



Creating innovation and improvement in patient care

Victorian Travelling Fellowship Program

Victorian Travelling Fellowship report



Melissa Heywood
2008-2010



Acknowledgements

Firstly I would like to thank and acknowledge the Department of Health and the Victorian Quality Council for the wonderful experience and opportunity that they have granted to me.

Secondly I would like to thank the Royal Children's Hospital and the Victorian Paediatric Palliative Care Program which includes the executive and my fantastic team for their support and encouragement in pursuing and undertaking the travelling fellowship.

Lastly the success of my travel phase would not have been possible if wasn't for the generosity of Harvard Medical School Center for Palliative Care, Children's Hospital of Boston/Dana-Farber Cancer Institute and Johns Hopkins Children's Center, Baltimore. Thank you for all your hospitality and openness in sharing information, knowledge and resources

I now look forward to keeping you updated on my progress back here in Australia and improving the quality of palliative care for many children and their families.

Thank you

Table of contents

Acknowledgements	2
1. Project information	4
2. Project summary	5
2.1. Rationale/purpose of the project	5
2.2. Top three outcomes of the travel phase	6
2.3. Main activities undertaken	6
3. Description of the study itinerary	8
4. Key lessons learned	22
5. Improving the victorian healthcare system	23
6. Sharing and promoting the project	24
7. Attachments	25
Attachment 1: Syllabus Overview	
Attachment 2: Teaching with an Interview	
Attachment 3: OSTE Overview	
Attachment 4: Effectiveness of Educational Intervention	

1. Project information

Fellow's name	Melissa Heywood
Title of project	The Nurse Link Project: Improving the quality of palliative care provided to children through the development of a state-wide educational initiative for nurses.
Fellow's study area	Access Workplace culture Chronic disease
Fellow's organisation	Victorian Paediatric Palliative Care Program Royal Children's Hospital
Fellow's contact details	melissa.heywood@rch.org.au Victorian Paediatric Palliative Care Program Royal Children's Hospital SE Building, 3 rd Floor Flemington Road Parkville 3052
Date of report	31 December 2009

2. Project summary

2.1. Rationale/purpose of the project

The Nurse Link Project: Improving the quality of palliative care provided to children through the development of a state-wide educational initiative for nurses.

Background:

Barriers exist to the provision of effective palliative care to dying children and their families. Health professionals working in the paediatric setting may be unfamiliar with palliative care while colleagues working in the palliative care setting may rarely encounter children. Lack of confidence, knowledge and skill may mean that children are denied access to services or are provided with inadequate care. The basic premise of this project is that the provision of education to health professionals in general and nurses in particular, is of critical importance to improving the quality of palliative care provided to children. To this end, I plan to introduce a state-wide educational initiative for nurses working in paediatrics and palliative care. In addition to running a comprehensive course for nurses, my vision is to create a system of ongoing education wherein key nurses are provided with:

- opportunities to update their skills and knowledge in paediatric palliative care through participation in annual study days
- regular updates on developments in the field through journal clubs and an email network
- links to colleagues in the field.

These nurses would then be expected to take a leadership role in their services and wards. This will help in the identification of children with palliative care needs, referral to appropriate services and improved standards of care. It will also help to build important linkages between paediatrics and palliative care.

My position within the Victorian Paediatric Palliative Care Program (VPPCP) provides a unique opportunity to coordinate a state-wide approach to education and training in this area. Although the VPPCP already offers educational activities for nurses including a university-accredited course, we have not been able to offer a system of ongoing education and support for those who participate. These nurses simply return to their place of work and have little opportunity to maintain and update their skills. Further, there has not been an opportunity to ensure that our teaching materials and methods are of a standard consistent with international best practice.

Project goals:

The proposed educational project will:

- improve the support provided to dying children and their families by enhancing the skills and confidence of those involved in caring for them
- encourage the sharing of expertise between health professionals in both paediatric and palliative care sectors, thus integrating palliative care into the acute health service system
- deliver education to key individuals from relevant organisations who will then adopt leadership roles within those organisations to facilitate the education of their colleagues
- create effective partnerships between palliative care providers, other health service providers and health systems to coordinate care for dying children across a range of settings
- ensure that education is delivered in a way that is consistent with international best practice.

2.2. Top three outcomes of the travel phase

There were a number of great outcomes from the travel phase, but the top three can be summarised as:

Teaching methods and strategies identified

Identification of the key educational methods and strategies that is applicable to an educational program, like the proposed Link Nurse Project – ‘Paed Pall Link Nurse’.

- Learning needs to be active - important that participants will be doing, experiencing, and practicing.
- Small group, problem-based learning will foster active learning, cooperative approaches that recognise a variety of learning styles, and a focus on attitudes and skills.
- Conventional lectures and a variety of more active and interactive large group teaching methods will also be utilised. These principles of adult learning and interactive teaching will be the basis in the design of the ‘Paed Pall Link Nurse’.
- There will be two key components to the teaching framework:
 - study program - train the trainer model
 - web-based supports – for continual ongoing support.

Establishment of nurse link curriculum

The identification of the core components required for the curriculum/syllabus.

The curriculum design will include five modules. The modules’ content will be based on the key fundamentals of established curriculums such as IPPC, ELNEC and PCEP Program.

The five modules will be:

- introduction to paediatric palliative care
- symptom management (pain, other symptoms, end of life care)
- psychosocial support (communication, supports, bereavement and self care)
- ethics
- being a ‘Paed Pall Care Link Nurse’: how to train, key concepts of learning and learning style.

Establishment of key partnerships

The travel phase provided an opportunity to establish links with other leading paediatric palliative care programs internationally. We are now working on developing an ongoing network that involves regular email contact, resource sharing, and case based discussions.

