

Palliative care knowledge of some South Island GPs

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ABSTRACT

A questionnaire designed to assess general practitioners' knowledge of palliative care was sent to the 469 general practitioners (GPs) who are members of South Link Health Incorporated Society. Of the 133 who responded, the majority demonstrated an understanding of the basic principles of palliative care. However, there appeared to be a number of important knowledge gaps. In particular some respondents were uncertain about the prescription of anti-emetics with opioids, some did not know how to respond to confusion and loss of renal function and some did not know the appropriate response to certain emergencies in palliative care. Furthermore, there appears to be uncertainty regarding the appropriate reasons for referral to a palliative care team.

Although, due to the low response rate, the findings may not be representative of New Zealand GPs, the data provides an indication as to how this group of GPs might best be served by palliative care educators and specialist palliative care services. It is hoped that GPs will consider the issues raised by this study as a means of reflecting on their own practice. Two of the more complicated issues in palliative care are discussed in more detail.

Keywords

End-of-life care, general practitioners, specialist palliative care services.

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Introduction

The overall goal of the New Zealand Palliative Care Strategy is that all people who could benefit from palliative care – both those who are dying and their families/whanau – have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way.^{1,2} GPs have a central role in the realisation of this goal. In recent years there has been a general trend, strongly supported by the present health strategies and District Health Boards, of shifting health care provision from institutions to the community. This includes in-patient hospices. While end-of-life care is increasingly being provided in the community, specialist palliative care

teams have the role of providing support and resources to both community carers and hospital teams alike.^{3,4} Hospices now provide more short-term in-patient admissions for complex symptom management, respite care and support for carers.

The ability of GPs to provide quality palliative care is naturally dependant upon their knowledge of palliative care principles and symptom management. In studies overseas it has been found that GPs have inadequate knowledge of pain control and the use of adjuvant therapies,^{5,6,7} as well as palliative care principles and philosophies.⁸ Barclay and colleagues concluded that addressing the educational needs of GPs and facilitating their access to advice from

specialist clinicians are important factors in improving people's access to palliative care.⁷ Field reported that the GPs he interviewed in Britain placed a high value on their role in providing end-of-life care to their patients, noting that they considered it to be an important and rewarding aspect of their work.⁹ Field also noted that tensions over the role of hospice and specialist terminal care services were an issue for the participants of his study. Considered as a whole, these studies portray GPs as highly motivated to provide quality palliative care, but nevertheless there appears to be a lack of certain important knowledge and skills. The studies highlight a need for better access for GPs to specialist clinicians, but

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also make clear that collaboration between these groups can be complicated by a lack of clarity about respective roles and by the difficulties of dividing care between individuals with different philosophical and experiential backgrounds.

In Canada, Barnabe and Kirk conducted a study in which they asked GPs to rate their ability to provide various aspects of palliative care.¹⁰ Interestingly, they found that the majority of GPs believed that they did have adequate knowledge of symptom management issues. Issues that they reported as being less confident with included bereavement and the psychosocial aspects of dying. These results parallel the findings of MacLeod and Nash in the UK over a decade ago.¹¹ The conflict of these results with those of other studies mentioned here might be attributable to the fact that individual doctors cannot always identify all of their learning needs.¹² However, others have argued that GPs are able to assess many aspects of their knowledge and educational needs, and that GPs have been shown to be more accurate at identifying areas where they lack knowledge than areas where their knowledge is comprehensive.^{13,14} The disparity between the results of these studies might be explained by groups of physicians being likely to differ in knowledge of palliative care principles and symptom management. If this is so, we should be cautious about the extent to which overseas studies are used in forming a description of local GPs.

What is needed are empirical studies of the physicians who are working in New Zealand. Hitherto there has been little research of this nature undertaken. The current study provides a provisional outline of some New Zealand GPs' knowledge of palliative care principles and symptom management. A clearer picture will be established through further study and the discernment of those who are close to the practice.

Method

A selection of palliative care specialists and primary health care professionals were consulted in order to determine what form the final questionnaire should take, and what particular aspects of palliative care should be covered. In this initial survey, 89 health care professionals were surveyed, including 44 GPs, 30 district nurses, eight hospice doctors, and seven specialist palliative care coordinators. Eighty-two per cent responded, including 36 GPs (82%), 23 district nurses (77%), seven hospice doctors (88%), and seven hospice care coordinators (100%).

Examination of the responses from both the primary health care practitioners and 'experts' was undertaken to identify the range and scope of 'important' areas to be included in the final questionnaire. The format of this questionnaire (case studies with multiple choice answers) reflected that which the primary health care professionals deemed most acceptable to them. Items to assess primary health care practitioners' attitudes to palliative care were selected from an attitude questionnaire used and validated in a recent study.¹⁵ By using the cumulative results from all the GPs and district nurses who took part in this study, any individual limitation in identifying educational need was minimised. Furthermore, objectivity was introduced by comparing the GPs' and district nurses' perceived needs with those of the specialist palliative care clinicians.

