

Beyond the randomised trial: *evidence and effectiveness in palliative care*

Report of a conference of the
Scottish Partnership for Palliative Care
10 September 2003

Scottish Partnership for Palliative Care

www.palliativecarescotland.org.uk

Contents

	page
Beyond the randomised trial: evidence and effectiveness in palliative care	3
Summary	
Chairman's welcome and opening remarks	5
Dr Derek Doyle OBE, Honorary President-elect of the Scottish Partnership for Palliative Care	
Evidence in medicine: the randomised control trial past, present and future	6
Professor Iain Crombie, Department of Epidemiology and Public Health, University of Dundee	
Effectiveness in palliative care: gathering the evidence	7
Professor Irene Higginson, Department of Palliative Care and Policy, King's College London	
Communication with patients when palliation is the goal	10
Professor Lesley Fallowfield, Cancer Research UK Psycho-social Oncology Group, Brighton & Sussex Medical School, University of Sussex	
Issues for Research Ethics Committees	12
Professor Patricia Peattie, Assistant Principal, Napier University and Chairman, Multi-centre Research Ethics Committee (B) for Scotland	
Out of Africa: contrasting end of life care in Scotland and Kenya	13
Dr Liz Grant, Research Fellow, Division of Community Health Sciences, University of Edinburgh and Dr Scott Murray, Senior Lecturer in General Practice, Division of Community Health Sciences, University of Edinburgh	
Workshop 1	
Identifying distress in people with communication difficulties	16
Lynn Gibson, Senior Physiotherapist and Dorothy Matthews, Senior Nurse, members of the Palliative Care Team led by Dr Claud Regnard at Northgate Hospital, Morpeth and St Oswald's Hospice	
Workshop 2	
Developing audit and evaluation in palliative care	17
Fiona Aspinall, Research Associate and Rhidian Hughes, Senior Research Fellow on behalf of the Project to improve the Management Of Terminal Illness (PROMOTE), Department of Palliative Care and Policy, King's College London	
Workshop 3	
Telling Tales: narrative analysis and palliative care	18
Dr Kirsty Boyd, Consultant in Palliative Medicine, Edinburgh Royal Infirmary and Dr Marilyn Kendall, Research Fellow Department of Community Health Sciences, University of Edinburgh	

Contents *(continued)*

	page
Workshop 4	19
Spiritual care in a largely secular NHS Dr Liz Grant, Research Fellow, Department of Community Health Sciences, University of Edinburgh	
Workshop 5	21
Qualitative research: how can we maximise its potential to improve our understanding of issues in palliative care? Carol Horne, Manager, Tak Tent Cancer Support and Professor Hazel Watson, Caledonian Nursing & Midwifery Research Centre, Glasgow Caledonian University	
Workshop 6	23
Complementary therapies in supportive and palliative care: developing evidence-based quality services Marianne Tavares, St Gemma's Hospice, Leeds (formerly Project Manager, Complementary Therapies in Palliative Care, The Prince of Wales's Foundation for Integrated Health)	
Workshop 7	24
An evidence-based approach to end of life care Dr Barbara Jack, Senior Research Fellow, and Lynne Jones, Macmillan Palliative Care Nurse Specialist, members of the Palliative Care Team led by Dr John Ellershaw at the Royal Liverpool Hospital	
Concluding remarks	27
Dr Derek Doyle OBE, Honorary President-elect of the Scottish Partnership for Palliative Care	

Beyond the randomised trial: evidence and effectiveness in palliative care

Introduction

The Scottish Partnership for Palliative Care's Annual Conference in Dunblane on 10 September 2003 attracted 190 delegates from Scotland and the UK. Those attending were given the opportunity, through a series of plenary and workshop sessions, to consider the many issues arising from the conference theme of evidence and effectiveness in palliative care. A series of keynote speakers outlined some of the issues for research and evidence-gathering in palliative care and workshop sessions were held in both the morning and afternoon to give delegates a further opportunity to learn and share experiences.

Conference Introduction

In his opening remarks the conference chairman, the Honorary President-elect, Dr Derek Doyle, challenged many of the present assumptions within the palliative care community. Although the service provided is highly regarded by patients, their carers and relatives, staff must not be complacent. There is a relative lack of evidence in palliative care when compared to other healthcare fields. If palliative care is to continue to be effective then greater evidence will be required to sustain and build upon existing good practice. It is a challenge that palliative care is well-placed to meet.

Keynote Speakers

The first keynote speaker of the morning was Professor Iain Crombie. He spoke of how the development through history of evidence-based medicine has led to the use of randomised control trials. These can be very useful research tools, though in some cases high quality cohort or 'observational' studies were felt to offer more value. A footnote to his message was that patients participating in randomised control trials generally receive a higher standard of treatment than is normally the case. This is mainly due to the higher levels of monitoring they receive.

Professor Irene Higginson talked next of the work involved in gathering the evidence required to assess the effectiveness of palliative care. The need for palliative care has now been demonstrated. The next step is to compile a comprehensive evidence base that will underpin future work, such as an education programme for all healthcare professionals in the principles of palliative care and how these should be applied to all fields of healthcare.

Professor Lesley Fallowfield introduced the key topic of communication with patients in palliative care. Doctors and Western culture in general have difficulty in communicating bad news. Research clearly shows that

patients prefer to be told the truth about their situation rather than cling to unrealistic hopes of what medicine and care can achieve for them. Professor Fallowfield put forward evidence to suggest that much of the current thinking in this area is misguided and in some cases detrimental to patient care.

Professor Patricia Peattie talked delegates through the role of Research Ethics Committees. Their main tasks are to protect the subjects of research and promote good research practice. These issues are especially relevant to the field of palliative care. The greater use made of qualitative research techniques and the need to tap into patient opinions illustrates how the correct ethical approach is fundamental to research in palliative care.

In the afternoon the conference shifted into new territory when Dr Liz Grant and Dr Scott Murray looked at the contrasting approaches to end-of-life care in Scotland and Kenya. This study reinforced the striking difference in approach, and especially inequality, in access to palliative care services in different parts of the world. Patients in Kenya will often die in great pain but patients in Scotland may have psycho-spiritual distress. We have much to learn from Kenya. While physical needs there often go unmet, the family, and the local and religious community can and do meet many psychological, social and spiritual end-of-life needs.

Workshops

This year the Partnership was able to offer delegates a choice from seven different workshops, held during sessions in both the morning and afternoon.

Workshop One was led by Lynn Gibson and Dorothy Matthews from Dr Claud Regnard's team at the Northgate Hospital, Morpeth and St Oswald's Hospice. They discussed how to understand and meet the needs of those patients with communication difficulties. By using the Disability Distress Assessment Tool (DisDAT) it is possible to track and recognise, document and monitor, signs of pain and distress in all patients with communication difficulties. It is also important to access the (unrecorded) skills that carers have developed in learning to communicate with their patients.

Workshop Two, delivered by Fiona Aspinall and Rhidian Hughes, assessed the application and benefits of audit and evaluation in the field of palliative care. Clinical audits depend on multidisciplinary working and are therefore particularly well-suited to the work of palliative care teams. Audits have been found to be a useful method for

improving services to meet the needs of service users (the patients), as well as indirect service users, such as their friends and families.

Workshop Three, by Dr Kirsty Boyd and Dr Marilyn Kendall, looked at the benefits of patient narrative analysis in the provision of palliative care services. This increasingly-used technique is a useful addition to the other means of conducting research, such as qualitative and quantitative studies. The main benefit of the narrative approach is that it allows patients to tell their story in their own way and not according to the structures imposed by a research study. The patient-centred approach of this research, or 'first-person analysis', also helps patients reaffirm their value as individuals and can enhance their experience of palliative care.

Workshop Four was led by Dr Liz Grant and Dr Scott Murray and looked at how spiritual distress, in its various forms, can have a profound affect on the quality of life of those facing death. Addressing patients' need for spiritual care may be an effective use of resources as spiritual distress can manifest itself as physical and psychological symptoms which may utilise considerable health resources. It is recognised that doctors and nurses who develop a positive relationship with patients inadvertently help to reduce spiritual distress.

Workshop Five, run by Professor Hazel Watson and Carol Horne, investigated the techniques of qualitative research and how they may be best applied to understanding and improving issues in palliative care. Qualitative analysis is generally conceptual. It is useful in that it can identify actual rather than reported behaviours and allow exploration of underlying reasons for behaviours or responses to quantitative studies, eg reasons for patient dissatisfaction. Ethical concerns are paramount. There will be many patients whom it is inappropriate to approach, and the continuing consent of those who do agree to participate must be sought at each stage of the research. Confidentiality and data protection issues must also be carefully addressed.

Workshop Six was led by Marianne Tavares. This workshop looked at the service and practice development of complementary therapies and discussed the issues that hindered or helped make these therapies available to patients. This was considered fundamental to the concept of patient choice. Many would support the integration of complementary therapies alongside mainstream healthcare services and think that a more robust system of regulation of therapists would help this process. At the same time there were concerns in some quarters that the structure of clinical governance could lead to unnecessary bureaucracy which could hinder innovation and the development of services. This workshop identified action across a number of areas where complementary therapies could become integrated, and therefore more widely available, within mainstream palliative care therapies.

Workshop Seven, by Dr Barbara Jack and Lynne Jones looked at the need for an evidence-based approach to end-of-life care. The example used was the Liverpool Integrated Care Pathway for the Dying Patient. Once implemented this procedure proved to be of long-term benefit to both the dying patient and staff. For example, it helped to:

- enhance care for patients
- increase job satisfaction for staff
- provide educational programmes for staff
- inform resource allocation
- provide data for audit work that will ultimately lead to long-term improvements in patient care.

Conference Close

In closing the conference the chairman emphasised that Scotland has the advantage of having a small and close-knit palliative care community where there is ample opportunity to share knowledge and work together. Dr Doyle thanked all delegates and the staff of the Scottish Partnership for Palliative Care for a most informative and stimulating day.

Chairman's welcome and opening remarks

Dr Derek Doyle, OBE, Honorary President-elect of the Scottish Partnership for Palliative Care

Introduction

Dr Derek Doyle, Honorary President-elect of the Scottish Partnership for Palliative Care, opened the conference by welcoming delegates and outlining the theme for the day. He indicated that the speakers and workshops would help guide participants through the issues around research in palliative care and the challenges involved in establishing an evidence base.

Evidence and research

"One of the privileges of my anecdotalism is being invited abroad to lecture and advise on key issues in palliative care. The commonest questions that I am asked, whether it be in Asia, Africa or Europe, are:

- is palliative care really needed?
- how do we know it is needed?
- how can we measure need?
- is palliative care effective and economically efficient?

These may seem obvious, even simple, questions but they go to the heart of our work.

How much of what we do and take for granted is well researched, evidence-based? I suggest to you that

palliative care is the least evidence-based discipline in medicine or nursing.

For example, we think that the non-steroidal anti-inflammatory drugs are effective for bone pain but there are no studies to prove this.

