OPCARE9 Report Summary

Project ID: 202112
Funded under: FP7-HEALTH
Country: United Kingdom

Final Report Summary - OPCARE9 (A European Collaboration to optimise research for the care of cancer patients in the last days of life)

Executive Summary:

Changing health and demographic profiles across Europe and beyond highlight the emergence of a longer lived and increasingly aged population. Accordingly, the pressure on health care services to meet the need of this ageing population, particularly in end of life care, is a pressing challenge for clinicians and policy makers alike.

OPCARE9 was a 3 year EU FP7 Co-ordination & Support Action grant funded collaborative project to optimise the care of cancer patients in the last day of life. The project was structured using both an inter-professional and international collaborative framework. The beneficiaries were:

- Marie Curie Palliative Care Institute, University of Liverpool - UK; Cologne University - Germany; Erasmus MC, University Medical Centre Rotterdam - Netherlands; National Cancer Research Institute, Genoa - Italy; Stockholms Sjukhem Foundation - Sweden; University Hospital for Respiratory and Allergic Diseases, Golnik - Slovenia; Cantonal Hospital St Gallen - Switzerland; Pallium Latinoamerica (NGO) - Argentina; Arohanui Hospice - New Zealand.

OPCARE9 sought to systematically investigate current practice and evaluate the evidence base across a range of healthcare environments and diverse cultures, using 5 key themes:

- Signs & Symptoms of Approaching Death; End of Life Decisions; Complementary Comfort Care; Psychological & Psychosocial support; and Voluntary Service.

Results indicate that scope of the current knowledge base within each of the themes examined lacks depth and breadth. Accordingly, there is the need for coordinated high quality research on which to base the delivery of care in the last days of life. OPCARE9 has provided consensus positions on optimum care and developed innovative research protocols to address identified knowledge gaps and needs.

The recommendations from the workpackages are also incorporated into the developing Liverpool Care Pathway for the Dying Patient (LCP) framework, and an International Reference Group for the global development of the LCP has been constructed. The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life.

A parallel evaluation, to examine the challenges involved and the successes achieved in inter-professional and international collaborative working, identified that the OPCARE9 group were operating at a level far in advance of their projected development and suggests that future collaborative projects emanating from the OPCARE9 collaborative will develop from a
strong structural and organisational footing.

The two major initiatives in design of the future collaborative working, grounded in the learning emerging from the developments within OPCARE9, are:

- The International OPCARE Research Collaborative (IORC)
- The International Liverpool Care Pathway - Reference group (ILCPRG).

These groups commit themselves to sustain the political debate, undertake collaborative research, and make a difference to care of the dying in Europe and beyond. The ambition is to build on the local and national research projects emanating from OPCARE9, developing a European (and beyond) wide cohort study - "Dying in Europe".

Project Context and Objectives:
OPCARE9 was a European collaborative project to optimise research for the care of cancer patients in the last day of life. It was a 3 year EU FP7 Co-ordination & Support Action grant. Through systematically investigating current practice across a range of healthcare environments and diverse cultures, it shares the existing knowledge base and identifies knowledge gaps to reach consensus positions on optimum care and develop innovative research protocols to address identified needs. The project does this within an international collaborative framework, across Europe and beyond, integrating knowledge from a range of healthcare environments and cultures (Table 1.1). Collaborations, such as OPCARE9, are an efficient way of organising people and resources to provide mechanisms to share information, tap new knowledge sets and increase opportunity for creating new approaches that may not be possible from working alone.

Table 1.1 OPCARE9 Beneficiaries

<table>
<thead>
<tr>
<th>Beneficiary Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Marie Curie Palliative Care Institute, University of Liverpool UK</td>
</tr>
<tr>
<td>2 Cologne University Germany</td>
</tr>
<tr>
<td>3 Erasmus MC, University Medical Centre Rotterdam Netherlands</td>
</tr>
<tr>
<td>4 National Cancer Research Institute, Genoa Italy</td>
</tr>
<tr>
<td>5 Stockholms Sjukhem Foundation Sweden</td>
</tr>
<tr>
<td>6 University Hospital for Respiratory and Allergic Diseases, Golnik Slovenia</td>
</tr>
<tr>
<td>7 Cantonal Hospital St Gallen Switzerland</td>
</tr>
<tr>
<td>8 Pallium Latinoamerica (NGO) Argentina</td>
</tr>
<tr>
<td>9 Arohanui Hospice New Zealand</td>
</tr>
</tbody>
</table>

The project consolidates and further develops an established collaboration around a specific programme to improve care in the last days of life - the Liverpool Care Pathway for the Dying Patient (LCP). Accordingly, OPCARE9 provided a rich and
dynamic interface for health care providers, educators and researchers within the field of palliative care and beyond.

The OPCARE9 collaborative was represented by researchers from clinical areas including medicine, nursing, pharmacy, psychology, education and other related areas such as epidemiology, sociology, social work, health research, ethics and law. This multinational and multi-professional project team worked in collaboration to integrate knowledge from a wide range of healthcare environments, addressing cultural diversity whilst also seeking to avoid the duplication of resource and effort.

This report will highlight the structure, organisation and outputs of the OPCARE9 project. The introductory chapter will outline the background to the project and detail the organisational approach taken to deliver on the identified objectives. Following this, summaries of the 5 primary Work Packages, and 2 executive Work Packages, will be presented. A final discussion will contextualise the findings from the project and consider opportunities to build on the outputs and established collaborative networks that have been generated by OPCARE9.

1.1 Background

The need for a coordinated approach to the structuring and development of end of life care services for cancer patients is perhaps most evident in the rapidly changing population demographics. For example, projections indicate that across Europe, median age will rise from 75.1 years to an estimated 81.2 years by 2050, and that the proportion of the population over the age of 65 will rise from a current 16.3% (119, 134) to 27.8% (189,118). These projections highlight an emerging burden of need, likely be exacerbated by an increasing demographic imbalance, placing healthcare systems across Europe under considerable strain.

Old age brings with it an increased risk of chronic disease such as cancer, respiratory disease and heart failure. Despite advances in treatment, the increasingly elderly population will require a wider range of integrated specialist interventions due to increased incidence of chronic co-morbidity in their final years, months and days. Cancer already makes a considerable contribution to the global disease burden and in 2002, 45% of all worldwide cancer deaths occurred in people aged 65 or older. The need for the development and implementation of health care policies and strategies focussed on end-of-life care for an ever increasing elderly population, including a growing number of elderly cancer patients, is starkly apparent.

There is a pressing requirement for palliative care, and care specific to the final days of life, to be enhanced and made available in all care settings before the weight of these needs become "unmanageable." Crucially for health care planners it should be noted that "if appropriate measures are implemented in time, population ageing does not inevitably lead to significantly higher health care expenditure." Accordingly, the WHO has expressed concern at the relative neglect in the stratified development of palliative care services paralleled by a concomitant "lack of awareness and knowledge of the scale of the problem. The slow pace of development is a concern for all as research indicates that cancer patients continue to experience "pain, physical suffering, helplessness, loneliness and marginalization" needlessly, due to "underassessment and under-treatment of their problems and lack of access to palliative care." Thus understanding the needs and challenges faced by cancer patients and their families in the last days of life has the potential to drive the improvement of care for a sizeable proportion of our population.
1.2 Objectives

The aim of OPCARE9 was to reach consensus positions, based on current practice and available research evidence, on the optimum care to be delivered in the last days of life to cancer patients and to identify gaps in the knowledge base within 5 primary themes.

- Signs & Symptoms of Approaching Death
- End of Life Decisions
- Complementary Comfort Care
- Psychological & Psychosocial support
- Voluntary Service

Subsequently, it was envisaged that the project would result in the development of innovative research methodologies and protocols to address identified gaps in knowledge through future international collaboration.

1.3 The Process

Conducting robust research with patients in the last days of their lives and their families is fraught with moral, ethical, methodological and practical challenges. Consequently, there is little evidence on which to base appropriate organization and service delivery. Understanding the needs of patients, informal carers, volunteers and health care professionals is vital as sub-optimal care in the last days of life can lead to poor symptom control for patients, reduced job satisfaction for staff, poor adjustment to bereavement and formal complaints from bereaved relatives.

Undertaking a review, systematically and collaboratively, with research active institutions across the EU (and beyond) has ensured a comprehensive and robust approach to the care of cancer patients in the last days of life and avoided unnecessary duplication of effort and resource.

1.4 Primary Work Packages

The project explores and shares existing knowledge and practice in 5 primary Work Packages commensurate with the identified themes:

- WP1 Signs & Symptoms of Approaching Death
- WP2 End of Life Decisions
- WP3 Complementary Comfort Care
- WP4 Psychological & Psychosocial support to patients, families, caretakers
- WP5 Voluntary Service

Each primary Work Package was facilitated by a specific host nation, with an identified Work Package lead (WL). Work Package leads were supported by a Scientific Project Assistant (SPA), who assisted in the structuring of the scientific tasks and
methodological processes that required attention from the Work Package members. Each Work Package had representation from all of the nine partner countries: the Work Package members (Appendix1).

Project Results:

2. OPCARE9: Work Package 1 - Signs and Symptoms of Approaching Death

Achieving best care of the dying should be recognised as a core clinical proficiency and an integral part of comprehensive cancer care, as basic as diagnosis and treatment. Patients during the dying phase should be supported properly, integrating technical expertise with a humanistic and ethical orientation. “Diagnosing dying” is regarded as a core competency during this process. Current pathways, such as the Liverpool Care Pathway for the dying patient (LCP), provide a framework that can support the clinicians in the process of identifying the beginning of the dying phase. However, the supportive evidence base requires development.

Limited research has been conducted to determine whether a core set of signs and symptoms are routinely seen in patients as they enter the last days of their lives. Such information is imperative for practice, as failure to recognise and respond to the dying phase (diagnosing dying) can lead to sub-optimal care. Accordingly, there is a need to identify whether a consensus (based on current practice and available research evidence) on what are the most useful signs and symptoms of approaching death exist. This will assist in facilitating the initiation of appropriate care delivered in the final days of life. Further, where evidence is lacking, innovative research studies need to be developed to clarify the situation.

