International Policy Fellowship
ID 0329 – PBH – LUN - SI

Identifying effective ways of implementation of palliative care into Slovene health care system

Research Paper

November 2005

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Outline

Executive summary

Transferring the palliative care model for care of the dying into hospitals and community settings is one of the greatest challenges for the palliative care movement. Integrated clinical pathways (ICPs) are a potentially powerful tool in the achievement of this goal. There are a number of important steps in the care of the dying which are often only partially or poorly performed in health care settings.

In this study, research on the evidence in the literature about different interventions, methods and policies on improvement of the practice of palliative care are examined. A series of strategies are outlined to overcome some of the barriers of development and effective implementation of palliative care into a public health system. Identifying the activities and opportunities that can improve the delivery of palliative care at the end of life is the first step toward developing corrective approaches. Special focus is made on different tools and methods of standardization of care on the basis of evidence in palliative care. This exploratory stage includes a short background, a review of current practices, policies and solutions and identification of opportunities for improvement of palliative care.

This study reports on the introduction of a common protocol. The Liverpool Clinical Pathway was chosen, because it promotes evidence-based palliative care across all settings in a health care system. It is based on the evolving standards of palliative care for patients in their last phase of life. Through a pilot project, implementation processes in different settings were explored. Propositions for financial evaluation of palliative care services are suggested. A study is part of an effort to develop information to propose policy recommendations to the Ministry of Health in a separate policy paper.

By examining what should be happening when and the expected results, the implementation of effective clinical pathways continues to be one of the most valuable and widely utilised methods of ensuring optimal outcomes for patients. Despite the wide spread use of pathways, rigorous scientific evidence as to their effectiveness must be studied further.

1. Introduction

A good death has always been important to all cultures[1]. The rise of hospice and palliative care has been a response to calls for greater dignity at the end of life[2]. The World Health Organization's definition of palliative care[3] has been defined as *“an approach that improves the quality of life of patients and their families facing the problems 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, psychological and spiritual.”*

The aim is to develop an understanding of the strengths and weaknesses of current arrangements, and establish a better basis for palliative care in clinical practice.

2. Background

Traditionally medicine has focused on treating episodic acute illness and prolonging life with all available means. Doctors are often reluctant to diagnose dying. Instead they feel that there must always be additional investigations and treatments to make their patients “better”. This attitude can be very destructive. Patients’ needs are not addressed properly and relatives are unprepared, often expressing the wish, that they had been warned – “If only someone had told us.”[4]
Lack of practical support is one of the most common reasons for admission to hospital or hospice at this time, and, therefore, consideration should be given to proper support well organized palliative care throughout all levels of the health care system.

Support means recognizing and addressing the physical, emotional, and psychological issues that may face patients, families, and carers during times of advanced disease. Honesty, listening, availability, and assurance that symptom control will continue are valued by patients and carers. Fears or religious concerns should be acknowledged and addressed appropriately, and respect for cultural differences should be assured. Explain what is happening, what is likely to happen, the drugs being used, the support available, and how the family can help with care. Most emergencies in the last 48 hours are irreversible, and treatment should be aimed at the urgent relief of distress and concomitant symptoms.

Evidence from palliative care consultations suggests that the absence of clear “goals of care” often led to unnecessarily long, complicated stays in hospital, contradictions among recommendations made by various clinicians, and care inconsistent with the patients' wishes.[5] Every clinician in all health care settings must be empowered to deliver high quality care to the dying with reasonable mutual goals.

Therefore, the principles of palliative care involve important cultural changes in the health care system, and also in society:

- changes from disease-based to person-and-family based care,
- from vertically organized to interdisciplinary – and horizontal – continuing care,
- liaison between levels of care,
- strong links with and understanding of society,
- new resources;

3. A gap between evidence and the reality at the patient’s bedside

Advances in diagnosis and therapeutics have redefined the field of palliative care in the last decades. But why is there a gap between evidence based palliative care, or knowledge acquired during training and the reality at the patient’s bedside? And why is it so difficult and frustrating, for those seeking to improve the quality of end-of-life care [6]?

If we look at pain relief, where the majority of advances have been made in the research, but studies consistently demonstrate that pain relief in various patient populations is inadequate, despite the fact that we have known the principles of pain relief for over a generation.[7],[8] [9],[10], [11]

There is evidence that people do not die in the places they wish, or with the peace they desire, further more, too many die alone, in pain, terrified, mentally unaware, without dignity, or feeling alienated. Modern dying involves a struggle for control: some doctors fear failure, because they cannot keep their patients alive. Patients with life-threatening diseases, especially those with cancer, are often subjected to aggressive attempts at cure even when they were likely to be futile.[12] Singer and colleagues recently showed that fear about the unwanted application of technology to prolong life was the most prevalent concern voiced by patients on dialysis, with AIDS, or receiving long-term care.[13] All too frequently, patient care was portrayed as a war to be won or lost. On such a battlefield, patients in the process of dying could only be seen as the ultimate losers. The issue is not whether, but how, to apply palliative care which includes modern technology together with a humanistic, gentle approach to patient and family needs.

Data suggest that hospitals and health professionals are not equipped or trained to handle the medical and psychosocial problems that face those who are chronically ill or dying[14],[15]. Although the barriers to achieving a peaceful death are many, they can be grouped into three broad categories[16]:

- professional knowledge and skills in palliative care,
- professional and public attitudes about the goals of medicine,
- financial and structural attributes of the health care system;

4. Evidence-based palliative care in practice

Evidence-based practice is the conscious, explicit and judicious use of current evidence in making decisions about the care of individual patients[17]. In palliative care this should be balanced with patient, family or carer choice[18].