Is there a need for interdisciplinary teams? How big should they be? Are they as effective and efficient as we like to think?

We claim that palliative care calls for a high nurse:patient ratio but have we proved this?

And the management of spirituality is neither tested nor proved in the palliative care field.

Most of us here work in so-called specialist palliative care units or services but have we so assessed the needs of our patients that we can be sure they need 'specialist' as opposed to 'generic' palliative care? We must research. We must look beyond what we presently assume and take for granted. Because we receive many plaudits from patients, we must not fall into the trap of complacency and mutual congratulation.

Today we shall find we still have so much to learn."

Evidence in medicine: the randomised control trial past, present and future

Professor Iain Crombie, Department of Epidemiology and Public Health, University of Dundee

Summary

Evidence-based medicine is principally based on the findings from randomised control trials (RCTs). When these studies are well-designed and conducted they provide powerful evidence on effectiveness. Poorly conducted RCTs can mislead. However RCTs are not always feasible. In some circumstances high quality cohort studies ('observational studies') need to be used to provide evidence. The challenge is to ensure the quality of clinical studies by eliminating biases.

Evidence in medicine – a history

The history of medicine is richly endowed with therapies that were widely used and then shown to be ineffective or frankly toxic. Folk belief and mistaken theories have over time given way to the use of clinical evidence and RCTs.

Examples from the past include the 'stone of folly'. This stone was removed from the patient's skull thus removing the source of the patient's ills. In reality the itinerant stone cutter would insert a stone, held secretly in his hand, into the wound, extracting it with a flourish.

Popeye was famous for eating spinach. This dates to the 1890s and is based on chemical estimation of its iron content. This became important in World War II when spinach was aggressively marketed. Unfortunately, the Germans found a mistake had been made in the decimal point. There is no more iron in spinach than in any other green vegetable, yet the myth persists.

Theories played a prominent role in the development and justification of treatment and medicines. The four humours (earth, air, fire and water) is one example. Hippocrates' theory was that illness resulted from imbalance in these humours within the body. The solution was thought to be bloodletting, ie to remove enough blood to even the balance of the humours. This process could go on and on, even until the patient's death. The theory held that if the patient died then it was because sufficient fluid had not been let quickly enough. In the case of George Washington, four and a half quarts of blood (from a bodily total of six) were let by Benjamin Rush (Washington's well-intentioned doctor). George Washington died. In the present day, theories are employed more and more, for example in the fields of chemotherapy, removal of bone marrow, or removing part of the liver. There is a need to challenge theories and there is now a greater willingness to challenge the accepted wisdom.

In the bloodletting controversy the theory was challenged by Hughes Bennet from the University of Edinburgh. He was then hounded by his professional colleagues on the basis that there were hundreds of years of clinical observation to support its use such that it 'can't be wrong'. Yet, it was wrong. It was a harmful treatment propagated by the profession. Venesection was responsible for a fearful mortality. Thus, we see that clinical experience may not be enough.

The last 300-400 years witnessed the use of experimentation together with clinical observation to develop new treatments. At a so-called 'inhalation party', a friend of Horace Wells inhaled so much nitrous oxide that he fell down a flight of stairs but felt no pain. Wells recognised the effect of anaesthesia. He announced it to the world at a public demonstration in 1844 at Massachusetts General Hospital. Unfortunately, he waited so long that the anaesthetic had worn off and the patient screamed in pain: Wells faced ignominy. Experimentation with anaesthesia was continued by William Morton, who used it successfully to perform the first public operation on a twenty-year old patient with a congenital vascular condition. Shortly afterwards, the whole world accepted anaesthesia. This was one of the quickest acceptances of a therapy worldwide.

Advent of the randomised control trial (RCT)

Tuberculosis (TB) was a feared disease for which many ineffective therapies were hazarded. In the early twentieth century treatments such as heliotherapy (exposure to sunlight) and bed rest were commonly used. However, the discovery of penicillin before World War II, and the development of streptomycin during wartime, led to streptomycin being tested on TB. Austin Bradford Hill tested it against an (untreated) control group. He only had enough supply for 55 people, so he included 110 in the study and assigned the treatment randomly; this meant that all that could receive treatment (ie 55) would. The statistics showed the treatment to be effective (with only 7% of the treated group dying within 6 months, compared with 27% of the control group). Hill's idea of the RCT was thus accepted into medicine. The random nature of this process, like the tossing of a coin, avoided the need to choose which patients received which therapy. This permitted fair comparisons to be made between therapies. Chance decided who would actually receive the treatment.

There was still resistance to the RCT for some time

thereafter, but RCTs are now the broadly accepted 'gold standard' method of assessing effectiveness. Randomised control trials remain the most scientifically sound and ethically correct means of evaluating therapies.

Limitations of the randomised control trial

But the search for evidence on effectiveness still faces challenges. Concerns about the quality of many RCTs have been raised. Applicability is also an issue, as most trials are undertaken in teaching hospitals on patients under the age of 65 years, where co-morbidities are excluded. Given that most patients are not typical of these categories, is it reasonable to extrapolate?

Some topics are also problematic. For example, RCTs are not practical in cases involving rare events, or long-term outcomes. The process of randomisation can be problematic when the intervention being tested is an aspect of service organisation for example, nurse:patient ratio.

The solution to these limitations lies in observational studies conducted in real clinical settings. For example, we can observe the effects of settings such as a high nurse:patient ratio contrasted with those of a lower ratio. Large databases enable these studies to be managed. Observational studies were promoted heavily in the USA in the 1970s and 1980s, but are now less popular. The potential problems lie in:

- patient selection - because fitter patients get the new treatment, the comparison will seem better
- patient care - because of the special treatment that patients receive, a new therapy will usually do better than upon the general patient population

- patient behaviour - because a patient is being treated well, they will usually adhere more to treatment, therefore producing a better overall effect
- observer bias
- service changes - as the NHS is always changing, apparent changes in patient outcome may really be due to changes in staffing and referral procedures.

In summing up, good RCTs provide the best evidence on effectiveness. Poor RCTs can mislead. However, RCTs are not always feasible. In these cases, high quality cohort studies ('observational studies') may be a suitable alternative. As yet, we do not know. But, when we pay real attention to the *quality* of clinical studies (ie by eliminating biases) we will get meaningful answers. The way forward is to use observational studies alongside RCTs.

Question: Does this mean then that patients should enter RCTs because they get better treatment?

Answer: The evidence of this is quite compelling: ancillary care, and monitoring in general, is simply better. If there is a choice, patients might want to participate but this depends on the potential for harm accruing from that intervention/therapy. Certainly, not enough patients are being put into RCTs, and consultants are encouraged to put patients into trials. By the 1980s thousands of patients were involved in RCTs. We need large studies to be able to identify modest but clinically beneficial therapies. The reality in medicine is that most new therapies will provide only modest improvements. It is by many small steps that we will obtain improvements in treatment.

Effectiveness in palliative care: gathering the evidence

Professor Irene J Higginson, Department of Palliative Care and Policy, King's College London

Summary

Palliative care provision varies widely, and the effectiveness of palliative and hospice care teams has long been unproven. However, this study now provides quantitative evidence of the effectiveness of palliative care teams, and it has been published in the UK NICE guidance and in the Journal of Pain and Symptom Management.

Meta-synthesis of all studies carried out to date has found wide variations in the type of service delivered by each team. There was no discernible difference in outcomes between urban and rural areas. Judging effectiveness in terms of the benefit that the patient received, this review found that most evidence related to home care.

A substantial amount of work is required to build a

comprehensive evidence-base for research in palliative care. This includes developing better methods of researching effectiveness, for example, using the MRC Framework for the Evaluation of Complex Interventions. It will be needed to underpin the education programme required for educating healthcare professionals in the principles of basic and advanced practice in palliative care.

Introduction

Palliative care is a relatively new discipline and as a result there is only a limited amount of evidence of practice available. Palliative care provision varies widely and, because of the lack of evidence, the effectiveness of palliative and hospice care teams remains unproven. The lack of evidence causes many difficulties, not the least of

which is the fact that we lack the means for presenting our case to policy makers, in the search for resources etc. In order to address this problem we need to look towards three key areas in which evidence might exist. These are:

- the huge amount of need and problems which arise when care is NOT effective
- assessing the importance of palliative care for patients and families (and society) in comparison to other healthcare priorities
- identifying effective solutions to problems that have been identified.

Evidence of need and meeting this need effectively

We know there is a significant unmet need for palliative care services, but we have not found an effective solution to this problem yet. We can use two methods to determine the effectiveness of palliative care. These are original research and systematic literature reviews

Systematic literature reviews

Systematic literature reviews allow us to locate, appraise and synthesise evidence from scientific studies in order to obtain a reliable overview of the available evidence. This can be used to determine whether a therapy or service works. It can also be used to produce the research evidence to describe a problem and potential solutions.

Methods used for systematic literature reviews include searching through electronic databases and unpublished literature. The literature reviews could include:

- evaluating interventions relevant to the topic
- randomised clinical trials (RCT)
- cost-benefit analyses (CBA)
- interrupted time studies (ITS)
- observational studies.

These will allow research to cover a wider area than is permitted through the traditional 'Cochrane' review. Other methods for systematic reviews are the extraction of standard data, grade studies, and the comparison and contrasting of data.

Research findings

Systematic review of different models of palliative care teams¹⁻⁵ was conducted by the Department of Palliative Care and Policy at King's College London in collaboration with colleagues at the University of Wales College of Medicine, and the London School of Hygiene and Tropical Medicine. It included reviewing ten databases and extensive unpublished literature. It is crucial that the research team has some training and experience in palliative care. Existing studies are graded three ways, their design is assessed in two ways and the other assessment is in terms of the study's relevance.

Results have shown that out of 44 studies, the 'effect size' (standardising change on one scale) could be calculated for 30 of the studies⁵. The 44 studies included 22 home care teams, nine hospital-based teams, four combined

home care and hospital teams, three in-patient units, six integrated home care and inpatients. One of the main problems we came across was that the study designs were poor (with few RCTs and most studies being of grade III). In some cases studies had failed to collect data because unfortunately the patients had died.