Accordingly, the following objectives of this Work Package were:

* To identify and collate a list of signs and symptoms that are associated with approaching death

* To systematically evaluate the available evidence for these signs and symptoms

* To develop protocols for future research to enhance the existing evidence base for signs and symptoms

* To identify tools and technologies currently available to screen and predict approaching death

* To systematically evaluate the evidence for each tool and/ or technology in order to provide a useful resource for clinical and/ or research use

* To develop protocols for future research to enhance the existing evidence base for prognostic indicators in care of the dying

* To review the current criteria for diagnosing dying on the LCP and make recommendations regarding modification and development of the pathway

2.1 Organization and collaboration: Work Package 1

Work Package 1 (WP1) has been conducted in collaboration between the Centre for Palliative Care, Cantonal Hospital St.Gallen in Switzerland and the Regional Palliative Care Network at the National Cancer Research Institute, Genoa in Italy. The Work Package lead (Dr Steffen Eychmüller) and SPAG members (Franziska Domeisen, Stefanie Schuler) prepared and structured all
WP activities. Tasks and responsibilities were stratified in regard of the "triplet" methodology:

a. Team A: Delphi process

b. Team B: Systematic literature review

c. Team C: Review of non-scientific literature

Country representatives from each OPCARE9 country actively supported and advised the Work Package 1 team throughout the project processes.

2.2 Challenges: Definition of the dying phase

Results from the project indicate that no common definition of the dying phase can be found. This is true neither for the literature nor for the expert opinion as captured by the Delphi process.

There might be two directions to work on in the future: a timely definition of the dying phase, or the definition of this phase by needs - needs by patients and carers. For the purpose of this project, a timely definition - "the last days" (up to seven days) of life have been chosen as a working definition for Delphi and Review.

After deliberation, two questions guided and informed the focus of the WP:

1. Which phenomena are considered to identify that somebody is in the last days of life?

2. Are these phenomena predictive for having only a few more days to live?

2.3 Methodology

An extensive search strategy was engaged, combining three different methods:

1. A systematic literature review (SLR)
   i) signs and symptoms of approaching death
   ii) tools and technologies

2. A three cycle Delphi survey asking professional experts and non-professionals accessed by the OPCARE9 collaboration

3. A systematic search strategy to screen available information from non-scientific literature (public library, internet fora, google)
2.4 Results - 1. Systematic literature review

From an initial 5602 hits in step 1, the systematic process employed resulted in 12 articles being included for final analysis. In addition, two separate lists of tools/instruments and technology were generated, one for assessing signs and symptoms of approaching death and another to accurately predict dying.

2.5 Results - 2i. Delphi

As a result of the Delphi process three different lists of phenomena or more specifically of "signs and symptoms of approaching death" were generated:

- A broad list of phenomena, observations or perceptions which seem to be important to identify that somebody is dying (n=194)

- A reduced list of important phenomena and "signs and symptoms" respectively highlighting the recognition of the last days of life (n=59)

- A final list of ranked phenomena and "signs and symptoms" respectively relevant to predict that someone will die within the next few hours/days (n=21) (See table 2.1).

In terms of categories, dying can be diagnosed based on expert opinion by assessing:

- Changes in breathing: change in breathing patterns

- General deterioration

- Lowering of consciousness

- Caregivers' clinical judgment

- Lowered oral intake

Table 2.1 : Ranked phenomena for predicting the entering of the last days of life

2.6 Comparison of outcomes systematic literature review and Delphi

Compared to the list resulting from the Delphi survey, phenomena such as laboratory values (low albumin, LDH
concentration), performance status (distinct daily activities, mobility), oliguria, oedema and number of metastatic sites were only identified by the systematic literature review. Pain and fever are phenomena identified by exclusively by Delphi 1.

2.6.1 Results - 2ii. Tools/technologies assessing the dying phase & accurately predicting dying

A list of 37 tools/ instruments has been collated. Several tools identified, such as the Karnofsky Performance Scale; Euro-QoL (EQ-5D: 5 items), MDS (Minimum Data Set), QLQ-C30 (Quality of life questionnaire), Profile of mood states (POMS), Impact of event scale (IES), Centre for epidemiologic studies-depression (CES-D), Positive states of mind (PSOM), have been studied and tested for:

- Predicting survival in patients with terminal cancer in combination with medical data
- Validity to predict mortality risk
- Psychosocial outcomes and survival

No single tool or technology has been developed and tested for the specific purpose of diagnosing dying or predicting the entering of the last days of life.

2.6.2 Results. 3 - Review of non-scientific literature

Non-scientific literature was reviewed, accessed via a variety of strategies: e.g. Local and City Libraries, Popular Literature, Journals/ Magazines, Internet Bookshops. Search engine (google.ch/.de/.com). The non-scientific literature contained phenomena related to communication patterns not identified by either the Delphi or Systematic review. This indicates a potentially important difference in the “known” phenomena predicting death and dying between the professional views and the lay literature. The perspective of lay carers is rarely systematically assessed and not included into scientific reviews on end of life issues.

2.7 Development of future research protocol

The aim of a future study is to construct and test a tool to estimate the sensitivity and specificity of a set of criteria/ dimensions in recognizing imminent death (defined as 7 days in a population of terminal cancer patients) in different settings of care (home care, hospital, hospice and nursing home).

Research Question/ main hypotheses are:

- Which clinical phenomena identified by prior research are predictive for the dying phase, and is it possible to compose a diagnostic test based on such phenomena?

- There are a number of clinically relevant phenomena specific for the dying phase which needs to be assessed regularly (“day by day”) by an inter-professional care team.
- A diagnostic test for entering the dying phase (last 7 days of life) can be developed and will identify the dying phase more accurately than other prognostic tools already available.

2.8 Critical Friend

Dr Paddy Stone provided many erudite challenges for the Work Package team to consider, and an engaging discussion has helped refine the thinking around the development of potential research protocols. Dr Stone commented:

- "Having undertaken a thorough and systematic review of the literature and a Delphi process the WP1 team have produced a draft research proposal to develop a new tool to "diagnose dying". The proposal appears to be well conceived and will address an important issue for palliative care clinical practice."

2.9 Conclusion

Although health care professionals often fail to recognize the entering of the dying phase, the results of this Work Package suggest that some consensus exists on phenomena which may help remedy this challenge.

A three cycle Delphi process enabled the compilation of a list of signs and symptoms (phenomena) being clinically relevant to recognize and identify the last days/ hours of life. Categories, such as changes in breathing, general deterioration, lowering of consciousness, caregivers' clinical judgment and lowered oral intake are considered to be most meaningful.

The results from systematic literature review show that various signs and symptoms of approaching death have been investigated. Some of those seem to be helpful in identifying imminent death. Nevertheless, there is evidence that health care professionals fail to recognize the entering of the dying phase. Results from non scientific-literature search suggest a possibly important difference in the phenomena predicting death and dying. Perspectives by lay carers and family should be actively included into further research.

Prognostic tests such as the Palliative Prognostic Score (Pap Score) and Palliative Prognostic Index (PPI) have been developed to accurately predict survival in terminally ill cancer patients and have been validated widely, but they are not specific to the imminent diagnosis of dying. In addition, none of these tests seem to be based on a broad literature review, taking into account that "dying" is not solely a medical problem. No single tool or technology has been developed and tested for the specific purpose of diagnosing dying or predicting the entering of the last days of life.

Defining the dying phase, not only by time but also by needs, will remain an ongoing and important task that must be linked directly to the needs and views of the population rather than professionals only. Based on the current review there is little evidence that phenomena in the dying phase differ between cancer and non-cancer so far, but future research is needed to strengthen this view.

2.10 Potential Impact

This project has accessed the best available evidence as a basis for further development and research. It is hoped that the proposed research protocol on developing a new tool to "diagnose the dying phase" will close an important gap, and feed back into current best practice in end of life care; e.g. the Liverpool Care Pathway (LCP). Furthermore, a better understanding of multiple phenomena at the very end of life may help to reduce fears and myths within the broad public. Such development is needed to avoid "medicalisation" of dying and death - a major challenge in our aging societies.

2.11 Observations - Support & Collaboration
The Work Package team consider the impact of this European (and beyond) collaboration project as both exceptional and vital for "capacity building" in end of life research in Switzerland. This is in relation to the research capacity and competency within our centre for palliative care, but also in regard of national and international collaboration. In addition, the project has helped to dramatically enhance the basis for future research projects and collaborations within and around our centre and national reference group. This is especially true for services, such as ours, that has a clear focus on clinical care (biggest palliative care service in Switzerland) but a far less developed academic background.

Project Deliverables

D 1.1 Month 37 Final report

Signs and Symptoms of approaching death: Final report

D 1.2 Month 37 A minimum of one article for publication


D 1.3 Month 37 A minimum of two presentations for future national/international conferences

Eychmüller S, Domeisen F. Presentation of Community Palliative Care research protocol at Annual Meeting of the International Primary Palliative Care Research Group in Lisbon (EAPC) in May 2011.

Eychmüller S, Domeisen F. Diagnosing dying - challenging the Liverpool Care Pathway. Abstract submitted to DGH0, Annual congress in Basel (CH). September/ October 2011

Eychmüller S, Domeisen F. Diagnosing dying - challenging the Liverpool Care Pathway. Abstract submitted to Palliative.ch Annual congress of Swiss Palliative care association in Biel (CH). November 2011

D 1.4 Month 37 A minimum of one protocol for future research to enhance the evidence base for end of life decisions

Protocol title: "Diagnosing dying" - development of a tool for identifying the last days of life

Authors: Eychmüller S, Costantini M and Domeisen F.

3. OPCARE9: Work Package 2 - End of Life Decisions

End of life care often requires difficult ethical decisions by the patients, their families and the clinical team. Numerous challenges exists, such as the use of deep sedation to control symptoms, withholding and/or withdrawing life sustaining treatments such as artificial hydration and feeding, ventilation and dialysis, and discussions and decisions around resuscitation
in the event of cardiac arrest. Robust research evidence concerning the effects of withdrawing/withholding treatments is relatively scarce and, at best, inconclusive. Here, as in all aspects of care at the end of life, cultural diversity (both within and between participating countries) impacts on such decisions and the opportunity to share and debate current knowledge with colleagues across Europe (and beyond) is invaluable.

The aim of this Work Package was to assess current practices around end-of-life decision making in the beneficiary countries, to establish the available evidence that can support end-of-life decision making, and to identify difficult issues in end-of-life decision making for which more evidence-based guidance might be useful. Accordingly, the Work Package objectives were;

* To collect and collate information regarding the key end of life decisions undertaken within beneficiary countries
* To explore cultural and legal differences and similarities within the beneficiary countries
* To identify and evaluate existing evidence regarding the effects of such end of life decisions on patients, carers and health care professionals
* To identify tools/technologies currently available to support the making of such decisions
* To systematically evaluate the current evidence base for such tools/technologies
* To identify and evaluate any current quality indicators for the making of such decisions
* To develop protocols for future research to enhance the evidence base for end of life decision making
* To review the LCP in relation to end of life decision making and make recommendations for its modification and development

3.1 Organization and collaboration

Work Package 2 has been led from the Dutch team from the Erasmus Medical Centre in Rotterdam. The Work Package leads (Dr Lia Van Zuylen and Dr Agnes van der Heide) and Scientific Project Assistant (Natasja Rajmakers, MSc) prepared and structured all WP activities. Country representatives from each OPCARE9 country were regularly consulted for advice and agreement, and also provided the entrance for the Delphi study to the national reference groups.