Patients with advanced diseases are among the most difficult to research, and there is no second chance to get care right. In spite of this fact, an enormous amount of research in palliative care is already available in the last decades, but there are still gaps in our knowledge. Clinical practice in palliative care can encounter a wide range of problems and issues. Patient and family circumstances can change quickly and there are usually multiple and multifactoral problems. There is often very little time to attempt to manage problems. It is unrealistic to imagine that a clinician will be able to review each problem for every patient seen. By the time the evidence is compiled the problem may have progressed or changed, or the patient may have died. Therefore, for the some common problems and procedures – such as symptoms of pain, fatigue, breathlessness, anxiety or communication difficulties – the clinician working in palliative care needs rapid access to evidence, in a meaningful format. Evidence-based guidelines, care pathways and services that abstract and synthesise information may help to meet this need.[19]

5. Effectiveness of palliative care policies

Outcomes such as the quality of care, quality of life measures including quality of death, and the best approaches to bereavement are hard to measure especially when patients are frail and very ill [20]. Qualitative research, which is relatively new to medicine, has opened new avenues to studies that are especially applicable to palliative care, where many of the challenging phenomena do not lend themselves to quantitative analysis. Most evidence is provided on the effectiveness of pain management, teamwork and communication. There are systematic analyses[21], in one 18 prospective comparative studies were considered, retrospective and observational studies, as well as randomised trials. When specialist palliative multidisciplinary care was compared with conventional care, four of the five randomised controlled trials and most of the comparative studies indicated that the specialist, coordinated approach resulted in similar or improved outcomes in terms of :

- patient pain, and symptoms;
- patient satisfaction;
- patients being cared for in the place of their choice;
- family satisfaction and control of family anxiety,
- benefit of palliative care home teams for patients, families and in training others available;

Studies that examined costs showed a reduction in hospital inpatient days, more time spent at home, and equal or lower costs. From a public health viewpoint, nationally organized implementation of palliative care can achieve public and geographic coverage, equity, quality, comparability, and user satisfaction.[22]

The increasing pressure from the public, authorities and researchers to establish specific indicators of quality and effectiveness in any segment of health care includes strategies to ensure optimal, consistent and comparable palliative care. Many national health care organizations and individuals have invested heavily in efforts to implement changes for improvement on different levels. However, most of the approaches are more based on beliefs than on scientific evidence: “Evidence based medicine should be complemented by evidence based implementation” [23]. So what is the evidence about the effectiveness of teaching, the use of guidelines and other tools for research/knowledge implementation?

6. Education and training in palliative care

Curricula at medical schools and residency training programs contain minimal formal courses on death and dying. The result is inadequate professional knowledge of palliative medicine, where evidence of inadequately treated pain has been consistently demonstrated in diverse patient populations (SUPPORT study – ref. 2). Curricula in palliative care have been published by numerous organizations [24], [25], [26], [27], [28], [29],

It is important to recognize in educating future health care professionals, that patient suffering can be alleviated by applying existing knowledge and that the time before death can be a rich and rewarding opportunity for communication between patients and their families[30]. Through proper education palliative care must become an integral component of primary medical care so that the arbitrary dichotomy between the medical care of persons who are perceived as having curable or chronic illness and those who are recognized as dying becomes a continuum, with palliative care measures gradually taking preference over life prolonging efforts when death is imminent.

The practical means of accomplishing these objectives include: establishing a staff of teaching mentors; mandating the inclusion of palliative care in the curriculum of medical schools and residency training programs; and including palliative care questions on board certification examinations, residency review committees, and hospital accreditation requirements.

When we look at the methods of teaching, classic continuing medical education has been shown to have little or no effect on change of practice (e.g. conferences, courses, seminars and educational materials), education is most effective if organised with multiple disciplines, in small groups, with interactive and experiential educational methods of learning, with methods of re-validation or re-certification. The effect of education is increased when combined with outreach visits, use of opinion leaders, feedback on performance and reminders [31],[32].

7. Importance of standards, clinical guidelines and clinical pathways

When the knowledge and skills about new evidence based palliative care are learned, what factors encourage or discourage its implementation into practice? A large number of clinical guidelines designed to meet national standards have been developed from existing evidence-based medicine or consensus-based recommendations in national standards. To improve and integrate the use of high quality guidelines in every day practice, clinical practice guidelines can be successfully integrated into clinical pathways. This is a method of implementing and monitoring best practice, and incorporating accepted guidelines and protocols into the health care setting directly[33]. Clinical pathways increase the visibility of patient's problems and the accountability of healthcare professionals. With the introduction of clinical pathways teamwork and interdisciplinary collaboration is encouraged, patients and their families are better informed, and omissions and duplications are prevented. It is neither feasible nor desirable to have clinical pathways for every kind of patient. However it seems essential to have pathways for the common types of patients. Clinical pathways:

- provide a mechanism to analyse persistent failures in achieving desired outcomes of care[34],
- offer measurable outcomes and enhanced education is easily provided,
- have the potential to create a fundamental clinical culture change in the care of the dying patient in all settings[35], [36], [37],[38].

Some difficulties in implementing pathways:

- it takes time for pathways to become accepted by staff, and for staff to gain confidence using them (11),
- they can't be implemented unless there is an effective clinical team,
- broad opinion, that clinical pathways are too prescriptive and the individual doctor's choice of what is best practice debated – often incorrectly, since no pathway removes the right and the responsibility of individual clinicians to do what they think best[39];

What really does make the difference? There are many different, sometimes competing approaches to changing practice, which all claim to be effective. Research so far shows that none of the approaches is superior for all clinical changes in all situations; we probably need them combined, well planned and co-ordinated. Maybe most important is the need for a change of beliefs, attitudes and behaviour. Secondly, teamwork, effective teaching and dialogue are preconditions for successful implementation of all organisational changes, e.g. standards, guidelines and clinical pathways. Where good working relationships exist, this is usually a consequence of individual initiatives rather than an inevitable consequence of good processes. They are actually a consequence of good working relationships.

7. 1. A research on national standards in palliative care

Fundamentally standards in all medical branches are developed to ensure all staff are knowledgeable and skilled, and have the support they need to fulfil their roles. They insure each health care organisation manages its activities, resources and functions in a manner consistent with its approach to care delivery.