Questions were drafted with reference to those validated in previous studies, and with consideration to the range of important issues identified by the primary health care practitioners and experts as outlined previously. Some of the questions used in overseas studies had limited rel-

evance to the New Zealand context, such as the use of different drug names, or different cultural practices. These were reviewed and re-written. The questions were then distributed to the 15 member 'expert' team for their feedback. Experts were asked to rate the degree to which they agreed with the answer to each question, the clarity of each question and the usefulness of the questions in test-

ing palliative care knowledge. From their responses, the final questionnaire was constructed (see Appendix).

Late in 2003 the questionnaire was mailed out to the 469 GPs who are members of the South Link Health

Incorporated Society. The participants, who remained anonymous, were asked to complete the questionnaire and return it to the sender. A reminder letter was sent out in January 2004 and then in March the data from the 133 returned questionnaires (28%) were collated onto a database.

Results

Questions related to symptom management were most consistently answered correctly. In particular, 99% of respondents correctly answered the question relating to the introduction of opioid therapy, 86% the question regarding the drug management of 'death rattle', and 78% the question about the institution of laxatives for the almost certain development of opioid-induced constipation. However, alongside these positive responses were the relatively low proportions of correct answers to a number of other symptom management questions. For example, only 67% of respondents answered correctly the question concerning nausea, and 62% that concerning hypercalcaemia. There was a high level of variance in the responses given to the questions that related to different

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morphine dosage regimens, individual patient responses to morphine, and to deteriorating renal function whilst on morphine. Only 23% correctly answered the question regarding the management of breathlessness.

The responses to two questions are worth close attention. The first relates to the reasons for referral to a palliative care service. Despite the fact that 78% of respondents answered correctly the question about appropriate timing of referral to a specialist palliative care team, there was a wide range of responses given for the question regarding the reasons for referring, with only 35% selecting the answer that we considered correct. Whilst it is possible that ours is not the definitive answer, the rigorous process undergone in creating the initial survey, and its subsequent validation by an expert panel, argues against this. We believe that the variation in the GPs' answers and the divergence of the majority of respondents from the expert panel's view suggest that there is a lack of clarity amongst the GP community about the role of specialist palliative care services.

The second question that we believe needs close consideration is that of how to respond when a patient stops eating and drinking. Ten per cent of respondents circled more than one answer in response to this question. Fifty-eight per cent of GPs believed their primary responsibility is to support their patient's wishes, which was the response believed to be appropriate by the survey authors. Twelve per cent indicated that their primary responsibility is to reassure and provide counselling to the patient's spouse, and 12% identified their responsibility being to offer sedation to the dying patient in order to ensure his comfort. Seven per cent said they felt they were obliged to use parenteral fluids to ensure their pa-

tient did not become dehydrated. The responses to this question reflect the complexity of the problem described, and suggest to us that there is a need for further discussion of this important and common issue.

Discussion

While the response rate of 28% is low, it is comparable with other studies of GPs that used postal surveys (Samaroo and Haines reported response rates of 18% and 31% respectively^{5,6}). A low response is therefore perhaps to be expected with studies of this nature. Despite the limited generalisability of the study, it has value as a starting point for gauging New Zealand GPs' knowledge of palliative care.

The results show that while respondents have a good understanding of many aspects of the provision of palliative care near the end of life, there are some significant areas of knowledge deficiency. For the most part these areas of knowledge deficiency lend themselves readily to edu-

cational interventions. However, we believe that the difficulties surrounding referral to specialist services and the withholding of treatment may be related to broader conceptual issues associated with the general understanding of the nature

of palliative care.

The issue of the relationship between GP services and specialist palliative providers has been highlighted by a number of other studies (as noted earlier), and in this study it was found that respondents lacked a clear sense of appropriate reasons for referring a patient to specialist services. This confusion may be ameliorated by consideration of the findings of Hibbert and colleagues.¹⁶ Drawing on data from focus group studies they outlined how medical practitioners engage in a process of negotiation about the roles and expertise of their own and other

specialties. Their study showed that the boundaries between specialties were dynamic and depended on such aspects as roles and status rather than an explicit or detailed rationale. They pointed out that palliative care expertise was more easily understood by other members of the medical world in terms of technical strategies for symptom management. What follows from this understanding is the notion that the generalist's task is to provide the psychosocial aspects of care, while the specialist's is to deal with particular symptom management issues. We believe that this sort of misconception must be avoided, as it denies palliative care specialists the ability to act as advocates and practitioners of the 'holistic' model of palliative care promoted by the original hospice movement. If specialist providers work with generalists in a way that includes identifying and assisting with the more indeterminate aspects of end-of-life care the respective roles are likely to be clarified.

