

Title page

FINAL REPORT

Promoting the integration of Continuous Care in the hospital

The Palliative Care mobile support team as a means to convey the philosophy of Continuous and Integrated Care. Analysing medical practice and research in new integration strategies

Web site; <http://www.mobileteam.irisnet.be>

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FINAL REPORT PART A

1. Title of the project and project website

Promoting the integration of Continuous Care in the hospital

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Web site; <http://www.mobileteam.irisnet.be>

2. Contract number:

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3. Official contractual period:

1.10.2000 – 30.9.2003

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6. Funding:

Euro 508 997

7. Abstract:

Suffering from the symptoms and distress due to incurable illness is a major healthcare problem in Europe

Palliative care is performed in various institutional configurations. In a hospital it may be entrusted to a specific unit or handled by the staff of existing services together with a mobile team specialised in this type of care. The hospital palliative care mobile team (PCMT) is a multidisciplinary team that supports acute care teams in the management of patients with palliative care needs. The PCMT also has a role associated with research and education. Occasionally some teams will be directly and actively involved in patient and family care.

The complexity of the interaction that exists in hospital institutions between the structures and the people has demonstrated the difficulty and the extraordinary importance that the integration of PCMTs constitutes as well as the impact that this integration has on public health.

Our project is oriented towards an analysis of the strengths and weaknesses of the "mobile team" model and the research into structural training and organisation tools for the

improvement of its integration into the hospital environment. An ethical and sociological study accompanied the training model.

We aimed to translate our experiences in the field into guiding principles for the future PCMTs that will be set up and begin to function in Europe

Overall objectives of the project:

Our proposal aimed to achieve the **following objectives**:

1. **To identify the main values and principles of Palliative and Continuous Care. To study the history** and functioning of hospital based Palliative Care mobile support teams in Europe through the European tradition and culture. **To identify** areas of resistance to the fundamental values and principles of a holistic approach in medicine.
2. **To renew and adapt** the contents of the Palliative Medicine philosophy to the reality of the hospital setting. To extend this approach to patients suffering from different types of chronic disorders.
3. **To identify** obstacles to **integrating** PCMTs and to evolution of a philosophy of patient-centred care through an assessment and analysis of the medical activity of PCMTs located in several European countries (B,F,UK,CH).
4. **To use this analysis to seek new strategies for communication and institutional integration**, and therefore to improve the way mobile support teams function and develop as vehicles for a philosophy of care that places the patient at the centre of the decision-making process

Experimental approach and working method

The project is directed towards Inter- and Pluri-disciplinary research among clinicians (responsible for mobile support teams), scientific experts (university institutes) and external consultants. The clinicians undertook an evaluation and assessment in their mobile support teams. A group of scientific experts from various European institutes/universities (research field: philosophy, ethics, sociology, palliative medicine) determined with the clinicians the methodology, realisation, synthesis and analysis of this assessment. The group of consultants (fields of expertise: education, communication, systemic-therapy, psychoanalysis) drew up a specific training programmes for mobile support team members in the light of the assessment analysis. The main steps of our research were to elaborate an appropriate methodology to evaluate the clinical activity of support teams, analyse the current stage of integration of PCMTs, design a training project and conduct pilot studies. The ethical and socio-political aspect is an integral part of future European recommendations and accompanies the teaching project.

8. Conclusions, results

- 1) The Evaluation Report: results from an evaluation programme with 7 European PCMT's (*the entire evaluation report is available at the scientific coordinator*)
- 2) A pilot training programme specific for mobile support team members to foster their collaboration with hospital services. (Focal points: integration strategies, inter-collegial communication, clinical ethics mediation)
- 3) European recommendations for institutional and educational strategies to set up mobile support teams and promote the philosophy of continuous care.

The 25 recommendations for the development of hospital palliative care mobile teams are the result of a collective work involving teams of palliative care practitioners, researchers, and consultants from various disciplines. The recommendations summarise discussions on the experience of teams practicing palliative care in pluralistic settings and in countries with different healthcare systems, different historical backgrounds and different legislations regarding the end of life and euthanasia.

9. Project related publications and relevant dissemination activities

Press release:

- Iris gazette (nr.15, 2/2001) "Un projet de recherche européen sur les équipes mobiles "
- Brugmann-news (nr.23,1sem.2001) "Signé Brugmann ; un projet de recherche de trois ans sur les Soins Continus "
- European journal for Palliative Care (September 2001) "Promoting the integration of Continuous Care in the hospital, a European research project "

Posters on congresses:

- 7th Congress of the European Association for Palliative Care (Sicily, April 2001): poster: "A European research project for promoting the Integration of Continuing Care. "
- 6e journées nationales des équipes mobiles de Soins Palliatifs (Montpellier, June 2001) poster: "Projet de recherche Européen sur l'intégration des équipes mobiles dans l'institution hospitalière "
- Poster for the international congress on bioethics in Brazil 11/2002
- Stéphane Leyens "Towards Specification of the Values Underlying the Practice of Palliative Care Mobile Team in Europe » Poster, « 8th Congress of the European Association of Palliative Care », The Hague, 5th April 2003
- R.M Smeding, E Weiher, M.Weber: The WHO definition, Palliative Care and Bereavement. Congress of the European Association for Palliative Care, The Hague, 4/2003

List of publications directly emanating from the project during the reporting period:

- Daniele Deschamps: Programmes d'évaluation dans 7 équipes mobiles européennes; volet psychologique, September 2002, being published
- Danièle Deschamps: "La mort de l'esprit de fraternité chez les soignants "revue Frontières, Montréal, Canada, June 2001
- Laurence Roux, France Lert, Catherine Markstein: L'intégration de l'équipe mobile de soins palliatifs à l'hôpital: enjeux institutionnels, professionnels et organisationnels" Synthesis of a European study, Med Pal 2003;2:6-1
- Mylene Baum Pourquoi la narrativité ? Tentative d'approches méthodologiques de l'éthique narrative, Centre de documentation et de recherche sociales CEDORES, mars 2001
- Mylene Baum: "La bioéthique et les femmes; les limites de l'éthique de la sollicitude" p 53 – 73 ed Marie Pinsart, Collection pour demain, Vrin Paris 2003
- Guy Lebeer: "Soins Palliatifs: la recherché de" l'entre deux", Sciences sociaux et santé, vol.21, 2003 pp 65-74

Conferences where the project has been mentioned:

- Prof. Ernst Berger: Enquete des österreichischen Parlaments; Sterbebegleitung 29 May 2001
- Prof. Ernst Berger: Expertenhearingder Grünen Fraktion im Wiener Landtag "Strategien und Konzepte der Palliativmedizin" 20.6.2001
- Dr.John Ellershaw: "Hospital Palliative Care Teams- A European Perspective" Royal Free and UCL Medical Scool, London 2002
- Daniele Deschamps: "Le défi des équipes mobiles en Soins Palliatifs, entre mythe et réalité" – 14th International Congress on Care of the Terminally Ill, Montreal, Canada 2002
- Stephane Leyens: "L'éthique narrative: de l'idée à la pratique. Le cas des équipes mobiles de soins palliatifs" Conférence "Midis de la bioéthique", Faculté de Médecine, Université de Louvain, 14 February 2003
- Mylène Baum: "Ethique narrative en fin de vie" Conférence "Midis de la bioéthique", Faculté de Médecine, Université de Louvain, 14 February 2003

- Catherine Markstein: "Les équipes mobiles de Soins palliatifs comme véhicule d'une philosophie de soins continus et intégrés" Conférence "Midis de la bioéthique" Faculté de Médecine, Université de Louvain, 14 February 2003
- D.Jaquemin, D.Mallet, B. Choteau: "Equipes mobiles des Soins Palliatifs: quelle pertinence éthique pour le maintien d'une pertinence palliative" EACM, Annual conference 2002 Soins Palliatifs
- Pascale Vinant: "Y a t-il une place pour le patient dans la décision médicale en fin de vie" Paper given at the *Journée de l'observatoire français de l'éthique clinique*, 9/2003
- Christiane Meyer Bornsen: "Transition and Interference between curative and palliative medicine" 8th Congress of the European Association of Palliative Care, The Hague, 5th April 2003
- Catherine Markstein: "Resultate aus dem Europaprojekt mobile team mediation" Magistrat der Stadt Wien, Strategische Planung und Qualitätsmanagement. 11.2003 Geriatriezentrum im Wienerwald (Vienna, Austria)

A Brochure containing the 25 recommendations, addressing Public Health officials, universities, schools of nursing and national Palliative Care associations will be published in English and French by the publication services of DG Research.