Standards of palliative care are developed to provide consistent and comparable responses to relieve the suffering and improve the quality of life of patients and families throughout their illness experience. Sometimes standards have been created also due to newly developing purchaser or provider relationships within health authorities. Standards are often used to form a framework for the development of evaluation and assessment of performance management systems.

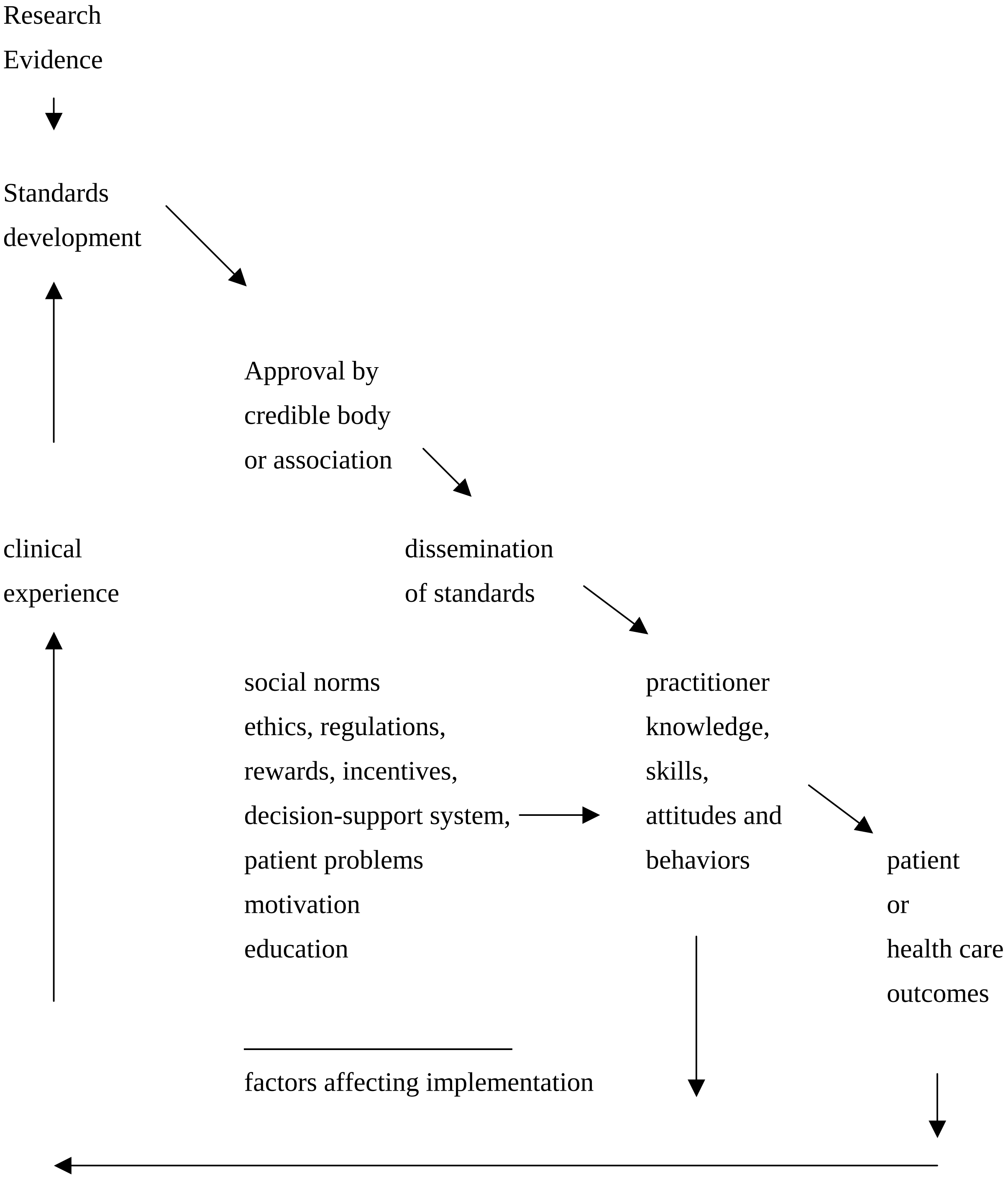
Standards present a so called “top-down” development of better practice into individual health care settings and most of the authors of standards are aware of the fact, that standards once written must be followed by several activities to foster their implementation in practice.
Policy makers are now able to use the standards as a guide to the development of new policy, regulation, and law, funding or service delivery models (e.g., provincial/state hospice palliative care policy and funding/service delivery strategies in Canada). Or opposite, National Plan and strategic framework for palliative care: 2000 - 2005 in United Kingdom for example, recommends the development of national standards, performance indicators and related minimum data sets[40]. But common definitions and goals for standards are often different and sometimes unclear.

7. 1. 1. Development and purpose of standards

The majority of standards were set up to provide criteria, which could be measured across a variety of settings. There is a growing base of evidence based palliative care knowledge and the question is what steps are needed for development of standards based on evidence to change the actual practice. Fig.1 shows the necessary steps in the cascade from development of standards to better outcomes and patient/family satisfaction[41].

Fig.1

The standard cascade: steps in the development and implementation of standards and factors influencing the adoption of standards. Adopted from Fox, Mazmanian and Putman.



The feelings of lack of ownership are most pronounced when a strictly "top-down" model of standards is adopted. In the process of development it is important to have the full participation of as many clinical staff and public representatives as possible. For standards to be owned by the users, it is important that clinicians and representatives of patients create the standards at all stages, rather than just merely being recipients. The way in which standards are developed is a key element of the process. Adopting an open and inclusive process involving a wide range of professionals and members of the public through a variety of mechanisms is important. It is also important to test standards through pilot reviews to ensure that they meet the principles of the creators, are measurable, and that they could be applied across a variety of settings.