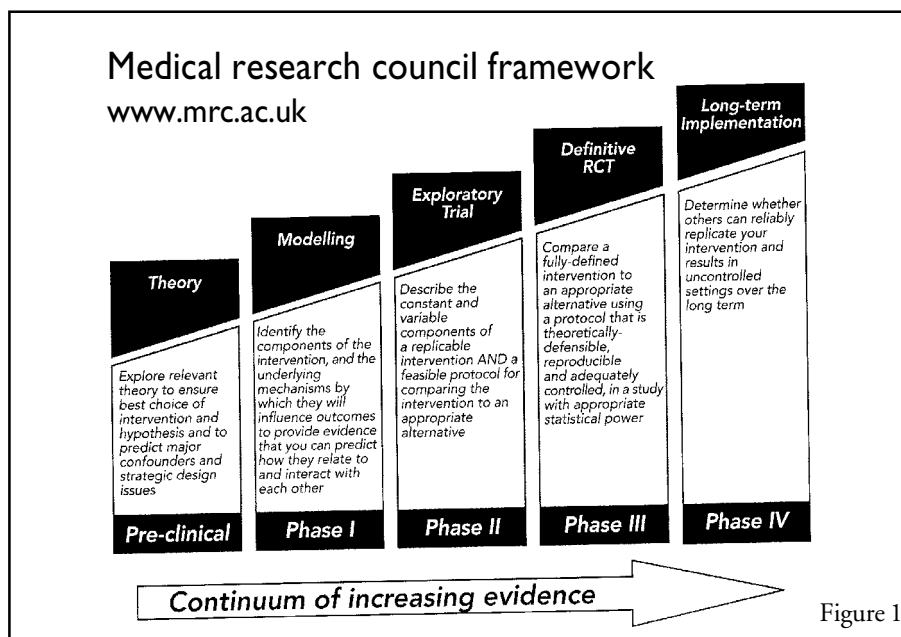
Evidence of effectiveness was shown by using different service models, for example service models for inpatient hospice, home care, hospital team, day care and a mixed evaluation of these components. There were nine hospital-based studies using specific hospital teams along with four mixed services in large teaching hospitals, using mixed areas⁴. Most studies were undertaken in the UK using one RCT, the rest being observational. Existing types of service vary between countries, ie in terms of staff, skill mix and work practices. There was evidence of improvement in some areas and meta-analysis was possible for some of the studies. The range of outcomes was assessed, including symptoms, quality of life, place of care and satisfaction. In summary there is some evidence of effectiveness and there is no evidence of harm.

The studies revealed a few problems, eg definition of the intervention, services being developed without evaluation or adequate descriptions, a lack of comparison within or between services, or between outcomes for different groups of people. Another issue was the lack of understanding of the changing trajectory of care and experience for patients. Are there geographical differences in terms of the quality of care received? Measuring outcomes can also be problematic. How does one judge quality of life, quality of death, experience, and satisfaction when these are very individual, subjective characteristics? RCTs are of some value when differences cannot be distinguished easily. But there is still a need for a more systematic review of the qualitative aspects that are important to patients and families, and of qualitative studies. The PROMOTE project (Project to impROve the Management Of Terminal IllnEss) in the Department of Palliative Care and Policy at King's is going some way towards addressing this problem.

The quality of expectation and disappointment varies. A paper published by the Royal School of Medicine shows that 35 out of 55 patients with likely advanced cancer in an oncology centre expected 'healing'. The quality of life ratings dropped most rapidly in 15 of these 35 patients whose 'healing' expectation was not fulfilled. Optimists have better coping strategies than pessimists⁶.

Conclusions and future work

The evidence to date does support specialist palliative care. This evidence has been used in the National Institute of Clinical Excellence guidance on supportive and palliative care⁷. This has resulted in improved funding for services. From the analysis of existing research it is recommended that work is undertaken to improve the design of many research studies. More work is required on making effective comparisons, the reason for interventions and analysis of outcomes from the



interventions (eg pain and symptoms). In addition, there is not enough evidence available at present to distinguish between the benefits and effectiveness of intermediate and specialist palliative care, and whether there is an issue of differing service provision in rural and urban areas. Some models of care have still to be considered and evaluated.

The framework for future evidence using research to both develop and evaluate services builds on the existing Medical Research Council framework (figure one) for the evaluation of complex interventions, which uses both qualitative and quantitative data methods. The Medical Research Council framework maps onto the traditional process of clinical trials for developing services, beginning with the pre-clinical stage and carrying on through to phase II stage. The Department of Palliative Care and Policy is using this framework in two studies. The first to develop and evaluate a new short term support group for carers^{8,9}, and the second for a new service for people with advanced multiple sclerosis.

The model for future evaluations of effectiveness in developing theory should include evidence of need, user reports, parallel studies and modelling services. The next stage is to evaluate the various ways of providing care, ie analysing activity, auditing, developing methods for evaluation and producing data. The final stage of improving evidence is developing expertise in comparative evaluation, of different solutions, and what is generally found to work for each set of patients in each care setting and at each stage of their illness. These elements should always be part of the development of any service.

Future work should aim to include substantial research and education, eg longitudinal studies of patients' wishes and experience. There is also benefit in comparison against 'current best practice' and assessing the effectiveness of individual therapies and treatments.

In many areas of palliative care 'need' has been demonstrated. Studies that examine only 'need' are perhaps now unethical in the sense that energies should be focused upon improving effectiveness and sharing best practice. There ought now to be a process of funding research into testing ways of meeting that need¹⁰.

References:

1. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AGK, Hood K et al. (2002; 13:257-264) *Palliative care in hospital, hospice, at home: results from a systematic review*. *Annals of Oncology*.
2. Goodwin DM, Higginson IJ, Edwards AGK, Finlay IG, Cook AM, Douglas H-R et al. (2002; 18:77-83) *An evaluation of systematic reviews of palliative care services*. *Journal of Palliative Care*.
3. Higginson IJ, Finlay IG, Goodwin DM, Cook AM, Edwards AGK, Hood K, Douglas HR and Normand CE (2000; 1-191) *Evaluation of effectiveness and cost-effectiveness of palliative care teams - a systematic review*. Wales Office for Research & Development (WORD), Cardiff.
4. Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AGK et al. (2002; 23:96-106) *Do hospital-based palliative teams improve care for patients or families at the end of life?* *Journal of Pain and Symptom Management*.
5. Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AGK, Cook A et al. (2003; 25:150-168) *Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers?* *Journal of Pain and Symptom Management*.
6. Koller M, Lorenz W, Wagner K, Keil A, Trott D, Engenhardt-Cabillic R et al. (2000; 93:621-628) *Expectations and quality of life of cancer patients undergoing radiotherapy*. *Journal of the Royal Society of Medicine*.
7. Department of Palliative Care and Policy (2004). www.kcl.ac.uk/palliative.
8. Harding R & Higginson IJ (2003; 17:63-74) *What is the best way to help caregivers in cancer and palliative care?* *Palliative Medicine*.
9. Harding R, Higginson IJ, Leam C, Donaldson N, Pearce A, George R et al. (2004; 27:396-408) *Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service*. *Journal of Pain and Symptom Management*.
10. Higginson IJ (2004; 18:85-6) *It would be NICE to have more evidence?* *Palliative Medicine*.

Website: www.kcl.ac.uk/palliative

Communication with patients when palliation is the goal

Professor Lesley Fallowfield, Cancer Research UK Psycho-social Oncology Group, Brighton and Sussex Medical School, University of Sussex

Summary

Healthcare workers often try to protect patients from bad news. But, research has shown that this can be counter-productive. The patient can prepare for death and deal with the issue better if they know what they are facing. Western culture prefers to deny death so discussion of this is often put off until the last moment. Some healthcare professionals and patients harbour unrealistic hopes about the likely therapeutic benefits of some medicines, preventing adaptation and focus on genuinely obtainable goals.

Introduction

The Cancer Research UK Psychosocial Oncology Group has undertaken a major six-year study of oncologists and patients throughout the UK. Scotland has been represented in this as doctors from the Edinburgh and Glasgow Cancer Centres and their patients contributed to the study¹.

Healthcare professionals censor information, usually in an attempt to 'protect' patients from sad and bad news. This well-intentioned, but misguided, action stems from the notion that what someone does not know will not hurt them, but the reverse is actually true. Censoring happens at all stages of the disease trajectory and may reflect a lack of awareness about 'harm' and differences in cultural expectations. Studies world wide on the information needs of patients usually find similar results.

There are five main reasons why healthcare professionals do not think it best to be truthful with the patient when discussing prognosis. These are:

- the belief that patients will ask if they wish to know
- the belief that patients will experience unnecessary emotional distress
- the belief that patients will lose hope
- the belief that patients will not enjoy the time that they have left
- the difficulty in predicting the outcome with accuracy.

Patients will ask if they wish to know

Many healthcare professionals assert that **patients will ask if they wish to know**. However, the evidence shows that:

- many patients assume that doctors will tell them all they need to know
- we still live in a deferential society, the effect being

that only brave patients will actually ask for an explanation

- people are often too scared to ask or do not know what they need to ask
- patients may wish to make things easier for the staff, whom they sense are uncomfortable with the issue of death
- healthcare professionals are skilled at deflecting oblique enquiries made by anxious patients.

How do we know patients need more information?

Our study compared the information needs of patients who were receiving potentially curative treatment and those receiving palliative care². The questionnaire was given to patients prior to seeing their doctor. Of these two groups only 7.8% of the palliative group, and 7.1% of the non-palliative group, wanted the degree of information given to be left to the doctor. Again, only 7.3% of palliative and 3.9% of non-palliative patients wanted additional news to be given only if it was 'good'. Rather, the overwhelming majority wanted as much information as possible (85% of the palliative group and 89% of the non-palliative group). Yet, for most, their desires were not met during their meeting with the doctor.

The specific information preferences in this study show very little difference between the palliative and non-palliative groups in terms of their need-to-know diagnosis (especially to know whether they have cancer), progress, chances of cure, and all possible treatments and side-effects. Often this need-to-know is not met. Therefore, we might ask why are doctors often not meeting these needs? Essentially, this is because of culture.

In Western cultures the tendency to deny death applies not just to patients. Both healthcare professionals and patients often harbour unrealistic expectations about the likely therapeutic benefits of modern medicine. We all need to believe in the same magic and miracles. But we get trapped into 'doing something' behaviours as a result, instead of the honest but painful conversations that are needed.

Research shows that doctors do not much like having these conversations with people². In one survey, 2,807 doctors were asked to score their satisfaction with their consultations immediately after the patients left the room. The mean scores were found to be significantly lower when palliation was discussed, which has some difficult implications. Often the outcome for many of the common solid tumours is not promising, thus an oncologist should be a palliative care physician as well because these

difficult discussions will form a large amount of their work.

We looked at a variety of things in the study, one being doctors' self-confidence in handling transitions from curative to palliative treatment. It is clear that doctors' confidence starts to fall when patients have a recurrence, and confidence then reduces further when active therapy is replaced with symptomatic care only. As healthcare professionals we do not like handling this transition; we are not confident at doing it, yet it constitutes the bulk of our consultations. We therefore need to hone our skills in these areas.

The researchers also noticed from videotaped consultations that, when uncomfortable, healthcare professionals delve into ambiguity. Some of this ambiguity is unintentional. A recent paper considered the lay population's understanding of terminology during oncology consultations³. Communication in this context is problematic because many words have opposing meanings in medical and lay terms; words such as cancer is *progressing* can mislead patients into thinking that all is well. Words such as *progressing, positive and negative nodes*, have the opposite meaning when used in the medical context. Studies show some gross misperceptions between what is said and what is heard. Some misleading terminology is deliberate. Non-verbal accompaniments give important clues to patients.