3.2 Challenges: Defining “end-of-life” decisions.

The first step for the Work Package was to find a common definition of what constitutes an end-of-life decision, to establish a shared base for this international collaboration. Through consultation, discussion and refinement, the Work Package members agreed on the following definition:

- A decision involving a person who is in the last days of life that has (may have) a significant impact on the quality, place and/or time of dying.

The definition is limited to persons who are in the last days of life as this is the focus of the OPCARE9 project. Subsequently, an inventory was made with the support of the national reference groups from the beneficiary countries of the end-of-life decisions that they considered most important.
3.3 International Inventory

The most frequently mentioned topics could be categorized in five groups:

1) withdrawing and/or withholding of medical treatment
2) symptom management
3) place of death
4) information & communication
5) social/relational issues

In the category withdrawing/withholding of treatment, artificial nutrition (AN) and artificial hydration (AH) were the most frequently mentioned topics, followed by stopping anti-cancer treatment. In the category symptom management, using sedatives was most frequently mentioned. Based on the inventory, decisions regarding the use of artificial nutrition, artificial hydration, and sedatives were chosen to serve as templates for further studying end-of-life decision making.

3.4 Methodology

The methods used to address objectives of the Work Package include:

- Literature review: systematic review
- Expert consultation: Delphi.

The inventory of end-of-life decisions was used to determine the focus for a systematic literature review and of a Delphi study. The focus of the systematic literature review consisted of decision making on whether or not to provide artificial nutrition (AN) and hydration (AH) at the end of life. Specific questions addressed were:

1) how and how often are AN and AH provided in the last week of life of cancer patients
2) what is the effect of AN and AH during the last week of life on symptoms, comfort and quality of life of cancer patients
3) does providing or not providing AN and AH hasten death or prolong life?

The focus of the Delphi was extended to include artificial nutrition and hydration and the use of sedatives at the end of life.

Besides the systematic literature review and the Delphi process, we also made an international inventory of legal frameworks and tools & technologies, i.e. protocols and guidelines, related to end-of-life decision making. All results were used to assess current practices and levels of knowledge and to define important, internationally relevant research questions and protocols.

3.5 Results - Systematic review

From an initial 2198 articles identified from the electronic databases, the systematic selection process yielded 15 papers for inclusion in the review. Reported percentages of patients receiving AN or AH in the last week of life varied from 3% to 53%
and from 12% to 88%, respectively. Five studies reported on the effects of AH: two found positive effects (less chronic nausea, less physical dehydration signs), two found negative effects (more ascites, more intestinal drainage) and four found also no effects on terminal delirium, thirst, chronic nausea and fluid overload. No study reported on the sole effect of AN.

Providing AN or AH to cancer patients who are in the last week of life is a frequent practice. However, the effects on comfort, symptoms and length of survival seem limited. Further research will contribute to better understanding of this important topic in end-of-life care.

3.6 Results - Delphi

Two rounds of Delphi were conducted. The first round established the commonest issues related to end-of-life decisions, and the most frequently mentioned issues related to;

1) medical aspects, such as futility of treatment and side effects
2) how to address patients' wishes
3) how to address relatives' wishes.

Other issues were related to; decision making, professional caregivers wishes, ethical issues, (such as autonomy of patient, hastening death), practical issues (such as insurance problems, cultural issues (such as the role of nutrition in a specific culture) and legal issues, (such as capacity of patient to decide when in low consciousness state).

The second round of the Delphi aimed to establish what further knowledge is required to end-of-life decision making. In total 55 experts responded (response rate 61%), identifying that the most important issues in need for more knowledge were:

1) Optimal strategies for communication with patient and relatives about needs and wishes
2) Appropriate indications for using sedatives in the last days of life
3) how to improve multidisciplinary medical decision making
4) effects of (de)hydration on patient comfort and quality of life.

Communication with terminally ill patients and relatives on end-of-life decision making is a challenging issue that could benefit from future research. Additionally, more evidence is needed on indications for and effects of providing or withholding specific medical treatments during the dying phase, such as artificial hydration or sedatives. These results serve well to prioritize future research for optimizing the care of the dying.

3.7 Tools & technologies: for end-of-life decision making

A review of the existence of, and support for, national protocols in end-of-life decision making was also undertaken to highlight differences and similarities (Table 3.1). All guidelines were the result of expert opinion. Only the Dutch guidelines integrated some evidence from research studies.

Table 3.1 - Availability of national protocols and guidelines on end-of-life decision making
3.8 Inventory of laws & legal frameworks

Differences and similarities between the beneficiary countries regarding legal regulations concerning patients’ legal right to refuse medical treatment, the legal status of advance directives and prohibition of euthanasia, assisted suicide and suicide are highlighted in the full report.

3.9 Development of Future Research protocols

Communication: Based on the work conducted, several research questions have been generated in line with the themes indicated by the international experts. Subsequent to discussion within the Work Package and with the critical friend, it was identified that as communication is an issue important for all (patients, relatives, professional caregivers, volunteers) and this should be the focus for development as it is likely to make a difference in the care for the dying. It is the intention to study different perspectives on, awareness of, and communication about the role of food and fluids at the end of life.

Liverpool Care Pathway: End-of-life decision making is one of the key elements in the Liverpool Care Pathway (LCP) for the dying patient. In the LCP (version 12) detailed prompts focus on assessment of whether artificial nutrition and hydration are indicated or not. It remains to be established that such detailed attention is applicable in other countries, because cross-national and cross-cultural perspectives on appropriate and ethically sound end-of-life decision making may vary.

3.10 Critical Friend

Professor Deliens commented on the validity of the potential outputs of Work Package 2, and the focus of the OPCARE9 project, opining:

"OPCARE9 used an interesting and efficient method to produce similar and complementary outcomes of the different WPs... Different protocols have been discussed... I am convinced that the topics indeed need further and more in-depth research."

"OPCARE9 is focusing on the last days of life. This choice can be defended from a point of feasibility and focus in future research. However this choice yields also some limitations. Improvement of end of life care has not only to be initiated by looking for barriers and facilitators within the last days of life, but very often the seeds for good (or for poor) end of life care have been developed up-stream in the disease trajectory and within the care givers patient and relatives interactions."

3.11 Conclusions

International and multidisciplinary consensus has established core themes in end-of-life decisions as:
- withholding or withdrawing of medical treatment
- symptom management
- communication
- place of death
- relational issues,

This shared interest is an important basis for international collaboration.

A systematic appraisal of the current literature showed that the evidence on the effects of artificial nutrition and hydration in the last week of life on comfort, symptoms and length of survival is limited. This is reflected in the limited number of protocols on artificial nutrition and hydration in place amongst the OPCARE9 beneficiaries. Expert consensus identified that communication on end-of-life care, indications for sedatives, interdisciplinary team decision making and effects of (de)hydration are topics that can benefit from future research; the results of which will contribute to better care for many (all) dying patients and their relatives.

Overall, the results of WP 2 in OPCARE9 serve well to prioritize future research on end-of-life decision making. It both accounts for and expands beyond the medical perspective, and provides a platform for integrating the health care professions to optimize care for the dying within Europe and beyond.

3.12 Potential impact

There is a common base of interest in issues around end-of-life decision making and a shared feeling of current gaps in knowledge despite cultural variety within the EU and beyond. This consensus should empower international cooperation to improve the quality of the evidence base, thus providing the means to improve care.

3.13 Observations - Support and Collaboration

The collaboration between the different countries and professions in this Work Package has been very successful. Over the 3 year project, contact during the colloquia proved to be very helpful in overcoming numerous challenges in communication and design.

This collaboration has led to a site visit of the Arohanui Hospice, Palmerston North, New Zealand, by the Scientific Project Assistant (Natasja Raijmakers). The aim was to plan and check the feasibility of further research, which was successful.

This site visit of the SPA has resulted in:

a) an oral presentation about the OPCARE9 collaboration at the 19th NZ Hospice Conference in Wellington, New Zealand,

b) an oral presentation about the progress of OPCARE9 at the Arohanui Hospice, Palmerston North, New Zealand,
c) attending the national research meeting palliative care NZ,

d) a paper in the national LCP newsletter of New Zealand.

In addition, three bi-lateral collaborations, between the Netherlands and New Zealand, Italy, and the UK have been designed to develop applied research studies that will address the questions generated by this Work Package:

- New Zealand: WP2-members from New Zealand and the Netherlands are planning to conduct a qualitative, comparative participant- observational study in a hospice in New Zealand and a hospice in the Netherlands.

- Italy: WP2-members from Italy and the Netherlands have decided to collaborate on data from a trial that assessed the effects of using the LCP in Italy.

- United Kingdom: WP2-members from the UK and the Netherlands have collaborated on a systematic literature review on the opinions and attitudes of patients, family and professional caregivers towards artificial nutrition and hydration in the last week of life.

Project Deliverables

D2.1 Month 37 Final report

End of Life Decisions: Final Report

D2.2 Month 37 A minimum of one article for publication

As patients enter the last days of life it is important that health care professionals adopt practices to promote patient comfort. This is in accordance with the World Health Organisation suggesting a focus on communication, psychological, social and spiritual care as well as measures to promote the physical comfort of patients through non-invasive, non-technological therapies; such as regular mouth care, bowel care, skin care, and appropriate pain and symptom management (both pharmacological and non-pharmacological). Although the evidence base for clinical care is developing, it is widely acknowledged that more research is needed to investigate symptoms that occur at the end of life. Accordingly, an understanding of the most prevalent systems, including both the severity and the degree to which they are problematic to patients is required.

The objectives of this Work Package were:

* To identify and systematically evaluate the evidence base for appropriate comfort measures in the last days and hours of life
including:

- Symptom control
- Nursing interventions
- Spiritual care

* To determine European consensus on the optimum management of symptoms at the end of life, including:
  - Pain
  - Terminal agitation
  - Respiratory tract secretions
  - Dyspnoea
  - Nausea and vomiting

* To determine European consensus on nursing interventions for care of the dying.