Secondly there is also plan to work in collaboration with Jody Chrastek, Pain & Palliative Care Coordinator, Children’s Hospitals & Clinics of Minnesota to share the interactive component (web support) of the link nurse in partnership with their palliative care team and hospital.

2.3. Main activities undertaken

1. Completed The Program in Palliative Care Education and Practice – Harvard Medical School Department of Continuing Education & Center for Palliative Care, Boston , Massachusetts, USA
2. Completed two hospital site visits:
 - a) Children's Hospital of Boston/Dana-Farber Cancer Institute, Massachusetts, Boston, USA
 - b) Johns Hopkins Children's Center, Baltimore, Maryland, USA

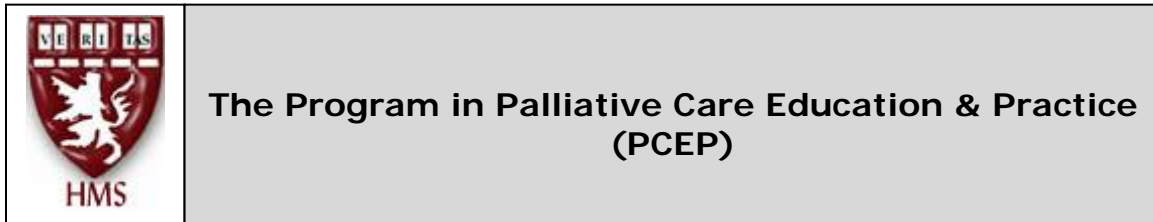
Objective templates were devised for the travel phase to ensure that all information could be gathered accurately. Given the different purpose of the planned activities, an individual template was developed for both the course and site visits.

The template was to be used as a trigger/guide for all observations and conversations and consisted of series questions and statements.

PCEP Course Template
<p>1. Strategy <i>What was the course's education model/plan?</i></p> <p>2. Curriculum <i>What were the key components of the course curriculum – examine and critique.</i> <i>Could the course's content be relevant for the link nurse project?</i></p> <p>3. Teaching Methods and Strategies <i>What key principles does PCEP use?</i> <i>Is the model based on adult learning?</i> <i>What are the educational methods that are utilised in the PCEP teaching sessions?</i></p> <p>4. Resources <i>Are there any key resources that could be utilised?</i> <i>What documentation/literature, educational tools are utilised throughout the course?</i></p>

Site Visits Template
<p>1. Strategy <i>What was the program's education model/plan?</i></p> <p>2. Curriculum <i>Is there curriculum based on any particular model?</i></p> <p>3. Teaching Methods and Strategies <i>What key principles does your program use?</i> <i>Is the model based on adult learning?</i> <i>What are the educational methods are utilised in your teaching sessions?</i> <i>What is the best model for ongoing education?</i></p> <p>4. Resources <i>Are there any key resources that you utilise and would recommend?</i> <i>What documentation/literature, educational tools utilised for education?</i></p>

3. Description of the study itinerary



Overview:

PCEP is a training course that offers an intensive learning experience for health professionals who wish to become expert in clinical practice and teaching in comprehensive, interdisciplinary palliative care, as well as an opportunity to gain expertise in leading and managing improvements in palliative care education and practice. From 2008, this program has been offering a specific paediatric stream.

Dates of course: 5-12 May and 11-17 November 2009

Key contacts:

Joanne Wolfe MD, MPH	<p>Division Chief, Pediatric Palliative Care Department of Psychosocial Oncology and Palliative Care, Dana-Faber Cancer Institute</p> <p>Director, Pediatric Palliative Care Boston Children's Hospital</p> <p>Assistant Professor of Pediatrics Harvard Medical School</p>
Tamara Vesel MD	<p>Fellowship Director/ Attending Physician Pediatric Palliative Care, Children's Hospital Boston Department of Psychosocial Oncology and Palliative Care, Dana-Faber Cancer Institute</p> <p>Instructor in Pediatrics Harvard Medical School</p>
J Andrew Billings MD	<p>Director, Palliative Care Services, Massachusetts General Hospital</p> <p>Associate Professor of Medicine</p> <p>Co-Director, Harvard Medical School Center for Palliative Care</p>
Susan D. Block MD	<p>Chair, Department of Psychosocial Oncology and Palliative Care Dana-Faber Cancer Institute Brigham and Women's Hospital</p> <p>Professor of Psychiatry and Medicine</p> <p>Co-Director, Harvard Medical School Center for Palliative Care</p>

Education strategy/model:

The PCEP program endeavours to provide two distinct learning opportunities for all participants. Each teaching session of the training program is an opportunity for greater understanding about both palliative care and adult learning. Considering what you know about a topic and how you would convey it to others, and an opportunity to reflect on the teaching style and framework that presenters employed.

Curriculum:

Curriculum was extremely extensive and covered a range of areas imperative to palliative care. (See **attachment 1** for overview)

The key topics covered can be summarised as the following:

- symptom Management – with a particular focus on pain
- communication – presented this in many different forms, this included breaking bad news, deepening the interview, negotiating treatment goals
- ethics
- grief and bereavement
- self care
- spirituality
- learning styles and teaching methods
- project work
- building and managing a paediatric palliative care program.

Although none of these topics were new to me, the brilliance of the PCEP curriculum was the way all the key topics were weaved throughout the different teaching sessions rather than as an individual session focusing on each individual topic.

Teaching methods and strategies:

Observation and participation in the teaching methodologies and strategies employed by PCEP allowed clarification and identification of the key methods/strategies required for an effective Link Nurse Project. The program provided the opportunity to experience best practice in teaching frameworks and adult learning.

PCEP, unlike other training courses, didn't just focus on building the knowledge of the participants it demonstrated and expanded on teaching skills. This was very unique, but crucial given all the PCEP participants were regarded as experts in palliative care and were required to provide regular education in their current roles.