The patient will experience emotional distress

I find intriguing the argument offered (against truth telling) that the 'patient will experience emotional distress'. People do not live in a dichotomous state of blissful ignorance or overwhelming distress dependent on the level of awareness about their condition. Moreover, studies show that more psychological harm accrues from evasion than from sensitive, honest disclosure. However, patients receiving palliative care do have high rates of psychological morbidity, and much of this goes unrecognised and therefore untreated. From video evaluation it is clear that many healthcare professionals lack effective communication skills that would help them to elicit psychosocial problems. Research by Ramirez also indicates that some doctors have similar GHQ (General Health Questionnaire) scores to patients!⁴ This makes empathic communication difficult, as the doctors' own stresses inhibit them offering an appropriate response to patients.

The patient will lose hope

The idea that the patient will lose hope might be true if their hope is centred solely on obtaining a cure. But, this is not what we should encourage patients to base their hopes around. Considerable collusion can take place surrounding mythical hopes and dreams. Such preservation of unrealistic hope prevents energies being directed towards attaining realistically achievable goals and hopes. I believe it is unethical to encourage physically weak and exhausted patients to keep fighting for an implausible outcome – we must question our

involvement in this encouragement.

The patient will not enjoy the time left

The argument that the patient will not enjoy the time left (if we tell them the truth) facilitates a false hope or false happiness. Sustaining a lie, or colluding with carers/loved ones to do so, depletes valuable emotional and physical resources. Moreover, worry due to lack of information, uncertainty and unexpressed fears about what lies ahead is the approach that consumes time and prohibits a patient's enjoyment of their remaining time.

Difficulties of predicting outcome accurately

In terms of the difficulties of predicting outcome accurately, it is possible to make some estimate and it is our clinical responsibility to impart information sensitively to patients. It is extraordinary that specialist doctors and nurses trained in oncology or palliative care seem so unwilling to discuss prognosis. Yet, these same doctors (who are not trained in psychology or psychiatry) seem very sure that they can predict the informational needs and likely emotional outcome of open disclosure to patients. Hence, we shirk the one thing that we should be able to do well – and I am not the only one to notice this.

Many studies have shown predictions of prognosis to be wildly inaccurate (eg Parkes 1972)⁵ but 90% of inaccurate predictions are in the overly optimistic direction. This contrasts with chance/random inaccuracy, which we might expect to generate 50% as optimistic and 50% as pessimistic. The latter does not happen because of our collusion in information delivery. Moreover, an interesting piece of research by Christakis suggests that, when a doctor knows his/her patient well, this heightens the likelihood of overestimating the patient's survival⁶. While we are all seeking a better therapeutic relationship with patients, this can lead to over-optimism, even hoping against hope.

Disclosure has two discreet elements. The Hippocratic Oath originally talked of foreseeing and foretelling. Foreseeing is our unexpressed cognitive estimate/prediction about survival. This is based on data, onto which we are often inclined to impose our own (optimistic) hopes. 'Foretelling' concerns our communication about this to the patient, which we know can be subject to conscious and accidental ambiguity or even deliberate evasion. From these two elements patients may become unwittingly twice removed from the truth of their illness (Lamont and Christakis, 1999)⁷

Conclusion

Certain side-effects flow from dishonesty. It is very difficult to maintain a lie and all members of a healthcare team need to remember what has been told to the patient. These inherent difficulties mean that the truth may be revealed in an unplanned way, without appropriate support and information. Hence, the patient then loses trust and becomes isolated. There are very few situations in which we should ever tell the relatives but not the patient.

I always try to tell the truth. As Mark Twain once said: "if you always tell the truth you never have to remember anything!"

References:

1. Fallowfield L, Jenkins V, Farewell V et al. (2002; **359**:650-656) *Efficacy of a Cancer Research UK communication skills model: a randomised controlled trial.* Lancet.
2. Fallowfield L, Jenkins V and Beveridge H. (2002; **16**:297-303) *Truth may hurt but deceit hurts more: communication in palliative care.* Palliative Medicine.
3. Chapman K, Abraham C, Jenkins V et al. (2003; **12**:557-566) *Lay understanding of terms used in cancer consultations.* Psycho-oncology.

4. Ramirez AJ, Graham J, Richards MA et al. (1995; **71**:1263-1269) *Burnout and psychiatric disorder among cancer clinicians.* British Journal of Cancer.
5. Parkes CM (1972; **2**:29-31) *Accuracy of predictions of survival in later stages of cancer.* British Medical Journal.
6. Christakis NA, Lamont EB (2000; **320**:469-472) *Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study.* British Medical Journal.
7. Lamont EB, Christakis NA (1999; **13**:1165-1170; discussion 11724; 1179-80) *Some elements of prognosis in terminal cancer.* Oncology (Huntington's)

Issues for Research Ethics Committees

Professor Patricia Peattie, Assistant Principal, Napier University and Chairman, Multi-centre Research Ethics Committee (B) for Scotland

Summary

Research Ethics Committees (RECs) have a useful role to play, especially in terms of protecting the subjects involved in the research and in promoting good research practice. Researchers are advised to note the requirements of RECs before submitting a research proposal. Some useful advice on the procedures to follow is outlined below.

Professor Peattie talked delegates through the role of ethics committees. Their tasks to protect the subjects of research and promote good research practice are issues especially relevant to the field of palliative care. The greater use made of qualitative research techniques and the need to tap into patient opinions reinforce how the correct ethical approach is fundamental to research in palliative care.

Introduction

For many years the NHS has had the benefit of a generally high standard of advice from its RECs. Local Research Ethics Committees (LRECs) were formally established in Scotland in 1992 and the first Multi-Centre Research Ethics Committee (MREC) in 1997-1998. There are now two MRECs in Scotland.

The role of research ethics committees are twofold. Firstly, they protect the subjects and secondly they promote good research practice.

Protecting subjects: methodology

RECs are convened to provide independent advice to participants, researchers, funding bodies, sponsors, employers, care organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards. The purpose of a REC in reviewing a proposed study is to protect the dignity, rights, safety and well-being of all actual or potential research subjects. Before any research can be undertaken

approval must be obtained from a REC.

RECs are responsible for acting primarily in the interest of potential research participants, but they should also take into account the interests, needs and safety of researchers who are trying to undertake research of good quality.

In assessing a research proposal RECs will ask a number of key questions:

- whether or not this research needs to be done, eg has the research been done already?
- are the stated objectives and methodology for the research clear?
- is the timescale realistic?
- does the research represent 'value for money'?
- are the project's objectives likely to be met?

In terms of research methodology the selection of a method that is biased, or would not answer the question, is putting subjects at risk unnecessarily, and is therefore unethical. So the REC needs to assess whether the methodology is appropriate and whether the research team is competent to undertake the research. Since many of the REC members are lay people the research proposal needs to be completed in straightforward language free of jargon etc.

In the palliative care field, it may well be that qualitative research methods are appropriate, but they are very hard to describe, and it is often difficult to provide specific details of how interviews/questions might evolve (for example using grounded theory or Delphi techniques). There is much more personal interaction between subject and researcher, and skills/biases are much more dependent on the competence the individual research practitioner has with the methodology. These are difficult things for RECs to assess, and indeed particularly for some members whose research grounding lies in the more quantifiable results of RCTs.

Another key question is access to subjects and/or their records. Not only must the Committee be satisfied that this is done via their treating clinical team, so that confidentiality and data protection issues are not breached, but it must also be clear to the subjects why they have been contacted by the researcher. The research question, if it involves drug trials, must also address matters of valid comparators, justify the use of placebo, clarify what alternatives there might be (including not having treatment at all) and specifically address the question of rescue medication, especially for placebo trials.

Protecting subjects: risk

Once the Committee is satisfied that the methodology is appropriate, it can turn its attention to risk issues. It may ask:

- what are the risks of the new treatment?
- how likely are these risks, and how serious would be the outcomes?
- why is previous treatment, especially if effective, being withdrawn?
- are additional investigations or expectations being placed upon the patient and how reasonable or realistic are these?
- if there are controls, are the patients being subjected to acceptable degrees of risk? And are there any published criteria or guidelines which help determine this, eg if patients are being subjected to irradiation?

It is not for the Committee to prevent subjects being exposed to *any* risk, but it is important that the patient is aware of risks and that these risks are being taken on ethical grounds, ie to help find solutions to problems that cannot be approached in any (safer) way.

Protecting subjects: communication

Having satisfied itself from the subject's perspective on both the methodology and the risk factors, the final aspect is the communication with subjects. By far the most frequent reason for seeking changes prior to approval is

the failure of researchers to write clear participant information sheets. These sheets contain all the required material that will enable the research subject to provide informed consent. When patients are invited to participate in research they must be informed that if they decline the opportunity to participate in the research this will not adversely affect how they will be treated. Subjects should be very clear what is involved, what the risks are, and why they might be suitable to participate.

Promoting good research: methodology

In promoting good research, much of what has been said above also applies. But it is in this consideration that the REC needs to carefully consider the reliability (statistically or otherwise) of any findings, ie:

- are the data collection and sampling approaches reliable and valid?
- how is anonymity being protected and bias avoided?

Research ethics and palliative care

Are there particular issues in the palliative care field that require special consideration by a REC? Probably not. In palliative care there is a preference for using qualitative research techniques, which would make time management and the need for sensitivity when dealing with patients even more critical. But none of these issues are unique to such patients, and a REC would ask itself questions on these points in all cases. Greater care may be required in designing patient information sheets for patients receiving palliative care. Researchers will need to be cautious about promoting the benefits of any research or drugs and thus giving unreasonable hope to patients. Effort must be made at all costs to avoid the possibility of adding to an already distressing situation for the individual, his family and friends.

If all the above points are taken into account, ie that participant information sheets are carefully devised, subjects are given the opportunity to make up their own mind on the basis of clear information and REC members are satisfied on all points, then the research proposal should receive ethical approval.

Out of Africa: contrasting end of life care in Scotland and Kenya

Dr Liz Grant, Research Fellow, Division of Community Health Sciences, University of Edinburgh and Dr Scott Murray, Senior Lecturer in General Practice, Division of Community Health Sciences, University of Edinburgh

Summary

From this study it has become even clearer that there are striking differences and inequalities between palliative care provision in a developed country and that in a developing country.

In Scotland the main issue is facing the prospect of death, whilst in Kenya the main issue is physical suffering and unrelieved pain. In Scotland the presence of services, treatments and analgesia cannot by themselves guarantee a 'good death'. Many patients in Scotland have unmet spiritual and existential needs.

There is much for Scotland to learn from developing countries about community sharing and meeting of spiritual needs. Greater acceptance of death, rather than seeing death as a medical failure, appears to help people cope with illness and death. Comparing patients' experiences and provision of care in contrasting cultural settings can highlight gaps in local frameworks of cancer care.

Introduction

This presentation sought to bring an international perspective to palliative care and it summarised an article published recently in the *British Medical Journal*. The research team comprised two groups of researchers, one based in Edinburgh, Scotland and the other in Chogoria Hospital, Kenya.

