Evaluating Palliative Care—A Review of the Literature

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Abstract: The purpose of this article was to investigate the outcome measures developed and used in palliative care. The paper involved a literature review of published research. Many of the reviewed papers concluded similarly that there was lack of good quality evidence on which to base conclusions. More high quality evidence is needed to compare the relative merits of the differences in models of palliative care services, so that we can learn from other appropriate systems of care at end of life. It follows that quality of life is the main outcome of palliative care, in which the patient instead of the disease represents the target of the clinical approach. Patients struggling with serious illness have other concerns, including managing pain and other symptoms, coordinating care among multiple providers and settings, ensuring that treatments reflect preferences and balance benefits and harms as well as clinical appropriateness, achieving empathic communication and care, fostering well-being, maintaining function and practically supporting family and caregivers through illness and bereavement.

Keywords: outcome assessment, advanced cancer patients, palliative care, quality of life

Introduction

Sound evidence to guide palliative care practice decisions is essential. However, questions are being raised about the source of evidence for palliative care and the framework within which that evidence ought to be obtained.

Information generated using outcome measures to assess the effectiveness of palliative care interventions is potentially invaluable. Depending on the measurement tool employed, the results can be used to monitor clinical care, carry out comparative research, provide audit data or inform purchasing decisions. However, the data collected can only ever be as good as the method used to obtain them. Measurement of the effectiveness and quality of health care services has become the norm over the past two decades. Most countries have witnessed the emergence of audit of clinical care and the development of a wealth of measurement tools employed to measure the effectiveness and quality of interventions and procedures. In palliative care, interventions and outcomes of care are even more difficult to define because the patients involved are terminally ill, and actively involving them and using their perspectives and concerns in data collection is a problem.

The problems associated with measuring both the effectiveness and quality of health services are exacerbated, due to the pressures from health insurance companies to ensure that the grants, contracts and reimbursements awarded to specialist providers represent good value for money, and whether the services meet the needs of the population and there is demonstrable health gain.

This review aimed to identify outcome measures that have been developed and used or proposed for use in the clinical audit of palliative care of patients with advanced cancer and addresses the following key questions:

1. What outcome variables are indicators of the quality of palliative care?
2. What individual outcome measures are used in palliative care?

Palliative Care—Theoretical Background

Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The aim of palliative

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care is to get the highest quality of life for patients and their families. This care aims to address the whole patient, including the physical, mental, spiritual and psychosocial needs.[2–3] Care should not only be restricted to the patient but also include the families by providing care and bereavement support. Therefore, there is a wide scope for research. In addition to the need for research in the areas outlined, there is also a need for research in the management and organisation of services.[3–5]

A definition of palliative care and an understanding of what is provided and how, is the pivot of any type of evaluation. It is important to be able to isolate the field of palliative care, so that it can be evaluated as an area of activity which is distinct from other forms of nursing and supportive care. Some definitions concentrate on the differences between palliative care approach, palliative interventions and specialist palliative care.[4] Not only did the services offered by specialist providers of palliative care such as hospices spread from the confines of hospice programmes into mainstream care through hospital liaison nurses, palliative care teams and hospice-at-home schemes, but also many non-specialist health care professionals apply the principles of palliative care during their routine work, and many indeed have specialist qualifications in palliative care, care of the dying, bereavement care and counselling.[6] The purpose of this literature review is to examine some questions of evaluation that relate to the care of people who are ill and reaching the end of their lives, that any active therapy being received is not being offered with curative intent, physical deterioration has come to affect everyday functioning, the deterioration has become progressive and irreversible, and that survival is likely to be counted in weeks and months rather than in years. Increasing pressure is being felt within the field of specialist palliative care for evidence to demonstrate the effectiveness, appropriateness and acceptability of services. Evaluation has become an important activity for health care planners and policymakers, as well as service providers. In times of economic retrenchment and fiscal constraint, evidence concerning the effectiveness, efficiency, acceptability, and appropriateness of services is important for resource allocation decisions. The review of the literature enlightens what other people have done by way of research in the area of palliative care to avoid tackling questions which have already been answered.

Method

Search strategy

This study is a literature review. A comprehensive search of the medical and nursing palliative care literature was conducted to identify studies addressing the key questions. Sources for this review included studies identified from a systematic search of computerized databases (Medline and CINAHL), hand-searching of specialist palliative care journals, and studying bibliographies and reference lists. The searches were limited to published articles in the English and German language, appearing in journals between the years 1995 and 2004 and did not include individual case reports.