FINAL REPORT PART B

Background

A Palliative Medicine

Palliative medicine is intended for any person suffering from an degenerative chronic disorder, regardless of what it is: cancer, AIDS, renal failure, degenerative lung ailments. Its field of action ranges from neonatology to geriatrics, as suffering goes hand in hand with healthcare issues. It offers specific expertise in treating the medical problems of incurable patients.

The key to the palliative approach is situating medical needs in a **philosophy of integrated and patient-centred care** whereby suffering and quality of life are seen as multi-faceted concepts. The care worker thus recognises the patient's uniqueness, as well as her historical, cultural and social context.

Patients in the palliative phase have physical, psychological, social and spiritual needs that are varied and dynamic. Patients and their families will have preferences regarding end-of-life care, be it home care, specialised units or hospital services. A comprehensive palliative care service responds to this diversity of needs and choices.

B. Palliative medicine practice in the European hospital context

Palliative care is performed in various institutional configurations. In a hospital it may be entrusted to a specific unit or handled by the staff of existing services together with a mobile team specialised in this type of care. The hospital palliative care mobile team (PCMT) is an multidisciplinary team that supports acute care teams in the management of patients with palliative care needs. The PCMT also has a role associated with research and education. Occasionally some teams will be directly and actively involved in patient and family care.

In Europe, the mobile teams developed in a wide range of cultural and historical contexts. This diversity is reflected in differences in the way our countries perceive the major demographic issues of our time and their consequences.

The tendency in Europe is presently to promote the creation of mobile support teams instead of residential palliative care units or hospices. (Dunlop 1998, Royal order N°1545,1997 Belgium, , circulaire ministerielle relative à l'organisation des Soins Palliatifs en France n°2002/98,2002)

The main reasons are:

1. **Public Health authority requirements** that Palliative Care be made available to the largest possible number of patients (limited number of beds in residential units!).
2. **Greater possibility for broader dissemination of the expertise specific to Palliative Medicine** which develops the knowledge and techniques (treating symptoms) that are appropriate to ease the suffering of patients, and the hospitals' growing acceptance of the integrated care philosophy that underlies Palliative Medicine.

In the hospital setting the PCMT caregivers act by assisting the referring teams through advice/consulting, support and training. Their direct involvement with the patients is negotiated with the referring teams who usually maintain responsibility for the decisions and carry out the treatments. Through the experience of the PCMT, whose members have been confronted with the full range of convictions held by persons in a hospital setting, the concept of Palliative Care/Terminal Care has been bolstered by the concept of **Continuous Care**. Continuous Care tends to **articulate** curative and palliative procedures rather than setting one form of therapy against the other. (Deckers, Markstein 1989)

Continuous Care is a multidisciplinary approach which brings together medical, social, and psychological concepts - as well as spiritual for some people - in a continuum starting from

the time a grave illness is announced and on up to the end of life, without any lapse. (WHO 1990)

In that context the role of the caregiver who is member of a PCMT is often transformed into one of **interface and training**.

The results presented from several studies support the use of specialist multi-professional teams in palliative care to improve the quality of life of patients suffering from advanced cancer and their families. There is evidence that PCMTs improve pain control and symptom management as a result of the specialist approach (Hearn,Higginson 1998, Edmonds 1998). Moreover, mobile support teams can reduce the overall cost of care by reducing the amount of time patients spend in acute hospital setting and in a long-term perspective mobile support teams promote ethical reflection and a patient centred attitude in care-givers.(Lassauniere 1991)

On the other hand, the PCMTs' experience also shows that co-operation between the mobile support team and the referral service is rarely without tension and a certain degree of resistance.(Ruzniewski, Zivkovic, 1999)

This resistance is often directed towards the integrated and patient-centred care message that perturbs the *a priori* efficiency ethics that motivate a curative team. The hospital context imposes rhythms and work methods, a division of professional roles that the mobile teams are unable to break through.(Baum 1997)

For that reason the integration of PCMTs does not seem to be possible without adopting a certain form of humility in daily practice, which undoubtedly limits the team's capacity to forge its own place in the institutions.

Starting from an evaluation of the present situation, the strong and weak points of the in-hospital mobile support team model we then proceeded to study alternatives in integration strategies and in inter-collegial communication and mediation.

We aimed to translate our experiences in the field into guiding principles for the future mobile support teams that will be set up and begin to function in Europe.

All detailed literature references you can find on our website:www.mobileteam.irisnet.be

Objectives

Main research objectives

- * Identify the internal and external mode of operating of seven palliative care mobile teams in Europe (F,B,CH,UK)
- * Identify the strong values and principles of the hospital palliative care mobile teams
- * Examine the background and the evolution of these teams through their different traditions and in the light of the different cultures in Europe.
- * Identify areas of resistance to the values and principles of palliative care
- * Identify the problems of integrating hospital palliative care mobile teams
- * Update and modify the contents of the philosophy on palliative care in line with the reality of hospital institutions.
- * Find new organisational and teaching strategies in order to improve the integration of palliative care mobile teams into hospital institutions and to promote continuous care.
- * Articulate the tension between the ethical, socio-political and training dimensions of the mobile teams' activities in order to reinforce their impact in the hospitals.

Methods put in place in order to achieve these research objectives

- * Inventory of the current situation regarding the integration of in-hospital mobile teams
- * Analysis of the results of the appraisal programmes
- * Creation of a training and communication programmes and inter-collegial mediation for members of mobile teams using the analysis of the inventory as the point of departure
- * Training laboratory for testing tools for communication, ethical mediation and organisation

Final Objective

To promote an integrated approach for the seriously ill with as a final aim, a care philosophy centred on the patient and on their needs for medical and psychosocial accompaniment

Innovative aspects in the research objectives

1. Prevention: we understand our project as a first step to a large European public health campaign to foster research in prevention of suffering (see future research needs)

2. Ethics mediation:

In their work the teams raise ethical questions and seek to mediate among the different people involved in the caregiving process.

The following questions often arise:

- How to launch a dialogue with curative ward teams that focuses on the needs of the patient (patient-centred medicine)?
- How to establish collaboration with curative ward teams in which the notions of "shared responsibility" and ethics are heeded and respected?
- How to articulate the rights of the patient with medical responsibility, and how can this be concretised in an institutional reference?

If a consensus cannot be found in conflicts of an ethical or medical nature, an ethics mediator is needed. Some PCMTs have developed this role, a particularly innovative step in the hospital culture.

3. Training

The discipline of Palliative Medicine promises to be a rich source of learning and growth for physicians in training.

A holistic approach to medicine affirms an essential dimension of the practice of Medicine - the importance of relationship-centred care. Mobile in-hospital support teams are excellent vehicles for teaching basic clinical competencies: communication, pain and symptom control, the importance of psycho-social and spiritual support, attention to quality of life as well as to diagnosis and treatment.

An additional research objective of our proposal was also to help develop educational tools to promote training of healthcare teams by interaction and collaboration with hospital palliative care mobile teams.

Methodology

The project methodology was based on the following elements:

1. **Inter- and Pluri-disciplinary research** among clinicians (responsible for PCMTs), scientific experts (university institutes) and outside consultants (in communications and training).
2. **Phenomenological description of the experience gained**: drawing up an evaluation chart, workshops with clinicians and experts (sociology, psychoanalysis and ethics) showing the extent to which the mobile support teams were integrated in the hospital culture. **Questionnaire** on the structural organisation of mobile support teams. (*annex1: elements of the questionnaire*)
3. **Implementation**: gathering the reports on the teams' experience + evaluation charts + questionnaire - work by the teams with the help of co-ordinators (individual or group interviews)
4. **Report** on the results (teams' experience / evaluation chart) circulated to research participants.
5. **Analysis and Synthesis** of the results by the Experts Committee (clinicians, scientific experts, consultants).

6. **Elaboration** of a specific training programmes based on analysis of the evaluation results.
7. **Pilot Projects:** volunteer mobile support teams followed the training.
8. **Evaluation** of the pilot projects and European recommendations.

A. Methodology of the evaluation programme

Scientific responsibility for the evaluation programmes: France Lert (Member 8, Inserm, France)

Introduction:

The methodology of the evaluation programme was based on three axes:

The sociological strand, which focused on the organisation of the team's work, professional practices, social ties and labour relations (A.1), the psychological strand, which focused on identity of PCMT members (A.2) and the ethical strand, which focused on how the team integrated ethical values in their clinical work (A.3) The interviews were preceded by a questionnaire on the team's institutional placement, history, composition and internal rules.