The timing for referral to palliative care services presents a particularly challenging problem. It is recognised that the times of greatest need for patients and their families are at the time of the initial diagnosis of a life-threatening disease and at the time when it is recognised that the patient is dying. Ideally referral to specialist services should come early, as this enables the palliative care team to familiarise themselves with the patient and family, to identify their needs and to institute an appropriate and patient-centred care plan. Late referral often means that issues remain unresolved at the time of death and may complicate bereavement. That the majority of respondents answered the question related to timing of referral correctly may be taken as an indication that they have an understanding of these points. However, there appears to be less certainty about the reasons for referral to specialist services. The disparity of specialist service provision in the South Island may be a complicating factor, alongside the ambiguities regarding the roles of generalist and specialist

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providers that have already been discussed. This situation may require GPs to work with their local palliative care providers to develop clear guidelines about the circumstances in which referral is most appropriate.

With regard to developing these guidelines, a useful and comprehensive summary of barriers to effective care for people who are dying is contained in the work of John Ellershaw and Chris Ward,¹⁷ in which they outlined the Liverpool integrated care pathway for the dying patient. It is hoped that this pathway might be developed for use within New Zealand to provide evidence-based guidelines on symptom control, psychological support and bereavement. This should serve to improve understanding of the particular roles of the various services, which may facilitate an improved relationship between GPs and specialist providers, and in turn clarify when referral is most appropriate.

The vexed issue of nutrition and hydration near the end of life creates uncertainty in many areas of medical practice. In New Zealand the debate about whether hydration and nutrition should be seen as medical treatment

has been clarified in the courts on a number of occasions.¹⁸ Nevertheless there remains a high level of ambiguity around this issue, and it appears that this is reflected in the results of this study. It is widely accepted that a doctor should always be respectful of a patient's wishes, particularly because

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overriding those wishes can irreparably damage a patient's trust in his doctor. Yet trust entails a confidence that another will act with the right motives in accordance with moral norms,¹⁹ and hence a doctor will seek to honour a patient's trust by acting in accordance with the particular moral principles he or she is guided by. Thus, in certain circumstances it may seem to a doctor that he or she ought to help a patient in a way that is at odds with what that patient wishes at that time, particularly when a family member or carer is distressed by those wishes. Such difficulties cannot be resolved by a priori moral reasoning but through sensitive consideration of the details of each case. A high level of practical wisdom is required, including a thorough understanding of the processes that accompany dying, to enable good judgments about whether or not it is in a

patient's interest to offer particular treatments. In the case described in this study, an understanding that it is typical for a dying person to experience a loss of appetite may allow a doctor to feel more at ease about respecting a patient's desire to stop eating and if this is explained to the carers then their distress may be lessened. Clear communication between providers and the patient and family will facilitate the most beneficial response in each given situation.

Conclusion

This survey provides some indication of the educational needs of the responding GPs. It also indicates that there may be a need for further clarification of the relationship of GPs to specialist palliative care services, and for wider discussion of the more difficult aspects of end-of-life care.

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Appendix: Knowledge Section of Final Questionnaire

(Bold type indicates the correct answer)

1. You attend a 77 year old man, Harry, who has just returned from hospital with a diagnosis of advanced lung cancer with metastases in his spine. He is asymptomatic. When would a referral to hospice be most appropriate?
 - a) As soon as the diagnosis is established
 - b) When his estimated prognosis is 9 months or less
 - c) When his estimated prognosis is 6 months or less
 - d) At any point in the course of his illness when assessment and/or intervention by the hospice is anticipated or necessary**
2. The following reasons for referring Harry to the hospice are appropriate EXCEPT for:
 - a) To help Harry and his caregiver with any psychological or spiritual issues that arise
 - b) To offer Harry care by the hospice if he expresses a desire to have hospice rather than GP care**
 - c) For social support in a day therapy setting
 - d) For familiarisation with the specialist palliative care team, if referral is needed later in his illness.