* To identify and evaluate current tools/technologies available to support
  - The measurement of symptom burden
  - The delivery of high quality complementary comfort care

* To develop protocols for future research to enhance the existing evidence base

* To review the LCP in relation to complementary comfort care and make recommendations for its modification and development

* To recommend European quality indicators in care of the dying

4.1 Organization and collaboration

Work Package 3 has been led by the Swedish and Slovenian teams involved in OPCARE9. Due to the scope of the Work Package objectives, three areas of investigation were operationalised;

* Pharmacological interventions

* Non-pharmacological care-giving activities

* Spiritual care.
Although delineated for investigation, pharmacological, non-pharmacological and spiritual care is viewed as integrally linked in the provision of “total care” for “total pain.”

The Work Package Lead (Prof Carl Johan Fürst) and Scientific Project Assistants (Dr Carina Lundh Hagelin & Dr Olav Lindqvist) prepared and structured all WP activities for pharmacological and non-pharmacological care. Dr Urska Lunder facilitated Work Package activities relating to Spiritual care. Representatives from each OPCARE9 country formed the core membership of this Work Package.

4.2 Challenges

Discussion within the Work Package, examining relevant knowledge and potential knowledge gaps, indicated that the practical and/or legal availability of relevant drugs and widespread implementation of good practice was a more salient issue than a review of literature on drugs for symptom control during the last days of life.

For non-pharmacological care-giving activities (NPCA), recognition of the limited systematic data on NPCA in the last days of life, led to a “free-listing” approach to explore the variation of practice in non-pharmacological care, to obtain guidance for future research.

4.3 Methodology

Following a survey of current drug use in 26 palliative care units, a two-stage Delphi method was employed: Stage 1) for building consensus on the use of necessary drugs, and Stage 2) to explore experts' views on drugs that are difficult to withdraw during the last days of life. The results provided a basis for a strategic literature review.

The free-listing exercise sought to identify the variety of non-pharmacological care-giving activities (NPCA) carried out by different professionals during the last days of a patient's life. Data was recorded by asking staff in each country to think and document practice activities over a 4 week period. Based on these NPCA’s, a strategic review of literature about supportive environments for the dying was performed and senior researchers were invited to generate research questions.

The concepts existential and spiritual care lack generally-accepted and consistent descriptions. Keeping this in mind, a literature search was performed for review articles regarding the existential and spiritual dimensions of care during the last days of life. Article summaries were then sent to a diverse sample of relevant experts in the OPCARE9 countries, who were asked to brainstorm new research questions to complement the extant literature.

4.4 RESULTS

The results are presented below.

4.4.1 Pharmacological Interventions.

The first round of the Delphi sought to: 1) identify drugs seen as essential in the last days of life, and 2) identify drugs and therapies seen as difficult to withdraw.

The most common first choice drug per symptom was:

- Anxiety: midazolam

- Dyspnoea/breathlessness: morphine
- Nausea and vomiting: metoclopramide
- Pain: morphine
- Respiratory tract secretions: hyoscine
- Terminal restlessness and agitation: midazolam (38%), haloperidol (38%).

The participants reported 334 drugs and therapies as difficult to withdraw, with 86% of responses concerning drugs for particular diagnoses (e.g. heart failure, Chronic Obstructive Pulmonary Disease drugs) and therapies perceived as potentially not medically necessary, but difficult to withdraw when patients or family perceive these to be necessary (e.g. oxygen and artificial hydration/nutrition).

The second Delphi round had the primary aim of forming consensus around a maximum 5 essential drugs from the list generated in the first Delphi and to explore further difficulties of withdrawing drugs.

- There was a high degree of consensus, with physicians regarding morphine, haloperidol and midazolam as essential. There was no clear consensus about drugs for respiratory tract secretions. Based on this Delphi, an essential drug list for broad use in non-specialised palliative care settings should consist of morphine, haloperidol, midazolam and an anticholinergic drug.
- A number of types of drug were perceived as difficult to withdraw due to a lack of evidence around the potential effects. In the main, these included antiepileptics, corticosteroids, drugs for use in diabetes and antithrombotics.

A literature review was conducted to examine existing knowledge on the pharmacological and physiological effects of drug withdrawal in the last days of life focusing on antiepileptics, corticosteroids, drugs used in diabetes, and antithrombotics.

4.4.2 Non-pharmacological care-giving activities:

The free-listing exercise identified a total of 985 NCPA's. An underlying feature in many NPCA is the effort to provide personalized and compassionate care through 'maintaining connections to the individual's everyday life'. Even refraining from action was described as a purposeful part of care provision. Analysis also indicated that many NCPA's were aimed at creating an aesthetic, safe and pleasing environment for the dying person and his/her family. The descriptions of NPCAs often appeared to seamlessly address bodily, spiritual, existential, psychological and social dimensions, and were often carried out in an integrated manner.

A literature review was conducted entitled "Supportive Environments in Palliative Care", guided by the question: What is known about the impact of sensory environment on patients' sense of well-being in palliative care?

4.4.3 Spiritual/existential support:

Fourteen review articles were identified, with five excluded as irrelevant in context. Although no article focused specifically on the last days of life, major themes identified included:

- Dignity - including what is important to the person as an individual and in relationships with others, what they value, and provision of 'dignity-conserving care'.

- Existential loneliness - , including interventions addressing this
- Integrated care - how spiritual/existential care can be provided through attending to a dying person's body.

4.5 Tools and technologies

Tools and Technologies (T&Ts) are means to facilitate comfort of the dying patient. A secondary analysis of the NPCA data from 16 settings in the nine OPCARE9 countries was performed, with the following examples of T&Ts used in one or more settings:

1) Mechanical devices: catheters; subcutaneous- or venous accesses; syringe-drivers; bed rails, etc. Other non-mechanical T&Ts used include: blankets; towels; perfume; light; music; pillows, etc.

2) Measurement and Assessment: fever thermometer; anamnesis of needs for the terminal phase. Other assessments described were of skin integrity; signs of discomfort through assessing body movements and facial expressions, etc.

3) Care pathways: Liverpool Care of the Dying Pathway

4) Other systematic approaches: written information; registration of death; systematic use of communication as evidence of conscious application of a palliative philosophy.

Although often defined and understood as mechanical devices and standardized measurement tools, this view is too limited for relevance in comfort care of the dying. In actuality, technologies used in the last days of life for comfort were primarily "low-tech" and readily available e.g. pillows, blankets, sheets, sound, light and aromas. Therapeutic use of staff providing care also is described as one of the foremost 'tools' (also called 'soft technologies') for comfort care as death becomes imminent.

4.6 Development of future research protocols

Three research protocols have been developed.

4.6.1 Pharmacological Interventions:

Based on the work results of the survey and two-stage Delphi, numerous areas for research development have been identified. Accordingly, a core research proposal has been developed to address the challenges outlined: "Withdrawal of drugs in the last week of life in cancer and palliative care".

4.6.2 Non-pharmacological care-giving activities:

As with Pharmacological interventions, numerous (over 150) research questions were generated. Based on these data a trans-disciplinary research project for sensory environment has been developed, with a feasibility study now underway: "Experiencing sensory environment at the end of life".

4.6.3 Spiritual/existential support:

Summaries of the reviewed articles were distributed to representatives of all OPCARE9 countries for discussion and dissemination to a sample of multi-disciplinary experts in the field from each respective country, to generate new research questions. From Sixty-two returned research questions, an overarching research proposal was formulated - "Exploring spiritual/existential care in the last days of life as experienced by patients, family members and staff in different settings and cultures".
4.7 Critical Friend

Critical discussion with Dr Julia Downing provided some challenges to the Work Package on conceptual and organisation aspects. For example, it was suggested that developed protocols could have wider international participation by utilising the networks nurtured through the OPCARE9 project. Accordingly, Dr Downing emphasised that "it is important to see this bigger picture and where the specific research sits" in order to promote improved care on a global axis.

4.8 Conclusions

There is a high level of consensus about appropriate pharmacological care for common symptoms in the last days of life among physicians in specialized palliative care. However all the recommended drugs are not presently available in all countries and care settings. Further, there are specific knowledge gaps in regard to drug withdrawal in the last days of life and these points to an important area for new, basic research and applied research.

A wide variety of refined and seamlessly integrated care-giving activities addressing fundamental and comfort needs of dying persons in the last days of life have been identified. However, the lack of a consistent common language to describe NPCAs hinders development of knowledge.

Limited research-based literature was identified which directly addressed spiritual/existential issues in the last days of life, through the search strategies used here. There is a notable lack of conceptual clarity in the existing literature on spiritual/existential care, which suggests a need for a conceptual analysis from different stakeholder perspectives.

4.9 Potential Impact

The consensus found in regard to appropriate pharmacological care for common symptoms, there is a potential to develop recommendations for standard care of patients with cancer approaching death. However, the lack of accessibility to different drugs in some countries and settings is an important factor, highlighting potential inequities. Nevertheless, the consensus on essential drugs for symptom treatment in the last days of life can provide a means of exerting pressure toward constructive change in local, regional, and national drug policies, as well as a basis for minimum standards of care.

While palliative care can now ameliorate many types of symptom distress, consensus is still lacking about the knowledge-base and skill-set needed to recognize, assess and compassionately address existential and spiritual aspects of the dying experience. An area notably lacking in most literature and of particular interest for future research is the relationship between bodily care and spiritual/existential comfort. Increasing knowledge in this area has already contributed to constructive suggestions on the revisions to the Liverpool Care Pathway.

Crucially, the three aspects examined in this Work Package have a complementary rather than hierarchical relationship in the provision of comfort care for the dying person and his/her family.

4.10 Observations - Support and Collaboration

Although OPCARE9 is focussed on cancer, the importance of disseminating knowledge from cancer-related end-of-life care to care-giving situations involving dying patients with similar needs is paramount, e.g. care in long-term residential facilities. In such settings, knowledge and professional resources are not as extensive as in specialized palliative care facilities. The importance of staff with competence in both non-pharmacological and pharmacological end-of-life care has become evident.
from the results generated from this Work Package.

Another key implication of the OPCARE9 collaborative is the development of a well-functioning network of professionals, without prior collaboration, within Sweden. This group is able to unify northern rural areas and the urban capital region, despite large distances, and will continue to work together in the future. One practical outcome of this new collaboration is a cluster randomized controlled trial investigating use of LCP in residential care homes in northern Sweden. Our group can function as a platform for further international collaboration to continue to optimize research for the care of patients with cancer in the last days of life.