The interviews were conducted with volunteers from each team, with an attempt made to allow for a broad as possible diversity of professions. These volunteers changed according to the research strand. The doctor participating in the project was the researchers' privileged reference point. It was up to her/him to mobilise the team for the interviews, i.e explaining the project, giving information about the methodology and information about the most propitious conditions for conducting the interviews (place, period, schedules.) The results were rendered anonymous in all oral and written outputs.

After presentation of the different approaches we proceed to a short conclusion of the results of the evaluation programme (A.4).

A.1 Sociological strand (Member 8, F. Lert, J-C. Mino, L. Roux)

The objective of this evaluation stage was to formulate hypotheses on the current gap between the operational principles for the Palliative Care consulting teams, and the actual way they run according to the teams themselves. In other words the aim was to enhance the group's reflection with a reconstruction of the team's experience as told by the team members.

This material on the teams' experience was constituted from:

- Written documents from the various teams involved in the project and reporting on their activities.
- Factual data gathered by questionnaire (*annex1: elements of the questionnaire*)
- Interviews with team members

Principle of the actual ,current and optimal situation

Given the relatively short time that was available for the interviews, and in order to avoid a discourse effect, we proposed to handle these questions by looking into cases of patients the mobile teams were involved with.

If by definition an evaluation follows the critical method, the objective is not to underline failures or difficulties, but to bring out the concrete supports on which the teams can develop their work now that they have reached their present stage of evolution, which can vary from one team to another. The principle adopted therefore was to focus on situations in which the teams were able to fully develop their activity and practices and base their action on the values of palliative care. On the occasion of these discussions, the people interviewed could mention how this situation was habitual or an exception, and to point out or explain cases or situations where they felt the team did not succeed.

Contents of the interviews on clinical work

Objective:

The principle of these interviews was to analyse the teams' current situation by describing precise cases the team was dealing with at the time of the interview. These cases were chosen among the ongoing cases in order to present the current optimal situations for the team in its own context. They were examined in depth to bring out the principles and action criteria the team had set itself in order to highlight what enabled them to reach their current stage of evolution and what could explain the gap between the team's actual activities and its ideals.

Contents of the interviews on institutional work

Objective: On the hypothesis that the objective of palliative care is a holistic approach to the patient guided by ethical principles and supported by specific techniques, the mobile teams therefore must spawn multidisciplinary in the referring services: how do they go about this? Once again, we referred to actual incidents in the life of the teams, in addition to the data from the questionnaire.

Collecting information

The interviews were recorded and transcribed to enable a maximal use of the information. We chose to conduct two or three interviews per team, depending on the size, on the clinical and institutional themes - in other words 4 to 6 interviews. Ideally all the professions were represented during one or another interview.

A.2 Psychological strand (Danièle Deschamps, psychologist, psychoanalyst, Member 1)

The interviews with two or three people in each of the 7 European teams focused on the following questions:

- What was your "vision" when you first joined this mobile team? How did the encounter with on-the-job reality change this vision? Along which lines?
- What is it like for you to no longer be directly involved at the bedside of patients and stepping back, in a way, from the first line of decision-making? How did you adapt to this "middle ground" - between two services, between healing and palliative medicine, with different medical skills and a more holistic form of questioning? Does this middle ground seem rich to you? Enriching or wearing? And viable over time? Does it give you the objective distance you need for your job? Too much or not enough distance?
- Do you feel any competition with healthcare staff, doctors, psychologists? How can you create an alliance with some of these other professionals? And with people on your own team?
- Is your identity clearer for you now, and is it better acknowledged? How would you define yourself? As an expert, a consultant? How does the interaction between "supply and demand" evolve over time? What are the positive and negative limits of your actions?
- Do you still enjoy participating in this team, and what proposals do you have on future training for mobile teams? How would you integrate the psychological dimension? On which subjects and in which form do you think this would be useful, or not useful?

A.3 Ethical strand (Mylène Botbol-Baum, Stéphane Leyens, Member 11)

The objective of the ethics aspect evaluation was to "bring out the characteristics of a PCMT as regards the values that underpin their practice". We first (1) clarified *the type of value* that is relevant to ethics, and then (2) undertook this *evaluation*.

- 1) The decision-making arising from clinical judgement is based on different *reasons*, *considerations* or *values* motivating the action. We can distinguish between ethical considerations and non-ethical considerations. The latter can be limited to a body of knowledge (an organism that functions well, the best way to manage an institution, etc...). What is specific to an ethics reason, however, is to refuse such reductions and

encompass the complexity of a particular situation. It answers the question "how must one live?". Thus a decision cannot be ethical if it is guided by the sole *scientific reason*, fitting a case to a law. Medical judgement is ethical in this sense because it concerns a patient who is the subject of his existence and not merely the object of scientific knowledge. Clinical decision-making is an act of *practical reason*, focusing on the value of "the good life".

Practical reason must *give meaning* to a given situation which cannot be immediately apprehended by a general principle. No matter how essential their biological data may be, a patient is nevertheless more than that. Practical reason must articulate these data with the history of a living subject and attempt to bring out their true significance in the context of the life the patient has lived. The narration is thus a crucial moment of medical judgement because it is at this time the history can be constituted and interpreted, that meaning can be given. The decision-making will thus be ethical.

Consequently, the notion of *narrative ethics* is based on the fact that all patients come to the hospital with a history whose narrative coherency can be suspended by illness, and that this illness must take on a meaning in the person's existence. It is the fact of practical reason that seeks to inscribe a biological event in a life the meaning of which it attempts to interpret.

- 2) Thus described, narrative ethics is at the heart of the philosophy of continuous care, understood as the articulation of the healing (curative) and palliative approaches, transcending the dichotomy between "idealising end-of-life care" and "efficient treatment". The question as to which extent mobile teams have integrated the philosophy of continuous care can therefore be posed in terms of narrative ethics.

Accordingly, the evaluation - i.e. the interviews –focused on the notion of "person". In the modern tradition this concept denotes both an absolute - a free and rational subject, endowed with free will and therefore worthy of respect - and a singular - a concrete embodied being who has a history. The person is both an object of biology and the subject of a history, but is also deserving of a good and accomplished life. This is what narrative ethics attempts to trace.

During the interviews, based on the account of a situation, we attempted together to understand how the actors of the mobile teams experienced this case as a success or a failure. Which approach towards the *person* underlied this judgement (success or failure) of the decision taken?

A.4. Short conclusion of the results of the evaluation programme *(see also below chapter research achievements)*

The researchers identified the axes that appeared to structure the understanding of the mobile teams' situations in the various hospital contexts in the three fields of study. These seven axes were:

- 1) The institutional issues at stake
- 2) the positions of the issues of palliative care with regard to moral or political issues; the question of euthanasia.
- 3) Autonomy and dependence,
- 4) being in the second line of care; communication, techniques and strategies,
- 5) time as the principal ethical value and the place of narrative ethics,
- 6) Clinical expertise and the holistic approach,
- 7) multidisciplinary

The advantage of a European study lies precisely in its ability to place the functioning of often very small teams in perspective against their broader cultural, institutional and professional contexts. Hospital-based palliative care can flourish only if the people involved in such projects can define their explicit positions within medicine and the health care system.

Whilst palliative care techniques can be taken up by hospital staff, there nevertheless exists a body of skills and knowledge specific to palliative care and as a result of which palliative care can be considered a discipline in its own right. This specialisation must be developed as such in the medical care and academic systems in order to support the palliative care provider's specific identity, to enable the field to be recognised and above all included in the hospital's structure and the care options on offer, and to allow training and research. It is thus a matter of recognising the specialisation and of having a complete range of services on offer, *i.e.*, residential services, mobile teams called in for hospital consultation, external PC consultations, and home care.

The 'end-of-life medical management = palliative care' paradigm must be redefined and perhaps renamed within the hospital context to assert itself in the simultaneously broader and more restrictive field of palliative care or actions.

Integrated mobile PC teams cannot confine themselves to a consultative role as they have done throughout this first phase. They must spell out their aims and corresponding activities in order to develop the hospital's ability to provide quality palliative care (basic training and further training) and draw the contours of their own areas of activity (expertise, consultancy and care). This clarification of activity, supported by sufficient means and a real organisational effort, should help bolster the mobile palliative care team members' identities.

The team's internal organisation and its forms of intervention in the hospital departments must allow for the way that the hospital is organised so as to be compatible with the hospital's division of labour. This means allowing for the specialisations' organisation in the provision of care, the organisation of work within the different departments (division of labour among doctors, between doctors and nurses, turn-over, 'branch' approach, etc.), the hospital's relations with external care services, etc.

Given the current context of the discussion about euthanasia, the stakes riding on this issue for each team, especially when it comes to the team's internal organisation and relations with the other departments and services and the patients and their families, must be discussed openly.