In developing countries there are many deaths from cancer. In these countries 5 million people die of cancer each year. Health services are struggling with population increases, under-funding, civil wars, the HIV pandemic and natural disasters. Hence, healthcare for the dying has a low priority compared to preventive and curative services. In Scotland, in contrast cancer is a priority and services are reasonably well developed.

This presentation examined and compared the illness experience, holistic needs and service utilisation of two groups of patients with incurable cancer, one in a developed country and the other in a developing country. It highlighted the differing inequalities in end-of-life care.

Background

In Scotland, as people are well aware, there is free access to primary and secondary healthcare and a comprehensive social security system. Running water and adequate food are taken for granted.

In South Meru, Kenya, many people live on less than \$1 a day. All health facilities, whether run by the government, church or private organisations, charge fees for their services. There are also traditional cultural restrictions on care-giving. There remains a latent, traditional fear of death occurring at home.

Research procedure

For the purposes of this study, in Scotland respiratory medicine consultants identified out-patients with inoperable lung cancer when returning for bronchoscopy results. In Chogoria Hospital, Kenya (the main health service provider in the region) doctors identified patients with a wide variety of cancers which were common locally, such as gastric, cervical and breast (lung cancer is less common in Kenya).

In Scotland, research took the form of an ongoing serial study. In-depth interviews were conducted at three-monthly intervals for up to a year, with 20 patients and their main informal carer in the patient's home. In Kenya, in-depth single interviews were undertaken using a semi-

structured interview schedule with 24 patients and 22 carers. The interviews were carried out in the local language, Kimeru. At both sites the qualitative package 'Nvivo' was used. Transcripts and field notes were checked and coded by two experienced researchers.

Research findings – patient attitudes

In Scotland patients were predominantly concerned with the *prospect* of death. Patients swung from periods of (mostly unrealistic) hope to deep despair. Stoicism was also common, eg 'the only thing is to try and lead an ordinary day', 'I just keep that to myself' etc. Patients often felt unable to share their distress with family, friends or professionals. During radiotherapy and chemotherapy, regular hospital visits dominated the lives of both patients and carers, giving support and hope. However, patients had to deal with side-effects of the treatment.

In Kenya, severity and constancy of pain dominated the disease journeys of all patients that we interviewed. Lack of money to buy analgesia and lack of money to pay for hospital services were constant issues. Patients accepted the prognosis they were given by doctors and the community's acceptance of the inevitability of death made it easier to bear. *'Death is a path we all must tread'* (Mrs GA). Religious beliefs provided a framework for understanding and coping with illness. *'God comforts me; my heart calms down when I remember this and I get emotional support'* (Mrs GA). A diagnosis of cancer ended searching for a cure, and signalled a time of preparation and waiting rather than intensive treatment. Patients frequently felt that they were a physical and financial burden to their family. *'Money is being spent on me instead of school fees'* (Mr JB).

Research findings – healthcare support

Patients in Scotland had access to support and effective analgesia at home through community care. Specialist services also offered support at home and some patients accessed day care facilities and hospice admission.

In Kenya, medical, nursing and social services were not available at home. Most homes were not suitable for home care, with no running water, indoor toilets, electricity, nor easy access to gloves or dressings. Specific local traditions prohibited families from some aspects of caring. *'There are parts of the body that you cannot show to your family members. There are some people who should not touch you'* (Mr BC). Voluntary groups such as church fellowships visited patients regularly, singing and praying for the person, and carrying small essential gifts such as food or soap.

Conclusion

Though living in a resource rich country with cancer a national priority, Scottish patients described unmet psycho-spiritual needs. Meeting of physical needs did not alone ensure a good death. In developing countries, while physical needs often go unmet, the family, and the local and religious community can and do meet many of the psychological, social and spiritual end-of-life needs. In the

West, the palliative care movement has succeeded in improving pain control. There is now an opportunity and an imperative to assist developing countries to do likewise. For end-of-life care to be humane, an analgesic “ladder” must be available and affordable. Flexible methods of essential drug dispensing, distribution, and payment should be developed, which recognise patient poverty. Pain relief for the dying should not be a luxury only for rich countries. However, the exchange of information and help can be two ways. The movement in the West can learn from developing countries about community involvement, health promoting end-of-life care, and the meeting of spiritual needs.

Question: There is a lot of physical suffering in Kenya which the UK has only in degree. However, the suicide rate in the UK in cancer patients is relatively low – how is that rate in Kenya?

Answer: Islamic/Christian beliefs are very strong, therefore even if they want to kill themselves they ‘cannot’ as they are prohibited by beliefs – hence the suicide rate is very low.

Question: You said that in Kenya there is a fear of

patients dying at home – could you help us to understand that?

Answer: Traditionally, tribal groups brought the dying person from their home into uncultivated forest area where hyenas eat the body (as death was seen as a curse bringing contamination to the whole village – if a person dies at home their hut would then be burned). In the past a spouse would go through a 3-month ritual purification. There is still a fear of death bringing contamination, and the dying may be brought to hospital at the point of death.

Today, while the dying are no longer taken out into uncultivated areas there still remains a latent fear of death. Many feel it is better for a relative to die outside the family home in a hospital ward. Alongside this wish there is also the practical issue that mortuary access is more easily arranged from a ward, than from home. It still remains important for the extended family to attend the funeral of a relative and as the family are now often geographically scattered there can be a significant time delay between death and burial, making mortuary storage essential. There is also a fear of the ‘last gasp’ (as in the UK).

Outline comparison between the two patient groups:

Edinburgh, Scotland

- main issue is **the prospect of death**
- pain unusual
- anger in the face of illness
- “just keep it to myself”
- spiritual needs evident
- diagnosis brought active treatment, then a period of watching and waiting
- patients concerned about how carer will cope in the future
- support from hospital and primary care team
- specialist palliative care services available in hospital, hospice and at home
- cancer a national priority in Scotland

Chogoria, Kenya

- main issue is **physical suffering, especially pain**
- analgesia unaffordable
- acceptance rather than anger
- acceptance of community support
- patients comforted and inspired by belief in God
- diagnosis signalled waiting for death
- patients concerned about being a present physical and financial burden to their family
- lack of medical support, treatment options, equipment, and basic necessities
- specialist palliative care services not available in the community
- cancer not a national priority in Kenya

Workshop I:

Identifying distress in people with communication difficulties

Lynn Gibson, Senior Physiotherapist and Dorothy Matthews, Senior Nurse, members of the Palliative Care Team led by Dr Claud Regnard at Northgate Hospital, Morpeth and St Oswald's Hospice

Workshop summary

This workshop covered ground that has been neglected in research terms. Lack of understanding, poor documentation and changes in staff can all lead to breakdowns in communication between staff and patients with communication difficulties. These issues can be addressed with the help of the Disability Distress Assessment Tool (DisDAT), a documentation / scoring tool that was developed for patients with learning disabilities. It can be used to track signs of distress in all patients with communication difficulties, eg those other patients who have no formal speech but use alternative methods such as gesture and those whose ability to communicate has been affected by their illness. The key is to establish a baseline of the patient's usual methods of communication when content, enabling staff and carers to use their existing skills in identifying distress and then documenting it, thus making something implicit explicit.

Introduction

There has been insufficient research into distress amongst people with communication difficulties. Patients could be experiencing these difficulties for a variety or combination of reasons. They may have a profound learning disability, a condition that has affected their speech (eg multiple sclerosis, stroke etc) or they may be in such a weakened state that they suffer hearing loss, fear, anxiety, confusion, disorientation, grief etc.

Carers have lacked the means of articulating their intuitive sense that the person concerned has an unmet need. The difficulty in identifying distress is magnified when people move between care environments or come into contact with new carers. The concept of identifying distress, rather than just pain, is an essential component of achieving comfort for people with severe communication difficulties.

'Alternative communication'

It is well known in healthcare that ineffective communication can lead to discomfort, serious incidents or complaints. England's Chief Nursing Officer has recently introduced communication as a new Essence of Care benchmark. Relatively little time is spent teaching communication skills to staff. 70% of all communication is non-verbal, so there is plenty of scope to understand those with learning disabilities. The problem is ours – the patient is trying to communicate with us but we do not

understand what they are saying. 'Alternative communication' is the term used rather than saying that a patient is suffering from communication problems and difficulties.

The expression and comprehension of information by people with learning disabilities can be shown in different ways, and the difficulty for staff and carers is knowing what these behaviours, signs and expressions mean for each individual. One example is a patient with liver metastases who laughed hysterically when he was in pain, so staff had difficulty in knowing that he was in distress. Verbal expressions, sounds, facial expressions, autonomic expressions (eg pale appearance or sweating), change in posture or activity can all indicate distress.

There is a difference between pain and distress. Once identified, pain can be addressed through clinical intervention. Distress is seen as vague and therapeutically frustrating. It can be physical, psychological or emotional. What is a minor issue for one person can be a major issue for another. We cannot assume that distress is pain as many of the clinical features of both are identical, for example, fear has the same automatic responses as pain.

The workshop was given the story of Ben, a learning disabilities patient. The story of his last days spent in hospital were told from his perspective. His comprehension was unchanged by the illness and his feelings and efforts to communicate were poignantly documented. In one final touching episode he was able to communicate with his mother so that she played his favourite CD before he died.

Research study

A study was made at Northgate Hospital in north-east England. Long-stay patients there with learning disabilities were suffering distress and pain, as other patients were, but since they had difficulty communicating their distress to staff they had poor access to pain control and support. A palliative care team was established for adults with severe learning difficulties in 1999 and awarded NHS Beacon status in 2000. The team, of which Dr Claud Regnard is part, has developed a documentation tool to learn the individual's language of distress. This disability distress assessment tool (DisDAT) sets a baseline for the patient when (s)he is content. Staff are then more aware of any changes in behaviour that may signify distress. By looking at signs of distress, behaviour and changes in these, an individual's language of distress can be learned.

The information can then be transferred with the patient to any environment. If a patient shows signs of distress or changes in behaviour then these can be checked against previous episodes, noting the context and pattern. In summary, this workshop provided useful insight into

what can be done to help meet the needs of those patients using 'alternative communication'. A final thought from the workshop is that distress may be hidden but it is never silent.

Workshop 2:

Developing audit and evaluation in palliative care

Fiona Aspinall, Research Associate and Rhidian Hughes, Senior Research Fellow on behalf of the Project to improve the Management Of Terminal Illness (PROMOTE), Department of Palliative Care and Policy, King's College London

Workshop summary

This workshop assessed the processes required for undertaking successful audits and evaluations in the area of palliative care. Clinical audits depend on multidisciplinary working and are therefore particularly well-suited to palliative care. A number of barriers were identified, but with careful planning these can be overcome. Audits have been found to be a useful method for improving services to meet the needs of service users (the patients), as well as indirect service users, such as their friends and families.

Introduction

Audit is used to assess the effectiveness of clinical services, procedures and individuals involved in delivering care. It can also be used to assess the impact upon direct service users; the patients, and indirect service users (such as family members). It therefore provides an extensive evaluation of care.