3. *Harry's wife and daughter tell you that they do not want any details of his prognosis to be given to him, as they know he would not cope with the news. As his general practitioner, your initial response should be:*
 - a) To honour the request of the family / whanau members and tell Harry only as much information as they deem necessary
 - b) To meet with members of the family / whanau to clarify issues around their concerns and to work with them to facilitate the exchange of information to the patient**
 - c) To tell the family / whanau that Harry has a right to all information and that you will not honour their request
 - d) To tell Harry some information, but withhold any information that you feel would destroy his hope
4. *Harry starts to experience some back pain and you work your way through the analgesic ladder. At what stage in his disease would you recommend opioid analgesic therapy for treatment of severe pain?*
 - a) At any time during the course of his cancer**
 - b) When his estimated prognosis is less than 1 year
 - c) When his estimated prognosis is less than 6 months
 - d) When his estimated prognosis is less than 3 months
5. *Harry is prescribed normal release oral morphine sulphate to be taken as required. On reassessment he is using 10mg every 4 hours. What dose of sustained-release morphine sulphate would be most appropriate for him?*
 - a) 10mg morphine sulphate 12 hourly
 - b) 10 mg morphine sulphate 8 hourly
 - c) 20 mg morphine sulphate 12 hourly
 - d) 30mg morphine sulphate 12 hourly**
6. *After several weeks on his morphine sulphate treatment, Harry complains of increasing pain. The most likely reason for this is:*
 - a) Development of opioid tolerance
 - b) Development of opioid dependence
 - c) Development of opioid addiction
 - d) Worsening of the disease process**
7. *Harry's renal function is deteriorating and he has become confused on the morphine sulphate dose he is on. What would be the most appropriate initial decision in this situation?*
 - a) Change the route of morphine sulphate administration from oral to subcutaneous
 - b) Add haloperidol to his drug regimen
 - c) Switch to normal release morphine sulphate, PRN, and titrate his dose to the level of pain**
 - d) Decrease his does of sustained-release morphine sulphate and monitor his pain levels
8. *Harry has a regular bowel habit up until now, normally opening his bowels daily. When first prescribing him strong opioids, at what stage would you suggest the use of a laxative?*
 - a) The same day as commencing opioids (prophylaxis)**
 - b) If his bowels haven't opened for several days
 - c) If his bowels haven't opened for 1 week or more
 - d) If he complains that he is passing bowel motions less frequently
9. *Harry has felt nauseated since starting morphine sulphate. The following drugs are appropriate for the initial treatment of his opioid induced nausea EXCEPT:*
 - a) Metoclopramide
 - b) Cyclizine
 - c) Ondansetron**
 - d) Haloperidol
10. *You see Harry on Friday afternoon. He says he is still enjoying a reasonably good quality of life, and his prognosis is estimated at around six months. He complains of increased back pain, paraesthesia in the L5 dermatome, and some urinary incontinence. You consider the diagnosis of spinal cord compression. What is the best course of management?*
 - a) urgent admission to cancer centre / oncologists for MRI scan**
 - b) urgent referral to A&E for an x-ray
 - c) review him on Monday morning and re-examine him for signs of cord compression
 - d) urgent referral to the hospice/palliative care service for assessment

11. *As his disease progresses, Harry develops hypercalcaemia. Which pattern of symptoms and signs is most characteristic of hypercalcaemia in advanced cancer?*
 - a) Confusion, diarrhoea and thirst
 - b) Nausea, constipation and confusion**
 - c) Diarrhoea, thirst and tinnitus
 - d) Nausea, tinnitus and dyspepsia
12. *When you next meet Harry, his disease is very advanced and he is much weaker. His most distressing symptom is breathlessness, which is intensified by movement and does not appear to be related to anxiety. Reassurance and breathing exercises have only helped minimally. What is the most appropriate next step in managing this?*
 - a) Home oxygen to ensure his oxygen saturations remain over 95%
 - b) Using a paper bag and teaching rebreathing technique
 - c) Trial of an immediate release opioid before exertion on a PRN basis**
 - d) Refer him for an urgent x-ray to determine whether the cause is related to airway obstruction or pleural effusion
13. *Harry decides that the quality of his life is so poor that he will stop eating and drinking. His wife is distressed about his decision. Your primary responsibility as his doctor is:*
 - a) To reassure his wife and provide counseling for her if needed
 - b) To ensure that Harry is adequately hydrated, using parenteral fluids
 - c) To support Harry's wishes**
 - d) To offer sedation to ensure his comfort
14. *Harry is being cared for at home during his last few days. His family / whanau is upset by his 'death rattle.' Repositioning the patient and comforting his family / whanau has failed to alleviate the situation. The drug of choice for managing his respiratory secretions is:*
 - a) lorazepam
 - b) morphine
 - c) hyoscine hydrobromide**
 - d) haloperidol
15. *You see Harry's wife two weeks after his death. Which of the following factors is most likely to indicate that she may need additional bereavement support?*
 - a) She has not cleared away any of his clothes as yet
 - b) She carries a photo of him and looks at it every few hours
 - c) She has fallen out with her daughter and has a poor network of friends / supports**
 - d) She starts to cry when you discuss her husband with her

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