There were a number of teaching methods utilised throughout the teaching sessions varying from didactic to interactive. The following teaching methods were demonstrated:

Teaching methods	Teaching in PCEP
Pre-reading	<p>Opportunity to prepare thoughts and expectations for the study ahead.</p> <p>PCEP provided a CD with a number of articles to read prior to the course commencing.</p>

Pre-course assessment tool	<p>Completed ‘Kolb Learning Style Inventory’ pre-course. During the session, Learning Styles & Teaching Methods participants revealed their dominant learning style by joining small groups of colleagues with the same learning style. In our small groups we reflected on four previous sessions in light of our learning styles.</p> <p>Through self discovery participants learnt how teaching methods can be used optimally with different kinds of learners.</p>
Modelling/demonstration	<p>This technique was used by the facilitator to help model/ demonstrate a particular skill or technique: often occurred as an introduction to the topic.</p> <p><i>For example: group interview</i> – participants watch facilitator complete an interview. In different sessions this involved interviewing fellow facilitators, actors and patients. Participants allowed a question time at end of all interviews, and then a reflection/debrief followed once patient or the actor left.</p> <p>See attachment 2 for tips on teaching with patients via an interview.</p>
Lecture	<p>Lecture format frequently incorporated PowerPoint presentations and usually large group discussion. This lecture only teaching style was not frequently seen. More often, facilitators/presenters added interactive small group exercises such as brainstorming and case study work.</p>
Role playing/simulation	<p>This was one of the main teaching methods incorporated in the course: role playing with each other, actors and patients.</p> <p>Role playing was best in small groups as it was imperative that there was the development of a safe setting for people to take risks.</p> <p>Key rules followed for a role play:</p> <ul style="list-style-type: none"> ▪ A participant was always assigned to be an observer to take notes and help provide feedback. ▪ Follow the ‘Ende feedback model.’ <ul style="list-style-type: none"> ○ role players reflect first ○ patient reflects second ○ observers reflect last. <p>Reflection on use of open-ended questions, Dr/RN talk time vs. Pt, use of silence, and response to patient’s emotions.</p>
Multi media	<p>Utilised DVDs and CDs as part of many sessions, for example, listened to a CD of poor executed conversation between a doctor and a patient about end of life interventions. We then critiqued the session, devised a plan around the goals of the conversation and then role played.</p>

Practical experience	Field work - this included visits to hospitals and homes where we interviewed patients and their families.
Experimental	Participated in hypnosis session.
Brainstorming	This was carried out in many different sessions, both large and small group work. <i>For example:</i> devised a teaching plan in small groups then presented back to large group.
Case study work	Frequently utilised to stimulate discussion. During ‘Cultural Issues in Palliative Care Session’ facilitator presented three clinical cases relating to cultural issues. Each case had an underlying ethical component that stimulated much discussion and conflict among participants. Case studies are an excellent tool for both large and small group work.
Objective structured teaching exercise (OSTE)	<p>Education’s equivalent of ‘speed dating.’ Course participants were divided into four groups then moved between four stations.</p> <ol style="list-style-type: none"> 1. negative feedback 2. formal presentation 3. one minute preceptor 4. conflict resolution. <p>Participants spent 45 minutes at each station. Range of teaching styles utilised at each station, very interactive and engaging teaching style. See attachment 3 for overview of this session.</p>
Writing reflection	Each participant writes a narrative describing the most emotional, powerful death he/she has been involved in. Narratives are then re-distributed to provide privacy and to facilitate participants to enter into their colleagues experiences. This stimulates deep reflection about the clinical work of palliative care. Best to occur in small group work.
Reflective inquiry	This occurred after every teaching session. Participants reflected on the teaching method, content and the effectiveness of the session. Applied a teaching framework that Kilpatrick devised and Hutchinson discussed in a journal article. (see attachment 4)
Project groups	<p>Pre-requisite that all course participants have a work place project to complete and allocated into small groups with similar projects.</p> <p>Group work involved presenting your project, then received feedback and reflection from peers. I utilised my Link Nurse Project.</p> <p>One of the key aspects of this session was during feedback the presenter (of the project) was to remain silent, only allowed to discuss points at end of timeframe.</p>

Resources obtained:*PCEP course syllabus*

Syllabus included the following:

- pre-reading articles
- daily course content
 - handouts
 - notes
 - journal articles
 - exercise/activity overview
 - case study overviews
 - role play scripts
 - other texts and journal articles of interest.

PCEP facilitator guide

This included:

- session objectives
- guide on how to teach session
- teaching method concepts.

Note: Syllabus and facilitator guide was made available for all participants in hard form and on a USB. Participants encouraged to utilise all of the PCEP material for future education.

CD/Audio Tape: Tulsky DNR discussion

Audio taping of poorly executed conversation between a doctor and a patient about end of life interventions, which can be incorporated into an education session.

Kolb Learning Style Inventory – LSI Workbook

Designed to help students understand how you learn best in educational settings and everyday life.

Pain Management Tables and Guidelines

A handbook produced for health professionals by Dana Farber Cancer Institute/Brigham & Women's Hospital, Pain and Palliative Care Program/BWH Pain Committee, 2007.



**Children's Hospital Boston:
Pediatric Advanced Care
Team (PACT)**

Overview/model of care:

The Pediatric Advanced Care Team (PACT), with members from Children's Hospital Boston and the Dana-Farber Cancer Institute was formed in 1997. PACT began as a demonstration project aimed at supporting children with advanced cancer, their families and medical teams. PACT expanded its reach to serve children with non-malignant conditions in 2000. PACT works with the primary

health care teams (inpatient and outpatient), families, and children with advanced illness with the goal of helping children live as well as possible for as long as possible. This aim is met by facilitating discussions regarding goals of care with the medical team and the patient and family. This care encompasses the physical, psychosocial and spiritual needs of the individual and the family.