Project Deliverables

D3.1 Month 37 Final report

Complementary Comfort Care

D3.2 Month 37 A minimum of one article for publication


D3.3 Month 37 A minimum of two presentations for future national/international conferences
4. OPCARE9: Work Package 4 - Psychological and psychosocial support for patients, families and caretakers

Psychological and psychosocial support (PPS) is an essential element of the "total" care philosophy, contributing to addressing the patient as a whole and enhancing quality of life of patients, their families and caretakers. However, the opportunity for in-depth psychological and psychosocial assessments and interventions is often limited in the last days of life. Nevertheless, interventions exist that may prove to be of benefit.

Psychological support is not only offered by psychologists, but by a range of professions. Endeavours to improve these aspects of palliative care have been undertaken in recent years. However, there is still lack of knowledge regarding the psychosocial needs of patients, relatives and their caretakers in the dying phase.

The aim of this Work Package was to facilitate debate on what constitutes appropriate supportive communication with patients in the final days of life. It aimed to establish both the research base and expert consensus regarding methods for engaging in such communication to provide guidance on appropriate ways to identify patients' and families' psychological and psychosocial needs. It also sought to develop innovative research protocols to further understanding in this area.

Accordingly, the Work Package objectives were:

* To identify and systematically evaluate the evidence base for the prevalence of psychological and psychosocial issues for:
Patients in the final days and hours of life

Those of their families and caretakers

* To identify and systematically evaluate current evidence regarding appropriate communication in the dying phase around issues such as recognition of dying with:

Patients

Families and caretakers

* To explore cultural differences, similarities and existing approaches to the identification of need and delivery of care

* To identify and systematically evaluate current tools/technologies to support

The measurement of psychological and psychosocial support needs for patients, families and caretakers

The delivery of high quality psychological and psychosocial support for patients, families and caretakers

* To identify and systematically evaluate any existing Quality Indicators for the measurement of need or delivery of care

* To develop protocols for future research to enhance the existing evidence base

* To review the LCP in relation to psychological and psychosocial support and make recommendations for its modification and development

* To recommend European quality indicators in care of the dying

5.1 Organization and collaboration

Work Package 4 has been led by the German team from the University of Cologne. The Work Package Lead Prof Raymond Voltz, with the support of Prof Christophe Ostgathe and the Scientific Project Assistants (Maren Galushko, Dr Ovidiu Popa-Velea and Vanessa Romotzky) prepared and structured all WP activities. Country representatives from each of the OPCARE9 beneficiaries participated in the core Work Package activities.

The aim of this WP was to use experts' view and evidence out of the literature to explore psychological and psychosocial support (PPS) for cancer patients in the last days of life and their relatives. Systematic review (SR) and Delphi methods were used to address the following research questions:

1) What is the perspective of experts on psychosocial, psychological and social support in the last days of life?

2) What topics and areas have been addressed in research so far in psychosocial, psychological and social support in the last days of life?

5.2 Methodology
Delphi: Three Delphi rounds on PPS were conducted with experts (i.e. experienced professionals working in the field of palliative care).

- Delphi 1 - explored the definition of PPS, persons who can deliver PPS and who should receive PPS in the last days of life.

- Delphi 2 - explored the needs of patients, relatives, staff and volunteers for different levels of support and aimed to identify the most important tasks for health professionals and volunteers in giving PPS. Additionally, consensus was sought on the provided working definitions (Table 5.1)

- Delphi 3 - addressed the responsibility of delivering PPS tasks in different countries, appropriate communication, measurements of distress and interventions, important issues for social support and future research.

Table 5.1 - Descriptors for Psychological and Psychosocial Care

Category Support

Specialised Psychological support / care that can only be delivered by specially trained mental health professionals (psycho-oncologists, psychotherapists, psychiatrists, etc.) - including therapeutic interventions such as cognitive behavioural therapy, systemic therapy, psychoanalytical interventions, etc.

Psychosocial support / care support that all health professionals (including specialists) should be able to deliver, including: being present; listening; giving room for the expression of strong emotions as well as providing contact to care / nursing teams; referring to hospices / specialists / chaplains, etc.

Psychological support / care support that can be delivered by health professionals with advanced training, including: using psychological techniques as patient-centred communication, problem solving, relaxation etc.

Social support support that can be given by social workers (or national equivalent) including: organizing further care; counselling in financial and legal issues, etc.

Relatives (family & friends) support given by family and friends, including: being present; listening; giving room for the expression of strong emotions, etc.

Systematic review: The aim of the systematic review (SR) was to identify and document the focus of research studies investigating PPS for cancer patients and their caretakers in the patients' dying phase.

5.3 Results

5.3.1 Delphi Survey:

Delphi 1 - The main tasks identified by the experts were to:

- support expressing and handling emotions, working on relationships
- reaching acceptance or reconciliation

- addressing existential issues and saying goodbye.

It was also assumed by the majority of experts that every palliative care team member and volunteer should be trained in providing basic PPS. For complex situations they considered specialised mental health professionals with additional training in palliative care to be important. This service should be part of every specialised palliative care team.

Delphi 2 - Consensus on the definitions of "specialised psychological support" "social support" and "psychological support" was established. Additionally, key tasks and issues for PPS were consensually agreed and conditions for delivery (Table 5.2)

Table 5.2 Key Tasks and Conditions for Delivery of Psychological and Psychosocial Care

Tasks - to discover and support the personal resources

- take care of individual needs / live and die in manner of their choice

- explicitly ask for patients' and relatives' needs & wishes.

- to generate a calm environment

- to help in the process of grief

- to bear patients’ and relatives’ emotions

- to develop a relationship with patients and relatives

- to address unfinished business

- to help making ones’ peace with the life lived - Patients - social support should be offered to all patients in the last days of life as part of routine care.

- Relatives

- social support should be offered to every relative as part of routine care.

- Every relative does not need specialised psychological support.

Health Professionals - all HP and volunteers interacting with patients and their relatives should participate in regular continuous discussions within the team (without an external supervisor).

- specialists for psychological and social support should also have an advanced training in PC to deliver psychosocial support for patients.

- doctors, nurses, social workers and chaplains need additional training to be able to offer psychological support for patients in the last days of life and their relatives.
- specialized psychological and social support should only be given by specialists.

- Health professionals and volunteers interacting with patients and relatives need psychological support.

Issues - to give patients and relatives room to express feelings and thoughts

- that it respects and meets the individual way of patients and relatives

- give patients the chance to experience positive emotions

- that it is needs-oriented

Delphi 3 - Documented consensus on key issues for support of patients and their relatives in the last days of life (table 5.3)

Table 5.3 - Social Support Tasks

Social Support - Emotional support for patients

- Responding immediately to acute needs

- Assure coordination and continuity of care

- Organisation of care according to patients' wishes

- Emotional support for relatives

- Activating resources of patients and relatives

- Assessing acute needs

- Assessing patients' preferences for place of care and death

- Prevention of complicated grief

- Support in maintaining relationships between patients and relatives

- Provide access to information about available services
- Help in family conflicts

- Organisation of transition of care (changing place of care)

Additionally, Delphi 3 integrated the findings from Delphi's 1&2, with the finding from the systematic review to examine communication issues and cultural nuances in PPS (Table 5.4)

Table 5.4 - Communication challenges in end of life care

Objectives to be addressed by palliative care teams - hospital ensuring a supportive environment encouraging calmness and peace, awareness and acceptance of death;

- encouraging creation of legacies, involving the dying individuals in the future plans of those they consider most important to them;

- offering framework to manifest spiritual beliefs;

- providing individualized information for relatives;

- discussing treatment decisions, possible complications, the final days, relatives’ needs after death;

- discussing preferences regarding place of death

- exploring fears / myths, existential issues.

Phenomena that professionals in palliative care should be aware of - most wanted information by relatives refers to patient's condition, course of illness, symptoms and treatment, alternatives and available resources;

- perception of staff as "gate-keepers";

- different rating of symptoms between relatives and patient with implications for action

- coping strategies across families can be very different

Equally, Delphi 3 and the Systematic Review highlighted cultural variances in the delivery of PPS. For example, there appeared to be distinct professional groups primarily responsible for those PPS; in Argentina social workers were in charge of much of the PPS care, whereas in Germany psychologists, and in Romania physicians were most often mentioned reflecting the composition of experts with their professional background in these countries

5.3.2 Systematic review

The majority of studies (27 = 59%) focused on patients, whereas the remainder 19 (41%) focused on relatives and/ or hospital caretakers. 30 studies (65%) used a qualitative methodology, whereas 14 (30%) had a quantitative methodology and two (4%) a mixed method approach.

The research questions (RQs) of the studies yielded were themed accordingly:
i. Characteristics of dying and death - Dying process; Good death / quality of death; Consequences; Coping strategies

ii. Symptoms, concerns, needs - Desire for hastened Death; Spiritual; Not Specified

iii. Interventions

iv. Bereavement

v. Euthanasia

vi. Communication

The largest category of Research Questions referred to the characteristics of dying and death studies (n=26), whereas the category least represented related to issues of euthanasia (n=3).

5.4 Tools and technologies

Delphi consensus identified the “clinical interview” as the best way to assess patients’ or relatives' psychosocial distress in different settings;

- in specialized psychological care for patients (71,4%),

- in specialized psychological care for relatives (70,6%)

- in general routine care for patients / for relatives (each 63,9%).

A broad scope of interventions (technologies - supportive, cognitive-behavioural, systemic, analytical and art or music therapies) were mentioned. They seemed to correlate with the professional background. More specialized forms of support (e.g. systemic or analytical) were mentioned by psychologists and physicians. A list of the tools and their focus (clinical/research; last days of life; national validation) is presented in the full report.

5.5 Development of Future Research Protocols

The findings of the systematic review suggested some important points to be considered in designing new protocols, such as:

1. the balance between qualitative and quantitative research methodologies, both having strengths, as well as flaws.

2. the high ethical demands of a research protocol targeted on dying patients and their relatives.

In Delphi 3, participants were asked to rank importance on issues to be addressed in future research. In accordance with the results, the proposal aims to evaluate the effects of attachment styles in the outcome of varied interventions to promote well-being and ameliorate distress for families attending patients with palliative care needs.
5.6 Critical Friend

Following lively and informative discussion with Professor Gary Rodin, it was agreed that new research might begin most efficiently by developing novel studies that build on established research programmes in different countries. Crucially, it was articulated that interventions that take place earlier in the course may have a profound impact in the last days of life. It was also appreciated that research findings needed to be considered within a national and cultural context, which may affect study results.