All results of the evaluation report have been integrated and translated into recommendations (see below chapter research achievements)

The entire report and additional information about the results of the evaluation report can be obtained from the scientific co-ordinator: catherine.markstein@skynet.be

B. Methodology and description of the pilot training programme

Scientific responsibility for the training programme: Dr Ruth-Marijke Smeding (consultant member 1) and Dr John Ellershaw (Member 3)

Introduction:

Chapter B deals entirely with the training programme methodology, design and its practical implementation with 8 European PCMTs.

We describe below the following elements of the pilot study: theoretical background (B.1), training design (B.2), the practical framework (B.3), contents of the session (B.4), evaluation of the repercussions of the pilot study in the work of 8 PCMTs (B.5), and the main conclusions of the training programme (B.6).

B.1.Theoretical background of the training programmes

1.1 The Learning Style inventory of the team

David Kolb (see "Experiential Learning: Experience as the source of Learning and Development", David Kolb, 1984, Prentice Hall P T R) formulated a model on experiential learning based on, and developed from, the theories of learning by Lewin, Dewey and Piaget. Worldwide research, scientific discussions and applications in many different fields have led to what may be called an evolutionary leap in the world of experiential learning.

One of Kolb's basic hypotheses, which were extensively researched, was the assumption that people vary in their learning styles.

This concept was used In the pilot study, to forward the idea of learning together, using the effects of each other's learning styles, in order to become a team.

The learning style inventory describes the different ways of learning and how to deal with ideas in day to day situations.

1.2 The model of effective training

Effective Training is training that occasions changed behaviour.

Effective training is focused on the following dimensions:

Skills: how to do something

Knowledge: why something works or should be done in a certain way

Attitudes: the underlying values and concerns that govern behaviour.

Effective training will:

- a.) give people the skills they need to do what they are being ask to accomplish
- b.) Give people the knowledge they need to understand what they are doing and why it is effective as opposed to other approaches to the task;
- c.) Demonstrate the appropriate attitudes and values that must accompany the skill and knowledge if they are to be fully incorporated into people's lives long term.

To achieve long term change in behaviour the training addressed all three dimensions.

B.2. The training design as a result of the evaluation report

In the evaluation report and discussion on Major Meetings the researchers and clinicians identified 10 topics for training which they considered to be the fundamental steps in the learning process towards good functioning for a Hospital Palliative Care mobile team.

The 10 topics were: ***Human resource, management, Clinical competence categories, patient focused care, communication skills, leadership and team issues, education, outcome – measures, ethics, research and development***

(See annex 2: 10 steps to functioning)

Two of these topics were chosen for the pilot training by the clinicians: Communication, Leadership and team issues.

B.3.The practical framework of the training program

3.1 Organisation of the training program

The experiment was set up as follows:

2 training days in Brussels, with team-representatives. Design addressed a two-level training (targeting both leaders and members of team), using the "train the trainers" format.	Home-based implementation by teams: 12 sessions 6 x 90 minutes and 6 x 60 minutes. Content: providing frame of reference, laying foundation, provide some training, reflect on results. Brussels-trained „teachers“ to provide support to home-based teams	2 days in Brussels: harvesting. Turning results into foundation materials for a training-report, aimed at educational and training design for Europe.
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3.2 The training tools used in the sessions

Role playing, questionnaires, evaluation grids, checklists, communication exercises, subject-centred team discussions

3.3 Roles in the training sessions

The sessions at the hospital (home-based sessions) were managed autonomously. The teams did not call on an outside mediator. Different roles during the sessions were delegated to various team members:

- leader**: the doctor responsible for the team, who handled the preparation, organisation and moderation of all the sessions;
 - recorder**: a team member who recorded the sessions; this person could change from one session to another;
 - observer**: changeable at each session
 - time keeper**: changeable
 - resource persons** could be invited according to need
- In case of problems the teams could contact Dr. Ruth Marijke Smeding, scientific responsible for the pilot programmes.

B.4. Contents of the sessions

4.1 Themes of the training sessions

Training workshop 1: Introduction of the teams into the pilot program. Training of the session leaders

Training workshop 2: Results of the pilot programme; presentation of the results and critical reflection of each team. Interviews with the participants by the sociologists
F. Lert et J.C. Mino (member 8)

Module1: Elements of Leadership and team effectiveness

Session 1+2: Reflections on the meaning of the way your team is composed

Session 3: Looking in the team mirror

Session 4: "How are we effective?"

Session 5: Shared values

Session 6: Communication among ourselves

Session 7: Reflections

Module 2: Communication

Session 8: Communication in the system

Session 9: Communication with units of care

Session 10: Conflicts in communication

Session 11: Working with the issue the team would like to repeat

Session 12: Compilations of reflections, actions

Session 13: Closing session; pilot project overview

A syllabus with the detailed description of each session can be obtained from the project coordinator: catherine.markstein@skynet.be

4.2 Main results of the training sessions

General conclusions

The teams conducted their training exercise in various manners: Although the principle was training as a team, the participation of all members was more or less organised by each individual team. One team shifted time-off to make sure everyone participated; in other teams the exercises were led by someone else when the group leader was on holidays; in other teams some members - critical of the model proposed - dropped out, which destabilised the team.

The exercises were planned differently depending on the team: all teams appreciated the framework structuring the training (strict planning of meetings, conclusions at the end of each session, fixed roles to conduct the meetings). Some teams saw it as a game, others as a rigid constraint, others truly considered it as an exercise to test the modules which should not have any negative effects on the team. The KOLB exercise (see learning styles A.1), occasionally abandoned during the sessions, fostered an interrogation on the different positions adopted within the team: positioning of personalities, of professions, positioning related to roles or in accordance with the team's values and objectives. This progressive shaking of the team's homogeneity came about as the sessions went on and depending on the theme addressed, even if some teams did not recognise the utility of all the exercises. The two modules tested dealt with forming the team and the question of leadership and communication - in other words, two out of the 10 subjects retained (see Annex 2; ten steps to functioning). Thus changes were not to be expected in all the dimensions that characterise a team.

In the determinate framework of each session the Clinicians discussed and worked out new strategies to improve teamwork and communication with acute cure-orientated services. The mobile teams have an educational function towards the referring teams, a function based on specialised competence in palliative care. The teams have been empowered to acquire specific competencies for successful working in the particular surrounding of a hospital. Working case by case on professional levels with those who need to be cure-oriented in most of their professional activities requires specific competencies, not generally taught in Palliative Care. Working with acute care teams in curative medicine requires the development of advanced skills to coach, co-operate and support the cure-oriented colleagues in both palliative and cure-oriented tasks

In utilising very effective and powerful training tools (see C.2) the participating PCMT's learned to clarify their work strategies, to improve communication and to change their mode of collaboration with the referring team especially on an institutional level:

Professional role and leadership:

They clarified the question of the teams identity and the work as a multidisciplinary team. Team members realized that working in a cure-oriented context requires continuous attention to communication and liaison skills (hospital personnel changes continuously). The participants of the pilot study also got aware that PCMT's need to work on team-based accountability, including leadership and team issues, according to current levels of professional knowledge and research.

The teams efficiency:

In working on concrete clinical situations they improved their capacity of clinical management in collaboration with the team of the acute ward. They became increasingly competent in handling both internal and external team issues. They agreed that good communication and sufficient time for reflection should be taken into account in decisions regarding clinical management, discharge or transfer. They learned to work on team-based accountability, including leadership and team issues, according to current levels of professional knowledge and research

The teams internal management:

They learned how to include educational topics for newly installed teams: adequate job-descriptions, development of assimilation criteria, induction programs, planning development (accommodation to existing structure, anticipation of team effects in interaction with such structures) and professional/clinical supervision and how to organise and to formalize team meetings for promoting a better circulation of information and a more effective team

collaboration. The teams also realized the importance of supervision by an outside trainer. They learned to categorize better their roles in case managements.

Institutional and clinical work:

Important strategies on an institutional level have been elaborated. These strategies you will find later translated into recommendations.

They worked out that the definition of a therapeutic plan will improve the integration of Palliative and curative procedures, taking into account the qualifications of each team involved and the temporal order of the treatment. It will thus clarify the respective contribution of the mobile team and the referring team.

They elaborated that collective work in team meetings concerns

- 1) the service's conceptual framework, philosophy and policy,
- 2) its "strategies" for integration in the institution, in particular its place and role in the institution and in its work with patients,
- 3) formalising documents or procedures,
- 4) improving the decision-making processes in the team and
- 5) organisation of the clinical work that solidifies the integrated approach: for example, in the schedule and hours required, responsibilities of each member, co-operation modes in the team, partnership work by staff of different professions.