The primary goal is to develop a cohesive palliative care plan. PACT makes home visits for consultation and assessment of the children as well as use teleconferencing when necessary. PACT is a statewide service and provides 24 hour service.

Date of visit: Monday 2 November – Friday 6 November 2009

Key contacts:

Joanne Wolfe, MD, MPH	Director/Attending Physician
Tamara Vesel, MD	Fellowship Director/ Attending Physician
Janet Duncan, PNP	PACT Nurse Practitioner
Marsha Joselow, LICSW	PACT Social Worker
Andrea Dimond, MD	PACT Clinician Fellow
Gaby Harrison, PNP	PACT NP Fellow
Cate Evans, LCSW	PACT Social Work Fellow
Rita Fountain	PACT Coordinator

Activities undertaken during visit:

<i>Clinical</i>	<ul style="list-style-type: none"> ▪ participated in ward rounds ▪ attended pact handovers ▪ attendance at family meetings – this included introducing palliative care and decision making/goals of care discussions ▪ symptom management consultations ▪ observed liaison with homecare and/or hospice services/providers ▪ observed transition to end of life care, either at home or in a medical facility ▪ attended case planning meetings
<i>Education</i>	<ul style="list-style-type: none"> ▪ attended and participated in education sessions that pact staff provided ▪ participated in state network educational meetings
<i>Interview</i>	<ul style="list-style-type: none"> ▪ interviewed team members about the program and how they addressed the educational component of their role
<i>Resource sharing</i>	<ul style="list-style-type: none"> ▪ shared and gathered resources

Education strategy/model

PACT employs a systematic approach to education and believed it is essential education is conceptualised in many different forms. Through discussion and observation identified that this encompassed, mentoring, targeted, opportunistic and academic methods.

Mentoring

- Taking 1:1 educational opportunities on the wards/in the community as they arise.
- Provide information and/or support around the emotional impact of the care.
- Overall objective is to develop relationship and trust between PACT team and staff.
- From this many resources have developed, such as a checklist for end of life care.

Targeted

- Formal and planned education for health professionals in the hospital and community.
- Inter-disciplinary and capacity building approach employed.
- Some of the education included:
 - Annual Palliative Care Competency Day for staff from hospital and community settings (includes hospice and the 'Paediatric Palliative Care Network of Massachusetts)
 - resident education
 - ward in-service
 - fellowship program – medical, nursing, social work
 - PCEP

Opportunistic

- Receive educational requests from a variety of individuals and programs. Requests typically come from wards, community and associations.
- Endeavour to accommodate most requests.

- This was a key strategy employed in program's infancy. Program growth has meant that this type of strategy needs closer monitoring and ongoing assessment as a team.

Academic

PACT team is very committed to the national and international profile of Paediatric Palliative Care. This is accomplished through:

- contributions to journal articles and text books
- research
- university partnership - Harvard
- development of key resources through collaboration with other state palliative care teams.

Curriculum

The PACT team has collaborated and contributed to the development of a number of curriculum models in USA.

The Initiative for Paediatric Palliative Care (IPPC)

IPPC was launched in 1997 as an education and quality improvement initiative aimed at enhancing family-centred care for children living with life-threatening conditions.

- A comprehensive, interdisciplinary curriculum addresses the knowledge, attitudes and skills that health care professionals need in order to better serve children and families.
- PACT have implemented IPPC quality improvement projects and have pilot-tested the IPPC curriculum.
- IPPC curriculum was developed to support children's hospitals, paediatric units in general hospitals, and hospice or home care programs.
- Module based curriculum which is available on-line for free. (Password protected).
- The modules are:
 1. Engaging with Children and Families
 2. Relieving Pain and Other Symptoms
 3. Analysing Ethical Challenges in Paediatric End-of-life Decision Making
 4. Responding to Suffering and Bereavement
 5. Improving Communication and Strengthening Relationships
- IPPC provides a facilitator guide – this includes presentations, key points, activities, handouts, DVDs.

End-Of-Life Nursing Education Consortium (ELNEC)

In 2002 the Institute of Medicine USA released their report on paediatric palliative care titled *When Children Die: Improving Palliative and End of Life Care for Children and Their Families*. This report called for improved professional education to address the care of children at the end of life and their families. A version for paediatric palliative care nursing education was adapted from the ELNEC curriculum to provide current education and extensive knowledge for nurses related to palliative care for children. In 2009, additional information on neonatal and perinatal palliative care was included to the curriculum.

- Curriculum was developed for nurses who currently work in hospitals, hospices, palliative care facilities, clinics, and community who want to increase their knowledge in end-of-life issues.
- This is a 'train-the-trainer' course and, upon completion, you will be able to take this information back to your institution and teach others.

- The ELNEC-Paediatric Palliative Care Training Program syllabus is model based. Each module is accompanied by objectives, outline, power point slides, 'talking points' for each slide, references, case studies, and supplemental teaching materials. The course syllabus is designed to support future educational endeavours within your institution and community.
- The paediatric curriculum focuses on ten end-of-life areas: introduction to paediatric palliative nursing, special considerations in paediatric palliative care, communication, ethical/legal issues, culture, pain management, symptom management, care at the time of death, grief and bereavement and models of excellence.

The Program in Palliative Care Education & Practice (PCEP)

- PACT team has worked in partnership with Harvard University to develop the paediatric curriculum of the PCEP program.
- Curriculum has medical and nursing approach.
- Background of PCEP has been discussed in detail already in this report.

PACT utilises snapshots of all these curriculums for their training, often dependent on the target audience.