The adoption of any innovation or dissemination of new knowledge should be considered in a holistic, contextual manner. Three large areas of influence on health care professional acceptance and compliance with standards are represented in the factors affecting implementation. Social norms, ethics and regulations represent socio-political and professional factors. Rewards or incentives, decision-support systems represent factors from practice. Motivation and education are the personal factors of health care professionals, but they all usually overlap and we need to address all of them in the implementation of any new innovation. Standards themselves are just "the starting point" in the cycle of continuous change towards better patient satisfaction and specific health care outcomes.

7. 1. 2. Analysis of standards in palliative care[42]

Existing standards were requested and collected from different organisations, associations, nations, committees:

- e-mailed to all collective members of European Association of Palliative Care (EAPC),
- Newsletter of EAPC east centre,
- personal contacts,
- web site search;

The search technique developed as an evolutionary process, following methods of qualitative research. Some of the documents were discarded from the database as they were found not to be relevant or, for example, they were superseded by another document. Decisions were made by discussion with the research team, for example: various standards documents may have been to one disease or to a narrow group of specific patients and not of major relevance as the standards documents of palliative care. On the other hand, others were included in the database, even when the title has not included the word *standard*, but the research team recognised those documents with the function of standards document for the particular country (Hungary: Palliative care of terminally ill patients; Professional Guidelines).

Documents on standards in palliative care are secondary data, in that they are produced in purposes others than research itself, so each document has to be processed, first by selection and than by interpretation. Constrains of the method include the practicalities of access to the documents and the time involved. Further limitations relate to the fact that documents are produced as a result of activities bounded by the particular national, social, historical, cultural and or administrative conditions in which they are produced. The interpretation is therefore in the further analyses divided to groups of similar documents and the representative documents are described shortly.

7. 1. 3. List of palliative care standards documents

There are several published standards in palliative care in Europe, also in the eastern part, and around the world, but there are great varieties among them. The list of standards is surely not complete and comprehensive. There is no accepted definition of standards and no common format for standards has been developed. Terminology used in documents is often unclear and sometimes confusing.

1. Australia
Standards for Palliative Provision, 3rd Edition, Oct 1999 (The Standards and Quality Committee of Palliative Care Australia)
www.pallcare.org.au/publications/Standards_99.pdf

2. Bulgaria

3. Canada
2001 Proposed Norms of Practice for Practice for Hospice Palliative Care (Canadian Palliative Care Association Standards Committee)
www.cpca.net

4. Canada
Hospice Palliative Care Nursing Standards of Practice, Feb 2002 (Canadian Hospice and

Palliative Care Association Nursing Standards Committee)
www.cpca.net

5. Hungary
Palliative Care of Terminally ill Patients suffering from malignant tumours. Professional Guidelines, 2nd edition, April, 2002. (Hungarian Hospice-Palliative Association)
Language: Hungarian, English
Contact: Katalin Hegedus, e-mail: hegkati@net.sote.hu

6. Italy
Recommendations and minimal prerequisites for palliative care in Italy (Societa italiana di Cure Palliative, Federazione Cure Palliative ONLUS)
Language: Italian
Contact: e-mail: fedcp@tin.it, c.fusco@legatumori.mi.it

7. Moldova
A guide to palliative care (Recommended by council of experts at the Ministry of Health, Moldova, 2002)
Language: Romanian
Contact: Irina Baicalau, e-mail: secondbr@beltsy.md

8. Norway

9. Poland
The Polish Standards of Pediatric Palliative Care. 1999 (Dangel T: Warsaw Hospice for Children and Department of Palliative Care. National Institute for Mother and child, Warsaw, Poland)
Language: Polish, summary in English
Contact: dangle@medianet.pl
www.hospicjum.waw.pl

10. Romania
National standards in palliative care, Romanian National Palliative Care Association in co-operation with the National Hospice and Palliative Care, Organization in the USA.
Language: Romanian, English
Contact: e-mail: hospice@rdslink.ro

11. Scotland
Clinical Standards: Specialist Palliative Care (Clinical Standards Board for Scotland, 2002)

Language: English
www.palliativecarescotland.org.uk/publications/

12. Scotland
National Care Standards: Hospice Care. (The National Care Standards Committee at Scottish Ministers, 2002)
Language: English
www.palliativecarescotland.org.uk/publications/

13. Spain
Palliative Care Services: Guide to Quality Criteria. 3rd Version Draft, April 2002 (SECPAL Consensus group)
Language: Spanish, English
Contact: e-mail: xgomez@ico.scs.es, rartigas@ico.scs.es

14. Switzerland
Standards. Grundsätze und Richtlinien für Palliative Medizin, Pflege und Begleitung in der Schweiz. März 2001 (Arbeitsgruppe "Standards" der Schweizerischen Gesellschaft für Palliative Medizin, Pflege und Begleitung SGPMPB)
Language: German, French
Contact: e-mail: frederic.stiefel@inst.hospvd.ch

15. UK
Trent Hospice Audit Group Palliative Care Core Standards. A Multidisciplinary Approach. For Trent Hospice Audit Group: Ahmedzai SH, Hunt J, Keeley V. The University of Sheffield, Second Edition, 1998.
Language: English.
Contact: john.hunt@sheffield.ac.uk

16. United States of America
National Hospice Organization. Hospice Standards of Practice. Arlington, VA: National Hospice Organization; April, 1999.
Language: English

17. United States of America
Standards of Practice for End-of-life Care in Correctional Settings. GRACE Project of Volunteers of America, the Robert Wood Johnson Foundation; 2000.