5.7 Conclusion

Psychological and psychosocial support is an important issue for all persons involved in the dying phase and needs to be oriented according to the individual dying trajectory. Accordingly, all health professionals and volunteers caring for dying patients should be able to provide basic PPS, and this necessitates that training (at all levels) requires a detailed and considered approach.

The philosophy of total care, that every staff member should be able to provide basic PPS, requires a flexible understanding of multiprofessional collaboration and necessarily dedicated time for team reflection (e.g. supervision). Future research requires a set of validated measurement tools for PPS to enable cross-cultural comparison. To date, there is a lack of evaluated interventions and studies are necessary to determine which approaches are suited to particular groupings.

5.8 Potential Impact

It was proposed that the qualification of staff was very important in the delivery of psychological and psychosocial support; the relationship between receiver and provider as being a key issue. Accordingly, the majority of experts considered every palliative care team member and volunteer to be trained at an appropriate level, suggesting also that all specialised palliative care teams should be able to provide general support, whilst having access to specialised PPS. Therefore, it is essential for all institutions aiming to provide high quality palliative care to take into account also the needs of staff for additional training, coordination, supervision and self-care. This includes improving the possibilities of reflection and coping with stressful care situations.

5.9 Observations - Support and Collaboration

The professional background of the respondents seemed to be associated with particular issues for psychological and psychosocial support, including interventions. As psychological distress is multi-factorial, different professions, by virtue of their differing training and experience address different factors contributing to the overall distress. However, this is a strength of multidisciplinary teams.

Most of the studies in the systematic review had a qualitative design. This illustrates that research at the end of life needs a careful approach, for which qualitative design may be most suited. In contrast, quantitative methodology was seldom used,
perhaps because of the ethical and clinical difficulties these designs may imply.

Project Deliverables

D 4.1 Month 37 Final report
Psychological and social support for patients, families and caretakers: Final Report

D 4.2 Month 37 A minimum of one article for publication

Popa-Velea O, Galushko M, Romotzky V, Simoni? A, Ostgathe C, Voltz R on behalf of OPCARE9. Psychological and psychosocial support for cancer patients and their relatives in the last days of life: What are the current research topics?


D 4.3 Month 37 A minimum of two presentations for future national/international conferences


Galushko M, Romotzky V, Popa-Velea O, Ostgathe, C, Ellershaw J, Voltz R. The dying phase: who is in need of and who can deliver psychological and psychosocial support - the perspective of palliative care experts in europe. 9th - 11th 2010. 8th conference of the German Association of Palliative Medicine (DGP) . Dresden, Germany.


D 4.4 Month 37 A minimum of one protocol for future research to enhance the evidence base for end of life decisions
Protocol title: Psychosocial support for relatives of dying patients


6. OPCARE9: Work Package 5 - Voluntary Service

The model of care championed by the modern hospice and palliative care movement seeks to improve quality of life (and death) by promoting appropriate physical, psychosocial and spiritual care of dying patients and their families. Palliative care services have developed very differently across Europe (and beyond) and in several countries (for example Germany, Italy, the Netherlands and the UK) the volunteer movement has been at the forefront of the delivery of such care. In other countries, however, there is little available data to illustrate the quality and number of volunteer services integrated into the care of severely ill and dying cancer patients. Through the systematic identification and scrutiny of current research findings and assessment of expert opinion, this collaboration has facilitated exploration, sharing and comparison of current volunteer provision in supporting, supplanting or supplementing services in each beneficiary country. It has facilitated examination of education and training needs, and identified where possible, curricula of excellence in this area. It has also allowed the identification of existing technologies and quality indicators and facilitated the development of new ones for the appropriate assessment of such services. Where current evidence is lacking, this collaboration has developed innovative research proposals.

Accordingly, the objectives of this Work Package were:

- To explore, share and compare current provision in each of the beneficiary countries

- To provide insights into the various roles undertaken by volunteers in different countries- i.e. support, supplanting and supplementing services (Payne, 1998), in relation to the dying patient and their families

- To identify current education and training provision to determine future need and establish curricula excellence in this area.

- To Identify appropriate models for the delivery of high quality volunteer services now and in the future

- To develop protocols for future research to enhance the existing evidence base

6.1 Organization and collaboration

Work Package 5 has been led by Dr Ruthmarijke Smeding (Marie Curie Palliative Care Institute Liverpool, UK). The Work Package lead was assisted by the Scientific Project Assistants Colin Bragg (MCPCIL, UK) and Margarita Jorge (Pallium Latinoamerica, Argentina), who assisted in the preparation and structuring of all WP activities. Representatives from each OPCARE9 country formed the core Work Package membership.
6.2 Challenges:

There were numerous challenges to overcome, both conceptual and organisational, in attempting to meet the Work Package objectives. Membership of the Work Package was very fluid over the 3 years of OPCARE9, and there were varying levels of connectedness to "volunteering" across the multidisciplinary Work Package members.

Establishing a "baseline" of volunteering roles and activities across OPCARE9 proved challenging due to the conceptual variations of volunteerism inherent in each country. The differences between direct and indirect patient care emerged from the onset. For example, we found that British volunteers are strongly involved in charity and fundraising, and rarely involved in direct patient care at the very end of life. This is in contrast to examples from Germany, Italy and the Netherlands. Multi-disciplinarity depicts the domain of volunteerism for Hospice & Palliative Care in general and accordingly it has been researched from many different disciplinary perspectives: in the systematized review, eight different disciplines were represented by primary authors alone. As a result, a need for clarification of terminology and paradigms to chart the terrain has been identified, reflecting the already known disparate state of the palliative care across Europe (and beyond).

Statistics and overviews are managed in a variety of categorizations, and although various organizations initially agreed to participate in (e.g. baseline surveys) answers to the questions generated were often not provided. As a group, WP5 agreed to stop this part of the data gathering process, though incomplete, as of the 1st of December 2009, acknowledging that information was either not provided, incomplete, or not available in the required format.

6.3 Methodology

Inductive formats were engaged, pulling together what was known in the group, before venturing out into uncharted terrain. A collated first baseline led to an initial survey of "volunteering" in the OPCARE9 countries, via 5 structured questions, posed to both volunteers and professionals. Subsequently, appropriate "Grey Literature" was collated.

Using strict "Systematic Review" and Delphi methodologies proved a challenge for Work Package 5. For example, engaging a traditional protocol for systematic review would have resulted in the exclusion of data from 7 of the 9 OPCARE9 countries. Similarly, a Delphi designed for the medical-academic world was projected to be of little value. Accordingly, as it was evidenced that as "Volunteerism" lives in native languages, a "thematic" review of the literature was generated (combining 32 articles in 8 native languages), to portray the state of the art, supplemented by a modified Delphi.

6.4 Results: Baseline Survey, Initial Survey and Grey Literature

General volunteering has a large value and is strongly engaged in all participating countries. However, the value of volunteering for Palliative Care appears to have a separate niche and depends on many variables - for example, where:

- reimbursement or financial streams range from governmentally subsidized, to, charity based (coordinators and health care insurance) to none, meaning self-raising, or providing funds

- palliative care volunteering is considered mainly for home situations, with exceptions that seem more to do with individuals and/or particular organizations allowing such in their institutions than with policies.

- direct patient care provided by volunteers in institutions was found in well developed, though structurally rather different formats, in Italy, Germany, the Netherlands and in Switzerland.

Analysis from the data initial survey shows the breadth, variety and the opening of dialogue between countries on volunteerism. More depth is uncovered in the "Grey Literature", listing the current heart and soul of the volunteering
movement. This information was collated and will be made centrally available on the public OPCARE9 website.

6.5 Systematic and Thematic Review.

The systematic review of the English scientific literature yielded 180 articles. Following the application selection and exclusion criteria, 42 articles remained for analysis. Exhausting the review criteria to find work in their own countries, Work Package 5 members found on a handpicked basis an additional 31 articles, in eight native languages, addressing the stipulated foci, which will be addressed in a separate article. Although a “core” sense was absent, key themes were yielded (Table 6.1).

Table 6.1 Key Themes in Volunteerism for End of Life Care

<table>
<thead>
<tr>
<th>Key Themes in Volunteerism for End of Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Importance of shifts in interpretative cadres &amp; advancement of volunteerism</td>
</tr>
<tr>
<td>* Service &amp; Organisational aspects of volunteering: role and emergent quality indicators</td>
</tr>
<tr>
<td>* Provision and effects of volunteering</td>
</tr>
<tr>
<td>* Education and Qualification for volunteers</td>
</tr>
<tr>
<td>* Methodological aspects of Education and Supervision</td>
</tr>
<tr>
<td>* Emerging research (Canada, the Netherlands and the United States)</td>
</tr>
</tbody>
</table>

The second part of the methodologically prescribed OPCARE9 project engaged a modified Delphi process to address the issues highlighted in the systematic review: to identify core issues, to benefit from such a process.

6.6 Delphi: Volunteers as non-professional experts

Academics with expert knowledge in volunteering for end of life care vary over a variety of disciplines, countries, and experience. Accordingly, this made consulting with internationally identified experts in a conventional Delphi practically impossible. Therefore, the modified Delphi engaged the opinions of volunteers active in end of life care. Volunteers from eight of the beneficiary countries (it was not practicable for a volunteer to attend from New Zealand), participated in a panel discussion based on questions resulting from the English language systematic review. The interview has provided a unique lens into the world of volunteering of the OPCARE9 countries. Key finding from the panel discussion: volunteers viewed their contribution as that of “non-professional experts”.

6.7 Tools and Technologies

Despite large numbers of volunteers engaging in the support of patients across Europe (and beyond), very few measuring instruments have been developed to assess the impact. The four identified are: Claxton-Oldfield (2009), Luykx and Schols (2009) and the Volunteering Impact Assessment Toolkit (Institute for Volunteering Research, 2004) and a psycho-social assessment of volunteer intervention (Wissert and Popelka, 2004).
6.8 Critical Friend

Feedback from Professor Allan Kellehear commended the Work Package team on the breadth and depth of the work undertaken, particularly in tying together a disparate body of knowledge. A number of potential papers for publication were identified from the collated material, and suggestions to encourage a de-medicalisation of the original search strategy and the incorporation of a more social and community development-based view of lay participation in palliative care services, were well received by the Work Package group.

6.9 Development of Future Research Protocol

From the findings of the systematic and thematic reviews, and complemented by outputs from the modified Delphi, three protocols for future research are in development.