Teaching methods and strategies:

PACT employed the same teaching methods and strategies that I experienced at PCEP (pp12-14 of this report). PACT education sessions commonly incorporated role playing, case studies, brain storming, multi-media and other interactive small group work.

This clarified that best practice is:

- interactive/active teaching – participants will be doing, experiencing, and practicing
- paramount to cater for all learning styles for learning to be effective.

Resources obtained:

ELNEC: Paediatric Palliative Care Training Program 2009 – CD

This includes:

- syllabus
- module objectives, outline, power point slides, 'talking points' for each slide, references, case studies, and supplemental teaching materials.

The Textbook of Palliative Nursing, 2nd Edition, Oxford University Press

Editors: Betty R. Ferrell, PhD, FAAN and Nessa Coyle, RN, PhD, FAAN

Features:

- paediatric palliative care
- models of excellence in palliative care
- covers all settings in which palliative nursing is given
- covers palliative care across the full course of a progressive incurable illness
- practical, user-friendly format.

Being Present: A Nurse's Resource for End-of-Life Communication

Marjorie Schaffer, RN, BA, MS, PhD, and Linda Norlander, RN, BSN, MS

This book offer strategies to help nurses talk with patients and families about their needs, hopes, and wishes as they face their own death or that of a loved one. Each chapter presents a real-life

account of nurses dealing with near-death patients and their families and includes the best communication techniques. Chapters also include topics for discussion and further reflection that are useful for group learning:

- respond to patient and family wishes and hopes
- cope with conflict
- help the patient say goodbye at the end of life
- incorporate cultural needs in end-of-life care.

Guidelines for Management of Escalating Pain/Dyspnea /Agitation at the End of Life: Dana Farber Cancer Institute and Children's Hospital Boston

Comfort Care/DNR Order Verification Form - Massachusetts Department of Public Health Office of Emergency Medical Services

My Wishes & Fives Wishes Booklets: Aging with Dignity, Florida

Palliative Care Competency Day Syllabus 2008 - Children's Hospital Boston

PACT Checklist - Physician/NP Responsibilities for Patients Facing End of Life

PACT Tool - End of Life Inpatient Communication

Palliative Care Communication Faux Pas - Examples



**John Hopkins Children's Center:
Harriet Lane Compassionate Care
(HLCC)**

Overview/model of care

The Harriet Lane Compassionate Care (HLCC) program provides palliative care – the comprehensive management of the physical, psychological, social and spiritual needs of children with life-limiting conditions and their families.

The program was developed after a hospital review of Paediatric Palliative Care in 2000. Initially the program's main objective was to provide support for staff through educational and emotional resources. The program assisted healthcare professionals on how to identify children who may benefit from palliative and end of life care support, by providing support and education around triggers for palliative care, assessment and resources.

Ensuring palliative care wasn't perceived to be taking over was the overall reason behind this initial model. Over time the program has grown into a consultation liaison service with billing rights.

Some of their initiatives have included:

- palliative care rounds – NICU and oncology
- patient care conferences
 - can be initiated by any discipline
 - frequently used to clarify goals and establish a palliative plan of care for the patient
- bereavement debriefing sessions
 - available after the death of a patient
 - the objective of the session is to offer a time and space to process the staff's responses to the death.
 - unique aspect of these sessions is that residents are notified of bereavement debriefing sessions by e-mails.
- annual tribute service
 - held to honour the children who have died
 - families and staff are invited
- staff memorial services
 - HLCC offers quarterly memorial services for staff of the Children's Center
- individual bereavement support
 - offered by the HLCC Bereavement Coordinator .

Date of visit: Wednesday 18 November – Thursday 19 November 2009

Key contacts:

Cynda Rushton, PhD,RN, FAAN	Program Director
Nancy Hutton, M.D.	Medical Director
Matt Norvell, MDiv	Family & Staff Support

Activities undertaken during visit:

<i>Clinical</i>	<ul style="list-style-type: none"> ▪ participated in ward rounds ▪ attended team handover and planning meeting ▪ participated in family meetings ▪ symptom management consultations ▪ attended case planning meetings ▪ attended NICU Goals of Care Meeting at John Hopkins Children’s Center ▪ observed the interdisciplinary meeting: Clinical Palliative Care Conference – representatives from all wards attend to discuss patients and current issues in palliative care
<i>Education</i>	<ul style="list-style-type: none"> ▪ attended and participated in hospital and university based education sessions that HLCC provided ▪ observed undergraduate nurse training in paediatric palliative care ▪ attended education planning meeting with the John Hopkins University School of Nursing
<i>Interview</i>	<ul style="list-style-type: none"> ▪ interviewed team members about the program and how they addressed the educational component of their role
<i>Resource sharing</i>	<ul style="list-style-type: none"> ▪ shared and gathered resources

Education strategy/model

Harriet Lane Compassionate Care has placed great emphasis on supporting health care professionals to develop clinical competence in providing palliative and end of life care through education, psychosocial support and research.

Harriet Lane Compassionate Care offers several different forums for promoting education:

- the Harriet Lane Compassionate Care Network:
 - network consists of bedside health professionals from Johns Hopkins and community based hospices with a specific interest in paediatric palliative care
 - members act as liaisons for the HLCC on the units, assist in identifying patients who could benefit from palliative care and participate in training sessions about paediatric palliative care
 - this network closely reassembled the proposed Link Nurse Project
 - conduct a regular annual network education day – this year’s focus was the, ‘Many Faces of Suffering’.