They also identified 3 fundamental phases in the learning process towards good functioning for a Hospital Palliative Care mobile team: These 3 steps, which conduct to integration of the PCMT in the hospital, are described and explained in chapter E and figure 1.

Values of the mobile team members

Team members learned to deal with values, convictions and ideologies in the team itself and in the contact with hospital teams especially in clinical situations that lead to ethical conflicts. In such situations mobile team members learned to specify the values that should guide the action. They learned how to deal with excessive idealistic expectations of the PCMT members and how to establish priorities and to provide the cure – oriented team with guidelines to handle conflicts.

All results of the training pilot study have been integrated and translated into recommendations (see below chapter research achievements)

B5. Evaluation of the training programmes during training workshop 2

(by France Lert, Jean Christophe Mino, Member 8)

a) Professional roles and leadership

The discussions and exchanges revealed that, as the sessions progressed there was a break-down of the fusional myth (ideal team), as an undifferentiated whole where roles would all be equivalent in the name of a utopic notion of pluridisciplinarity, the team's relation to medical power, collective work, the holistic approach, etc. As different styles of learning emerged, the diversity of roles was seen in a new light which reflects not only functions and professions, but also the diversity of personalities and ways of relating to the team.

The categorisation of roles was accepted for the exercises themselves, but not necessarily as a permanent factor characterising the team.

The doctors explicitly recognised their role as session leader to affirm a position of leadership, choose, decide, and opt for efficient actions. The doctors thus explicitly accept (and it was clear from the initial phase that classical professional roles were well-preserved) the leadership that comes with the dominant position of doctors in the hospital context. The explicit positioning was a relief for certain team members.

The head nurses pointed out that they were trained in organising and managing a team, not the doctors who derive their legitimacy as team leader solely from their clinical expertise. They could thus help "translate" certain notions of management in the training contents.

The role of a head nurse in future teams or in relatively large teams calls for a more in-depth reflection.

The reflection on professional roles for teams working in tandem, a principle for some teams but not all, was also broached.

Several people mentioned the need for the moderator or trainer to be from the outside, in particular for the exercises (especially role playing) seen as potentially threatening to the team. This reservation echoed a strong influence from the psychoanalytical supervision model which functions virtually as a separate place where difficult matters can be expressed in a safe environment.

b)The team's efficiency

Approaching the clinical case as a question of an individual remains the paradigm through which medicine, in the large sense including healthcare treatments, sees its accomplishment. This holds even more for palliative care, particularly through its strong psychoanalytical colouring. The preliminary research showed that a crucial issue in the mobile teams' activity was juggling the time available with the demand. The exercise allowed them to work on these questions from the angle of efficiency - in other words, how to mobilise the available resources to be better placed to deal with a greater number of patients without sacrificing the objectives and values of palliative care. This led the participants to accept a greater degree of formality in their work, by defining and installing procedures in the teams or services work specifications or procedures, responding by phone, detailed description of the case when the referring team requests the mobile team's services, and the team spending less time narrating each case.

c)The team's internal management

The structured meeting required by the training exercises led the teams to question the meeting ritual. While meetings are frequent in Palliative Care (clinical meetings, bibliography meetings, supervisions, informal exchanges), they primarily concern clinical matters (the case) and the psychological dimension of the work (discussion group, supervision). On this occasion a meeting discussing how the team was organised and how it functioned enabled new themes to be developed. Formalisation of the project's meetings brought out the defects of other types of meetings: badly programmed, badly managed, not well-focused, seeming to go on and on. As a result some teams revamped the schedule and objectives of their meetings.

d)Institutional work

Some teams launched real institutional work by undertaking different types of actions: the management language style enabled them to inscribe and defend their activities and projects in the context of the hospital.

Others developed a veritable institutional strategy to gain recognition: participating in hospital institutions, more systematic relations with the hospital actors, and even making use of the institutional workings itself.

e) Clinical work

Most participants affirmed that their clinical work was not affected by the training process. And admittedly, the training did not touch on this aspect of their activity. Nevertheless the reflection on the team's functioning could have been expected to influence the clinical facet. The team members found it hard to acknowledge how improving the team's functioning related or could relate to their work for the patient or the patient's suffering. Only one team acknowledged that the exercise facilitated their work with the patients.

f) Values and objectives

The participants greatly appreciated the exercise on values. It consolidated the values underpinning the team and fostered the acculturation of younger team members. Some teams felt it was important to return to the subject of values, but this section of the training was not addressed in depth.

g) The newly formed team

Whereas older teams wondered whether the model was relevant for teams just starting up, the Antwerp team felt it was beneficial in raising more quickly and efficiently matters concerning the mobile team's insertion and functioning in the hospital.

h) Psychoanalytical paradigm and the behaviourist/managerial paradigm

For the French-speaking teams so versed in the psychoanalytical paradigm, the managerial/behaviourist language raised some reticence, resistance even. But it also opened new horizons. Some participants recognised the complementarity of the two approaches. This calls for more in-depth conceptual and methodological preparation.

B6 An educational plan for PCMT's as one of the main achievements of the pilot study (see also below chapter research achievements)

In the the analysis of the training and the evaluation programme it became clear that the 10 identified issues (*more detailed explanations of the 10 topics see annex 2*) which are fundamental in the learning process towards good functioning, must be integrated in each phase of the development of a PCMT.

A PCMT needs to be phased in 3 fundamental steps;

1. Developmental phase 2. Integrative phase 3. Sustaining phase (figure 1)

To pass through these phases constitutes the main learning and educational process for PCMT's. Each phase is associated with an educational programme, which is adapted to the level of evolution of the team;

In the **developmental phase**, which is considered as the first step of a new team in the hospital, clinical and specific PCMT competencies are the most important issues in the training of the team.

As the teams become functional in the **integrating phase** communication skills , patient centered care,management skills and how to deal with the questions of human resources become the main subjects of learning for the team.

Following the integrating phase of a PCMT it is important to recognise **the sustaining phase** and the changing needs of the PCMT. This phase raises other specific subjects for PCMT's in the form of ethics, education, leadership and team issues, outcome measures programmes and research and development. These issues will foster the team's working at the interface of cure and care.

FOCUS OF DEVELOPMENT	PHASE OF DEVELOPMENT	10 CORE EDUCATION & TRAINING CATEGORIES
(FUTURE) TEAM MEMBERS	1. Developmental phase	1. Clinical and specific PCMT competencies
VALUES & RELATIONSHIP WITH INSTITUTE	2. Integrative phase	2. Communication and liaison skills 3. Patient Centred Care 4. Management skills 5. Human resources
EVALUATION & DEVELOPMENT OF SKILLS & ATTITUDES	3. Sustaining phase	6. Ethics 7. Education 8. Leadership and team issues 9. Outcome measures 10. Research and development

Research Achievements

1. Research findings and European recommendations; analysis, synthesis and conclusions from evaluation report and training pilot program

Introduction:

We can summarise the research findings under 3 main items: I. Institutional and public health issues, II. Education and organisation of the work, III. Communication and ethics.

The research findings of each item have been formulated into recommendations. The recommendations are organised by the level of responsibility they address, namely, the public authorities, the hospital, and the mobile team itself. Each recommendation is underpinned by the observations made in this project and the research findings. In formulating these recommendations, we were also guided by the various phases in the development of a mobile team, (figure 1).

I. Institutional and public health issues

Research findings:

In the hospital setting the PCMT caregivers act by assisting the referring teams through advice/consulting, support and training. Their direct involvement with the patients is negotiated with the referring teams who usually maintain responsibility for the decisions and perform the treatments. However, participating in a PCMT can be extremely stressful. Transectoral care can generate stresses for both the team and its individual members, particularly where there is poor integration with acute care services and a lack of clearly identified role. PCMT members can feel compromised in terms of asserting their identity as a caregiver and this exacerbates the risk of burn-out, individual or collectively for the team. Therefore, members of the team may need the possibility to practice in various types of arrangements, either over a successive period or simultaneously on a part-time basis in different structures.

The PCMT has a unique role based on a philosophy of 'care' in contrast to the philosophy of 'cure' that often prevails in the hospital setting. The PCMT has a unique role and objectives that distinguish it from other clinical teams and settings offering patient care.

The recognition of PCMTs within hospitals is still precarious due to the lack of a status for the speciality of palliative care. The instability of the team members' employment contracts, a low level of autonomy, and at times conflict within the institution regarding the function of the PCMT are problems that developing teams may encounter.