Language: English
www.voa.org

18. United States of America
Compendium of Health Care Organization Guidelines and Position Statements on Issues Related to the Care of the Dying. Last acts, 2001.
www.lastacts.org

19. Wales
Specialist Palliative Care as Applied to Cancer Services. All Wales Minimum Standards, 2000. (Issued by the Cancer Services Co-ordinating Group)
Language: English
www.pallcare-wales.net/downloads/minstandards.pdf

Assessment document:
Palliative Care Australia: Self Assessment Service Audit in Palliative Care. Pilot Project, Dec, 2001 CD-ROM
Contact: e-mail: pcainc@pallcare.org.au
www.pallcare.org.au

7. 1. 4. Common values and principles in national standards documents

Inspite of the differences among national standards analysis revels a series of common values and principles. Hospice and palliative care activities recognise and promise to ensure the following values (a) and guiding principles (b):

a. Values:
1. The intrinsic value of each person as an autonomous and unique individual.
2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualisation.
3. The need to address patients’ and families’ suffering, expectations, needs, hopes and fears.
4. Care is only provided when the patient and / or family is prepared to accept it.
5. Care is guided by quality of life as defined by individual.
6. Caregivers enter into therapeutically relationship with patients and families based on dignity and integrity.

7. A unified response to suffering strengthens communities.

b. Guiding Principles

1. Patient/family focused
2. High quality
3. Safe and effective
4. Accessible
5. Adequately resourced
6. Collaborative
7. Knowledge-based
8. Advocacy-based
9. Research-based

Standards are written to ensure these values and guidelines, but their ranking in different document/countries are sometimes different.

7. 1. 5. Structure of standards

Standards of practice are usually based on nationally or regionally accepted principles of practice or statements and evidence based knowledge. They are formed by a wide range of experts, and only sometimes users are also involved (Scottish). The process of policy procedure is often based on the best available evidence or opinion-based preferred practice guidelines (Canada), including standards on data collection/documentation guidelines that are based on validated measurement tools (Trent, Canada, Australia, both Scottish).

Standards documents should:

- focus on clinical issues and include non-clinical factors that impact on the quality of care,
- be written in simple language,
- be based on evidence (recognising that levels and types of levels will vary),
- be applicable to all patients, including those with non-malignant disease, who are identified through assessment as requiring palliative care services,
- be clear and measurable,
- be flexible in that they may be applied across the range of palliative care services,
- be developed by healthcare professionals and members of the public,
- be widely reviewed,

- be published in international journals and as the internet,
- be regularly reviewed and revised to remain relevant and up-to-date,
- be distributed across all settings;

Instead of palliative care being seen as “care for the dying”, through the standards established by a variety of documents and guiding principles, palliative care will be known as “care that aims to relieve suffering and improve the quality of life throughout the illness and bereavement experience, so that patients and families can realise their full potential to live even when they are dying” (Canada).

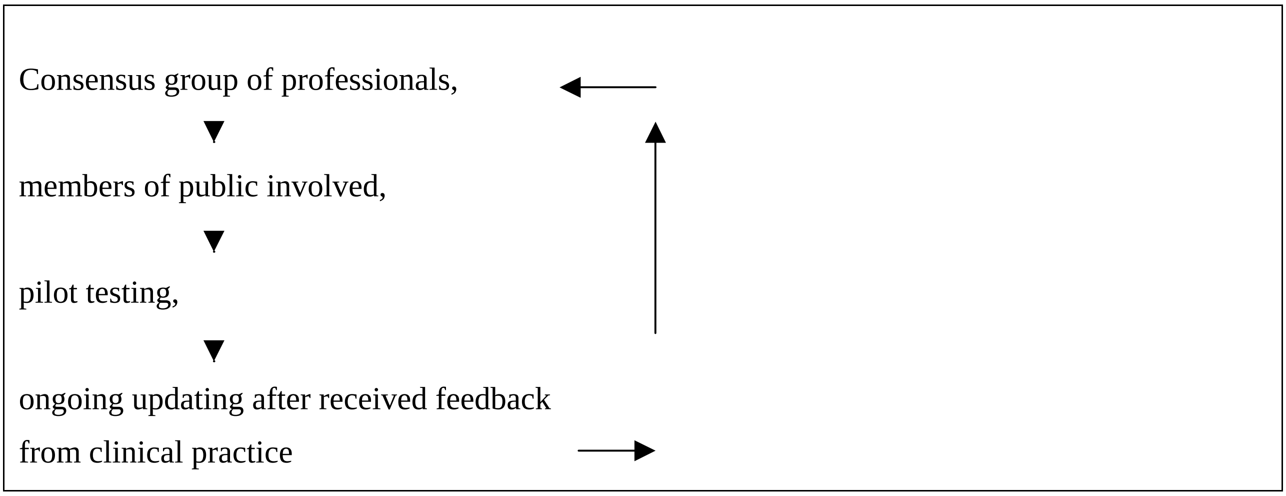
7. 1. 6. CORE standards? MINIMUM standards? NORMS of practice?

Standards may identify the most important values, the basic criteria for service and organisation of care (Trent Core Standards, Scottish), or they may focus more on the structure and how they will be used (Hungary, Poland, Spain, Switzerland, Norway). Minimum standards of practice are frequently developed by stakeholder associations to guide their members’ practice, or by policy makers who wish to regulate the field of palliative care. Minimum standards establish the basis or “minimum practice” acceptable to meet a given condition (e.g., labelling, licensure). Compliance with “minimum standards” may be voluntary and used as a guide, or mandatory as a performance criterion for accreditation and licensure. Norms and principles of practice from Canada present the ideal practice to which palliative care providers and organisations can aspire. They do not present current standards of practice.

The pprocess of developing standards ideally includes beginning consensus group of professionals, members of public, approval by credible body or association, pilot testing, ongoing updating after receive feedback and back to consensus group of experts for refinement (Fig 2.)