- leadership group
 - consists of interdisciplinary staff
 - meet regularly
 - smaller group who have buy in and can make changes
- annual resident and palliative care series
 - six modules in palliative and end of life care are offered during regularly scheduled conferences for paediatric residents.
- specialised educational sessions
 - offered upon request
- work in partnership with John Hopkins University: School of Nursing – provide under and post graduate education
- actively involved in national and international education and research. For example the HeartSongs Project (2008). This is a two-year project that developed a worldwide network of professionals, parents and affected children who share a common vision of comprehensive and integrated care for children with life-threatening neuromuscular diseases. The project focused on exploring communication, decision making, quality of life and ethical challenges. The project developed recommendations regarding best practices.

Curriculum

Like PACT has been a major stakeholder in the development of paediatric palliative care based curriculums both nationally and internationally.

The Initiative for Paediatric Palliative Care (IPPC)

- Like PACT, HLCC members participated in the development of IPPC's paediatric palliative care curriculum and served as a pilot site for the curricular materials (see details earlier in report).
- John Hopkins Children's Center is an institutional partner in the IPPC.
- HLCC continues to work with IPPC in developing and adapting the curriculum
 - created a neonatal stream in 2009
 - just secured a NIH grant in partnership with John Hopkins School of Nursing to further develop the IPPC curriculum
 - hope to develop and test documentary videos of children and families that are geared towards integrating palliative care into the chronic paediatric diseases
 - will focus on children with Duchene muscular dystrophy and sickle cell disease.
- majority of education provided by HLCC is modelled on this curriculum.

Being with the Dying Program

This is an interdisciplinary training program that aims to enhance basic clinical skills in end-of-life care, as well as introducing approaches in the psycho- social, ethical, spiritual aspects of care of the dying. The curriculum covers such areas as:

- care of the dying – ethical, spiritual, psychological, and social aspects
- exploration of contemplative interventions
- community-building around dying persons
- cross-cultural issues related to dying
- exploration of pain, suffering, and peri-death phenomena

- caring of the caregiver
- strategies – grief support
- contemplative approaches to care of the dying and their families
- implementation of psycho-social and spiritual content into conventional medical settings
- hopefully in 2010 will expand to include a train the trainer component to its curriculum.

Cynda Ruston is faculty member for this training program.

End-Of-Life Nursing Education Consortium (ELNEC)

A foundation member and was actively involved in the development of the curriculum.

Teaching methods and strategies

Further reinforcement that the teaching methods experienced at PCEP can be recognised as best practice. HLCC’s educational programs employed similar teaching methods to PCEP. The only new teaching method I observed was in the undergraduate nurse program, where a debate around ethical issues in paediatric palliative care was run.

Resources obtained:

The Initiative for Paediatric Palliative Care (IPPC) Website

This included access to facilitator guide, curriculum and teaching methods.

<http://www.ippcweb.org/>

The Initiative for Paediatric Palliative Care (IPPC) DVD Series

Text Book – ‘Being with the Dying’ – Joan Halifax, 2008

Being with the Dying Website

<http://www.upaya.org/bwd/index.php>

4. Key lessons learned

Throughout the travel phase of the fellowship there was many key lessons discovered. These lessons will now help shape the structure of the Link Nurse Project and influence the Victorian health system.

Link Nurse Project

- The Link Nurse Project needs to emphasise essential areas and challenging questions about paediatric palliative care, while stressing educational methods particularly appropriate for facilitating learning. Each teaching session of the training program should be an opportunity for greater understanding about both palliative care and adult learning – for considering what you know about a topic and how you would convey it to others.
- It is important that the Link Nurse Project is flexible enough to meet the needs of a variety of learners.
- Teaching methods must ensure learners are active so that they can do, experience and practice.
- Teaching about fundamental knowledge and about palliative care is less important than improving attitudes and skills. Motivated learners with good communication skills can acquire much of the knowledge through listening carefully to patients, a variety of clinical learning opportunities, and reading. Thus, the Nurse Link Project needs to focus on teaching attitudes and communication skills, particularly focusing on facilitating discussions with families to establish or revisit goals of care and decision making regarding quality of life concerns.
- Link nurse curriculum should consider the key components of existing paediatric palliative care curriculums – PCEP, ELNEC and IPPC. These have been developed through collaborative approaches between leading paediatric palliative care programs and academic institutions and are modelled on best practice.
- The link nurse curriculum will facilitate learning and practice by providing outlines of the presentations, copies of slides and overheads, resources for further learning, and suggestions for alternate teaching approaches and be available online. These skills will ensure link nurses can provide ongoing education and support to their colleagues.
- Personal growth needs to be a goal in both practice and teaching. Self-reflection promotes growth. The course will need to encourage self-reflection, and will coach the participant on how to foster these qualities with patients, families, colleagues, and students.

The Victorian health system

- confirmation that current Department of Health and VPPCP education strategy aligns with international practice
- imperative to develop ongoing partnerships with academic facilities, such as universities
- important to learn from our overseas counterparts about partnering with other state paediatric palliative care services, to establish stronger relationships and sharing of resources
- network and partner with our international peers.

5. Improving the Victorian healthcare system

The impact that the fellowship could have on the Victorian healthcare system could be significant, given VPPCP is a state-wide consultation liaison service. This means there are potential implications at organisational, local and state level. Link Nurse Project is a program that the VPPCP has wanted to initiate for some time. Education is an essential part of this process and while we have the necessary links and content knowledge, we have not had the resources to develop a comprehensive system of education conducted according to best practice.

The fellowship has enabled me to gain information and knowledge about the most appropriate model of education for nurses in Victoria, by informing me on how to educate nurses effectively, key principles of adult learning and latest teaching methodologies.

