	17	7.3	12	5.2	.36	n.s.
	No	107	46.1	96	41.4		
Access to Advice from Practitioners Experienced in Palliative Care	Yes	10	4.3	19	8.2	.57	n.s.
	No	85	36.6	118	50.9		
None of these	Yes	2	.9	27	11.6	.25	n.s.
	No	27	11.6	183	78.9		

* $p < .05$