The lack of statutory recognition for palliative care in many countries, both at the academic and/or professional level, appears to lead to questioning of the competence of those who practice this type of care.

In the palliative phase the patient and those close to them, are faced with experiences which may cause great distress. There are still numerous situations in which the patient and/or the family are not completely informed that the patient has a limited life expectancy and will die. Many health care professionals and families still consider announcing the truth to have an adverse effect on the patient and/or family. In this context, the arrival of the PCMT to the bedside may be associated with 'death and dying' and met with refusal by the referring team or the patient. To avoid this situation some PCMT members conceal their identity and present

themselves as part of a unit responsible for pain management, comfort or psychological support.

Moreover, confusion regarding the definition of palliative care and misunderstanding about the specific mission of PCMTs mean that in acute care hospitals mobile teams are called almost exclusively by the referring teams. In general the patient or family cannot themselves ask for the specialised involvement of Palliative Care.

Recommendations (RC):

The research findings in this category led to the following recommendation topics which we addressed by level of responsibility to the public authorities and society.

Contents of the recommendations in this category:

- RC1.** How to foster the integration of Palliative Medicine into European healthcare systems.
- RC2.** The importance to integrate Palliative Care Mobile Teams (PCMT) in a wider palliative care network an integral part of the wider palliative care services.
- RC3.** How to develop the Hospital Palliative Care Mobile Teams in a public health perspective.
- RC4.** The necessity of the recognition of a specific status for palliative care practitioners.
- RC5.** The importance of information on Palliative Care for the general public.
- RC6.** The involvement of local, national and European associations in the promotion of PMCT's

II.Education and organisation of the team work

Research findings Mobile teams are a new initiative proposing care practices that differ from those in acute care services. With the philosophy of palliative care still contested on a regular basis, PCMT projects are often initiated by a few people on an ad hoc basis, or as a result of a request imposed from outside the hospital. Isolation in the preparatory work to set up a team adversely affects the future of these projects.

PCMTs are often quite small, especially at the beginning - sometimes just one or two people working part-time. As such they cannot truly call themselves a team.

The mobile teams have an educational function towards the referring teams, a function based on specialised competence in palliative care. If the mobile teams recruit staff who are insufficiently trained in the concepts, knowledge and techniques of palliative care it is hard for them to accomplish their mission correctly.

Mobile teams are often small structures (3 - 4 members) responsible for developing quality palliative and end-of-life care in very large institutions (often several hundred beds). The PCMTs take direct action only in the most complex cases and act primarily by reinforcing the competencies of the hospital teams through training, general advice and support.

Current guidelines provided by the World Health Organisation require PCMTs to work on multi-disciplinary bases. Most teams are currently not empowered to acquire competencies for successful working in the particular surrounding of a hospital. Exclusive and unprofessional practices, such as institutional "abandonment" (or not being invited to participate) on policy, structure, and financial levels and resources reflect badly both on the institution and on the team. Working case by case on professional levels with those who need to be cure-oriented in most of their professional activities requires specific competencies, not generally taught in Palliative Care.

Mobile teams are often set up with one or two people in existing care units that provided the initial logistical, administrative and professional support. This situation may restrict the team's

autonomy, especially in its recruitment, management and its strategy for relations with other care units. This situation, moreover, may hamper the mobile team's visibility and understanding of its role with the referring services and caregivers.

The objective to offer palliative care routinely to patients who need these services calls for developing the competences of the generic caregivers in the hospital. These caregivers may already have highly diverse skills, based on their experience and training.

Various modes for collaboration with the services are possible:

- designating key individuals in the services most concerned
- meetings with other services to discuss the most significant cases or co-operation issues
- a training programmes, defining robust procedures for the PCMT's functions in the hospital
- consultations or treatments in common with the patients and their family/friends
- a system to describe the PCMT activity that will make it possible to adequately measure the balance between resources and needs.

In today's healthcare services, the organisation of care is submitted to heavy economic pressures, which are often reflected in time constraints. Treatments are thus often segmented, rapid or interrupted. This leaves the patient, who is often exhausted and distressed, with little time to express his/her questions, story, or wishes. Additionally the caregivers, do not always have the opportunity to accompany their technical tasks with as much listening and support, as they would like. This time constraint may prove to be particularly harmful in the palliative phase. In this phase, the time taken for care procedures is thus necessarily longer regardless of whether they are performed by staff of the referring team or by the mobile team.

Differences or disagreements often occur in the comprehension of the patient's situation by various parties (patient, relatives, and caregivers) and in the solutions recommended. A lapse of time, often a few extra days, enables the parties involved to find a convergence in their points of view or positions. Economic and medical standards may lead to shortening hospital stays when the technical procedures are terminated, which thus impedes the process to reduce dissonances and find compromises.

Hospital Palliative Care, by way of its mobile teams, adheres to the philosophical rationale of Palliative Care and its normal professional developments. However, it also has a highly specific branch as a result of its continuous work in otherwise cure-oriented surroundings. Maintenance to the high standards of practice in patient care and development of advanced competencies is hampered by lack of appropriate structures on national and international levels. For newly installed teams, it is further recommended that they seek mentorship of already functioning teams, whereas the latter should make themselves available for such, to mutual avail: such tasks assist established teams own reflective practice.

Recommendations (RC):

The research findings in this category led to the following recommendation topics which we addressed by level of responsibility to hospital and the PCMT in its developmental phase.

Contents of the recommendations in this category:

- RC7.** The importance that the institution supports concretely the implantation of a PCMT. with a project group
- RC8.** How to guide the institutional development of a PCMT.
- RC9.** How to define a palliative care team
- RC10.** How to guarantee the competence and the experience of the mobile team staff.
- RC11.** The minimum conditions of functioning for a PCMT.
- RC12.** Specific training and education for PMCT members
- RC13.** The importance to situate the mobile team in the hospital organisation structure in a manner that ensures its autonomy and participation in decision and management bodies
- RC14.** Define the development modes in a realistic plan
- RC15.** How to deal with time in the specific Palliative Care Approach: Recognise and put a value on the time spent with the patient as a specific palliative care procedure
- RC16.** How to ensure high professional quality output for Hospital Based Palliative Care

III. Communication and Ethics

As the teams become functional in the integrating phase, they become increasingly competent in handling both internal and external issues. This is almost exclusively based in advanced experience, not yet tied to systematic and shared reflective practice.

When the team is well installed in the hospital structure, it is operating and working on normal team development lines of reflection and improvement. Working in a cure-oriented context requires continuous attention to communication and liaison skills (hospital personnel changes continuously). This raises another specific issue for PCMTs in the form of leadership and team issues given the team's working at the interface of cure and care.

The integrated approach calls for multidisciplinary in the team's composition and interdisciplinarity in work practices

In view of their limited resources and their objectives, the PCMTs often do not have the responsibility for the execution of the decisions nor do they perform medical and nursing treatments directly. This practice is not well understood by the referring teams, who sometimes prefer either to limit the mobile team's involvement to mere advice or on the contrary expect a true case management. Our research suggests that the mobile team may be perceived somewhat as spared (protected from) the "dirty jobs" that have to be done by teams affected by economic constraints and growing quality requirements

Continuity and the integrated approach to a case are conditions for the effectiveness of palliative care. This continuity depends on information assembled and shared collectively among the PCMT staff. The team's organisation fosters this continuity through communication among members that is formalised to a certain extent. Too much segmentation through division of the work in part-time schedules can be harmful, especially in small teams who thus spend a disproportionate part of their time available in meetings.

In their work on a PCMT the caregivers are confronted with a heavy emotional burden. This results from their interactions with patients, families, acute care professionals, teams and the institution, as well as questions regarding one's identity as caregiver.

The position of PCMTs regarding decision-making gives rise to an exacerbated tension between the ideal of the action and its practical application, between idealistic values and the way they are translated in practice.

In such a situation, it is vital to specify the values that should guide the action. The absence of clearly identified values may become a source of frustration, particularly in attempts to resolve interdisciplinary conflicts, and may engender problems of identity for the team.

To specify, or to make explicit, a value means determining, *in terms of clinical practice*, the ethical commitments that correspond to that value, e.g. (a) the limit to be drawn between an acceptable compromise and unacceptable compromising of oneself, (b) the criteria to be recognised to judge the patient's well-being, or (c) the limits not to be overstepped in interpreting the patient's words or attitude.

The PCMT may be confronted with requests for euthanasia from patients or their family, and with questions regarding the practice of euthanasia by referring teams. In the countries where euthanasia is allowed by law, the involvement of the PCMT may also be called on for patients requesting euthanasia. The position of Palliative Care professionals is often refusal of euthanasia. However, the positions on this issue are nevertheless diverse and often remain implicit in the mobile team itself. Confronting the practice of euthanasia is often a point of conflict, open or latent, with the referring teams.