The application of these findings should:

- Lead to the development and implementation of a successful state-wide Link Nurse Project, which caters for nurses working in paediatrics and palliative care.
- An improvement in the skills, knowledge and confidence of nurses required to deliver palliative and end-of-life-care to children and their families in both the palliative care and paediatric sectors.
- An improvement in the quality of palliative care provided to Victorian children and their families.
- An increase in the profile of the Victorian paediatric palliative care program so that health professionals are aware of the existence of this important resource.
- The establishment of relationships with leading international paediatric palliative care organisations, such as the IPPC, ELNEC.
- Strengthening of links between palliative care and paediatric services across community, hospital and hospice settings.
- Encourage the sharing of expertise between health professionals in both paediatric and palliative care sectors, thus integrating palliative care into the acute health service system.
- Deliver education to key individuals from relevant organisations who will then adopt leadership roles within those organisations to facilitate the education of their colleagues.

Most importantly this will be influential in making a substantial and long-term difference to the standard of palliative care provided to children and their families across Victoria.

6. Sharing and promoting the project

It will be imperative that all my learning and achievements from the travel phase be shared with the Victorian health system. Given that the project encompasses the paediatric and palliative care sectors, both populations will need to be considered and addressed.

In the short term:

- provide a detailed fellowship report both for the Department of Health and The Royal Children's Hospital
- meet and present my project and recommendations to the Chief Executive Officer at The Royal Children's Hospital
- present the project to Victorian Paediatric Palliative Care Program's Executive
- use my established links with the University of Melbourne and Flinders University to promote and inform these organisations about the education initiative and further strengthen academic links.

Long term:

- Evaluate the Link Nurse Project
 - present findings at state, national and international paediatric and palliative care conferences
 - publish articles in recognised paediatric and palliative care journals.

7. Attachments

Syllabus overview



Harvard Medical School Program in Palliative Care Education and Practice May ✦ 2009

Tuesday, 5 May 2009 – Welcome

4:30-5:30	Faculty Meeting	
5:30-6:30	Registration and Reception	
6:30-7:30	Dinner	
7:30-8:00	Welcome and Introduction to the Course	Andy Billings Susan Block
8:00-9:00	Personal Narratives: Pathways to Palliative Care	Small Groups

Wednesday, 6 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Introduction to Opening Exercise	Andy Billings Susan Block
8:15-9:00	What is a Good Death?	Andy Billings
9:00-10:15	Communication Challenges	Susan Block
10:15-10:30	Teaching Reflection	Susan Block
10:30-11:00	Break	
11:00-1:00	'I Hate Role Plays' and Breaking Bad News	Small Groups
1:00-2:00	Lunch	
2:00-3:30	Understanding Life-Threatening illness: Patient Interview in Large Group	Susan Block
3:30-3:45	Teaching Reflection	Susan Block

3:45-4:15	Break	
4:15-5:45	Understanding Life – Threatening Illness: Patient Interview in Small Groups	Small Groups
5:45-6:15	Faculty Meeting	

Thursday, 7 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-10:00	Introduction to Pain Management Case Studies	Small Groups
10:00-10:30	Break	
10:30-11:30	Complex Pain Management	Janet Abraham
11:30-1:30	Project Review #1 Project Groups	Box Lunch

ELECTIVE AFTERNOON

Please choose and sign-up for one of the sessions listed below

Group 1 12:30-3:30	Pediatric Advance Care Team (PACT) Rounds) Children’s Hospital Boston Pediatric Issues in End-of-Life Care	Joanne Wolfe
Group 2 2:00-4:00	Nursing Education Forum Royal Sonesta Hotel	Connie Dahlin
Group 3 3:00-5:00	Palliative Care Unit	Janet Abraham
Group 4 3:00-5:00	Out-Patient Palliative Care	Vicki Jackson
Group 5 3:00-5:00	Fellowship start-up/Competencies	Susan Block
Group 6 3:00-5:00	Teaching Psychosocial Aspects of Palliative Care	Marshall Forstein

Friday, 8 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-10:15	Discussing DNR Orders	Small Groups
10:15-10:30	Break	
10:30-12:00	Hope	Christopher Feudtner
12:00-1:00	Lunch	
1:00-2:45	Developing a Palliative Care Program I	David Weissman
	Designing a Palliative Care Program for Pediatrics	Tamara Vesel/ Christopher Feudtner
2:45-3:30	Break	
3:30-4:45	Developing a Palliative Care Program II	David Weissman
	Palliative Care for Children with Chronic Illness	Tamara Vesel/ Christopher Feudtner
4:45-5:00	Teaching Reflection	Susan Block
5:00-5:45	Best Learning Experiences	Susan Block

Saturday, 9 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:45	Organizational Change and Educational Planning I	David Weissman
9:45-10:15	Break	
10:15-12:00	Organizational Change and Educational Planning II	David Weissman
12:00-12:30	Break	
12:30-1:30	What is Culture?	Marshall Forstein

Free Afternoon

Sunday, 10 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:45	Learning Styles and Teaching Methods	Susan Block
9:45-10:15	Break	
10:15-12:15	Deepening the Interview 1, 2, 3, 4 OR Negotiating Treatment Goals 5, 6, 7, 8	Small Groups
12:15-1:15	Lunch	
1:15-3:15	Deepening the Interview 5, 6, 7, 8 OR Negotiating Treatment Goals 1, 2, 3, 4	Small Groups
3:15-3:45	Break	
3:45-5:15	Project Review #2	Project Group
5:15-6:15	Faculty Meeting	

Monday, 11 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-10:15	Palliative Care Across the Life Cycle	Joanne Wolfe
Small Groups Self-facilitated		
10:15-10:45	Break	
10:45-12:00	Psychosocial and Spiritual Assessment	Andy Billings
12:00-1:15	Lunch	
1:15-2:30	Depression in Palliative Care Depression in the Pediatric Population	Marshall Forstein Nina Muriel
2:30-3:00	Break	