Selection criteria

Articles that clearly met the following criteria were excluded: studies that enrolled only a pediatric population (age 18 years and under); those that were case studies with fewer than 50 cases; those that did not consider palliative care; those that enrolled a non-Western population or were published in a non-English or non-German journal; reviews that were not systematic, clinical trials of chemotherapy, radiotherapy, stent, laser, endoscopy or surgery; descriptions of ethical, legal or regulatory issues, descriptions of research processes; editorials, histories, personal narratives, and other descriptive non-clinical articles, articles about professional education (unless clinical or patient outcomes were described) and studies in which the outcomes were laboratory or radiological tests or other physiological indicators. The criteria for the inclusion and assessment were studies with measures assessing more than one domain and a target population of advanced disease or palliative care. Of the 1200 titles identified through literature searches, 435 were considered to be of possible relevance and subject to abstract review, 35 of which satisfied the inclusion criteria. These covered aspects of physical, psychological and spiritual domains. Each measure meets some but not all of the objectives of measurement in palliative care, and fulfils some but not all of the criteria for validity, reliability, responsiveness and appropriateness, and should evaluate, summarize and collate the situation of terminally ill cancer

patients in different palliative care settings in Germany. The more recent reviews were more rigorous compared with the former ones.

Results

The traditional indicators of the health intervention outcomes, namely mortality and morbidity, are insufficient or inadequate;[7] hence there is a need to extend the scope of research in palliative care by addressing different objectives. Outcome measures aim to the effects of palliative care services or certain interventions on certain aspects of care. As the objectives of such interventions are likely to be unique to palliative care, the outcome measures should reflect the special concerns within palliative care. This is a complex task because, by definition, the best source of information is the patient;[8] however with terminally ill patients it is often hard to evaluate. It is worthy of note that the aspects of care relevant to some outcome measures were not supported by a clear consensus either within or beyond palliative care, for example, quality of life measures.[9]

The prevalence of symptoms regarding patients with terminal cancer is described in many papers but there is little consistency between different studies, probably reflecting differences in patient populations and the tools used to assess symptom frequency. Some studies combined the prevalence of vomiting and/or nausea,[17] while others assessed these symptoms separately and many others assessed more symptoms. In different studies the frequency of nausea varies from 13% to 44% and vomiting from 10% to 27%.[22] In studies combining vomiting and nausea, the frequency ranges from 9% to 51%.[23]

Cancer pain relief is an ubiquitous but negligently treated public health problem in many countries. Every day, more than three and[18] a half million people suffer from cancer pain in Germany, but only a fraction of them receive the relevant treatment. Adequate pain relief is not reaching a great number of cancer patients in developed countries. In the developing countries, where more than half of the world's cancer patients live and where the majority of them are incurable at the time of diagnosis, pain relief (often the only relevant humane alternative) is not offered on the whole.[19] Pain is the most frequently investigated symptom for patients suffering from a terminal illness. However, the reported frequency considerably varies from 11% to 84% in different patient groups.[17,20] This variation may be caused by methodological differences, in particular, the method of symptom ascertainment, selection of patients and the use of proxy reporting. Pain is obviously expected to be severest in the most serious cases treated in specialist units. However, similar levels were reported in a random sample of 45 hospice services and cancer patients.[21]

Respiratory problems are also frequently cited in studies of terminal cancer patients, with a prevalence varying from 21% to 64% for mixed cancer sites. As expected, it was substantially higher (87%) in patients suffering from lung cancer.[20] Two major methods were proposed to assess the prevalence of symptoms in patients in the terminal stages of their disease. Patients were examined during their stay in specialist healthcare facilities, or relatives or healthcare professionals are contacted after the patients died to ascertain the symptoms prior to death.[24] A lot of work was done to examine the psychological impact of the terminal disease on the patient and their families.[27] Holland, one of the most well-known American psycho oncologist[28] highlighted in the American Cancer Society Award lecture (2003), the importance of psychological care of patients. Hopwood et al. established that 27% of females with advanced breast cancer either suffered from anxiety, depression or a combination of both.[29] Anxiety and depression are reported in a variety of palliative care research studies.[30] Some studies discovered that families coping with a terminally ill relative also suffered from psychological distress.[31] Obviously, palliative care services have to address psychological as well as physical symptoms associated with the disease process not only to the patient, but also to the family units supporting the patient.

In some studies it was suggested that a multiprofessional team increases the speed of the referral process, the coordination of care and the communication between health care professionals and patients and families.[32] The input of a specialist team can facilitate increased patient and family satisfaction and integration with primary care. Poor communication is cited by the Audit Commission[33] as one of the most common reasons for litigation and complaint in the health service. Evidence suggests that poor communication results in dissatisfaction and increased co morbidity of both the cancer patient and their family or carers.[34] Effectiveness in palliative care is judged in terms of