Decisions concerning a patient often entail the confrontation of diverging points of view on a situation that is dynamic and uncertain. In most cases, no formal framework is available to confront the positions of all the caregivers involved and foster a decision that gives the rightful place to points of view of the patient and/or family/friends.

The patient and family/friends are fully engaged in the decision-making processes. Each caregiver involved in the patient's case expresses the elements personally available in order to comprehend, identify the problems to be solved, propose means of action to achieve a better balance between therapeutic efficiency and the patient's wishes. In a situation of uncertainty, allowing time may enable the approaching (or convergence) of points of view on the basis of a common interpretation. This confrontation of points of view (stories) can be formalised in meetings assembling the caregivers and, depending on the case, the patient and family/friends.

Recommendations (RC):

The research findings in this category led to the following recommendation topics which we addressed by level of responsibility to the hospital and the PCMT in its integrative and sustaining phase.

Contents of the recommendations in this category:

- RC17.** The importance to recognise the integrating phase and the changing needs of the PCMT.
- RC18.** The importance to recognise the sustaining phase and the changing needs of the PCMT
- RC19.** The importance to promote multidisciplinary in the organisation of the work of the PCMT
- RC20.** How to foster the direct involvement of the PCMT in case management
- RC21.** How to define an organisational mode that guarantees continuity in communication and treatment
- RC22.** The importance to enlist an external third party for collective reflection on the emotional issues of work on a PCMT
- RC23.** The necessity to discuss ethical commitments collectively
- RC24.** The importance to define collectively the PCMT's responsibility regarding requests for euthanasia.
- RC25.** How to promote a formal process to confront differing information and positions, associating as far as possible the patient and family

2. Areas of disagreement and discussion

- a) The clinicians discussed the delicate balance between **"making compromises and compromising oneself" in ethical and clinical matters** This subject lies at the heart of their ethical questionings in their practices with the patients and the referring teams. The

situations are complex with several elements entering into play which calls for in-depth study of the mobile team's attitude when faced with conflictual decisions. The clinicians feel the need for evaluation grids adapted to clinical situations. Some clinicians are uncomfortable with the term "**interpreting the patient's words**" (see evaluation report ethical section) for its connotation of deforming the patient's words, when their process is actually listening for what the patient is trying to say.

- b) Being "**in second-line**" (a consulting team not directly involved in treatment) when they communicate with the referring teams the mobile teams often adopt a "**low profile**" (a term taken from the systemic approach). The researchers wonder about the consequences of such a stance. Most clinicians defend this position for it fits in with the logic of a consulting or advisory team. It is seen as a communication strategy and is necessary to gain the trust of the referring team. At the same time, however, the clinicians stress the need for self-interrogation and thinking about their feelings towards aggressiveness and conflict as an important element in their relations with the referring teams.
- c) **The issue of euthanasia** is crucial for a mobile team at two levels. Within the team itself it is essential to determine how it is addressed in projects, statements, and when recruiting team members. In particular it is important to perceive the role it plays in the cohesion of the group. This issue is also crucial in the importance it is given in interactions between the mobile team and referring teams. For some PCMTs who staunchly defend their values, convictions and "ideologies" in their dealings with the referring teams, the patients and their families this issue can become a source of permanent conflict. It is not the mobile team's place, however, to impose its vision but rather it is up to the institution, through the Medical Council for instance, to provide a framework that will enable the team to deal with requests for euthanasia. In some institutions that frequently hasten end-of-life without the patient's consent, the PCMT can serve as a Super Ego of sorts. Each team should undertake some serious work on values and convictions concerning euthanasia. The clinicians stress that the mobile team should not feel they must "lead the fight against euthanasia". Their focus is on the patient!
- d) **Conflicts within the team itself**: A issue often raised is difficulties managing conflicts of values within the team itself. These conflicts arise especially when coping with the day-to-day realities of the hospital environment, which is often quite divorced from a mobile team's philosophical and medical ideals. Frustration and disappointment can often paralyse certain teams, demotivating them or leading to aggressive (or even "dogmatic") attitudes towards staff on the referring team. The key to managing these "vertical" conflicts is to find a balance between utopia and reality. Each individual team member must first look within him/herself and only then should the team reflect on this question together. The clinicians ask for tools to manage conflicts within the group. In the evaluation programmes interviews the clinicians affirmed a culture that resisted the efficiency-first mentality as an ethical movement. At the same time, however efficiency is not without value either. Therefore, how can these values be integrated and a dialogue take shape in more subjective terms? The team member must be able to cope with this constant tension. The very definition of "value" and the objective of the ethics evaluation was the subject of several discussions.
- e) The complex problem of the **caregiver identity** of a PCMT member. There was a long discussion on the considerable work accomplished by Danièle Deschamps on this theme in her report (see evaluation report, psychological facet). The clinicians felt the analysis reflected their own experiences.
- f) Many clinicians had problems dealing with the **time available**. (Note: the enquiry showed that PCMT members spend more time than other caregivers listening to what the patients have to say, thus "temporality" as a mobile team ethical value). Reactions by referring teams, who can't spare as much time to listen to the patients, can cause feelings of guilt.

The issue here is to be aware of one's own ethical choices in order to be able to deconstruct criticism from the referring teams. In this context, there were discussions on the role of **narrative ethics** in the clinical action of mobile teams and temporality as their main ethical value.

- g) The mobile team members felt they needed to build up **other skills** in addition to healthcare treatments and palliative care: knowledge of the hospital's policy system, the policies of the region they work in (systemic view), managing interdisciplinarity and hierarchy, being in touch with academia, research, etc. Another sociological analysis should be undertaken on the issue of a **team's instrumentalisation**: "Why do hospitals have mobile teams? What are they supposed to remedy? Who set them up and why?" On the other hand, some ask for a framework that determines limits for their work and skills.
- h) The clinicians expressed discomfort in not feeling **attached to a structure**: A team's integration depends on its administrative attachment. If the team is attached to a service whose head is not on good standing within the institution it can hamper the mobile team's clinical activity. On the other hand, an attachment that works harmoniously fosters the diffusion of PC practices among the relevant services.
- i) **What do PC mobile team members call themselves** when they meet the patients? Some mobile teams present themselves explicitly as palliative care workers. Others use different terms (continuous care, etc.). In any case, it is important to first evaluate the impact the words used have on the patients. This question is also linked to the problem of a mobile team member's **identity**.
- j) It is essential for the PC mobile teams to be **integrated in the public health system**. The mobile team's arrival in an institution must also be prepared by evaluating how it will be received by the administration, medical corps and paramedical teams (for example with the help of a questionnaire).
- k) **Evolution of the clinical activity of PCMTs**: Some clinicians note a greater diffusion of the palliative care approach and pain treatment, which leads to more autonomy for the treatment teams. As a result they call less on the mobile teams, but this is seen as a sign of efficiency, that things are working well. At the same a parallel evolution in explicit requests to the mobile teams demonstrates growing confidence! Examples: Providing support to the referring team or an individual, with a dialogue on therapeutic options.
- l) **Recruiting new team members and the role of each individual**: New team members are usually recruited by the doctor, ideally with the help of the psychologist. A general set of recruitment procedures should be described and set down. The clinicians consider this procedure to be an important element in future recommendations.

The roles and responsibilities in the team itself tend to become defined more in time as the mobile team develops and the members grow to understand what they have undertaken to do. To parry the risk, however, that they define their own priorities and work in different directions it is absolutely necessary for the role and function of each new member to be defined from the start.
- m) **Pluridisciplinarity**: The utopia of transversality (working in a non-hierarchical, egalitarian way) comes up against the need for a hierarchy as the PCMT develops, in order to give it a reference point and clearly defined roles. The clinicians feel a reflection is needed on this subject, even though the absence of a hierarchical model is also stimulating in inciting creativity and interaction.
- n) The clinicians stressed how essential it was for mobile teams to go beyond their internal hospital activity and evolve towards **openness to the outside** (see the sociological analysis) by setting up networks, etc.
- o) **Volunteer teams**: The notion of volunteer work is an important facet of the palliative care "culture", but it should not be imposed on a hospital structure that does not have the

tradition or custom of volunteers. The arrival of PC volunteers should therefore be prepared by explanations to the hospital healthcare staff and an open discussion with the staff, the administration and patients associations.

- p) **The status and salary of mobile team doctors, as well as recognition of their specialisation and training** were other important issues. Some European countries lack criteria to recognise the competencies of doctors who practice Palliative Care. This is a crucial point that should be addressed in the recommendations.