Fig. 2

Process of development of standards



7. 1. 7. Common issues covered by standards documents

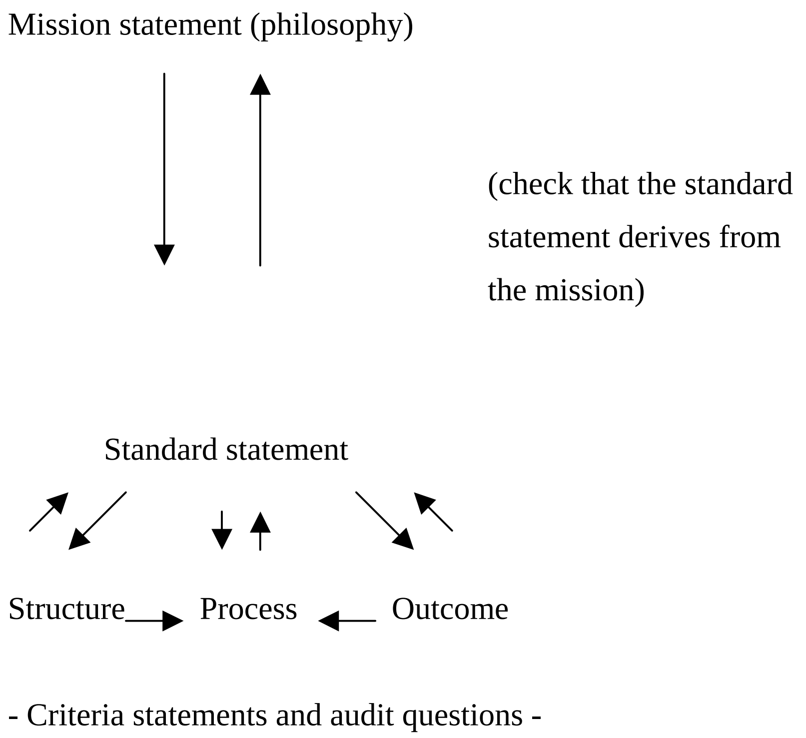
In all collected standards at least the following domains are usually covered in different ways:

- definition of palliative care, values, and philosophical view of palliative care,
- domains of palliative care services (clinical symptom control, psychosocial and spiritual aspects),
- staff management and management of resources;

Information sharing process (Trent, Canada, both Scottish, Wales) and documentation standards are set also (Trent, Australia, both Scottish, Switzerland, Spain). Clinical audit is the main focus in the Trent standards, and is also specific to the Donabedian's model: *Structure – Process – Outcome* showed in Fig.3. It demonstrates how standard and criteria statements are developed at the same time as the audit tool questions. It is also a model of checking back to ensure that criteria statements are related to the standard statement. Similarly, the standard statement should be related to the mission statement (and evidence based knowledge). Even if structure and outcome can be measured, the association between them is changeable and poorly defined, quality of care is difficult to quantify and the ideal outcome may be debatable[43].

Fig. 3

The development of standards and criteria statements together with the audit tool questions[44]



The target group of standards documents are mainly adult patients, including those with non-malignant diseases, but a few include paediatric palliative care (Poland, both Scottish standards). Most of the standards cover all settings where palliative care is delivered or are focused only on specialist palliative care services (Scottish). Nursing standards from Canada for example are targeting one discipline in palliative care. Scottish National Care Standards – Hospice Care are explicitly patient/family oriented. In other words, standards are meant to inform patients and their families about the minimum standard they can expect in different situations and conditions. The Australian, Trent and both Scottish standards documents offer self-assessment tools for all members of palliative care team. Both Scottish standards documents also cover the accreditation regimen.

On the other side, there are a group of standard documents covering common issues in palliative care and mainly defining organisational requirements, infrastructure and special qualification /education requirements for palliative care professionals (Hungary, Poland, Italy, Spain, and

Switzerland). Some of them go into detailed instruction about the framework of palliative care services (Norway).

7. 1. 8. How to achieve implementation of standards in practice?

Difficulties arise in introducing standards into daily practice. One of the most consistent findings in research of palliative care services is the gap between evidence based palliative care and practice. When standards require complex changes in clinical practice or better collaboration between disciplines or changes in the organisation of care, their implementation is difficult. Existing evidence about the introduction of standards or the impact of standards on the quality of performance in palliative care is very modest. It seems to be difficult to identify the most effective and efficient approaches to achieve implementation of standards in practice.

A variety of approaches have been introduced to provide solutions for better quality of patient palliative care, including assessment tools, accreditation regimens, audit, clinical guidelines, accountability, clinical pathways, shared documentation processes, total quality management, recognition of relative performance (ways of discussing errors and seeing them as opportunities for improvement), professional development, patient empowerment and permanent improvement of standards.

Improving the quality of patient care is complex and it is unrealistic to expect one approach for implementation of standards to solve all the problems for better quality of palliative care delivery. There has been tremendous work done in some countries who have a long history in palliative care, with complex but simple to use and understand style in established standards, together with the audit tool (Trent standards), self-assessment tools (Australia, both Scottish), or education instructions and model of implementation of palliative care services (Canada).

Increasing findings and new facts about the most effective ways and measures developed to bring standards into practice are the subject of present and future research. Some studies in other medical branches show that education is most effective when experiential educational methods of learning include re-evaluation in small multidisciplinary groups. Clinical guidelines have shown very little impact on practice change, but developed together with clinical pathways, are promising methods of implementation of standards in practice for the future not only in palliative care but elsewhere in health care.

7. 2. Clinical guidelines

As health care organizations moved from quality assurance to continuous quality improvement, they looked for new methods to identify and use evidence-based care processes to improve desired patient outcomes. Simultaneously, payers and business coalitions became interested in guideline-based quality measurements for evaluating provider employees or evaluating the care received by beneficiaries[45]. The development of clinical guidelines was driven in the early eighties by concerns regarding the rapid escalation of care costs and quality of care. Guidelines were incorporated into policies and procedures, quality assurance, and quality improvement efforts.

Clinical guidelines are systematically developed statements to assist practitioners in providing patients care for specific clinical circumstances. However, evidence about the effect of clinical guidelines on practice shows serious deficiencies, thought partly due to the low quality of the guidelines. The international AGREE (AGREE instrument: Appraisal of Guidelines for Research and Evaluation) collaboration has developed a specific instrument to assess the development of guidelines[46]. Many attempts and a lot of input of energy in all kinds of different guidelines for better quality of clinical practice have been only moderately successful or not at all. The guideline documents are essential, but strategies are necessary for them to be implemented into practice?[47]

7. 3. Clinical pathways

The two most common tools used to integrate guidelines into practice were critical pathways and algorithm decision trees. The difference between both is that critical pathways include all care processes and decision trees focus on medical diagnosis and treatment.