quality of life prior to death, quality of life at the time of death, a good death and the impact on the family or carers.[35] Some studies examined the costs and revealed a tendency towards a reduction in the number of days that inpatients spent in hospitals, and more time was spent at home with equal or lower costs.[36] In the intervention group they discovered an increase of satisfaction with interpersonal care and involvement in care, but there was no difference in patients with pain, in satisfaction with the environment, symptoms, activities of daily life, anxiety and depression scores. Ventafridda et al. measured the costs and effectiveness of home care compared to hospital care for advanced cancer patients.[37] In this small sample of 60 cancer patients with pain, they established an improvement of the performance status and the overall quality of life index, less patients were feeling very ill, less care received was judged as insufficient and costs were estimated as being lower. In Italy, Peruselli et al. defined some potential indicators of palliative care outcomes with the aim of assessing the quality of home care provided by a palliative care unit.[38,39] With an Italian version of the Symptom Distress Scale, they assessed the degree of the symptom distress and decided that this was similar to quality of life. Edmonds et al. reported on the use of an expanded support team assessment schedule (E-STAS) to determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team.[36] The study showed statistically significant improvements from first to last assessment in all symptoms except depression. Ellershaw et al. assessed in a prospective study the effectiveness of a hospital palliative care team with a recently developed palliative care assessment tool (PACA).[40] This tool was developed in order to assess the outcome of interventions made within two weeks upon referral with regard to: symptom control, change in the patients' and their relatives' insight regarding diagnosis and prognosis as well as facilitation of patient placement. Critchley et al.[41] conducted a systematic review of comparative studies looking at the effectiveness of different models to provide palliative care services.[41] They defined the service provision models by location of provision, type of patient, service providers, and hours of availability. They assessed the models with a view to their impact on patients, family members, health professionals and the health care system and tried to find sufficient evidence from the studies that helped to establish whether some models were more effective than others and to identify areas where additional research is required.

Considerable work was carried out to develop quality of life measures for patients with cancer and various assessment tools are available specifically for being used in the palliative care context.[12] It is not the intention of this article to review the various instruments of quality of life in detail; this was already very adequately done elsewhere: for cancer in general,[13] palliative oncology[14,15] and palliative care.[16] Patients' quality of life was an outcome measured in 13 papers and was a specified primary outcome in four of them. Four studies assessed caregivers' quality of life. Several instruments were used to assess quality of life: the Multidimensional Quality of Life Scale-Cancer Version; the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30, the Medical Outcomes Study Short Form (SF-36 or SF-20), the Functional Living Index-Cancer; the Sickness Impact Profile; the General Health Rating Index; the Hospice Quality of Life Index; the Spitzer Quality of Life Index and Uniscale, and the Caregiver Quality of Life Index-Cancer. Only one of the studies used a quality-of-life measure that was specific for a palliative care population.

However, some assessment of the patient's well-being is central to the evaluation of alternative models of palliative care. The term "quality of life" has intuitive appeal for oncology and palliative care nurses who focus on assisting people to adapt to the losses and sometimes the debilitating effects of cancer and its treatment. In palliative care nursing research, QoL often signifies what makes life more worthwhile for those patients and the caring aspects of nursing.[42] Despite the relevance and significance of QoL in palliative care, nurses' conceptual definitions are general and difficult to compare. The World Health Organization defines quality of life as "individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns."[43] The definition includes six wide domains: physical health, psychological state, levels of independence, social relationships, environmental features, and spiritual concerns. In palliative cancer literature, investigators' definitions of QoL have parallels to those of other disciplines with a focus on the multidimensional nature of the concept.

Corner et al. reported in their study about a method which was developed for evaluating outcomes of nursing care in complex situations such as care of people who are dying.[44] Positive outcomes of care for patients that were directly attributable to the care provided by Macmillan specialist palliative care nurses were found for the majority of patients but they did not offer any definition about quality of life. Nevertheless, all studies indicated a small positive effect of the hospital team on palliative cancer patients. No study did offer quality of life definitions as baseline for their research on nursing outcome.

Conclusion

Outcome research in palliative care represents a new dimension of clinical research that should be investigated in the near future. The limits in outcome research are not well defined in nursing research or in palliative care dimension, but it should be properly linked to evidence based practice. The palliative care needs of society are likely to increase in the future, although the magnitude of changes is difficult to be gauged accurately.[45] Palliative care services should be in line with WHO recommendations and further attempts made to assess unsatisfied requirements and intervene where necessary. These unsatisfied requirements and the increase of patients with dementia and other diagnoses in need for palliative care[46] are probably the driving force behind these services in the future. This literature review of studies measuring outcomes of palliative care services in different ways suggests that identifying high-quality, effective and appropriate palliative care services are a long way away. Such a lack of definition takes a universal understanding of these terms for granted, despite the fact that there is no consensus among the palliative care community.