- A proposal for a 2 year project with international collaboration, to engage volunteer support for dying patients and their families in the primary care setting in Liverpool has been developed and successfully secured £240,000 of funding from the Dimbleby Marie Curie Cancer Care Research Fund. Following validation of the newly to develop educational model, based on international experiences from Italy, Germany, the Netherlands, Canada and the UK, opportunities will exist to expand the intervention in both national and international contexts.

- A proposal has been developed to examine and document the activities of Palliative Care volunteers in supporting patients and their families in the last days and hours of life across all health care settings in Cologne, Germany. This project would be part of a hypothesis generating process, for further development of research protocols and follows directly a report in Argentina, from prospective research undertaken to chart the contributions of volunteers.

- A proposal to investigate the determinate factors that prompt individuals to volunteer in palliative care: based within Liguria, Italy.

6.10 Conclusion

The Public Health oriented approach, which aims to empower the community and its citizens, shows signs of taking hold in engaging active support for patients and families at the end of life. In Germany some 80,000 volunteers (trained over the last 20 years) have developed into a strong force to support care of the dying, developing important strategies which both supplement and surpass existing community structures. Further examples are evident in the organisation of volunteers in Italy, and the Netherlands, where we found a curriculum expressively focusing on care of the dying. These developments provide the platform for establishing collaborations to compare, develop and evaluate a methodology and curriculum of excellence for volunteerism in end of life care.

6.11 Potential Impact

A recent article for the German Hospice and Palliative Care Association (DHPV), calculated the fiscal contribution of volunteers as some 95 million Euros per year. Similarly, in a 2006 pilot survey of independent hospices in the UK, Help the Hospices calculated a £12 million pounds contribution, an equivalent of the NHS contributions in those days. Accordingly, the contribution of volunteers is not to be underplayed.
Strengthening an infra-structure to enable patients to die a supported dignified death should be irrespective of place of death. The submitted research proposals from Germany, Italy and the UK support a development strategy for volunteering, as do existing Italian and Dutch curricula. Accordingly, OPCARE9 has opened the doors to a research and development strategy to establish a core-curriculum of excellence. With our international collaboration in place, further coordinated and supported development can now be realistically anticipated.

6.12 Observations - Support and Collaboration

This Work Package has not been without its challenges. "Volunteers" as a subject, demonstrated an "otherness" in OPCARE9, which required adjustments in the (mainly) medically oriented structures and processes. Given the complexity of the task, the members of WP5 in a variety of formats have been a remarkable and supportive group, journeying on a sometimes very challenging path. The loss of the dedicated Scientific Project Assistant provided a major challenge that was addressed by member of the Work Package and the wider OPCARE9 supportive structures. Particular thanks must be extended to the support offered from Germany, Switzerland and Argentina, the latter taking on an extra role in providing a new SPA - Margarita Jorge. With each challenge, the group has sought to address issues where possible, and engage in lateral thinking to provide solutions to unanswered questions. In this, the group’s efforts parallel that of the early hospice pioneers - the quest to improve the care given to patients and their families at the end of life.

Project Deliverables

D5.1 Month 37 Final report

Volunteerism and care of the dying. Final Report for OPCARE9

D5.2 Month 37 A minimum of one article for publication


D5.3 Month 37 A minimum of two presentations for future national/international conferences


D5.4 Month 37 A minimum of one protocol for future research to enhance the evidence base for voluntary service

Protocol Title - A Living Community Presence-an innovative approach for volunteers to support the care of patients and their families in the last hours and days of Life

Authors - Smeding R, Mason S, Voltz R, Salmon P and Ellershaw JE

Potential Impact:

11. OPCARE9 - Conclusions and Future Developments

As evidenced in the Work Package reports, the scope of the current knowledge base within each of the themes examined lacks depth and breadth. Evident is the need for co-ordinated high quality research on which to base the delivery of care in the last days of life. The established collaboration provided a supportive forum for debate and critical challenge to promote best practice. The Coordination and Support Actions funding scheme, has provided the basis for future local, national and international collaborative research to improve and expedite the equitable delivery of care for cancer patients (and their families) in the last days of life.


At the end of the three year programme, an international conference was held in Liverpool to disseminate the findings from the individual Work Packages and celebrate the successes of the collaborative venture. Clinicians, researchers, policy makers, patients and carers were invited to engage and reflect on the achievements and future challenges inherent in optimising palliative care. In parallel with the conference, a policy summit was hosted, which offered an opportunity to review the continued development of international palliative care, and to prepare strategies to provide an environment in which future collaborative research would be realised to improve the evidence base for clinicians caring for dying patients and their families.

Some reflections from conference attendees, speakers and chairs included:

"As a patient / carer I am very positive that OPCARE9 has the right approach in ensuring that the LCP, embedded in international research is the pathway of choice for all terminally ill patients, no matter what country they are unfortunate to receive that dreadful news. It is reassuring to know that out of the conference policy summit meeting there is an agreed strategy which includes patient / carer involvement in the measurement of that care." Sharon Bird

Patient & Carer Representative

Liverpool, North Cheshire & Wirral Cancer Locality Group.

"It was an excellent day and I felt privileged to be invited."
Barbara Burkey
Vice chair of the Patient/Healthcare Professional Partnership Group.
Member of the End of Life and Palliative Care Clinical Network Group
User Representative & Taskforce Member: Merseyside and Cheshire Cancer Network

"The work of OPCARE9 has placed emphasis on how different countries and cultures provide care for the dying and how a collaborative approach to research can bring benefits to patients here in the UK and beyond. We need to continue to work between nations" Professor Sir Mike Richards

National Clinical Director of Cancer & End of Life Care, Department of Health, England.

"The research collaboratives that have been established, with so much effort and so much energy, have to be kept going... I'm quite happy to hear of the research proposals being constructed from the results of the OPCARE9 meeting. The exchange between the countries, between the cultures is really important to get down to the basics of what's behind palliative care." Professor Lukas Radbruch

President of the European Association of Palliative Care (EAPC)

11.2 Conclusions: Collaboration and Support

Key aspects of international collaborative working have been learned from participation in this project. This forms the basis for the continued work and development of the group beyond OPCARE9. For example, prior to the start of the collaboration, a management structure was engaged to lead this project. Although based on considered principles, and on experience from participants involved in previous European Union Framework collaborative projects, it was not anticipated that the structure would perform as designed, rather that a process of learning, adjustment and assimilation would emerge.

Working internationally, 2 aspects were anticipated:

1. A structure only works when the people working in it, can own it.

2. The structure needs to integrate and synchronise existing high power leadership in the nine beneficiary countries - that means different concepts, styles and contexts.

We were aware that it would take time, careful listening, flexibility and continuous reflections, to optimise the functioning of the new structure employed. The confidence of the group to work in this way was further developed with the invitation of a Critical Friend, Professor Susan Block, to review and examine the functioning and output the collaborative during the 4th
colloquium in Germany. Following this successful experiment, the colloquium expanded to the invitation to employ critical friends for each workpackage to attend the penultimate colloquium and provide specific contextual feedback on progress and outputs generated.

The levels of reflection, as these emerged during the 6th Colloquium, demonstrated both a sense of group and subject-maturity. Where challenged one day, the group reflected and by the next day demonstrated that it was competent to receive and work with such criticism, following the generated path with confidence, where the scientific dialogue involves discussion that either adjusts it’s course along the lines of the criticism provided, or strengthens its position from the ability to support the criticism on deeper levels, staying with the original design.

I had the privilege of participating in the Cologne and Rotterdam meetings as a critical friend. I found the level of engagement, enthusiasm, commitment, and effort at both meetings to be extremely high. The role of a critical friend is a privileged perspective as one is both an insider and an outsider. I felt that, in my role, I was able to see the strengths and weaknesses of the project from both perspectives. It was challenging at the first meeting to get a sense of the goals, objectives, processes, and desired outcomes of the project, as well as what was expected of me. It was much clearer at the second visit. By the second meeting, I had a greater sense of where the project was going and what the project asked of me. I hope my contributions were useful to the group; I also felt that I learned a great deal from my participation in the project.

Professor Susan Block - Harvard Medical School

In addition to the testing of OPCARE9 by the critical friends, both as a functioning collaborative and in its scientific endeavours, two further developments emerged as key in the success of the collaboration.

The first consideration relates to the genesis of the structural organisation of the project. The design of the project methodology was set up by the team at the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in the UK. This design, functioning as an invitational format, was based in MCPCIL’s experience of that time, in working cooperatively and collaboratively, including working with different cultures. This initial and invitational design was consequently used in a facilitated manner, that is, the collective membership, was invited to sculpt a format that would fit the whole group. This "invitational facilitation" was used continuously, sculpting and shaping a process, in which all would be encompassed. Systematic reflections, both in the PSG and as MCPCIL co operational leadership, were used, to continue facilitating, until a fitting and workable format emerged. It is this aspect of a successful creation, by way of adjustment to international collaboration and cooperation that we would like to own as an OPCARE9 PSG team. We anticipate that there is far more to be learned in this context, yet over the years, this was a continuous and major learning process, in which we now can, in shared ownership of newly created structures, move forward together. The process has allowed for an open format that is adjustable. This "gain" can be viewed as a professional trust that has created an operational basis from which we seek to research “care of the dying” in Europe and beyond.

The second consideration, evident upon reflection, related to the consolidation of established international relationships. There has been great benefit in working with an international group of colleagues, already established as leaders in their field, whom we already knew through the emerging International Liverpool Care Pathway network. This network had previously been steered and led by the MCPCIL, as the owners and designers of the LCP. The MCPCIL team was already engaged in a leadership position for the implementation of the complex intervention (the LCP) in both a national (British) and an International perspective (the LCP is currently used in 21 different countries). This process is one of continual development, and meshed seamlessly with the key aims of OPCARE9: realised as a discrete executive Work Package 7b. Accordingly, the OPCARE9 project has provided further impetus into the development of the international development of the LCP, in the formation of an International LCP Reference Group, and this opportunity for reciprocal development has immeasurably strengthened both elements: OPCARE9 & International LCP.
11.3 Conclusions: OPCARE9 Scientific Project Assistants Group (SPAG)

Early in the OPCARE9 project, it became evident that, besides the Project Steering Group (PSG), an interconnection on the operational level was needed in the project. For this reason, a group of young researchers from the five primary Work Packages was established in October 2008; the Scientific Project Assistants Group (SPAG). The objectives of SPAG were to consolidate and standardize research methodologies throughout the project, support and learn from each other, act as a channel for fast and easy contact and to avoid a duplication of work. The SPAG has over the years had different compositions, but most of the time the SPAG has consisted of 3 senior lecturers and 6 junior researchers with different levels of experience and professions (social scientist, physician, nurse and social worker). Besides the face to face meeting at OPCARE9 colloquiums, additional communication tools have been used, such as e-mail, a dedicated web-based forum for sharing documents and discussions (VOCAL), and monthly web meetings. Topics discussed have focused on methodological issues and progress actions across the collaborative, as well as a collaboration activity of quality indicators and communication with PSG. To ensure the connection between management and the operational level, a rotating SPAG member has acted as a group representative towards the PSG.