A clinical pathway (CP) is defined as “systematically developed statements to assist both practitioner and patient decisions about appropriate care for specific clinical circumstances”[48].
A CP is a tool that embeds guidelines, protocols and evidence-based, patient-centred, best practice into everyday use for the individual patient.

An integrated clinical pathway (ICP) is a document that describes the process for a discreet element of service. It sets out anticipated, evidence-based, best practice and outcomes that are locally agreed upon and that reflect a patient-centered, multi-disciplinary, multi-agency approach. The ICP document is structured around the unique ICP Variance Tracking tool. When used with a patient/client, the ICP document becomes all or part of the contemporaneous patient/client record, where both completed activities and outcomes, and variations between planned and actual activities and outcomes, are recorded at the point of delivery.[49]

ICP aims to have the right people doing the right things in the right order and at the right time. ICP:

- offers clear criteria when palliative care for the patient can start and end - identification of patients for palliative care
- brings better outcomes and satisfaction for the patients,
- improves teamwork,
- improves communication between clinicians and patients/their relatives,
- educates clinicians and prevent omissions or duplication of services
- offers the same level of standard for the same type of services in all settings

and most important for the evaluation, it aims to compare planned care with care actually given. It is this last point that sets ICPs apart from the myriad of other tools supporting best practice.

In recent research on the extension of clinical pathways usage in health care in European Union[50], authors claim that clinical pathways are widely used especially in health systems in United Kingdom, Ireland, Germany and France, and outside the EU in Australia, New Zealand, and the United States. Authors conclude that there is a lot of evidence of effectiveness of a clinical pathway as a tool for direct implementation of new findings into practice, but much more must be done to achieve a common understanding among clinicians about the ideas of pathway, strategic asset planning, and the interrelationships. They propose including pathways in licensing and accreditation activities. They further propose linking pathways to service classification and specifying their use in purchaser-provider contracts, encouraging health care provider agencies to use pathways as the basis for internal resource allocation, internal clinical auditing, and running clinical teambuilding processes. Much more must be done to achieve better understanding of clinical pathways in the future. Although the research about the efficiency of clinical pathways is already proving it, many health care professionals and particularly physicians don’t know clearly what the essence of clinical pathways is.

The philosophy of palliative care emphasises a holistic approach to an individual and the family. ICPs initially seem at odds with this palliative care philosophy, appearing to be too rigid to facilitate the delivery of care in a palliative care setting. However, several care pathways have been developed in a palliative care setting (36, 37, 38). ICPs do not prevent the delivery of individualized care, instead they allow the clinical freedom to provide care within an evidence-based framework. They are particularly appropriate in palliative care, acting as a multiprofessional document which staff can use to co-ordinate and record the care of the patient.

7. 3. 1. Liverpool Clinical Pathway (LCP)

For palliative care in the last days or in the last 48 hours of life the Liverpool Clinical Pathway (LCP) is currently incorporated in the Cancer Collaborative project in the Merseyside and North Chesire Cancer Network outside England. It is being implemented in different hospitals and home care systems in the Netherlands, New Zealand and recently also in Sweden.

LCP consist of four major parts:

- identifying patients to be included in a pathway
- initial assessment and care
- ongoing assessment
- care of the relatives after death

The LCP highlights the need to deliver holistic care during the dying phase and gives guidance on the different aspects of care required. It particularly recognizes the areas of care which present most difficulties such as identifying the patient entering the dying phase. The LCP gives the clinical freedom to provide care within an evidence-based framework and acts as a multidisciplinary document which staff can use to co-ordinate and record the care of the patient.

The multidisciplinary emphasis ensures that all team members are involved in the decision making process. The key supporting documentation are:

- facilities leaflet
- symptom control guidelines
- bereavement leaflet

If the pathway is not followed at any point, the heath care professional records a reason for the deviation as a variance. Analysis of this variance provides a mechanism for analysing the reason for not achieving the desired outcomes of care. It directs educational initiatives and resource utilization in order to achieve maximum impact in the provision of clinical care. It is an important part of the LCP that variances are analysed and acted on when appropriate.

To achieve a change in practice by implementing an ICP involves a major time commitment. First, it needs to be introduced into an organization that has signed up at the executive level to implement it. The next step is to undertake a Base Review. This is a retrospective review of current practice and establishes a base line from which post-implementation data can be compared. It also encourages the development of reflective practice in the health care professionals who are using the ICP.

It is important not to underestimate the amount of the educational commitment required in order to implement an ICP for the dying patient. It can take from 6-18 months before the ICP can be introduced into a new clinical area. Importantly however, the ICP can be a powerful educational tool for palliative care professionals. So often we educate at a level which merely informs the participants that we know more than they do. As a result, when health care professionals care for a patient with palliative care needs they automatically refer to the palliative care services. This leads to overall deskilling of health care professionals. Palliative care advisory teams can never hope, nor should they aim, to be involved in all deaths occurring in a hospital and a community. It is essential that generic palliative care, including care of the dying, be delivered by *all* health care professionals. It is of critical importance that an ICP for care of the dying facilitate education at a level appropriate to the generic health care professionals, to avoid deskilling and to promote staff empowerment.

7. 3. 2. Slovene experience

The plan was for an experimental group of patients and families in primary care at their homes or in hospitals to follow the criteria of admission to a palliative care terminal phase[51] supported by a Liverpool Clinical Pathway. The aim and objectives of the research project were to introduce a common protocol for delivering palliative care at a terminal stage in order to introduce common standards into practice and to develop basics for building a classifying system in palliative care for the management and payment purposes on the national level.