There are a number of benefits arising from the audit of clinical care. For example, it will:

- help provide an evidence base (of practice and of the extent to which the practice is used/needed)
- demonstrate the effectiveness of the service and therefore provide argument for funding issues
- test the effectiveness of clinical interventions
- enable staff to identify areas where they may require further training.

Audit can, therefore, contribute towards staff development programmes. By the same token it can identify areas of expertise. The whole process can also promote better understanding and communication between professionals and services that contribute to palliative care provision.

Clinical audit and palliative care share similar aims: palliative care aims to improve quality of life and clinical audit allows overall quality of care to be assessed which in turn may affect quality of life. Palliative care prides

itself on being a multi-professional discipline and clinical audit enables every professional's input to be assessed.

Audit methodology

There is a greater chance of an audit leading to a successful conclusion if staff follow good practice in audit methodology. Care needs to be taken right from the start in choosing a topic for audit. Is the area chosen one where improvements are both desirable and realisable? Will there be sufficient resources and support for undertaking an audit in this area? After choosing a suitable topic the next step is to measure existing practice and establish a baseline against which any future progress can be assessed. Having identified a baseline it is then necessary to identify a standard or benchmark where practice should aim to move towards. Data is collected and analysed against the standards or benchmark. From this comparison it should be possible to identify areas for improvement. Recommendations for changes are made, these are implemented and allowed time to take effect, then at a later stage the changes are assessed to check if they have indeed led to improvements in practice. The cycle of audit can then begin again. It is an evolutionary process.

Outcomes from the workshop

Participants were invited to discuss how they might undertake audits in a variety of areas, for example, one audit looked at oral care for stroke patients.

It was agreed that there was benefit right from the start in seeking to keep the audit as simple as possible. An audit that has clear and straightforward aims is more likely to gain the support of staff involved and is, therefore, more likely to lead to improvements in practice. Many had experienced difficulty in finding a subject that could be clearly audited. Before beginning any work it is essential to plan each stage of the audit process in detail. For instance, it is worth considering which method will be best to collect data, quantitative research or a qualitative study, given the resources available and the nature of the audit work involved. It may be worth using a validated questionnaire to collect data.

From discussions it also became clear that it was important to establish whether staff would be available to collect and analyse data, and also whether they had been trained to do so. It was suggested that medical and nursing students could be used to assist in processing audit data. This could form a valuable part of their training. Excel spreadsheets are routinely available on personal computers and can be used to analyse data. Staff working in the community explained that they have particular difficulty in finding the time to undertake audit work.

The consensus view was that a top-down management approach to audit work can antagonise staff so a team-working approach is preferred, which should fit with the multi-disciplinary nature of palliative care. Attention needs to be paid in managing audit work across the

organisation as a whole. If too much time is being spent on audit work then this can prove very demanding for staff, and in many cases take them away from more immediate front-line duties.

It was felt that with many audits of palliative care provision the standards could be based upon well-grounded opinion rather than statistical evidence, especially as the amount of statistical evidence is less in palliative care than in many other clinical areas.

Conclusion

In summary, the workshop illustrated the difficulties of identifying a topic that could be clearly audited, and the necessity of keeping the audit simple. It was also essential to plan the audit project and for the various clinicians and others to work together.

Workshop 3:

Telling tales: narrative analysis and palliative care

Dr Kirsty Boyd, Consultant in Palliative Medicine, Edinburgh Royal Infirmary and Dr Marilyn Kendall, Research Fellow, Department of Community Health Sciences, University of Edinburgh

Workshop summary

Narratives of patients' experiences with palliative care are a useful resource for both patients and healthcare professionals alike. They are a useful addition to the other means of conducting research, such as qualitative and quantitative studies. Narrative is a rich resource for research, education and practice. The main benefit of the narrative approach is that it allows patients to tell their story in their own way and not according to the structures imposed by a research study. The patient-centred approach of this research, or 'first person analysis' helps patients reaffirm their value as individuals and can enhance their experience of palliative care.

Introduction

This research approach utilises both carers' and patients' natural urge to 'tell stories'. It is patient-centred and as such allows patients to place the issues that are important to them in their own context. Healthcare professionals and researchers are often looking for different stories than those that the patient can provide, for example to confirm trends and hypotheses.

Research using patient narratives

'Are you sitting comfortably? Then I'll begin' – from this opener we all know what would be coming next. The structure of narrative is not imposed on us – we are surrounded by stories. Through them we know about our place in the world. Stories are fashioned from materials around us. Humans are story-telling animals – particularly at times of crisis/change/disruption, such as

illness. Narrative is a way of integrating meaning from our personal experiences.

In palliative care there is the chance for the final retelling of a life story. The story of our own death is often silenced as few people are around. In illness and health generally the most popular story is one of 'restitution' (ie getting better). But this is obviously not appropriate to palliative care. It is important that healthcare practitioners find ways to help patients find another story – and to open up to contradictory stories. The story of our own death is one that we cannot tell, but nevertheless in palliative care narrative is not yet being used to its full extent. What relevance do stories have for clinicians?

- They can listen to constructs of patients and families and then reformulate diagnosis and so on in *that form* (undergraduate training now includes this approach).
- It puts the illness of the patient in the context of their wider life. This unique insight into the experience of illness, can enable staff to learn more about how palliative care is experienced in the daily lives of patients and their carers, and hence to develop more effective ways of care giving.
- It allows staff to examine how they react to patient stories, what issues the stories raise, and what the main learning points are.

Canadian research has shown that people benefited from being allowed to record their end-of-life narrative as a means of closure. Cultural narratives of this kind can also benefit the family and community. There have been developments in narrative research, as ways of working with stories in social research.

Views of workshop participants

Research has been carried out with lung cancer and heart failure clients. Participants were handed examples of narratives from these patients. A number of interesting points emerged from group discussion around this material.

The first point noted was the attention to detail in most of the scripts – an indication of how important this was to those telling the stories. Participants could see the benefits of this approach for the patient but were aware that in some cases time would have to be made available for staff to sit with patients. Whilst it might not always be possible for staff to assist in this way it was recognised that it was a role that could be filled by volunteers on certain occasions.

Many felt that the narrative scripts had ‘something missing’, especially in terms of not being able to hear the

inflections used in the voice and see the non-verbal communication. Workshop participants agreed that the scripts could be interpreted in several different ways, depending on what one was looking for. There may therefore be some barriers still to overcome in helping patients tell their own story.

In this workshop a general feeling of ‘sadness’ was noted for the patients concerned. This observation led to discussion of what support could be provided for healthcare professionals when delivering bad news. Many have great difficulty with this because of the feelings of sadness that they will inflict upon the patient, and also upon themselves.

In conclusion, all present acknowledged that the technique of narrative analysis was a useful addition to research into understanding and meeting the needs of each individual patient.

Workshop 4:

Spiritual care in a largely secular NHS

Dr Liz Grant, Research Fellow, Department of Community Health Sciences, University of Edinburgh and Dr Scott Murray, Senior Lecturer in General Practice, Division of Community Health Sciences, University of Edinburgh

Workshop summary

This workshop was based on the results of a qualitative study to investigate the spiritual issues and needs of patients with advanced cancer and non-malignant disease. Spiritual distress, in its various forms, can have a profound affect on the quality of life of those facing death. Addressing patients’ need for spiritual care is an effective use of resources as this distress can manifest itself in both physical and psychological symptoms. It is recognised that GPs who develop a positive relationship with patients inadvertently help reduce the patient’s spiritual distress.

Introduction

This workshop will first establish what spiritual needs mean to patients today. Having done so it will then explore what is currently being done to meet these needs. It is recommended that this area is given further attention as there are benefits to all concerned if patients’ spiritual needs are recognised and met.

Project methodology

Twenty patients whom GPs considered to be in the last year of life were recruited: thirteen of these patients had cancer and seven had a non-malignant illness. Two qualitative interviews, conducted three months apart, were planned for each patient. We interviewed each patient’s GP after each patient interview. A total of 66 interviews were taped and analysed using Nvivo.

Definition

Every person will have their own understanding of their spiritual side. This may include some or all of the following characteristics:

- a sacred journey
- the experience of the radical truth of being
- the meaning and purpose of life
- a sense of connection to a greater something
- a belief that relates the person to the world
- a search for a transcendent relationship based on this life’s relationships
- a recognition that life cannot be explained by the parameters and boundaries of the visible world.

Unfortunately, a lack of clear definitions has hindered research into spiritual needs.

There is the paradox that the western ideal of ‘the good death’ co-exists with the persistent social attitude that denies death. Death is sometimes seen as a personal or a medical failure. The lack of public familiarity with death and dying results in less community support for the dying in Western society. Consequently, many who are dying feel that they have lost their significance, value and purpose in life. Lack of medical and social support may confirm this suspicion to them. There is an accumulation of research evidence to point to the fact that spiritual or existential distress is a key factor in negative well-being and end-of-life despair. Patients’ spiritual beliefs have significant influence on clinical outcomes. Patients who

have hope are more likely to achieve a better level of health than those without hope.

It was noted that patients do not always recognise spiritual distress within themselves so it is often helpful if someone is there to identify those patients who are in this state and who would benefit from spiritual care, in whatever form it may take for each patient.

Spiritual care and religion

Spirituality has become a buzzword in the social and healthcare fields. However, it is only in Western culture that spirituality is treated as a separate concept. Elsewhere religious faith, health and well-being are inextricably linked. The growing interest in the West parallels that of the complementary medicine field and the surge in interest in holistic medicine as a philosophy and ethic, reflecting the search of many for a better quality of life.

The emergence of spiritual care as a legitimate concept has been taken on board by the Scottish Executive. Spiritual care, once the clear domain of chaplains, is now recognised as a care which should be available to all people. The Scottish Executive has recognised that spiritual care is more than simply religious care and through a recent Health Department Letter (HDL) have requested all chief executives of NHS Boards to develop and implement a spiritual care policy for their Board area, to be followed by local plans that comply with the Board policy.

Spiritual distress

Healthcare workers will be familiar with signs of spiritual distress. Spiritual distress can be seen in those patients who:

- exhibit signs of isolation
- feel abandoned by structures expected to provide support
- feel a lack of control over their environment and often feel like a victim ('why has this happened to me?' etc).

Feelings of anger, fear, doubt and lack of peace are also very common. Such distress can contribute to sleeplessness, panic attacks and other forms of anxiety. These feelings are often much worse at night and result in patients making use of health service resources to help allay fears. Examples of spiritual needs are:

- 'Who am I?'
- 'How do I relate to other people?'

- 'Is there something beyond humanity that will apply to me?'

All patients expressed views relating to the meaning and purpose of their life in relation to a greater whole and transcendent being. Searching for significance in life and in their impending death were frequent themes. Having identified spiritual distress it is then crucial that someone is on hand to provide the patient with the spiritual care that they require, in whatever form this may take.

Spiritual care

What is spiritual care? Patients want to be as independent as they were before. Patients wanted recognition of who they are. They want to be listened to. Many have a fear of the dying process but not necessarily of death itself.