3:00-4:00	Suffering	Eric Cassell
4:00-5:00	'I want everything' - Enter the Ethics	Andy Billings Consultant Craig Blinderman
6:15	Depart from Royal Sonesta Hotel for Reception at Andy and Susan's Home	

Tuesday, 12 May 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:00	Panel Discussion: Why We Did What We Did	Susan Block
9:00-10:15	Grief and Bereavement	Susan Block
10:15-10:45	Break	
10:45-11:30	Grief and Loss: Experiential Exercise	Susan Block
11:30-1:00	Good-bye	Box Lunch Small Groups



Harvard Medical School
Program in Palliative Care Education and Practice
November ✦ 2009

Wednesday, 11 November 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening	
8:15-8:45	Welcome Back ❖ Introduction to Part 2 ❖ Reflection on Teaching ❖ Assign sessions to small groups for review	Andy Billings Susan Block
8:45-10:15	Communication: Large Group Interview	Susan Block
10:15-10:45	Break	
10:45-12:15	Most Emotionally Powerful Death	Small Groups
12:15-1:15	Lunch	
1:15-3:15	Personal Spiritual History	Small Groups
3:15-3:45	Break	
3:45-5:45	Project Review 1 ❖ Original Goals ❖ Progress ❖ Barriers ❖ Questions for the Group	Project Groups

Thursday, 12 November 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:45	Managing Family Conflict	Small Groups
9:45-10:15	Break	
10:15-11:45	How to Help Parents Help	Paula Rauch

Children When a Parent is Dying

How to Help Siblings during a Child's Life Limiting Illness **Nina Muriel**

11:45-12:45

Box Lunches

12:45-1:30

The Sick Person

Eric Cassell

1:30-2:00

Debrief: The Sick Person

Andy Billings

2:00-5:00

Intensive Communication Teaching

Sign-up for:

- ❖ Home Visit
- ❖ Inpatient Visit
- ❖ Long-Term Care Facility Visit
- ❖ Ambulatory Patients
- ❖ Pediatric

Small Groups

6:00-8:00

Optional Activity: David Eliot Memorial Lecture
Speaker TBA
Tosteson Medical Education Center (TMEC)
Harvard Medical School

Friday, 13 November 2009

7:15-8:00

Breakfast

8:00-8:15

Opening Exercise

8:15-10:00

Quality Improvement Workshop

Rachelle Bernacki
Susan Block

10:00-10:30

Break

10:15-11:30

Hypnosis in Pediatric Palliative Care

Tamara Vesel

10:30-11:30

Advances in Managing
End-Stage Congestive
Heart Failure

Lynne Stevenson

11:45-12:30

Reflection on Teaching

Susan Block

12:30-1:30

Lunch

1:30-3:00

Project Groups

Project Groups

3:00-3:30

Break

3:30-5:00

'Don't Give Up On Me'

Small Groups

5:00-6:00	Role of Palliative Care in the ICU	Tamara Vesel
5:30	Optional – Hypnosis	Eric Cassell

Saturday, 14 November 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:15	Prognosis Communication in Advanced Illness	Jenny Mack
9:15-9:45	Break	
9:45-1:00	Objective Structured Teaching Exercise (OSTE)	
	❖ Negative Feedback	Kristen Schaefer Eva Chittenden
	❖ Formal Presentation	Marshall Forstein
	❖ One-Minute Preceptor	Joanne Wolfe Venus Watson
	❖ Conflict Negotiation	Andy Billings Juliet Jacobsen
	Free Afternoon	

Sunday, 15 November 2009

7:45-8:30	Breakfast	
8:30-8:45	Opening Exercise	
8:45-10:15	Cultural Issues in Palliative Care II	Marshall Forstein
10:15-10:45	Break	
10:45-12:15	Saying Goodbye to Patients And Writing Condolence Notes	Small Groups
12:15-1:30	Lunch	
1:30-2:00	Reflection on Teaching	Susan Block
2:00-3:15	Dealing with Moral Ambiguity In Palliative Care: The Case for Palliative Sedation	Andy Billings Susan Block
3:15-3:30	Break	

3:30-5:00	Palliative Sedation Patients Request for Hastened Death Ethics and Practice of Palliative Sedation	Small Groups (Pedi Groups) Charles Berde
-----------	--	--

5:00 Faculty Meeting

Monday, 16 November 2009

7:15-8:00	Breakfast	
8:00-8:15	Opening Exercise	
8:15-9:15	Bedside Assessment In Palliative Care Care of Children with Advanced Neurological Conditions	Eduardo Bruera Julie Hauer
9:15-10:15	Anorexia and Cachexia Perinatal Palliative Care	Eduardo Bruera Jody Chrastek
10:15-10:45	Break	
10:45-12:00	Chronic Nausea Advanced Pain Management in Children	Eduardo Bruera Stefan Friedrichsdorf
12:00-1:30	Lunch	
12:00-1:30	Non-Pain Symptoms in Palliative Care	Stefan Friedrichsdorf
1:30-2:45	Caring for our Patients and Ourselves In Palliative Care	Eduardo Bruera
2:45-3:00	Break	
3:00-4:30	Burn Out	Small Groups
5:30	Group Photo with Reception to immediately follow	Charles AB
6:30-8:30	Closing Dinner and Graduation	

Tuesday, 17 November 2009

7:15-8:00	Breakfast Feedback on Pediatric Track	Joanne Wolfe Tamara Vesel
-----------	---	--------------------------------------

8:00-8:15	Opening Exercise	
8:15-9:45	Fundraising and Development in Palliative Care	Susan Paresky David Ford
9:45-10:15	Break	
10:15-11:15	Saying Good-bye	Small Groups
11:30-12:15	Who's Caring For Me?	Joanne Wolfe
1:00	Faculty Meeting	