The objectives of the research

- To create and organize a pilot study for the introduction of a modified palliative care clinical pathway.
- To develop basics for classifying in palliative care for managing, planning and funding purposes. The purpose for the classification is to be based on the characteristics of the patient and on the goal of intervention, not the method of service classification.
- To clarify what constitutes a good clinical practice: define basis for national clinical standards in palliative care.
- To establish ways of empowering individual initiatives for palliative care teamwork.
- To propose an implementation model for palliative care in the Slovene health care system.
- To produce a policy paper for experts in the field and for the Slovene Ministry of Health.

The research hypothesis

Clinical pathways for palliative care offer better clinical practice measured by patient and family satisfaction.

Appropriate education and introduction of the clinical pathway can offer greater satisfaction for the staff and a better subjective opinion on teamwork.

It is possible to make a basis for classification of palliative care in the frame of a clinical pathway.

Methods

The education (which mostly included experiential workshops, and hands-on education) consisted of palliative care clinical knowledge, symptom control guidelines, and technical education on the palliative care clinical pathway implementation.

Production of the documentation:

- The form of protocol (The Liverpool Clinical Pathway) was translated. At the time of the first assessment, every patient was assigned to care using pathway with the criteria of the Liverpool Clinical Pathway, which predicts that the patient is: bed bound, semicomatose, only able to take sips of fluid, and no longer able to take tablets. When at least two of the four criteria are true, the pathway for the patient can start. There is a form for the clinical pathway that is separate for the hospital and separate for the community (ambulatory).

- A leaflet of information on the research project is available for the patients, their families and the staff.
- Production of the common symptom control guidelines (translated and modified from Ellershaw[52]).
- Production of a bereavement leaflet for family members.
- If the pathway was not followed at any point, the health care professional records the reason for the deviation as a “variance”. Analysis of the variances provides a mechanism for analysing the reasons for not achieving the desired outcomes of the care. This, in turn, directs educational initiatives and resource utilization in order to achieve maximum impact in the provision of clinical care. Variances were recorded and discussed once per month in meetings with each team. As weaknesses were noted in the pathway form, the form design was modified.
- Consultations among the clinicians and a coordinator were available on line.
- Variances were discussed monthly with each team.

All the final results are not ready yet, and the research is going on, but several lessons can be drawn at this stage.

7. 3. 2. 1. Lessons learned from the pilot

The benefits of CP are numerous. The introduction of the ICP greatly improves symptom control for patients and support for relatives.

Documentation and communication were improved within the multidisciplinary team. The result was a profound promotion of teamwork and care planning with educational benefits.

As it is already known, addressing attitudinal influences on the care of dying patients, requires fundamental shifts in the prevailing life-prolonging ethos in medicine. The introduction of ICP brings this process in motion. From the questionnaires of clinicians involved in the ICP implementation process, it seems that knowledge, skills and attitudes improved during the process of education and use of the ICP influences on the care of patients earlier in their disease and not only in the last days of life.

Many health care professionals were raising questions about how to diagnose dying more clearly. The most difficult dilemma for clinicians and nurses is to diagnose dying or when to start using the ICP. This was particularly difficult when a patient was acutely ill, or where the disease trajectory may be unpredictable, or in a post-operative state. It was a very unrealistic expectation to achieve a complete number of patients involved in the ICP in short time. We have learned that there can be valid reasons why the ICP was not used in many patients: in the case of sudden death, a cardiac arrest, or in a case where it was hard to diagnose dying. Sometimes, simply a member of the staff in charge, or on duty over the weekend, was not familiar with the tool. Diagnosing dying (the last hours or days of life) is often a very complex process. In cancer patients, the following signs are often associated with the dying phase:

- The patient becomes bed bound
- The patient is semicomatose
- The patient is able to take only sips of fluid
- The patient is no longer able to take oral drugs

This predictability of the dying phase is not always as clear as in other chronic incurable diseases.

ICPs have potential to set standards and to be used for quality assurance within palliative care unit or hospice settings. They can add a new empowerment for a better culture of dying.

There are major points to be improved in the future implementation that were learned through the process of a pilot study:

- Our struggle to reach clinicians seems to be partly due to the lack of a well organized introduction into each organization. There was a lack of response on the side of government to give the study the necessary impact and backup. We were counting on enthusiastic individuals with a strong desire to support the pilot research although it required extra work with no reward or other incentive.
- We underestimated the amount of the educational commitment required to implement an ICP. Much more time (6 – 18 months) is needed.
- It is essential that ICP education is given to all health care professionals and not only to some individual clinicians in a unit or primary care office.

- We did not realize how costly and time consuming the project would be. A careful, sensitive consideration for every new patient was needed and personal involvement in the coaching the staff to use the tool.
- In the majority of situations staff found it very difficult to accept the ICP as a replace meant for all other forms of documentation, so they completed the previous and the ICP documentation. This meant a lot of additional work for the staff and occasionally negative attitudes were encountered.

8. Conclusions

The importance of the quality of clinical care has been emphasized lately in new plans of health systems. The objective of clinical governance is to ensure that the patient receives the best quality of care throughout their journey and to learn from patient experiences in order to provide services that better meet patient needs.

With the intention of finding appropriate standards, different national documents were reviewed from around the world wide. For their implementation into palliative care practice, different tools were explored and introduced internationally. There is already some prove and evidence of their effectiveness. Guidelines seem to be essential and clinical pathways can contribute to their practical implementation.

For payment purposes, new ways of classifying the patients and services of a multidisciplinary palliative care team will be needed. They will need to be adaptable to all levels of the health care system across the entire range of national palliative care services.

ICPs are a promising way of direct implementation of standards and guidelines and have several positive effects: better outcomes for the patients and their families and caregiver; improved communication between health care professionals and patients with their families, and better teamwork. With ICPs omissions and duplications are avoided and waste is reduced.

It seems likely that the main issues relate to identifying patients who need palliative care: how patients are selected and where care is provided: hospitals, primary care, nursing homes, their own homes – to achieve the place where patients wish to die.

Finally, there could be concerns about how staff could be better educated and the community more involved.

Before proceeding further, it is necessary to develop a common view on the changes that need to be made in the practice of palliative care in Slovenia.

9. Literature

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