The methods of symptoms evaluation are problematic in providing accurate assessments for patient populations. For the first method only those patients are interviewed that attend a particular health facility. It is generally acknowledged that patients attending such units are atypical of the patient populations as a whole. In order to overcome this problem, random samples of patients dying from a particular cause can be identified by the relevant death certificates. This method could be able to produce a representative sample, but also leads to errors due to proxy reporting of symptoms by a patient's relative or healthcare provider.[25] There is evidence that, as opposed to patients, carers overestimate the severity of symptoms and that general practitioners usually record less symptoms than hospital nurses, whereas relatives often state a higher frequency of symptoms than health professionals.[26] The important question will always be that of the difficulty in separating the effects of a team from the effects of input of any specialist. In terms of patient satisfaction, i.e. care being given where the patient wishes., family satisfaction, family anxiety as well as patient pain and symptom control, many studies showed that specialist palliative care is more effective than conventional care. Critchley et al.[41] concluded that the success of any effort to monitor or improve the quality of health care at the end of life will depend on the definition of what high-quality care in different circumstances represents.[41]

Quality of life is a concept relevant to the discipline of nursing. If QoL is to be a major outcome variable in nursing research, many of the methodological issues will have to be addressed and resolved. As the interest in quality of life continues, nurses carry on being actively involved at a local, regional, national and international level. Oncology and palliative care nurses continue to assess the impact of cancer and cancer treatment on QoL and implement strategies to decrease adverse physical, psychological, social, and spiritual effects on the lives of patients with cancer. It will be crucial to maintain the nursing and patient perspectives when conducting future research and attempting to influence clinical care and outcomes. There is no single QoL instrument serving as the definitive outcome measure for all aspects of nursing research in oncology and palliative care. This is due to the desired characteristics of an instrument varying according to the purpose it is used for. A brief and simple instrument for clinical management is required which can be used as an adjunct to clinical assessment and is feasible to integrate into routine practice. Such an instrument is probably useful for clinical audit as well. As knowledge is gained of the quality of life, the purpose of nursing as a science of caring will become more comprehensible and will further enable to foster, nurture and strengthen its quality. The relationship between symptom improvement and quality of life will have to be well defined and investigated, and the identification of quality of life (or, better health-related quality of life) will probably represent the

dimension that will be able to combine clinical research and outcome research.

Reliable and validated instruments are necessary and all those involved need to have confidence in the findings of a tool and this tool must be applied in a reliable manner in the setting it is used in. Services must pay greater attention to the requirements of standards in palliative care and form networks between partners in the health care system to evaluate care and identify best practice. Developing standards that apply to all services and evaluating those aspects of palliative care which are still unevaluated should have priority. Although palliative care is still a young discipline in research, the time is probably ripe for reviewing the palliative approach looking at the dimension of palliative care with evidence-based tools and outcome-oriented criteria, and research and clinical practice should go on towards this new dimension.

Recommendation

More high quality evidence is needed to compare the relative merits of the differences in models of palliative care services, so that countries can learn from other appropriate systems of care at end of life.

There is an apparent requirement for prospective studies to accurately record symptoms in random samples of the patient populations. Without these studies the assessment of need to manage these symptoms and the suffering will be open to inaccuracies.

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Disclosure

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Appendices

Table 1. Outcome indicators in palliative care.

Patient-based outcomes	Methods of assessment
Control/severity of symptoms	Structured self-complete Symptom checklists
	Patient-generated symptom Checklists (with or without Visual Analogue Scale or weighting procedure)
Quality of life	Structured self-complete instruments or self evaluations (e.g. EORTC, SEIQoL)
Satisfaction with location of care, speed and nature of response of health and social care professionals (including communication)	Questionnaires and interviews
Home carer-based outcomes	**Methods of assessment**
Satisfaction with care given to patient and with care and support (practical help) given to home carer (including communication)	Questionnaires (e.g. FAMCARE) and interviews
Household costs (financial and social) associated with terminal illness	Diaries and detailed questionnaires during terminal illness
Risk of severe grief reaction	Structured measures of psychological morbidity (e.g. HADS) Risk assessment scores
Satisfaction with bereavement support	Questionnaires and interviews
Staff-based outcomes	**Methods of assessment**
Satisfaction with nature of care delivered	Questionnaires (e.g. STAS) and interviews
Efficiency of communication between different professionals	Telephone interviews, checklists, questionnaires
Speed of response to requests for help	Audit of records (e.g. time between referral to services and take-up)
Satisfaction with working environment, clinical supervision, and staff support procedures	Records of staff turnover and absences, questionnaires, interviews, focus group discussions
Service-based outcomes	**Methods of assessment**
Utilization of services	Routine activity data
Staff workload and staffing levels	Staff rotas and case-load figures
Perceptions of different service providers of quality of services	Questionnaires, focus group discussions
Place of death	Mortality data
Costs of different types of care	Accounts from hospices, specialist teams, nursing homes, and other providers, with additional prescribing data where possible