The SPAG had an active, ongoing creative and inspiring learning process during the OPCARE9 that has resulted in international collaborative network of young researchers that have been vital for the success of the project. Collaborating, debating and discussing research projects with researchers and clinicians of different levels, and to learn to argue for this has been vital for these young researchers during the project. Hence, empowerment of young professionals should be considered by every extensive collaborative as a possibility for establishment of a new generation of researchers.

11.4 Conclusions: OPCARE9 International Policy summit: "Rethinking dying in Europe and beyond- a roadmap for change"

OPCARE9 has addressed focused questions in the care of the dying and highlighted enormous gaps in terms of research, education and clinical guidance. The gaps and unmet needs identified during the 3 years OPCARE9 project have been repeatedly discussed with various professionals from different countries and background. Such discussion finally led to the insight that policy makers from all over Europe - and potentially from all over the world - must pay great attention to this last phase of life to serve their communities well. Accordingly, the "Liverpool declaration" was created and a policy summit was held on this topic during the project's final conference in Liverpool in March 2011.

The OPCARE9 Liverpool Declaration

1. Every person has the right to live in societies where death and dying are acknowledged as part of life. We commit ourselves to improving societal and public health approaches to meet this goal.

2. Every person has the right to die receiving optimal care with respect to their wishes. We commit ourselves to improving awareness to meet this goal.

3. Every person has the right to access adequate palliative and hospice care in all settings. We commit ourselves to improving healthcare structures to meet this goal.

4. Every person has the right to this care given by professionals and volunteers who are appropriately trained. We commit ourselves to implementing care of the dying in all curricula for healthcare professionals and volunteers.
5. Every person has the right to continuous improvement of palliative and hospice care through transfer of research results into practice. We commit ourselves to improving conditions for research for care of the dying and implementation of research results.

6. Every person has the right to equitable access to high quality end of life care across all countries. We commit ourselves to the setting of international standards and evaluating their ongoing implementation.

During this summit, various domains of most needed activities, both national and international have been identified. Professor Sir Mike Richards from the UK as chair of this summit summarized a list of future actions. These points of future action based on the Liverpool declaration can only move forward this widely neglected area of need, if discussed, evaluated and adapted on a regular basis. Therefore the International OPCARE Research Collaboration (IORC) and the International Liverpool Care Pathway - Reference Group (IR-LCP) as the two major collaborations coming out of OPCARE9, commit themselves to sustain this political debate.

Following the policy summit, it was recommend that a bi-annual international conference should be convened in Liverpool, inviting clinicians, educators, researchers and policy makers to demonstrate their will to improve the care of the dying in Europe and beyond. It is proposed that a further policy summit will be conducted to progress the agenda.

11.5 Future Developments: International OPCARE Research Collaborative

Growing together into a democratic structure for OPCARE9 is based in a concerted effort and a mutual commitment for growth, understanding and continuous exchange of all involved. Accordingly, what has emerged from OPCARE9 is a strong collaborative and coordinated network of research active clinical and educational groups, all with a key aim of generating the evidence which will inform practice and improve the care of dying patients across the partner countries and beyond.

I think that OPCARE9 is primarily a great opportunity to create an international platform for international and multidisciplinary collaboration on end-of-life care research and palliative care. The researchers... ...are at the forefront of the end-of-life care research community in Europe and an interesting mixed group of people from different backgrounds and disciplines. The fruitful interaction between different professions groups (physicians, nurses, psychologists and social researchers) and between researchers from Canada and the US during the meetings will contribute to capacity building in Europe and beyond. It will facilitate future collaborations in concrete research projects. OPCARE9 has also identified important end-of-life issues to be studied in the near future. Hence, it has contributed to the development of a research agenda for the years to come. Although it is a complicated project because it is not about research itself, it facilitated enormously the development of joint international collaboration and research.

Professor Luc Deliens- University of Amsterdam

In order to realize the potential generated by OPCARE9, the collaborative network has restructured as The International OPCARE Research Collaborative (IORC). Accordingly, terms of reference for membership of IORC have been drafted (Table 11.1).

Table 11.1 IORC Terms of Reference
International OPCARE Research Collaborative - Terms of Reference

The IORC - is responsible for:

* Developing the research protocols collated as part of the OPCARE9 EU 7th Framework Coordination and Support Action Programme.

* Ensuring the effective communication between members of the Collaborative.

* Responding to the research agenda as set by the International OPCARE9 Research Collaborative Steering Group (IORC-SG).

* Collating reports and action plans and reporting to the IORC-SG and provide detailed research protocols for optimising care of the dying into the future within an international framework.

* Horizon scanning to develop future collaborative research programmes to attract ongoing funding / resources within the agreed research portfolio as set by the IORC-SG.

Membership

* Key Researchers and Country Leads from the OPCARE9 EU 7th Framework Coordination & Support Action Programme.

As with OPCARE9, a Steering Group (IORC-SG) has been constructed to coordinate and monitor the development of the IORC. Accordingly, the IORC will seek to potentiate the development of local and national research projects examining care of the dying, and will serve as a platform to elevate suitable studies for international collaboration. This structure is illustrated in figure 11.1.

Figure 11.1 - IORC development of local, national and international research development
The IORC emerges as a collaborative structure to potentiate the research protocols that have emerged from the OPCARE9 project. Further, IORC will also look to support the development of collaborative working that develops from the established networks both with and beyond the OPCARE9 project. In addition, the IORC-SG will play a facilitative role in linking developments with the International LCP Reference Group and the activities of the IORC, making sure that engaged research will produce appropriate outcomes to improve practice, and reciprocally that the research agenda is driven by appropriate need.

Consideration as to the necessary support structure necessary has already been given, and development in terms of design guidance and core management activities have already been drafted. For example, a developed research protocol may seek to engage in research at a local/national level - for example, Work Package 2 "Communication amongst clinicians regarding end of life care decisions in the last 48 hours of life". The developed protocol, can be used to apply for funding in line with the local/national implementation. However, the potential exists for IORC to provide a collaborative exchange to examine whether the methodology is amenable to application in a partner country, and develop data to establish internationally comparative data. Equally, developed protocols may be designed with an existing international collaborative framework, and IORC will be able to identify interest and source the collaboration required.
A timetable of meetings has been established to sustain the momentum of establishing the IORC from the outputs of OPCARE9 (Table 11.2).

Table 11.2 - Schedule for International OPCARE Research Collaborative


OPCARE 9 Conference EAPC Lisbon

International LCP Conference (UK) IORC Meetings

- IORC

- IORC-SG International LCP Conference

Launch of IORC Meetings;

IORC

IORC- SG Meetings;

IORC

IORC- SG Meetings;

IORC

IORC- SG

In reference to the potential developments of research championed by the IORC, a clear focus on care of the dying has emerged. However, what has also been apparent in the assessment of the available evidence is that to fully understand and engage with care of the dying, an appreciation of the factors that shape the dying phase is crucial. Therefore, although the focus of the IORC is to develop evidence to improve practice in the dying phase, this may require engaging with the wider illness trajectory to ascertain the interplay of key determinants (Figure 11.3). For example, the protocol emanating from Work Package 4 seeks to establish the effect of attachment style in promoting well being and ameliorating distress. However, it will be important to understand whether attachment style (e.g. in relation the interaction of patients with clinicians) is a malleable concept and whether it is altered over the illness trajectory. Such would be an important finding, particularly in terms of the influence in guiding potential interventions.

Figure 11.3 - IORC Focus for developing the evidence base in end of life care.

11.6 International Cohort Study
A key factor in facilitating the development of the OPCARE9 collaborative was the shared use and belief in the Liverpool Care Pathway for the Dying Patient (LCP) as a tool to drive up quality for care of the dying and provide a method for ensuring an equitable base standard of support. Equally, the LCP provides an opportunity to be the fulcrum of a large international cohort study to both explore the complexity and diversity of care of the dying and undertake intervention studies in care of the dying in Europe and beyond.

The LCP guides and enables healthcare professional to focus on care in the last house or days of life. This provides high quality care tailored to the patient's individual needs, when their death is expected. Key goals of care are regularly assessed and formally documented (4 hourly) on a standardised pro-forma. The opportunity exists to use the LCP as a platform to develop additional "recording modules" that could facilitate the appropriate collection of research data that goes beyond the core LCP documentation of the goals of care, for example; evaluating the quality of care received as perceived by the patient, the family and both formal and informal careers. The LCP is currently used in over 2,500 practice sites across Europe and beyond, providing a feasible and established infrastructure for such an ambitious, but crucial study. Nevertheless, the complexity of engaging on an international project on this scale is not insignificant. However, the experience and relationships developed within OPCARE9 place the group in a unique position to begin fielding the data that will articulate and shape the future care for dying patients and their families.

11.7 Conclusions

There in one indisputable commonality for humankind; that we will all die. Yet, as evidenced in the outputs of OPCARE9, little attention is given to the care of the dying throughout international health care systems. Public information, health care education, research and societal debate all demonstrate the lack of knowledge, skills and attitude towards this topic compared to the significance and impact of dying on each person's life. Changing demographics and the increasing number of people requiring appropriate palliative care has highlighted "care of the dying" as a key issue for clinicians, politicians and society.

The design of the future collaborative working grounded in the learning emerging from the developments within OPCARE9 are the two major initiatives; The International OPCARE Research Collaborative (IORC) and The International Liverpool Care Pathway - Reference group (IR-LCP). These groups commit themselves to sustain the political debate, undertake collaborative research, and make a difference to care of the dying in Europe and beyond.

List of Websites:
www.opcare9.eu

Contact - Jane Dowson, Project Manager at jane.dowson@liverpool.ac.uk

Related information

<table>
<thead>
<tr>
<th>Result In Brief</th>
<th>Advancing knowledge on care for cancer patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documents and Publications</td>
<td>final1-opcare9-final-report-may-2011-.pdf</td>
</tr>
</tbody>
</table>

Reported by

THE UNIVERSITY OF LIVERPOOL
United Kingdom

Subjects