Final note

These recommendations for the development of hospital palliative care mobile teams are the result of a collective work which began in the year 2000 involving teams of palliative care practitioners, researchers, and consultants from various disciplines. The recommendations summarize discussions on the experience of teams practicing palliative care in pluralistic settings and in countries with different healthcare systems, different historical backgrounds and different legislations regarding the end of life and euthanasia

The recommendations reflect the diversity of the members' viewpoints - the areas of agreement and of disagreement.

In our view it is crucial to disseminate the evaluation results and pilot projects - which will be experimental training laboratories - to a wide public.

The entire text of the recommendations you find on our website: [www. mobileteam.irisnet.be](http://www.mobileteam.irisnet.be)

Project related publications and relevant dissemination activities

Press release:

- Iris gazette (nr.15, 2/2001) "Un projet de recherche européen sur les équipes mobiles "
- Brugmann-news (nr.23,1sem.2001) "Signé Brugmann ; un projet de recherche de trois ans sur les Soins Continus "
- European journal for Palliative Care (September 2001) "Promoting the integration of Continuous Care in the hospital, a European research project "

Posters on congresses:

- 7th congress of the European Association for Palliative Care (Sicily, April 2001): poster: "A European research project for promoting the Integration of Continuing Care. "
- 6e journées nationales des équipes mobiles de Soins Palliatifs (Montpellier, juin 2001) poster: "Projet de recherche Européen sur l'intégration des équipes mobiles dans l'institution hospitalière "
- Poster for the international congress on bioethics in Brazil 11/2002
- Stéphane Leyens "Towards Specification of the Values Underlying the Practice of Palliative Care Mobile Team in Europe »
Poster, « 8th Congress of the European Association of Palliative Care », The Hague, 5th April 2003
- R.M Smeding, E. Weiher, M. Weber: The WHO definition, Palliative Care and Bereavement. congress of the European association for Palliative Care, Den Haag, 4/2003

List of publications directly emanating from the project during the reporting period:

- Daniele Deschamps: "Programmes d'évaluation dans 7 équipes mobiles européennes; volet psychologique", September 2002, being published
- Danièle Deschamps: "La mort de l'esprit de fraternité chez les soignants", revue Frontières, Montréal, Canada, juin 2001
- Laurence Roux, France Lert, Catherine Markstein: "L'intégration de l'équipe mobile de soins palliatifs à l'hôpital: enjeux institutionnels, professionnels et organisationnels. Synthesis of a European study", Med Pal 2003;2:6-1
- Mylene Baum Pourquoi la narrativité ? Tentative d'approches méthodologiques de l'éthique narrative, Centre de documentation et de recherche sociales CEDORES, mars 2001
- Mylene Baum: "La bioéthique et les feMs.s; les limites de l'éthique de la sollicitude" pp 53-73, ed. Marie Pinsart, Collection pour demain, Vrin Paris 2003
- Guy Lebeer: "Soins Palliatifs: la recherché de" l'entre deux" Sciences sociales et santé, vol. 21, 2003 pp 65-74

Conferences where the project has been mentioned:

- Prof. Ernst Berger: "Enquete des österreichischen Parlaments"; Sterbebegleitung 29. Mai 2001
- Prof. Ernst Berger: Expertenhearingder Grünen Fraktion im Wiener Landtag "Strategien und Konzepte der Palliativmedizin" 20.6.2001
- Dr. John Ellershaw: "Hospital Palliative Care Teams- A European Perspective" Royal Free and UCL Medical School, London
- Daniele Deschamps: "Le défi des équipes mobiles en Soins Palliatifs, entre mythe et réalité" – 14th International Congress on Care of the Terminally Ill, Montreal, Canada

- Stephane Leyens: "L'éthique narrative: de l'idée à la pratique. Le cas des équipes mobiles de soins palliatifs » Conférence "Midis de la bioéthique", Faculté de Médecine, Université de Louvain, 14 February 2003
- Myène Baum: "Ethique narrative en fin de vie" Conférence "Midis de la bioéthique", Faculté de Médecine, Université de Louvain, 14 February 2003
- Catherine Markstein » Les équipes mobiles de Soins palliatifs come véhicule d'une philosophie de soins continus et intégrés» Conférence "Midis de la bioéthique", Faculté de Médecine, Université de Louvain, 14 February 2003
- D. Jaquemin, D. Mallet, B. Choteau "Equipes mobiles des Soins Palliatifs: quelle pertinence éthique pour le maintien d'une pertinence palliative", EACM, Annual conference 2002 Soins Palliatifs
- Pascale Vinant: "Y a-t-il une place pour le patient dans la décision médicale en fin de vie", Paper given at the *Journée de l'observatoire français de l'éthique clinique*, 9/2003
- Christiane Meyer Bornsen: "Transition and Interference between curative and palliative medicine" 8th Congress of the European Association of Palliative Care, The Hague, 5 April 2003
- Catherine Markstein: "Resultate aus dem Europaprojekt mobile team mediation" Magistrat der Stadt Wien, Strategische Planung und Qualitätsmanagement. 11.2003 Geriatriezentrum im Wienerwald (Vienna, Austria)

A Brochure containing the 25 recommendations, addressing Public Health officials, universities, schools of nursing and national Palliative Care associations will be published in English and French by the publication services of DG Research.

Legal and Policy implications

Suffering from the symptoms and distress due to incurable illness is a major healthcare problem in Europe

The discipline of Palliative Medicine promises to be a rich source of learning and growth for physicians to help incurably ill patients and their families.

PCMTs are excellent vehicles for teaching basic clinical competencies: communication, pain and symptom control, the importance of psycho-social and spiritual support, attention to quality of life as well as to diagnosis and treatment.

The analysis of the situations of the mobile teams showed that the factors fostering or hampering their actions to treat patients at the end of life in their somatic dimension and enabling the patients and their entourage to express themselves and be taken into account are situated at the level of: healthcare policies, organisation of the care institution, values and representations of caregivers and the general population alike, the palliative care movement and the way the teams themselves were organised. These dimensions arise from an evolving and variable context depending on the country and should be re-examined periodically.

The recommendations thus target different actors in the European healthcare systems:

- The national European governments and health authorities: to implement the budgets needed to allow European citizens access to palliative medicine and recognise the mobile teams as privileged in-hospital vehicles of this new discipline. Recognising a specific status for palliative care and palliative care practitioners, and establish university training in this field.
- Decision-makers and managers of local health policies and care institutions: to guarantee for each hospital the minimal financial, structural and organisational conditions to create and maintain a PCMT. To promote specific training programmes and networks for the members of PCMTs in a wide European spectrum, and foster

the legal recognition of these programmes by the local public health authorities of each country

It is now time that Europe assumes its responsibility and pioneering role to ease the physical suffering of patients and their families who are faced with a serious and incurable illness.

Future Research needs

- Creation of a large research network with the goal **to promote prevention of suffering**

The main objective of the research network is to build a model for prevention of suffering based on two parameters: (1) pain and symptom evaluation and (2) training of healthcare workers. The research will focus primarily on two paradigmatic elements of prevention of suffering : (1) physical pain and (2) Palliative Care Mobile Teams. The research subject is therefore directly linked with the project “QLG6-CT-2000-00119 Mobile Team Mediation”, in which the operation of mobile teams was evaluated, and extends it with training programmes for mobile teams : it is indeed through appropriate assessment procedure of pain as well as proper training programmes that mobile teams would be in position to improve the prevention of suffering. Furthermore the effectiveness and the impact of training programmes on the quality of life of patients will be evaluated.

The expected achievement : Foster the cooperation of the different aspects of prevention of suffering and promote like that the quality of life of chronically ill patients.

- **Research on Narrative ethics as a privileged instrument in the decision making procedure in medicine and particularly in Palliative and end-of-life care .**

Promote an interdisciplinary research network to elaborate a training programme in narrative ethics, which are here understood as the articulation of the healing (curative) and palliative approaches. Better understanding of ethics issues and the patient's story will improve clinical work with patients and families, especially in palliative and end of life care.

- **Promote research for standard training programmes for PCMTs**

Promote a specific training programmes and network for the members of PCMTs in a broad European spectrum, and foster legal recognition of that programmes by the public health authorities of each country.

- **Promote pilot projects and the creation of PCMTs in hospitals in Europe**

Our Austrian partners are the initiators of a major pilot project in several public hospitals in Vienna (Austria). This is a direct result of the European project and recommendations. Start up: January 2004. The co-ordinator was invited, as expert, in November 2003 to meet with Public Health officials in Vienna