Training in offering spiritual care is available, but in many cases those who are not trained are perfectly competent in delivering spiritual care. Anyone can give good spiritual care if they are good at listening to people and recognising an individual's needs. This alone is enough to affirm and show value for the individual. It was felt that the guidance from the Scottish Executive HDL on spiritual care carried the danger of 'mechanising' much of the good work that is presently carried out informally. At the same time however it was felt that there is value in allocating resources to awareness-raising and training which can provide support to staff when required.

Many patients in the study reported that they received spiritual comfort from those who had not set out to provide them with spiritual care but who were treating them in a holistic way.

Often spiritual needs are not met by others, but are best met by the person concerned. Offering the person the support to utilise their own resources to understand their anxieties, fears, searches for meaning and relationships is generally the best way to provide spiritual care within the health service. Regardless of whether patients express specific religious views they should have the opportunity to talk about how they feel as death approaches. Training to help professionals uncover any anxieties that the patient has about dying may be necessary as part of training in holistic care.

It would be useful to build on the work of this study and learn if any additional measures are necessary to meet the needs of younger patients and those with learning disabilities or who are mentally incapacitated by their illness.

Workshop 5:

Qualitative research: how can we maximise its potential to improve our understanding of issues in palliative care?

Carol Horne, Manager, Tak Tent Cancer Support and Professor Hazel Watson, Glasgow Caledonian University

Workshop summary

This workshop discussed the value and key components of qualitative research.

Qualitative research is a valuable resource, both in its own context and when used in conjunction with quantitative research. When using qualitative research within the area of palliative care there are a number of special considerations which must be taken into account, such as the consent of patients and their carers, confidentiality and data protection issues. Qualitative research is seen by many as the poorer relation of quantitative research, which is unfortunate as its methods have particular relevance to the area of palliative care. Ethical considerations are paramount. A number of ways to utilise qualitative research for palliative care were discussed.

Introduction

Unlike quantitative research, qualitative research has in the past been viewed with scepticism. It has now, however, become recognised as a more valid approach in health services research, with funding bodies more willing to finance qualitative projects. The aim of this workshop is to suggest evaluative criteria that might be of value to researchers, grant-giving bodies and other interested parties. Particular reference is also made to how qualitative research needs to be tailored to meet the needs of palliative care.

It is worth noting that qualitative research does not 'fit' with the current recognised quality rating criteria as used by the Scottish Intercollegiate Guideline Network (SIGN) and the National Institute for Clinical Excellence (NICE). The lack of a grading system by these organisations for qualitative research downgrades it (as all that is available is a 'good practice' tick). Greater reliance is placed upon randomised control trials.

Methodology

Qualitative research is quite distinct from quantitative research. It is concerned with processes, personal views and experiences (which are complex). It can focus upon the users' perspective and is therefore a technique that has a very useful application in the area of palliative care. Qualitative research collects data from small samples through unstructured or semi-structured interview, observation, or diary extracts, usually in a verbal form and can be used to complement quantitative research.

Analysis is generally conceptual. It is useful in that it can identify actual rather than reported behaviours and allow exploration of underlying reasons for behaviours or responses to quantitative studies, eg reasons for patient dissatisfaction.

There are of course limitations to what qualitative research can be expected to achieve. It is by nature subjective. Fundamentally in research, the research questions should drive the method rather than making research fit the researcher's preferred method. The sample is not usually selected randomly, and the researcher must therefore explain what (s)he has carried out, then the reader can determine whether the findings are relevant to them. The main methodologies that are currently used in qualitative research are:

- grounded theory – comes from social psychology and assesses the meanings of interactions. It is used where little is known about a topic as a means of developing hypotheses and theories which can subsequently be tested using quantitative research.
- phenomenology – is based in hermeneutic philosophy and explores the lived experience of people.
- ethnography – is concerned with the cultural impact on the way we live our lives.
- action research – this usually involves mixed methods: the group develops a research question and works together to a solution/intervention, then enters a process of re-evaluation and further development. This approach uses a lot of theories of change.

Quality

An appropriate balance is needed in the research team, especially as qualitative research deals with sensitive issues. It is vital that the research team has a balance of expertise in clinical and research methods. Sample sizes are generally small with a maximum of approximately 40 individuals. A number of methods can be used to select samples. These are:

- purposive – the aim here is to choose a 'typical' sample rather than a 'general' sample (and it is important that the research team state clearly their reasons for selecting individuals). It is also important that subjective elements are acknowledged openly in the report.
- maximal variation – identifies key characteristics.
- snowball – recruits one individual and then asks

them for similar contacts.

- theoretical – this selects particular recruits with characteristics that we would expect but might raise other issues that are unconsidered yet. It is therefore developmental, uncovering as many opportunities as possible.

With regard to qualitative research in the area of palliative care a number of particular issues arise: one example is the question of where data should be collected. Is it safe for researchers to go into a patient's home? Or might confidentiality be compromised by using the 'safe' environment of a hospice room? These aspects must be thought through. In effect, the standard in research contexts is higher than in the clinical setting because, for example, in a four-bed ward clinical consultation with a patient would take place without confidentiality being considered.

Thought will need to be given to how the privacy of patients will be safeguarded along with the anonymity / confidentiality of the information they provide. For example, within report writing, if individual characteristics are being discussed this can effectively identify if, say, there are only two male research subjects. If anonymity is not to be maintained then the patient's permission is required. Then there are the questions of who will have access to the data and how the data will be stored, prepared for analysis and destroyed? The provisions of the Data Protection Act (1998) must be observed. Thus, any length of storage must be stated and the storage must be secure. If destruction of the data is recommended then the patient has the right of ownership of any tape or transcript. Also, if a secretary is transcribing tapes the material should have been anonymised, and a confidentiality undertaking obtained from the secretary. Particular problems arise in terms of palliative care patients providing their consent as their condition is likely to deteriorate during the course of research to the extent that consent may no longer be available later in the research process.

Data analysis

A number of issues arise when it comes to the stage of analysing the data. Data could be analysed using any of the following techniques:

- thematic analysis, eg Nvivo, which takes account of patterns/themes common to many transcripts
- constant comparative method used with grounded

theory: the first interview is coded and analysed, and then forms the basis of the second interview, the results of the second are compared with the first and so on

- discourse analysis looks at language used by individuals and in policy and the press.

Steps will need to be taken to ensure that the results of the research project are reliable and robust. The following aspects are as important as in quantitative research:

- auditability - is the paper trail adequate (ie in terms of research methods used, project remit, how data was obtained and analysed etc)?
- credibility - ideally the research findings should be fed back to the participants and there should be independent ratification of the analysis by a second researcher
- transferability - can readers judge that the findings are applicable to cases for which circumstances are similar? ¹

Ethical considerations

These should underpin all of the research work:

- beneficence/non-maleficence – work in this area does, of course, have great potential for causing emotional distress
- respect for autonomy – patient consent should be both informed and ongoing. Discussing one's own experiences can be a very seductive process and subjects may reveal information that they would not otherwise want to reveal. Also, patients and families can sometimes be so appreciative (of palliative care teams) that they will do anything to try to help the team. Palliative care researchers need to be careful with this, and information must be elicited carefully.

Closing remarks

Qualitative research is a useful research tool that is as relevant to the field of palliative care as any other technique. It can add to any research project, in its own right or if it is complementing harder, quantitative data. It has the benefit of involving users directly.

Reference:

1. Lincoln YS & Guba EG (1985) *Naturalistic enquiry*. Beverley Hills, CA, Sage.

Workshop 6:

Complementary therapies in supportive and palliative care: developing evidence-based quality services

Marianne Tavares, Complementary Therapies Co-ordinator, St Gemma's Hospice (formerly Project Manager, Complementary Therapies in Palliative Care, The Prince of Wales's Foundation for Integrated Health)

Workshop summary

This workshop was based on the National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care, as produced by The Prince of Wales's Foundation for Integrated Health and the National Council for Hospice and Specialist Palliative Care Services.

In summary, it was widely acknowledged that complementary therapies bring many benefits to healthcare and should be made more widely available to patients, especially if patient choice is to be fully recognised. These therapies are not more widely available as complementary therapy remains, to a large extent, outside the mainstream of healthcare.

Many support the integration of complementary therapies alongside mainstream healthcare services and agree that services should be developed systematically, with attention paid to quality. At the same time there were concerns in some quarters that the process of clinical governance could lead to unnecessary bureaucracy which could hinder the development of services.

The workshop identified action across a number of areas where complementary therapies could become integrated, and therefore more widely available, within mainstream palliative care services.

Introduction

Within the palliative care community, complementary therapies are used to complement care that is provided by medical and nursing staff, and allied health professionals. Although there are a number of centres providing these therapies, provision is patchy in some areas of the country. On the evidence of those attending the workshop, it is estimated that between a third to half of all organisations provide some form of complementary therapies to patients. It is worth noting, and is also disappointing, that complementary therapies are not considered in the NICE Supportive and Palliative Care Guidance to be a core service. If patient choice is to become a reality then providers need to find ways of allowing complementary therapies to be made available to any patient that requests this option.

Clinical governance and complementary therapies

It is clear that many organisations see the value of applying clinical governance framework to the ongoing development of complementary therapy services. There is also a view that the clinical governance framework, as it currently exists, might be too rigid to accommodate innovation, which is a hallmark of complementary therapy services. For example, there have been difficulties in the way in which some organisations have identified staff competence when conventional healthcare professionals wish to integrate complementary therapies within their primary role. However, on balance it was agreed that processes and safety checks were important, particularly in terms of building wider confidence in the use of complementary therapies.

Research issues

There is no centre which co-ordinates information on research activities in complementary therapies in palliative care and makes this information easily accessible. Whilst there is the option to register and share research through the National Research Register, this resource is not widely used and does not include evaluations of services. A 'central point' for reference would certainly encourage more staff to undertake and share research processes and outcomes, and thereby increase the evidence base for complementary therapies.

Co-ordination of research activity will help avoid wasteful effort in 'reinventing wheels' and, through the development of an evidence base, will assist in the identification and dissemination of best practice.

It would be useful if individuals informed the National Association of Complementary Therapists in Hospice and Palliative Care of their audit, evaluations and research activities, as this would provide incentive towards the creation of a national database.

Regulation

The regulatory framework for complementary therapies is fragmented across a number of different bodies at the moment. This has not helped in building professional confidence and support for complementary therapies.

The report of the House of Lords' Select Committee on Science and Technology on Complementary and Alternative Medicine recommends that the different

disciplines should work towards statutory or voluntary self-regulation under one umbrella body for each therapy. The Prince of Wales's Foundation for Integrated Health can be contacted for up-to-date information on the regulation of a number of therapies.

Service and Practice Development

In practice, it is possible to develop services safely, despite the lack of conventional evidence on the effects of complementary therapies. A substantial number of cancer patients now opt to use complementary therapies.

Whilst professionals question what has actually helped the improvement of symptoms and quality of life, in practice, there are many instances when patients attribute improvement to the use of a particular therapy with a particular therapist. Patients are not as concerned about RCTs proving effectiveness, as they are with their own experience.

Job descriptions

In the interests of professionalism, it was recognised that job and role descriptions are helpful, and there are examples in the National Guidelines. Volunteer therapists are mostly highly qualified professionals, and are a valuable resource. Providers need to consider how volunteer therapists are valued and recognised for their work. It is important, however, that volunteer therapists, like paid therapists, hold qualifications that enable them to be registered with a professional body for the therapy and be insured to practice.

Paediatric guidelines

No guidelines are currently available for the use of complementary therapies in this area. The National Guidelines relate to adult services.

Conclusion

Further debate is necessary at local and national level on how best to promote the availability of complementary therapies.

Workshop 7:

An evidence-based approach to end-of-life care

Dr Barbara Jack, Senior Lecturer, Royal Liverpool University Hospitals NHS Trust and Marie Curie Senior Research Fellow, Marie Curie Centre Liverpool and Lynne Jones, Macmillan Palliative Care Clinical Nurse Specialist

Workshop summary

Following the publication of the NHS National Cancer Plan (England), the Specialist Palliative Care Unit across Liverpool University Hospitals and the Marie Curie Centre Liverpool has developed the Liverpool Integrated Care Pathway for the Dying Patient (LCPDP). The project is designed to translate the excellent model of hospice care into the acute arena and develop outcome measures for end-of-life care. It is aimed at all healthcare workers.

Once given time to be fully implemented it was recognised that the Pathway brought many benefits, particularly in terms of:

- *enhanced care for the patients*
- *increased job satisfaction for staff*
- *developing educational programmes for staff*
- *informing resource allocation*
- *data for audit work that will ultimately lead to long-term improvements in patient care.*

Lack of care and dignity for dying patients

'Providing the best possible care for dying patients remains of paramount importance. Too many patients still experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate

communication from healthcare professionals during the final stages of an illness. The care of all dying patients must improve to the level of the best.'

**NHS National Cancer Plan
(England) September 2000**

Introduction

An education programme was drawn up to implement the Pathway in a hospital setting. Its effectiveness was judged by comparing outcome measures of care for the dying patient between hospice and hospital settings. The project also aimed to help empower other healthcare workers in caring for dying patients and bereaved relatives.

It is recognised that hospices have an established model of 'best practice' in care of the dying patient. There is a clear need to transfer hospice care into the hospital setting as only 12% of all UK deaths occur in hospices whilst 54% occur in hospitals.

Beacon status

The current project work has attracted local, national and international interest and the project has been disseminated further due to the support of Beacon Status

(the NHS Beacon Programme supports the delivery of high quality, patient-centred care by spreading good practice across the NHS).

The Pathway has given doctors and nurses useful advice and greater freedom of action in delivering high quality care to dying patients and their relatives. It has also helped facilitate multi-professional communication and documentation, integrating national guidelines into clinical practice. The Pathway is now in use across 20 centres and four care settings and the Pathway has been piloted in Australia and The Netherlands. It has also been applied across the Trust itself, with adaptations being made for specialised areas such as renal care, the intensive therapy unit (ITU), haematology and care of the elderly which include supportive guidelines for the needs of the patient cohort.

A rapid discharge pathway is currently being piloted to speed up the discharge process for those patients who express the wish to die at home. The goal is for the patient to be discharged within 48 hours of their request. A pathway document supporting the patient on their journey from admission to final outcome is presently being developed across the hospital / hospice sectors.

Staff education opportunities

The programme promotes a flexible range of learning opportunities to match individual as well as team needs. Options for staff include: Beacon site visits to the Marie Curie Centre, Liverpool and/or the Royal Liverpool University Hospitals, where the participant is introduced to the palliative care service provision at the site; or, attendance at a foundation study day which examines the place of the integrated care pathway in the healthcare arena and illustrates the development and implementation of the LCPDP. Advanced study days are held at the Marie Curie Centre, Liverpool and are designed to build on earlier knowledge acquired. Overall, the Pathway has had a very positive impact on Hospital Palliative Care Teams with reduced referrals, leaving time to devote to more complex issues and particular patient needs. There has also been increased job satisfaction among staff.

Outcome-based measures for palliative care

Is an outcome-based culture achievable in the speciality of palliative care? Often the complexity of the measurement of palliative care intervention has thwarted effective outcome measures being developed, but this pathway has the ability to change practice, promote multi-professional collaboration and articulate evidence-based practice.

A small pilot study was introduced into a ward area. LCPDP documentation was introduced alongside the then current hospital documentation, as it proved too difficult to use only the pathway documents. The ward staff then followed an educational programme and through time staff became more confident using the LCPDP documentation. At that time the hospital documentation was discontinued. The palliative care team visited the

ward and went through the Pathway helping staff to complete any missing data. The Pathway is reviewed annually.

The multi-professional team agreed that to be included in the Pathway, the patient should be entering the terminal dying phase with at least two of the following criteria applying:

- the patient being bed-bound
- the patient being only able to take sips of fluid
- the patient being semi-comatose, or
- the patient being unable to take tablets.

The Pathway is split into three sections; initial assessment and care, ongoing care and care after death.

Each section contains outcome measures (goals) which incorporate physical, social, psychological and spiritual/religious aspects around the care of the dying patient.

Initial assessment

Initial assessment includes the judgement of comfort measures for pain and interventions, the discussion of the patient's psychological needs, the assessment of religious/spiritual support, the discussion of the impending death and other relevant information with family members and making the GP aware of the patient's condition.

Ongoing care

Ongoing care focuses on four hourly observations for the control of patients' symptoms including pain, agitation and respiratory tract secretions and the patients' comfort including mouth-care, syringe driver care and administration of medication. In the majority of cases these observations are recorded by nursing staff within the healthcare setting.

These observations are recorded as either symptom not controlled which is marked as a 'V' denoting a variance or symptom controlled which is marked as an 'A' denoting achieved. For example, if the patient had pain at 1200 hours this was recorded as 'V', and if the patient was pain-free at 1600 hours this was recorded as 'A'. Variances are also recorded using qualitative methods on a separate sheet at the back of the Pathway. This ensures that what the variance is, why it has occurred and what action was taken is recorded.

Ongoing assessment every 12 hours is carried out for mobility and pressure area care, and bowel management. Psychological support is offered, ensuring that the patient becomes aware of the situation as appropriate and that the family/others are prepared for the patient's imminent death with the aim of achieving peace of mind and acceptance. Appropriate religious/spiritual support should have been given and the needs of the family/others attending the patient are accommodated.

The outcome measures are recorded as either goal

achieved (achieved) or goal not achieved (variance). A variance denotes some type of deviation in the patient's plan of care and does not necessarily mean a failure in care on the part of the health professional or the healthcare setting. Therefore, variances enable individualised care to be given to dying patients, whilst maintaining the continuity of care. Variance analysis is seen as a positive and not a negative process.

Care after death

The GP is contacted regarding the patient's death and procedures for laying out the body are adhered to as per hospital policy. Procedures following the death are discussed and carried out and the family and friends are given information on the hospital procedures. Hospital policy is followed regarding the patient's valuables and belongings and necessary documentation and advice is given to the appropriate person(s). A grieving leaflet is

given to family/others.

Conclusion: what the Pathway has achieved

There was some initial scepticism about the time taken to introduce the Pathway and the extra work created for staff at the beginning of the project, but after the time allowed for implementation, the Pathway is now seen as a major step forward in the delivery of high quality care for all dying patients in our society.

During the first year of the Pathway, there were 171 patients (53% of all deaths) on the Pathway at the Marie Curie Centre, Liverpool. The duration of the Pathway was 48 hours (median). There were 58 patients on the Pathway at the Royal Liverpool University Hospital. Again the duration of the Pathway was 48 hours (median).

The project can be contacted at: icp@mariecurie.org.uk

Concluding remarks

Dr Derek Doyle, OBE, Honorary President-elect of the Scottish Partnership for Palliative Care

Dr Derek Doyle, OBE, Honorary President-elect of the Scottish Partnership for Palliative Care brought the conference to a close with the following remarks.

“Palliative care has a central role to play in modern medicine. It is the right of everyone who needs it to receive it and the responsibility of all clinicians to ensure that it is provided to the highest possible standard, wherever the patient is being cared for. Provision of palliative care has no opt-out clause.

We already have a vast amount of skill and knowledge. We have come a long way and have achieved a great deal in the short time since palliative medicine and nursing became specialties. But, there is still far more to learn and we must accelerate this learning. We have covered a lot of ground today and now have a clearer idea of the challenges and work that lie ahead of us in terms of gathering and using evidence to both demonstrate and improve our overall effectiveness. But, we can also see that much research still needs to be done if we are to advance and be able to hold our heads high alongside other specialties. We have no right to expect their respect otherwise.

The main message that I have taken away from this year’s conference is that we must continue to do all we can to recognise, acknowledge and meet the needs of each individual patient. We must continually improve our means of communicating with all patients, and help them to communicate their needs to us. We must recognise that patients have the right to a quality service and to choice, whether this be choice of therapies, spiritual support, where to spend their last days or, indeed, who will care for them.

Scotland is privileged in being a small, friendly community where we have the opportunity to share knowledge and work together in developing our expertise. No one need feel daunted by research ethics committee submissions or statistical evaluations. There are always palliative care colleagues on hand to help.

On behalf of everyone here today I would like to thank Pat Wallace and her team for organising what has proved to be a very fruitful series of presentations, workshops and discussions. Thank you to everyone involved.”

Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland. It works to ensure that people in Scotland who have a progressive life-threatening condition, such as cancer, motor neurone disease or advanced heart failure, receive good palliative care. Palliative care aims to achieve the best possible quality of life for patients and their families or carers by:

- controlling pain and other distressing symptoms
- helping patients and families cope with the emotional upset and practical problems of the situation
- helping people to deal with spiritual questions which may arise from their illness
- helping people to live as actively as possible despite their illness
- supporting families and friends in their bereavement.

The Scottish Partnership for Palliative Care brings NHS bodies and voluntary and professional organisations together to promote better understanding of palliative care, to make it available to all those who need it and to improve standards of care everywhere for patients and families. It contributes to national thinking and policy in relation to palliative care, and promotes improvements in service delivery at local level.

Membership of the Partnership includes all the NHS Boards and voluntary hospices in Scotland as well as a range of professional organisations, national charities and support groups. The Council of the Scottish Partnership for Palliative Care is elected by the membership through its network of national and regional groups.

The Scottish Partnership for Palliative Care is taking the lead in Scotland in promoting access to palliative care for all.

Find out more at www.palliativecarescotland.org.uk

Published by:
Scottish Partnership for Palliative Care
1a Cambridge Street
Edinburgh EH1 2DY

Tel: 0131 229 0538
Fax 0131 228 2967
office@palliativecarescotland.org.uk

Charity No. SC017979

ISBN: 0-9542396-3-6

